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# Life and Health Skills Development in School Networking: Lessons Learnt from Teachers and Nurses

Learning life skills has been recognized as important for life-long adaptation. According to the World Health Organization (WHO), life skills are those essential skills that enable individuals to deal with every life challenges and demands, resulting in positive and adaptive behaviors.[1] Life skills, therefore, consist of both psychosocial competencies and interpersonal skills. In terms of health behavior, life skills can be applied to explain the interpersonal relationship that may conducive to health as behavior would affect person's environment.[2] Additionally, the WHO launched the Global School Health Initiative in 1995 to improve the health of students, school personnel, families and other members of the community. In this initiative, children are expected to perform healthy behaviors. Coordinated school health education programs are interventions which essentially provide knowledge and skills for children to become healthy and productive adults[3, 4]. However, health risk behaviors among Thai children are reported, such as: poor eating habits, game addiction, and sedentary activities.[5,6,7] Additionally, poor hygiene is concerning among Thai school children[8-10].

Children's healthy behaviors and healthy adaptation are the main thrusts of development in the Life Skill and Health Skill Training Program or LHSD under the Human Potential Development Project, Faculty of Medicine Ramathibodi Hospital, Mahidol University in Bangkok. In several research reports this Program has been shown to be effective in improving the life skills and health skills of school children aged 10-11years old.[11-13] Most of the Life Skill and Health Skill Intervention focuses on adolescent health risk behavior reduction. The most famous Botvin's Life Skill programs now have been offered paid-online training for school teachers, with the use of variety learning aids and materials. Evidently, it is able to cut drug use, alcohol use, tobacco use and violence in the U.S. and South Africa[14-16]. Our Program consists of a combination of reading 14 cartoon booklets and active learning activities, such observational learning or modeling in order to encourage new behaviors and discourage unwanted behaviors. Active participation in learning process has been successfully implemented in formal and informal education.[17] The students' life skill and health skill were evaluated using self-administered questionnaires. Evidently, only the experimental group who attend the program had improved their life skill and health skill significantly, but not the control group[18-19]. The Program has been disseminated to 10 elementary schools in two provinces through school networking activities, which were used to provide social support among group members to achieve common goal of the groups.

The purpose of this article is to identify lessons learnt from developing a network for LHSD experience during a series of workshop and field supervision. In particular, various strategies of implementing activities among target schools were examined.

### Enabling Process: Networking

Networking was used as the essential process to empower school teachers. Through a partnership effort, the networking was performed under the collaboration between Human Potential Development Project of The Faculty of Medicine, Ramathibodi Hospital, Mahidol University and The Office of Basic Education under the Commission of Basic Education, Ministry of Education. There were seven government schools and one private school targeted as model schools, and two school health nurses from health promoting services outside Bangkok participated in the networking.

**Lessons Learnt:**

All schools implemented The LHSD program as extracurricular activities and the academic team from the University helped them to embed the Program into each school's plan of activities according to that school's convenience. Eighty per cent of the schools implemented all the 14 lessons from the LHSD Program.

**Strategies of the LHSD program: implementing and disseminating**

It was found that participants preferred their own unique way to disseminate the LHSD program to other teachers and schools using three major methods:

1. *Facilitating*. It was revealed that school nurses, who attended the network workshop, acted as initiator and facilitator after participating in the LHSD workshop. School nurses set up a training program for other school teachers from the additional 10 schools to use LHSD program. Community participation was evident. The Program was funded by the local administration authority in their Municipality. Then, the teachers who attended the training program used the Program in their schools. Details as shown in Figure 1.

2. *Modeling*. The participants who were teachers reported to the school principals after the workshop. In turn the principals deployed a policy to all teachers to teach life skills and health skills in their schools. Later they trained other teachers how to use the Program and invited other teachers to observe. Details as shown in Figure 2.

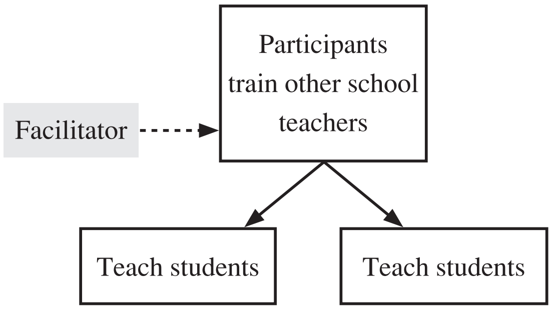

Figure 1 Facilitating pattern

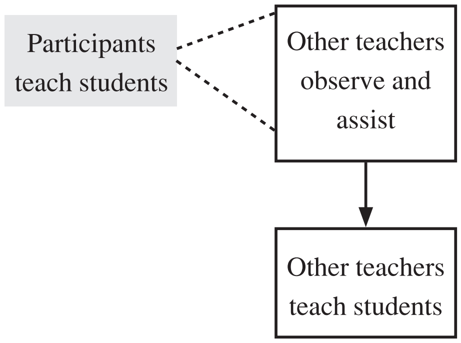

Figure 2 Modeling pattern

3. *Twinning-school*. Those additional 10 schools where teachers were trained by school nurses, twinned their school with another in close proximity. They helped each other while implementing LHSD program. They shared teaching materials and jointly taught some teaching activities. These activities help them to continue teaching LHSD Program in their schools.

**Essential enabling factors**

From the experience of school networking shared in the workshops and discussion, the networking pattern and learnt experiences were shared among 10 network schools. The most important enabling factors were the policy development and implementation from the school principal to establish the Program in each school. It was clear that those teachers who received support from their school principal were successful in implementing the Program. Notably, when school principals attended the LHSD workshop themselves, they started the Program shortly after the workshop. After the school administrator addressed life skill and health skill development as school policy, the HLSD Program could be effectively implemented. Thus, further implementation should include inviting elementary school administrators to be actively involved in the HLSD network development. Additionally, a teacher's positive attitude towards teaching life skills and health skills were equally important in the success of the Program implementation.

**Limitation**

The most mentioned problem was the tight school schedule that allow minimal extracurricular activities. Most schools want to use their extra-time for academic purposes rather that teaching life skills and health skills. Therefore, it is important for establishing a school health policy to include life skill and health skill development in elementary school students.

A lesser concern is the availability of the cartoon booklets. All 14 books are now opened for free download at the Faculty of Medicine Ramathibodi Hospital, Mahidol University website: http://med.mahidol.ac.th/sdmc/thaipopulation/BookDevelopThaiPopulation-th

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# The Influence of Basic Conditioning Factors and Self–Care Agency on Self–Care Behaviors in Thais with Hypertension

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**Abstract:** Individuals with uncontrolled hypertension have a high risk for heart disease, stroke, and renal diseases. Self-care behavior is important for hypertension control. This study aimed to test the Self-Care Deficit Nursing Theory by exploring the pattern of relationship among basic conditioning factors, self-care agencies, and self-care behaviors regarding hypertension control. The participants consisted of 402 people with hypertension who received treatment at outpatient medical clinics of three regional hospitals in the central part of Thailand. In addition to the Demographic and Health Information Sheet, the Chronic Illness Resources Survey, the Revised Illness Perceptions Questionnaire, the Knowledge of Self-Care Demands Questionnaire, and the Self-Care Behavior Questionnaire were used for data collection. The data were analyzed using Structural Equation Modelling.

Results showed that the modified hypothesized model of self-care behaviors for hypertension controls fitted with the empirical data and explained 49% of variance in the self-care behaviors regarding hypertension control. Patient-provider communication had positive direct and indirect effects on self-care behaviors for hypertension control through knowledge about hypertension, knowledge about self-care demands, and perception about hypertension.

The results supported the Self-Care Deficit Nursing Theory regarding the influence of basic conditioning factors on self-care agency. They provide evidence for the development a nursing intervention program to promote patient-provider communication for helping individuals with hypertension to increase self-care behaviors regarding hypertension control.

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**Keywords:** Hypertension, Knowledge, Patient-provider communication, Perception, Self-care behaviors, Self-Care Deficit Nursing Theory, Theory testing

## Introduction

Uncontrolled hypertension is a major global health problem and a cause of cardiovascular disease, which is a leading cause of death worldwide.[1] Less than half of people with hypertension successfully control their hypertension.[1] Approximately 3.5 million people aged $\geq$60 years have hypertension.[2] The number

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of people with hypertension, people with the disease related to hypertension (e.g stroke, heart disease), and hospitalized people with hypertension increase in each year.[2] Only one-seventh of Thai males, and one-fourth of Thai females within the country succeed in controlling their blood pressure to within normal limits.[2] People with hypertension cannot control their blood pressure if they do not regularly practice self-care by medication taking and lifestyle modification.[3] These self-care behaviors take time and much effort, and most people cannot sustain these behaviors over a long period.[3] A systematic review[4] and a meta-analysis[5] showed that previous interventions were effective in increasing self-care behaviors for hypertension control. However, most of the interventions were based on social cognitive learning theory such as the Health Belief Model,[6] Self-efficacy construct,[7-9] or Self- Regulation Theory.[10] Even though Orem's Self-Care Theory[11] placed an emphasis on self-care, it is rarely used to guide intervention research, since it is very abstract. We argue that the middle range theory, which is derived from Orem's Self-Care Theory, is needed to guide interventions because the concepts of the theory are relevant with the concepts used in this study. Thus, the purpose of this study was to develop middle theory from Orem's Self-Care Theory, which specifies the pattern of relationships among the relevant concepts when predicting self-care behaviors among people with hypertension. The study not only provides the benefits of guiding the intervention but also in the expansion of nursing science in explaining how each concept influence self-care.

## Conceptual Framework and Literature Review

In Self-Care Deficit Nursing Theory (SCDNT), Orem[11] proposes relationships among the four major concepts namely; self-care, self-care agency, self-care demands, and nursing agency as well as one peripheral concept, basic conditioning factors.

Self-care is practicing an activity in which people initiate and undertake themselves in order to maintain life, health, and well-being. Self-care is a series of complex deliberate actions with the intention of achieving a specific goal and seeking results, which are determined before performing the actions.[11]

Self-care agency is the ability of a person to know and to perform self-care actions to meet self-care demands. Self-care agency consists of many levels; foundational capabilities and dispositions, ten power components and operational capabilities. Operational capabilities involve the ability to perform deliberate actions, which includes estimative, transitional, and productive operation.[11] Estimative operation is seeking knowledge and understanding about a situation and what should be done to control that situation. Transitional operation is making a decision about self-care and productive operation is actions for meeting self-care demands, monitoring self-care practice (i.e., actions, results, effects), and decisions about subsequence actions.[11] People can make a decision (transitional operation) to begin and maintain self-care actions (productive operation) if they have success in their self-investigation about their self-care (estimative operation). According to Orem,[11] self-care requires learning and the use of knowledge. Knowledge includes both scientific and commonsense knowledge. People use scientific and commonsense knowledge along the state of deliberate action of self-care.[11] However, most studies related to self-care of people with hypertension are focused on scientific knowledge but not include perception.[4,5] Perception is formed based on knowledge receiving from health-care providers and other sources such as family, media, friend, and illness experience of a person.[12] A person uses perception to making decision about self-care. In psychology theories, perception of illness influenced personal behaviors in responding to a health threat such as following with the treatment regimens.[13]

Knowledge about hypertension and self-care demands, and perception about hypertension are important self-care agency of people with hypertension. Previous studies supported the relationships between self-care behaviors for hypertension control and other factors, including knowledge about hypertension,[14-16] knowledge about self-care demands[17], and perceptions about hypertension,[12,18-20]

The basic conditioning factors are personal conditions and circumstances which affect self-care demands and self-care agency or self-care behaviors. Basic conditioning factors are related to age, gender, developmental state, state of health, socio-cultural orientation, healthcare system factors, family system factors, patterns of living, environmental factors, and resource availability and adequacy.[11] An understanding is required of the types of specific basic conditioning factors and their patterns of relationships affecting person's self-care behaviors and health status. In addition, people with hypertension live with the disease over a long period, do daily activities with their family, and communicate with healthcare providers about treatments and self-care. Therefore, the duration of hypertension, family support, and patient-provider communications are the basic conditioning factors that affect their self-care behavior. Patient-provider communication, duration of hypertension, and family support are health-care system factors, health state, and family system factors, respectively. Previous evidence supports the relationships between self-care behaviors for hypertension control and the basic conditioning factors, including patient-provider communication,[18,21,22] duration of hypertension,[23,24] and family support.[14,25] However, how all aforementioned factors work to influence self-care behaviors is not known. Thus this study aimed to develop a causal model, to specify the pattern of relationships among the basic conditioning factors (patient-provider communication, duration of hypertension duration, and family support), self-care agency (knowledge about hypertension, knowledge about self-care demands, and perception about hypertension), and self-care behaviors for hypertension control. The hypothesized model is shown in Figure 1.

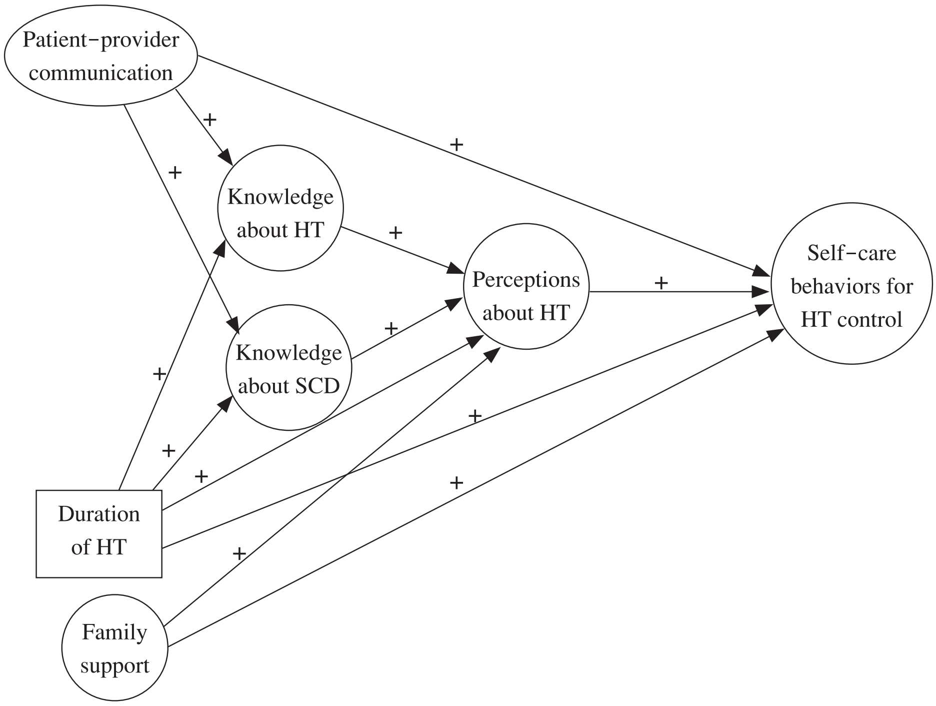

**Figure 1** The hypothesized model of factors influencing self-care behaviors for hypertension control

## Methods

**Design:** A descriptive cross-sectional design was used.

**Participants and setting:** Data were collected from people with hypertension who received treatment at outpatient medical clinics at three regional hospitals in the central part of Thailand. These hospitals provide specialized tertiary care for patients with complex health problems. Inclusion criteria for the sample was: aged >18 years; having been diagnosed with essential hypertension for at least one year; receiving antihypertensive medication; not being dependent on others for care, understanding the Thai language, and having normal cognitive and movement function. Participants aged ≥60 years were screened for cognitive function using the Short Portable Mental Status questionnaire[26] because approximately 12.3% of Thai people aged ≥60 years have dementia.[2] The cutoff point to indicate normal cognitive function was the score at least eight out of ten. Exclusion criteria were people with diabetes or severe complications of hypertension such as having suffered from a severe stroke or on dialysis.

**Sample size:** There are approximately 100,000 people with hypertension who receive treatment in the regional hospitals in the central part of Thailand. Based on Yamane's formula,[27] and for an alpha of .05, at least 398 people with hypertension were required for the study. Purposive sampling was used in this study.

**Ethical considerations:** The research proposal was approved by the Institutional Review Board of Mahidol University and the hospitals used as study sites. Prior to data collection, the researcher explained objectives, procedures, protection of confidentiality and the right to refuse or withdraw from the study to the potential participants. The confidentiality of the participants was protected by avoiding writing the participants' names on the questionnaires, presenting the results as a whole. All participants who were willing to participate in the study gave informed consent.

**Instruments:** Data were obtained using 5 questionnaires as follows:

**The Demographic and Health Information Sheet (DHIS)** was developed by the researchers for collecting personal and health information such as: age, gender, marital status, education, career, income, living with family, history of hypertension in family, body weight, history of smoking and alcohol consumption, and history of any comorbidities.

**The Chronic Illness Resources Survey (CIRS)** was developed by Glasgow for measuring social support.[28] The Family subscale and the Physician and Healthcare Team subscale of the CIRS were used for measuring family support and patient-provider communication, respectively. Both subscales were translated into Thai using the back translation process.[29] The questionnaire was translated from English into Thai by the researchers' advisors. The translated Thai version was back-translated from Thai into English by two Thai nursing instructors who were bilingual. They did not get access to the source of the questionnaires. The back-translated version and the original version were compared for any discrepancies in translation and relevancy to the Thai culture by the dissertation's major advisor and three nursing instructors. The Family subscale of the CIRS consists of 7 items for measuring family support. The response is scored using the five-level Likert scale ranging from 1 (not at all) to 5 (a great deal). The total score ranges from 7 to 35. The higher score indicates higher support received from family members. The mean score of the variable was equally classified to three intervals which indicated "mild" (the interval of the low possible score), "moderate" (the interval of the middle possible score) and "high" (the interval of the high possible score) levels. The range of the total score from 7 to 16.3, 16.4 to 25.7, and 25.8 to 35 indicated "mild", "moderate", and "high" support received from family members, respectively. An example item is "Have your family exercised with you?"

**The Physician and Healthcare Team subscale of the CIRS** contains 6 items for measuring the perception of support which a person received from a physician and health care team in the past three months. The response is scored using a five-level Likert scale ranging from 1 (not at all) to 5 (a great deal). The total score ranges from 6 to 30. A higher score indicates a higher quality of provider communication. The range of the total score from 6 to 14, 14.1 to 22, and 22.1 to 30 indicates "mild", "moderate", and "high" quality of provider communication, respectively. An example item is "Has your doctor or other health advisors (nurse, dietician) clearly explained what you need to do to manage your illness?"

**The Revised Illness Perceptions Questionnaire (IPQ-R)** was developed by Moss-Morris et al.[30] for measuring perceptions about hypertension. The Thai version IPQ-R was translated by Sriprasong.[31] The IPQ-R consists of 37 items and 7 subscales, including timeline (acute/chronic), consequences, timeline (cyclical), controllability by person, controllability by treatment, understanding about illness, and emotional representation. The participants responded on the five-level Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree). The negative item scores were reversed before summation into the total scores. The total score ranges from 37 to 185. The higher scores indicate a cognitive view of hypertension to be threatening to personal health which is a chronic and cyclical condition, negative outcomes of illness, ability to control of illness, and understanding of a condition. The range of the total score from 37 to 86.3, 86.4 to 135.7, and 135.8 to 185 indicates "mild", "moderate", and "high" viewing of hypertension to be threatening to health, respectively. An example item is "Will my illness last a short time?"

**The Knowledge about Self-Care Demands Questionnaire (KSCDQ)** was developed by Rujiwatthanakorn[17] for measuring the level of understanding of hypertension and self-care demands for hypertension control. The KSCDQ consists of 36 items. The response is "yes" (score = 1) or "no" (score = 0). The first part (13 items) is used for measuring knowledge about hypertension. Total scores range from 0 to 13. A higher score indicates a greater understanding about hypertension. The range of the total score from 0 to 4.3, 4.4 to 8.7, and 8.8 to 13 indicates "mild", "moderate", and "high" understanding about hypertension, respectively. The example item is "Do persons with hypertension have a risk for stroke more than persons with normal blood pressure?"

The second part was used for measuring knowledge about self-care demands for hypertension control. It consists of 23 items and 6 subscales, including medication-taking, dietary and body weight control, aerobic exercise, stress management, risk behavior avoidance, and self-monitoring. The response is "yes" (score = 1) or "no" (score = 0). The total score ranges from 0 to 23. Higher scores indicate greater understanding of self-care demands for hypertension control. The range of the total score from 0 to 7.7, 7.8 to 15.5, and 15.6 to 23 indicates "mild", "moderate", and "high" understanding of self-care demands for hypertension control, respectively. An example item is "Can persons with hypertension stop taking their drug when they feel normal and workable?"

**The Self-Care Behavior Questionnaire (SCBQ)** was modified from the Perceived Self-Care Efficacy Measurement (PSEM).[32] The PSEM was developed by Panpakdee and colleagues for measuring personal confidence in practicing activities for hypertension control.[32] The SCBQ was modified by changing the word "confidence to practice activities for hypertension control" to "frequency of practicing self-care activities for hypertension control" and changing the eleven-point graphing scale to four-point Likert scale ranging from 0 (rarely to never done) to 3 (always). The SCBQ consists of 31 items and 6 subscales, including sodium reduction, healthy diets and weight control, physical activity, medication management, self-monitoring, and risk avoidance. The total score ranges from 0 to 93. A higher score indicates more frequently practiced self-care for hypertension control. The range of the total score from 0 to 31, 31.1 to 62, and 62.1 to 93 indicates "mild", "moderate", and "high" frequently practiced self-care for hypertension control, respectively. An example item is "How often did you add salty condiments in your foods (cooked foods) in the past one month?"

A panel of 5 expert nursing instructors who were specialists in chronic illness validated the content of the Chronic Illness Resources Survey (CIRS) Thai version, the Revised Illness Perceptions Questionnaire (IPQ-R), the Knowledge about Self-Care Demands Questionnaire (KSCDQ) and the Self-Care Behavior Questionnaire (SCBQ). The content validity and the reliability of the instruments are shown in the table 1.

**Table 1** The reliability coefficients of the questionnaires

| Instruments | Content validity index (CVI) | | Reliability (Cronbach's alpha) | | |
|---|---|---|---|---|---|
| | | This study | | This study | |
| | | | | N= 30 | N= 402 |
| SCBQ | - | 0.83 | - | 0.81 | 0.57 |
| CIRS (family) | - | 0.88 | 0.75 | 0.84 | 0.84 |
| CIRS (healthcare provider) | - | 0.94 | 0.91 | 0.79 | 0.55 |
| IPQ-R | 0.87 | - | | 0.79 | 0.71 |
| KSCDQ | 0.97 | - | 0.84 | 0.66 | 0.76 |

Note: SCBQ = Self-Care Behavior Questionnaire, CIRS = Chronic Illness Resource Survey, IPQ-R = Revised Illness

**Procedure:** Data were collected after the protocol of the study was approved by the IRB committees of the investigator's university and each hospital. Data were collected by the researcher and two research assistants between February and June, 2014. The researcher approached the participants and screened them according to the criteria. Objectives of the study and the right of human subjects were informed to the participants. The questionnaires were sent or read to the participants in sequential order, starting with the Self-Care Behaviors Questionnaire, the Chronic Illness Resource Surveys, the Revised Illness Perception Questionnaire, the Knowledge about Hypertension Questionnaire, the Knowledge about Self-Care Demands Questionnaire, and the Demographic and Health Information Sheet.

There were 450 eligible participants, and 10% (n = 45) refused to participate in answering the questionnaires because of time limitations. Finally, 402 people participated in this study. Ninety-five percent (n = 378) answered the questionnaires at an interview and 5% (n = 24) by self-administration. They each took approximately 20-30 minutes for the completion of the questionnaires.

**Data analysis:** Descriptive statistics and Pearson's correlation were used to analyze the characteristics of the samples and variables using the Statistical Package for Social Science (SPSS) version 18. The pattern of relationships among the variables in the hypothesized model was analyzed using the Mplus program version 7.1. The assumptions for analysis using structural equation modeling were checked before data analysis. Knowledge of self-care demands did not display normal distribution. The estimation of parameters using maximum likelihood with standard errors and a mean-adjusted chi-square or MLM was selected for increasing the robustness of the parameter estimation in the data with non-normal distribution.[33]

## Results

**Participant characteristics:** Overall 402 participants with hypertension participated in the study and their age ranged from 32 to 88 years (mean = 59.87 years, SD = 9.56). The majority were female (64.4%), with a primary level education (70.4% %), married (66.9%), housekeepers (22.1%), incomes of less than 5,000 baht (38.6%), living with family (89.8%), overweight or obese (59.7%), and with a family history of hypertension (56.2%). The participants who currently smoked or drank alcohol were 4.5%, and 11.9%, respectively. Over half (56.5%) were successful in controlling their blood pressure to a level of less than 140/90 mmHg. Comorbidities with hypertension were heart diseases (6.2%), strokes (3.7%), renal diseases (1.6%), transient ischemic attacks (0.9%), and dyslipidemia (67.1%). The antihypertensive drug used was calcium channel blockers (21.4%), β-blocker (13.7%), angiotensin converting enzyme inhibitors (12.9%), and antilipidemic agents (23.6%).

**Study variables' characteristics:** The participants perceived healthcare providers as having a moderate quality of communication. The duration of their hypertension ranged from 1 to 46 years (mean = 7.3, SD = 5.4) and they received moderate support from a family member. The majority had an enhanced knowledge about hypertension and self-care demands for hypertension control. They perceived hypertension as a moderate threat to them and practiced self-care behaviors for hypertension control at a moderate level. The study variables' characteristics are shown in the table 2.

**Table 2** Descriptive statistics of the study variables (N = 402)

| Variables | Possible range | Actual range | Mean | SD | Interpretation |
|---|---|---|---|---|---|
| Patient-provider communication | 6 - 30 | 12-29 | 20.1 | 3.2 | Moderate quality |
| Duration of HT (year) | ≥ 1 | 1 - 46 | 7.3 | 5.4 | Long duration |
| Family support | 7 - 35 | 7 - 34 | 21.2 | 7.1 | Moderate support |
| Knowledge about HT | 0 - 13 | 2 - 13 | 9.8 | 2.1 | High understanding |
| Knowledge about SCD | 0 - 23 | 8 - 23 | 21.9 | 1.9 | High understanding |
| Perception about HT | 37 - 185 | 80 - 158 | 123.4 | 11.4 | Moderate threat |
| Self-care behaviors | 0 - 93 | 41-83 | 58.6 | 6.8 | Moderate practicing |

Note: SD = Standard deviation, HT = Hypertension, SCD = Self-care demands

**Measurement model testing:** All subscales of the KSCDQ and SCBQ were significant at $p < 0.001$ and IPQ-R were significant at $p < 0.001$ or $p < 0.05$, except for coherence ($p = 0.150$). Overall results of the measurement model testing were acceptable for the theoretical model analysis.

**Hypothesized model testing:** The hypothesized model did not fit the empirical data with the values of Chi-square = 612.301, *df* = 219, $p < 0.0001$, CFI = 0.650, TLI = 0.595, RNI = 0.650, RMSEA = 0.067, and SRMR = 0.082, therefore the hypothesized model was modified. Finally, the modified hypothesized model fitted with the empirical data with the values of Chi-square = 232.672, *df* = 154, $p < 0.0001$, CFI = 0.923, TLI = 0.895, RNI = 0.923, RMSEA = 0.036, and SRMR = 0.053. The results show that the model explains 49% of the variance of self-care behaviors for hypertension control. Patient-provider communication had a positive direct effect on self-care behaviors for hypertension control ($\gamma = 0.52$, $p < 0.001$) and a positive indirect effect on self-care behaviors for hypertension control through knowledge about hypertension ($\gamma = 0.13, p < 0.05$), knowledge about self-care demands ($\gamma = 0.18, p < 0.05$), and perception about hypertension ($\beta = 0.42, p < 0.001$). The results of the hypothesized model testing are presented in Figure 2 and Table 3.

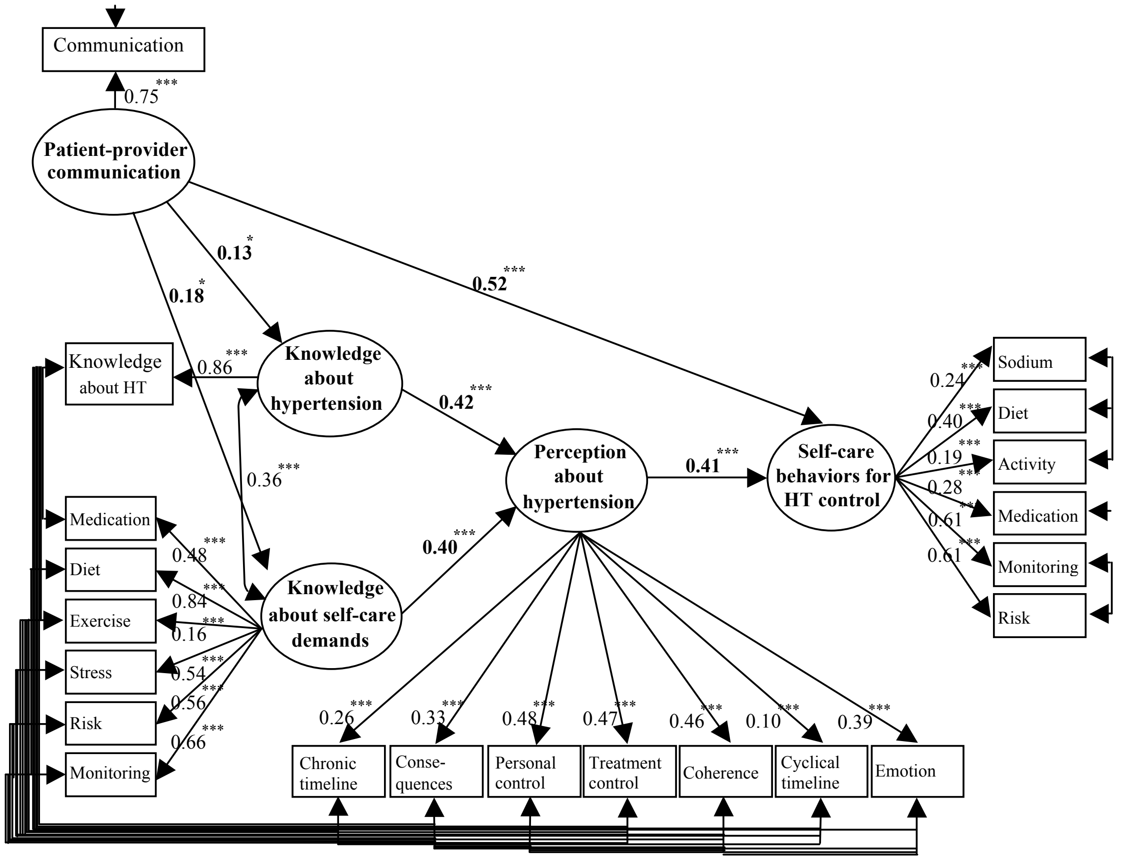

**Figure 2** The modified hypothesized model of factors influencing self-care behaviors for hypertension control

**Table 3** Direct effects, indirect effects, and total effects of study variables in the modified hypothesized model

| Causal variables | Knowledge about HT | | | Knowledge about SCD | | | Perception about HT | | | Self-care behaviors | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | TE | IE | DE | TE | IE | DE | TE | IE | DE | TE | IE | DE |
| Patient-provider communication | 0.13* | 0.02 | 0.11* | 0.18* | 0.05 | 0.13* | - | - | - | 0.52*** | | 0.52*** |
| Knowledge about HT | - | - | - | - | - | - | 0.42*** | - | 0.42*** | - | - | - |
| Knowledge about SCD | - | - | - | - | - | - | 0.40*** | - | 0.40*** | - | - | - |
| Perception about HT | - | - | - | - | - | - | - | - | - | 0.41*** | - | 0.41*** |
| Structural equation | $R^2 = 0.02$ | | | $R^2 = 0.03$ | | | $R^2 = 0.46$ | | | $R^2 = 0.49$ | | |

**Note:** * = p < .05, *** = p <.001, TE = Total effect, IE = Indirect effect, DE = Direct effect, HT = Hypertension, SCD = Self-care demands

## Discussion

The hypothesized model testing results supported the validity of the SCDNT regarding the influence of basic conditioning factors on self-care agency. Patient-provider communication had a strong effect both directly and indirectly on self-care behavior through knowledge about hypertension, knowledge about self-care demands, and perception about hypertension. The findings support the proposition of Orem's SCDNT in that "Self-care is learned within the context of social groups by human interaction and communication".[34] Orem also emphasized that nurses must exercise nursing agency to increase the self-care agency of the clients through patient interaction.[34]

Patient-provider communication had a strong positive direct effect on self-care behaviors for hypertension control. The results can be explained by the fact that patient-provider communication increases understanding and awareness about hypertension control[21,22,35] and helps to solve problems and addresses health concerns.[21] This finding is consistent with Tian et al[35] who found that patient-provider communication was effective in the increase of self-care behaviors of people with chronic illness. Patient-provider communication is positively associated with antihypertensive medication adherence[14,21,22] and information provided by healthcare providers is important for adherence to antihypertensive treatments.[36]

Patient-provider communication also had a positive indirect effect on self-care behaviors for hypertension control through knowledge about hypertension, knowledge about self-care demands, and perceptions about hypertension. This result can be explained by knowledge about hypertension and knowledge about self-care demands changing perceptions about hypertension being consistent with scientific knowledge. Perception about hypertension are used for investigation about an unchangeable condition (the condition of having hypertension) and what self-care activities are required for the control of changeable factors (e.g., eating, exercising, and taking medication) in the estimative operation. Perceptions about hypertension are used for making the decision to begin and to maintain self-care actions for hypertension control. If people have clear and correct perceptions about hypertension, they are more likely to make appropriate decisions about self-care in the transitional operation process. Finally, people with hypertension create their own course of action and evaluate the performance, results, and subsequent actions in the productive operation process. Therefore, these findings confirm Orem's statement that scientific knowledge and commonsense knowledge (perception) are used along with states of deliberate action and are essential in the estimative operation.[34] The findings also supported the illness perception concept in that the perceptions about illness influences personal behaviors in response to a health threat such as following treatment regimens.[13] In addition, the results supported that perception about hypertension was associated with self-care behaviors for hypertension control[13,20,21] and adherence to antihypertensive treatments.[37]

The duration of hypertension did not affect self-care agency and self-care behaviors for hypertension control. The findings of previous research were inconsistent in demonstrating the relationship between the duration of hypertension and self-care behaviors for hypertension control. A long duration of hypertension had positive,[23,24] negative,[38] and no associations[39] with self-care behaviors for hypertension control. In the present study, a half of the participants could not control their blood pressure, but they had a low level of comorbidities and complications of hypertension thus they might perceive that they are healthy, and they might accept practicing self-care behaviors as usual was enough for their health. This reason could be supported by Panpakdee et al[20] who found that Thais with hypertension were not practicing self-care when were recovering from a crisis or symptom of hypertension.

Family support did not affect self-care agency and self-care behaviors for hypertension control. It could be explained that people with hypertension could care for themselves, which lead to the perception of being healthy. Social support is a factor for reducing stress that affects health.[28] In a situation without stress, social support might not be perceived as a necessity. In contrast to some studies, family support was associated with self-care behaviors for hypertension control.[14,25] People who have both hypertension and diabetes mellitus were not included in this study. The participants may not be stressed due to the perception of having a less severe disease such as hypertension. Therefore, family support is not perceived as a necessity for helping them to control hypertension. This reason could be supported by Anthony et al[40] who found that people with hypertension and diabetes perceived their hypertension as a chronic disease with more of an impact on their daily life than those without diabetes.

## Limitations

This cross sectional study did not meet the assumptions of structural equation modeling in the aspect of temporality (the requirement in measuring a variable in a model at a different time point).[41] The use of purposive sampling limited the generalization only to people with hypertension who had the same characteristics as the participants of this study.

## Conclusions and recommendations

Patient-provider communication is a powerful factor, which has a large positive direct effect on the self-care behaviors for hypertension control as well as an indirect effect on self-care behaviors through knowledge about hypertension and self-care demands, and perceptions about hypertension. Thus, the implications for nursing practice is for the development of a nursing intervention program and the health service system to promote patient-provider communication for helping individuals with hypertension to increase their self-care behaviors, for the control of hypertension. Future studies should also be designed to test the effectiveness of various types of patient-provider communication such as computer-based approach.

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# อิทธิพลของปัจจัยพื้นฐานและความสามารถในการดูแลตนเองต่อพฤติกรรมการดูแลตนเองในคนไทยที่เป็นความดันโลหิตสูง

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**บทคัดย่อ:** ผู้ที่เป็นความดันโลหิตสูงและไม่สามารถควบคุมโรคได้มีความเสี่ยงต่อการเกิดโรคหัวใจ โรคหลอดเลือดสมอง และโรคไต พฤติกรรมการดูแลตนเองมีความสำคัญในการควบคุมความดันโลหิตสูง การศึกษาครั้งนี้เป็นการทดสอบทฤษฎีความพร่องในการดูแลตนเอง เพื่อศึกษาแบบแผนความสัมพันธ์ของปัจจัยพื้นฐานและความสามารถในการดูแลตนเองที่มีอิทธิพลต่อพฤติกรรมการดูแลตนเองเพื่อควบคุมความดันโลหิตสูง กลุ่มตัวอย่างเป็นผู้ที่ได้รับการวินิจฉัยว่าเป็นความดันโลหิตสูงจำนวน 402 ราย ที่ได้รับการรักษาที่แผนกผู้ป่วยนอกของโรงพยาบาลศูนย์ 3 แห่ง ในภาคกลางของประเทศไทย การเก็บรวบรวมข้อมูลโดยใช้แบบสอบถามข้อมูลส่วนบุคคล แบบสำรวจแหล่งสนับสนุนของผู้เจ็บป่วยเรื้อรัง แบบสอบถามการรับรู้เกี่ยวกับการเจ็บป่วยฉบับปรับปรุง แบบสอบถามความรู้เกี่ยวกับความต้องการการดูแลตนเอง และแบบสอบถามพฤติกรรมการดูแลตนเอง วิเคราะห์แบบแผนความสัมพันธ์ โดยใช้แบบจำลองสมการเชิงโครงสร้าง

ผลการวิจัยพบว่าโมเดลพฤติกรรมการดูแลตนเองเพื่อควบคุมความดันโลหิตสูงที่ได้รับการปรับปรุงมีความสอดคล้องกับข้อมูลเชิงประจักษ์ โมเดลสามารถทำนายความแปรปรวนของพฤติกรรมการดูแลตนเองได้ ร้อยละ 49 การติดต่อสื่อสารระหว่างผู้ใช้บริการและทีมสุขภาพเป็นปัจจัยที่มีอิทธิพลด้านบวกทั้งทางตรงและทางอ้อมต่อพฤติกรรมการดูแลตนเองโดยผ่านความรู้เกี่ยวกับโรคความดันโลหิตสูง ความรู้เกี่ยวกับความต้องการการดูแลตนเอง และการรับรู้เกี่ยวกับโรคความดันโลหิตสูง

ผลการศึกษาครั้งนี้สนับสนุนทฤษฎีความพร่องในการดูแลตนเองของโอเร็มเกี่ยวกับปัจจัยพื้นฐานมีอิทธิพลต่อความสามารถในการดูแลตนเอง ผลการศึกษาเป็นหลักฐานเชิงประจักษ์ในการพัฒนาโปรแกรมการส่งเสริมการสื่อสารระหว่างบุคลากรทีมสุขภาพกับผู้ป่วย เพื่อช่วยให้ผู้ที่เป็นความดันโลหิตสูงมีพฤติกรรมการดูแลตนเองเพื่อควบคุมความดันโลหิตดีขึ้น

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**คำสำคัญ:** ความดันโลหิตสูง ความรู้ การติดต่อสื่อสารระหว่างผู้ใช้บริการและทีมสุขภาพ การรับรู้ พฤติกรรมการดูแลตนเอง ทฤษฎีความพร่องการดูแลตนเอง การทดสอบทฤษฎี

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# Family Caregiver Capacity Building Program for Older People with Dependency in Thailand: A Randomized Controlled Trial

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**Abstract:** This randomized control trial investigated the effectiveness of the Family Caregiver Capacity Building Program on caregivers' care ability and quality of care. A sample of 55 family caregivers, currently caring for older people with dependency in two rural communities in a central Thailand, were randomly assigned to a control group (n=29) and an experimental group (n=26). The experimental group received the Program based on Hulme's work in family empowerment. The control group received usual home visits. Data were collected at baseline, week 12 for caregiver ability, and at week 24 for quality of care at week 24. Data were analysed using descriptive statistics, independent t-test, and paired t-test.

Results revealed that after attending the Program the experimental group had significantly higher overall care ability than at the baseline, except for social aspect. There were significant differences in overall quality of care, physical, psychological, and financial aspects but not for environmental, medical management, and human rights dimensions. When comparing between groups, the experimental group had significantly higher overall care ability than those in the control group, except for social aspect. However, there were no significant differences of overall quality of care and their dimensions, except for physical aspect. Findings revealed that the Program was effective in improving the ability of care givers to provide quality care for older people with dependency. Nurses in Thai district hospitals or sub-district health promoting hospitals could apply this Program to improve care ability of family caregivers for older people with dependency in similar communities in Thailand. However, it is recommended that the Program be further evaluated with larger or different groups.

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**Keywords:** Capacity building; Caregiver program; Dependency; Care ability; Family caregiver; Older people; Quality of care

## Introduction

Older people with dependency needs experience limitations in and loss of their physical, psychological, social, and economic abilities, including a decrease in intellectual talent. They need assistance from others and cannot live their lives as they have previously been accustomed to doing.[1,2] Mostly, this population

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experiences physical disabilities in carrying out daily activities of living such as bathing, dressing, standing up, moving, and using the toilet (both urination and defecation).[1-4]

In 2014, there were approximately 180,000 older people with dependency in Thailand. This number is estimated to increase to 741,766 by 2020 and 1,103,754 by 2030.[1-3] Families have to provide a primary family caregiver without wages or compensation. Ongoing care for the older people with dependency needs requires a daily routine in terms of socialization, emotional stability, mental acuity, health care, and problem solving when faced with an emergency.[3-5] The problems with which family caregivers are confronted become a complicated process of either solving problems or supporting decisions regarding caregiving.[5,6] The complications are associated with family caregiving result in escalating family expenses with a significant impact on family members' lives as family capacity for caregiving diminishes.[1,3-6] Caregiving capability may further decline, especially in terms of essential knowledge and skills for caregiving assistance.[3-6] Thus, family caregiving ability needs to be strengthened through family empowerment in providing care for older people with dependency. [3-8]

The concept of family empowerment, proposed by Hulme[9], was developed from Gibson's empowerment concept.[10] This encourages families to be able to face the challenge of caregiving for older people with chronic illnesses[7-11] and empowers caregivers through capacity building to improve family members' relationships and increase their awareness of their own ability; develop self-worth and improve knowledge and skills. These translate to better patient care, by affecting the care ability and quality of care (QoC) that family caregivers are able to provide to older people.[9-11] This enhanced ability reflects the caregiver's acceptance of the role of caregiving through a process of learning, understanding, and giving appropriate care such as hygiene, feeding, dressing, mobility, and toileting. Family caregiving also involves social aspects such as shopping, preparation of meals, telephoning, financial management, participate in religious ceremonies, healthcare, and coordination with a healthcare professional.[12-15] Moreover, such capacity which can be viewed as a structure, process, or result, and ultimately, QoC represents the potential to give the best care to older people by the family caregiver. Activities of care involve environmental, physical, psychological, and economic aspects, as well as respect towards older people.[16-20] Previous studies have concluded that problems of caregiving often result from knowledge deficit, lack of care ability, and resources of family caregivers which leaded to a diminished QoC.[13-18] There are a paucity of studies of capacity strengthening of family caregivers for older people with dependency in Thailand, so the researcher was interested in developing and testing the Family Caregiver Capacity Building Program (FCCBP) using empowerment strategies and following the empowerment phases of Hulme[7.] The FCCBP emphasizes the interaction between the family caregivers and the researcher via education, skill training and support to empower them to take responsibility for managing and providing care to older people with dependency.

## Review of Literature

Capacity-building empowerment increases a person's ability to complete a task and improves processes to achieve better results or efficiency and standardization.[12-16, 23-26] Empowerment influences caregivers to provide efficient care.[12-13, 23-25] Gibson explained that the process of empowerment requires discovering reality, that is, recognition, understanding, and acceptance of true incidents expresses recognition and sensation. Critical reflection requires people to carefully review an incident to make decisions and properly fix the problem. Taking charge of a reasonable belief leads to effective executions that are sustainable. Learning processes cause changes at the individual, family, and community level and include social interaction among people who make decisions and solve problems through their participation and appropriate utilization of resources in order to increase their capability to achieve the goal.[10, 11] Hulme's[7] family empowerment encourages the family to be able to face the challenge of caregiving through capacity building. This requires healthcare personnel, whom the family trust, to participate in initial care giving while helping family members to be able to participate in making care decisions. After that, the capacity building process transitions the balance of power until family members have full knowledge, capability, and confidence to take care of their family member themselves.

Capacity building via empowerment of the family creates abilities and improves the quality of care for the older person with dependency needs.[27-29] Caregivers meet the needs of their older relatives in caring for various physical and daily life needs because they are limited in their own ability to perform self-care,[3-6] such as transfers, opening doors, going outdoors, managing stairs, and physical activities of daily living, such as combing their hair, washing their bodies, going to the toilet, dressing, cutting fingernails or toenails, and more.[3-6] Caregivers reflect acceptance of the caregiving role through a process of learning, understanding, and giving appropriate care in hygiene, feeding, dressing, mobility, and toileting. Family caregivers also are involved in social aspects such as shopping, preparation of meals, telephoning, use of money, aid in participation in religious ceremonies, health care, and coordination with healthcare professionals.[3-8, 12-18] Moreover, capacity building affects the QoC that is available to an older person.[13-15, 29-31.] Proper environmental management and establishing guidelines or standards are the responsibilities of health personnel. They need to aim for the highest consumer benefits in terms of efficiency, effectiveness, acceptance, assistance, access to health services and equality in terms of rules and professional standards that utilize empirical evidence to judge the value of care in order to meet consumers' needs.[19-21] From these studies, we concluded that empowerment programs will help family caregivers improve their ability to provide care for older people with dependency by enhancing their knowledge and training skills[8,12-18] Moreover, capacity building affects the QoC that is available to older people.[13-15, 29-31] Furthermore, these studies emphasized empowerment through individual, family, and community in interventions that had significant outcomes.[18,29] Empowerment can help make caregivers confident, experienced, and skillful in caring for the older people with dependency and improve their QoC.[16-18,19- 31]

The FCCBP was based on critical reviews of Hulme's family empowerment model[7] and consists of changing behavior through empowerment strategies in four phases: professional-dominated phase, participatory phase, challenging phase, and collaborative phase. The first phase builds trust by creating rapport with the families and establishing a direct relationship with the family caregivers, prioritizing the family's perceived needs, providing accurate and complete information, and supporting family caregivers in setting goals, including knowledge related to problems and needs of older people with dependency, such as common chronic illnesses, geriatric syndrome, and rehabilitation. The second phase, participatory, helps the family determine setting goals and family care plan, guides them in assessing their resources, and skills training such as activities of daily living, vital sign monitoring, feeding, oxygen, and catheter care.

The challenging phase supports family caregivers in a peer support group reinforcing their ability to identify choices in health care, discuss advocacy techniques, and build the caregivers' skills in negotiating with health professionals. This phase enhances their ability in caring for their older relative. The last phase, the collaborative phase, involves monitoring and supporting caregiving skills at home and acknowledging caregivers as their care improves. The interactions between family caregivers and the researcher in the process of empowerment[12-13, 24-25] can help to strengthen care ability by increasing caregiver knowledge and confidence by creating a sense of self-worth, and leading to higher QoC for older people with dependency.[13-16, 29-31]

## Study Aim and Hypothesis

This study determined the effects of the FCCBP on the care ability score and QoC score of family caregivers providing care for older people with dependency needs. The following hypotheses were proposed:

1) In the experimental group, the family caregivers receiving the Program would have a significantly higher care ability at week 12 and QoC at week 24 than at baseline.

2) When comparing between groups, the family caregivers receiving the Program would have a significantly higher in care ability at week 12 and QoC at week 24 than the control group.

## Methods

***Design:*** A randomized controlled trial.

***Ethical Considerations:*** Study approval was obtained from the Institutional Review Board, Faculty of Nursing, Chiang Mai University, and the local Public Health District and Provincial Health Office. All participants received written and verbal explanations of the study. Before giving written informed consent they learnt of the objectives, methods, risks, benefits, and their right to withdraw from the study at any time.

***Setting:*** This study was conducted in two sub-districts in central Thailand. These had comparable characteristics in terms of socioeconomic conditions, location, transportation, culture, and health services from the sub-districts' health-promoting hospitals.

***Sample:*** The sample was family caregivers of older people with partial or total dependency needs, aged 60 years and living in two sub-districts in central Thailand. Inclusion criteria were: family caregivers aged 20-59 years living with their older relative; willing to participate in the Program; had not participated in another family capacity program for at least 6 months prior to the beginning of this study; and able to communicate in Thai. Multi-stage random sampling was used during the first phase to randomize ten villages from two rural communities. Sample size was estimated based on the findings of another study regarding skills training.[14] We enrolled 58 family caregivers intending to obtain sufficient statistical power (80%) and a significant of $p<0.05$. There were 1,018 family caregivers who lived with older people with dependency. One hundred and thirty five family caregivers who met the study criteria were recruited using a computer-generated randomization list and assigning the 58 participants to either the experimental group (n = 29) and control group (n = 29). At week 12, one older relative being cared for by a participant in the experimental group had died, another was admitted in the hospital, and one moved to another area, so we excluded three participants. At week 24, two participants of the experimental group and four from the control group lost with the same reasons. Therefore, data were analyzed using 49 participants as shown in **Figure 1**.

***Intervention Program:*** The Program was developed by the researcher based on the family empowerment concept proposed by Hulme.[7] It has 11 sessions spread over s weeks and the length of intervention given at each session is 90 minutes. There are four phases: professional-dominated phase, participatory phase, challenging phase, and collaborative phase. The Program contains individual and group education, caregiving skill training, and home and telephone visits (see **Table 1**). The Program content was validated by five experts in the fields of gerontology, education, and family nursing. This was revised according to the recommendations of those experts, and piloted with three older people with dependency and their family caregivers before full implementation.

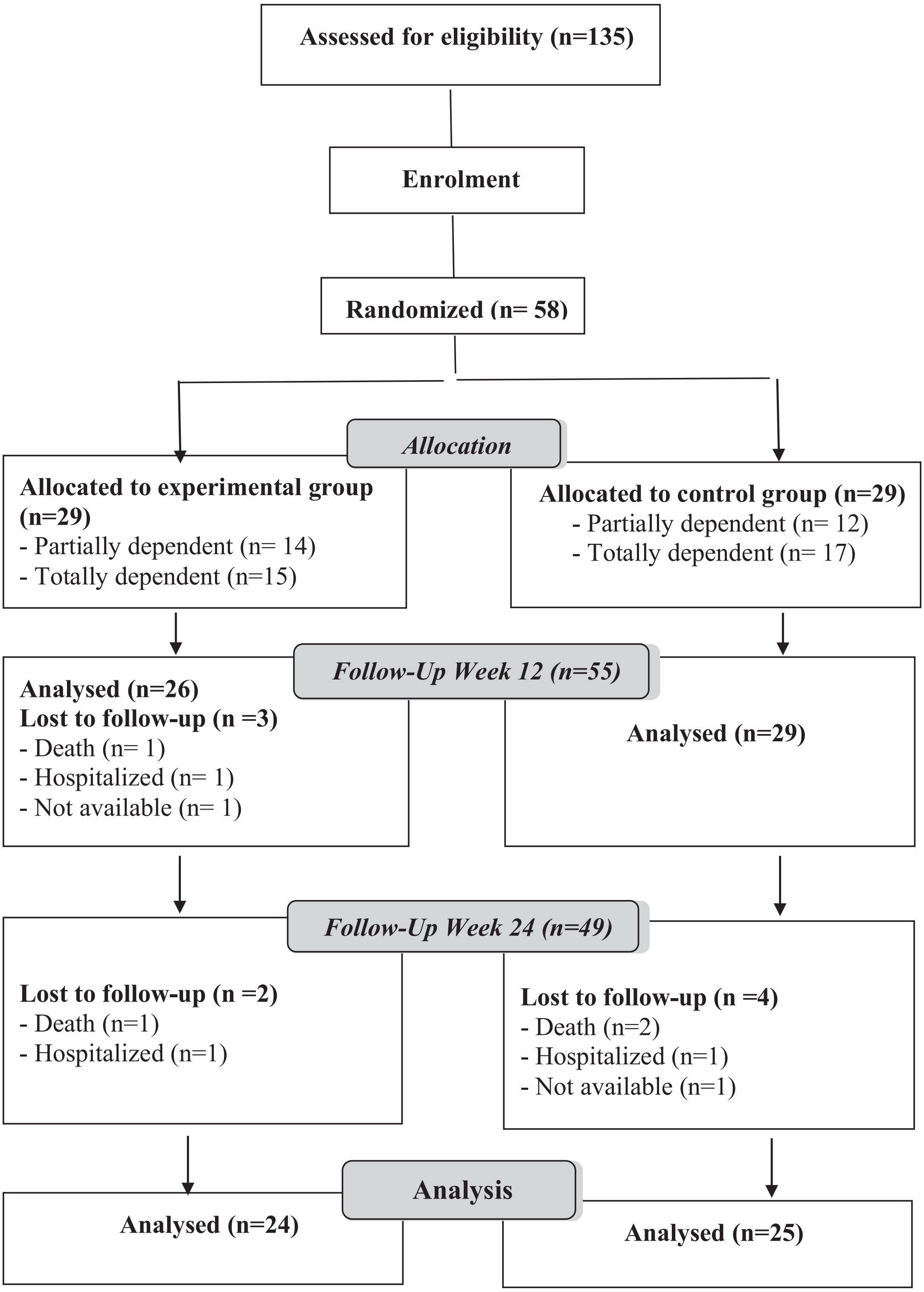

**Figure 1**: Flow Diagram of Recruitment and Analysis

**Table 1** Schedule and Content of FCCBP Intervention Program

| Week/Session | Content | Empowerment Strategies |
|---|---|---|
| **Week 1** | **Professional-dominated phase** | |
| Session1 (90 mins) | Information about problems and needs of older people with dependency and needed skills to fulfill those needs. | - Building trust by creating rapport with the families and establish a direct relationship with the family caregivers. |
| Session2 (90 mins) | Information about most common chronic diseases, common geriatric syndrome, approaches to self-care. | - Prioritizing families' perceived needs.<br>- Providing accurate and complete information. |
| **Week 2** | Information about roles of caregivers, caregiving activities, and home and environment modification. | |
| Session 3 (90 mins) | | - Supporting caregivers to set goals. |
| Session 4 (30 mins) | Refreshing knowledge session 1-3. | |
| **Week 2** | | |
| Session 3 (90 mins) | Information about roles of caregivers, caregiving activities, and home and environment modification. | - Providing accurate and complete information. |
| Session 4 (30 mins) | Refresh knowledge session 1-3. | - Supporting the caregivers in setting goals |
| **Week 3** | **Participatory phase** | |
| Session 5 (90 mins) | Group and individual demonstration and return demonstration on the basic activities of daily living, including bathing, dressing, eating, mobility, moving from chair to bed and vital signs monitoring. | - Helping family determine the family care.<br>- Providing accurate and complete information.<br>- Supporting caregivers in setting goals. |
| Session 6 (90 mins) | Information about prevention of complications of immobilization, care activities for persons with drainage, feeding, urinary catheter care and constipation prevention and management. | - Guiding caregivers in assessing support system, resources and strengths.<br>- Strengthening capacity of caregivers in caring and problem solving. |
| **Week 4** | | |
| Session 7 (90 mins) | Information on rehabilitation. | |
| Session 8 (30 mins) | Refresh knowledge session 5-8. | |
| **Week 5** | **Challenging phase** | |
| Session 9 (90 mins) | Communication strategies, and partnership relationship development. | - Supporting caregivers in peer support group. |
| Session 10 (90mins) | Problem solving and negotiation skills. | - Reinforcing family's ability to identify healthcare choices. |

**Table 1** Schedule and Content of FCCBP Intervention Program (continued)

| Week/Session | Content | Empowerment Strategies |
|---|---|---|
| | | - Discussions with caregivers regarding advocacy techniques.<br>- Building skills in negotiating with health professionals. |
| **Week 6** | **Collaborative phase** | |
| Session 11 (90 mins) | Repeating implementation by reviewing skills and troubleshooting; questioning knowledge until score indicates improvement of preparedness for caregiving. | - Monitoring and supporting about caregiving skills at home.<br>- Acknowledging family caregivers for their better care. |

***Data collection:*** Three instruments were used:

*The Caregiver's Care Ability Scale* (CCAS) was developed by Pukdeeporm[34] to measure the ability of family caregivers to care for older people with dependency. It consists of 14 positive and negative questions that measure the ability to provide care in four dimensions, physical care, psychological care, social care, and environmental care. Each item is assessed on a Likert-type scale from 1-5, where 1 = "I do not agree at all" and 5 = "I completely agree." A higher score means higher ability of care, while a lower score means lower ability of care. Five experts in the fields of gerontology, education, and family nursing validated the content. The content validity index was .83. The explanations and suggestions from experts were taken into attention to revise the CCAS. The pre-test reliability for the CCAS was tested with 15 family caregivers who were similar to the sample. Cronbach's alpha demonstrated an acceptable reliability of 0.93, and 0.81 for the main study.

The *Quality of Care Assessment Scale* (QUALCARE) was developed in English by Philips *et al.*[19-21] to measure QoC. It contains 53 items that measure six components: environmental, physical, psychosocial, medical management, human rights, and financial aspects. The scoring for this 5-level measurement ranges from 1 (best possible care) to 5 (worst possible care) points. A lower scores indicates higher QoC.

The QUALCARE was translated from English into Thai by the researcher and a translator, who was an expert in foreign language, and then back-translated from Thai into English by two bilingual experts. Comparison of the back-translated version of the QUALCARE to the original English version was made by the research team. Finally, the original English version and the back-translated English version were compared for semantic equivalence in translation. The QUALCARE was tested for its internal consistency reliability using inter-rater reliability. This technique was used to assess the degree to which different observers gave consistent estimates of the same phenomena. A research assistant and researcher were assigned to observe the QoC of one participant by following the items on the QUALCARE and providing a score with three family caregivers. Then the calculation of the correlation between the ratings of the observers was conducted and the results indicated an acceptable inter-rater agreement index which was 1.0.

The *Preparedness for Caregiving Scale* (PCS)[35-38] was developed by Wirojratana[38] to measure preparedness of Thai family caregivers caring for older people. The PCS includes 8 items with a 5-point scale ranging from 0 (not at all prepared) to 4 (very well prepared). The higher the score the better prepared are the family members for caregiving.

***Data collection procedures:*** At baseline assessment in the first week, all participants were asked to provide demographic information and data on preparedness of care, caregiver's care ability, and QoC at their own home. The intervention began one week after the baseline measures were administered. The experimental groups received the FCCBP program of 11 sessions, 90 minutes per session for 6 weeks, including individual and group education, caregiving skill training, and home and telephone visits, while the control group received only usual home visit. Data were obtained at weeks 12 for caregiver care ability and at week 24 for QoC.

***Data Analysis*:** Descriptive statistics were used to explain the demographic data. Chi-square, Fisher's tests, and t-tests were used to examine the differences between the experimental and control groups. Paired t-tests and independent t-tests were conducted to test the differences in the mean scores of caregiver care ability and QoC.

## Results

The participants were 59 family caregiver of older people with dependency needs randomly divided into the experimental and control groups, 29 in each group. There were three dropped cases (15.51%) after the 12 weeks and six dropped out cases after 24 weeks. The mean ages in the experimental and control groups were 46.7 years (SD = 8.0) and 45.3 years (SD = 11.5) respectively. There were more female participants than male in both groups (92.3% vs. 7.7% in the experimental group, 86.2% vs.13.8% in the control group). More than half the participants in both groups were married (73.1% vs. 82.8%), and most had at least primary school education (76.9% vs. 72.1%). The majority of caregivers were daughters of the older relative (61.6% vs. 62.1%). All demographic characteristics were not significantly different between experimental and control groups **(Table 2)**.

**Table 2:** Comparison of Demographic Characteristics of Family Caregivers between Experimental and Control Groups

| **Variable** | **Experimental Group (n=26)** | **Control Group (n=29)** | **t-test** | **$X^2$-test** | **Fisher's Exact** | ***p*-value** |
|---|---|---|---|---|---|---|
| | **n (%)** | **n (%)** | | | | |
| Age | | | | | | |
| 20-29 | 2 (7.7) | 3 (10.3) | 1.224 | | | .227 |
| 30-39 | 1 (3.8) | 3 (10.3) | | | | |
| 40-49 | 13 (50.0) | 14 (48.3) | | | | |
| 50-59 | 10 (38.5) | 9 (31.0) | | | | |
| ($\overline{X}$, SD) | (46.7, 8.0) | (43.5,11.5) | | | | |
| Gender | | | | | | |
| Male | 2 (7.7) | 4 (13.8) | | .525 | | .672 |
| Female | 24 (92.3) | 25 (86.2) | | | | |
| Marital status | | | | | | |
| Single | 6 (23.1) | 5 (17.2) | | 1.513 | | .469 |
| Married | 19 (73.1) | 24 (82.8) | | | | |
| Separated | 1 (3.8) | | | | | |
| Educational level | | | | | | |
| No formal education | 4 (15.4) | 9 (31.0) | | | | |
| Primary school | 20 (76.9) | 18 (62.1) | | 1.870 | | .393 |
| Secondary school and higher | 2 (7.7) | 2 (6.4) | | | | |
| Occupation | | | | | | .827 |
| Working at home | 9 (34.6) | 7 (24.1) | | .895 | | |
| Civil servant | 1 (3.8) | 1 (3.4) | | | | |
| Employee | 13 (50.1) | 18 (62.2) | | | | |
| Farmer | 3 (11.5) | 3 (10.3) | | | | |

**Table 2:** Comparison of Demographic Characteristics of Family Caregivers between Experimental and Control Groups (continued)

| Variable | Experimental Group (n=26) | Control Group (n=29) | t-test | $X^2$-test | Fisher's Exact | *p*-value |
|---|---|---|---|---|---|---|
| | n (%) | n (%) | | | | |
| Relationship | | | | | | .558 |
| Daughter | 16 (61.6) | 18 (62.1) | | | .440 | |
| Son | 4 (15.4) | 1 (3.4) | | | | |
| Daughter-in-law/son-in-law | - | 3 (10.3) | | | | |
| Grandchild | 4 (15.4) | 6 (20.7) | | | | |
| Sister/brother | 1 (3.8) | 1 (3.4) | | | | |
| Spouse | 1 (3.8) | - | | | | |
| Sufficiency of income | | | | | | .155 |
| Sufficient income | 6 (23.1) | 13 (44.8) | | 2.868 | | |
| Not sufficient income | 20 (76.9) | 16 (55.2) | | | | |

After attending the Program the experimental group had significantly higher overall care ability than at the baseline ($p<.05$), except social aspect. There were significant differences in overall QoC, physical, psychological, and financial aspects ($p<.01$), but environmental, medical management, and human rights dimensions **(Table 3)**. When comparing between groups, the experimental group had significantly higher overall care ability and their dimensions than those in the control group ($p < .01$), except social aspect. There were no significant differences in overall QoC and its dimensions, except for the physical aspect ($p < .05$) **(Table 4)**. Furthermore, the effect size was analyzed and interpreted using Cohen's classification (0.2 = small, 0.5 = medium, and 0.8 = large). Effect size for caregiver care ability (0.75) and QoC (0.27) were medium and small, respectively.

**Table 3** Comparison of Caregiver Care Ability and Quality of Care (QoC) of Family Caregivers in the Experimental Group

| Variables | Mean(SD) | | t | *p*-value |
|---|---|---|---|---|
| | Baseline | Post-test | | |
| **Care Ability*** | 47.44(3.65) | 50.35(3.69) | -4.72 | .00 |
| Physical | 24.25(2.28) | 26.85(3.15) | -5.49 | .00 |
| Psychological | 6.13(0.96) | 5.80(0.83) | 2.23 | .03 |
| Social | 9.82(1.11) | 9.69(0.98) | 0.63 | .53 |
| Environmental | 7.24(0.88) | 7.73(0.97) | -3.03 | .00 |
| QoC** | 127.00(20.10) | 120.10(20.33) | 3.76 | .00 |
| Environmental | 33.02(7.66) | 33.45(7.66) | -0.63 | .53 |
| Physical | 26.06(4.28) | 21.98(4.91) | 6.18 | .00 |
| Medical Management | 12.61(2.91) | 12.43(2.29) | 0.51 | .61 |
| Psychological | 27.29(4.80) | 25.08(4.33) | 3.36 | .00 |
| Human Rights | 14.49(2.69) | 14.76(2.47) | -0.56 | .58 |
| Financial Aspect | 13.53(2.81) | 12.41(3.10) | 3.09 | .00 |

* Post-test = Data were collected 12 weeks after completion of the interventions.

** Post-test = Data were collected 24 weeks after completion of the interventions.

**Table 4** Comparison of Caregiver's Care Ability and QoC of Family Caregivers between the Experimental and Control Groups Pre- and Post-Intervention

| Variables | Experimental Group | Control Group | t | *p*-value |
|---|---|---|---|---|
| | **M (SD)** | **M (SD)** | | |
| Baseline Care Ability | 47.69 (3.73) | 47.41(3.70) | 0.28 | .78 |
| Physical | 24.21(2.13) | 24.41(2.39) | 0.73 | .59 |
| Psychological | 6.34(0.89) | 6.00(1.94) | 1.36 | .18 |
| Social | 9.83(1.36) | 9.79(0.92) | 0.11 | .91 |
| Environmental | 7.31(0.89) | 7.21(0.86) | 0.45 | .65 |
| Baseline QoC | 123.96(13.92) | 129.92(24.56) | -1.05 | .30 |
| Environmental | 32.17(5.23) | 33.84(9.47) | -0.77 | .45 |
| Physical | 25.13(3.42) | 26.96(4.88) | -1.53 | .13 |
| Medical management | 12.21(2.50) | 13.00(3.25) | -0.96 | .34 |
| Psychological | 26.58(4.09) | 27.96(5.38) | -1.01 | .32 |
| Human Rights | 14.58(1.84) | 14.40(3.35) | .24 | .81 |
| Financial Aspect | 13.29(2.71) | 13.76(2.93) | -.58 | .56 |
| Post-test Caregiver Care Ability | 51.73 (3.57) | 49.10 (3.40) | 2.79 | .00 |
| Physical | 28.58(2.25) | 25.31(3.07) | 4.53 | .00 |
| Psychological | 5.50(0.81) | 6.07(0.75) | -2.69 | .00 |
| Social | 9.46(0.86) | 9.90(1.05) | 53 | .97 |
| Environmental | 8.04(0.87) | 7.45(0.99) | 2.36 | .02 |
| Post-test QoC | 117.29 (13.36) | 122.80 (25.29) | -0.96 | .34 |
| Environmental | 33.83(6.72) | 33.08(8.59) | .34 | .73 |
| Physical | 20.54(2.04) | 23.37(6.34) | -2.11 | .04 |
| Medical management | 12.04(2.07) | 12.80(2.47) | -1.17 | .25 |
| Psychological | 24.54(2.45) | 25.60(5.58) | -1.01 | .32 |
| Human rights | 14.38(1.47) | 15.12(3.14) | -1.07 | .29 |
| Financial aspects | 11.96(2.64) | 12.84(3.45) | -1.00 | .32 |

## Discussion

The findings of this study partially support the hypotheses in that after receiving the Program, the experimental group had a significantly higher overall mean scores on caregiver care ability and on physical, psychological and environmental dimension than at baseline and compared to the control group. However, there was no significant difference in the social aspect. These results are congruent with the assumptions of Hume's family empowerment to focus on assisting the change of behavior conditions through the Program following strategies in four stages: professional-dominated, participatory, challenging, and collaborative phase. The Program achieved its aim of building the care ability of caregivers by giving health education and skills, establishing a relationship between an older people and family caregivers, discussing in small group to share their experiences, supporting and empowering family caregivers to do good performance for older adults.[12-13, 24-25] Thus, we believed the Program strengthened the confidence of family caregivers, improving care by creating a sense of self-worth, and lowering expenditures for patient care and all of which lead to a higher QoC for older people with dependency.[13-16, 29-31] The results of this study were consistent with the findings of previous studies of caregiver-empowerment programs, based on Gibson's concept of empowerment[9-11,25] involving recognizing the caregiving burden, realizing the potential value of care, and committing to care for six months, showing that the mean difference in the burden of care at the posttest compared to before the Program had a statistically significant difference.[10-11] Unfortunately, there were no significant differences in the mean social aspect in this study in the experimental group and between groups. The findings are not surprising since these two groups had similar limitations in earning incomes in their family. That is, they did not have sufficient income and they had to take responsibility to care for their older relative in congruence with Thai traditions of family responsibility. This might limit caregivers in both groups to find chances to participate in social activities with the community, resulting in a lack of practice of skills in empowering themselves in taking care of older people.[1-3, 38]

For the QoC the overall mean scores at posttest and on physical, psychological and financial dimensions were improved significantly from those at baseline, but there was a significant difference in the environmental, medical management, and human rights dimensions. When compared with the control group, there was no significant difference between groups on overall mean score at posttest and other aspects except physical dimension. These results partially achieved following Hulme's family empowerment concept reporting that care ability will lead to better QoC for older people.[16-20,30-31] However, this study did not show significant differences in every aspect either in the experimental group or between groups that might result from many factors including inappropriate home environment, family income, health education, community resources, and health insurance.[1-3,18,21] Thus, nurses can help work family problems out through considering and educating them about factors that assist with better QoC for older adults with dependency. Moreover, the activities of the Program were concerned individual and group education, caregiving skill training, and home and telephone visits to enhance their care ability.

These findings were congruent with a controlled trial study of hospitalized older people in the CARE program (Creating Avenues for Relative Empowerment) which reported that there had no difference in emotional coping measures for QoC at 2 weeks and 2 months, except for the care role of family caregivers.[18] However, some studies found that follow-up activities for one year including home visits and telephone, and positive reinforcement for caregiver skills significantly increased QoC.[16-18]

## Limitations and Issues in Study

The researcher met with the experimental group on 11 occasions for 90 minutes per session, assisting them and collecting data. However, the participants found it was inconvenient to join the group for every meeting because they were involved with caregiving at home. Thereafter, the researcher met the participants individually in home visits. In future studies, the program could be adjusted to have more appropriate follow up using health care volunteers in community.

## Conclusion and Implication for Nursing Practice

Findings revealed that the Program could be an effective intervention for the strengthening care ability of family caregivers who provide care for older people with dependency. Nurses in the district hospitals or sub-district health promoting hospitals could apply the Program to improve care ability of family caregivers resulting in achieving QoC for their relatives. In future studies researchers should consider meeting with the experimental group less frequency and use a double-blinded technique. As well we recommend that there should be follow up for at least a year after the initial Program, using home visits and telephone calls, and data collection should be undertaken in the home as well.

## Acknowledgements

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# โปรแกรมการเสริมสร้างศักยภาพญาติผู้ดูแลในครอบครัวสำหรับผู้สูงอายุที่มีภาวะพึ่งพิงในประเทศไทย: การวิจัยแบบทดลองเชิงสุ่ม

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การวิจัยทดลองแบบสุ่มครั้งนี้มีวัตถุประสงค์เพื่อศึกษาผลของโปรแกรมการเสริมสร้างศักยภาพญาติผู้ดูแลในครอบครัวต่อความสามารถในการดูแลและคุณภาพการดูแลของผู้ดูแลในครอบครัว กลุ่มตัวอย่างเป็นผู้ดูแลผู้สูงอายุที่มีภาวะพึ่งพิงที่อาศัยอยู่ใน 2 ชุมชนชนบทในเขตภาคกลางของประเทศไทย จำนวน 55 รายได้รับการสุ่มเข้ากลุ่มควบคุมจำนวน 29 รายและกลุ่มทดลองจำนวน 26 ราย กลุ่มทดลองได้รับโปรแกรมเสริมสร้างศักยภาพ ที่สร้างขึ้นตามแนวคิดการเสริมสร้างศักยภาพครอบครัวของฮูม กลุ่มควบคุมได้รับการเยี่ยมบ้านจากอาสาสมัครตามปกติ รวบรวมข้อมูลความสามารถในการดูแลก่อนและหลังการได้รับโปรแกรม 12 สัปดาห์และประเมินคุณภาพการดูแลก่อนและหลังการได้รับโปรแกรม 24 สัปดาห์ วิเคราะห์ข้อมูลโดยใช้สถิติเชิงพรรณนาและสถิติที

ผลการศึกษาพบว่า ภายหลังได้รับโปรแกรมในกลุ่มทดลอง มีคะแนนเฉลี่ยความสามารถในการดูแลโดยรวมสูงกว่าก่อนทดลองอย่างมีนัยสำคัญทางสถิติ ยกเว้นมิติด้านสังคม ส่วนคะแนนเฉลี่ยคุณภาพการดูแลโดยรวม ด้านร่างกาย ด้านจิตใจ และประเด็นทางการเงิน ดีกว่าก่อนทดลองอย่างมีนัยสำคัญทางสถิติ ยกเว้นด้านสิ่งแวดล้อม ด้านการจัดการความเจ็บป่วย และด้านสิทธิผู้ป่วย เมื่อเปรียบเทียบระหว่างกลุ่มพบว่ากลุ่มทดลองมีคะแนนเฉลี่ยความสามารถในการดูแลโดยรวมและรายด้านดีกว่ากลุ่มควบคุมอย่างมีนัยสำคัญทางสถิติ ยกเว้นด้านสังคม ส่วนคะแนนเฉลี่ยคุณภาพการดูแลโดยรวมไม่แตกต่างกันอย่างมีนัยสำคัญทางสถิติ ยกเว้นด้านร่างกาย ค้นพบครั้งนี้แสดงให้เห็นว่าโปรแกรมการเสริมสร้างศักยภาพญาติผู้ดูแลในครอบครัวมีประสิทธิภาพในการเพิ่มความสามารถของญาติในการดูแลและคุณภาพการดูแลผู้สูงอายุที่มีภาวะพึ่งพิงพยาบาลที่ปฏิบัติงานในโรงพยาบาลชุมชนหรือโรงพยาบาลส่งเสริมสุขภาพตำบลควรนำโปรแกรมไปส่งเสริมศักยภาพของญาติผู้ดูแลในครอบครัวทำให้เกิดคุณภาพการดูแล การศึกษาครั้งต่อไปควรทดสอบประสิทธิผลของโปรแกรมในชุมชนที่มีความความคล้ายกันในประเทศไทย

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# Predicting Factors of Uncertainty in Illness Among Children with Leukemia Undergoing Chemotherapy

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**Abstract:** Leukemia in children is a life-threatening disease and chemotherapy is a complex treatment with severe side effects and complications. Furthermore, the treatment results are unpredictable. This leads to uncertainty in illness resulting in psychological distress. This descriptive cross sectional study aims to examine the predicting factors of uncertainty in illness among children with leukemia undergoing chemotherapy. Ninety-six children with leukemia undergoing chemotherapy in four tertiary hospitals in Bangkok participated in this study. The research instruments included the Children's Uncertainty in Illness Scale, the Symptom Pattern Scale of Children with Cancer, the Information Support from Health Care Provider Scale, the Information Support from Parent Scale, the Information Support from Peer Scale, the Illness Knowledge Scale, and the Parent Perception of Uncertainty Scale. The results of stepwise multiple regression analysis revealed that symptom pattern, information support from health care providers, illness-related knowledge, and parental uncertainty accounted for 34.8% of variance in uncertainty in illness among the participants. This study provides more understanding for predicting factors of child uncertainty. The results of this study can be used for developing a nursing intervention to reduce uncertainty in illness among children with leukemia undergoing chemotherapy if nurses help them to better understand symptoms as having a pattern, provide information support and illness related knowledge, and decrease parental uncertainty.

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**Keywords:** Chemotherapy; Children; Illness uncertainty; Information support; Leukemia; Predicting factors; Thailand.

## Introduction

Leukemia is the most common childhood cancer.[1,2] Leukemia in children under 15 years of age accounts for about 70% of childhood cancers in the United States[3] and for about 50% of childhood cancers in Thailand.[4] The annual incidence in 2008 for lymphoblastic leukemia in children aged under 15 years was 21 per million in boys and 10 in girls.[5] As chemotherapy is the primary treatment modality for

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leukemia in children, this incidence indicates that a large number of children with leukemia are affected by illness and chemotherapy.[6,7]

Potentially life-threatening aspects of leukemia and suffering from side effects and complications of chemotherapy lead to uncertainty in illness among children with cancer during the time of cancer diagnosis and through each stage of treatment.[8] Previous studies have demonstrated that children with cancer undergoing chemotherapy experience moderate to high levels of uncertainty in illness.[9,10] This uncertainty in illness leads to psychological distress,[11,12] interferes with children's ability to cope with illness-related stressors, and decreases their ability to take care of themselves.[12] Thus, nurses should be aware of uncertainty in illness of children with leukemia undergoing chemotherapy and its consequences, and provide nursing interventions to reduce their uncertainty. Currently, there is no research on interventions for reducing uncertainty in illness of these children. Interventions in any form can be effectively developed only if predicting factors of uncertainty in illness are clearly identified.

To date, knowledge regarding the predicting factors of uncertainty in illness among children with cancer is limited. There have been only two studies examining factors predicting uncertainty in illness of children with cancer.[10,12] One study was conducted with American children with cancer aged 8 - 18 years and another was done in Thai children with cancer aged 8 - 15 years receiving chemotherapy. The findings from the two studies did not support well Mishel's uncertainty in illness theory[13]. According to Mishel,[13] uncertainty in illness is influenced by the stimuli frame including symptom pattern, event familiarity and event congruence; as well as social support. However, a previous study[10] revealed that the stimuli frame and social support explained only 9.3% of variance in uncertainty in illness. As children's level of cognitive development could differently affect their ability to determine the meaning of illness-related events,[14] younger children might have had difficulty understanding the abstract nature of the stimuli frame and vice versa. In addition, various types of cancer and different treatment modalities - i.e. chemotherapy, radiation and surgery - would result in different illness-related events, and thus different experiences. Therefore, previous studies of factors predicting uncertainty in illness done in a heterogeneous sample might yield different result from that done in a homogenous one. This finding needs to be confirmed in a homogenous sample of children with similar cognitive development level.

To overcome the limitations in previous studies regarding age, cancer types and treatment modalities, this study examined the level of uncertainty in illness and its predicting factors among children with leukemia aged 10-15 years undergoing chemotherapy. The findings of this study can be used to develop an effective intervention to reduce uncertainty of these children, thereby increasing their well-being.

## Theoretical framework and Review of Literature

Uncertainty in illness theory[13] was used to guide this study. According to this theory, uncertainty is the inability to determine the meaning of an illness event. Uncertainty in illness of individuals occurs during the diagnostic and treatment phases in four forms: ambiguity regarding illness events, complexity about the treatment, lack of information about the diagnosis and the illness, and unpredictability of the health outcome.[13,15]

Uncertainty in illness is influenced by the stimuli frame that includes symptom pattern, event familiarity and event congruence. In addition, uncertainty is also influenced by structure providers, including social support from friends, family and those with similar experiences, as well as information from credible authorities such as health care providers also influence uncertainty.[15]

Symptom pattern is the degree to which symptom occurrence – including number, frequency, intensity, duration and location – has enough consistency to be perceived as having a pattern.[13,15] A symptom pattern is a predicting factor of uncertainty explaining 9.2% of the variance in uncertainty of children with leukemia and lymphoma.[16] According to Mishel,[15] the symptom pattern is considered the important component of the stimuli frame, a major concept relating to uncertainty. It was thus included in the present proposed model predicting uncertainty in illness among children with leukemia in this study.

Information support, as a dimension of social support, is another major factor influencing uncertainty in illness, and has been argued to be more likely than other dimensions to directly affect uncertainty.[15] Sharing information with persons in their social network assists the individual to properly appraise symptoms, which results in lower uncertainty.[17] Children with cancer need information about their diagnosis, treatment and side effects, and care practices from health care providers.[18,19] They need information for problem solving and modifying their uncertainty.[15] Information support, according to House[20] is the perceived and provided advice, suggestions, and information for problem solving. Prior studies have revealed that information support from parents, friends, nurses, and physicians were a predicting factor of uncertainty in illness among Thai children with cancer receiving chemotherapy[16], and children with SLE.[21] However those studies did not investigate if the support from each separate source was related to uncertainty. As information support can be from various sources depending on the children's perception and preference, it is worth identifying the source. Information support from parents, peers and health care provider were proposed to have association with the children's uncertainty in this study.

Parental uncertainty regarding their child's illness is another factor that has been found to influence the uncertainty of children and adolescents with cancer.[12] Evidence has shown that parental uncertainty has a significant effect on uncertainty among children 8-18 years who were undergoing treatment for any form of cancer.[12] In addition, maternal uncertainty was a predicting factor of child uncertainty in illness among children with chronic illnesses between 8 and 12 years of age.[22]

Illness-related knowledge is another factor associated with the uncertainty of chronically-ill children. A moderate negative relationship was found between knowledge regarding the illness and illness uncertainty of children with SLE.[21] The empirical evidence on the relationship between illness-related knowledge and uncertainty in illness of children with cancer is inconsistent. Stewart's study[12] indicated that higher cancer knowledge predicted lower uncertainty in a given age of child. However, illness-related knowledge of Thai children with leukemia and lymphoma was not a predicting factor of uncertainty in illness.[10] Therefore, illness-related knowledge should be investigated for its predictability of children's uncertainty.

## Research Hypothesis

Symptom pattern, information support from health care providers, information support from parents, information support from peers, parental uncertainty, and illness-related knowledge can predict uncertainty in illness among children with leukemia undergoing chemotherapy.

## Methods

**Design:** A cross-sectional, predictive design was used.

**Sample and Setting:** The target population of this study was children with leukemia aged 10-15 years who were undergoing chemotherapy in tertiary hospitals and their parents. There were two groups of subjects: one was the children and the other was parents, either the mother or father. Purposive sampling was used to select children based on the following inclusion criteria: (1) ability to understand and communicate in Thai, and (2) willingness to participate in this study. Meanwhile, the parents of those children with leukemia were recruited based on the following inclusion criteria: (1) ability to understand and communicate in Thai, (2) willingness to participate in this study, (3) cohabitation with the child, and (4) provision of care for their child at the hospital.

The sample size was determined with consideration of the representative sample to reduce type II errors using power analysis, with a significance level of .05, a power of .80, and the moderate effect size ($f^2$) of 0.15.[23] The final sample size was 96 children and 96 parents.

**Ethical Considerations:** Ethics approval was obtained from the Ethics Review Committee for Research Involving Human Research Subjects of the Faculty of Nursing, Chiang Mai University, as well as from four data collection hospitals. Each potential participant was informed about the details of the study and was assured of his or her confidentiality, anonymity, and the right to withdraw at any time without repercussion. The children had to have parental permission to participate and they were able to ask questions regarding the study and could withdraw from the study at any time without having any effect on their treatment or services provided. A signed informed consent form from the parents and a signed-assent form from the child were obtained.

**Instruments:** Seven questionnaires were used to collect data as follows:

The *Children's Uncertainty in Illness Scale* (CUIS) was originally developed by Mullins and Hartman[24] and translated into Thai by Kantawang.[25] It is a 23-item self-report questionnaire used to measure the child's perceived illness uncertainty about the course, prognosis and treatment of their illness, and assesses their perceived ambiguity and unpredictability about their condition and the lack of information. Participants rate items (e.g., "I have a lot of questions about my illness, I don't know what the answers are") on a 5-point scale ranging from 1 (very true) to 5 (very false). The total score is obtained by summing up the score across all items, with the higher the score, the higher the uncertainty. This score was classified into three levels including low (23 - 53), moderate (54 - 84), and high (85 - 115). The Cronbach alpha coefficient pilot-tested with 10 children with leukemia undergoing chemotherapy was .81. The reliability of the CUIS with the whole group 96 participants was .71.

The *Symptom Pattern Scale of Children with Cancer* (SPCC) is a subscale of the Stimuli Frame of Children with Cancer Scale developed by Tathong et al.[10] based on the symptom pattern concept of Mishel's uncertainty in illness theory (1988). It consists of 8 items (e.g., "My condition worsened in the first two weeks of receiving chemotherapy") with a 3-point scale rating scale (1= disagree, 2 = agree, and 3 = strongly agree). The total score is obtained by summing up the score across all items. The higher the score indicated the higher the symptom pattern. The content validity of the SPCC was not determined because this study used the original questionnaire, which has already been validated for content to measure symptom pattern of Thai children with cancer.[10] The Cronbach alpha coefficient pilot-tested with 10 participants was .80. The reliability of the SPCC with the whole group of 96 participants was .79.

The *Information Support from Health Care Provider Scale* (ISHCP) was modified from the Information Support Subscale of Social Support of Children with Cancer Scale with the permission of the owner.[10] It is used to assess the perception of children about information support from nurses and physicians. Six items of the original version were used and 6 new items were added. It consists of 12 items (e.g., "I received an explanation about the disease and the treatment from nurses or doctors") with a 3-point rating scale, including 1 (not true), 2 (true), and 3 (very true). The total score is obtained by summing up the score across all items, with the higher the score, the higher the information support from health care providers. The scale-level content validity index (S-CVI) was 1.00 determined by 5 experts. They were three nurse instructors who had expertise in caring of children with cancer, one pediatric oncology physician, and one advanced practice nurse in pediatric oncology. The Cronbach alpha coefficient was .90 in the pilot tested and .81 for the whole group.

The *Information Support from Parent Scale* (ISPS) was modified from the Information Support Subscale of Social Support of Children with Cancer Scale with the permission of the owner.[10] It is used to assess perception of children about information support from parents. Six items of the original version were used and 3 new items were added. It consists of 9 items (e.g., "I've been receiving information about the disease and chemotherapy from parents") with a 3-point rating scale including 1 (not true), 2 (true), and 3 (very true). The total score is obtained by summing up the score across all items, with the higher the score, the higher the information support from parents. The S-CVI was 1.00 determined by 5 experts. The Cronbach alpha coefficient was .81 in the pilot tested and .61 for the whole group.

The *Information Support from Peer Scale* (ISPeerS) was modified from the Information Support Subscale of Social Support of Children with Cancer Scale with the permission of the owner.[10] It is used to assess the perception of children about information support from friends who were children with leukemia. Five items of the original version were used and 3 new items were added. It consisted of 8 items (e.g., I've been receiving information about the disease and chemotherapy from friends who are children with my illness") with a 3-point rating scale, including 1 (not true), 2 (true), and 3 (very true). The total score is obtained by summing up the score across all items, with the higher the score, the higher the information support from peers. The S-CVI was 1.00 determined by 5 experts. The Cronbach alpha coefficient was .94 in the pilot tested and .90 for the whole group.

The *Illness Knowledge Scale* (IKS) was modified from the Illness Knowledge of Children with Cancer Scale of Tathong et al[8] which got permission to use. A modified version of the instrument was used to assess the children's understanding regarding leukemia, side effects and complications of chemotherapy, and care practices. It consists of 37 true-false questions (e.g., "Children with illness will be exhausted, pale, bleeding and often have a fever"). The total score is obtained by summing up the score across all items, with the higher the score, the higher the illness-related knowledge. The S-CVI was 1.00 determined by 5 experts. The Cronbach alpha coefficient was .80 in the pilot tested and .83 for the whole group.

The *Parent Perception of Uncertainty Scale* (PPUS) was developed by Mishel and translated into Thai by Suwanna-o-sod.[26] It is used to assess parents' uncertainty about their child's illness. It has 31 items (e.g., "I don't know what's wrong with my child") using a 5-point Likert scale (strongly disagree to strongly agree). The total score is obtained by summing up the score across all items, with the higher the score, the higher the parental uncertainty. The content validity of PPUS was not determined because this study used the original Thai version questionnaire, indicating a good content validity to measure parental uncertainty of Thai parents' children with cancer.[26] The Cronbach alpha coefficient was .91 in the pilot tested and .86 for the whole group.

## Data Collection

Data were collected at both pediatric oncology wards and a chemotherapy unit for outpatients by the researcher and a research assistant trained in these data-gathering processes. The children completed six questionnaires by answering each item read to them by the researcher/ a research assistant for 20 minutes, with a 5-minute intermission period. At the same time, the parents completed the PPUS by themselves.

## Data Analysis

Descriptive statistics including frequency and percentage were used to provide a portrait of participants' demographics, as well as the uncertainty in illness of children with leukemia. Stepwise multiple regression analysis was used to examine the predictability of the symptom pattern, information support from health care providers, information support from parents, information support from peers, illness-related knowledge and parental uncertainty on uncertainty in illness of the children with leukemia. The assumptions of normality, linearity, homoscedasticity, and multicollinearity were met for this multiple regression analysis.

## Results

Ninety-eight children participated in this study, two of whom were excluded: one was not allowed by his mother to participate, the other was too fatigued to participate. Of the 96 children with leukemia, more than half were male (54.2%) aged between 12 - 15 years (56.25%), and in primary school (55.2%). The majority of parents were mothers (76.0%) of whom 49.0% were laborers. Regarding family income, 33.3% had an income <15,000 baht/month (469 US$) and another 33.3% had an income of 15,000-30,000 baht/month (469-938 US$). Two-thirds of the children (67.7%) had been diagnosed with leukemia > 1year. More than half (58.3%) had been admitted to the hospital 10 times or less. About 66% had undergone the maintenance phase of chemotherapy. During the data collection period, most of them (91.7%) had side effects from chemotherapy and 75% had more than one symptom. Of the children, 41.7% had complications including infection, bleeding, and anemia.

The descriptive statistics of the dependent variables, uncertainty in illness and the independent variables, including symptom pattern, information support from health care providers, information support from parents, information support from peers, parental uncertainty, and illness-related knowledge, are presented in Table 1. Based on Table 1, the levels of uncertainty in illness, symptom pattern, information support from peers, parental uncertainty and illness-related knowledge were at a moderate level, while the levels of information support from health care providers and parents were at a high level.

**Table 1** Descriptive Statistics for the Study Variables

| Variables | Possible Range | Actual Range | $\overline{X}$ | *SD* | Level |
|---|---|---|---|---|---|
| Uncertainty in illness | 23-115 | 48 – 91 | 70.05 | 8.52 | Moderate |
| Symptom pattern | 8 - 24 | 8 - 24 | 17.63 | 4.04 | Moderate |
| Information support from health care providers | 12 – 36 | 20- 36 | 30.94 | 4.27 | High |
| Information support from parents | 9 – 27 | 16- 27 | 23.53 | 2.69 | High |
| Information support from peers | 8 – 24 | 8- 24 | 13.38 | 4.69 | Moderate |
| Knowledge of illness | 0 – 37 | 14- 37 | 28.90 | 5.23 | Moderate |
| Parental uncertainty | 31 – 155 | 51- 125 | 86.42 | 14.56 | Moderate |

Pearson's product moment correlation was used to examine the relationships between the dependent variable and each independent variable, and the uncertainty in illness was positively associated with symptom pattern and parental uncertainty at a low level. In addition, uncertainty in illness was negatively associated with information support from health care providers and illness-related knowledge at a moderate level, as shown in Table 2.

**Table 2** Correlation Matrix of the Study Variables

| | CUnc | SymP | IHCP | IPar | IPeer | Know | PUnc |
|---|---|---|---|---|---|---|---|
| CUnc | 1 | | | | | | |
| SymP | .232* | 1 | | | | | |
| IHCP | -.319** | .253* | 1 | | | | |
| IPar | -.148 | .250* | .386** | 1 | | | |
| IPeer | .083 | .089 | .229* | .081 | 1 | | |
| Know | -.314** | .391** | .438** | .416** | .114 | 1 | |
| PUnc | .216* | -.008 | -.033 | -.211* | .090 | -.007 | 1 |

*p< .05, **p< .01

CUnc = Child uncertainty in illness

SymP = Symptom pattern

IHCP = Information support from health care providers

IPar = Information support from parents

IPeer = Information support from peers

Know = Knowledge related-illness

PUnc = Parental uncertainty

The multiple regressions revealed that symptom pattern, information support from health care providers, parental uncertainty, and illness-related knowledge were the predicting factors of uncertainty in illness among children with leukemia undergoing chemotherapy and accounted for 34.8% of the variances in uncertainty in illness, as shown in Table 3.

**Table 3** Multiple Regression for Predicting the Factors of Uncertainty in Illness

| Variables | $R^2$ | $R^2_{Change}$ | β | $p$ |
|---|---|---|---|---|
| Constant | | | | .000*** |
| Information support from health care providers | .102 | .102 | -.262 | .007** |
| Symptom pattern | .206 | .104 | .445 | .000*** |
| Knowledge-related illness | .305 | .099 | -.371 | .000*** |
| Parental uncertainty | .348 | .043 | .209 | .016* |

$SE^{est}$ = 7.025 F= 12.166 $p$ = .000*

## Discussions

In this study, four variables out of six, including symptom pattern, information support from health care providers, illness-related knowledge and parental uncertainty were found to be the main predicting factors of uncertainty in illness, accounting for 34.8% of the variance in uncertainty in illness among children with leukemia undergoing chemotherapy.

Information support from health care providers was found to be the predicting factor of the uncertainty of children with leukemia (β = - 0.262, p < .01). The children who reported higher information support from health care providers were less likely to have uncertainty. This might be because two-thirds of the children (67.7%) had been diagnosed with leukemia for longer than one year and 42.7% were admitted to hospitals more than 10 times. The children who experienced complex illness-related events may have gotten more information from nurses and physicians. The long duration of illness and frequent hospitalization led to a high probability of illness-related information.

Moreover, patients who develop a strong alliance with health care provider have maintained a higher level of well-being and greater perceived health care provider support.[27] The information helped those patients reduce the ambiguities and complexities, increased their understanding, reduced their unpredictability and made it simpler to clarify symptom patterns, leading to lower uncertainty.[15,19] The findings were congruent with the result of previous studies[16] that information support from health care providers can predict uncertainty in illness among children.

Symptom pattern was the predicting factor of uncertainty in illness among children with leukemia receiving chemotherapy ($\beta = 0.445$, $p < .001$). The children who perceived high symptom pattern had high uncertainty. Theoretically, when the children perceive symptoms as having consistency in frequency, intensity, and duration, their uncertainty is low. This might be because the majority of these children (66.6%) had undergone treatment in the maintenance phase, during which the children received low doses of chemotherapy. They had a long intermission period of two to three years[28] resulting in having symptoms with side effects that were sufficiently consistent that the children could perceive it as having a pattern. In general, during the maintenance phase, the children receive low doses of chemotherapy and should have fewer side effects and complications related to chemotherapy. However, most children in this study (91.7%) had side effects of chemotherapy: 75% had more than one symptom, and 41.7% had complications of chemotherapy that led them to experience complex illness-related events resulting in high uncertainty.[8] Furthermore, children with cancer within one to four years after diagnosis remained uncertain about the meaning of any pain, the unpredictability of physical distress, and the changing course of the illness.[29] Therefore, despite the fact that these children perceived a high symptom pattern in the maintenance phase, they might still have high uncertainty. Another possibility may be associated with the research instrument. The symptom pattern scale of children with cancer was developed on the basis of illness events that would occur during the induction phase. For example "I suffered from mouth sores and could not eat," or "I had to be placed in an isolated room after I received chemotherapy." Most of the questions/events in this instrument would not occur while experiencing the maintenance phase chemotherapy.

Illness-related knowledge was found to be another predictive factor of uncertainty of children with leukemia ($\beta = -0.371$, $p < .001$), in such a way that as illness-related knowledge increased, child uncertainty in illness decreased. This might be because the majority of children with leukemia had undergone the maintenance phase (66.6%) and possibly might have learned about their illness. Illness-related knowledge including leukemia, side effects and complications of chemotherapy, and care practices might assist children in interpreting their symptoms and illness-related events, resulting in low uncertainty. Similarly, uncertainty can be reduced by knowledge.[15] The findings were congruent with previous studies[12, 21] in which illness-related knowledge had a negative relationship with child uncertainty.

Parental uncertainty was found to be a predictive factor of uncertainty in children with leukemia ($\beta = 0.209$ $p < .05$), in such a way that as parental uncertainty increased, child uncertainty in illness also increased. Parental uncertainty has a negative impact on interactions with their children.[30] Parents' uncertainty about their child's illness could interfere with their capacity to provide information to support their child's illness schema formation, resulting in child uncertainty. Typically, the incidence of children with cancer may strengthen the link between parent and child psychological functioning.[31] The findings were congruent with previous studies[12] that parental uncertainty was found to be a predicting factor of child uncertainty. In addition, the majority of parents were mothers (76.0%), and this was consistent with previous studies[22] which showed that maternal uncertainty was the predictive factor of child uncertainty in illness.

Information support from parents and peers did not predict the uncertainty experienced by the children with leukemia. However, these two variables had a significant positive correlation with information support from health care providers ($r = .386$, $p < .01$; $r = .229$, $p < .05$; respectively). The children receiving more information support from health care providers would also get more information support from parents and peers. A possible explanation could be that information support from parents and peers alone may not be strong enough to directly affect child uncertainty in illness. In addition to illness-related information, parents also rely on their relationship with health care providers when their children are seriously ill.[32] Parents revealed that the cancer-specific knowledge was more highly valued by health professionals.[33] However, the children might lack opportunities to meet and talk to other children in hospitals who also had cancer which would result in suffering from the side effects and complications of chemotherapy. Children mentioned a strong desire to rest allowing the fatigue resulting from the experience, whether from the disease, the chemotherapy or the hospitalization to be observed.[34] Therefore, to address uncertainty in illness, children may request information explicitly that could affect their ability to determine the meaning of their illness-related events, while the information from parents or peers may not be clear enough for understanding.

The four variables including symptom pattern, information support from health care providers, illness-related knowledge and parental uncertainty could explain 34.8% of the variance in uncertainty in illness among children with leukemia undergoing chemotherapy. Further research, using the theoretical framework of this study may be needed to examine key predictive factors associated with child uncertainty which were not addressed in this study. There might be another predictive factor of child uncertainty, which concerns emotional support. Children with cancer reported that emotional support was an area of unmet need.[35] The previous study[21] in children with SLE indicated that emotional support had a negative relationship with illness uncertainty. Thus, emotional support may influence child uncertainty.

## Limitations

The majority of the participants were children with leukemia who were in the maintenance phase of chemotherapy. Thus, generalizations of the findings in other phase groups of children undergoing chemotherapy should be addressed cautiously. Therefore, further studies are needed to investigate various predictive factors in each phase of chemotherapy. This would include the induction, consolidation and maintenance phases. In addition, because of the low level of internal consistency in the Information Support from Parent Scale, further research is needed in order to refine or create more effective instrument.

## Conclusions and Implications for Nursing Practice

Symptom pattern, information support from health care providers, illness-related knowledge and parental uncertainty were found to be predicting factors of uncertainty in illness among children with leukemia undergoing chemotherapy. The results can provide a better understanding of predicting factors of their uncertainty, which can be used for further exploration into the possibility of designing effective nursing interventions that can reduce the uncertainty in illness of these children through the provision of information and knowledge from nurses and through a decrease in parental uncertainty. The results can also provide information for pediatric oncology nurses in order to make them aware of predicting factors for uncertainty in illness and guide nursing intervention.

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# ปัจจัยทำนายความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กป่วยโรคมะเร็งเม็ดเลือดขาวที่ได้รับเคมีบำบัด

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**บทคัดย่อ:** มะเร็งเม็ดเลือดขาวเป็นโรคที่คุกคามต่อชีวิตเด็ก เคมีบำบัดเป็นการรักษาที่ซับซ้อนและมีอาการข้างเคียงและภาวะแทรกซ้อนที่รุนแรง และไม่สามารถทำนายผลการรักษาได้อย่างชัดเจน ทำให้เด็กป่วยเกิดความรู้สึกไม่แน่นอนในความเจ็บป่วยขึ้น ส่งผลให้เด็กป่วยมีความทุกข์ทรมานทางจิตใจ การศึกษาเชิงพรรณนาแบบภาคตัดขวางนี้มีวัตถุประสงค์เพื่อศึกษาปัจจัยทำนายความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กป่วยโรคมะเร็งเม็ดเลือดขาวที่ได้รับเคมีบำบัด กลุ่มตัวอย่างคือเด็กป่วยโรคมะเร็งเม็ดเลือดขาวจำนวน 96 ราย ที่ได้รับเคมีบำบัดในโรงพยาบาลระดับตติยภูมิในกรุงเทพมหานคร 4 แห่ง เครื่องมือวิจัย ประกอบด้วยแบบประเมินความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กป่วย แบบประเมินแบบแผนอาการแสดงของความเจ็บป่วย แบบสอบถามการสนับสนุนด้านข้อมูลจากบุคลากรทางสุขภาพ แบบสอบถามการสนับสนุนด้านข้อมูลจากบิดามารดา แบบสอบถามการสนับสนุนด้านข้อมูลจากเพื่อน แบบประเมินความรู้สึกไม่แน่นอนของบิดามารดาในความเจ็บป่วยของบุตร และแบบประเมินความรู้เกี่ยวกับความเจ็บป่วย ผลการวิเคราะห์ข้อมูลด้วยสถิติการวิเคราะห์ถดถอยพหุคูณพบว่าแบบแผนอาการแสดงของความเจ็บป่วย การสนับสนุนด้านข้อมูลจากบุคลากรทางสุขภาพ ความรู้เกี่ยวกับความเจ็บป่วย และความรู้สึกไม่แน่นอนของบิดามารดาในความเจ็บป่วยของบุตรอธิบายความผันแปรของความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กป่วยโรคมะเร็งเม็ดเลือดขาวที่ได้รับเคมีบำบัดได้ร้อยละ 34.8 การศึกษาครั้งนี้ให้ความรู้เกี่ยวกับปัจจัยทำนายของความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กเพิ่มขึ้น ผลการศึกษาสามารถนำไปใช้ในการพัฒนาวิธีการทางการพยาบาลเพื่อลดความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กป่วยโรคมะเร็งเม็ดเลือดขาวที่ได้รับเคมีบำบัด โดยพยาบาลช่วยให้เด็กมีความเข้าใจในแบบแผนอาการแสดงของความเจ็บป่วย ให้การสนับสนุนด้านข้อมูลและความรู้ รวมถึงลดความรู้สึกไม่แน่นอนในความเจ็บป่วยของบิดามารดาเด็กป่วย

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**คำสำคัญ** เคมีบำบัด เด็ก ความรู้สึกไม่แน่นอนในความเจ็บป่วย การสนับสนุนด้านข้อมูล มะเร็งเม็ดเลือดขาว ปัจจัยทำนาย ประเทศไทย

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# Development and Psychometric Testing of the Nursing Performance for Patient Safety Scale

*Sopaporn Panthulawan, Wipada Kunaviktikul, Raymoul Nantsupawat, Wichit Srisuphan*

**Abstract:** In Thailand, patient safety measurement is based on nursing and midwifery standards. In this study we developed the Nursing Performance for Patient Safety Scale to assess individual nurses. The instrument development process involved six steps: 1) Identification of constructs from concept analysis. These included six sub-domains: protection, prevention, mitigation, promotion, interpersonal facilitation, and dedication; 2) Generating 141 items for item pool; 3) Determining format for measurement. Scaling responses were determined using a 6-point Likert-scale; 4) Verification of the 141 items by five experts and 73 items remained after the second round with the S-CVI of 1.00; 5) Determining reliability. The Cronbach's alpha coefficient was 0.95; and 6) Field testing for construct validity.

The study settings were 8 regional and 9 general hospitals governed by Thailand Ministry of Public Health. There were 759 nurses selected using multistage sampling in four regions of Thailand, and simple random sampling was used. Item-total correlation ranged from 0.24 to 0.75. Principal component and oblique rotation by directoblimin was used for exploratory factor analysis. The final Scale had 64 items with 9 domains 1) protection through communication; 2) protection through risk management; 3) prevention through right drug and solution administration; 4) prevention through implementation of practice guideline; 5) prevention emergency adverse events through critical care; 6) prevention through effective patient care process; 7) mitigation; and 8) promotion through team and responsibility and 9) dedication to patient safety. This Scale can be used to produce evidence to helping to improve patient safety performance by nurses in Thailand. However, future studies are needed to refine the Scale.

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**Keyword:** Instrument development; Patient safety; Nursing performance; Psychometric testing; Quality; Safety

## Introduction

Patient safety is a major issue supporting quality improvement in healthcare. Many countries have increasingly recognized the importance of improving patient safety. In 2002, the World Health Organization (WHO) member states agreed on a World Health Assembly resolution on patient safety. The WHO then launched the Patient Safety Program

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in 2004, and over 140 countries have worked to address the challenges of unsafe care.[1] Moreover, the Joint Commission established the National Patient Safety Goals program in 2002 and approved a new program in 2013 to help accredited organizations address specific areas of concern in regard to patient safety.[2] In Thailand the Healthcare Accreditation Institute set the Thai Patient Safety Goal[3] with the aim of preventing procedures that could potentially cause harm to hospitalized patients. The goals deal with safe surgery, infection control, medication safety, patient care process safety, avoiding catheterization and tubing misconnections, and emergency response. Additionally, the Ministry of Public Health (MOPH) and the Thailand Nursing and Midwifery Council (TNMC) has set nursing and midwifery practice standards for patient safety goals.[4,5] Nursing organizations urge all nurses to comply with patient safety practice guidelines in order to save patients from harm.

An essential step for patient safety improvement are specific measures which have achieved high levels of patient safety. These safety measures should recognize hospital efforts toward patient safety and achievements in patient safety. In the nursing literature, the Donabedian's structure-process-outcome framework has been used for evaluating the quality of nursing care.[6] This evaluation structure consists of material resources, human resources, and organizational structure, and the evaluation process consists of the patient's activities in seeking care and caring it out, as well as the practitioner's activities in making a diagnosis and recommending or implementing treatment. The evaluation of outcomes consists of the effects of care on the health status of patients and populations.[7] Process and structural measures signal what hospitals have done to improve safety and outcome measures reflect whether a hospital has actually achieved safety goals. These process, structural, and outcome measures should be of equal weights of 50%[8], and the measures should address a process proximate to the desired outcome.[9] Although hospitals are voluntarily seeking to improve performance on standard sets of measures,[8] there is little evidence that these sets are focused on process assessment. Most of the evidence has shown outcome assessment[10] but existing measures are incapable of judging the quality of the process.[9] In Thailand, process measurement for patient safety consists of the rate of incident reports, the application of the nursing process to regular practice, and nursing documentation indicating the quality of nursing care.[4,5] Outcome measurement is based on 10 indicators for patient safety[4] and requires six months to one year to see evidence in the decreasing rate of errors.[11] In comparison, process measurement may take as little as one month. Thus, process measurement for patient safety can provide accurate and timely information for feedback to nurses to improve patient safety.

In reality, process measurements are faced with the problem of evidence which reflects accurate results. They use the number of incident reports of nurses as indicators, but incidence data are under-reported.[12] Therefore, using the number of incident reports as an indicator of process measurement cannot guarantee that nursing organizations with low reported incidence can control risks and actually practice patient safety. Effective process measurements require evaluation from the nurses performing certain processes that have been demonstrated to achieve desired aims, and avoiding processes that tend to cause harm.[13] Performance measurement is the most appropriate measurement for assessment by individual nurses to determine whether or not they comply with patient safety procedures.[14] Measurement of performance at an individual level will provide information for human resource managers to design interventions to ensure that nurses strictly adhere to patient safety guidelines and build up a safety culture in the nursing organization. Moreover, nurses can utilize measurement of performance for self-monitoring when providing nursing care to patients and prevent the possible risk. At present, the commonly-existing scales used to measure patient safety focus on the patient safety culture. These include the Hospital Survey on Patient Safety Culture (HSPSC)[15] and the Safety Attitude Questionnaire (SAQ).[16] These do not include performance measurements and have rarely been applied to the performance concept as a conceptual framework in the healthcare sector. This is the first study known in Thailand to try to address this issue. We developed the Nursing Performance for Patient Safety Scale (NPPSS) to assess nursing performance regarding patient safety at the individual nurse level. This new scale is important for patient safety because nursing organizations require high individual performance which could lead to accomplishing patient safety goals.

## Review of Literature

In general, patient safety refers to minimizing risks of harm to patients and providers through both system effectiveness and individual performance.[17] This involves promoting a culture of safety, protecting the patient from hazardous situations[18], minimizing the impact of incidence, and maximizing recovery from adverse events.[19] Therefore,the Joint Commission on Accreditation of Healthcare Organization (JCAHO) in the USA established national patient safety goals to address specific areas of concern regarding patient safety. These consist of: 1) the improvement of accuracy in patient identification, 2) improvement in the effectiveness of communication among caregivers, 3) improvement in the safety of using medications, 4) reducing the risk of health care-associated infections, 5) accurately and completely reconciling medications across the continuum of care, and 6) identifying safety risks inherent in its patient population.[20] In 2012, new national patient safety goals of the USA were approved with the intent of reducing the risk of patient harm resulting from falls and pressure ulcers, as well as preventing "wrong site, wrong procedure, wrong person surgery".[2]

Nurses are important since they are pivotal to enhancing patient safety improvements and comprise the largest group of healthcare providers. They have more contact with patients than other healthcare provider. Furthermore, healthcare organizations need high performing individual nurses in order to accomplish patient safety goals and thus patient safety needs to be evaluated from the perspective of nurse behaviors. Their behaviour needs to be evaluated to test their degree of effectiveness as it is synonymous with performance.[21] There are two attributes of the performance concept: task performance and contextual performance.[22] Task performance refer to core technical behaviour and activities involved in the job.[23] Contextual performance refers to behaviours that demonstrate an employee's willingness to participate with another member.[24] There are two facets of contextual performance: interpersonal facilitation and job dedication.[25]

Nursing performance for patient safety refers to the behaviours that individual nurses perform which are relevant to patient safety goals. It is the responsibility of all nurses to perform in a manner that achieves these goals. The dimensions of patient safety performance are nursing task performance for patient safety and nursing contextual performance for patient safety. The details of each dimension are described below:

**Nursing task performance for patient safety** refers to an individual nurse's behaviors that accomplish patient safety goals. Nurses' behaviors include protection, prevention, mitigation, and promotion.

*Protection* refers to an individual nurse's behaviors in against harm before reaching the patient. These behaviors consist of identifying risks inherent in the patient population,[3] patient assessment,[13] and identifying the multiple factors involved in failures[19] which could cause incidents.

*Prevention* refers to an individual nurse's behaviors that attempt to stop harm before reaching patients. These behaviors consist of adhering to guidelines for patient safety[26] and accurately reporting incidents.[27]

*Mitigation* refers to an individual nurse's behaviors in reducing the severity of complications after something goes wrong in the patient's treatment that puts him or her at risk. These behaviors consist of immediately solving the problem,[26] improving the effectiveness of communication among caregivers,[2] patients, and their families, and providing immediate care based on the role of nurses.[3]

*Promotion* refers to an individual nurse's behaviors in performing their function and continual responsibility in order to enhance patient safety. These behaviors consist of promoting a culture of incident reporting,[28] using patient safety goals as a professional nursing development goal, and continued training in patient safety procedures.[18]

**Nursing contextual performance for patient safety** refers to an individual nurse's behaviors in a cooperative work environment with healthcare providers to care for patients and to enhance patient safety. In this study, these behaviors are classified into two dimensions: interpersonal facilitation for patient safety and dedication to patient safety. Each dimension is defined as follows.

*Interpersonal facilitation for patient safety* refers to an individual nurse's behaviors in cooperating with and immediately responding to requests from other team members in emergency situations, demonstrate the capacity to help someone without being asked, and participate in patient safety meetings.[3]

*Dedication to patient safety* refers to an individual nurse's behaviors that show that he or she is striving for patient safety; such behavior consists of activities that demonstrate effort initiatively to solve patient safety problems, persistence, and self-discipline. These behaviors consist of putting in extra hours to receive training in patient safety, tackling difficult work assignments enthusiastically, and setting patient safety goals as the target behavior that they want to achieve for the day.[17]

## Study Aim

The purpose of this study was to develop an instrument to measure nursing performance for patient safety for nurses in Thailand.

## Methods

**Design:** This instrument development research was divided into six steps: 1) identification of construct 2) generating an item pool, 3) determining the format for measurement, 4) reviewing for content validity by experts, 5) determining of reliability, clarity, and readability, and 6) field testing for evaluating the items by determination of item analysis and construct validity testing with factor analysis.

**Ethical considerations:**

This study was approved by the Research Ethics Review Committee of the Faculty of Nursing, Chiang Mai University, Thailand and prior to data collection, permission was also obtained from the ethics committee of each of the selected hospitals. All participants were informed about the purpose, methods, time required for the study, confidentiality, anonymity issues, and the right to withdraw from the study at any time without losing benefits. Finally, the participants who agreed to participate were asked to sign the informed consent form.

**Data Collection and Data Analysis:**

*Step 1: Identification of construct*: this was a process of identifying the domains from an analysis of patient safety concepts. A literature search was conducted using several search engines: CINAHL, Medline, PubMed, and Cochrane Review. Key words used were "patient safety", "quality of nursing care", "safer care", and "risk management process". The attributes of the concepts were identified, categorized, and arranged into the construct of the NPPSS. There were two dimensions of nursing performance for patient safety, consisting of: 1) nursing task performance for patient safety including protection, prevention, mitigation, and promotion, and 2) nursing contextual performance for patient safety, including interpersonal facilitation for patient safety and dedication to patient safety.

*Step 2: Generating an Item Pool:* This was generated from the specified domains of nursing performance for patient safety, identified during the previous step of construct identification. The number of identified items was at least twice as many as the desired number for the final scale.[29] Under the operational definition of 2 dimensions and 6 sub-dimensions, items were identified, and 141 items were generated. These were written in Thai and then translated into English by a bilingual person.

*Step 3: Determining the format for measurement:* the NPPSS format was composed of two parts: the demographic data form, and the performance assessment scale. The scaling responses were defined with a 6-point Likert-type scale ranging from 0-5, where 0=never done, 1=scarcely done, 2=rarely done, 3=sometimes done, 4=often done, and 5=always done.

*Step 4: Reviewing for content validity by experts:* the developed items were reviewed for content validity in the first draft of the NPPSS by five experts. These included two faculty members, one was an expert in instrument development and the other was an expert in patient safety, two nurse administrators, experts in patient safety management, and one nurse who was an expert in patient safety practice.

The NPPSS was revised based on the experts' comments. Some items required revision for clarity. The I-CVI of the 141 items ranged from 0.2 to 1.00 and the I- CVI was 0.88. The S-CVI/UA was 0.58. Inter-rater agreement was 0.79, which was less than required by the criteria and thus 62 items were deleted from the scale and 79 items were retained. The second draft of the NPPSS was submitted to the same experts for the second round. The I-CVI of 79 items ranged from 0.8 to 1.00 and the I-CVI was 0.98. The S-CVI/UA was 0.92, which was less than the criteria (1.00). Thus, 6 items were deleted from the scale and 73 items were retained. The I-CVI of 73 items was 1.00 and the S-CVI/UA was also 1.00. Inter-rater agreement was 0.97,which meet the criteria about I-CVIs should be 1.00 with five experts.[30] The accepted value of inter-rater agreement should be at least 0.90.[31] The third draft was retained.

*Step 5: Determining reliability, clarity, and readability;* the third draft of the NPPSS development was the determination of the scale's reliability through pre-testing. The sample for the pre-testing was 30 staff nurses. Their recruitment was conducted with multi-stage sampling, beginning with four regions of Thailand, to draw one hospital for pre-testing. Then to draw the nurses who have experience in inpatient unit for at least two years, simple random sampling without replacement was used.

Finding revealed that all of the items were clear (100%), most of the items were understandable (96.7%), all of items were practical (100%), and 100% of the staff nurses agreed that the length of the questionnaire was appropriate. The length of time for filling out the scale ranged from 13-81 minutes, with a mean time of 43.53 minutes. Internal consistency reliability was estimated using Cronbach's alpha coefficient for the six subscales and ranged from 0.76 to 0.97. The scale's overall was 0.95. Therefore 73 items were retained.

*Step 6: Field testing for evaluating the item by determination of item analysis and construct validity testing with factor analysis*, 730 nurses that should be ten participants for each item being tested[31]plus the expected attrition rate of 20%, totaling 876 nurses were the participants. Eight regional hospitals and eight general hospitals were selected. The recruitment of participants was the same as Step 5. The third draft of the NPPSS was mailed to the directors of nursing service who then distributed this to the participants. Ten items of the Marlowe Crowne

Social Desirability Scale (10-SDS) was distributed along with the third draft of the NPPSS.

The 10-SDS was also administered because the Thailand Nursing and Midwifery Council, the Ministry of Public Health, and the Bureau of Nursing, Office of Permanent Secretary, Ministry of Public Health (BON) urge all nurses to comply with patient safety practice. The fact that some of the items might have been perceived as socially desirable could have contributed to the nurses giving answers that said "good things" rather than "bad things" about themselves. Ten items of the Marlowe-Crowne Social Desirability Scale were originally written in English, translated into Thai, and back-translated into English by a bilingual person to assure that no changes in meaning occurred during the translation process.

The third draft of the NPPSS with 73 items were returned 831 case (94.86%) and 72 uncompleted (13.67%). Therefore, there were 759 cases (86.33%) for analysis. The analysis of the psychometric properties of the scale included internal consistency reliability, item analysis. The Kuder-Richardson (KR-20) was use to determined reliability of 10- SDS. The Spearman's rank-order correlation coefficient was use to describe correlation between the score of individual items and ten items of the 10-SDS. The exploratory factor analysis was used for construct validity. The process of this study was organized in 6 steps, as shown in Figure 1.

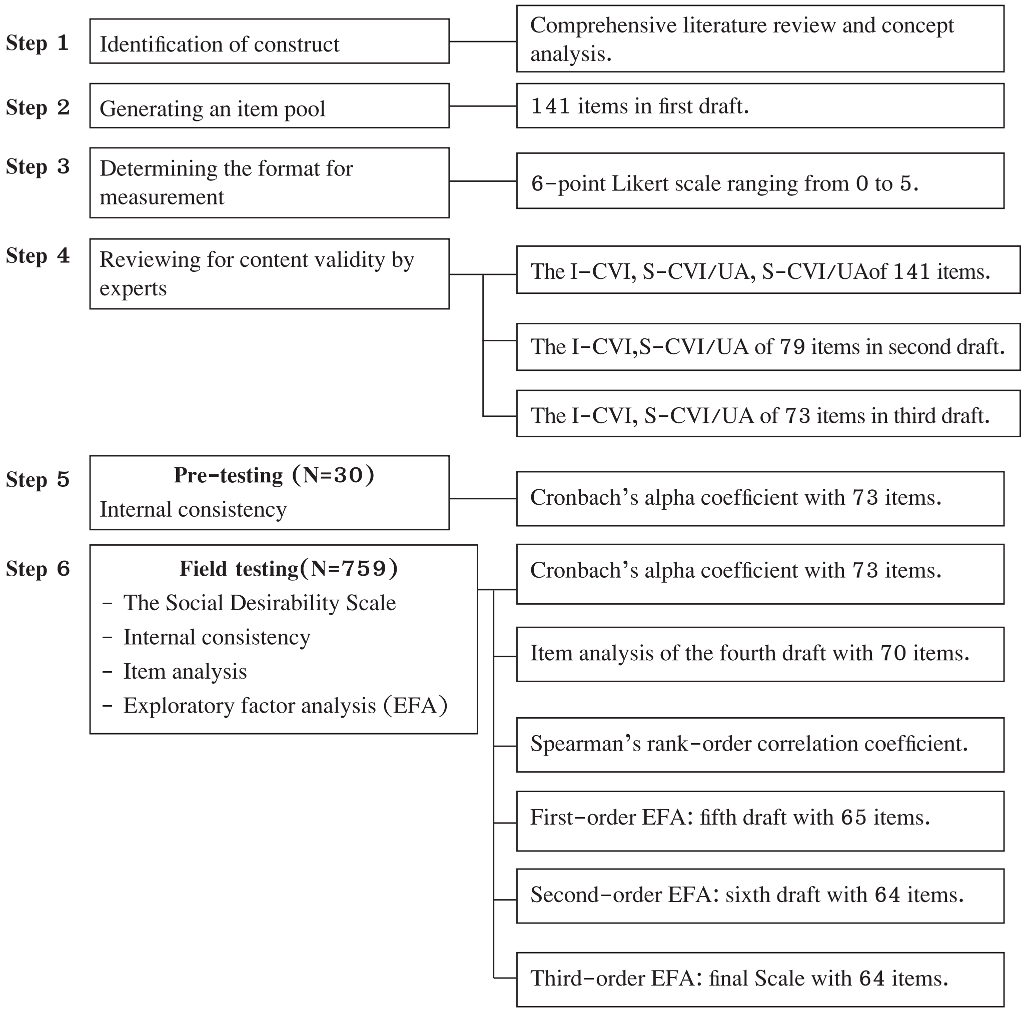

**Figure 1** Stages of the development of the Nursing Performance for Patient Safety Scale

## Results

The participants ranged from 22 to 60 years, with a mean age of 43.82 years (S.D. = 8.97), and most of them were female (98.16%) and 79.84% had a bachelor degree. Over half (52.17%) worked in a regional hospital and the rest worked in a general hospital (47.83%). Their experience in patient care varied widely, from 2 to 38 years, with an average experience of 13.30 years (S.D.=8.56). Half of the participants (54.15%) had attended a training course in patient safety.

## Social Desirability

Kuder-Richardson reliability for the 10-SDS scale was calculated at 0.70, which was acceptable. There was no significance between the overall of the third draft of the NPPSS and 10-SDS ($r = 0.02$, $p<0.05$), which was acceptable for correlation between the score of item and 10-SDS. Therefore it is assumed that the nurses provided truthful data for nursing performance in patient safety.

**Reliability Testing**

The internal consistency reliability of the 73 items was estimated using Cronbach's alpha coefficient of 0.98, which was an acceptable alpha value for newly-developed instruments.[32]

Item means ranged from 4.00 to 4.50, with a standard deviation ranging from 0.51 to 0.71. A mean close to the center of the range of possible scores was desirable. The mean of item variances was 0.23, with a range from 0.26 to 0.50, which was less than the criteria. Since, the statement of items indicated good practices for patient safety. It will not discriminate among individuals with different levels of the construct of patient safety performance being measured. [31]Therefore, these items are less extreme.

**Subscale-subscale correlation and subscale-total correlation:** the criteria of the subscale-subscale correlation were more than 0.30. The correlation between subscales of the third draft of the NPPSS ranged from 0.54 to 0.78. The subscale-total correlation as the correlation between each subscale to the overall scale ranged from 0.86 to 0.95. Thus, all items were considered to be related to the concept within the subscale and accepted for retention in the third draft of the NPPSS.

The corrected item-total correlation of the 73 items ranged from 0.24 to 0.75. One item had low correlation and some items with high correlation. The results of item to subscale correlation indicated that most of items correlations over 0.70 are redundant.[32] The Cronbach's alpha coefficient of all items was 0.97. The alpha coefficient, if items deleted, for all items ranged from 0.972 to 0.974. The results revealed that when three items were dropped from the scale, the Cronbach's alpha increased. Therefore, three items in the NPPSS were dropped from the scale. Thus, the fourth draft with 70 items was retained for further factor analysis.

**Validity Testing**

The principal component analysis with oblique rotation by direct oblimin was selected because it yielded the best possibility to interpret the factor solution. The criteria for retention of an item include in the components with eigenvalues greater than 1, an item loading above .30 on each factor, no or few cross-loading items, determining the number of common factors with a screen test, and any factors with fewer than three items. [32, 33]

The 70 items of the NPPSS demonstrated that the Kaiser-Meyer-Olkin measure was 0.97, which was acceptable for sampling adequacy.[34] The Bartlett's test was significant ($x^2 = 38113.494$, $p = .000$), indicating the overall significance of the correlation matrix. Thus, the set of data was appropriate for the factor analysis.

The final draft of the NPPSS was summarized based on the results of the third-order factor analysis. Nine components of the scale with 64 items could explain 63.54% of total of variance. All items retrieved with factor loading ranging from 0.34 to 0.90, eigen values ranged from 1.12 to 25.33. (Table 1 to 5).

**Table 1** Factor, Factor loading, Eigenvalue, and % of Variance of Component *Protection*

| Item | Description of item | Factor loading |
|---|---|---|
| | **Protection through communication** | |
| PT12 | Estimate patients' cooperation to use it for exploration of plausible risks. | 0.81 |
| PT13 | Promote communication between nurses and patients via many channels to enhance patients' safety. | 0.78 |
| PT15 | Spend time explaining self-management to patients to promote cooperation in nursing care. | 0.75 |
| PT11 | Evaluate patients' knowledge to use it for exploration of possible risks. | 0.73 |
| PT14 | Promote communication in the multidisciplinary team through many channels to enhance patient safety. | 0.57 |
| | Eigenvalue = 3.60; % of variance = 5.63 | |
| | **Protection through risk management** | |
| PT1 | Explore the risks of patients individually. | -0.78 |
| PT2 | Classify risks at work. | -0.75 |
| PT3 | Evaluate risk strengths likely associated with patients under care. | -0.75 |
| PT4 | Use the data from risk assessment to establish a health plan to protect patients. | -0.73 |
| PT5 | Reduce all kinds of risks once they are found. | -0.63 |
| PT6 | Provide solutions suitable for each patient risk. | -0.62 |
| PT8 | Use the results from risk evaluation of personal information in prior planning to prevent an adverse event. | -0.52 |
| PT7 | Carefully evaluate each patient's personal information for any potential risks. | -0.44 |
| PT10 | Investigate communication issues in the multidisciplinary team, which can lead to an adverse event. | -0.44 |
| PT9 | Seek communication problems between nurses and patients, which can lead to an adverse event. | -0.42 |
| PV1 | Understand the important of writing incident reports in the unit. | -0.34 |
| | Eigenvalue = 1.12; % of variance = 1.74 | |

**Table 2** Factor, Factor loading, Eigenvalue, and % of variance of component *Prevention*

| Item | Description of item | Factor loading |
|---|---|---|
| | **Prevention through right drug and solution administration** | |
| PV7 | Use an infusion pump to control the volume of concentrated solution that will flow into patient. | 0.76 |
| PV8 | Check doctor's prescription before giving medication to patient. | 0.61 |
| PV9 | Check the quantity of concentrated solution in patients every hour and every time before nursing care. | 0.57 |
| PV14 | Report the abnormal results of any laboratory examination directly to the responsible physician immediately. | 0.54 |
| | Eigenvalue = 2.79; % of variance = 4.36 | |
| | **Prevention through the implementation of practice guidelines** | |
| PV17 | Follow hospital guidelines to prevent decubitus ulcers. | -0.84 |
| PV16 | Examine the skin of the patient under responsibility with the risk of decubitus ulcers. | -0.80 |
| PV18 | Evaluate the patient's risk of falling from fall history, age, and use of antidepressant drugs prior to nursing care. | -0.77 |
| PV19 | Follow the hospital guidelines to prevent falling. | -0.57 |

**Table 2** Factor, Factor loading, Eigenvalue, and % of variance of component *Prevention* (continued)

| Item | Description of item | Factor loading |
|---|---|---|
| PV21 | Check every catheterization or tubing from their origin to the connection port to verify attachments before practice and every treatment provision. | -0.39 |
| | Eigenvalue = 1.41;% of variance = 2.20 | |
| | **Prevention emergency adverse events through critical care** | |
| PV24 | Call the rapid response team once a patient's condition changes into crisis. | -0.90 |
| PV22 | Understand the guidelines for requests from team or the rapid response team once a patient's condition changes into crisis. | -0.78 |
| PV23 | Evaluate patient symptoms of deterioration, using criteria set by hospital. | -0.46 |
| PV25 | Provide immediate nursing care to a patient whose condition changes into crisis. | -0.40 |
| PV27 | Explain to patients and relatives about possible risks to prevent incidents. | -0.35 |
| | Eigenvalue = 1.33; % of variance = 2.09 | |
| | **Prevention through effective patient care process** | |
| PV12 | Never use the bed or room number to identify the patients under care. | 0.72 |
| PV11 | Prior to nursing care always verify patient identity in a minimum of two ways, asking for name and hospital ID number. | 0.62 |
| PV10 | Advise patients or relatives about medication and its side effects. | 0.56 |
| PV13 | Allocate the patient data to the team via SBAR (situation, background, assessment, recommendation). | 0.46 |
| PV5 | Clean hands effectively as required before and after nursing procedures. | 0.40 |
| | Eigenvalue = 1.24; % of variance = 1.93 | |

**Table 3** Factor, Factor loading, Eigenvalue, and % of Variance of Component *Mitigation*

| Item | Description of item | Factor loading |
|---|---|---|
| | **Mitigation** | |
| MT7 | Provide feasible care instructions to patients and relatives affected by adverse events, with mutual agreement of multidisciplinary team. | -0.87 |
| MT8 | Listen to patients and relatives expressions of frustration about an adverse event. | -0.84 |
| MT6 | Provide information of any adverse events to patients or relatives, together with the multidisciplinary team, using the hospital's information report guidelines. | -0.83 |
| MT9 | Spend time listening to patients and relatives, who have been affected by adverse events. | -0.80 |
| MT5 | Provide honest information regarding adverse events to patients or relatives, and the multidisciplinary team, using the hospital information report guidelines. | -0.61 |
| MT10 | Use error information as a lesson in finding ways to prevent recurrence. | -0.51 |
| MT3 | Interpret unwanted changes in a patient's condition affected by discovered adverse events. | -0.45 |
| MT2 | Evaluate symptoms of patients who have been affected by any incident in hospital-based practices. | -0.44 |
| MT4 | Give first aid immediately to minimize loss following an adverse event. | -0.41 |
| MT1 | Understand the hospital practices stipulated to reduce adverse events. | -0.35 |
| | Eigenvalue = 1.57; % of variance = 2.46 | |

**Table 4** Factor, Factor loading, Eigenvalue, and % of Variance of Component *Promotion through team and responsibility*

| Item | Description of item | Factor loading |
|---|---|---|
| | **Promotion through team and responsibility** | |
| PM4 | Be aware that nursing practice that focuses on patient safety is a core value of nursing organizations. | 0.63 |
| PM6 | Practice nursing as an example to the team members so they work to emphasize patient safety. | .063 |
| PM2 | Explain details of an adverse event for a common understanding within the team. | 0.59 |
| IF3 | Coordinate with team members to enhance patient safety. | 0.55 |
| PM7 | Propose the development of practices to enhance safety. | 0.53 |
| IF2 | Volunteer to help team members to promote patient safety. | 0.53 |
| PM5 | Comply with safety practice guidelines that set by unit. | 0.52 |
| PM3 | Do not predict unknowingly the adverse events information. | 0.51 |
| PM8 | Apply the concept of safety in all nursing practice. | 0.50 |
| IF1 | Provide immediate assistance to team members in any emergency situation. | 0.48 |
| IF5 | Join activities in wards or hospitals, organized to enhance patient safety. | 0.47 |
| IF4 | Emotionally support team members who experience adverse events. | 0.42 |
| | Eigenvalue = 25.33; % of variance = 39.58 | |

**Table 5** Factor, Factor loading, Eigenvalue, and % of Variance of Component *Dedication to patient safety*

| Item | Description of item | Factor loading |
|---|---|---|
| | **Dedication to patient safety** | |
| DP2 | Attend quality development activities even on off-duty days. | 0.76 |
| DP1 | Spend personal off-duty time attending patient safety training. | 0.75 |
| DP4 | Develop innovations to enhance patient safety. | 0.70 |
| DP3 | Develop methods to prevent adverse events and to suit patients under care. | 0.65 |
| DP5 | Demonstrate eagerness in finding practices that focus on patient safety even though these tasks are complicated and complex. | 0.63 |
| PM9 | Receive ongoing patient safety training. | 0.56 |
| IF6 | Share ideas at meetings to target patient safety in wards and nursing departments. | 0.48 |
| | Eigenvalue = 2.27;% of variance = 3.35 | |

Reliability Testing. The internal consistency of the NPPSS with 64 items was 0.91, which was high for a new scale. All of the subscale reported sufficient correlation. Moreover, all items revealed sufficient item-total correlations ranging from 0.40 to 0.81.

## Discussion

The NPPSS was designed to evaluate the nursing performance for patient safety of nurses in Thailand based on the guidelines for developing a measurement scale of DeVellis.[32] There were two dimension and six sub-dimensions. They were described as follows: Dimension 1: *Nursing task performance for patient safety* consisting of the sub-dimensions of *Protection, Prevention, Mitigation*, and *Promotion* and Dimension 2: *Nursing contextual performance for patient safety* consisting of the sub-dimensions of *Inter-personal facilitation for patient safety* and *Dedication to patient safety*.

The psychometric properties of the data revealed that nine components were associated with nursing performance for patient safety. They were reorganized from the pre-sub dimension and indicated that the specific nurses' behaviors for patient safety were better than those for the pre-dimension. They provided a better understanding of patient safety performance along with the nursing role for patient safety.

The components *Protection through communication* and *Protection through risk management* came from reorganizing the pre-sub dimension *Protection*. These focused on evaluation of the patient in order to exploring possible risks through communication with the team. These behaviors represent important roles for nurses in term of protecting the patient from harm through communication. Currently, ineffective communication is a factor contributing to most cases of patient harm.[35] It is the single biggest cause of nearly 70% of adverse events in the hospital. Therefore, improving the effectiveness of communication among caregivers is a specific area of concern in regards to patient safety.[3] Furthermore, patient safety also focuses on exploring risks, reducing risks, and providing treatment suitable for each patient's risk. These behaviors are included in the area of risk management. This consists of risk identification, risk assessment, analysis, understanding, and acting on risk issues in order to reach an optimal balance of risks, benefits and cost.[28] Managing risk will help protect providers and patients from becoming involved in legal matters.[36] Therefore, protection through communication and through risk management is specific and necessary so that nurses can provide safe patient care.

The components *Prevention through right drug and solution administration*, *Prevention through the implementation of practice guidelines*, *Prevention emergency adverse events through critical care*, and *Prevention through effective patient care process* came from reorganizing the pre-sub dimension *Prevention*. Prevention here means an individual nurse's behaviors that attempts to stop harm before reaching the patient, therefore the use of the five rights of medication administration helps to provide consistent quality care,[37] and is critical for preventing medication errors. The nurse role for patient safety also involves to practice guidelines. These guidelines should explicitly define patient safety goals and patient safety solutions,[2,3] including standardized processes, protocols, and checklists.[37] The results of reorganizing the pre-sub dimension of *prevention* was specific nurses' behaviors to prevent harm to patients.

*Mitigation* all of the items came from the pre-sub dimension of *Mitigation*. These items explained the nurse's behaviors in reducing the severity of complications after errors were identified. These behaviors consist of providing immediate care based on the role of the nurses, communicating hazards and incidents to other team members, patients and their families[28] which should be build trust and openness[38], and asking immediately for help. The action taken to make better or compensate for any harm after an incident would reduce loss or damage to patients, family, and the organization.[28]

The component *Promotion through team and responsibility* was a combination of the pre-sub dimension of *Promotion with interpersonal facilitation for patient safety*. It focuses on the nurses' function and continually promotes patient safety through teamwork. Teamwork is functioning effectively within nursing and inter-professional teams, fostering open communication, mutual respect, and shared decision-making to achieve quality patient care.[38] As mentioned in the literature review, lack of team work is an important contributing factor to adverse events.[27] Furthermore, the application of teamwork and collaboration among caregivers enhance the achievement of a system-wide culture of patient safety.[39] Thus, prevention of harm to patients is based on teamwork and is required for nursing performance for patient safety.

The component *Dedication to patient safety* is a combination of the pre-sub dimension of *Dedication to patient safety*, *Promotion*, and *Interpersonal facilitation for patient safety*. When considering the meaning of the items, the focus is on the nurses' behaviors that demonstrate that they are striving for patient safety through undergoing training on patient safety and sharing ideas about patient safety since patient safety solutions are needed to tackle the underlying causes of unsafe care. These included learning from mistakes in order to improve process and enhance awareness among medical staff.[38] Therefore, nurses should explain how to design solutions and implement them based on training which is strongly emphasized in developing countries.[36] Continuing training in patient safety procedures causes the practice improvement for patient safety in care settings.[3] Dedication to patient safety through continuous learning for patient safety will improve nursing performance for patient safety.

The items of the NPPSS indicated more specific nurses' behaviors for patient safety than the conceptual framework. They also provided a better understanding of the nurses' role regarding patient safety, appropriate for the context of the TNMC and the BON standards. The NPPSS demonstrated adequate reliability and validity for measuring patient safety performance for nurses in Thailand. The NPPSS will additionally provide information which shows the frequency of the patient safety performance of individual nurse.

## Limitations

The sub-scale total correlation of the NPPSS ranged from 0.86 to 0.95, which indicated redundancy. Thus items within the subscale may not be distinct and hence they should be further examined through research. Secondly, the assessment of validity was tested using only one group type and thus a test using contrast group validity is recommended in order to arrive at more accurate validity of the NPPSS. Thirdly, this study was also limited in terms of testing for criterion-related validity because an existing scale was not available to compare it with. Thus, this should also be further examined.

## Conclusions

The final version of the 64 items with 9 components is a self-report questionnaire with a 6-point Likert scale. The results indicated an adequate sample, and adequate reliability and validity for measuring nursing performance regarding patient safety. The results of the item- to-subscale correlation indicated that most of the items with a correlation over 0.70 were redundant. The findings and limitations suggested the need for future inquiry. Thus, future studies are needed to refine the instrument and to strengthen its psychometric properties.

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# การพัฒนาเครื่องมือวัดการปฏิบัติการพยาบาลเพื่อความปลอดภัยของผู้ป่วย

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**บทคัดย่อ**:ในประเทศไทย การวัดความปลอดภัยของผู้ป่วยอาศัยมาตรฐานการพยาบาลและการผดุงครรภ์ การพัฒนาเครื่องมือวัดการปฏิบัติการพยาบาลเพื่อความปลอดภัยในครั้งนี้จึงเป็นครั้งแรกที่ได้พัฒนาขึ้น โดยมีวัตถุประสงค์เพื่อพัฒนาและตรวจสอบคุณภาพของเครื่องมือวัดการปฏิบัติการพยาบาลเพื่อความปลอดภัยของผู้ป่วยสำหรับพยาบาลกระบวนการพัฒนาเครื่องมือมี 6 ขั้นตอน คือ การกำหนดโครงสร้าง โดยการวิเคราะห์มโนทัศน์ ประกอบด้วย 6 องค์ประกอบ คือ การปกป้อง การป้องกัน การบรรเทาความรุนแรง การส่งเสริมความปลอดภัย การช่วยเหลือกัน และการอุทิศตน ขั้นตอนที่ 2 ข้อคำถาม จำนวน 141 ข้อ ขั้นตอนที่ 3 กำหนดมาตราวัด ซึ่งใช้ลิเคริตสเกล 6 ระดับ ขั้นตอนที่ 4 จำนวน 141 ข้อและตรวจสอบความตรงเชิงเนื้อหาโดยผู้เชี่ยวชาญจำนวน 5 คน ครั้งที่สองเหลือข้อคำถาม 73 ข้อ ได้ค่าความตรงเชิงเนื้อหาทั้งฉบับเท่ากับ 1.00 ขั้นตอนที่ 5 ทดสอบความเที่ยงของเครื่องมือ ได้ค่าสัมประสิทธิ์แอลฟาครอนบาคเท่ากับ 0.95 ขั้นตอนที่ 6 คือการทดสอบความตรงเชิงโครงสร้าง

บริบทของการทำวิจัยในครั้งนี้ คือ โรงพยาบาลศูนย์ 8 แห่ง และโรงพยาบาลทั่วไป 9 แห่ง ซึ่งเป็นโรงพยาบาลในสังกัดกระทรวงสาธารณสุข ทดสอบความตรงเชิงโครงสร้างในพยาบาลจำนวน 759 รายได้มาโดยการสุ่มแบบหลายขั้นตอนจากโรงพยาบาลทั้ง 4 ภาคของประเทศไทยและสุ่มอย่างง่าย ความสัมพันธ์ของข้อคำถามกับคะแนนรวมของข้อคำถามที่เหลือของแบบประเมินทั้งฉบับมีค่าระหว่าง 0.24 ถึง 0.75 การวิเคราะห์องค์ประกอบเชิงสำรวจที่สกัดองค์ประกอบโดยพิจารณาองค์ประกอบจากกลุ่มของตัวแปรที่มีความสัมพันธ์กันและหมุนแกนในลักษณะที่องค์ประกอบไม่เป็นอิสระกัน พบว่า แบบประเมินฉบับสุดท้ายมีจำนวน 64 ข้อ ประกอบด้วย 9 ด้าน ได้แก่ 1) การปกป้องอันตรายต่อผู้ป่วยโดยการสื่อสาร 2) การปกป้องอันตรายต่อผู้ป่วยโดยการจัดการความเสี่ยง 3) การป้องกันอันตรายต่อผู้ป่วยโดยการบริหารยาและสารละลายที่ถูกต้อง 4) การป้องกันอันตรายต่อผู้ป่วยโดยการปฏิบัติตามแนวทางปฏิบัติ 5) การป้องกันเหตุการณ์ไม่พึงประสงค์ที่เกิดจากสถานการณ์ฉุกเฉินโดยให้การพยาบาลผู้ป่วยในระยะวิกฤต 6) การป้องกันอันตรายต่อผู้ป่วยโดยการปฏิบัติตามกระบวนการดูแลผู้ป่วยที่มีประสิทธิผล 7) การบรรเทาความรุนแรงจากอันตรายที่เกิดขึ้นต่อผู้ป่วย 8) การส่งเสริมให้เกิดความปลอดภัยแก่ผู้ป่วยโดยการทำงานเป็นทีมและความรับผิดชอบ 9) อุทิศตัวเพื่อความปลอดภัยของผู้ป่วย

แบบประเมินการปฏิบัติการพยาบาลเพื่อความปลอดภัยของผู้ป่วยนี้มีความเชื่อมั่น ความตรงเชิงเนื้อหา และความตรงเชิงโครงสร้าง สามารถนำไปใช้เป็นแบบประเมินการปฏิบัติการพยาบาลเพื่อความปลอดภัยของผู้ป่วย อย่างไรก็ตามควรได้มีการปรับปรุงเครื่องมือนี้ต่อไป

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**คำสำคัญ:** การพัฒนาเครื่องมือ ความปลอดภัยของผู้ป่วย การปฏิบัติการพยาบาล การทดสอบคุณภาพของเครื่องมือทางจิตวิทยา คุณภาพ ความปลอดภัย

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# A Qualitative Study of Factors Influencing Thai Women with Breast Cancer to Use Complementary and Alternative Medicine

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**Abstract:** While taking conventional medicines to cure cancer, some people also use complementary and alternative medicine to improve their health and well-being. This study used Leininger's ethnonursing method to identify cultural factors influencing 17 Thai women with breast cancer to select complementary and alternative medicines for their health and well-being. They were recruited from a hospital in the lower northern part of Thailand and in-depth interviews and field notes were utilized with each participant. Data were analyzed by using Leininger's method. Findings revealed that factors influencing them to select complementary and alternative medicine centred on (1) kinship, (2) social factors, (3) economic status, and (4) beliefs and lifestyles. Findings suggested that many important factors influenced participants' decisions about using complementary and alternative medicines. Family members and significant others were the most important resources of information. Financial issues were a barrier to continue or discontinue use of complementary and alternative medicines. The beliefs and lifestyles of Thai people also influenced the selection of types of alternative medicine used by the participants. Therefore, nurses should assess patients' perspectives, such as their beliefs and their social networks. Moreover, significant persons should be involved between the health care provider and the patient regarding care practice decision-making.

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**Keywords:** Alternative medicine, Breast cancer, Care practices, Complementary medicine, Decision-making, Ethnonursing, Qualitative research, Thailand, Women

## Introduction

Breast cancer is the leading cause of cancer death (after lung cancer) among women worldwide.[1] In Thailand, during the period 1998-2000, breast cancer was the second most common cancer after cervical cancer among Thai women with the incidence rate of 20.5 per 100,000 women.[2] However, within this current decade, breast cancer has been reported to be the leading cancer among Thai women with an incidence rate of 20.9 per 100,000.[3]

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Previous studies have shown that many physical and psychosocial problems persist after completion of treatment.[4] For example, one study[5] reported that at the end of treatment, common stressors for women with breast cancer include uncertainty about treatment and follow-up, physical concerns, difficulty concentrating, and attitudes about body changes. Another study[6] also reported that the greatest source of stress for women with breast cancer following treatment completion is the side effects of treatment such as hair loss, fatigue, and lymphedema. Further, approximately 33.3% of Thai patients with cancer use complementary and alternative medicine (CAM) as a complement to mainstream treatment,[7] while a cross-sectional study reported that Thai patients with cancer who used CAM therapies selected types of CAM based on their cancer-related symptoms.[8] In addition, findings from a cross-sectional study [9]showed that to improve their quality of life, Thai women with breast cancer take herbal medicines (38.1%), change their nutrition (36.5%) or lifestyle (31.7%), or practice praying (16.8%). A qualitative study[10] described that the meaning of complementary therapy as perceived by Thai women with breast cancer included: cancer-controlling treatment, mental strengthening, mind and body therapy, self-determination, natural therapy, and conventional therapy integration. Some participants believed that CAM could cure cancer. However, there are a few studies which have confirmed the efficacy of CAM as being appropriate for women with breast cancer. This is a challenge that health care providers should address as some usage may lead to problems such as a delay in seeking medical treatment or even more serious problems, such as interactions between CAM and conventional treatment.[11] If we know why breast cancer survivors use CAM, it may provide important information about the beliefs, values, expectations, and hopes of consumers.[12] In addition, since culture shapes how people respond to disease, it is essential that health care providers explore perspectives of patients regarding their health care practice within a cultural context.[13]

Leininger[13] asserted that cultural and social structure factors, including education, economics, politics, cultural values and lifeways, kinship, religion, and technology, also influence individuals' care practices. Accordingly, if nurses understand what factors motivate survivors to use CAM as their care practices, better counseling related to CAM use may be effectively provided.[14] Study results serve as a foundation for better understanding the significance of cultural influences on health behaviors, and help nurses to develop cultural nursing interventions to improve health outcomes for Thai women with breast cancer, and enhance provision of culturally-consistent care.

### Purpose of Study

To identify the cultural and social structure factors that influence Thai women with breast cancer to select CAM care practices to promote their health and well-being.

### Research Question

What are the factors that influence the selection of CAM care practices by Thai women with breast cancer?

## Methods

**Design:** The qualitative ethnonursing method of Leininger[15] was used in this study. This uses naturalistic and open inquiry modes to discover the participants' world of knowing and experiencing life.[15] This method is unique and essential to the study of caring and healing practices, beliefs, and values in diverse cultural and environmental perspectives. The theory of Culture Care Diversity and Universality developed by Leininger[15] was chosen to inform this study as it was only theory explicitly focused on the close interrelationship of culture and care on well-being, health, illness, and death. It also focuses on the complex interrelationship of many factors, including lifeways, religion, kinship, politics, law, education, technology, language, environment context, and worldview, that contribute to culturally congruent care.

**Participants:** were recruited using a purposive selection process from one hospital in the lower northern part of Thailand. Inclusion criteria were: >18 years of age; able to read and speak Thai; diagnosis of breast cancer at least one year previously; and experienced in CAM use. A list of possible participants who gave permission to be contacted by the researcher was obtained from a nurse who was a referral source. The researcher then contacted these possible participants to explain details of the study and invite their participation,

**Ethical Considerations:** The study was approved by the Health Sciences Institutional Review Board of Buddhachinaraj Hospital, Phitsanulok, Thailand and the University of Missouri. All participants were informed about standard principles of protection of human subjects and were provided with written informed consent under the principle of full disclosure. Efforts to maintain participant confidentiality included keeping information secure and private throughout the study. All participants signed an informed consent form.

**Data Collection:** Two in-depth interviews were performed with each participant, for 30 to 60 minutes, with at least two weeks between each of the two interviews, during two months of 2011. Examples of open-ended questions for the interview were: 'Tell me about your decision to use particular health care practices?; How do you care for yourself to promote health and well-being?'; 'How do these factors influence your decision-making regarding care practices'; and 'How do you care for yourself to promote health and well-being?'. Data saturation was achieved by continuing to collect data until no further new information was obtained.[15]

*Verbatim* data obtained from audiotaped and transcribed interviews were translated and back-translated into English before analysis by the first author who is fluent in both Thai and English and confirmed by a second bilingual person. Finally, a translated English version was reviewed by two monolingual English-speaking collaborators and co-researchers.

**Data analysis:** This was conducted using the four phases of the ethnonursing qualitative data analysis method proposed by Leininger[15]. Data analysis began on the first day of research and continued with regular data coding, processing, and analysis until all data were collected. The second phase began with organizing all recurrent components into the NVivo software program to clarify their meanings line by line and word by word. Thereafter, data were reviewed to discover patterns related to the research question, what factors influenced them to use CAM. Finally, the main themes and sub-themes were formulated to explain how those factors influence their decision-making regarding care practices.[15]

**Trustworthiness and Rigor of the Study:** The six qualitative criteria described by Leininger[15] were used in this study to establish trustworthiness and rigor of the study: credibility, confirmability, meaning-in-context, recurrent patterning, saturation, and transferability. To achieve credibility, a triangulation method including observation, field notes, and interview were performed. To achieve confirmability and meaning-in-context, the transcription, field notes, on-going data analysis, and findings were shared with research team. To achieve recurrent patterning, re-reading and re-checking the transcripts several times were performed. To achieve saturation, continuing to collect data until no further new information was obtained. To achieve transferability, providing rich, thick description in describing more details about phenomenon was undertaken.

## Results

There were 17 Thai women with breast cancer with an average age of 49.5 (ranged from 24 to 63 years) years. Ten had less than a high school education and the rest had higher than a high school education. Twelve women reported it was <6 years since the diagnosis of their breast cancer; the rest reported diagnosis between 9-16 years earlier. Nine women reported they were at stage II of diagnosis, whereas five women had stage III, and three had stage I. Eleven women had received three types of treatment (surgery, chemotherapy, and radiation); five women had received surgery and chemotherapy; and one had been treated by surgery only. Sixteen were Buddhists. Ten women earned < 10,000 baht (<US$333) a month and the rest earned more than 10,000 baht (>US$333) a month

There were four themes that emerged: kinship, social factors, economic status, and beliefs and lifestyles.

*Kinship*

When making decisions about their care practices in CAM, participants with breast cancer stated that they were influenced by kinship, including recommendations of family members and friends.

One participant said that she decided to take herbs because of her father:

> *I have been interested in using herbs because my father knew about herbal medicines, as my grandmother was a traditional midwife. She gave him Thai traditional medicine textbooks, so he was an expert in herbs. When I was sick, he sought out and studied from his old textbooks.* (P1)

Another participant decided to use CAM because she had direct experience in taking care of her mother who was diagnosed with breast cancer and also used CAM:

> *After my mom was diagnosed with cancer, I studied a lot, whatever could be helpful for my mother, both alternative medicine and Western medicine. So from this direct experience, I have used it for myself when I found out that I had breast cancer.* (P8)

Friends were also identified in care practices in CAM. For example, a participant explained that she first decided to be treated with alternative medicine because of the recommendation from her friend:

> *At first, I did not want to be treated with Western medicine. My friend, a Thai traditional medicine doctor, recommended that I be treated with alternative medicine. She suggested to me to take herbal medicines. So at that time, I took herbal medicines for my self-care practice.* (P13)

*Social Factors*

Social factors that contributed to CAM practices were support group and media. In terms of participating in a support group, one participant stated,

> *At that time, when I was diagnosed with breast cancer, I started to get involved with the volunteer club. So, they suggested that I take herbal medicine.* (P10)

In addition, media, such as radio, TV, the internet, and books, also influenced their CAM care practices, for example:

> *I heard about it on the radio, and then I found it in a book. I love to read books. The book stated that there are many types of therapeutic food that we can eat.* (P3)
>
> *I did research through books about cancer, through word of mouth from friends who have cancer, and also from the TV. I like to watch TV because I'm like this: I must learn about things directly because I want to have a long life.* (P5)

*Economic status*

Economic status was identified as an important factor to continue or discontinue with those CAM practices. The categories of this theme included costs outweigh benefits and benefits outweigh costs. Participants reflected on the cost of CAM as costs outweigh benefits in performing care practices in CAM. For example, one participant said that the cost of alternative products was a barrier to continue with CAM practices. She said:

> *I used to eat some food supplement, but I do not eat it anymore because it is too expensive. I could only eat one package in one month. I took it for three packages, and then I quit because it is so expensive.* (P6)

Another participant chose a product that she could afford, instead of using one was too expensive for her:

> *Now, I eat rice germ oil. It's very cheap, only 12 baht (US40 cents) per tablet. I do not buy other herbs that are too expensive.* (P14)

Despite the cost of CAM, selected participants decided to use this as they perceived the benefits outweighed the costs. For example, a participant with an income of US$666 a month realized how expensive CAM products were, but she still continued to use those products for her health:

> *Now I eat supplementary product of one company. I also drink mineral water from this company. It's a little bit over 3000 baht (~US$100) to help the kidneys. Although I have no money, I am more concerned about my health.* (P7)

*Beliefs and Lifestyles*

Participants reflected that personal beliefs and lifestyle were significant factors contributing to their CAM care practices. This theme contains two subthemes: beliefs and lifestyles.

It was evident that one important factor to CAM use was beliefs in participants' natural lifestyle. For example, one participant shared her view regarding how her beliefs and lifestyles affect the selection of care practices in CAM by returning to natural food.

> *When looking back at food, I saw that grilled food, fried food, and fast food were my favorite foods. So I thought, are these risk factors of cancer or not? So I reduced these foods and chose more natural food. Natural food is eating organic food, reducing meat, but increasing more fruits and vegetables. I think this links to natural healing.* (P8)

Some participants believed that herbal medicines were not as harmful as the Western medicine, so they tried them. For example, one participant stated,

> *I think it is a folk medicine that is not dangerous. So I try to eat some.* (P1) *Another agreed, saying: It's like this is the way that Thai people believe. There's no big loss with these kinds of things, especially herbal medicine. Most herbs are not harmful, unlike Western medicines (which) are dangerous drugs.* (P10)

In addition to belief in a natural lifestyle, religious belief was identified as influencing the use of CAM. For example, one Buddhist participant believed that prayer helped her to be able to take all the courses of chemotherapy courses:

> *The first time that I received chemotherapy, I could not eat anything and vomited all the time for about three days. The second time, my sister told me to pray any chapter from a chanting book that I wanted. So when they started my injection, I closed my eyes and prayed. Believe it or not, the second time I never vomited. I ate like a pregnant woman. Although my mouth was burned, I was able to eat everything.* (P2)

Another Buddhist participant shared her story of how meditation and prayers changed her personality:

> *When my breast was cut off, I thought too much about my body image. I was afraid that my husband would leave me one day. I was so stressed. Later, when I practiced meditation and pray, I found I did not depend on him. I can let him go.* (P12)

## Discussion

Participants explained that their care practices in CAM were influenced by many factors, including: kinship, social factors, economic status, and beliefs and lifestyles. This concurs with Leininger's theory of Culture Care Diversity and Universality,[13] in that religion, cultural value and lifeways, economic, kinship factors and social factors are the most significant forces influencing care which help people to face disabilities, illness, and death. A Western study found that kinship, economic, education, and belief factors were the important influencing factors for American breast cancer survivors in making decisions about their care practices, using both Western and alternative medicines.[16]

Family members and friends were important in influencing participants to make decisions about using CAM to promote their health and well-being. This might be explained by the fact that the majority of our participants were young women in stage II of breast cancer. They hoped to live longer and sought out health information from other people around them. This finding is consistent with another study in that sources of information about CAM for Thai women with breast cancer were family members, or friends.[17] Our findings are also consistent with previous studies conducted in other countries that demonstrated the most common source of CAM information for women with breast cancer were family members and friends.[18-19] In the Thai context, particularly in the north of Thailand, Thais live with or near their parents, and they have a strong family relationship with each other. Moreover, Thai Buddhists also perceive that sickness is often dealt with through strong family ties. Therefore, when someone in the family is ill, others support that person as much as they can.[17,20] Additionally, a method involved in finding care practices in CAM for Thai women with breast cancer may result from Thai culture. Thais usually learn how to use herbal medicines from old books or from the records of their older family members.[21] As can be seen from this study, one participant decided to use herbs in her care practices because her father had the traditional medicine textbooks, received from her grandmother.

In addition to kinship, social factors, particularly media (i.e., radio, television, books, and the Internet), also played an important role as a source of CAM information for participants. This finding is consistent with a study which found that mass media, such as television, radio, and magazines, influenced the use of herbal medicine of Thai elderly people.[21] Likewise, a cross-sectional study[22] reported that the majority of Thais in Bangkok, Thailand, received information about herbal medicines from mass media, similar to another study in Korea.[23] Similarly, in a cross-sectional study to assess patterns of CAM use by patients with breast cancer from 11 countries in Europe (N = 282), about one-third of participants reported that they received their information about CAM from media.[18] Moreover, one study conducted a cross-sectional study with patients with breast cancer in Malaysia to identify their information sources of CAM.[24] The results showed that, in addition to friends or family members, mass media was also the common information source about CAM for women.

Another study reported that social factors can influence the selection of care practices in CAM by patients with cancer through their personal experience, social interaction, and the interface with the mass media.[25] The challenge is that most media describe CAM in a positive fashion, and more specifically, as a potential cure for cancer, but did not describe the risk and the cost information.[26,27] This is a clear indication that the knowledge base about CAM needs to be improved for patients with breast cancer.

The economic status of participants influenced decisions to continue or discontinue CAM practices. Participants reported that they would select CAM types that were not too expensive for them. They would choose the one that they could afford. This might be explained by the fact that the majority were likely to have low incomes and perceived the cost of CAM as a barrier to its use. There is no doubt that the Thai government realizes how important CAM is for Thai people's health, as the practices of Thai Traditional Medicine (TTM) have been integrated into the national health care service system in Thailand since 1978. The Thai government has set the policy to provide financial support for the use of TTM to promote health for Thai people.[21]

However, despite an increasing number of approved herbal medicines being included on the national list of essential drugs in Thailand so that doctors will have more herbal medicines to choose in hospitals,[28] many CAM types are still available only outside the hospitals. As a result, these CAM types are not reimbursed by the Thai Universal Coverage system. Thus, many patients need to pay entirely out-of-pocket for CAM products. Therefore, it is not surprising that CAM use can be an expensive undertaking for women with breast cancer who perceive economic factors as a barrier to the use of CAM. This finding is consistent with a qualitative study which reported that Taiwanese cancer patients would be less committed to expensive therapies.[29] Similarly, a cross-sectional study reported that when CAM became more costly and more difficult to access, Canadians with breast cancer were less likely to use these.[30] Likewise, a qualitative study reported that foreign-born Chinese women with breast cancer in the U.S. perceived that the high cost of CAM was a major barrier to CAM use because most treatments were not covered by medical insurance.[31]

However, although financial factors seem to be a barrier for CAM use by women with breast cancer, and the perceived value of CAM by patients could affect their decision-making as to whether they would choose to use CAM or not.[32] If they evaluate that the pros of CAM are higher than its cons, they may decide to use CAM for their care practices. In addition, if they perceive that CAM is beneficial for their health, they will possibly decide to continue to use CAM for their care practices, despite its high cost, as mentioned by one participant in our study who decided to continue to use CAM in her care practice, even though its cost was high.

Study findings showed that beliefs and lifestyles had a strong influence for selection of care practices in CAM. Herbal medicines have been traditional household medications in Thai society for a long period of time.[21] Thai people have used herbs both as food and as medicine by the traditional learning from one generation to the next generation. In addition, as the majority of participants in this study had less than a high school education level, one influencing factor for their selection of care practices was by the nature of Thai people who usually believe in herbal medicines. Moreover, many participants believed that CAM therapies were more natural and less likely to be harmful to their health than conventional medicines. This finding is consistent with a qualitative study[33] which reported that CAM was seen to be less harmful than conventional treatments. Likewise, in family physicians' views, one reason that patients with cancer decided to use CAM was because they believed it was more natural and therefore less toxic.[33]

Regarding religious beliefs, it is noteworthy that Buddhism beliefs influenced the selections of some types of CAM by participants, namely mind and body medicine, such as meditation, making merit or prayer. According to Buddhism, the state of well-being is not dependent on external circumstances. On the other hand, mental balance will lead to greater well-being and the imbalance of the mind will result in mental suffering,[34] In addition, Thai Buddhists also believe that illness results from an individual's past karma (past actions).[34-36] Consequently, Thai people select to do good things, such as practicing meditation, making merits, chanting, or listening to Dharma, because they believe that these kinds of Buddhist practices are considered as good deeds which can promote their psychological well-being and lead to a good life, both in the present life and in the future life.[34,3]

**Strengths and limitations**

This qualitative study is one of a few known studies of care practices incorporating CAM in Thailand focused on patients with breast cancer. Our findings are important to inform the preparation of nursing care to promote quality of life of Thais who have had breast cancer. All participants were Thais living in the north of Thailand. Accordingly, the findings of this study may not represent Thai women with breast cancer in other parts of Thailand and in other countries. More work is required to explore whether there are similarities or differences in factors that influence Thai women with breast cancer to use CAM in other areas of the country.

## Conclusions

In essence, these findings emphasis many important factors in Thailand, namely kinship, social factors, economic status, and beliefs and lifestyles. Family members and significant others around them were the most important resources of information. Social factors, such as media and support group were also influenced factors for the participants to use CAM. Financial issues was a barrier to continue or discontinue use of complementary and alternative medicines. The beliefs and lifestyles of Thai people also influenced the selection of types of alternative medicine used by the participants.

## Implications for nursing practice

The findings of this study have several important implications for practicing health care professionals as a decision making to CAM use is related to many factors, namely kinship, social factors, economic status, and beliefs and lifestyles. Therefore, it is necessary that health care providers assess patients' contexts, such as their beliefs and their social network. More importantly, significant persons should be encouraged to be involved in conversations between the health care provider and the patient regarding care practice decision-making.

Mass media is a valuable source of information about CAM. The challenge is that, whereas the information from these media sources is likely to be accessible, it may be unscientific, and thus less likely to be accurate and unbiased.[18,24] Nurses for example could prepare educational printed materials which include a list of reliable sources about CAM, as well as giving reliable information for treatment decision-making, by providing an interpretive medical and nursing information guideline for them.

**Implications for Research**

Finally, the findings of this study indicated that although CAM therapies have the potential for harm or benefit, some participants described CAM as more natural and harmless. Although sometimes they had to pay out-of-pocket expenses due to no types of CAM having been included on the national list of essential drugs in Thailand, they were still likely to use CAM in their care practices. Accordingly, future research to examine the efficacy and safety of CAM using a rigorous design such as a randomized control trial and cost-benefit economic research on CAM use are needed. This will lead to stronger evidence in supporting health policy and holistic implications.

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# วิจัยเชิงคุณภาพ: ปัจจัยที่มีอิทธิพลต่อการใช้การแพทย์ทางเลือกของสตรีไทยที่เป็นมะเร็งเต้านม

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**บทคัดย่อ:** ในขณะรักษามะเร็งด้วยการแพทย์แผนปัจจุบันผู้ป่วยบางรายเลือกที่จะใช้การแพทย์ทางเลือกเพื่อส่งเสริมสุขภาพตนเอง บทความนี้เป็นการศึกษาวิจัยเชิงชาติพันธ์วรรณนาโดยใช้เทคนิคของไลนิงเกอร์เพื่อศึกษาปัจจัยทางวัฒนธรรมที่มีอิทธิพลต่อการเลือกใช้การแพทย์ทางเลือกของผู้ป่วยมะเร็งเต้านมไทย กลุ่มตัวอย่างคือผู้ป่วย มะเร็งเต้านมไทยที่ใช้การแพทย์ทางเลือกจากโรงพยาบาลแห่งหนึ่งในเขตภาคเหนือตอนล่าง เก็บข้อมูลโดยการสัมภาษณ์แบบเจาะลึกผลการวิจัยพบว่า ปัจจัยที่กระตุ้นให้ผู้ป่วยมะเร็งเต้านมเลือกใช้การแพทย์ทางเลือก คือปัจจัยทางด้านครอบครัวและสังคมเศรษฐกิจ ความเชื่อและวิถีชีวิต จากการศึกษาบ่งชี้ให้เห็นว่ามีปัจจัยสำคัญมากมายที่กระตุ้นให้ผู้ป่วยมะเร็งเต้านมตัดสินใจใช้การแพทย์ทางเลือก ทั้งนี้สมาชิกในครอบครัวและคนใกล้ชิดเป็นแหล่งข้อมูลที่สำคัญที่สุด ส่วนปัจจัยทางด้านเศรษฐกิจอาจเป็นอุปสรรคที่มีผลต่อการใช้หรือหยุดการใช้การแพทย์ทางเลือก ในขณะที่ความเชื่อและวิถีชีวิตของคนไทยก็เป็นปัจจัยหนึ่งที่มีอิทธิพลต่อการเลือกใช้การแพทย์ทางเลือกของผู้ป่วยมะเร็งเต้านมเช่นกัน ดังนั้นพยาบาลควรมีการประเมินบริบทของผู้ป่วย เช่น ความเชื่อและเครือข่ายทางสังคมของผู้ป่วย นอกจากนี้บุคคลที่มีความสำคัญกับผู้ป่วยควรได้รับการช่วยเหลือให้เข้ามามีส่วนร่วมในการพูดคุยเกี่ยวกับการตัดสินใจดูแลผู้ป่วยร่วมกับแพทย์ผู้ดูแลด้วย

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# Struggling to Restore Normalcy: Thai Parents' Experiences in Being Caregivers of Children with Early Schizophrenia

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**Abstract:** Although caregiving for persons with early schizophrenia is a difficult task, little is known about the caregiving process in early schizophrenia. This study explored the caregiving process for children with early schizophrenia. Twenty-five Thai parents of children diagnosed with schizophrenia within the last five years were interviewed indepth at outpatient clinics and wards of a large psychiatric hospital in Thailand. A Straussian grounded theory approach was used and data analysed using constant comparative analysis.

"Struggling to restore normalcy" emerged as the core category that comprised six sub-categories: *learning the diagnosis*, *facing shattered dreams*, *caregiving as an unavoidable role*, *struggling to control psychotic symptoms*, *struggling to deal with the illness impacts*, and *accepting a new normal*. The parents felt as if they were facing shattered dreams after learning the diagnosis. They viewed their caregiving as an unavoidable role, as they strived for their child's normalcy. They tried to control their child's unstable psychotic symptoms by maintaining medication adherence, monitoring and managing the symptoms, and preventing symptom exacerbation and relapse. They had to deal with the impacts of the illness including their child's poor decision-making, illness-related stigma, and their feeling of loss and difficulties. They gradually accepted the incurability of schizophrenia which was their child's new normal.

The unique study findings add to nursing's knowledge about caregiving for this group of children, and have implications for the development of an intervention program that nurses and others can use to help parents cope with caregiving challenges. Future studies should compare mothers' and fathers' experiences in caring for children with early schizophrenia.

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**Keywords:** Caregiving; Children; Experience; Grounded theory; Parents; Schizophrenia

## Background

Schizophrenia is one of the most severe and chronic mental illnesses. The characteristics of the illness are disturbances of perceptual and thinking process, behaviors, and social function.[1] In Thailand, the numbers of person with mental illness including schizophrenia that attended at outpatient clinic of public hospitals increase from 1,076,155 in 2012 to 1,109,183, in 2013.[2] The prevalence of schizophrenia is approximately 8.8 per 1,000. The incidence rate

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was 0.3 per 1,000 with a peak at age of 15-24.[3] The estimate annual costs for the entire population with schizophrenia is high (THB 31,000 million or $US925 million). Hospitalization was the largest component of direct medical cost (50%). Additionally, 61% of the total economic burden is indirect cost of unemployment.[4] The majority of sufferers (98%) reside with their families and their parents were primary caregivers.[3]

The first five years after a diagnosis with schizophrenia is critical and sufferers need continuing care. The psychotic symptoms of early schizophrenia are particularly prominent, unstable, and marked by exacerbations, remissions, and relapse requiring rehospitalization.[5-6] Research evidence revealed that relapse rates were very high even after the first psychotic episode[6-8] and each subsequent relapse was associated with a poor response to treatment, a long time to remission, and a deterioration of functions.[8-9] Hence, caregiving in the early phase of schizophrenia is vital to prevent relapse and promote recovery.[10]

To date, the majority studies of caregiving in western countries has been focused on impact of schizophrenia on caregivers.[11-15] It is evident that caregivers faced multiple challenges to integrate caregiving into their lives and all aspects of their lives were impacted. The studies exploring caregiving process in chronic schizophrenia suggest that following a diagnosis of schizophrenia, caregivers struggle to understand what had happened to their loved ones.[10,12,16-17,20] They experience a sense of crisis and seek ways to solve unpredictable problems and to adjust emotionally to a demanding illness. There are many types of care that caregivers have to provide, including physical, psychological, medical, and social care.[11,16-18] Caregivers experience trial and error processes to overcome caregiving stress and to move toward a state of balance, normalcy, and mastery.[18-19]

In the Thai context, Buddhism has influenced people's perspectives of life and is an integral part of Thai culture.[21] Parental responsibility is culturally prescribed and centered on familial ethics and values which expect that caregiving for children is direct responsibility of parents.[22-24] Therefore, the majority primary caregivers of person with schizophrenia are parents.[10,25-27] Research evidence on parental caregiving support that parents utilized Buddhist principles in managing their feelings in caregiving.[23,26-27] Similar to western studies, caring for children with schizophrenia brings enormous impacts to families and parents' lives.[10] Parents have to adjust their lives in dealing with each phase of illness and the repetitive problems over time.[10, 26] They provide the close and thoughtful caregiving in managing the unpredictability psychotic symptoms and gradually develop caregiving skills and strategies for various circumstances by experiential learning.[10,25-27] Although informative, these studies provide information about caregiving experiences across a wide range of duration, from seven months to over 10 years, however caregiver's experience at the early phase of schizophrenia has been barely researched. Thus, little is known about how parents manage the challenges of being caregivers for their children with early schizophrenia in Thai context.

## Study Aim

The aim of this qualitative study was to explore parental caregiving processes in Thailand during the early phase of schizophrenia.

## Methods

**Study design:** A Straussian's grounded theory approach was employed to elicit parents' descriptions of dynamic process of managing caregiving in the early phase of schizophrenia.[28]

**Participants and setting:** Study participants were recruited from the outpatient clinic and wards of the largest psychiatric hospital in Thailand, initially through purposive sampling. The inclusion criteria were: 1) parents who served as primary caregivers and lived in the same household with the child since the first episode of schizophrenia: 2) had been informed by a psychiatrist that their child was diagnosed with schizophrenia no more than five years ago; and 3) spoke and understood Thai language. Parents who provided care for family members with chronic diseases in the same household and those who had been diagnosed with psychiatric illness were excluded from the study. Nurses in the clinic or wards were asked to approach parents who came with or visited their children with schizophrenia and asked if they were interested in participating in this study. If they indicated their interest, the researcher informed them about the nature and purpose of the study as well as their rights as research participants. The rest of the study participants were recruited through theoretical sampling, which based on emergent concepts from data analysis.

**Ethical considerations**: Approval for informed consent procedures and protection of human subjects was obtained from the Institutional Review Board of Nursing Faculty, Mahidol University and the selected hospital. Each participant was given monetary compensation of 200 Baht (US$6) for each interview.

**Data collection and analysis**: Data collection and analysis was conducted concurrently from August 2012 to July 2013. Indepth interviews ranged from 30 to 110 minutes. The general opening statement for all participants was "Tell me about your experiences since your child's illness begin." Additional questions were used to elicit more details about their experiences. Demographic data was completed after each interview using a brief paper and pencil survey.

Transcripts of the first three interviews were initially examined with open coding, by closely examining phrases or single words to identify types of specific events, activities, and behaviors.[28] Codes that shared common characteristics were grouped into concepts and categories. The beginning categories, and explanatory questions were used to refine the questions in the interview guide and to suggest comparative groups of further nine subsequent interviews. Early categories emerged from data analysis, and were elaborated and refined over the course of analysis through theoretical sampling. Then axial coding and selective coding were used.[28] The emerged concepts were compared against those emerging from eight subsequent interviews and linked to each other. At this point, data saturation was achieved, that is nothing new emerged from analysis. The categories were refined, compared, and linked; memos simultaneously recorded and diagrams representing the linkages were drawn. Writing a story line technique was used. Once the core category emerged, five further interviews were conducted to validate those relationships and hypotheses.

**Trustworthiness**: To enhance the credibility of the findings, each interview was audio-taped, then transcribed verbatim for analysis, checked the accuracy of transcriptions, and codes by the first author. Additionally, peer debriefing and member checking were used.[29] In peer debriefing, the analyses and conceptual abstractions of the data were presented to two experts in grounded theory approach to explore and shape the first author's interpretations. The preliminary findings were presented to five participants in the second interview for member checking.[29-30] Moreover, analyzing negative cases technique was used to increase explanatory power of the substantive theory. An audit trail including notes, field notes, transcribed interviews, and memos were recorded and reviewed by the second author, to enhance dependability of the findings.[29-30]

## Findings

### Characteristics of the study participants

The participants included 25 parents (17 mothers, 8 fathers). Their ages ranged from 44 to 77 years with a mean of 56.24. Duration of caregiving ranged from four months to five years with a mean of 3.20 years. None of them reported having any prior experience in caring for patients with mental illness. All participants were Buddhist and the majority of them were living in urban areas in the central region of

Thailand. The average age of children with schizophrenia when first diagnosed was 26.50 years (range 16-47 years). They had been first diagnosed for an average of 2.27 years. All of them were single, unemployed, and lived together with their parents. Half of them had 1-3 hospitalizations while the rest had more than 3 hospitalizations.

**The grounded theory of struggling to restore normalcy**

"Struggling to restore normalcy" emerged as a core category to describe the basic psycho-social processes of parents' experiences as they assumed roles of primary caregivers for their children with early schizophrenia and face their unstable psychotic symptoms, which was viewed as the basic social and psychological problems for the parents. The core category encompassed six sub-categories: learning the diagnosis, facing shattered dreams, caregiving as an unavoidable role, struggling to control psychotic symptoms, struggling in dealing with the illness impacts, and accepting a new normal, as described below (see in Figure 1).

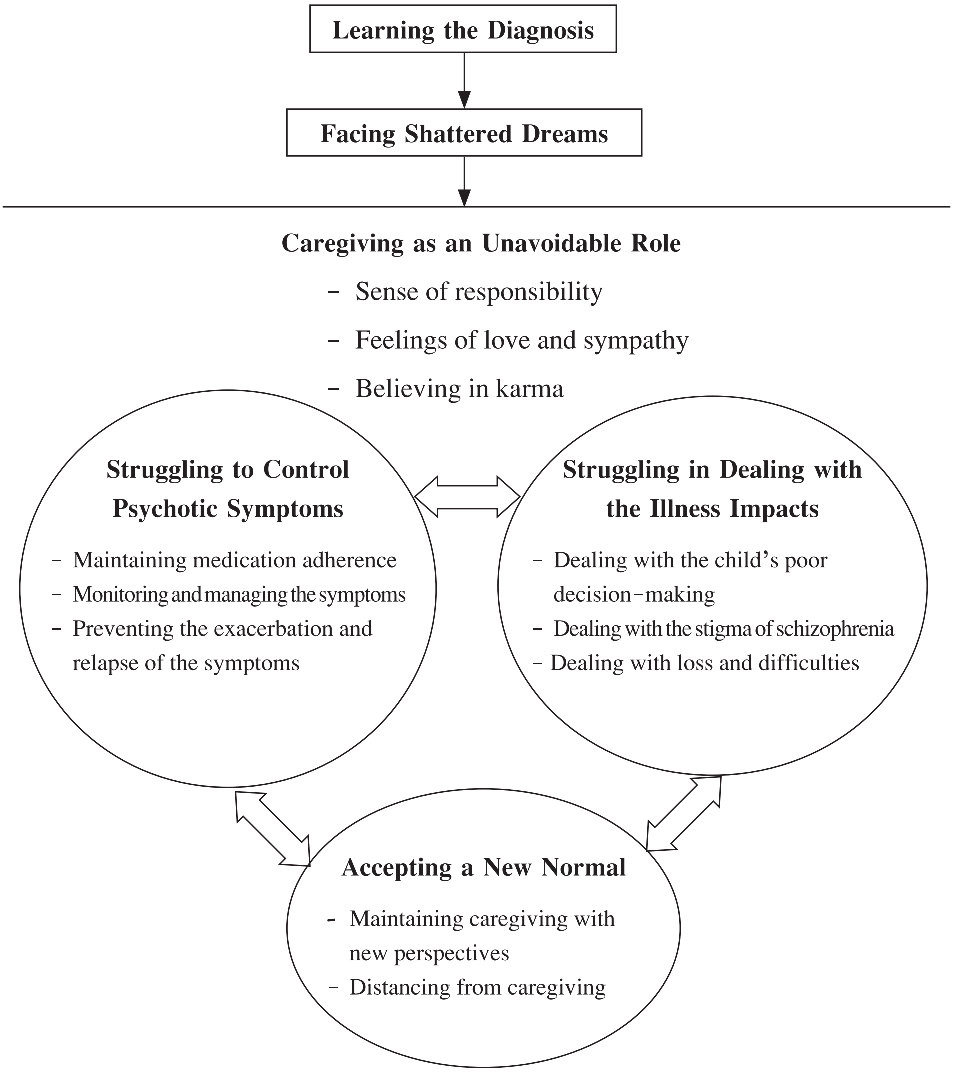

**Figure 1.** The grounded theory of struggling to restore normalcy.

**1. Learning the Diagnosis:** This was a process that began with noticing behavioral changes. The participants reported perceiving gradual changes in their child's behaviors such as increased social isolation or decreased daily activities. Most of them initially thought that those behaviors were normal or reflective of adolescent rebellion as most children first exhibited changed behaviors during their transition to adolescence. As the children's symptoms persisted and became more severe, they began suspecting the behaviors to be abnormal. After the diagnosis, participants reported responses as shock and disbelief at such an unexpected situation. One mother said: *It shocked us, unexpected. I couldn't believe, we brought her up so well.* These reactions were followed by feelings of guilt about whether they had caused or could have prevented the illness.

**2. Facing Shattered Dreams:** The majority of participants were aware that schizophrenia is both an incurable and highly stigmatized condition. Thus, they felt that the dreams that they had for their child and their future had been lost. They experienced anxiety when they thought about the future and their role as caregiver. One mother described:

> *Oh! It seemed that everything was ruined. All parents wish their children to have a prosperous future, to be a soldier, to be a police officer which is good for their lives. When he became like this, did not recover from the illness, could not do anything, he lost his future.*

**3. Caregiving as an Unavoidable Role:** After learning the diagnosis, the participants believed that they were obligated to fullfill the caregiving role for their child. This perception was associated with a number of feelings or reasons:

***Sense of responsibility.*** Most participants perceived that caring for the children especially when they were sick was the direct responsibility of the parents. As one mother said,

> *I don't think anything....It's my duty. If I do not take care of him, who does? As mother, it does not matter if he is a child or an adult. He is our adult child.*

***Feelings of love and sympathy.*** All participants engaged in caregiving with feelings of love and sympathy for their children. They experienced extreme pity for them especially when their children showed psychotic symptoms or had to be restrained or secluded in a hospital. As one mother described while she sobbed:

> *When I saw him while he was eating, I was sad and felt sympathy. He used chopsticks instead of a spoon, wore trousers backwards, took a shower many times a day, and scratched his foot with a brooch [wipe her tears].... He had not been ill since he was born.*

***Believing in karma.*** Karma concerns intentional actions which have their consequences: good karma brings good consequences and bad karma brings bad consequences.[31] All participants believed that they were facing these current struggles because of their karma. They must have treated their children badly or committed a bad deed against someone in their past life. Therefore, they could not avoid repaying such karma. One mother mentioned,

> *I think that it is karma that I had to repay to him. Most of us think that karma involves something that we have done in the past.*

**4. Struggling to Control Psychotic Symptoms:** A primary caregiving task included managing their children's unstable psychotic symptoms. The participants used the following strategies in an attempt to control the illness:

***Maintaining medication adherence.*** All participants understood that medication adherence could control the psychotic symptoms; therefore, they used various approaches to maintain their children's medication adherence. They *took control of medication adminstration* when they viewed that their child was unable to prepare and take medications by themselves. One mother explained:

> *I prepare the pills for him, put them in his hand, and ask him to take them immediately every meal time. I have to do this to make sure that he takes medication correctly and completely. I watch him swallow the pills.*

The participants began to *promote their children's self-responsibility for medication* when they noticed an improvement in symptoms. They gradually decreased their control. Though some of them still prepared medications for their children, they let them to take medication by themselves without observation. Some participants began to teach their children how to prepare the medication by explaining details of medication regimes, preparation, through testing their understanding, reminding their children to prepare and take medication, and re-checking whether the medication was prepared correctly.

In addition, the participants had to *deal with medication discontinuation.* They tried to persuade their children about the importance of medication adherence for recovery. They also used threats and force when their child spat out the medications. Some participants used deception such as crushing tablets and surreptitiously mixing them with food or drink without their children's acknowledge. One mother described her approach:

> *I will try to put it in "Birdy coffee" [an instant coffee beverage] that he likes. I thought he could not know because it is black, unlike "Ohishi tea" [a green tea beverage], he could see the powder left on the bottom of the bottle.*

The participants whose children were not compliant with medication duez to the side effects of the antipsychotic drugs consulted or asked for help from their psychiatrist and tried to diminish the side effects by themselves. For example, some participants provided natural laxatives or fiber foods for their child to alleviate constipation.

***Monitoring and managing the symptoms.*** This approach was used to evaluate the treatment outcome and adjust their responses in managing their children's psychotic symptoms. The participants observed changes in psychotic symptoms from those their children expressed at the first onset of the illness. They determined the severity by comparing with the previous symptoms, in terms of the frequency and their effects on the child's daily activities and security. They additionally determined whether the changed behaviors were normal or were psychotic symptoms through considering the appropriateness of their child's thoughts and perceptions within the current context. The participants gradually comprehended their child's psychotic symptoms through a monitoring approach. A father, whose daughter had auditory hallucinations, stated:

> *If she had auditory hallucinations, her emotion changed. She would rebuke people. I used to ask why and she said that she heard something. Sometimes it was like someone wanted to brawl with her. Thus, she quarreled with it. That was her response to hallucination that I learned.*

They utilized accumulated knowledge for further observation and managing the psychotic symptoms. For example, they would make secret observations to prevent the escalation of their child's paranoia. If their child had a delusion or hallucination, they would redirect their children into reality by initially explaining the reality and giving logical explanations for reconsideration. If their child did not believe them, they expended more effort by presenting related evidences to prove the reality. One mother, whose son believed that he was the king's child, explained her strategy,

> *I showed him the picture of when he was a kid. 'Look! These are your pictures of when you were young.' ..... I rented a car three times and I paid a thousand each time for DNA testing.*

When their children expressed aggressive and violent behaviors, most participants used a complying approach to calm them down because they learned that such psychotic symptoms which may increase if they were forced to try to stop such behaviour. If such behaviours were harmless, they did what their child wanted or allowed them to continue their aggressive and violent behaviors.

***Preventing the exacerbation and relapse of the symptoms.*** Most participants realized that their child was vulnerable to stress, anxiety, and to substance abuse which induced symptom recurrence and relapse. Therefore, they tried to prevent symptom exacerbation and relapse by comforting their child's mind, maintaining cheerfulness, and preventing substance abuse. For example, when their children were facing stress or anxiety, they tried to make the children felt better and realize that the situation was not so bad. As one mother described her response to her daughter's worrying about being admited into a psychiatric hospital:

> *'Mom, it is written on the pillow.' Then, I said, 'That's right, this is the hospital. But you are not mentally ill. You have a chance to recover because you are simply stressed, but need to stay together with them in this hospital,'* I said.

When the child's distress was subsiding, the participants maintained their child's cheerfulness by pleasing them with their favorite foods, providing entertaining activities, and limiting stress in the environment. To prevent substance abuse, they convinced their child by refering to the psychiatrist's information that substance abuse could induce relapse of the psychotic symptoms. Some participants threatened their child that they would not take care of them if their symptoms were worsened by addictive substances. They tried to prevent access to substances by prohibiting their child to meet addicted friends. Some participants decided to take their children away from environments where there were drugs.

**5. Struggling in Dealing with the Illness Impacts**: The participants tried to lessen the impacts associated with schizophrenia, including their child's poor decision-making, the stigma of schizophrenia, and their feelings of loss and difficulties.

***Dealing with the child's poor decision-making.*** This poor decision-making resulted in alterations in daily activities, such as staying in their room, not eating or not taking care of their hygiene as usual. They tried to encourage them. If their child did not comply, the participants would complete it by themselves, such as cooking for them or taking care of their clothes and hygiene.

The participants also thought that their child might harm other people or might be exposed to both physical and sexual harm as a result of their poor decision-making and vulnerability. To prevent their child from being harmed or harming other people, they kept an eye on them, watched carefully and did not leave them alone, and followed them everywhere. They also kept sharp materials away when their children were likely to harm themselves. As one mother narrated:

> *I keep observing him and being cautious. I usually stay with him, not to let him stay alone. He will not be surrounded with any sharp materials. I did not cook at home since cooking requires some utensils such as knives.*

When they perceived that the children were uncontrollable and might injure another person or damage property, they secluded their children in a locked room until they were able to take them to a hospital.

To protect their children from sexual harm, such as sexually transmitted diseases for the sons, or sexual abuse for the daughters, the participants tried to limit their child going outside by assigning them to do housework. Some participants cut the Internet signal at home to prevent them from contacting their boyfriend or girlfriend.

***Dealing with the stigma of schizophrenia.*** The majority of participants concealed their child's illness to try to prevent negative consequences. Most were likely to conceal the schizophrenia from relatives and neighbours after learning the diagnosis as they still had hope for a cure. They did not mention the child's illness if symptoms were not severe enough to arouse neighbours' suspicions. They told a lie when the neighbours suspected and asked questions when the child showed more severe psychotic symptoms or changed their lifestyle due to their illness. Some participants told their neighbours that their child suffered with other conditions, such as tension or stress. The participants whose children ran away from home answered questions from others by giving such reasons that their children went to work somewhere else. Some others concealed the name of the hospital to prevent others from visiting and finding out about their child's illness.

However, after time passed and psychotic symptoms were still severe requiring frequent re-hospitalization, most participants could no longer conceal their child's illness. Some unavoidably disclosed the illness in the early phase, for example, when they needed to keep in contact with their relatives, lived nearby their relatives whom they could see regulary, or when their son needed a waiver for conscription for army service. A father explained, *It was because we needed to submit the medical certificate to waive conscription for an army service due to his being mentally ill, so the matter was known to all the villagers.*

***Dealing with loss and difficulties.*** To be able to continue restoring normalcy for their children, the participants used various approaches to cope with their feeling of loss and difficulties, including *thum-jai*, searching for information about the illness, and gaining support from others. *Thum-jai* is a common approach that Thai people use when they face unpleasant situations and in order to overcome unpleasant feelings, calm their mind, and be able to accept them.[32] The strategies for *thum-jai* included being here and now, and thinking positively. These strategies related to the Buddhist principle regarding mindfulness, to be in the present time.[31] As one mother stated, *I had to be aware of every situation. I suffered whenever I saw my son as a mentally ill patient. .... Just only being here and now could enable me to restrain my mind.* Thinking positively was another way to *thum-jai* included finding existing good things and comparing themselves with other inferior persons.

***Searching for information about the illness*** included the participants' actions in trying to understand schizophrenia, in terms of the course of the illness, symptom management, and sources of help. Some discussed this with relatives of the other patients, while the others read from books or pamphlets or watched some health programs on television. The knowledge that they acquired helped them to face the reality and deal with their child's symptoms more effectively, for example, one mother said:

> *I read from books that we have to comply with the patients. I did not fight against her symptoms especially when she showed aggressive behaviors. I let her to do what she wanted so I could avoid facing more difficulties.*

***Gaining support from others.*** The majority of participants received financial, emotional, and informational support from their spouse, children, or partner. In addition, their family members or their child with schizophrenia assisted them to do household work. Two participants received both informational and emotional support from health care providers. Such support helped them to feel comfortable and made it easier to overcome their caregiving difficulties. One mother who lived alone with her son alone, and suffered from heart disease and hypertension, and used to have suicidal ideas, narrated about her experience:

> *Previously, I wanted to commit suicide. I felt discouraged .... When I saw he cleaned our house, I came up with an idea that I could take care of a dog even though it could not talk to me. My son could talk to me and help me to clean up the house, whereas the dog just lay down and waited to be fed [laugh].*

6. **Accepting a New Normal**: Accepting a new normal is a consequence of struggling to restore normalcy. It refers to the participants' realization that the pre-illness normal state of their children would never be restored though they put so much effort to control their psychotic symptoms. Their child still would be a person with schizophrenia. Then, they began to adjust themselves in two ways: maintaining caregiving with new perspectives and distancing from caregiving.

***Maintaining caregiving with new perspectives.*** When a child's psychotic symptoms were controllable for a period of time participants could maintain caregiving as usual with less emotional distress. They still had hope that it might be possible for their children to be better. They let things go, no longer worried about their child's future, and maintained caregiving as much as they could. They adjusted their previous expectation that their children would have a normal life, be self-reliant, have no violent behaviors, or adhere to their medications. Some participants gained optimistic views through a reciprocal relationship with their child while caring for them and living together. One mother, who divorced and let her son live with her husband since his childhood, noted about her optimism:

> *When my son lives with me, I gained opportunity to provide him with warmth. He used to live with his father when we were separated. I experience good feelings. He also looks so happy and is very close to me.*

***Distancing from caregiving.*** Four fathers whose children's psychotic symptoms had not improved due to medication noncompliance, decreased the intensity of their struggle to restore the child's normalcy. Two of them cared for their child alone but they showed continual intense psychotic symptoms requiring frequent re-hospitalization. Another two participants shared the caregiving role with their wives for nearly five years. They reported that the long-lasting and frequent recurrence of their child's symptoms always disturbed their family's normal life. They adjusted to restore their normal life rather than their child's life. They no longer tried to maintain medication adherence and stopped searching for the strategies to manage psychotic symptoms. One father separated himself from his daughter, though he was in the same household, while another one moved away to live in another place and came back to visit his son occasionally. These fathers just waited to take their children to the hospital when the psychotic symptoms became severe. One father said:

> *I had to go away to have a normal life and I left him to stay alone. It was just like staying without peace. I eventually gave up. What happens, happens. He had never taken care of himself, no one could help him .... I came back to see him occasionally and give him some food. If his symptoms became severe, I just took him back to the hospital.*

## Discussion

While prior research has described the caregiving process in long-term care of schizophrena, the current study provided valuable data about the caregiving process in the early schizophrenia. Data analysis indicated that the children's unstable symptoms and the impacts of the illness were the basic psychosocial problems for their parents as caregivers. As a result, struggling to restore normalcy emerged as the core category describing the complex process of Thai parents' adaptations to their caregiving role in early schizophrenia. The findings shared some common attributes with "pursuing normalcy" in a study among family caregivers of severe mental illness.[18] Although that study demonstrated normalcy as a family caregivers' coping response to a chronic mental illness, the current study adds to body of knowledge that normalcy is also the goal of caregiving in the early schizophrenia. It indicates that, for parents, independence and productivity of their children are their optimal needs, regardless of where they were in the illness experience.

The participants in this study struggled with difficulties in dealing with their child's psychotic symptoms both before and after the diagnosis. Before the diagnosis, they experienced struggling in trying to understand and deal with things that happened to their children and which was consistent with findings from prior studies,[11,16-17,33] where caregivers recognized the abnormalities of their relatives, but they were unable to define them.

After diagnosis and treatment for schizophrenia, the participants struggled to restore normalcy for their children. Because of their lack of experience and caregiving skills, they experienced agony in controlling the unstable psychotic symptoms, especially in maintaining medication adherence, managing symptoms, and preventing the exacerbation and relapse of psychotic symptoms. This is similar to other studies,[16,18-19] where the researchers reported that caregivers experienced a cycle of instability and recurrent crises of care recipients' symptoms and they became aware of the chronic trajectory through the cycle of exacerbations and relapses.

Unlike findings of studies focusing on caregiving over a long-term period in which caregivers achieved mastery in caregiving,[10, 18-19,25-27] the participants in this study still struggled with uncertainty and wondered how to appropriately respond to the unstable and unpredictable nature of their child's symptoms. Previous studies supported that caregivers took a long time in adjusting themselves to living with and caring for people with schizophrenia.[10,15] Hence, it was impossible for them to reach a state of stability in caring for the early phase of schizophrenia. They still had to learn through trial and error to control unstable psychotic symptoms and the impacts of the illness.

It is evident that struggling to control psychotic symptoms and to deal with the impacts of the illness influenced participants' coping responses. These could be either adaptive or maladaptive. When a child's psychotic symptoms were controllable for some period of time, participants still had to maintain caregiving whilst developing new perspectives after accepting a new normal. This finding is consistent with other studies[17,22,34] where the researchers noted that most caregivers who experienced the positive side of caregiving usually were those who had hoped for improvement in their relative'condition. The caregivers' hopes and encouragement were maintained if their ill relatives had some signs of improvement or reciprocated their love. These encouraged the caregivers to continue their caregiving.

On the other hand, four fathers, whose children had never complied with medication and their psychotic symptoms had not improved, distanced themselves from caregiving. Two of them shared the caregiving role with their wives for nearly five years, while the others provided caregiving alone and their children showed continual intense psychotic symptoms requiring frequent re-hospitalization. This finding is consistent with previous studies[33,35-36] which noted that the caregivers responded in a negative way if they did not experience the recovery of their care recipients in long-term care. After they experienced failure in trying to control the psychotic symptoms, they felt exhaustion, boredom, and hopelessness. Another possible explanation for this issue concerns gender-specific behaviors associated with the Thai cultural values. Because Thai society expects women to be family caregivers,[23-24,26] these fathers might think that it was not their direct responsibility to be caregivers. A recent study supported that such thinking might be associated with family tradition that the main responsibility of child rearing and caregiving belonged to mothers.[37] Although they distanced themselves from caregiving, their wives still maintained a caregiving role. However, because of the limited number of fathers, it was not enough information to draw a conclusion and to compare with the mothers' experiences and this aspect of gendered caregiving needs further study.

The findings of the current study indicated that dealing with severe psychotic symptoms continuously is a barrier to the positive side of caregiving. Since the nature of psychotic symptoms in the early phase of illness is unstable, living with severe and unstable psychotic symptoms makes it very difficult for the participants to sustain their efforts to handle the illness over time. However, the majority of them could maintain caregiving because they perceived caregiving as an unavoidable role. It is a positive appraisal of the caregiving role which is in line with many studies in Asian culture.[22-23,26,32,34,36] This evidence suggests that caregiving is a strong cultural value and Thai culture and Buddhist principles have deeply influenced Thai caregivers and helped them to overcome distress in managing their children's conditions and their caregiving role.

## Limitations of the Study

Although the study included both mothers and fathers, which seemed to be a strength of the study, there were limited numbers of the fathers. In addition, the study findings were based on interview only. As such, interpretation and conclusion about the differences between mothers' and fathers' experiences which were gender-specific should be undertaken with care. Recruiting larger number of fathers and obtaining data from medical records would enhance variation and saturation of the theory. Survey research may help to extend study findings, as would be a triangulation approach to data collection.

## Conclusions

Our findings add to body of knowledge that normalcy is also the goal of parents in dealing with early schizophrenia. The experiences of caregivers provides more understanding to parents of children affected with schizophrenia, and to mental health care providers about the uniqueness of the caregiving in the early phase of the condition. It was a devastating experience for parents struggling to restore normalcy for their children. Caregiving in the early phase of schizophrenia has been demonstrated to be a critical period needing a high level of support from mental health care providers. In addition, Thai culture and Buddhist principles have deeply influenced Thai parents' responses to schizophrenia.

## Implications for Nursing Practice and Research

Information from this study has implications for the development of effective and supportive services for parents of children with schizophrenia. Given the importance of the caregiving role, parents should be provided with systematic education to help them to deal with multiple problems of caregiving. This educational and support program should be started soon after the first diagnosis, and include providing information about schizophrenia, its prognosis, the nature of its symptoms and management, as well as side effects of antipsychotic drugs and management. Parents should be trained in caregiving skills, typically for monitoring the symptoms, maintaining medication adherence, and dealing with delusions, hallucinations, and aggressive and violent behaviors. Based on the study findings, of particular concern are the needs of fathers who are providing care for their children alone or who are faced with continual psychotic symptoms. Skill training for dealing their children's symptoms is essential for them to prevent maladaptive coping responses. A program could be implemented in a group format to promote the parents' learning from the others' experiences and for mutual support.

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# การดิ้นรนต่อสู้เพื่อการกลับสู่ภาวะปกติ: ประสบการณ์ของบิดามารดาไทยในการเป็นผู้ดูแลบุตรโรคจิตเภทระยะแรก

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**บทคัดย่อ:** แม้ว่าการดูแลผู้ป่วยโรคจิตเภทระยะแรกจะซับซ้อนและยุ่งยาก ความรู้เรื่องกระบวนการดูแลในระยะนี้ยังมีจำกัด การวิจัยนี้จึงมุ่งศึกษากระบวนการดูแลบุตรโรคจิตเภทระยะแรก โดยการสัมภาษณ์เชิงลึกบิดามารดา 25 คนที่บุตรเป็นโรคจิตเภทได้รับการวินิจฉัยภายใน 5 ปีแรก ที่แผนกผู้ป่วยนอกและหอผู้ป่วยในของโรงพยาบาลจิตเวชแห่งหนึ่งในประเทศไทย วิเคราะห์ข้อมูลโดยการเปรียบเทียบข้อมูลอย่างต่อเนื่องตามวิธีวิจัยเชิงทฤษฎีพื้นฐานของสเตราส์

การดิ้นรนต่อสู้เพื่อการกลับสู่ภาวะปกติเป็นหัวข้อเรื่องหลัก ประกอบด้วย 6 หัวข้อย่อยคือ การรู้ว่าบุตรป่วยทางจิต การเผชิญกับฝันสลาย การดูแลเป็นบทบาทที่เลี่ยงไม่ได้ การพยายามควบคุมอาการทางจิต การจัดการผลกระทบของโรค และการยอมรับความเป็นปกติใหม่ หลังจากรู้ว่าบุตรป่วยทางจิต บิดามารดารู้สึกเหมือนกำลังเผชิญกับฝันสลาย จากการรับรู้ว่าการดูแลเป็นบทบาทที่เลี่ยงไม่ได้ จึงดิ้นรนต่อสู้ให้บุตรกลับมาเป็นปกติ โดยพยายามควบคุมอาการทางจิตที่ไม่คงที่ด้วยวิธีการต่างๆ ประกอบด้วย ดูแลให้ได้รับยาต่อเนื่อง เฝ้าระวังและจัดการกับอาการ และป้องกันการกำเริบและกลับเป็นซ้ำของอาการ อีกทั้งต้องจัดการกับผลกระทบของโรค ได้แก่ การตัดสินใจที่ไม่ดีของบุตร ตราบาปของโรค และความรู้สึกสูญเสียและความยุ่งยาก บิดามารดาค่อยๆยอมรับการรักษาไม่หายของโรคซึ่งเป็นความปกติใหม่ของบุตร

ผลการวิจัยเพิ่มองค์ความรู้ทางการพยาบาลเกี่ยวกับการดูแลบุตรในกลุ่มนี้ สามารถนำมาเป็นแนวทางพัฒนาโปรแกรมการช่วยเหลือบิดามารดาที่เป็นผู้ดูแล เพื่อให้ข้ามพ้นความยุ่งยากไปได้ การศึกษาต่อไปควรเปรียบเทียบประสบการณ์การดูแลบุตรโรคจิตเภทระยะแรกของบิดากับมารดา

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# Life and Health Skills Development in School Networking: Lessons Learnt from Teachers and Nurses

Learning life skills has been recognized as important for life-long adaptation. According to the World Health Organization (WHO), life skills are those essential skills that enable individuals to deal with every life challenges and demands, resulting in positive and adaptive behaviors.[1] Life skills, therefore, consist of both psychosocial competencies and interpersonal skills. In terms of health behavior, life skills can be applied to explain the interpersonal relationship that may conducive to health as behavior would affect person's environment.[2] Additionally, the WHO launched the Global School Health Initiative in 1995 to improve the health of students, school personnel, families and other members of the community. In this initiative, children are expected to perform healthy behaviors. Coordinated school health education programs are interventions which essentially provide knowledge and skills for children to become healthy and productive adults[3, 4]. However, health risk behaviors among Thai children are reported, such as: poor eating habits, game addiction, and sedentary activities.[5,6,7] Additionally, poor hygiene is concerning among Thai school children[8-10].

Children's healthy behaviors and healthy adaptation are the main thrusts of development in the Life Skill and Health Skill Training Program or LHSD under the Human Potential Development Project, Faculty of Medicine Ramathibodi Hospital, Mahidol University in Bangkok. In several research reports this Program has been shown to be effective in improving the life skills and health skills of school children aged 10-11years old.[11-13] Most of the Life Skill and Health Skill Intervention focuses on adolescent health risk behavior reduction. The most famous Botvin's Life Skill programs now have been offered paid-online training for school teachers, with the use of variety learning aids and materials. Evidently, it is able to cut drug use, alcohol use, tobacco use and violence in the U.S. and South Africa[14-16]. Our Program consists of a combination of reading 14 cartoon booklets and active learning activities, such observational learning or modeling in order to encourage new behaviors and discourage unwanted behaviors. Active participation in learning process has been successfully implemented in formal and informal education.[17] The students' life skill and health skill were evaluated using self-administered questionnaires. Evidently, only the experimental group who attend the program had improved their life skill and health skill significantly, but not the control group[18-19]. The Program has been disseminated to 10 elementary schools in two provinces through school networking activities, which were used to provide social support among group members to achieve common goal of the groups.

The purpose of this article is to identify lessons learnt from developing a network for LHSD experience during a series of workshop and field supervision. In particular, various strategies of implementing activities among target schools were examined.

## Enabling Process: Networking

Networking was used as the essential process to empower school teachers. Through a partnership effort, the networking was performed under the collaboration between Human Potential Development Project of The Faculty of Medicine, Ramathibodi Hospital, Mahidol University and The Office of Basic Education under the Commission of Basic Education, Ministry of Education. There were seven government schools and one private school targeted as model schools, and two school health nurses from health promoting services outside Bangkok participated in the networking.

**Lessons Learnt:**

All schools implemented The LHSD program as extracurricular activities and the academic team from the University helped them to embed the Program into each school's plan of activities according to that school's convenience. Eighty per cent of the schools implemented all the 14 lessons from the LHSD Program.

**Strategies of the LHSD program: implementing and disseminating**

It was found that participants preferred their own unique way to disseminate the LHSD program to other teachers and schools using three major methods:

1. *Facilitating*. It was revealed that school nurses, who attended the network workshop, acted as initiator and facilitator after participating in the LHSD workshop. School nurses set up a training program for other school teachers from the additional 10 schools to use LHSD program. Community participation was evident. The Program was funded by the local administration authority in their Municipality. Then, the teachers who attended the training program used the Program in their schools. Details as shown in Figure 1.

2. *Modeling*. The participants who were teachers reported to the school principals after the workshop. In turn the principals deployed a policy to all teachers to teach life skills and health skills in their schools. Later they trained other teachers how to use the Program and invited other teachers to observe. Details as shown in Figure 2.

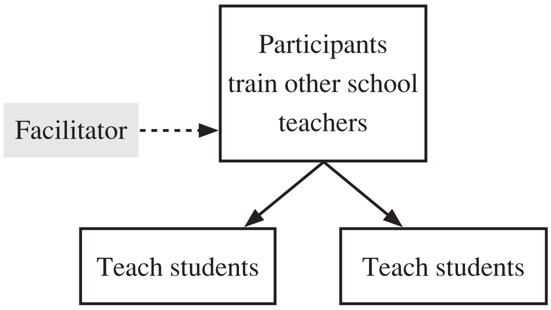

Figure 1 Facilitating pattern

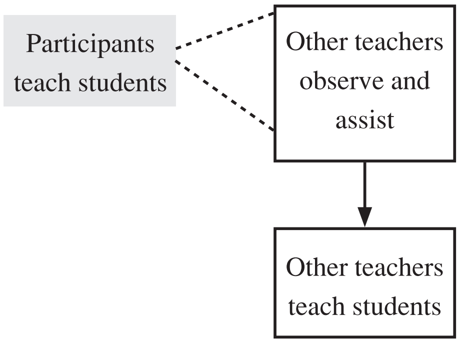

Figure 2 Modeling pattern

3. *Twinning-school*. Those additional 10 schools where teachers were trained by school nurses, twinned their school with another in close proximity. They helped each other while implementing LHSD program. They shared teaching materials and jointly taught some teaching activities. These activities help them to continue teaching LHSD Program in their schools.

**Essential enabling factors**

From the experience of school networking shared in the workshops and discussion, the networking pattern and learnt experiences were shared among 10 network schools. The most important enabling factors were the policy development and implementation from the school principal to establish the Program in each school. It was clear that those teachers who received support from their school principal were successful in implementing the Program. Notably, when school principals attended the LHSD workshop themselves, they started the Program shortly after the workshop. After the school administrator addressed life skill and health skill development as school policy, the HLSD Program could be effectively implemented. Thus, further implementation should include inviting elementary school administrators to be actively involved in the HLSD network development. Additionally, a teacher's positive attitude towards teaching life skills and health skills were equally important in the success of the Program implementation.

**Limitation**

The most mentioned problem was the tight school schedule that allow minimal extracurricular activities. Most schools want to use their extra-time for academic purposes rather that teaching life skills and health skills. Therefore, it is important for establishing a school health policy to include life skill and health skill development in elementary school students.

A lesser concern is the availability of the cartoon booklets. All 14 books are now opened for free download at the Faculty of Medicine Ramathibodi Hospital, Mahidol University website: http://med.mahidol.ac.th/sdmc/thaipopulation/BookDevelopThaiPopulation-th

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# The Influence of Basic Conditioning Factors and Self-Care Agency on Self-Care Behaviors in Thais with Hypertension

*Ladda Saleema, Orasa Panpakdee, Manee Arpanantikul, Teeradej Chai-Aroon*

**Abstract:** Individuals with uncontrolled hypertension have a high risk for heart disease, stroke, and renal diseases. Self-care behavior is important for hypertension control. This study aimed to test the Self-Care Deficit Nursing Theory by exploring the pattern of relationship among basic conditioning factors, self-care agencies, and self-care behaviors regarding hypertension control. The participants consisted of 402 people with hypertension who received treatment at outpatient medical clinics of three regional hospitals in the central part of Thailand. In addition to the Demographic and Health Information Sheet, the Chronic Illness Resources Survey, the Revised Illness Perceptions Questionnaire, the Knowledge of Self-Care Demands Questionnaire, and the Self-Care Behavior Questionnaire were used for data collection. The data were analyzed using Structural Equation Modelling.

Results showed that the modified hypothesized model of self-care behaviors for hypertension controls fitted with the empirical data and explained 49% of variance in the self-care behaviors regarding hypertension control. Patient-provider communication had positive direct and indirect effects on self-care behaviors for hypertension control through knowledge about hypertension, knowledge about self-care demands, and perception about hypertension.

The results supported the Self-Care Deficit Nursing Theory regarding the influence of basic conditioning factors on self-care agency. They provide evidence for the development a nursing intervention program to promote patient-provider communication for helping individuals with hypertension to increase self-care behaviors regarding hypertension control.

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**Keywords:** Hypertension, Knowledge, Patient-provider communication, Perception, Self-care behaviors, Self-Care Deficit Nursing Theory, Theory testing

## Introduction

Uncontrolled hypertension is a major global health problem and a cause of cardiovascular disease, which is a leading cause of death worldwide.[1] Less than half of people with hypertension successfully control their hypertension.[1] Approximately 3.5 million people aged $\geq$60 years have hypertension.[2] The number

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of people with hypertension, people with the disease related to hypertension (e.g stroke, heart disease), and hospitalized people with hypertension increase in each year.[2] Only one-seventh of Thai males, and one-fourth of Thai females within the country succeed in controlling their blood pressure to within normal limits.[2] People with hypertension cannot control their blood pressure if they do not regularly practice self-care by medication taking and lifestyle modification.[3] These self-care behaviors take time and much effort, and most people cannot sustain these behaviors over a long period.[3] A systematic review[4] and a meta-analysis[5] showed that previous interventions were effective in increasing self-care behaviors for hypertension control. However, most of the interventions were based on social cognitive learning theory such as the Health Belief Model,[6] Self-efficacy construct,[7-9] or Self- Regulation Theory.[10] Even though Orem's Self-Care Theory[11] placed an emphasis on self-care, it is rarely used to guide intervention research, since it is very abstract. We argue that the middle range theory, which is derived from Orem's Self-Care Theory, is needed to guide interventions because the concepts of the theory are relevant with the concepts used in this study. Thus, the purpose of this study was to develop middle theory from Orem's Self-Care Theory, which specifies the pattern of relationships among the relevant concepts when predicting self-care behaviors among people with hypertension. The study not only provides the benefits of guiding the intervention but also in the expansion of nursing science in explaining how each concept influence self-care.

## Conceptual Framework and Literature Review

In Self-Care Deficit Nursing Theory (SCDNT), Orem[11] proposes relationships among the four major concepts namely; self-care, self-care agency, self-care demands, and nursing agency as well as one peripheral concept, basic conditioning factors.

Self-care is practicing an activity in which people initiate and undertake themselves in order to maintain life, health, and well-being. Self-care is a series of complex deliberate actions with the intention of achieving a specific goal and seeking results, which are determined before performing the actions.[11]

Self-care agency is the ability of a person to know and to perform self-care actions to meet self-care demands. Self-care agency consists of many levels; foundational capabilities and dispositions, ten power components and operational capabilities. Operational capabilities involve the ability to perform deliberate actions, which includes estimative, transitional, and productive operation.[11] Estimative operation is seeking knowledge and understanding about a situation and what should be done to control that situation. Transitional operation is making a decision about self-care and productive operation is actions for meeting self-care demands, monitoring self-care practice (i.e., actions, results, effects), and decisions about subsequence actions.[11] People can make a decision (transitional operation) to begin and maintain self-care actions (productive operation) if they have success in their self-investigation about their self-care (estimative operation). According to Orem,[11] self-care requires learning and the use of knowledge. Knowledge includes both scientific and commonsense knowledge. People use scientific and commonsense knowledge along the state of deliberate action of self-care.[11] However, most studies related to self-care of people with hypertension are focused on scientific knowledge but not include perception.[4,5] Perception is formed based on knowledge receiving from health-care providers and other sources such as family, media, friend, and illness experience of a person.[12] A person uses perception to making decision about self-care. In psychology theories, perception of illness influenced personal behaviors in responding to a health threat such as following with the treatment regimens.[13]

Knowledge about hypertension and self-care demands, and perception about hypertension are important self-care agency of people with hypertension. Previous studies supported the relationships between self-care behaviors for hypertension control and other factors, including knowledge about hypertension,[14-16] knowledge about self-care demands[17], and perceptions about hypertension,[12,18-20]

The basic conditioning factors are personal conditions and circumstances which affect self-care demands and self-care agency or self-care behaviors. Basic conditioning factors are related to age, gender, developmental state, state of health, socio-cultural orientation, healthcare system factors, family system factors, patterns of living, environmental factors, and resource availability and adequacy.[11] An understanding is required of the types of specific basic conditioning factors and their patterns of relationships affecting person's self-care behaviors and health status. In addition, people with hypertension live with the disease over a long period, do daily activities with their family, and communicate with healthcare providers about treatments and self-care. Therefore, the duration of hypertension, family support, and patient-provider communications are the basic conditioning factors that affect their self-care behavior. Patient-provider communication, duration of hypertension, and family support are health-care system factors, health state, and family system factors, respectively. Previous evidence supports the relationships between self-care behaviors for hypertension control and the basic conditioning factors, including patient-provider communication,[18,21,22] duration of hypertension,[23,24] and family support.[14,25] However, how all aforementioned factors work to influence self-care behaviors is not known. Thus this study aimed to develop a causal model, to specify the pattern of relationships among the basic conditioning factors (patient-provider communication, duration of hypertension duration, and family support), self-care agency (knowledge about hypertension, knowledge about self-care demands, and perception about hypertension), and self-care behaviors for hypertension control. The hypothesized model is shown in Figure 1.

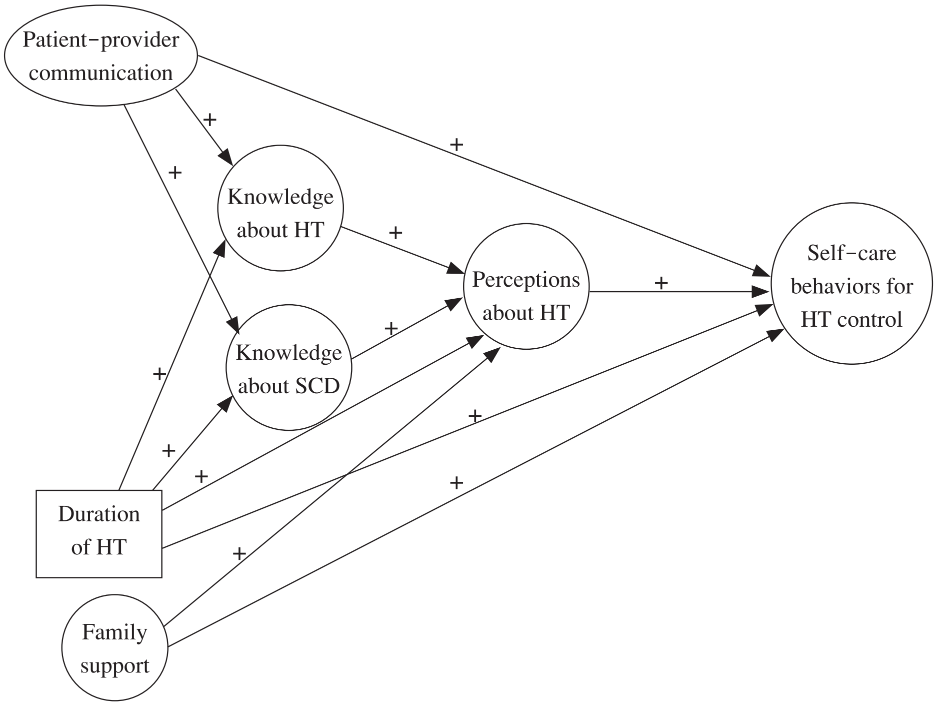

**Figure 1** The hypothesized model of factors influencing self-care behaviors for hypertension control

## Methods

**Design:** A descriptive cross-sectional design was used.

**Participants and setting:** Data were collected from people with hypertension who received treatment at outpatient medical clinics at three regional hospitals in the central part of Thailand. These hospitals provide specialized tertiary care for patients with complex health problems. Inclusion criteria for the sample was: aged >18 years; having been diagnosed with essential hypertension for at least one year; receiving antihypertensive medication; not being dependent on others for care, understanding the Thai language, and having normal cognitive and movement function. Participants aged ≥60 years were screened for cognitive function using the Short Portable Mental Status questionnaire[26] because approximately 12.3% of Thai people aged ≥60 years have dementia.[2] The cutoff point to indicate normal cognitive function was the score at least eight out of ten. Exclusion criteria were people with diabetes or severe complications of hypertension such as having suffered from a severe stroke or on dialysis.

**Sample size:** There are approximately 100,000 people with hypertension who receive treatment in the regional hospitals in the central part of Thailand. Based on Yamane's formula,[27] and for an alpha of .05, at least 398 people with hypertension were required for the study. Purposive sampling was used in this study.

**Ethical considerations:** The research proposal was approved by the Institutional Review Board of Mahidol University and the hospitals used as study sites. Prior to data collection, the researcher explained objectives, procedures, protection of confidentiality and the right to refuse or withdraw from the study to the potential participants. The confidentiality of the participants was protected by avoiding writing the participants' names on the questionnaires, presenting the results as a whole. All participants who were willing to participate in the study gave informed consent.

**Instruments:** Data were obtained using 5 questionnaires as follows:

**The Demographic and Health Information Sheet (DHIS)** was developed by the researchers for collecting personal and health information such as: age, gender, marital status, education, career, income, living with family, history of hypertension in family, body weight, history of smoking and alcohol consumption, and history of any comorbidities.

**The Chronic Illness Resources Survey (CIRS)** was developed by Glasgow for measuring social support.[28] The Family subscale and the Physician and Healthcare Team subscale of the CIRS were used for measuring family support and patient-provider communication, respectively. Both subscales were translated into Thai using the back translation process.[29] The questionnaire was translated from English into Thai by the researchers' advisors. The translated Thai version was back-translated from Thai into English by two Thai nursing instructors who were bilingual. They did not get access to the source of the questionnaires. The back-translated version and the original version were compared for any discrepancies in translation and relevancy to the Thai culture by the dissertation's major advisor and three nursing instructors. The Family subscale of the CIRS consists of 7 items for measuring family support. The response is scored using the five-level Likert scale ranging from 1 (not at all) to 5 (a great deal). The total score ranges from 7 to 35. The higher score indicates higher support received from family members. The mean score of the variable was equally classified to three intervals which indicated "mild" (the interval of the low possible score), "moderate" (the interval of the middle possible score) and "high" (the interval of the high possible score) levels. The range of the total score from 7 to 16.3, 16.4 to 25.7, and 25.8 to 35 indicated "mild", "moderate", and "high" support received from family members, respectively. An example item is "Have your family exercised with you?"

**The Physician and Healthcare Team subscale of the CIRS** contains 6 items for measuring the perception of support which a person received from a physician and health care team in the past three months. The response is scored using a five-level Likert scale ranging from 1 (not at all) to 5 (a great deal). The total score ranges from 6 to 30. A higher score indicates a higher quality of provider communication. The range of the total score from 6 to 14, 14.1 to 22, and 22.1 to 30 indicates "mild", "moderate", and "high" quality of provider communication, respectively. An example item is "Has your doctor or other health advisors (nurse, dietician) clearly explained what you need to do to manage your illness?"

**The Revised Illness Perceptions Questionnaire (IPQ-R)** was developed by Moss-Morris et al.[30] for measuring perceptions about hypertension. The Thai version IPQ-R was translated by Sriprasong.[31] The IPQ-R consists of 37 items and 7 subscales, including timeline (acute/chronic), consequences, timeline (cyclical), controllability by person, controllability by treatment, understanding about illness, and emotional representation. The participants responded on the five-level Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree). The negative item scores were reversed before summation into the total scores. The total score ranges from 37 to 185. The higher scores indicate a cognitive view of hypertension to be threatening to personal health which is a chronic and cyclical condition, negative outcomes of illness, ability to control of illness, and understanding of a condition. The range of the total score from 37 to 86.3, 86.4 to 135.7, and 135.8 to 185 indicates "mild", "moderate", and "high" viewing of hypertension to be threatening to health, respectively. An example item is "Will my illness last a short time?"

**The Knowledge about Self-Care Demands Questionnaire (KSCDQ)** was developed by Rujiwatthanakorn[17] for measuring the level of understanding of hypertension and self-care demands for hypertension control. The KSCDQ consists of 36 items. The response is "yes" (score = 1) or "no" (score = 0). The first part (13 items) is used for measuring knowledge about hypertension. Total scores range from 0 to 13. A higher score indicates a greater understanding about hypertension. The range of the total score from 0 to 4.3, 4.4 to 8.7, and 8.8 to 13 indicates "mild", "moderate", and "high" understanding about hypertension, respectively. The example item is "Do persons with hypertension have a risk for stroke more than persons with normal blood pressure?"

The second part was used for measuring knowledge about self-care demands for hypertension control. It consists of 23 items and 6 subscales, including medication-taking, dietary and body weight control, aerobic exercise, stress management, risk behavior avoidance, and self-monitoring. The response is "yes" (score = 1) or "no" (score = 0). The total score ranges from 0 to 23. Higher scores indicate greater understanding of self-care demands for hypertension control. The range of the total score from 0 to 7.7, 7.8 to 15.5, and 15.6 to 23 indicates "mild", "moderate", and "high" understanding of self-care demands for hypertension control, respectively. An example item is "Can persons with hypertension stop taking their drug when they feel normal and workable?"

**The Self-Care Behavior Questionnaire (SCBQ)** was modified from the Perceived Self-Care Efficacy Measurement (PSEM).[32] The PSEM was developed by Panpakdee and colleagues for measuring personal confidence in practicing activities for hypertension control.[32] The SCBQ was modified by changing the word "confidence to practice activities for hypertension control" to "frequency of practicing self-care activities for hypertension control" and changing the eleven-point graphing scale to four-point Likert scale ranging from 0 (rarely to never done) to 3 (always). The SCBQ consists of 31 items and 6 subscales, including sodium reduction, healthy diets and weight control, physical activity, medication management, self-monitoring, and risk avoidance. The total score ranges from 0 to 93. A higher score indicates more frequently practiced self-care for hypertension control. The range of the total score from 0 to 31, 31.1 to 62, and 62.1 to 93 indicates "mild", "moderate", and "high" frequently practiced self-care for hypertension control, respectively. An example item is "How often did you add salty condiments in your foods (cooked foods) in the past one month?"

A panel of 5 expert nursing instructors who were specialists in chronic illness validated the content of the Chronic Illness Resources Survey (CIRS) Thai version, the Revised Illness Perceptions Questionnaire (IPQ-R), the Knowledge about Self-Care Demands Questionnaire (KSCDQ) and the Self-Care Behavior Questionnaire (SCBQ). The content validity and the reliability of the instruments are shown in the table 1.

**Table 1** The reliability coefficients of the questionnaires

| Instruments | Content validity index (CVI) | | Reliability (Cronbach's alpha) | | |
|---|---|---|---|---|---|
| | | This study | | This study | |
| | | | | N= 30 | N= 402 |
| SCBQ | - | 0.83 | - | 0.81 | 0.57 |
| CIRS (family) | - | 0.88 | 0.75 | 0.84 | 0.84 |
| CIRS (healthcare provider) | - | 0.94 | 0.91 | 0.79 | 0.55 |
| IPQ-R | 0.87 | - | | 0.79 | 0.71 |
| KSCDQ | 0.97 | - | 0.84 | 0.66 | 0.76 |

Note: SCBQ = Self-Care Behavior Questionnaire, CIRS = Chronic Illness Resource Survey, IPQ-R = Revised Illness

**Procedure:** Data were collected after the protocol of the study was approved by the IRB committees of the investigator's university and each hospital. Data were collected by the researcher and two research assistants between February and June, 2014. The researcher approached the participants and screened them according to the criteria. Objectives of the study and the right of human subjects were informed to the participants. The questionnaires were sent or read to the participants in sequential order, starting with the Self-Care Behaviors Questionnaire, the Chronic Illness Resource Surveys, the Revised Illness Perception Questionnaire, the Knowledge about Hypertension Questionnaire, the Knowledge about Self-Care Demands Questionnaire, and the Demographic and Health Information Sheet.

There were 450 eligible participants, and 10% (n = 45) refused to participate in answering the questionnaires because of time limitations. Finally, 402 people participated in this study. Ninety-five percent (n = 378) answered the questionnaires at an interview and 5% (n = 24) by self-administration. They each took approximately 20-30 minutes for the completion of the questionnaires.

**Data analysis:** Descriptive statistics and Pearson's correlation were used to analyze the characteristics of the samples and variables using the Statistical Package for Social Science (SPSS) version 18. The pattern of relationships among the variables in the hypothesized model was analyzed using the Mplus program version 7.1. The assumptions for analysis using structural equation modeling were checked before data analysis. Knowledge of self-care demands did not display normal distribution. The estimation of parameters using maximum likelihood with standard errors and a mean-adjusted chi-square or MLM was selected for increasing the robustness of the parameter estimation in the data with non-normal distribution.[33]

## Results

**Participant characteristics:** Overall 402 participants with hypertension participated in the study and their age ranged from 32 to 88 years (mean = 59.87 years, SD = 9.56). The majority were female (64.4%), with a primary level education (70.4% %), married (66.9%), housekeepers (22.1%), incomes of less than 5,000 baht (38.6%), living with family (89.8%), overweight or obese (59.7%), and with a family history of hypertension (56.2%). The participants who currently smoked or drank alcohol were 4.5%, and 11.9%, respectively. Over half (56.5%) were successful in controlling their blood pressure to a level of less than 140/90 mmHg. Comorbidities with hypertension were heart diseases (6.2%), strokes (3.7%), renal diseases (1.6%), transient ischemic attacks (0.9%), and dyslipidemia (67.1%). The antihypertensive drug used was calcium channel blockers (21.4%), β-blocker (13.7%), angiotensin converting enzyme inhibitors (12.9%), and antilipidemic agents (23.6%).

**Study variables' characteristics:** The participants perceived healthcare providers as having a moderate quality of communication. The duration of their hypertension ranged from 1 to 46 years (mean = 7.3, SD = 5.4) and they received moderate support from a family member. The majority had an enhanced knowledge about hypertension and self-care demands for hypertension control. They perceived hypertension as a moderate threat to them and practiced self-care behaviors for hypertension control at a moderate level. The study variables' characteristics are shown in the table 2.

**Table 2** Descriptive statistics of the study variables (N = 402)

| Variables | Possible range | Actual range | Mean | SD | Interpretation |
|---|---|---|---|---|---|
| Patient-provider communication | 6 - 30 | 12-29 | 20.1 | 3.2 | Moderate quality |
| Duration of HT (year) | $\geq$ 1 | 1 - 46 | 7.3 | 5.4 | Long duration |
| Family support | 7 - 35 | 7 - 34 | 21.2 | 7.1 | Moderate support |
| Knowledge about HT | 0 - 13 | 2 - 13 | 9.8 | 2.1 | High understanding |
| Knowledge about SCD | 0 - 23 | 8 - 23 | 21.9 | 1.9 | High understanding |
| Perception about HT | 37 - 185 | 80 - 158 | 123.4 | 11.4 | Moderate threat |
| Self-care behaviors | 0 - 93 | 41-83 | 58.6 | 6.8 | Moderate practicing |

Note: SD = Standard deviation, HT = Hypertension, SCD = Self-care demands

**Measurement model testing:** All subscales of the KSCDQ and SCBQ were significant at $p < 0.001$ and IPQ-R were significant at $p < 0.001$ or $p < 0.05$, except for coherence ($p = 0.150$). Overall results of the measurement model testing were acceptable for the theoretical model analysis.

**Hypothesized model testing:** The hypothesized model did not fit the empirical data with the values of Chi-square = 612.301, *df* = 219, $p < 0.0001$, CFI = 0.650, TLI = 0.595, RNI = 0.650, RMSEA = 0.067, and SRMR = 0.082, therefore the hypothesized model was modified. Finally, the modified hypothesized model fitted with the empirical data with the values of Chi-square = 232.672, *df* = 154, $p < 0.0001$, CFI = 0.923, TLI = 0.895, RNI = 0.923, RMSEA = 0.036, and SRMR = 0.053. The results show that the model explains 49% of the variance of self-care behaviors for hypertension control. Patient-provider communication had a positive direct effect on self-care behaviors for hypertension control ($\gamma = 0.52$, $p < 0.001$) and a positive indirect effect on self-care behaviors for hypertension control through knowledge about hypertension ($\gamma = 0.13, p < 0.05$), knowledge about self-care demands ($\gamma = 0.18, p < 0.05$), and perception about hypertension ($\beta = 0.42, p < 0.001$). The results of the hypothesized model testing are presented in Figure 2 and Table 3.

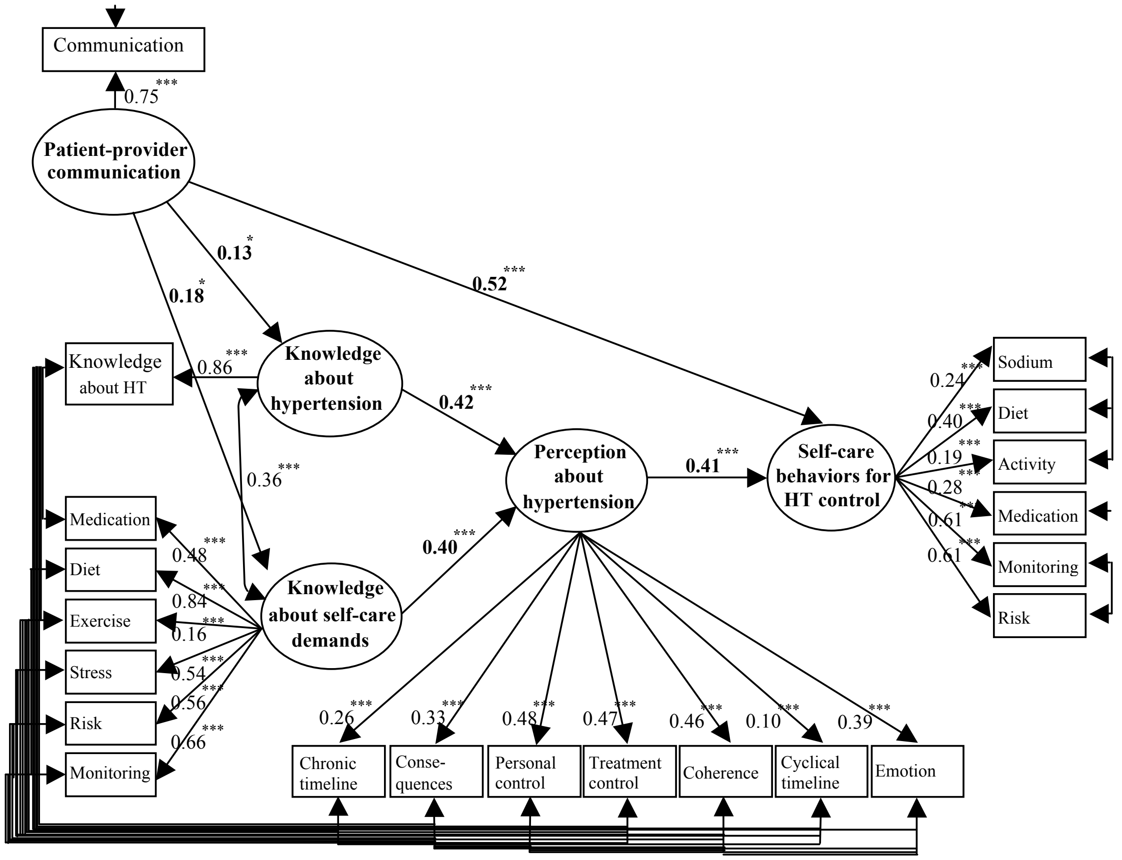

**Figure 2** The modified hypothesized model of factors influencing self-care behaviors for hypertension control

**Table 3** Direct effects, indirect effects, and total effects of study variables in the modified hypothesized model

| **Causal variables** | **Affected variables** | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **Knowledge about HT** | | | **Knowledge about SCD** | | | **Perception about HT** | | | **Self-care behaviors** | | |
| | **TE** | **IE** | **DE** | **TE** | **IE** | **DE** | **TE** | **IE** | **DE** | **TE** | **IE** | **DE** |
| Patient-provider communication | 0.13* | 0.02 | 0.11* | 0.18* | 0.05 | 0.13* | - | - | - | 0.52*** | | 0.52*** |
| Knowledge about HT | - | - | - | - | - | - | 0.42*** | - | 0.42*** | - | - | - |
| Knowledge about SCD | - | - | - | - | - | - | 0.40*** | - | 0.40*** | - | - | - |
| Perception about HT | - | - | - | - | - | - | - | - | - | 0.41*** | - | 0.41*** |
| Structural equation | $R^2 = 0.02$ | | | $R^2 = 0.03$ | | | $R^2 = 0.46$ | | | $R^2 = 0.49$ | | |

**Note**: * = $p < .05$, *** = $p < .001$, TE = Total effect, IE = Indirect effect, DE = Direct effect, HT = Hypertension, SCD = Self-care demands

## Discussion

The hypothesized model testing results supported the validity of the SCDNT regarding the influence of basic conditioning factors on self-care agency. Patient-provider communication had a strong effect both directly and indirectly on self-care behavior through knowledge about hypertension, knowledge about self-care demands, and perception about hypertension. The findings support the proposition of Orem's SCDNT in that "Self-care is learned within the context of social groups by human interaction and communication".[34] Orem also emphasized that nurses must exercise nursing agency to increase the self-care agency of the clients through patient interaction.[34]

Patient-provider communication had a strong positive direct effect on self-care behaviors for hypertension control. The results can be explained by the fact that patient-provider communication increases understanding and awareness about hypertension control[21,22,35] and helps to solve problems and addresses health concerns.[21] This finding is consistent with Tian et al[35] who found that patient-provider communication was effective in the increase of self-care behaviors of people with chronic illness. Patient-provider communication is positively associated with antihypertensive medication adherence[14,21,22] and information provided by healthcare providers is important for adherence to antihypertensive treatments.[36]

Patient-provider communication also had a positive indirect effect on self-care behaviors for hypertension control through knowledge about hypertension, knowledge about self-care demands, and perceptions about hypertension. This result can be explained by knowledge about hypertension and knowledge about self-care demands changing perceptions about hypertension being consistent with scientific knowledge. Perception about hypertension are used for investigation about an unchangeable condition (the condition of having hypertension) and what self-care activities are required for the control of changeable factors (e.g., eating, exercising, and taking medication) in the estimative operation. Perceptions about hypertension are used for making the decision to begin and to maintain self-care actions for hypertension control. If people have clear and correct perceptions about hypertension, they are more likely to make appropriate decisions about self-care in the transitional operation process. Finally, people with hypertension create their own course of action and evaluate the performance, results, and subsequent actions in the productive operation process. Therefore, these findings confirm Orem's statement that scientific knowledge and commonsense knowledge (perception) are used along with states of deliberate action and are essential in the estimative operation.[34] The findings also supported the illness perception concept in that the perceptions about illness influences personal behaviors in response to a health threat such as following treatment regimens.[13] In addition, the results supported that perception about hypertension was associated with self-care behaviors for hypertension control[13,20,21] and adherence to antihypertensive treatments.[37]

The duration of hypertension did not affect self-care agency and self-care behaviors for hypertension control. The findings of previous research were inconsistent in demonstrating the relationship between the duration of hypertension and self-care behaviors for hypertension control. A long duration of hypertension had positive,[23,24] negative,[38] and no associations[39] with self-care behaviors for hypertension control. In the present study, a half of the participants could not control their blood pressure, but they had a low level of comorbidities and complications of hypertension thus they might perceive that they are healthy, and they might accept practicing self-care behaviors as usual was enough for their health. This reason could be supported by Panpakdee et al[20] who found that Thais with hypertension were not practicing self-care when were recovering from a crisis or symptom of hypertension.

Family support did not affect self-care agency and self-care behaviors for hypertension control. It could be explained that people with hypertension could care for themselves, which lead to the perception of being healthy. Social support is a factor for reducing stress that affects health.[28] In a situation without stress, social support might not be perceived as a necessity. In contrast to some studies, family support was associated with self-care behaviors for hypertension control.[14,25] People who have both hypertension and diabetes mellitus were not included in this study. The participants may not be stressed due to the perception of having a less severe disease such as hypertension. Therefore, family support is not perceived as a necessity for helping them to control hypertension. This reason could be supported by Anthony et al[40] who found that people with hypertension and diabetes perceived their hypertension as a chronic disease with more of an impact on their daily life than those without diabetes.

## Limitations

This cross sectional study did not meet the assumptions of structural equation modeling in the aspect of temporality (the requirement in measuring a variable in a model at a different time point).[41] The use of purposive sampling limited the generalization only to people with hypertension who had the same characteristics as the participants of this study.

## Conclusions and recommendations

Patient-provider communication is a powerful factor, which has a large positive direct effect on the self-care behaviors for hypertension control as well as an indirect effect on self-care behaviors through knowledge about hypertension and self-care demands, and perceptions about hypertension. Thus, the implications for nursing practice is for the development of a nursing intervention program and the health service system to promote patient-provider communication for helping individuals with hypertension to increase their self-care behaviors, for the control of hypertension. Future studies should also be designed to test the effectiveness of various types of patient-provider communication such as computer-based approach.

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# อิทธิพลของปัจจัยพื้นฐานและความสามารถในการดูแลตนเองต่อพฤติกรรมการดูแลตนเองในคนไทยที่เป็นความดันโลหิตสูง

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**บทคัดย่อ:** ผู้ที่เป็นความดันโลหิตสูงและไม่สามารถควบคุมโรคได้มีความเสี่ยงต่อการเกิดโรคหัวใจ โรคหลอดเลือดสมอง และโรคไต พฤติกรรมการดูแลตนเองมีความสำคัญในการควบคุมความดันโลหิตสูง การศึกษาครั้งนี้เป็นการทดสอบทฤษฎีความพร่องในการดูแลตนเอง เพื่อศึกษาแบบแผนความสัมพันธ์ของปัจจัยพื้นฐานและความสามารถในการดูแลตนเองที่มีอิทธิพลต่อพฤติกรรมการดูแลตนเองเพื่อควบคุมความดันโลหิตสูง กลุ่มตัวอย่างเป็นผู้ที่ได้รับการวินิจฉัยว่าเป็นความดันโลหิตสูงจำนวน 402 ราย ที่ได้รับการรักษาที่แผนกผู้ป่วยนอกของโรงพยาบาลศูนย์ 3 แห่ง ในภาคกลางของประเทศไทย การเก็บรวบรวมข้อมูลโดยใช้แบบสอบถามข้อมูลส่วนบุคคล แบบสำรวจแหล่งสนับสนุนของผู้เจ็บป่วยเรื้อรัง แบบสอบถามการรับรู้เกี่ยวกับการเจ็บป่วยฉบับปรับปรุง แบบสอบถามความรู้เกี่ยวกับความต้องการการดูแลตนเอง และแบบสอบถามพฤติกรรมการดูแลตนเอง วิเคราะห์แบบแผนความสัมพันธ์ โดยใช้แบบจำลองสมการเชิงโครงสร้าง

ผลการวิจัยพบว่าโมเดลพฤติกรรมการดูแลตนเองเพื่อควบคุมความดันโลหิตสูงที่ได้รับการปรับปรุงมีความสอดคล้องกับข้อมูลเชิงประจักษ์ โมเดลสามารถทำนายความแปรปรวนของพฤติกรรมการดูแลตนเองได้ ร้อยละ 49 การติดต่อสื่อสารระหว่างผู้ใช้บริการและทีมสุขภาพเป็นปัจจัยที่มีอิทธิพลด้านบวกทั้งทางตรงและทางอ้อมต่อพฤติกรรมการดูแลตนเองโดยผ่านความรู้เกี่ยวกับโรคความดันโลหิตสูง ความรู้เกี่ยวกับความต้องการการดูแลตนเอง และการรับรู้เกี่ยวกับโรคความดันโลหิตสูง

ผลการศึกษาครั้งนี้สนับสนุนทฤษฎีความพร่องในการดูแลตนเองของโอเร็มเกี่ยวกับปัจจัยพื้นฐานมีอิทธิพลต่อความสามารถในการดูแลตนเอง ผลการศึกษาเป็นหลักฐานเชิงประจักษ์ในการพัฒนาโปรแกรมการส่งเสริมการสื่อสารระหว่างบุคลากรทีมสุขภาพกับผู้ป่วย เพื่อช่วยให้ผู้ที่เป็นความดันโลหิตสูงมีพฤติกรรมการดูแลตนเองเพื่อควบคุมความดันโลหิตดีขึ้น

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**คำสำคัญ:** ความดันโลหิตสูง ความรู้ การติดต่อสื่อสารระหว่างผู้ใช้บริการและทีมสุขภาพ การรับรู้ พฤติกรรมการดูแลตนเอง ทฤษฎีความพร่องการดูแลตนเอง การทดสอบทฤษฎี

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# Family Caregiver Capacity Building Program for Older People with Dependency in Thailand: A Randomized Controlled Trial

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**Abstract:** This randomized control trial investigated the effectiveness of the Family Caregiver Capacity Building Program on caregivers' care ability and quality of care. A sample of 55 family caregivers, currently caring for older people with dependency in two rural communities in a central Thailand, were randomly assigned to a control group (n=29) and an experimental group (n=26). The experimental group received the Program based on Hulme's work in family empowerment. The control group received usual home visits. Data were collected at baseline, week 12 for caregiver ability, and at week 24 for quality of care at week 24. Data were analysed using descriptive statistics, independent t-test, and paired t-test.

Results revealed that after attending the Program the experimental group had significantly higher overall care ability than at the baseline, except for social aspect. There were significant differences in overall quality of care, physical, psychological, and financial aspects but not for environmental, medical management, and human rights dimensions. When comparing between groups, the experimental group had significantly higher overall care ability than those in the control group, except for social aspect. However, there were no significant differences of overall quality of care and their dimensions, except for physical aspect. Findings revealed that the Program was effective in improving the ability of care givers to provide quality care for older people with dependency. Nurses in Thai district hospitals or sub-district health promoting hospitals could apply this Program to improve care ability of family caregivers for older people with dependency in similar communities in Thailand. However, it is recommended that the Program be further evaluated with larger or different groups.

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**Keywords:** Capacity building; Caregiver program; Dependency; Care ability; Family caregiver; Older people; Quality of care

## Introduction

Older people with dependency needs experience limitations in and loss of their physical, psychological, social, and economic abilities, including a decrease in intellectual talent. They need assistance from others and cannot live their lives as they have previously been accustomed to doing.[1,2] Mostly, this population

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experiences physical disabilities in carrying out daily activities of living such as bathing, dressing, standing up, moving, and using the toilet (both urination and defecation).[1-4]

In 2014, there were approximately 180,000 older people with dependency in Thailand. This number is estimated to increase to 741,766 by 2020 and 1,103,754 by 2030.[1-3] Families have to provide a primary family caregiver without wages or compensation. Ongoing care for the older people with dependency needs requires a daily routine in terms of socialization, emotional stability, mental acuity, health care, and problem solving when faced with an emergency.[3-5] The problems with which family caregivers are confronted become a complicated process of either solving problems or supporting decisions regarding caregiving.[5,6] The complications are associated with family caregiving result in escalating family expenses with a significant impact on family members' lives as family capacity for caregiving diminishes.[1,3-6] Caregiving capability may further decline, especially in terms of essential knowledge and skills for caregiving assistance.[3-6] Thus, family caregiving ability needs to be strengthened through family empowerment in providing care for older people with dependency.[3-8]

The concept of family empowerment, proposed by Hulme[9], was developed from Gibson's empowerment concept.[10] This encourages families to be able to face the challenge of caregiving for older people with chronic illnesses[7-11] and empowers caregivers through capacity building to improve family members' relationships and increase their awareness of their own ability; develop self-worth and improve knowledge and skills. These translate to better patient care, by affecting the care ability and quality of care (QoC) that family caregivers are able to provide to older people.[9-11] This enhanced ability reflects the caregiver's acceptance of the role of caregiving through a process of learning, understanding, and giving appropriate care such as hygiene, feeding, dressing, mobility, and toileting. Family caregiving also involves social aspects such as shopping, preparation of meals, telephoning, financial management, participate in religious ceremonies, healthcare, and coordination with a healthcare professional.[12-15] Moreover, such capacity which can be viewed as a structure, process, or result, and ultimately, QoC represents the potential to give the best care to older people by the family caregiver. Activities of care involve environmental, physical, psychological, and economic aspects, as well as respect towards older people.[16-20] Previous studies have concluded that problems of caregiving often result from knowledge deficit, lack of care ability, and resources of family caregivers which leaded to a diminished QoC.[13-18] There are a paucity of studies of capacity strengthening of family caregivers for older people with dependency in Thailand, so the researcher was interested in developing and testing the Family Caregiver Capacity Building Program (FCCBP) using empowerment strategies and following the empowerment phases of Hulme[7.] The FCCBP emphasizes the interaction between the family caregivers and the researcher via education, skill training and support to empower them to take responsibility for managing and providing care to older people with dependency.

## Review of Literature

Capacity-building empowerment increases a person's ability to complete a task and improves processes to achieve better results or efficiency and standardization.[12-16, 23-26] Empowerment influences caregivers to provide efficient care.[12-13, 23-25] Gibson explained that the process of empowerment requires discovering reality, that is, recognition, understanding, and acceptance of true incidents expresses recognition and sensation. Critical reflection requires people to carefully review an incident to make decisions and properly fix the problem. Taking charge of a reasonable belief leads to effective executions that are sustainable. Learning processes cause changes at the individual, family, and community level and include social interaction among people who make decisions and solve problems through their participation and appropriate utilization of resources in order to increase their capability to achieve the goal.[10, 11] Hulme's[7] family empowerment encourages the family to be able to face the challenge of caregiving through capacity building. This requires healthcare personnel, whom the family trust, to participate in initial care giving while helping family members to be able to participate in making care decisions. After that, the capacity building process transitions the balance of power until family members have full knowledge, capability, and confidence to take care of their family member themselves.

Capacity building via empowerment of the family creates abilities and improves the quality of care for the older person with dependency needs.[27-29] Caregivers meet the needs of their older relatives in caring for various physical and daily life needs because they are limited in their own ability to perform self-care,[3-6] such as transfers, opening doors, going outdoors, managing stairs, and physical activities of daily living, such as combing their hair, washing their bodies, going to the toilet, dressing, cutting fingernails or toenails, and more.[3-6] Caregivers reflect acceptance of the caregiving role through a process of learning, understanding, and giving appropriate care in hygiene, feeding, dressing, mobility, and toileting. Family caregivers also are involved in social aspects such as shopping, preparation of meals, telephoning, use of money, aid in participation in religious ceremonies, health care, and coordination with healthcare professionals.[3-8, 12-18] Moreover, capacity building affects the QoC that is available to an older person.[13-15, 29-31.] Proper environmental management and establishing guidelines or standards are the responsibilities of health personnel. They need to aim for the highest consumer benefits in terms of efficiency, effectiveness, acceptance, assistance, access to health services and equality in terms of rules and professional standards that utilize empirical evidence to judge the value of care in order to meet consumers' needs.[19-21] From these studies, we concluded that empowerment programs will help family caregivers improve their ability to provide care for older people with dependency by enhancing their knowledge and training skills[8,12-18] Moreover, capacity building affects the QoC that is available to older people.[13-15, 29-31] Furthermore, these studies emphasized empowerment through individual, family, and community in interventions that had significant outcomes.[18,29] Empowerment can help make caregivers confident, experienced, and skillful in caring for the older people with dependency and improve their QoC.[16-18,19- 31]

The FCCBP was based on critical reviews of Hulme's family empowerment model[7] and consists of changing behavior through empowerment strategies in four phases: professional-dominated phase, participatory phase, challenging phase, and collaborative phase. The first phase builds trust by creating rapport with the families and establishing a direct relationship with the family caregivers, prioritizing the family's perceived needs, providing accurate and complete information, and supporting family caregivers in setting goals, including knowledge related to problems and needs of older people with dependency, such as common chronic illnesses, geriatric syndrome, and rehabilitation. The second phase, participatory, helps the family determine setting goals and family care plan, guides them in assessing their resources, and skills training such as activities of daily living, vital sign monitoring, feeding, oxygen, and catheter care.

The challenging phase supports family caregivers in a peer support group reinforcing their ability to identify choices in health care, discuss advocacy techniques, and build the caregivers' skills in negotiating with health professionals. This phase enhances their ability in caring for their older relative. The last phase, the collaborative phase, involves monitoring and supporting caregiving skills at home and acknowledging caregivers as their care improves. The interactions between family caregivers and the researcher in the process of empowerment[12-13, 24-25] can help to strengthen care ability by increasing caregiver knowledge and confidence by creating a sense of self-worth, and leading to higher QoC for older people with dependency.[13-16, 29-31]

## Study Aim and Hypothesis

This study determined the effects of the FCCBP on the care ability score and QoC score of family caregivers providing care for older people with dependency needs. The following hypotheses were proposed:

1) In the experimental group, the family caregivers receiving the Program would have a significantly higher care ability at week 12 and QoC at week 24 than at baseline.

2) When comparing between groups, the family caregivers receiving the Program would have a significantly higher in care ability at week 12 and QoC at week 24 than the control group.

## Methods

***Design:*** A randomized controlled trial.

***Ethical Considerations:*** Study approval was obtained from the Institutional Review Board, Faculty of Nursing, Chiang Mai University, and the local Public Health District and Provincial Health Office. All participants received written and verbal explanations of the study. Before giving written informed consent they learnt of the objectives, methods, risks, benefits, and their right to withdraw from the study at any time.

***Setting:*** This study was conducted in two sub-districts in central Thailand. These had comparable characteristics in terms of socioeconomic conditions, location, transportation, culture, and health services from the sub-districts' health-promoting hospitals.

***Sample:*** The sample was family caregivers of older people with partial or total dependency needs, aged 60 years and living in two sub-districts in central Thailand. Inclusion criteria were: family caregivers aged 20-59 years living with their older relative; willing to participate in the Program; had not participated in another family capacity program for at least 6 months prior to the beginning of this study; and able to communicate in Thai. Multi-stage random sampling was used during the first phase to randomize ten villages from two rural communities. Sample size was estimated based on the findings of another study regarding skills training.[14] We enrolled 58 family caregivers intending to obtain sufficient statistical power (80%) and a significant of $p<0.05$. There were 1,018 family caregivers who lived with older people with dependency. One hundred and thirty five family caregivers who met the study criteria were recruited using a computer-generated randomization list and assigning the 58 participants to either the experimental group (n = 29) and control group (n = 29). At week 12, one older relative being cared for by a participant in the experimental group had died, another was admitted in the hospital, and one moved to another area, so we excluded three participants. At week 24, two participants of the experimental group and four from the control group lost with the same reasons. Therefore, data were analyzed using 49 participants as shown in **Figure 1**.

***Intervention Program:*** The Program was developed by the researcher based on the family empowerment concept proposed by Hulme.[7] It has 11 sessions spread over s weeks and the length of intervention given at each session is 90 minutes. There are four phases: professional-dominated phase, participatory phase, challenging phase, and collaborative phase. The Program contains individual and group education, caregiving skill training, and home and telephone visits (see **Table 1**). The Program content was validated by five experts in the fields of gerontology, education, and family nursing. This was revised according to the recommendations of those experts, and piloted with three older people with dependency and their family caregivers before full implementation.

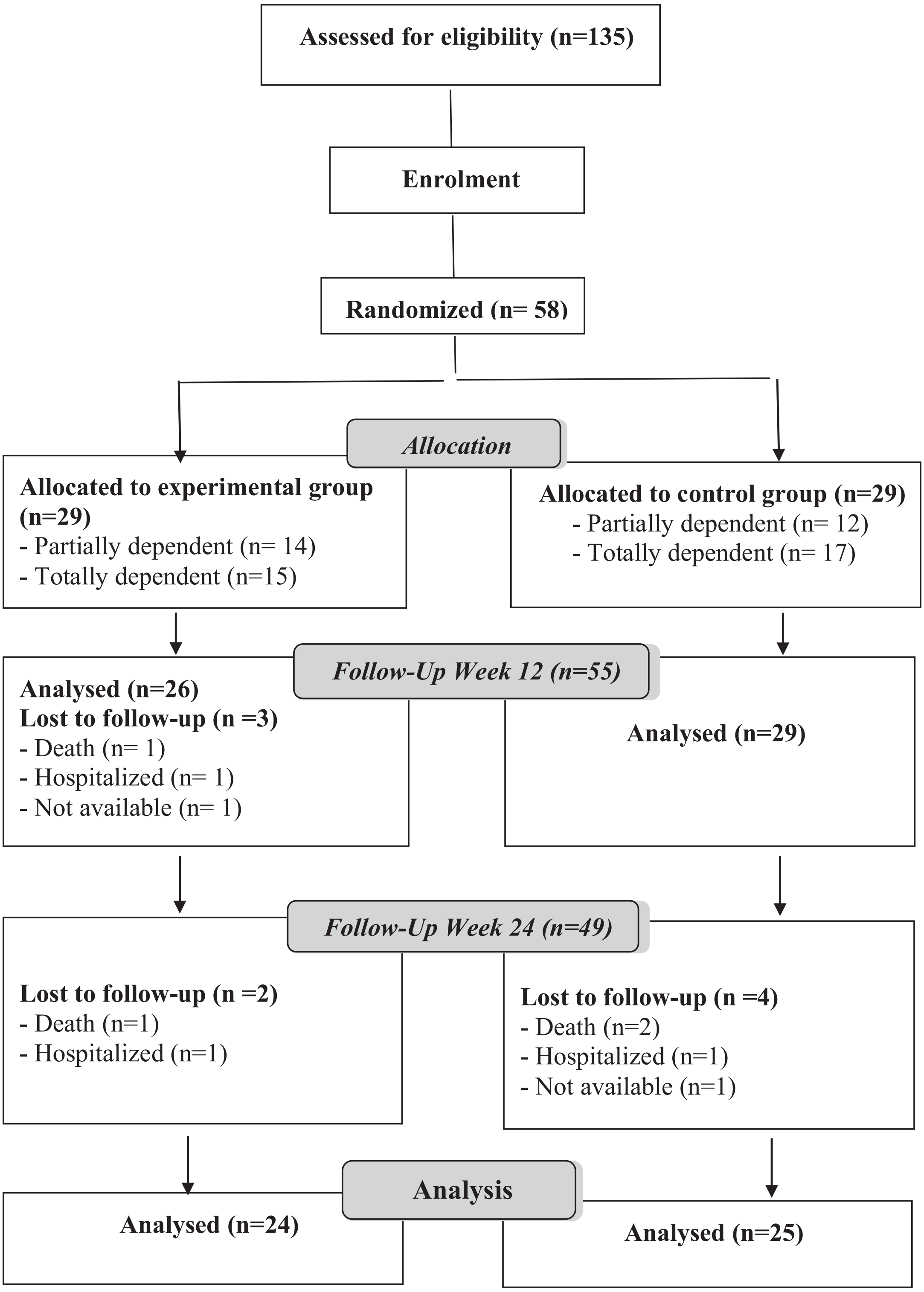

**Figure 1**: Flow Diagram of Recruitment and Analysis

**Table 1** Schedule and Content of FCCBP Intervention Program

| Week/Session | Content | Empowerment Strategies |
|---|---|---|
| **Week 1** | **Professional-dominated phase** | |
| Session1 (90 mins) | Information about problems and needs of older people with dependency and needed skills to fulfill those needs. | - Building trust by creating rapport with the families and establish a direct relationship with the family caregivers. |
| Session2 (90 mins) | Information about most common chronic diseases, common geriatric syndrome, approaches to self-care. | - Prioritizing families' perceived needs.<br>- Providing accurate and complete information. |
| **Week 2** | Information about roles of caregivers, caregiving activities, and home and environment modification. | |
| Session 3 (90 mins) | | - Supporting caregivers to set goals. |
| Session 4 (30 mins) | Refreshing knowledge session 1-3. | |
| **Week 2** | | |
| Session 3 (90 mins) | Information about roles of caregivers, caregiving activities, and home and environment modification. | - Providing accurate and complete information. |
| Session 4 (30 mins) | Refresh knowledge session 1-3. | - Supporting the caregivers in setting goals |
| **Week 3** | **Participatory phase** | |
| Session 5 (90 mins) | Group and individual demonstration and return demonstration on the basic activities of daily living, including bathing, dressing, eating, mobility, moving from chair to bed and vital signs monitoring. | - Helping family determine the family care.<br>- Providing accurate and complete information.<br>- Supporting caregivers in setting goals. |
| Session 6 (90 mins) | Information about prevention of complications of immobilization, care activities for persons with drainage, feeding, urinary catheter care and constipation prevention and management. | - Guiding caregivers in assessing support system, resources and strengths.<br>- Strengthening capacity of caregivers in caring and problem solving. |
| **Week 4** | | |
| Session 7 (90 mins) | Information on rehabilitation. | |
| Session 8 (30 mins) | Refresh knowledge session 5-8. | |
| **Week 5** | **Challenging phase** | |
| Session 9 (90 mins) | Communication strategies, and partnership relationship development. | - Supporting caregivers in peer support group. |
| Session 10 (90mins) | Problem solving and negotiation skills. | - Reinforcing family's ability to identify healthcare choices. |

**Table 1** Schedule and Content of FCCBP Intervention Program (continued)

| Week/Session | Content | Empowerment Strategies |
|---|---|---|
| | | - Discussions with caregivers regarding advocacy techniques.<br>- Building skills in negotiating with health professionals. |
| **Week 6** | **Collaborative phase** | |
| Session 11 (90 mins) | Repeating implementation by reviewing skills and troubleshooting; questioning knowledge until score indicates improvement of preparedness for caregiving. | - Monitoring and supporting about caregiving skills at home.<br>- Acknowledging family caregivers for their better care. |

***Data collection:*** Three instruments were used:

*The Caregiver's Care Ability Scale* (CCAS) was developed by Pukdeeporm[34] to measure the ability of family caregivers to care for older people with dependency. It consists of 14 positive and negative questions that measure the ability to provide care in four dimensions, physical care, psychological care, social care, and environmental care. Each item is assessed on a Likert-type scale from 1-5, where 1 = "I do not agree at all" and 5 = "I completely agree." A higher score means higher ability of care, while a lower score means lower ability of care. Five experts in the fields of gerontology, education, and family nursing validated the content. The content validity index was .83. The explanations and suggestions from experts were taken into attention to revise the CCAS. The pre-test reliability for the CCAS was tested with 15 family caregivers who were similar to the sample. Cronbach's alpha demonstrated an acceptable reliability of 0.93, and 0.81 for the main study.

The *Quality of Care Assessment Scale* (QUALCARE) was developed in English by Philips *et al.*[19-21] to measure QoC. It contains 53 items that measure six components: environmental, physical, psychosocial, medical management, human rights, and financial aspects. The scoring for this 5-level measurement ranges from 1 (best possible care) to 5 (worst possible care) points. A lower scores indicates higher QoC.

The QUALCARE was translated from English into Thai by the researcher and a translator, who was an expert in foreign language, and then back-translated from Thai into English by two bilingual experts. Comparison of the back-translated version of the QUALCARE to the original English version was made by the research team. Finally, the original English version and the back-translated English version were compared for semantic equivalence in translation. The QUALCARE was tested for its internal consistency reliability using inter-rater reliability. This technique was used to assess the degree to which different observers gave consistent estimates of the same phenomena. A research assistant and researcher were assigned to observe the QoC of one participant by following the items on the QUALCARE and providing a score with three family caregivers. Then the calculation of the correlation between the ratings of the observers was conducted and the results indicated an acceptable inter-rater agreement index which was 1.0.

The *Preparedness for Caregiving Scale* (PCS)[35-38] was developed by Wirojratana[38] to measure preparedness of Thai family caregivers caring for older people. The PCS includes 8 items with a 5-point scale ranging from 0 (not at all prepared) to 4 (very well prepared). The higher the score the better prepared are the family members for caregiving.

***Data collection procedures:*** At baseline assessment in the first week, all participants were asked to provide demographic information and data on preparedness of care, caregiver's care ability, and QoC at their own home. The intervention began one week after the baseline measures were administered. The experimental groups received the FCCBP program of 11 sessions, 90 minutes per session for 6 weeks, including individual and group education, caregiving skill training, and home and telephone visits, while the control group received only usual home visit. Data were obtained at weeks 12 for caregiver care ability and at week 24 for QoC.

***Data Analysis*:** Descriptive statistics were used to explain the demographic data. Chi-square, Fisher's tests, and t-tests were used to examine the differences between the experimental and control groups. Paired t-tests and independent t-tests were conducted to test the differences in the mean scores of caregiver care ability and QoC.

## Results

The participants were 59 family caregiver of older people with dependency needs randomly divided into the experimental and control groups, 29 in each group. There were three dropped cases (15.51%) after the 12 weeks and six dropped out cases after 24 weeks. The mean ages in the experimental and control groups were 46.7 years (SD = 8.0) and 45.3 years (SD = 11.5) respectively. There were more female participants than male in both groups (92.3% vs. 7.7% in the experimental group, 86.2% vs.13.8% in the control group). More than half the participants in both groups were married (73.1% vs. 82.8%), and most had at least primary school education (76.9% vs. 72.1%). The majority of caregivers were daughters of the older relative (61.6% vs. 62.1%). All demographic characteristics were not significantly different between experimental and control groups (**Table 2**).

**Table 2:** Comparison of Demographic Characteristics of Family Caregivers between Experimental and Control Groups

| **Variable** | **Experimental Group (n=26)** n (%) | **Control Group (n=29)** n (%) | **t-test** | **$X^2$-test** | **Fisher's Exact** | ***p*-value** |
|---|---|---|---|---|---|---|
| Age | | | | | | |
| 20-29 | 2 (7.7) | 3 (10.3) | 1.224 | | | .227 |
| 30-39 | 1 (3.8) | 3 (10.3) | | | | |
| 40-49 | 13 (50.0) | 14 (48.3) | | | | |
| 50-59 | 10 (38.5) | 9 (31.0) | | | | |
| ($\overline{X}$, SD) | (46.7, 8.0) | (43.5,11.5) | | | | |
| Gender | | | | | | |
| Male | 2 (7.7) | 4 (13.8) | | .525 | | .672 |
| Female | 24 (92.3) | 25 (86.2) | | | | |
| Marital status | | | | | | |
| Single | 6 (23.1) | 5 (17.2) | | 1.513 | | .469 |
| Married | 19 (73.1) | 24 (82.8) | | | | |
| Separated | 1 (3.8) | | | | | |
| Educational level | | | | | | |
| No formal education | 4 (15.4) | 9 (31.0) | | | | |
| Primary school | 20 (76.9) | 18 (62.1) | | 1.870 | | .393 |
| Secondary school and higher | 2 (7.7) | 2 (6.4) | | | | |
| Occupation | | | | | | .827 |
| Working at home | 9 (34.6) | 7 (24.1) | | .895 | | |
| Civil servant | 1 (3.8) | 1 (3.4) | | | | |
| Employee | 13 (50.1) | 18 (62.2) | | | | |
| Farmer | 3 (11.5) | 3 (10.3) | | | | |

**Table 2:** Comparison of Demographic Characteristics of Family Caregivers between Experimental and Control Groups (continued)

| Variable | Experimental Group (n=26) | Control Group (n=29) | t-test | $X^2$-test | Fisher's Exact | $p$-value |
|---|---|---|---|---|---|---|
| | n (%) | n (%) | | | | |
| Relationship | | | | | | .558 |
| Daughter | 16 (61.6) | 18 (62.1) | | | .440 | |
| Son | 4 (15.4) | 1 (3.4) | | | | |
| Daughter-in-law/son-in-law | - | 3 (10.3) | | | | |
| Grandchild | 4 (15.4) | 6 (20.7) | | | | |
| Sister/brother | 1 (3.8) | 1 (3.4) | | | | |
| Spouse | 1 (3.8) | - | | | | |
| Sufficiency of income | | | | | | .155 |
| Sufficient income | 6 (23.1) | 13 (44.8) | | 2.868 | | |
| Not sufficient income | 20 (76.9) | 16 (55.2) | | | | |

After attending the Program the experimental group had significantly higher overall care ability than at the baseline ($p<.05$), except social aspect. There were significant differences in overall QoC, physical, psychological, and financial aspects ($p<.01$), but environmental, medical management, and human rights dimensions **(Table 3)**. When comparing between groups, the experimental group had significantly higher overall care ability and their dimensions than those in the control group ($p < .01$), except social aspect. There were no significant differences in overall QoC and its dimensions, except for the physical aspect ($p < .05$) **(Table 4)**. Furthermore, the effect size was analyzed and interpreted using Cohen's classification (0.2 = small, 0.5 = medium, and 0.8 = large). Effect size for caregiver care ability (0.75) and QoC (0.27) were medium and small, respectively.

**Table 3** Comparison of Caregiver Care Ability and Quality of Care (QoC) of Family Caregivers in the Experimental Group

| Variables | Mean(SD) Baseline | Mean(SD) Post-test | t | $p$-value |
|---|---|---|---|---|
| **Care Ability***  | 47.44(3.65) | 50.35(3.69) | -4.72 | .00 |
| Physical | 24.25(2.28) | 26.85(3.15) | -5.49 | .00 |
| Psychological | 6.13(0.96) | 5.80(0.83) | 2.23 | .03 |
| Social | 9.82(1.11) | 9.69(0.98) | 0.63 | .53 |
| Environmental | 7.24(0.88) | 7.73(0.97) | -3.03 | .00 |
| QoC** | 127.00(20.10) | 120.10(20.33) | 3.76 | .00 |
| Environmental | 33.02(7.66) | 33.45(7.66) | -0.63 | .53 |
| Physical | 26.06(4.28) | 21.98(4.91) | 6.18 | .00 |
| Medical Management | 12.61(2.91) | 12.43(2.29) | 0.51 | .61 |
| Psychological | 27.29(4.80) | 25.08(4.33) | 3.36 | .00 |
| Human Rights | 14.49(2.69) | 14.76(2.47) | -0.56 | .58 |
| Financial Aspect | 13.53(2.81) | 12.41(3.10) | 3.09 | .00 |

* Post-test = Data were collected 12 weeks after completion of the interventions.

** Post-test = Data were collected 24 weeks after completion of the interventions.

**Table 4** Comparison of Caregiver's Care Ability and QoC of Family Caregivers between the Experimental and Control Groups Pre- and Post-Intervention

| Variables | Experimental Group | Control Group | t | *p*-value |
|---|---|---|---|---|
| | M (SD) | M (SD) | | |
| Baseline Care Ability | 47.69 (3.73) | 47.41(3.70) | 0.28 | .78 |
| Physical | 24.21(2.13) | 24.41(2.39) | 0.73 | .59 |
| Psychological | 6.34(0.89) | 6.00(1.94) | 1.36 | .18 |
| Social | 9.83(1.36) | 9.79(0.92) | 0.11 | .91 |
| Environmental | 7.31(0.89) | 7.21(0.86) | 0.45 | .65 |
| Baseline QoC | 123.96(13.92) | 129.92(24.56) | -1.05 | .30 |
| Environmental | 32.17(5.23) | 33.84(9.47) | -0.77 | .45 |
| Physical | 25.13(3.42) | 26.96(4.88) | -1.53 | .13 |
| Medical management | 12.21(2.50) | 13.00(3.25) | -0.96 | .34 |
| Psychological | 26.58(4.09) | 27.96(5.38) | -1.01 | .32 |
| Human Rights | 14.58(1.84) | 14.40(3.35) | .24 | .81 |
| Financial Aspect | 13.29(2.71) | 13.76(2.93) | -.58 | .56 |
| Post-test Caregiver Care Ability | 51.73 (3.57) | 49.10 (3.40) | 2.79 | .00 |
| Physical | 28.58(2.25) | 25.31(3.07) | 4.53 | .00 |
| Psychological | 5.50(0.81) | 6.07(0.75) | -2.69 | .00 |
| Social | 9.46(0.86) | 9.90(1.05) | 53 | .97 |
| Environmental | 8.04(0.87) | 7.45(0.99) | 2.36 | .02 |
| Post-test QoC | 117.29 (13.36) | 122.80 (25.29) | -0.96 | .34 |
| Environmental | 33.83(6.72) | 33.08(8.59) | .34 | .73 |
| Physical | 20.54(2.04) | 23.37(6.34) | -2.11 | .04 |
| Medical management | 12.04(2.07) | 12.80(2.47) | -1.17 | .25 |
| Psychological | 24.54(2.45) | 25.60(5.58) | -1.01 | .32 |
| Human rights | 14.38(1.47) | 15.12(3.14) | -1.07 | .29 |
| Financial aspects | 11.96(2.64) | 12.84(3.45) | -1.00 | .32 |

## Discussion

The findings of this study partially support the hypotheses in that after receiving the Program, the experimental group had a significantly higher overall mean scores on caregiver care ability and on physical, psychological and environmental dimension than at baseline and compared to the control group. However, there was no significant difference in the social aspect. These results are congruent with the assumptions of Hume's family empowerment to focus on assisting the change of behavior conditions through the Program following strategies in four stages: professional-dominated, participatory, challenging, and collaborative phase. The Program achieved its aim of building the care ability of caregivers by giving health education and skills, establishing a relationship between an older people and family caregivers, discussing in small group to share their experiences, supporting and empowering family caregivers to do good performance for older adults.[12-13, 24-25] Thus, we believed the Program strengthened the confidence of family caregivers, improving care by creating a sense of self-worth, and lowering expenditures for patient care and all of which lead to a higher QoC for older people with dependency.[13-16, 29-31] The results of this study were consistent with the findings of previous studies of caregiver-empowerment programs, based on Gibson's concept of empowerment[9-11,25] involving recognizing the caregiving burden, realizing the potential value of care, and committing to care for six months, showing that the mean difference in the burden of care at the posttest compared to before the Program had a statistically significant difference.[10-11] Unfortunately, there were no significant differences in the mean social aspect in this study in the experimental group and between groups. The findings are not surprising since these two groups had similar limitations in earning incomes in their family. That is, they did not have sufficient income and they had to take responsibility to care for their older relative in congruence with Thai traditions of family responsibility. This might limit caregivers in both groups to find chances to participate in social activities with the community, resulting in a lack of practice of skills in empowering themselves in taking care of older people.[1-3, 38]

For the QoC the overall mean scores at posttest and on physical, psychological and financial dimensions were improved significantly from those at baseline, but there was a significant difference in the environmental, medical management, and human rights dimensions. When compared with the control group, there was no significant difference between groups on overall mean score at posttest and other aspects except physical dimension. These results partially achieved following Hulme's family empowerment concept reporting that care ability will lead to better QoC for older people.[16-20,30-31] However, this study did not show significant differences in every aspect either in the experimental group or between groups that might result from many factors including inappropriate home environment, family income, health education, community resources, and health insurance.[1-3,18,21] Thus, nurses can help work family problems out through considering and educating them about factors that assist with better QoC for older adults with dependency. Moreover, the activities of the Program were concerned individual and group education, caregiving skill training, and home and telephone visits to enhance their care ability.

These findings were congruent with a controlled trial study of hospitalized older people in the CARE program (Creating Avenues for Relative Empowerment) which reported that there had no difference in emotional coping measures for QoC at 2 weeks and 2 months, except for the care role of family caregivers.[18] However, some studies found that follow-up activities for one year including home visits and telephone, and positive reinforcement for caregiver skills significantly increased QoC.[16-18]

## Limitations and Issues in Study

The researcher met with the experimental group on 11 occasions for 90 minutes per session, assisting them and collecting data. However, the participants found it was inconvenient to join the group for every meeting because they were involved with caregiving at home. Thereafter, the researcher met the participants individually in home visits. In future studies, the program could be adjusted to have more appropriate follow up using health care volunteers in community.

## Conclusion and Implication for Nursing Practice

Findings revealed that the Program could be an effective intervention for the strengthening care ability of family caregivers who provide care for older people with dependency. Nurses in the district hospitals or sub-district health promoting hospitals could apply the Program to improve care ability of family caregivers resulting in achieving QoC for their relatives. In future studies researchers should consider meeting with the experimental group less frequency and use a double-blinded technique. As well we recommend that there should be follow up for at least a year after the initial Program, using home visits and telephone calls, and data collection should be undertaken in the home as well.

## Acknowledgements

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# โปรแกรมการเสริมสร้างศักยภาพญาติผู้ดูแลในครอบครัวสำหรับผู้สูงอายุที่มีภาวะพึ่งพิงในประเทศไทย: การวิจัยแบบทดลองเชิงสุ่ม

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การวิจัยทดลองแบบสุ่มครั้งนี้มีวัตถุประสงค์เพื่อศึกษาผลของโปรแกรมการเสริมสร้างศักยภาพญาติผู้ดูแลในครอบครัวต่อความสามารถในการดูแลและคุณภาพการดูแลของผู้ดูแลในครอบครัว กลุ่มตัวอย่างเป็นผู้ดูแลผู้สูงอายุที่มีภาวะพึ่งพิงที่อาศัยอยู่ใน 2 ชุมชนชนบทในเขตภาคกลางของประเทศไทย จำนวน 55 รายได้รับการสุ่มเข้ากลุ่มควบคุมจำนวน 29 รายและกลุ่มทดลองจำนวน 26 ราย กลุ่มทดลองได้รับโปรแกรมเสริมสร้างศักยภาพ ที่สร้างขึ้นตามแนวคิดการเสริมสร้างศักยภาพครอบครัวของฮูม กลุ่มควบคุมได้รับการเยี่ยมบ้านจากอาสาสมัครตามปกติ รวบรวมข้อมูลความสามารถในการดูแลก่อนและหลังการได้รับโปรแกรม 12 สัปดาห์และประเมินคุณภาพการดูแลก่อนและหลังการได้รับโปรแกรม 24 สัปดาห์ วิเคราะห์ข้อมูลโดยใช้สถิติเชิงพรรณนาและสถิติที

ผลการศึกษาพบว่า ภายหลังได้รับโปรแกรมในกลุ่มทดลอง มีคะแนนเฉลี่ยความสามารถในการดูแลโดยรวมสูงกว่าก่อนทดลองอย่างมีนัยสำคัญทางสถิติ ยกเว้นมิติด้านสังคม ส่วนคะแนนเฉลี่ยคุณภาพการดูแลโดยรวม ด้านร่างกาย ด้านจิตใจ และประเด็นทางการเงิน ดีกว่าก่อนทดลองอย่างมีนัยสำคัญทางสถิติ ยกเว้นด้านสิ่งแวดล้อม ด้านการจัดการความเจ็บป่วย และด้านสิทธิผู้ป่วย เมื่อเปรียบเทียบระหว่างกลุ่มพบว่ากลุ่มทดลองมีคะแนนเฉลี่ยความสามารถในการดูแลโดยรวมและรายด้านดีกว่ากลุ่มควบคุมอย่างมีนัยสำคัญทางสถิติ ยกเว้นด้านสังคม ส่วนคะแนนเฉลี่ยคุณภาพการดูแลโดยรวมไม่แตกต่างกันอย่างมีนัยสำคัญทางสถิติ ยกเว้นด้านร่างกาย ค้นพบครั้งนี้แสดงให้เห็นว่าโปรแกรมการเสริมสร้างศักยภาพญาติผู้ดูแลในครอบครัวมีประสิทธิภาพในการเพิ่มความสามารถของญาติในการดูแลและคุณภาพการดูแลผู้สูงอายุที่มีภาวะพึ่งพิงพยาบาลที่ปฏิบัติงานในโรงพยาบาลชุมชนหรือโรงพยาบาลส่งเสริมสุขภาพตำบลควรนำโปรแกรมไปส่งเสริมศักยภาพของญาติผู้ดูแลในครอบครัวทำให้เกิดคุณภาพการดูแล การศึกษาครั้งต่อไปควรทดสอบประสิทธิผลของโปรแกรมในชุมชนที่มีความความคล้ายกันในประเทศไทย

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# Predicting Factors of Uncertainty in Illness Among Children with Leukemia Undergoing Chemotherapy

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**Abstract:** Leukemia in children is a life-threatening disease and chemotherapy is a complex treatment with severe side effects and complications. Furthermore, the treatment results are unpredictable. This leads to uncertainty in illness resulting in psychological distress. This descriptive cross sectional study aims to examine the predicting factors of uncertainty in illness among children with leukemia undergoing chemotherapy. Ninety-six children with leukemia undergoing chemotherapy in four tertiary hospitals in Bangkok participated in this study. The research instruments included the Children's Uncertainty in Illness Scale, the Symptom Pattern Scale of Children with Cancer, the Information Support from Health Care Provider Scale, the Information Support from Parent Scale, the Information Support from Peer Scale, the Illness Knowledge Scale, and the Parent Perception of Uncertainty Scale. The results of stepwise multiple regression analysis revealed that symptom pattern, information support from health care providers, illness-related knowledge, and parental uncertainty accounted for 34.8% of variance in uncertainty in illness among the participants. This study provides more understanding for predicting factors of child uncertainty. The results of this study can be used for developing a nursing intervention to reduce uncertainty in illness among children with leukemia undergoing chemotherapy if nurses help them to better understand symptoms as having a pattern, provide information support and illness related knowledge, and decrease parental uncertainty.

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**Keywords:** Chemotherapy; Children; Illness uncertainty; Information support; Leukemia; Predicting factors; Thailand.

## Introduction

Leukemia is the most common childhood cancer.[1,2] Leukemia in children under 15 years of age accounts for about 70% of childhood cancers in the United States[3] and for about 50% of childhood cancers in Thailand.[4] The annual incidence in 2008 for lymphoblastic leukemia in children aged under 15 years was 21 per million in boys and 10 in girls.[5] As chemotherapy is the primary treatment modality for

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leukemia in children, this incidence indicates that a large number of children with leukemia are affected by illness and chemotherapy.[6,7]

Potentially life-threatening aspects of leukemia and suffering from side effects and complications of chemotherapy lead to uncertainty in illness among children with cancer during the time of cancer diagnosis and through each stage of treatment.[8] Previous studies have demonstrated that children with cancer undergoing chemotherapy experience moderate to high levels of uncertainty in illness.[9,10] This uncertainty in illness leads to psychological distress,[11,12] interferes with children's ability to cope with illness-related stressors, and decreases their ability to take care of themselves.[12] Thus, nurses should be aware of uncertainty in illness of children with leukemia undergoing chemotherapy and its consequences, and provide nursing interventions to reduce their uncertainty. Currently, there is no research on interventions for reducing uncertainty in illness of these children. Interventions in any form can be effectively developed only if predicting factors of uncertainty in illness are clearly identified.

To date, knowledge regarding the predicting factors of uncertainty in illness among children with cancer is limited. There have been only two studies examining factors predicting uncertainty in illness of children with cancer.[10,12] One study was conducted with American children with cancer aged 8 - 18 years and another was done in Thai children with cancer aged 8 - 15 years receiving chemotherapy. The findings from the two studies did not support well Mishel's uncertainty in illness theory[13]. According to Mishel,[13] uncertainty in illness is influenced by the stimuli frame including symptom pattern, event familiarity and event congruence; as well as social support. However, a previous study[10] revealed that the stimuli frame and social support explained only 9.3% of variance in uncertainty in illness. As children's level of cognitive development could differently affect their ability to determine the meaning of illness-related events,[14] younger children might have had difficulty understanding the abstract nature of the stimuli frame and vice versa. In addition, various types of cancer and different treatment modalities - i.e. chemotherapy, radiation and surgery - would result in different illness-related events, and thus different experiences. Therefore, previous studies of factors predicting uncertainty in illness done in a heterogeneous sample might yield different result from that done in a homogenous one. This finding needs to be confirmed in a homogenous sample of children with similar cognitive development level.

To overcome the limitations in previous studies regarding age, cancer types and treatment modalities, this study examined the level of uncertainty in illness and its predicting factors among children with leukemia aged 10-15 years undergoing chemotherapy. The findings of this study can be used to develop an effective intervention to reduce uncertainty of these children, thereby increasing their well-being.

## Theoretical framework and Review of Literature

Uncertainty in illness theory[13] was used to guide this study. According to this theory, uncertainty is the inability to determine the meaning of an illness event. Uncertainty in illness of individuals occurs during the diagnostic and treatment phases in four forms: ambiguity regarding illness events, complexity about the treatment, lack of information about the diagnosis and the illness, and unpredictability of the health outcome.[13,15]

Uncertainty in illness is influenced by the stimuli frame that includes symptom pattern, event familiarity and event congruence. In addition, uncertainty is also influenced by structure providers, including social support from friends, family and those with similar experiences, as well as information from credible authorities such as health care providers also influence uncertainty.[15]

Symptom pattern is the degree to which symptom occurrence – including number, frequency, intensity, duration and location – has enough consistency to be perceived as having a pattern.[13,15] A symptom pattern is a predicting factor of uncertainty explaining 9.2% of the variance in uncertainty of children with leukemia and lymphoma.[16] According to Mishel,[15] the symptom pattern is considered the important component of the stimuli frame, a major concept relating to uncertainty. It was thus included in the present proposed model predicting uncertainty in illness among children with leukemia in this study.

Information support, as a dimension of social support, is another major factor influencing uncertainty in illness, and has been argued to be more likely than other dimensions to directly affect uncertainty.[15] Sharing information with persons in their social network assists the individual to properly appraise symptoms, which results in lower uncertainty.[17] Children with cancer need information about their diagnosis, treatment and side effects, and care practices from health care providers.[18,19] They need information for problem solving and modifying their uncertainty.[15] Information support, according to House[20] is the perceived and provided advice, suggestions, and information for problem solving. Prior studies have revealed that information support from parents, friends, nurses, and physicians were a predicting factor of uncertainty in illness among Thai children with cancer receiving chemotherapy[16], and children with SLE.[21] However those studies did not investigate if the support from each separate source was related to uncertainty. As information support can be from various sources depending on the children's perception and preference, it is worth identifying the source. Information support from parents, peers and health care provider were proposed to have association with the children's uncertainty in this study.

Parental uncertainty regarding their child's illness is another factor that has been found to influence the uncertainty of children and adolescents with cancer.[12] Evidence has shown that parental uncertainty has a significant effect on uncertainty among children 8-18 years who were undergoing treatment for any form of cancer.[12] In addition, maternal uncertainty was a predicting factor of child uncertainty in illness among children with chronic illnesses between 8 and 12 years of age.[22]

Illness-related knowledge is another factor associated with the uncertainty of chronically-ill children. A moderate negative relationship was found between knowledge regarding the illness and illness uncertainty of children with SLE.[21] The empirical evidence on the relationship between illness-related knowledge and uncertainty in illness of children with cancer is inconsistent. Stewart's study[12] indicated that higher cancer knowledge predicted lower uncertainty in a given age of child. However, illness-related knowledge of Thai children with leukemia and lymphoma was not a predicting factor of uncertainty in illness.[10] Therefore, illness-related knowledge should be investigated for its predictability of children's uncertainty.

## Research Hypothesis

Symptom pattern, information support from health care providers, information support from parents, information support from peers, parental uncertainty, and illness-related knowledge can predict uncertainty in illness among children with leukemia undergoing chemotherapy.

## Methods

**Design:** A cross-sectional, predictive design was used.

**Sample and Setting:** The target population of this study was children with leukemia aged 10-15 years who were undergoing chemotherapy in tertiary hospitals and their parents. There were two groups of subjects: one was the children and the other was parents, either the mother or father. Purposive sampling was used to select children based on the following inclusion criteria: (1) ability to understand and communicate in Thai, and (2) willingness to participate in this study. Meanwhile, the parents of those children with leukemia were recruited based on the following inclusion criteria: (1) ability to understand and communicate in Thai, (2) willingness to participate in this study, (3) cohabitation with the child, and (4) provision of care for their child at the hospital.

The sample size was determined with consideration of the representative sample to reduce type II errors using power analysis, with a significance level of .05, a power of .80, and the moderate effect size ($f^2$) of 0.15.[23] The final sample size was 96 children and 96 parents.

**Ethical Considerations:** Ethics approval was obtained from the Ethics Review Committee for Research Involving Human Research Subjects of the Faculty of Nursing, Chiang Mai University, as well as from four data collection hospitals. Each potential participant was informed about the details of the study and was assured of his or her confidentiality, anonymity, and the right to withdraw at any time without repercussion. The children had to have parental permission to participate and they were able to ask questions regarding the study and could withdraw from the study at any time without having any effect on their treatment or services provided. A signed informed consent form from the parents and a signed-assent form from the child were obtained.

**Instruments:** Seven questionnaires were used to collect data as follows:

The *Children's Uncertainty in Illness Scale* (CUIS) was originally developed by Mullins and Hartman[24] and translated into Thai by Kantawang.[25] It is a 23-item self-report questionnaire used to measure the child's perceived illness uncertainty about the course, prognosis and treatment of their illness, and assesses their perceived ambiguity and unpredictability about their condition and the lack of information. Participants rate items (e.g., "I have a lot of questions about my illness, I don't know what the answers are") on a 5-point scale ranging from 1 (very true) to 5 (very false). The total score is obtained by summing up the score across all items, with the higher the score, the higher the uncertainty. This score was classified into three levels including low (23 - 53), moderate (54 - 84), and high (85 - 115). The Cronbach alpha coefficient pilot-tested with 10 children with leukemia undergoing chemotherapy was .81. The reliability of the CUIS with the whole group 96 participants was .71.

The *Symptom Pattern Scale of Children with Cancer* (SPCC) is a subscale of the Stimuli Frame of Children with Cancer Scale developed by Tathong et al.[10] based on the symptom pattern concept of Mishel's uncertainty in illness theory (1988). It consists of 8 items (e.g., "My condition worsened in the first two weeks of receiving chemotherapy") with a 3-point scale rating scale (1= disagree, 2 = agree, and 3 = strongly agree). The total score is obtained by summing up the score across all items. The higher the score indicated the higher the symptom pattern. The content validity of the SPCC was not determined because this study used the original questionnaire, which has already been validated for content to measure symptom pattern of Thai children with cancer.[10] The Cronbach alpha coefficient pilot-tested with 10 participants was .80. The reliability of the SPCC with the whole group of 96 participants was .79.

The *Information Support from Health Care Provider Scale* (ISHCP) was modified from the Information Support Subscale of Social Support of Children with Cancer Scale with the permission of the owner.[10] It is used to assess the perception of children about information support from nurses and physicians. Six items of the original version were used and 6 new items were added. It consists of 12 items (e.g., "I received an explanation about the disease and the treatment from nurses or doctors") with a 3-point rating scale, including 1 (not true), 2 (true), and 3 (very true). The total score is obtained by summing up the score across all items, with the higher the score, the higher the information support from health care providers. The scale-level content validity index (S-CVI) was 1.00 determined by 5 experts. They were three nurse instructors who had expertise in caring of children with cancer, one pediatric oncology physician, and one advanced practice nurse in pediatric oncology. The Cronbach alpha coefficient was .90 in the pilot tested and .81 for the whole group.

The *Information Support from Parent Scale* (ISPS) was modified from the Information Support Subscale of Social Support of Children with Cancer Scale with the permission of the owner.[10] It is used to assess perception of children about information support from parents. Six items of the original version were used and 3 new items were added. It consists of 9 items (e.g., "I've been receiving information about the disease and chemotherapy from parents") with a 3-point rating scale including 1 (not true), 2 (true), and 3 (very true). The total score is obtained by summing up the score across all items, with the higher the score, the higher the information support from parents. The S-CVI was 1.00 determined by 5 experts. The Cronbach alpha coefficient was .81 in the pilot tested and .61 for the whole group.

The *Information Support from Peer Scale* (ISPeerS) was modified from the Information Support Subscale of Social Support of Children with Cancer Scale with the permission of the owner.[10] It is used to assess the perception of children about information support from friends who were children with leukemia. Five items of the original version were used and 3 new items were added. It consisted of 8 items (e.g., I've been receiving information about the disease and chemotherapy from friends who are children with my illness") with a 3-point rating scale, including 1 (not true), 2 (true), and 3 (very true). The total score is obtained by summing up the score across all items, with the higher the score, the higher the information support from peers. The S-CVI was 1.00 determined by 5 experts. The Cronbach alpha coefficient was .94 in the pilot tested and .90 for the whole group.

The *Illness Knowledge Scale* (IKS) was modified from the Illness Knowledge of Children with Cancer Scale of Tathong et al[8] which got permission to use. A modified version of the instrument was used to assess the children's understanding regarding leukemia, side effects and complications of chemotherapy, and care practices. It consists of 37 true-false questions (e.g., "Children with illness will be exhausted, pale, bleeding and often have a fever"). The total score is obtained by summing up the score across all items, with the higher the score, the higher the illness-related knowledge. The S-CVI was 1.00 determined by 5 experts. The Cronbach alpha coefficient was .80 in the pilot tested and .83 for the whole group.

The *Parent Perception of Uncertainty Scale* (PPUS) was developed by Mishel and translated into Thai by Suwanna-o-sod.[26] It is used to assess parents' uncertainty about their child's illness. It has 31 items (e.g., "I don't know what's wrong with my child") using a 5-point Likert scale (strongly disagree to strongly agree). The total score is obtained by summing up the score across all items, with the higher the score, the higher the parental uncertainty. The content validity of PPUS was not determined because this study used the original Thai version questionnaire, indicating a good content validity to measure parental uncertainty of Thai parents' children with cancer.[26] The Cronbach alpha coefficient was .91 in the pilot tested and .86 for the whole group.

## Data Collection

Data were collected at both pediatric oncology wards and a chemotherapy unit for outpatients by the researcher and a research assistant trained in these data-gathering processes. The children completed six questionnaires by answering each item read to them by the researcher/ a research assistant for 20 minutes, with a 5-minute intermission period. At the same time, the parents completed the PPUS by themselves.

## Data Analysis

Descriptive statistics including frequency and percentage were used to provide a portrait of participants' demographics, as well as the uncertainty in illness of children with leukemia. Stepwise multiple regression analysis was used to examine the predictability of the symptom pattern, information support from health care providers, information support from parents, information support from peers, illness-related knowledge and parental uncertainty on uncertainty in illness of the children with leukemia. The assumptions of normality, linearity, homoscedasticity, and multicollinearity were met for this multiple regression analysis.

## Results

Ninety-eight children participated in this study, two of whom were excluded: one was not allowed by his mother to participate, the other was too fatigued to participate. Of the 96 children with leukemia, more than half were male (54.2%) aged between 12 - 15 years (56.25%), and in primary school (55.2%). The majority of parents were mothers (76.0%) of whom 49.0% were laborers. Regarding family income, 33.3% had an income <15,000 baht/month (469 US$) and another 33.3% had an income of 15,000-30,000 baht/month (469-938 US$). Two-thirds of the children (67.7%) had been diagnosed with leukemia > 1year. More than half (58.3%) had been admitted to the hospital 10 times or less. About 66% had undergone the maintenance phase of chemotherapy. During the data collection period, most of them (91.7%) had side effects from chemotherapy and 75% had more than one symptom. Of the children, 41.7% had complications including infection, bleeding, and anemia.

The descriptive statistics of the dependent variables, uncertainty in illness and the independent variables, including symptom pattern, information support from health care providers, information support from parents, information support from peers, parental uncertainty, and illness-related knowledge, are presented in Table 1. Based on Table 1, the levels of uncertainty in illness, symptom pattern, information support from peers, parental uncertainty and illness-related knowledge were at a moderate level, while the levels of information support from health care providers and parents were at a high level.

**Table 1** Descriptive Statistics for the Study Variables

| Variables | Possible Range | Actual Range | $\overline{X}$ | *SD* | Level |
|---|---|---|---|---|---|
| Uncertainty in illness | 23-115 | 48 – 91 | 70.05 | 8.52 | Moderate |
| Symptom pattern | 8 - 24 | 8 - 24 | 17.63 | 4.04 | Moderate |
| Information support from health care providers | 12 – 36 | 20- 36 | 30.94 | 4.27 | High |
| Information support from parents | 9 – 27 | 16- 27 | 23.53 | 2.69 | High |
| Information support from peers | 8 – 24 | 8- 24 | 13.38 | 4.69 | Moderate |
| Knowledge of illness | 0 – 37 | 14- 37 | 28.90 | 5.23 | Moderate |
| Parental uncertainty | 31 – 155 | 51- 125 | 86.42 | 14.56 | Moderate |

Pearson's product moment correlation was used to examine the relationships between the dependent variable and each independent variable, and the uncertainty in illness was positively associated with symptom pattern and parental uncertainty at a low level. In addition, uncertainty in illness was negatively associated with information support from health care providers and illness-related knowledge at a moderate level, as shown in Table 2.

**Table 2** Correlation Matrix of the Study Variables

| | CUnc | SymP | IHCP | IPar | IPeer | Know | PUnc |
|---|---|---|---|---|---|---|---|
| CUnc | 1 | | | | | | |
| SymP | .232$^{*}$ | 1 | | | | | |
| IHCP | -.319$^{**}$ | .253$^{*}$ | 1 | | | | |
| IPar | -.148 | .250$^{*}$ | .386$^{**}$ | 1 | | | |
| IPeer | .083 | .089 | .229$^{*}$ | .081 | 1 | | |
| Know | -.314$^{**}$ | .391$^{**}$ | .438$^{**}$ | .416$^{**}$ | .114 | 1 | |
| PUnc | .216$^{*}$ | -.008 | -.033 | -.211$^{*}$ | .090 | -.007 | 1 |

*$p< .05$, **$p< .01$
SymP = Symptom pattern
IPar = Information support from parents
Know = Knowledge related-illness
CUnc = Child uncertainty in illness
IHCP = Information support from health care providers
IPeer = Information support from peers
PUnc = Parental uncertainty

The multiple regressions revealed that symptom pattern, information support from health care providers, parental uncertainty, and illness-related knowledge were the predicting factors of uncertainty in illness among children with leukemia undergoing chemotherapy and accounted for 34.8% of the variances in uncertainty in illness, as shown in Table 3.

**Table 3** Multiple Regression for Predicting the Factors of Uncertainty in Illness

| Variables | $R^2$ | $R^2_{Change}$ | β | $p$ |
|---|---|---|---|---|
| Constant | | | | .000$^{***}$ |
| Information support from health care providers | .102 | .102 | -.262 | .007$^{**}$ |
| Symptom pattern | .206 | .104 | .445 | .000$^{***}$ |
| Knowledge-related illness | .305 | .099 | -.371 | .000$^{***}$ |
| Parental uncertainty | .348 | .043 | .209 | .016$^{*}$ |

SE$^{est}$ = 7.025 F= 12.166 $p$ = .000$^{*}$

## Discussions

In this study, four variables out of six, including symptom pattern, information support from health care providers, illness-related knowledge and parental uncertainty were found to be the main predicting factors of uncertainty in illness, accounting for 34.8% of the variance in uncertainty in illness among children with leukemia undergoing chemotherapy.

Information support from health care providers was found to be the predicting factor of the uncertainty of children with leukemia ($\beta = -0.262$, $p < .01$). The children who reported higher information support from health care providers were less likely to have uncertainty. This might be because two-thirds of the children (67.7%) had been diagnosed with leukemia for longer than one year and 42.7% were admitted to hospitals more than 10 times. The children who experienced complex illness-related events may have gotten more information from nurses and physicians. The long duration of illness and frequent hospitalization led to a high probability of illness-related information.

Moreover, patients who develop a strong alliance with health care provider have maintained a higher level of well-being and greater perceived health care provider support.[27] The information helped those patients reduce the ambiguities and complexities, increased their understanding, reduced their unpredictability and made it simpler to clarify symptom patterns, leading to lower uncertainty.[15,19] The findings were congruent with the result of previous studies[16] that information support from health care providers can predict uncertainty in illness among children.

Symptom pattern was the predicting factor of uncertainty in illness among children with leukemia receiving chemotherapy ($\beta = 0.445$, $p < .001$). The children who perceived high symptom pattern had high uncertainty. Theoretically, when the children perceive symptoms as having consistency in frequency, intensity, and duration, their uncertainty is low. This might be because the majority of these children (66.6%) had undergone treatment in the maintenance phase, during which the children received low doses of chemotherapy. They had a long intermission period of two to three years[28] resulting in having symptoms with side effects that were sufficiently consistent that the children could perceive it as having a pattern. In general, during the maintenance phase, the children receive low doses of chemotherapy and should have fewer side effects and complications related to chemotherapy. However, most children in this study (91.7%) had side effects of chemotherapy: 75% had more than one symptom, and 41.7% had complications of chemotherapy that led them to experience complex illness-related events resulting in high uncertainty.[8] Furthermore, children with cancer within one to four years after diagnosis remained uncertain about the meaning of any pain, the unpredictability of physical distress, and the changing course of the illness.[29] Therefore, despite the fact that these children perceived a high symptom pattern in the maintenance phase, they might still have high uncertainty. Another possibility may be associated with the research instrument. The symptom pattern scale of children with cancer was developed on the basis of illness events that would occur during the induction phase. For example "I suffered from mouth sores and could not eat," or "I had to be placed in an isolated room after I received chemotherapy." Most of the questions/events in this instrument would not occur while experiencing the maintenance phase chemotherapy.

Illness-related knowledge was found to be another predictive factor of uncertainty of children with leukemia ($\beta = -0.371$, $p < .001$), in such a way that as illness-related knowledge increased, child uncertainty in illness decreased. This might be because the majority of children with leukemia had undergone the maintenance phase (66.6%) and possibly might have learned about their illness. Illness-related knowledge including leukemia, side effects and complications of chemotherapy, and care practices might assist children in interpreting their symptoms and illness-related events, resulting in low uncertainty. Similarly, uncertainty can be reduced by knowledge.[15] The findings were congruent with previous studies[12, 21] in which illness-related knowledge had a negative relationship with child uncertainty.

Parental uncertainty was found to be a predictive factor of uncertainty in children with leukemia ($\beta = 0.209$ $p < .05$), in such a way that as parental uncertainty increased, child uncertainty in illness also increased. Parental uncertainty has a negative impact on interactions with their children.[30] Parents' uncertainty about their child's illness could interfere with their capacity to provide information to support their child's illness schema formation, resulting in child uncertainty. Typically, the incidence of children with cancer may strengthen the link between parent and child psychological functioning.[31] The findings were congruent with previous studies[12] that parental uncertainty was found to be a predicting factor of child uncertainty. In addition, the majority of parents were mothers (76.0%), and this was consistent with previous studies[22] which showed that maternal uncertainty was the predictive factor of child uncertainty in illness.

Information support from parents and peers did not predict the uncertainty experienced by the children with leukemia. However, these two variables had a significant positive correlation with information support from health care providers ($r = .386$, $p < .01$; $r = .229$, $p < .05$; respectively). The children receiving more information support from health care providers would also get more information support from parents and peers. A possible explanation could be that information support from parents and peers alone may not be strong enough to directly affect child uncertainty in illness. In addition to illness-related information, parents also rely on their relationship with health care providers when their children are seriously ill.[32] Parents revealed that the cancer-specific knowledge was more highly valued by health professionals.[33] However, the children might lack opportunities to meet and talk to other children in hospitals who also had cancer which would result in suffering from the side effects and complications of chemotherapy. Children mentioned a strong desire to rest allowing the fatigue resulting from the experience, whether from the disease, the chemotherapy or the hospitalization to be observed.[34] Therefore, to address uncertainty in illness, children may request information explicitly that could affect their ability to determine the meaning of their illness-related events, while the information from parents or peers may not be clear enough for understanding.

The four variables including symptom pattern, information support from health care providers, illness-related knowledge and parental uncertainty could explain 34.8% of the variance in uncertainty in illness among children with leukemia undergoing chemotherapy. Further research, using the theoretical framework of this study may be needed to examine key predictive factors associated with child uncertainty which were not addressed in this study. There might be another predictive factor of child uncertainty, which concerns emotional support. Children with cancer reported that emotional support was an area of unmet need.[35] The previous study[21] in children with SLE indicated that emotional support had a negative relationship with illness uncertainty. Thus, emotional support may influence child uncertainty.

## Limitations

The majority of the participants were children with leukemia who were in the maintenance phase of chemotherapy. Thus, generalizations of the findings in other phase groups of children undergoing chemotherapy should be addressed cautiously. Therefore, further studies are needed to investigate various predictive factors in each phase of chemotherapy. This would include the induction, consolidation and maintenance phases. In addition, because of the low level of internal consistency in the Information Support from Parent Scale, further research is needed in order to refine or create more effective instrument.

## Conclusions and Implications for Nursing Practice

Symptom pattern, information support from health care providers, illness-related knowledge and parental uncertainty were found to be predicting factors of uncertainty in illness among children with leukemia undergoing chemotherapy. The results can provide a better understanding of predicting factors of their uncertainty, which can be used for further exploration into the possibility of designing effective nursing interventions that can reduce the uncertainty in illness of these children through the provision of information and knowledge from nurses and through a decrease in parental uncertainty. The results can also provide information for pediatric oncology nurses in order to make them aware of predicting factors for uncertainty in illness and guide nursing intervention.

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# ปัจจัยทำนายความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กป่วยโรคมะเร็งเม็ดเลือดขาวที่ได้รับเคมีบำบัด

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**บทคัดย่อ:** มะเร็งเม็ดเลือดขาวเป็นโรคที่คุกคามต่อชีวิตเด็ก เคมีบำบัดเป็นการรักษาที่ซับซ้อนและมีอาการข้างเคียงและภาวะแทรกซ้อนที่รุนแรง และไม่สามารถทำนายผลการรักษาได้อย่างชัดเจน ทำให้เด็กป่วยเกิดความรู้สึกไม่แน่นอนในความเจ็บป่วยขึ้น ส่งผลให้เด็กป่วยมีความทุกข์ทรมานทางจิตใจ การศึกษาเชิงพรรณนาแบบภาคตัดขวางนี้มีวัตถุประสงค์เพื่อศึกษาปัจจัยทำนายความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กป่วยโรคมะเร็งเม็ดเลือดขาวที่ได้รับเคมีบำบัด กลุ่มตัวอย่างคือเด็กป่วยโรคมะเร็งเม็ดเลือดขาวจำนวน 96 ราย ที่ได้รับเคมีบำบัดในโรงพยาบาลระดับตติยภูมิในกรุงเทพมหานคร 4 แห่ง เครื่องมือวิจัย ประกอบด้วยแบบประเมินความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กป่วย แบบประเมินแบบแผนอาการแสดงของความเจ็บป่วย แบบสอบถามการสนับสนุนด้านข้อมูลจากบุคลากรทางสุขภาพ แบบสอบถามการสนับสนุนด้านข้อมูลจากบิดามารดา แบบสอบถามการสนับสนุนด้านข้อมูลจากเพื่อน แบบประเมินความรู้สึกไม่แน่นอนของบิดามารดาในความเจ็บป่วยของบุตร และแบบประเมินความรู้เกี่ยวกับความเจ็บป่วย ผลการวิเคราะห์ข้อมูลด้วยสถิติการวิเคราะห์ถดถอยพหุคูณพบว่าแบบแผนอาการแสดงของความเจ็บป่วย การสนับสนุนด้านข้อมูลจากบุคลากรทางสุขภาพ ความรู้เกี่ยวกับความเจ็บป่วย และความรู้สึกไม่แน่นอนของบิดามารดาในความเจ็บป่วยของบุตรอธิบายความผันแปรของความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กป่วยโรคมะเร็งเม็ดเลือดขาวที่ได้รับเคมีบำบัดได้ร้อยละ 34.8 การศึกษาครั้งนี้ให้ความรู้เกี่ยวกับปัจจัยทำนายของความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กเพิ่มขึ้น ผลการศึกษาสามารถนำไปใช้ในการพัฒนาวิธีการทางการพยาบาลเพื่อลดความรู้สึกไม่แน่นอนในความเจ็บป่วยของเด็กป่วยโรคมะเร็งเม็ดเลือดขาวที่ได้รับเคมีบำบัด โดยพยาบาลช่วยให้เด็กมีความเข้าใจในแบบแผนอาการแสดงของความเจ็บป่วย ให้การสนับสนุนด้านข้อมูลและความรู้ รวมถึงลดความรู้สึกไม่แน่นอนในความเจ็บป่วยของบิดามารดาเด็กป่วย

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**คำสำคัญ** เคมีบำบัด เด็ก ความรู้สึกไม่แน่นอนในความเจ็บป่วย การสนับสนุนด้านข้อมูล มะเร็งเม็ดเลือดขาว ปัจจัยทำนาย ประเทศไทย

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# Development and Psychometric Testing of the Nursing Performance for Patient Safety Scale

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**Abstract:** In Thailand, patient safety measurement is based on nursing and midwifery standards. In this study we developed the Nursing Performance for Patient Safety Scale to assess individual nurses. The instrument development process involved six steps: 1) Identification of constructs from concept analysis. These included six sub-domains: protection, prevention, mitigation, promotion, interpersonal facilitation, and dedication; 2) Generating 141 items for item pool; 3) Determining format for measurement. Scaling responses were determined using a 6-point Likert-scale; 4) Verification of the 141 items by five experts and 73 items remained after the second round with the S-CVI of 1.00; 5) Determining reliability. The Cronbach's alpha coefficient was 0.95; and 6) Field testing for construct validity.

The study settings were 8 regional and 9 general hospitals governed by Thailand Ministry of Public Health. There were 759 nurses selected using multistage sampling in four regions of Thailand, and simple random sampling was used. Item-total correlation ranged from 0.24 to 0.75. Principal component and oblique rotation by directoblimin was used for exploratory factor analysis. The final Scale had 64 items with 9 domains 1) protection through communication; 2) protection through risk management; 3) prevention through right drug and solution administration; 4) prevention through implementation of practice guideline; 5) prevention emergency adverse events through critical care; 6) prevention through effective patient care process; 7) mitigation; and 8) promotion through team and responsibility and 9) dedication to patient safety. This Scale can be used to produce evidence to helping to improve patient safety performance by nurses in Thailand. However, future studies are needed to refine the Scale.

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**Keyword:** Instrument development; Patient safety; Nursing performance; Psychometric testing; Quality; Safety

## Introduction

Patient safety is a major issue supporting quality improvement in healthcare. Many countries have increasingly recognized the importance of improving patient safety. In 2002, the World Health Organization (WHO) member states agreed on a World Health Assembly resolution on patient safety. The WHO then launched the Patient Safety Program

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in 2004, and over 140 countries have worked to address the challenges of unsafe care.[1] Moreover, the Joint Commission established the National Patient Safety Goals program in 2002 and approved a new program in 2013 to help accredited organizations address specific areas of concern in regard to patient safety.[2] In Thailand the Healthcare Accreditation Institute set the Thai Patient Safety Goal[3] with the aim of preventing procedures that could potentially cause harm to hospitalized patients. The goals deal with safe surgery, infection control, medication safety, patient care process safety, avoiding catheterization and tubing misconnections, and emergency response. Additionally, the Ministry of Public Health (MOPH) and the Thailand Nursing and Midwifery Council (TNMC) has set nursing and midwifery practice standards for patient safety goals.[4,5] Nursing organizations urge all nurses to comply with patient safety practice guidelines in order to save patients from harm.

An essential step for patient safety improvement are specific measures which have achieved high levels of patient safety. These safety measures should recognize hospital efforts toward patient safety and achievements in patient safety. In the nursing literature, the Donabedian's structure-process-outcome framework has been used for evaluating the quality of nursing care.[6] This evaluation structure consists of material resources, human resources, and organizational structure, and the evaluation process consists of the patient's activities in seeking care and caring it out, as well as the practitioner's activities in making a diagnosis and recommending or implementing treatment. The evaluation of outcomes consists of the effects of care on the health status of patients and populations.[7] Process and structural measures signal what hospitals have done to improve safety and outcome measures reflect whether a hospital has actually achieved safety goals. These process, structural, and outcome measures should be of equal weights of 50%[8], and the measures should address a process proximate to the desired outcome.[9] Although hospitals are voluntarily seeking to improve performance on standard sets of measures,[8] there is little evidence that these sets are focused on process assessment. Most of the evidence has shown outcome assessment[10] but existing measures are incapable of judging the quality of the process.[9] In Thailand, process measurement for patient safety consists of the rate of incident reports, the application of the nursing process to regular practice, and nursing documentation indicating the quality of nursing care.[4,5] Outcome measurement is based on 10 indicators for patient safety[4] and requires six months to one year to see evidence in the decreasing rate of errors.[11] In comparison, process measurement may take as little as one month. Thus, process measurement for patient safety can provide accurate and timely information for feedback to nurses to improve patient safety.

In reality, process measurements are faced with the problem of evidence which reflects accurate results. They use the number of incident reports of nurses as indicators, but incidence data are under-reported.[12] Therefore, using the number of incident reports as an indicator of process measurement cannot guarantee that nursing organizations with low reported incidence can control risks and actually practice patient safety. Effective process measurements require evaluation from the nurses performing certain processes that have been demonstrated to achieve desired aims, and avoiding processes that tend to cause harm.[13] Performance measurement is the most appropriate measurement for assessment by individual nurses to determine whether or not they comply with patient safety procedures.[14] Measurement of performance at an individual level will provide information for human resource managers to design interventions to ensure that nurses strictly adhere to patient safety guidelines and build up a safety culture in the nursing organization. Moreover, nurses can utilize measurement of performance for self-monitoring when providing nursing care to patients and prevent the possible risk. At present, the commonly-existing scales used to measure patient safety focus on the patient safety culture. These include the Hospital Survey on Patient Safety Culture (HSPSC)[15] and the Safety Attitude Questionnaire (SAQ).[16] These do not include performance measurements and have rarely been applied to the performance concept as a conceptual framework in the healthcare sector. This is the first study known in Thailand to try to address this issue. We developed the Nursing Performance for Patient Safety Scale (NPPSS) to assess nursing performance regarding patient safety at the individual nurse level. This new scale is important for patient safety because nursing organizations require high individual performance which could lead to accomplishing patient safety goals.

## Review of Literature

In general, patient safety refers to minimizing risks of harm to patients and providers through both system effectiveness and individual performance.[17] This involves promoting a culture of safety, protecting the patient from hazardous situations[18], minimizing the impact of incidence, and maximizing recovery from adverse events.[19] Therefore,the Joint Commission on Accreditation of Healthcare Organization (JCAHO) in the USA established national patient safety goals to address specific areas of concern regarding patient safety. These consist of: 1) the improvement of accuracy in patient identification, 2) improvement in the effectiveness of communication among caregivers, 3) improvement in the safety of using medications, 4) reducing the risk of health care-associated infections, 5) accurately and completely reconciling medications across the continuum of care, and 6) identifying safety risks inherent in its patient population.[20] In 2012, new national patient safety goals of the USA were approved with the intent of reducing the risk of patient harm resulting from falls and pressure ulcers, as well as preventing "wrong site, wrong procedure, wrong person surgery".[2]

Nurses are important since they are pivotal to enhancing patient safety improvements and comprise the largest group of healthcare providers. They have more contact with patients than other healthcare provider. Furthermore, healthcare organizations need high performing individual nurses in order to accomplish patient safety goals and thus patient safety needs to be evaluated from the perspective of nurse behaviors. Their behaviour needs to be evaluated to test their degree of effectiveness as it is synonymous with performance.[21] There are two attributes of the performance concept: task performance and contextual performance.[22] Task performance refer to core technical behaviour and activities involved in the job.[23] Contextual performance refers to behaviours that demonstrate an employee's willingness to participate with another member.[24] There are two facets of contextual performance: interpersonal facilitation and job dedication.[25]

Nursing performance for patient safety refers to the behaviours that individual nurses perform which are relevant to patient safety goals. It is the responsibility of all nurses to perform in a manner that achieves these goals. The dimensions of patient safety performance are nursing task performance for patient safety and nursing contextual performance for patient safety. The details of each dimension are described below:

**Nursing task performance for patient safety** refers to an individual nurse's behaviors that accomplish patient safety goals. Nurses' behaviors include protection, prevention, mitigation, and promotion.

*Protection* refers to an individual nurse's behaviors in against harm before reaching the patient. These behaviors consist of identifying risks inherent in the patient population,[3] patient assessment,[13] and identifying the multiple factors involved in failures[19] which could cause incidents.

*Prevention* refers to an individual nurse's behaviors that attempt to stop harm before reaching patients. These behaviors consist of adhering to guidelines for patient safety[26] and accurately reporting incidents.[27]

*Mitigation* refers to an individual nurse's behaviors in reducing the severity of complications after something goes wrong in the patient's treatment that puts him or her at risk. These behaviors consist of immediately solving the problem,[26] improving the effectiveness of communication among caregivers,[2] patients, and their families, and providing immediate care based on the role of nurses.[3]

*Promotion* refers to an individual nurse's behaviors in performing their function and continual responsibility in order to enhance patient safety. These behaviors consist of promoting a culture of incident reporting,[28] using patient safety goals as a professional nursing development goal, and continued training in patient safety procedures.[18]

**Nursing contextual performance for patient safety** refers to an individual nurse's behaviors in a cooperative work environment with healthcare providers to care for patients and to enhance patient safety. In this study, these behaviors are classified into two dimensions: interpersonal facilitation for patient safety and dedication to patient safety. Each dimension is defined as follows.

*Interpersonal facilitation for patient safety* refers to an individual nurse's behaviors in cooperating with and immediately responding to requests from other team members in emergency situations, demonstrate the capacity to help someone without being asked, and participate in patient safety meetings.[3]

*Dedication to patient safety* refers to an individual nurse's behaviors that show that he or she is striving for patient safety; such behavior consists of activities that demonstrate effort initiatively to solve patient safety problems, persistence, and self-discipline. These behaviors consist of putting in extra hours to receive training in patient safety, tackling difficult work assignments enthusiastically, and setting patient safety goals as the target behavior that they want to achieve for the day.[17]

## Study Aim

The purpose of this study was to develop an instrument to measure nursing performance for patient safety for nurses in Thailand.

## Methods

**Design:** This instrument development research was divided into six steps: 1) identification of construct 2) generating an item pool, 3) determining the format for measurement, 4) reviewing for content validity by experts, 5) determining of reliability, clarity, and readability, and 6) field testing for evaluating the items by determination of item analysis and construct validity testing with factor analysis.

**Ethical considerations:**

This study was approved by the Research Ethics Review Committee of the Faculty of Nursing, Chiang Mai University, Thailand and prior to data collection, permission was also obtained from the ethics committee of each of the selected hospitals. All participants were informed about the purpose, methods, time required for the study, confidentiality, anonymity issues, and the right to withdraw from the study at any time without losing benefits. Finally, the participants who agreed to participate were asked to sign the informed consent form.

**Data Collection and Data Analysis:**

*Step 1: Identification of construct*: this was a process of identifying the domains from an analysis of patient safety concepts. A literature search was conducted using several search engines: CINAHL, Medline, PubMed, and Cochrane Review. Key words used were "patient safety", "quality of nursing care", "safer care", and "risk management process". The attributes of the concepts were identified, categorized, and arranged into the construct of the NPPSS. There were two dimensions of nursing performance for patient safety, consisting of: 1) nursing task performance for patient safety including protection, prevention, mitigation, and promotion, and 2) nursing contextual performance for patient safety, including interpersonal facilitation for patient safety and dedication to patient safety.

*Step 2: Generating an Item Pool:* This was generated from the specified domains of nursing performance for patient safety, identified during the previous step of construct identification. The number of identified items was at least twice as many as the desired number for the final scale.[29] Under the operational definition of 2 dimensions and 6 sub-dimensions, items were identified, and 141 items were generated. These were written in Thai and then translated into English by a bilingual person.

*Step 3: Determining the format for measurement:* the NPPSS format was composed of two parts: the demographic data form, and the performance assessment scale. The scaling responses were defined with a 6-point Likert-type scale ranging from 0-5, where 0=never done, 1=scarcely done, 2=rarely done, 3=sometimes done, 4=often done, and 5=always done.

*Step 4: Reviewing for content validity by experts:* the developed items were reviewed for content validity in the first draft of the NPPSS by five experts. These included two faculty members, one was an expert in instrument development and the other was an expert in patient safety, two nurse administrators, experts in patient safety management, and one nurse who was an expert in patient safety practice.

The NPPSS was revised based on the experts' comments. Some items required revision for clarity. The I-CVI of the 141 items ranged from 0.2 to 1.00 and the I- CVI was 0.88. The S-CVI/UA was 0.58. Inter-rater agreement was 0.79, which was less than required by the criteria and thus 62 items were deleted from the scale and 79 items were retained. The second draft of the NPPSS was submitted to the same experts for the second round. The I-CVI of 79 items ranged from 0.8 to 1.00 and the I-CVI was 0.98. The S-CVI/UA was 0.92, which was less than the criteria (1.00). Thus, 6 items were deleted from the scale and 73 items were retained. The I-CVI of 73 items was 1.00 and the S-CVI/UA was also 1.00. Inter-rater agreement was 0.97,which meet the criteria about I-CVIs should be 1.00 with five experts.[30] The accepted value of inter-rater agreement should be at least 0.90.[31] The third draft was retained.

*Step 5: Determining reliability, clarity, and readability;* the third draft of the NPPSS development was the determination of the scale's reliability through pre-testing. The sample for the pre-testing was 30 staff nurses. Their recruitment was conducted with multi-stage sampling, beginning with four regions of Thailand, to draw one hospital for pre-testing. Then to draw the nurses who have experience in inpatient unit for at least two years, simple random sampling without replacement was used.

Finding revealed that all of the items were clear (100%), most of the items were understandable (96.7%), all of items were practical (100%), and 100% of the staff nurses agreed that the length of the questionnaire was appropriate. The length of time for filling out the scale ranged from 13-81 minutes, with a mean time of 43.53 minutes. Internal consistency reliability was estimated using Cronbach's alpha coefficient for the six subscales and ranged from 0.76 to 0.97. The scale's overall was 0.95. Therefore 73 items were retained.

*Step 6: Field testing for evaluating the item by determination of item analysis and construct validity testing with factor analysis*, 730 nurses that should be ten participants for each item being tested[31]plus the expected attrition rate of 20%, totaling 876 nurses were the participants. Eight regional hospitals and eight general hospitals were selected. The recruitment of participants was the same as Step 5. The third draft of the NPPSS was mailed to the directors of nursing service who then distributed this to the participants. Ten items of the Marlowe Crowne

Social Desirability Scale (10-SDS) was distributed along with the third draft of the NPPSS.

The 10-SDS was also administered because the Thailand Nursing and Midwifery Council, the Ministry of Public Health, and the Bureau of Nursing, Office of Permanent Secretary, Ministry of Public Health (BON) urge all nurses to comply with patient safety practice. The fact that some of the items might have been perceived as socially desirable could have contributed to the nurses giving answers that said "good things" rather than "bad things" about themselves. Ten items of the Marlowe-Crowne Social Desirability Scale were originally written in English, translated into Thai, and back-translated into English by a bilingual person to assure that no changes in meaning occurred during the translation process.

The third draft of the NPPSS with 73 items were returned 831 case (94.86%) and 72 uncompleted (13.67%). Therefore, there were 759 cases (86.33%) for analysis. The analysis of the psychometric properties of the scale included internal consistency reliability, item analysis. The Kuder-Richardson (KR-20) was use to determined reliability of 10- SDS. The Spearman's rank-order correlation coefficient was use to describe correlation between the score of individual items and ten items of the 10-SDS. The exploratory factor analysis was used for construct validity. The process of this study was organized in 6 steps, as shown in Figure 1.

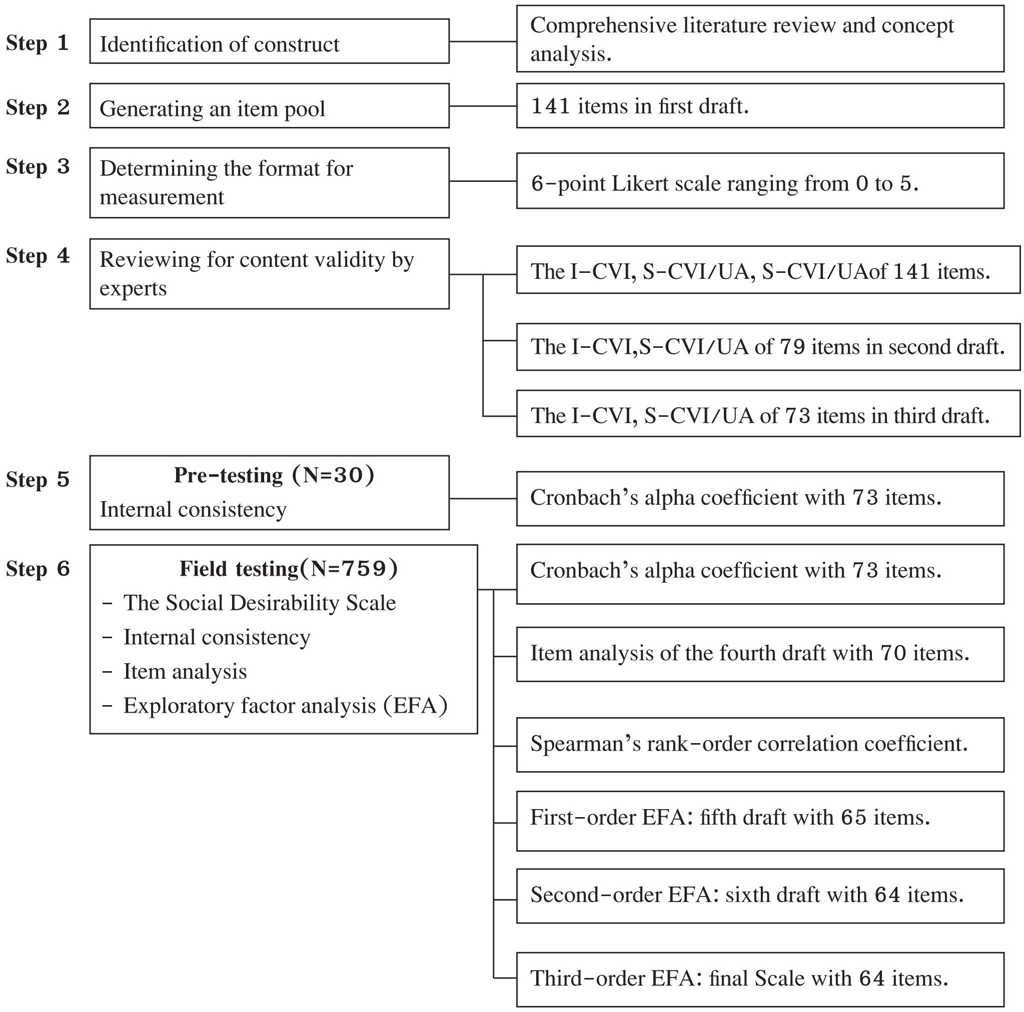

**Figure 1** Stages of the development of the Nursing Performance for Patient Safety Scale

## Results

The participants ranged from 22 to 60 years, with a mean age of 43.82 years (S.D. = 8.97), and most of them were female (98.16%) and 79.84% had a bachelor degree. Over half (52.17%) worked in a regional hospital and the rest worked in a general hospital (47.83%). Their experience in patient care varied widely, from 2 to 38 years, with an average experience of 13.30 years (S.D.=8.56). Half of the participants (54.15%) had attended a training course in patient safety.

## Social Desirability

Kuder-Richardson reliability for the 10-SDS scale was calculated at 0.70, which was acceptable. There was no significance between the overall of the third draft of the NPPSS and 10-SDS (r = 0.02, $p<0.05$), which was acceptable for correlation between the score of item and 10-SDS. Therefore it is assumed that the nurses provided truthful data for nursing performance in patient safety.

**Reliability Testing**

The internal consistency reliability of the 73 items was estimated using Cronbach's alpha coefficient of 0.98, which was an acceptable alpha value for newly-developed instruments.[32]

Item means ranged from 4.00 to 4.50, with a standard deviation ranging from 0.51 to 0.71. A mean close to the center of the range of possible scores was desirable. The mean of item variances was 0.23, with a range from 0.26 to 0.50, which was less than the criteria. Since, the statement of items indicated good practices for patient safety. It will not discriminate among individuals with different levels of the construct of patient safety performance being measured. [31]Therefore, these items are less extreme.

**Subscale-subscale correlation and subscale-total correlation**: the criteria of the subscale-subscale correlation were more than 0.30. The correlation between subscales of the third draft of the NPPSS ranged from 0.54 to 0.78. The subscale-total correlation as the correlation between each subscale to the overall scale ranged from 0.86 to 0.95. Thus, all items were considered to be related to the concept within the subscale and accepted for retention in the third draft of the NPPSS.

The corrected item-total correlation of the 73 items ranged from 0.24 to 0.75. One item had low correlation and some items with high correlation. The results of item to subscale correlation indicated that most of items correlations over 0.70 are redundant.[32] The Cronbach's alpha coefficient of all items was 0.97. The alpha coefficient, if items deleted, for all items ranged from 0.972 to 0.974. The results revealed that when three items were dropped from the scale, the Cronbach's alpha increased. Therefore, three items in the NPPSS were dropped from the scale. Thus, the fourth draft with 70 items was retained for further factor analysis.

**Validity Testing**

The principal component analysis with oblique rotation by direct oblimin was selected because it yielded the best possibility to interpret the factor solution. The criteria for retention of an item include in the components with eigenvalues greater than 1, an item loading above .30 on each factor, no or few cross-loading items, determining the number of common factors with a screen test, and any factors with fewer than three items. [32, 33]

The 70 items of the NPPSS demonstrated that the Kaiser-Meyer-Olkin measure was 0.97, which was acceptable for sampling adequacy.[34] The Bartlett's test was significant ($x^2$= 38113.494, p = .000), indicating the overall significance of the correlation matrix. Thus, the set of data was appropriate for the factor analysis.

The final draft of the NPPSS was summarized based on the results of the third-order factor analysis. Nine components of the scale with 64 items could explain 63.54% of total of variance. All items retrieved with factor loading ranging from 0.34 to 0.90, eigen values ranged from 1.12 to 25.33. (Table 1 to 5).

**Table 1** Factor, Factor loading, Eigenvalue, and % of Variance of Component *Protection*

| Item | Description of item | Factor loading |
|---|---|---|
| | **Protection through communication** | |
| PT12 | Estimate patients' cooperation to use it for exploration of plausible risks. | 0.81 |
| PT13 | Promote communication between nurses and patients via many channels to enhance patients' safety. | 0.78 |
| PT15 | Spend time explaining self-management to patients to promote cooperation in nursing care. | 0.75 |
| PT11 | Evaluate patients' knowledge to use it for exploration of possible risks. | 0.73 |
| PT14 | Promote communication in the multidisciplinary team through many channels to enhance patient safety. | 0.57 |
| | Eigenvalue = 3.60; % of variance = 5.63 | |
| | **Protection through risk management** | |
| PT1 | Explore the risks of patients individually. | -0.78 |
| PT2 | Classify risks at work. | -0.75 |
| PT3 | Evaluate risk strengths likely associated with patients under care. | -0.75 |
| PT4 | Use the data from risk assessment to establish a health plan to protect patients. | -0.73 |
| PT5 | Reduce all kinds of risks once they are found. | -0.63 |
| PT6 | Provide solutions suitable for each patient risk. | -0.62 |
| PT8 | Use the results from risk evaluation of personal information in prior planning to prevent an adverse event. | -0.52 |
| PT7 | Carefully evaluate each patient's personal information for any potential risks. | -0.44 |
| PT10 | Investigate communication issues in the multidisciplinary team, which can lead to an adverse event. | -0.44 |
| PT9 | Seek communication problems between nurses and patients, which can lead to an adverse event. | -0.42 |
| PV1 | Understand the important of writing incident reports in the unit. | -0.34 |
| | Eigenvalue = 1.12; % of variance = 1.74 | |

**Table 2** Factor, Factor loading, Eigenvalue, and % of variance of component *Prevention*

| Item | Description of item | Factor loading |
|---|---|---|
| | **Prevention through right drug and solution administration** | |
| PV7 | Use an infusion pump to control the volume of concentrated solution that will flow into patient. | 0.76 |
| PV8 | Check doctor's prescription before giving medication to patient. | 0.61 |
| PV9 | Check the quantity of concentrated solution in patients every hour and every time before nursing care. | 0.57 |
| PV14 | Report the abnormal results of any laboratory examination directly to the responsible physician immediately. | 0.54 |
| | Eigenvalue = 2.79; % of variance = 4.36 | |
| | **Prevention through the implementation of practice guidelines** | |
| PV17 | Follow hospital guidelines to prevent decubitus ulcers. | -0.84 |
| PV16 | Examine the skin of the patient under responsibility with the risk of decubitus ulcers. | -0.80 |
| PV18 | Evaluate the patient's risk of falling from fall history, age, and use of antidepressant drugs prior to nursing care. | -0.77 |
| PV19 | Follow the hospital guidelines to prevent falling. | -0.57 |

**Table 2** Factor, Factor loading, Eigenvalue, and % of variance of component *Prevention* (continued)

| Item | Description of item | Factor loading |
|---|---|---|
| PV21 | Check every catheterization or tubing from their origin to the connection port to verify attachments before practice and every treatment provision. | -0.39 |
| | Eigenvalue = 1.41;% of variance = 2.20 | |
| | **Prevention emergency adverse events through critical care** | |
| PV24 | Call the rapid response team once a patient's condition changes into crisis. | -0.90 |
| PV22 | Understand the guidelines for requests from team or the rapid response team once a patient's condition changes into crisis. | -0.78 |
| PV23 | Evaluate patient symptoms of deterioration, using criteria set by hospital. | -0.46 |
| PV25 | Provide immediate nursing care to a patient whose condition changes into crisis. | -0.40 |
| PV27 | Explain to patients and relatives about possible risks to prevent incidents. | -0.35 |
| | Eigenvalue = 1.33; % of variance = 2.09 | |
| | **Prevention through effective patient care process** | |
| PV12 | Never use the bed or room number to identify the patients under care. | 0.72 |
| PV11 | Prior to nursing care always verify patient identity in a minimum of two ways, asking for name and hospital ID number. | 0.62 |
| PV10 | Advise patients or relatives about medication and its side effects. | 0.56 |
| PV13 | Allocate the patient data to the team via SBAR (situation, background, assessment, recommendation). | 0.46 |
| PV5 | Clean hands effectively as required before and after nursing procedures. | 0.40 |
| | Eigenvalue = 1.24; % of variance = 1.93 | |

**Table 3** Factor, Factor loading, Eigenvalue, and % of Variance of Component *Mitigation*

| Item | Description of item | Factor loading |
|---|---|---|
| | **Mitigation** | |
| MT7 | Provide feasible care instructions to patients and relatives affected by adverse events, with mutual agreement of multidisciplinary team. | -0.87 |
| MT8 | Listen to patients and relatives expressions of frustration about an adverse event. | -0.84 |
| MT6 | Provide information of any adverse events to patients or relatives, together with the multidisciplinary team, using the hospital's information report guidelines. | -0.83 |
| MT9 | Spend time listening to patients and relatives, who have been affected by adverse events. | -0.80 |
| MT5 | Provide honest information regarding adverse events to patients or relatives, and the multidisciplinary team, using the hospital information report guidelines. | -0.61 |
| MT10 | Use error information as a lesson in finding ways to prevent recurrence. | -0.51 |
| MT3 | Interpret unwanted changes in a patient's condition affected by discovered adverse events. | -0.45 |
| MT2 | Evaluate symptoms of patients who have been affected by any incident in hospital-based practices. | -0.44 |
| MT4 | Give first aid immediately to minimize loss following an adverse event. | -0.41 |
| MT1 | Understand the hospital practices stipulated to reduce adverse events. | -0.35 |
| | Eigenvalue = 1.57; % of variance = 2.46 | |

**Table 4** Factor, Factor loading, Eigenvalue, and % of Variance of Component *Promotion through team and responsibility*

| Item | Description of item | Factor loading |
|---|---|---|
| | **Promotion through team and responsibility** | |
| PM4 | Be aware that nursing practice that focuses on patient safety is a core value of nursing organizations. | 0.63 |
| PM6 | Practice nursing as an example to the team members so they work to emphasize patient safety. | .063 |
| PM2 | Explain details of an adverse event for a common understanding within the team. | 0.59 |
| IF3 | Coordinate with team members to enhance patient safety. | 0.55 |
| PM7 | Propose the development of practices to enhance safety. | 0.53 |
| IF2 | Volunteer to help team members to promote patient safety. | 0.53 |
| PM5 | Comply with safety practice guidelines that set by unit. | 0.52 |
| PM3 | Do not predict unknowingly the adverse events information. | 0.51 |
| PM8 | Apply the concept of safety in all nursing practice. | 0.50 |
| IF1 | Provide immediate assistance to team members in any emergency situation. | 0.48 |
| IF5 | Join activities in wards or hospitals, organized to enhance patient safety. | 0.47 |
| IF4 | Emotionally support team members who experience adverse events. | 0.42 |
| | Eigenvalue = 25.33; % of variance = 39.58 | |

**Table 5** Factor, Factor loading, Eigenvalue, and % of Variance of Component *Dedication to patient safety*

| Item | Description of item | Factor loading |
|---|---|---|
| | **Dedication to patient safety** | |
| DP2 | Attend quality development activities even on off-duty days. | 0.76 |
| DP1 | Spend personal off-duty time attending patient safety training. | 0.75 |
| DP4 | Develop innovations to enhance patient safety. | 0.70 |
| DP3 | Develop methods to prevent adverse events and to suit patients under care. | 0.65 |
| DP5 | Demonstrate eagerness in finding practices that focus on patient safety even though these tasks are complicated and complex. | 0.63 |
| PM9 | Receive ongoing patient safety training. | 0.56 |
| IF6 | Share ideas at meetings to target patient safety in wards and nursing departments. | 0.48 |
| | Eigenvalue = 2.27;% of variance = 3.35 | |

Reliability Testing. The internal consistency of the NPPSS with 64 items was 0.91, which was high for a new scale. All of the subscale reported sufficient correlation. Moreover, all items revealed sufficient item-total correlations ranging from 0.40 to 0.81.

## Discussion

The NPPSS was designed to evaluate the nursing performance for patient safety of nurses in Thailand based on the guidelines for developing a measurement scale of DeVellis.[32] There were two dimension and six sub-dimensions. They were described as follows: Dimension 1: *Nursing task performance for patient safety* consisting of the sub-dimensions of *Protection, Prevention, Mitigation*, and *Promotion* and Dimension 2: *Nursing contextual performance for patient safety* consisting of the sub-dimensions of *Inter-personal facilitation for patient safety* and *Dedication to patient safety*.

The psychometric properties of the data revealed that nine components were associated with nursing performance for patient safety. They were reorganized from the pre-sub dimension and indicated that the specific nurses' behaviors for patient safety were better than those for the pre-dimension. They provided a better understanding of patient safety performance along with the nursing role for patient safety.

The components *Protection through communication* and *Protection through risk management* came from reorganizing the pre-sub dimension *Protection*. These focused on evaluation of the patient in order to exploring possible risks through communication with the team. These behaviors represent important roles for nurses in term of protecting the patient from harm through communication. Currently, ineffective communication is a factor contributing to most cases of patient harm.[35] It is the single biggest cause of nearly 70% of adverse events in the hospital. Therefore, improving the effectiveness of communication among caregivers is a specific area of concern in regards to patient safety.[3] Furthermore, patient safety also focuses on exploring risks, reducing risks, and providing treatment suitable for each patient's risk. These behaviors are included in the area of risk management. This consists of risk identification, risk assessment, analysis, understanding, and acting on risk issues in order to reach an optimal balance of risks, benefits and cost.[28] Managing risk will help protect providers and patients from becoming involved in legal matters.[36] Therefore, protection through communication and through risk management is specific and necessary so that nurses can provide safe patient care.

The components *Prevention through right drug and solution administration*, *Prevention through the implementation of practice guidelines*, *Prevention emergency adverse events through critical care*, and *Prevention through effective patient care process* came from reorganizing the pre-sub dimension *Prevention*. Prevention here means an individual nurse's behaviors that attempts to stop harm before reaching the patient, therefore the use of the five rights of medication administration helps to provide consistent quality care,[37] and is critical for preventing medication errors. The nurse role for patient safety also involves to practice guidelines. These guidelines should explicitly define patient safety goals and patient safety solutions,[2,3] including standardized processes, protocols, and checklists.[37] The results of reorganizing the pre-sub dimension of *prevention* was specific nurses' behaviors to prevent harm to patients.

*Mitigation* all of the items came from the pre-sub dimension of *Mitigation*. These items explained the nurse's behaviors in reducing the severity of complications after errors were identified. These behaviors consist of providing immediate care based on the role of the nurses, communicating hazards and incidents to other team members, patients and their families[28] which should be build trust and openness[38], and asking immediately for help. The action taken to make better or compensate for any harm after an incident would reduce loss or damage to patients, family, and the organization.[28]

The component *Promotion through team and responsibility* was a combination of the pre-sub dimension of *Promotion with interpersonal facilitation for patient safety*. It focuses on the nurses' function and continually promotes patient safety through teamwork. Teamwork is functioning effectively within nursing and inter-professional teams, fostering open communication, mutual respect, and shared decision-making to achieve quality patient care.[38] As mentioned in the literature review, lack of team work is an important contributing factor to adverse events.[27] Furthermore, the application of teamwork and collaboration among caregivers enhance the achievement of a system-wide culture of patient safety.[39] Thus, prevention of harm to patients is based on teamwork and is required for nursing performance for patient safety.

The component *Dedication to patient safety* is a combination of the pre-sub dimension of *Dedication to patient safety*, *Promotion*, and *Interpersonal facilitation for patient safety*. When considering the meaning of the items, the focus is on the nurses' behaviors that demonstrate that they are striving for patient safety through undergoing training on patient safety and sharing ideas about patient safety since patient safety solutions are needed to tackle the underlying causes of unsafe care. These included learning from mistakes in order to improve process and enhance awareness among medical staff.[38] Therefore, nurses should explain how to design solutions and implement them based on training which is strongly emphasized in developing countries.[36] Continuing training in patient safety procedures causes the practice improvement for patient safety in care settings.[3] Dedication to patient safety through continuous learning for patient safety will improve nursing performance for patient safety.

The items of the NPPSS indicated more specific nurses' behaviors for patient safety than the conceptual framework. They also provided a better understanding of the nurses' role regarding patient safety, appropriate for the context of the TNMC and the BON standards. The NPPSS demonstrated adequate reliability and validity for measuring patient safety performance for nurses in Thailand. The NPPSS will additionally provide information which shows the frequency of the patient safety performance of individual nurse.

## Limitations

The sub-scale total correlation of the NPPSS ranged from 0.86 to 0.95, which indicated redundancy. Thus items within the subscale may not be distinct and hence they should be further examined through research. Secondly, the assessment of validity was tested using only one group type and thus a test using contrast group validity is recommended in order to arrive at more accurate validity of the NPPSS. Thirdly, this study was also limited in terms of testing for criterion-related validity because an existing scale was not available to compare it with. Thus, this should also be further examined.

## Conclusions

The final version of the 64 items with 9 components is a self-report questionnaire with a 6-point Likert scale. The results indicated an adequate sample, and adequate reliability and validity for measuring nursing performance regarding patient safety. The results of the item- to-subscale correlation indicated that most of the items with a correlation over 0.70 were redundant. The findings and limitations suggested the need for future inquiry. Thus, future studies are needed to refine the instrument and to strengthen its psychometric properties.

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# การพัฒนาเครื่องมือวัดการปฏิบัติการพยาบาลเพื่อความปลอดภัยของผู้ป่วย

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**บทคัดย่อ**:ในประเทศไทย การวัดความปลอดภัยของผู้ป่วยอาศัยมาตรฐานการพยาบาลและการผดุงครรภ์ การพัฒนาเครื่องมือวัดการปฏิบัติการพยาบาลเพื่อความปลอดภัยในครั้งนี้จึงเป็นครั้งแรกที่ได้พัฒนาขึ้น โดยมีวัตถุประสงค์เพื่อพัฒนาและตรวจสอบคุณภาพของเครื่องมือวัดการปฏิบัติการพยาบาลเพื่อความปลอดภัยของผู้ป่วยสำหรับพยาบาลกระบวนการพัฒนาเครื่องมือมี 6 ขั้นตอน คือ การกำหนดโครงสร้าง โดยการวิเคราะห์มโนทัศน์ ประกอบด้วย 6 องค์ประกอบ คือ การปกป้อง การป้องกัน การบรรเทาความรุนแรง การส่งเสริมความปลอดภัย การช่วยเหลือกัน และการอุทิศตน ขั้นตอนที่ 2 ข้อคำถาม จำนวน 141 ข้อ ขั้นตอนที่ 3 กำหนดมาตราวัด ซึ่งใช้ลิเคริตสเกล 6 ระดับ ขั้นตอนที่ 4 จำนวน 141 ข้อและตรวจสอบความตรงเชิงเนื้อหาโดยผู้เชี่ยวชาญจำนวน 5 คน ครั้งที่สองเหลือข้อคำถาม 73 ข้อ ได้ค่าความตรงเชิงเนื้อหาทั้งฉบับเท่ากับ 1.00 ขั้นตอนที่ 5 ทดสอบความเที่ยงของเครื่องมือ ได้ค่าสัมประสิทธิ์แอลฟาครอนบาคเท่ากับ 0.95 ขั้นตอนที่ 6 คือการทดสอบความตรงเชิงโครงสร้าง

บริบทของการทำวิจัยในครั้งนี้ คือ โรงพยาบาลศูนย์ 8 แห่ง และโรงพยาบาลทั่วไป 9 แห่ง ซึ่งเป็นโรงพยาบาลในสังกัดกระทรวงสาธารณสุข ทดสอบความตรงเชิงโครงสร้างในพยาบาลจำนวน 759 รายได้มาโดยการสุ่มแบบหลายขั้นตอนจากโรงพยาบาลทั้ง 4 ภาคของประเทศไทยและสุ่มอย่างง่าย ความสัมพันธ์ของข้อคำถามกับคะแนนรวมของข้อคำถามที่เหลือของแบบประเมินทั้งฉบับมีค่าระหว่าง 0.24 ถึง 0.75 การวิเคราะห์องค์ประกอบเชิงสำรวจที่สกัดองค์ประกอบโดยพิจารณาองค์ประกอบจากกลุ่มของตัวแปรที่มีความสัมพันธ์กันและหมุนแกนในลักษณะที่องค์ประกอบไม่เป็นอิสระกัน พบว่า แบบประเมินฉบับสุดท้ายมีจำนวน 64 ข้อ ประกอบด้วย 9 ด้าน ได้แก่ 1) การปกป้องอันตรายต่อผู้ป่วยโดยการสื่อสาร 2) การปกป้องอันตรายต่อผู้ป่วยโดยการจัดการความเสี่ยง 3) การป้องกันอันตรายต่อผู้ป่วยโดยการบริหารยาและสารละลายที่ถูกต้อง 4) การป้องกันอันตรายต่อผู้ป่วยโดยการปฏิบัติตามแนวทางปฏิบัติ 5) การป้องกันเหตุการณ์ไม่พึงประสงค์ที่เกิดจากสถานการณ์ฉุกเฉินโดยให้การพยาบาลผู้ป่วยในระยะวิกฤต 6) การป้องกันอันตรายต่อผู้ป่วยโดยการปฏิบัติตามกระบวนการดูแลผู้ป่วยที่มีประสิทธิผล 7) การบรรเทาความรุนแรงจากอันตรายที่เกิดขึ้นต่อผู้ป่วย 8) การส่งเสริมให้เกิดความปลอดภัยแก่ผู้ป่วยโดยการทำงานเป็นทีมและความรับผิดชอบ 9) อุทิศตัวเพื่อความปลอดภัยของผู้ป่วย

แบบประเมินการปฏิบัติการพยาบาลเพื่อความปลอดภัยของผู้ป่วยนี้มีความเชื่อมั่น ความตรงเชิงเนื้อหา และความตรงเชิงโครงสร้าง สามารถนำไปใช้เป็นแบบประเมินการปฏิบัติการพยาบาลเพื่อความปลอดภัยของผู้ป่วย อย่างไรก็ตามควรได้มีการปรับปรุงเครื่องมือนี้ต่อไป

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**คำสำคัญ:** การพัฒนาเครื่องมือ ความปลอดภัยของผู้ป่วย การปฏิบัติการพยาบาล การทดสอบคุณภาพของเครื่องมือทางจิตวิทยา คุณภาพ ความปลอดภัย

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# A Qualitative Study of Factors Influencing Thai Women with Breast Cancer to Use Complementary and Alternative Medicine

*Ausanee Wanchai*, Jane M. Armer, Bob R. Stewart*

**Abstract:** While taking conventional medicines to cure cancer, some people also use complementary and alternative medicine to improve their health and well-being. This study used Leininger's ethnonursing method to identify cultural factors influencing 17 Thai women with breast cancer to select complementary and alternative medicines for their health and well-being. They were recruited from a hospital in the lower northern part of Thailand and in-depth interviews and field notes were utilized with each participant. Data were analyzed by using Leininger's method. Findings revealed that factors influencing them to select complementary and alternative medicine centred on (1) kinship, (2) social factors, (3) economic status, and (4) beliefs and lifestyles. Findings suggested that many important factors influenced participants' decisions about using complementary and alternative medicines. Family members and significant others were the most important resources of information. Financial issues were a barrier to continue or discontinue use of complementary and alternative medicines. The beliefs and lifestyles of Thai people also influenced the selection of types of alternative medicine used by the participants. Therefore, nurses should assess patients' perspectives, such as their beliefs and their social networks. Moreover, significant persons should be involved between the health care provider and the patient regarding care practice decision-making.

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**Keywords:** Alternative medicine, Breast cancer, Care practices, Complementary medicine, Decision-making, Ethnonursing, Qualitative research, Thailand, Women

## Introduction

Breast cancer is the leading cause of cancer death (after lung cancer) among women worldwide.[1] In Thailand, during the period 1998-2000, breast cancer was the second most common cancer after cervical cancer among Thai women with the incidence rate of 20.5 per 100,000 women.[2] However, within this current decade, breast cancer has been reported to be the leading cancer among Thai women with an incidence rate of 20.9 per 100,000.[3]

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Previous studies have shown that many physical and psychosocial problems persist after completion of treatment.[4] For example, one study[5] reported that at the end of treatment, common stressors for women with breast cancer include uncertainty about treatment and follow-up, physical concerns, difficulty concentrating, and attitudes about body changes. Another study[6] also reported that the greatest source of stress for women with breast cancer following treatment completion is the side effects of treatment such as hair loss, fatigue, and lymphedema. Further, approximately 33.3% of Thai patients with cancer use complementary and alternative medicine (CAM) as a complement to mainstream treatment,[7] while a cross-sectional study reported that Thai patients with cancer who used CAM therapies selected types of CAM based on their cancer-related symptoms.[8] In addition, findings from a cross-sectional study [9]showed that to improve their quality of life, Thai women with breast cancer take herbal medicines (38.1%), change their nutrition (36.5%) or lifestyle (31.7%), or practice praying (16.8%). A qualitative study[10] described that the meaning of complementary therapy as perceived by Thai women with breast cancer included: cancer-controlling treatment, mental strengthening, mind and body therapy, self-determination, natural therapy, and conventional therapy integration. Some participants believed that CAM could cure cancer. However, there are a few studies which have confirmed the efficacy of CAM as being appropriate for women with breast cancer. This is a challenge that health care providers should address as some usage may lead to problems such as a delay in seeking medical treatment or even more serious problems, such as interactions between CAM and conventional treatment.[11] If we know why breast cancer survivors use CAM, it may provide important information about the beliefs, values, expectations, and hopes of consumers.[12] In addition, since culture shapes how people respond to disease, it is essential that health care providers explore perspectives of patients regarding their health care practice within a cultural context.[13]

Leininger[13] asserted that cultural and social structure factors, including education, economics, politics, cultural values and lifeways, kinship, religion, and technology, also influence individuals' care practices. Accordingly, if nurses understand what factors motivate survivors to use CAM as their care practices, better counseling related to CAM use may be effectively provided.[14] Study results serve as a foundation for better understanding the significance of cultural influences on health behaviors, and help nurses to develop cultural nursing interventions to improve health outcomes for Thai women with breast cancer, and enhance provision of culturally-consistent care.

### Purpose of Study

To identify the cultural and social structure factors that influence Thai women with breast cancer to select CAM care practices to promote their health and well-being.

### Research Question

What are the factors that influence the selection of CAM care practices by Thai women with breast cancer?

## Methods

**Design:** The qualitative ethnonursing method of Leininger[15] was used in this study. This uses naturalistic and open inquiry modes to discover the participants' world of knowing and experiencing life.[15] This method is unique and essential to the study of caring and healing practices, beliefs, and values in diverse cultural and environmental perspectives. The theory of Culture Care Diversity and Universality developed by Leininger[15] was chosen to inform this study as it was only theory explicitly focused on the close interrelationship of culture and care on well-being, health, illness, and death. It also focuses on the complex interrelationship of many factors, including lifeways, religion, kinship, politics, law, education, technology, language, environment context, and worldview, that contribute to culturally congruent care.

**Participants:** were recruited using a purposive selection process from one hospital in the lower northern part of Thailand. Inclusion criteria were: >18 years of age; able to read and speak Thai; diagnosis of breast cancer at least one year previously; and experienced in CAM use. A list of possible participants who gave permission to be contacted by the researcher was obtained from a nurse who was a referral source. The researcher then contacted these possible participants to explain details of the study and invite their participation,

**Ethical Considerations:** The study was approved by the Health Sciences Institutional Review Board of Buddhachinaraj Hospital, Phitsanulok, Thailand and the University of Missouri. All participants were informed about standard principles of protection of human subjects and were provided with written informed consent under the principle of full disclosure. Efforts to maintain participant confidentiality included keeping information secure and private throughout the study. All participants signed an informed consent form.

**Data Collection:** Two in-depth interviews were performed with each participant, for 30 to 60 minutes, with at least two weeks between each of the two interviews, during two months of 2011. Examples of open-ended questions for the interview were: 'Tell me about your decision to use particular health care practices?; How do you care for yourself to promote health and well-being?'; 'How do these factors influence your decision-making regarding care practices'; and 'How do you care for yourself to promote health and well-being?'. Data saturation was achieved by continuing to collect data until no further new information was obtained.[15]

*Verbatim* data obtained from audiotaped and transcribed interviews were translated and back-translated into English before analysis by the first author who is fluent in both Thai and English and confirmed by a second bilingual person. Finally, a translated English version was reviewed by two monolingual English-speaking collaborators and co-researchers.

**Data analysis:** This was conducted using the four phases of the ethnonursing qualitative data analysis method proposed by Leininger[15]. Data analysis began on the first day of research and continued with regular data coding, processing, and analysis until all data were collected. The second phase began with organizing all recurrent components into the NVivo software program to clarify their meanings line by line and word by word. Thereafter, data were reviewed to discover patterns related to the research question, what factors influenced them to use CAM. Finally, the main themes and sub-themes were formulated to explain how those factors influence their decision-making regarding care practices.[15]

**Trustworthiness and Rigor of the Study:** The six qualitative criteria described by Leininger[15] were used in this study to establish trustworthiness and rigor of the study: credibility, confirmability, meaning-in-context, recurrent patterning, saturation, and transferability. To achieve credibility, a triangulation method including observation, field notes, and interview were performed. To achieve confirmability and meaning-in-context, the transcription, field notes, on-going data analysis, and findings were shared with research team. To achieve recurrent patterning, re-reading and re-checking the transcripts several times were performed. To achieve saturation, continuing to collect data until no further new information was obtained. To achieve transferability, providing rich, thick description in describing more details about phenomenon was undertaken.

## Results

There were 17 Thai women with breast cancer with an average age of 49.5 (ranged from 24 to 63 years) years. Ten had less than a high school education and the rest had higher than a high school education. Twelve women reported it was <6 years since the diagnosis of their breast cancer; the rest reported diagnosis between 9-16 years earlier. Nine women reported they were at stage II of diagnosis, whereas five women had stage III, and three had stage I. Eleven women had received three types of treatment (surgery, chemotherapy, and radiation); five women had received surgery and chemotherapy; and one had been treated by surgery only. Sixteen were Buddhists. Ten women earned < 10,000 baht (<US$333) a month and the rest earned more than 10,000 baht (>US$333) a month

There were four themes that emerged: kinship, social factors, economic status, and beliefs and lifestyles.

*Kinship*

When making decisions about their care practices in CAM, participants with breast cancer stated that they were influenced by kinship, including recommendations of family members and friends.

One participant said that she decided to take herbs because of her father:

> *I have been interested in using herbs because my father knew about herbal medicines, as my grandmother was a traditional midwife. She gave him Thai traditional medicine textbooks, so he was an expert in herbs. When I was sick, he sought out and studied from his old textbooks.* (P1)

Another participant decided to use CAM because she had direct experience in taking care of her mother who was diagnosed with breast cancer and also used CAM:

> *After my mom was diagnosed with cancer, I studied a lot, whatever could be helpful for my mother, both alternative medicine and Western medicine. So from this direct experience, I have used it for myself when I found out that I had breast cancer.* (P8)

Friends were also identified in care practices in CAM. For example, a participant explained that she first decided to be treated with alternative medicine because of the recommendation from her friend:

> *At first, I did not want to be treated with Western medicine. My friend, a Thai traditional medicine doctor, recommended that I be treated with alternative medicine. She suggested to me to take herbal medicines. So at that time, I took herbal medicines for my self-care practice.* (P13)

*Social Factors*

Social factors that contributed to CAM practices were support group and media. In terms of participating in a support group, one participant stated,

> *At that time, when I was diagnosed with breast cancer, I started to get involved with the volunteer club. So, they suggested that I take herbal medicine.* (P10)

In addition, media, such as radio, TV, the internet, and books, also influenced their CAM care practices, for example:

> *I heard about it on the radio, and then I found it in a book. I love to read books. The book stated that there are many types of therapeutic food that we can eat.* (P3)

> *I did research through books about cancer, through word of mouth from friends who have cancer, and also from the TV. I like to watch TV because I'm like this: I must learn about things directly because I want to have a long life.* (P5)

*Economic status*

Economic status was identified as an important factor to continue or discontinue with those CAM practices. The categories of this theme included costs outweigh benefits and benefits outweigh costs. Participants reflected on the cost of CAM as costs outweigh benefits in performing care practices in CAM. For example, one participant said that the cost of alternative products was a barrier to continue with CAM practices. She said:

> *I used to eat some food supplement, but I do not eat it anymore because it is too expensive. I could only eat one package in one month. I took it for three packages, and then I quit because it is so expensive.* (P6)

Another participant chose a product that she could afford, instead of using one was too expensive for her:

> *Now, I eat rice germ oil. It's very cheap, only 12 baht (US40 cents) per tablet. I do not buy other herbs that are too expensive.* (P14)

Despite the cost of CAM, selected participants decided to use this as they perceived the benefits outweighed the costs. For example, a participant with an income of US$666 a month realized how expensive CAM products were, but she still continued to use those products for her health:

> *Now I eat supplementary product of one company. I also drink mineral water from this company. It's a little bit over 3000 baht (~US$100) to help the kidneys. Although I have no money, I am more concerned about my health.* (P7)

*Beliefs and Lifestyles*

Participants reflected that personal beliefs and lifestyle were significant factors contributing to their CAM care practices. This theme contains two subthemes: beliefs and lifestyles.

It was evident that one important factor to CAM use was beliefs in participants' natural lifestyle. For example, one participant shared her view regarding how her beliefs and lifestyles affect the selection of care practices in CAM by returning to natural food.

> *When looking back at food, I saw that grilled food, fried food, and fast food were my favorite foods. So I thought, are these risk factors of cancer or not? So I reduced these foods and chose more natural food. Natural food is eating organic food, reducing meat, but increasing more fruits and vegetables. I think this links to natural healing.* (P8)

Some participants believed that herbal medicines were not as harmful as the Western medicine, so they tried them. For example, one participant stated,

> *I think it is a folk medicine that is not dangerous. So I try to eat some.* (P1) *Another agreed, saying: It's like this is the way that Thai people believe. There's no big loss with these kinds of things, especially herbal medicine. Most herbs are not harmful, unlike Western medicines (which) are dangerous drugs.* (P10)

In addition to belief in a natural lifestyle, religious belief was identified as influencing the use of CAM. For example, one Buddhist participant believed that prayer helped her to be able to take all the courses of chemotherapy courses:

> *The first time that I received chemotherapy, I could not eat anything and vomited all the time for about three days. The second time, my sister told me to pray any chapter from a chanting book that I wanted. So when they started my injection, I closed my eyes and prayed. Believe it or not, the second time I never vomited. I ate like a pregnant woman. Although my mouth was burned, I was able to eat everything.* (P2)

Another Buddhist participant shared her story of how meditation and prayers changed her personality:

> *When my breast was cut off, I thought too much about my body image. I was afraid that my husband would leave me one day. I was so stressed. Later, when I practiced meditation and pray, I found I did not depend on him. I can let him go.* (P12)

## Discussion

Participants explained that their care practices in CAM were influenced by many factors, including: kinship, social factors, economic status, and beliefs and lifestyles. This concurs with Leininger's theory of Culture Care Diversity and Universality,[13] in that religion, cultural value and lifeways, economic, kinship factors and social factors are the most significant forces influencing care which help people to face disabilities, illness, and death. A Western study found that kinship, economic, education, and belief factors were the important influencing factors for American breast cancer survivors in making decisions about their care practices, using both Western and alternative medicines.[16]

Family members and friends were important in influencing participants to make decisions about using CAM to promote their health and well-being. This might be explained by the fact that the majority of our participants were young women in stage II of breast cancer. They hoped to live longer and sought out health information from other people around them. This finding is consistent with another study in that sources of information about CAM for Thai women with breast cancer were family members, or friends.[17] Our findings are also consistent with previous studies conducted in other countries that demonstrated the most common source of CAM information for women with breast cancer were family members and friends.[18-19] In the Thai context, particularly in the north of Thailand, Thais live with or near their parents, and they have a strong family relationship with each other. Moreover, Thai Buddhists also perceive that sickness is often dealt with through strong family ties. Therefore, when someone in the family is ill, others support that person as much as they can.[17,20] Additionally, a method involved in finding care practices in CAM for Thai women with breast cancer may result from Thai culture. Thais usually learn how to use herbal medicines from old books or from the records of their older family members.[21] As can be seen from this study, one participant decided to use herbs in her care practices because her father had the traditional medicine textbooks, received from her grandmother.

In addition to kinship, social factors, particularly media (i.e., radio, television, books, and the Internet), also played an important role as a source of CAM information for participants. This finding is consistent with a study which found that mass media, such as television, radio, and magazines, influenced the use of herbal medicine of Thai elderly people.[21] Likewise, a cross-sectional study[22] reported that the majority of Thais in Bangkok, Thailand, received information about herbal medicines from mass media, similar to another study in Korea.[23] Similarly, in a cross-sectional study to assess patterns of CAM use by patients with breast cancer from 11 countries in Europe ($N = 282$), about one-third of participants reported that they received their information about CAM from media.[18] Moreover, one study conducted a cross-sectional study with patients with breast cancer in Malaysia to identify their information sources of CAM.[24] The results showed that, in addition to friends or family members, mass media was also the common information source about CAM for women.

Another study reported that social factors can influence the selection of care practices in CAM by patients with cancer through their personal experience, social interaction, and the interface with the mass media.[25] The challenge is that most media describe CAM in a positive fashion, and more specifically, as a potential cure for cancer, but did not describe the risk and the cost information.[26,27] This is a clear indication that the knowledge base about CAM needs to be improved for patients with breast cancer.

The economic status of participants influenced decisions to continue or discontinue CAM practices. Participants reported that they would select CAM types that were not too expensive for them. They would choose the one that they could afford. This might be explained by the fact that the majority were likely to have low incomes and perceived the cost of CAM as a barrier to its use. There is no doubt that the Thai government realizes how important CAM is for Thai people's health, as the practices of Thai Traditional Medicine (TTM) have been integrated into the national health care service system in Thailand since 1978. The Thai government has set the policy to provide financial support for the use of TTM to promote health for Thai people.[21]

However, despite an increasing number of approved herbal medicines being included on the national list of essential drugs in Thailand so that doctors will have more herbal medicines to choose in hospitals,[28] many CAM types are still available only outside the hospitals. As a result, these CAM types are not reimbursed by the Thai Universal Coverage system. Thus, many patients need to pay entirely out-of-pocket for CAM products. Therefore, it is not surprising that CAM use can be an expensive undertaking for women with breast cancer who perceive economic factors as a barrier to the use of CAM. This finding is consistent with a qualitative study which reported that Taiwanese cancer patients would be less committed to expensive therapies.[29] Similarly, a cross-sectional study reported that when CAM became more costly and more difficult to access, Canadians with breast cancer were less likely to use these.[30] Likewise, a qualitative study reported that foreign-born Chinese women with breast cancer in the U.S. perceived that the high cost of CAM was a major barrier to CAM use because most treatments were not covered by medical insurance.[31]

However, although financial factors seem to be a barrier for CAM use by women with breast cancer, and the perceived value of CAM by patients could affect their decision-making as to whether they would choose to use CAM or not.[32] If they evaluate that the pros of CAM are higher than its cons, they may decide to use CAM for their care practices. In addition, if they perceive that CAM is beneficial for their health, they will possibly decide to continue to use CAM for their care practices, despite its high cost, as mentioned by one participant in our study who decided to continue to use CAM in her care practice, even though its cost was high.

Study findings showed that beliefs and lifestyles had a strong influence for selection of care practices in CAM. Herbal medicines have been traditional household medications in Thai society for a long period of time.[21] Thai people have used herbs both as food and as medicine by the traditional learning from one generation to the next generation. In addition, as the majority of participants in this study had less than a high school education level, one influencing factor for their selection of care practices was by the nature of Thai people who usually believe in herbal medicines. Moreover, many participants believed that CAM therapies were more natural and less likely to be harmful to their health than conventional medicines. This finding is consistent with a qualitative study[33] which reported that CAM was seen to be less harmful than conventional treatments. Likewise, in family physicians' views, one reason that patients with cancer decided to use CAM was because they believed it was more natural and therefore less toxic.[33]

Regarding religious beliefs, it is noteworthy that Buddhism beliefs influenced the selections of some types of CAM by participants, namely mind and body medicine, such as meditation, making merit or prayer. According to Buddhism, the state of well-being is not dependent on external circumstances. On the other hand, mental balance will lead to greater well-being and the imbalance of the mind will result in mental suffering,[34] In addition, Thai Buddhists also believe that illness results from an individual's past karma (past actions).[34-36] Consequently, Thai people select to do good things, such as practicing meditation, making merits, chanting, or listening to Dharma, because they believe that these kinds of Buddhist practices are considered as good deeds which can promote their psychological well-being and lead to a good life, both in the present life and in the future life.[34,3]

**Strengths and limitations**

This qualitative study is one of a few known studies of care practices incorporating CAM in Thailand focused on patients with breast cancer. Our findings are important to inform the preparation of nursing care to promote quality of life of Thais who have had breast cancer. All participants were Thais living in the north of Thailand. Accordingly, the findings of this study may not represent Thai women with breast cancer in other parts of Thailand and in other countries. More work is required to explore whether there are similarities or differences in factors that influence Thai women with breast cancer to use CAM in other areas of the country.

## Conclusions

In essence, these findings emphasis many important factors in Thailand, namely kinship, social factors, economic status, and beliefs and lifestyles. Family members and significant others around them were the most important resources of information. Social factors, such as media and support group were also influenced factors for the participants to use CAM. Financial issues was a barrier to continue or discontinue use of complementary and alternative medicines. The beliefs and lifestyles of Thai people also influenced the selection of types of alternative medicine used by the participants.

## Implications for nursing practice

The findings of this study have several important implications for practicing health care professionals as a decision making to CAM use is related to many factors, namely kinship, social factors, economic status, and beliefs and lifestyles. Therefore, it is necessary that health care providers assess patients' contexts, such as their beliefs and their social network. More importantly, significant persons should be encouraged to be involved in conversations between the health care provider and the patient regarding care practice decision-making.

Mass media is a valuable source of information about CAM. The challenge is that, whereas the information from these media sources is likely to be accessible, it may be unscientific, and thus less likely to be accurate and unbiased.[18,24] Nurses for example could prepare educational printed materials which include a list of reliable sources about CAM, as well as giving reliable information for treatment decision-making, by providing an interpretive medical and nursing information guideline for them.

**Implications for Research**

Finally, the findings of this study indicated that although CAM therapies have the potential for harm or benefit, some participants described CAM as more natural and harmless. Although sometimes they had to pay out-of-pocket expenses due to no types of CAM having been included on the national list of essential drugs in Thailand, they were still likely to use CAM in their care practices. Accordingly, future research to examine the efficacy and safety of CAM using a rigorous design such as a randomized control trial and cost-benefit economic research on CAM use are needed. This will lead to stronger evidence in supporting health policy and holistic implications.

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# วิจัยเชิงคุณภาพ: ปัจจัยที่มีอิทธิพลต่อการใช้การแพทย์ทางเลือกของสตรีไทยที่เป็นมะเร็งเต้านม

*อัศนี วันชัย*  Jane M. Armer, Bob R. Stewart*

**บทคัดย่อ:** ในขณะรักษามะเร็งด้วยการแพทย์แผนปัจจุบันผู้ป่วยบางรายเลือกที่จะใช้การแพทย์ทางเลือกเพื่อส่งเสริมสุขภาพตนเอง บทความนี้เป็นการศึกษาวิจัยเชิงชาติพันธ์วรรณนาโดยใช้เทคนิคของไลนิงเกอร์เพื่อศึกษาปัจจัยทางวัฒนธรรมที่มีอิทธิพลต่อการเลือกใช้การแพทย์ทางเลือกของผู้ป่วยมะเร็งเต้านมไทย กลุ่มตัวอย่างคือผู้ป่วย มะเร็งเต้านมไทยที่ใช้การแพทย์ทางเลือกจากโรงพยาบาลแห่งหนึ่งในเขตภาคเหนือตอนล่าง เก็บข้อมูลโดยการสัมภาษณ์แบบเจาะลึกผลการวิจัยพบว่า ปัจจัยที่กระตุ้นให้ผู้ป่วยมะเร็งเต้านมเลือกใช้การแพทย์ทางเลือก คือปัจจัยทางด้านครอบครัวและสังคมเศรษฐกิจ ความเชื่อและวิถีชีวิต จากการศึกษาบ่งชี้ให้เห็นว่ามีปัจจัยสำคัญมากมายที่กระตุ้นให้ผู้ป่วยมะเร็งเต้านมตัดสินใจใช้การแพทย์ทางเลือก ทั้งนี้สมาชิกในครอบครัวและคนใกล้ชิดเป็นแหล่งข้อมูลที่สำคัญที่สุด ส่วนปัจจัยทางด้านเศรษฐกิจอาจเป็นอุปสรรคที่มีผลต่อการใช้หรือหยุดการใช้การแพทย์ทางเลือก ในขณะที่ความเชื่อและวิถีชีวิตของคนไทยก็เป็นปัจจัยหนึ่งที่มีอิทธิพลต่อการเลือกใช้การแพทย์ทางเลือกของผู้ป่วยมะเร็งเต้านมเช่นกัน ดังนั้นพยาบาลควรมีการประเมินบริบทของผู้ป่วย เช่น ความเชื่อและเครือข่ายทางสังคมของผู้ป่วย นอกจากนี้บุคคลที่มีความสำคัญกับผู้ป่วยควรได้รับการช่วยเหลือให้เข้ามามีส่วนร่วมในการพูดคุยเกี่ยวกับการตัดสินใจดูแลผู้ป่วยร่วมกับแพทย์ผู้ดูแลด้วย

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# Struggling to Restore Normalcy: Thai Parents' Experiences in Being Caregivers of Children with Early Schizophrenia

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**Abstract:** Although caregiving for persons with early schizophrenia is a difficult task, little is known about the caregiving process in early schizophrenia. This study explored the caregiving process for children with early schizophrenia. Twenty-five Thai parents of children diagnosed with schizophrenia within the last five years were interviewed indepth at outpatient clinics and wards of a large psychiatric hospital in Thailand. A Straussian grounded theory approach was used and data analysed using constant comparative analysis.

"Struggling to restore normalcy" emerged as the core category that comprised six sub-categories: *learning the diagnosis*, *facing shattered dreams*, *caregiving as an unavoidable role*, *struggling to control psychotic symptoms*, *struggling to deal with the illness impacts*, and *accepting a new normal*. The parents felt as if they were facing shattered dreams after learning the diagnosis. They viewed their caregiving as an unavoidable role, as they strived for their child's normalcy. They tried to control their child's unstable psychotic symptoms by maintaining medication adherence, monitoring and managing the symptoms, and preventing symptom exacerbation and relapse. They had to deal with the impacts of the illness including their child's poor decision-making, illness-related stigma, and their feeling of loss and difficulties. They gradually accepted the incurability of schizophrenia which was their child's new normal.

The unique study findings add to nursing's knowledge about caregiving for this group of children, and have implications for the development of an intervention program that nurses and others can use to help parents cope with caregiving challenges. Future studies should compare mothers' and fathers' experiences in caring for children with early schizophrenia.

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**Keywords:** Caregiving; Children; Experience; Grounded theory; Parents; Schizophrenia

## Background

Schizophrenia is one of the most severe and chronic mental illnesses. The characteristics of the illness are disturbances of perceptual and thinking process, behaviors, and social function.[1] In Thailand, the numbers of person with mental illness including schizophrenia that attended at outpatient clinic of public hospitals increase from 1,076,155 in 2012 to 1,109,183, in 2013.[2] The prevalence of schizophrenia is approximately 8.8 per 1,000. The incidence rate

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was 0.3 per 1,000 with a peak at age of 15-24.[3] The estimate annual costs for the entire population with schizophrenia is high (THB 31,000 million or $US925 million). Hospitalization was the largest component of direct medical cost (50%). Additionally, 61% of the total economic burden is indirect cost of unemployment.[4] The majority of sufferers (98%) reside with their families and their parents were primary caregivers.[3]

The first five years after a diagnosis with schizophrenia is critical and sufferers need continuing care. The psychotic symptoms of early schizophrenia are particularly prominent, unstable, and marked by exacerbations, remissions, and relapse requiring rehospitalization.[5-6] Research evidence revealed that relapse rates were very high even after the first psychotic episode[6-8] and each subsequent relapse was associated with a poor response to treatment, a long time to remission, and a deterioration of functions.[8-9] Hence, caregiving in the early phase of schizophrenia is vital to prevent relapse and promote recovery.[10]

To date, the majority studies of caregiving in western countries has been focused on impact of schizophrenia on caregivers.[11-15] It is evident that caregivers faced multiple challenges to integrate caregiving into their lives and all aspects of their lives were impacted. The studies exploring caregiving process in chronic schizophrenia suggest that following a diagnosis of schizophrenia, caregivers struggle to understand what had happened to their loved ones.[10,12,16-17,20] They experience a sense of crisis and seek ways to solve unpredictable problems and to adjust emotionally to a demanding illness. There are many types of care that caregivers have to provide, including physical, psychological, medical, and social care.[11,16-18] Caregivers experience trial and error processes to overcome caregiving stress and to move toward a state of balance, normalcy, and mastery.[18-19]

In the Thai context, Buddhism has influenced people's perspectives of life and is an integral part of Thai culture.[21] Parental responsibility is culturally prescribed and centered on familial ethics and values which expect that caregiving for children is direct responsibility of parents.[22-24] Therefore, the majority primary caregivers of person with schizophrenia are parents.[10,25-27] Research evidence on parental caregiving support that parents utilized Buddhist principles in managing their feelings in caregiving.[23,26-27] Similar to western studies, caring for children with schizophrenia brings enormous impacts to families and parents' lives.[10] Parents have to adjust their lives in dealing with each phase of illness and the repetitive problems over time.[10, 26] They provide the close and thoughtful caregiving in managing the unpredictability psychotic symptoms and gradually develop caregiving skills and strategies for various circumstances by experiential learning.[10,25-27] Although informative, these studies provide information about caregiving experiences across a wide range of duration, from seven months to over 10 years, however caregiver's experience at the early phase of schizophrenia has been barely researched. Thus, little is known about how parents manage the challenges of being caregivers for their children with early schizophrenia in Thai context.

## Study Aim

The aim of this qualitative study was to explore parental caregiving processes in Thailand during the early phase of schizophrenia.

## Methods

**Study design:** A Straussian's grounded theory approach was employed to elicit parents' descriptions of dynamic process of managing caregiving in the early phase of schizophrenia.[28]

**Participants and setting:** Study participants were recruited from the outpatient clinic and wards of the largest psychiatric hospital in Thailand, initially through purposive sampling. The inclusion criteria were: 1) parents who served as primary caregivers and lived in the same household with the child since the first episode of schizophrenia: 2) had been informed by a psychiatrist that their child was diagnosed with schizophrenia no more than five years ago; and 3) spoke and understood Thai language. Parents who provided care for family members with chronic diseases in the same household and those who had been diagnosed with psychiatric illness were excluded from the study. Nurses in the clinic or wards were asked to approach parents who came with or visited their children with schizophrenia and asked if they were interested in participating in this study. If they indicated their interest, the researcher informed them about the nature and purpose of the study as well as their rights as research participants. The rest of the study participants were recruited through theoretical sampling, which based on emergent concepts from data analysis.

**Ethical considerations:** Approval for informed consent procedures and protection of human subjects was obtained from the Institutional Review Board of Nursing Faculty, Mahidol University and the selected hospital. Each participant was given monetary compensation of 200 Baht (US$6) for each interview.

**Data collection and analysis:** Data collection and analysis was conducted concurrently from August 2012 to July 2013. Indepth interviews ranged from 30 to 110 minutes. The general opening statement for all participants was "Tell me about your experiences since your child's illness begin." Additional questions were used to elicit more details about their experiences. Demographic data was completed after each interview using a brief paper and pencil survey.

Transcripts of the first three interviews were initially examined with open coding, by closely examining phrases or single words to identify types of specific events, activities, and behaviors.[28] Codes that shared common characteristics were grouped into concepts and categories. The beginning categories, and explanatory questions were used to refine the questions in the interview guide and to suggest comparative groups of further nine subsequent interviews. Early categories emerged from data analysis, and were elaborated and refined over the course of analysis through theoretical sampling. Then axial coding and selective coding were used.[28] The emerged concepts were compared against those emerging from eight subsequent interviews and linked to each other. At this point, data saturation was achieved, that is nothing new emerged from analysis. The categories were refined, compared, and linked; memos simultaneously recorded and diagrams representing the linkages were drawn. Writing a story line technique was used. Once the core category emerged, five further interviews were conducted to validate those relationships and hypotheses.

**Trustworthiness:** To enhance the credibility of the findings, each interview was audio-taped, then transcribed verbatim for analysis, checked the accuracy of transcriptions, and codes by the first author. Additionally, peer debriefing and member checking were used.[29] In peer debriefing, the analyses and conceptual abstractions of the data were presented to two experts in grounded theory approach to explore and shape the first author's interpretations. The preliminary findings were presented to five participants in the second interview for member checking.[29-30] Moreover, analyzing negative cases technique was used to increase explanatory power of the substantive theory. An audit trail including notes, field notes, transcribed interviews, and memos were recorded and reviewed by the second author, to enhance dependability of the findings.[29-30]

## Findings

### Characteristics of the study participants

The participants included 25 parents (17 mothers, 8 fathers). Their ages ranged from 44 to 77 years with a mean of 56.24. Duration of caregiving ranged from four months to five years with a mean of 3.20 years. None of them reported having any prior experience in caring for patients with mental illness. All participants were Buddhist and the majority of them were living in urban areas in the central region of

Thailand. The average age of children with schizophrenia when first diagnosed was 26.50 years (range 16-47 years). They had been first diagnosed for an average of 2.27 years. All of them were single, unemployed, and lived together with their parents. Half of them had 1-3 hospitalizations while the rest had more than 3 hospitalizations.

**The grounded theory of struggling to restore normalcy**

"Struggling to restore normalcy" emerged as a core category to describe the basic psycho-social processes of parents' experiences as they assumed roles of primary caregivers for their children with early schizophrenia and face their unstable psychotic symptoms, which was viewed as the basic social and psychological problems for the parents. The core category encompassed six sub-categories: learning the diagnosis, facing shattered dreams, caregiving as an unavoidable role, struggling to control psychotic symptoms, struggling in dealing with the illness impacts, and accepting a new normal, as described below (see in Figure 1).

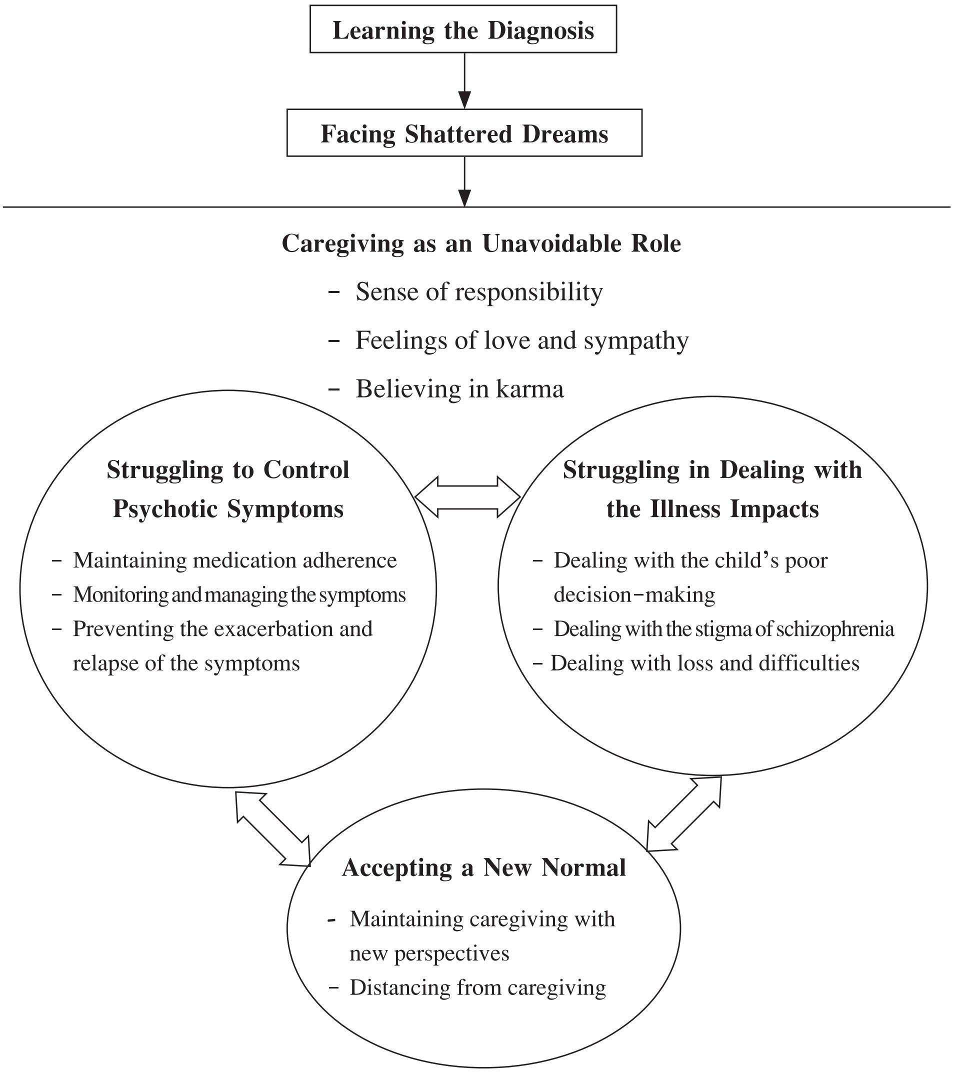

**Figure 1.** The grounded theory of struggling to restore normalcy.

**1. Learning the Diagnosis:** This was a process that began with noticing behavioral changes. The participants reported perceiving gradual changes in their child's behaviors such as increased social isolation or decreased daily activities. Most of them initially thought that those behaviors were normal or reflective of adolescent rebellion as most children first exhibited changed behaviors during their transition to adolescence. As the children's symptoms persisted and became more severe, they began suspecting the behaviors to be abnormal. After the diagnosis, participants reported responses as shock and disbelief at such an unexpected situation. One mother said: *It shocked us, unexpected. I couldn't believe, we brought her up so well.* These reactions were followed by feelings of guilt about whether they had caused or could have prevented the illness.

**2. Facing Shattered Dreams:** The majority of participants were aware that schizophrenia is both an incurable and highly stigmatized condition. Thus, they felt that the dreams that they had for their child and their future had been lost. They experienced anxiety when they thought about the future and their role as caregiver. One mother described:

> *Oh! It seemed that everything was ruined. All parents wish their children to have a prosperous future, to be a soldier, to be a police officer which is good for their lives. When he became like this, did not recover from the illness, could not do anything, he lost his future.*

**3. Caregiving as an Unavoidable Role:** After learning the diagnosis, the participants believed that they were obligated to fullfill the caregiving role for their child. This perception was associated with a number of feelings or reasons:

***Sense of responsibility.*** Most participants perceived that caring for the children especially when they were sick was the direct responsibility of the parents. As one mother said,

> *I don't think anything....It's my duty. If I do not take care of him, who does? As mother, it does not matter if he is a child or an adult. He is our adult child.*

***Feelings of love and sympathy.*** All participants engaged in caregiving with feelings of love and sympathy for their children. They experienced extreme pity for them especially when their children showed psychotic symptoms or had to be restrained or secluded in a hospital. As one mother described while she sobbed:

> *When I saw him while he was eating, I was sad and felt sympathy. He used chopsticks instead of a spoon, wore trousers backwards, took a shower many times a day, and scratched his foot with a brooch [wipe her tears].... He had not been ill since he was born.*

***Believing in karma.*** Karma concerns intentional actions which have their consequences: good karma brings good consequences and bad karma brings bad consequences.[31] All participants believed that they were facing these current struggles because of their karma. They must have treated their children badly or committed a bad deed against someone in their past life. Therefore, they could not avoid repaying such karma. One mother mentioned,

> *I think that it is karma that I had to repay to him. Most of us think that karma involves something that we have done in the past.*

**4. Struggling to Control Psychotic Symptoms:** A primary caregiving task included managing their children's unstable psychotic symptoms. The participants used the following strategies in an attempt to control the illness:

***Maintaining medication adherence.*** All participants understood that medication adherence could control the psychotic symptoms; therefore, they used various approaches to maintain their children's medication adherence. They *took control of medication adminstration* when they viewed that their child was unable to prepare and take medications by themselves. One mother explained:

> *I prepare the pills for him, put them in his hand, and ask him to take them immediately every meal time. I have to do this to make sure that he takes medication correctly and completely. I watch him swallow the pills.*

The participants began to *promote their children's self-responsibility for medication* when they noticed an improvement in symptoms. They gradually decreased their control. Though some of them still prepared medications for their children, they let them to take medication by themselves without observation. Some participants began to teach their children how to prepare the medication by explaining details of medication regimes, preparation, through testing their understanding, reminding their children to prepare and take medication, and re-checking whether the medication was prepared correctly.

In addition, the participants had to *deal with medication discontinuation.* They tried to persuade their children about the importance of medication adherence for recovery. They also used threats and force when their child spat out the medications. Some participants used deception such as crushing tablets and surreptitiously mixing them with food or drink without their children's acknowledge. One mother described her approach:

> *I will try to put it in "Birdy coffee" [an instant coffee beverage] that he likes. I thought he could not know because it is black, unlike "Ohishi tea" [a green tea beverage], he could see the powder left on the bottom of the bottle.*

The participants whose children were not compliant with medication duez to the side effects of the antipsychotic drugs consulted or asked for help from their psychiatrist and tried to diminish the side effects by themselves. For example, some participants provided natural laxatives or fiber foods for their child to alleviate constipation.

***Monitoring and managing the symptoms.*** This approach was used to evaluate the treatment outcome and adjust their responses in managing their children's psychotic symptoms. The participants observed changes in psychotic symptoms from those their children expressed at the first onset of the illness. They determined the severity by comparing with the previous symptoms, in terms of the frequency and their effects on the child's daily activities and security. They additionally determined whether the changed behaviors were normal or were psychotic symptoms through considering the appropriateness of their child's thoughts and perceptions within the current context. The participants gradually comprehended their child's psychotic symptoms through a monitoring approach. A father, whose daughter had auditory hallucinations, stated:

> *If she had auditory hallucinations, her emotion changed. She would rebuke people. I used to ask why and she said that she heard something. Sometimes it was like someone wanted to brawl with her. Thus, she quarreled with it. That was her response to hallucination that I learned.*

They utilized accumulated knowledge for further observation and managing the psychotic symptoms. For example, they would make secret observations to prevent the escalation of their child's paranoia. If their child had a delusion or hallucination, they would redirect their children into reality by initially explaining the reality and giving logical explanations for reconsideration. If their child did not believe them, they expended more effort by presenting related evidences to prove the reality. One mother, whose son believed that he was the king's child, explained her strategy,

> *I showed him the picture of when he was a kid. 'Look! These are your pictures of when you were young.' ..... I rented a car three times and I paid a thousand each time for DNA testing.*

When their children expressed aggressive and violent behaviors, most participants used a complying approach to calm them down because they learned that such psychotic symptoms which may increase if they were forced to try to stop such behaviour. If such behaviours were harmless, they did what their child wanted or allowed them to continue their aggressive and violent behaviors.

***Preventing the exacerbation and relapse of the symptoms.*** Most participants realized that their child was vulnerable to stress, anxiety, and to substance abuse which induced symptom recurrence and relapse. Therefore, they tried to prevent symptom exacerbation and relapse by comforting their child's mind, maintaining cheerfulness, and preventing substance abuse. For example, when their children were facing stress or anxiety, they tried to make the children felt better and realize that the situation was not so bad. As one mother described her response to her daughter's worrying about being admited into a psychiatric hospital:

> *'Mom, it is written on the pillow.' Then, I said, 'That's right, this is the hospital. But you are not mentally ill. You have a chance to recover because you are simply stressed, but need to stay together with them in this hospital,'* I said.

When the child's distress was subsiding, the participants maintained their child's cheerfulness by pleasing them with their favorite foods, providing entertaining activities, and limiting stress in the environment. To prevent substance abuse, they convinced their child by refering to the psychiatrist's information that substance abuse could induce relapse of the psychotic symptoms. Some participants threatened their child that they would not take care of them if their symptoms were worsened by addictive substances. They tried to prevent access to substances by prohibiting their child to meet addicted friends. Some participants decided to take their children away from environments where there were drugs.

**5. Struggling in Dealing with the Illness Impacts**: The participants tried to lessen the impacts associated with schizophrenia, including their child's poor decision-making, the stigma of schizophrenia, and their feelings of loss and difficulties.

***Dealing with the child's poor decision-making.*** This poor decision-making resulted in alterations in daily activities, such as staying in their room, not eating or not taking care of their hygiene as usual. They tried to encourage them. If their child did not comply, the participants would complete it by themselves, such as cooking for them or taking care of their clothes and hygiene.

The participants also thought that their child might harm other people or might be exposed to both physical and sexual harm as a result of their poor decision-making and vulnerability. To prevent their child from being harmed or harming other people, they kept an eye on them, watched carefully and did not leave them alone, and followed them everywhere. They also kept sharp materials away when their children were likely to harm themselves. As one mother narrated:

> *I keep observing him and being cautious. I usually stay with him, not to let him stay alone. He will not be surrounded with any sharp materials. I did not cook at home since cooking requires some utensils such as knives.*

When they perceived that the children were uncontrollable and might injure another person or damage property, they secluded their children in a locked room until they were able to take them to a hospital.

To protect their children from sexual harm, such as sexually transmitted diseases for the sons, or sexual abuse for the daughters, the participants tried to limit their child going outside by assigning them to do housework. Some participants cut the Internet signal at home to prevent them from contacting their boyfriend or girlfriend.

***Dealing with the stigma of schizophrenia.*** The majority of participants concealed their child's illness to try to prevent negative consequences. Most were likely to conceal the schizophrenia from relatives and neighbours after learning the diagnosis as they still had hope for a cure. They did not mention the child's illness if symptoms were not severe enough to arouse neighbours' suspicions. They told a lie when the neighbours suspected and asked questions when the child showed more severe psychotic symptoms or changed their lifestyle due to their illness. Some participants told their neighbours that their child suffered with other conditions, such as tension or stress. The participants whose children ran away from home answered questions from others by giving such reasons that their children went to work somewhere else. Some others concealed the name of the hospital to prevent others from visiting and finding out about their child's illness.

However, after time passed and psychotic symptoms were still severe requiring frequent re-hospitalization, most participants could no longer conceal their child's illness. Some unavoidably disclosed the illness in the early phase, for example, when they needed to keep in contact with their relatives, lived nearby their relatives whom they could see regulary, or when their son needed a waiver for conscription for army service. A father explained, *It was because we needed to submit the medical certificate to waive conscription for an army service due to his being mentally ill, so the matter was known to all the villagers.*

***Dealing with loss and difficulties.*** To be able to continue restoring normalcy for their children, the participants used various approaches to cope with their feeling of loss and difficulties, including *thum-jai*, searching for information about the illness, and gaining support from others. *Thum-jai* is a common approach that Thai people use when they face unpleasant situations and in order to overcome unpleasant feelings, calm their mind, and be able to accept them.[32] The strategies for *thum-jai* included being here and now, and thinking positively. These strategies related to the Buddhist principle regarding mindfulness, to be in the present time.[31] As one mother stated, *I had to be aware of every situation. I suffered whenever I saw my son as a mentally ill patient. .... Just only being here and now could enable me to restrain my mind.* Thinking positively was another way to *thum-jai* included finding existing good things and comparing themselves with other inferior persons.

***Searching for information about the illness*** included the participants' actions in trying to understand schizophrenia, in terms of the course of the illness, symptom management, and sources of help. Some discussed this with relatives of the other patients, while the others read from books or pamphlets or watched some health programs on television. The knowledge that they acquired helped them to face the reality and deal with their child's symptoms more effectively, for example, one mother said:

> *I read from books that we have to comply with the patients. I did not fight against her symptoms especially when she showed aggressive behaviors. I let her to do what she wanted so I could avoid facing more difficulties.*

***Gaining support from others.*** The majority of participants received financial, emotional, and informational support from their spouse, children, or partner. In addition, their family members or their child with schizophrenia assisted them to do household work. Two participants received both informational and emotional support from health care providers. Such support helped them to feel comfortable and made it easier to overcome their caregiving difficulties. One mother who lived alone with her son alone, and suffered from heart disease and hypertension, and used to have suicidal ideas, narrated about her experience:

> *Previously, I wanted to commit suicide. I felt discouraged .... When I saw  he cleaned our house, I came up with an idea that I could take care of a dog even though it could not talk to me. My son could talk to me and help me to clean up the house, whereas the dog just lay down and waited to be fed [laugh].*

6. **Accepting a New Normal**: Accepting a new normal is a consequence of struggling to restore normalcy. It refers to the participants' realization that the pre-illness normal state of their children would never be restored though they put so much effort to control their  psychotic symptoms. Their child still would be a person with schizophrenia. Then, they began to adjust themselves in two ways: maintaining caregiving with new perspectives and distancing from caregiving.

***Maintaining caregiving with new perspectives.*** When a child's psychotic symptoms were controllable for a period of time participants could maintain caregiving as usual with less emotional distress. They still had  hope that it might be possible for their children to be better. They let things go, no longer worried about their child's future, and maintained caregiving as much as they could.  They adjusted their previous expectation that their children would have a normal life,  be self-reliant, have no violent behaviors, or adhere to their medications. Some participants gained optimistic views through a reciprocal relationship with their child while caring for them and living together. One mother, who divorced and let her son live with her husband since his childhood, noted about her optimism:

> *When my son lives with me, I gained opportunity to  provide him with warmth. He used to live with his father when we were separated. I experience good feelings. He also looks so happy and is very close to me.*

***Distancing from caregiving.*** Four fathers whose children's psychotic symptoms had not improved due to medication noncompliance, decreased the intensity of their struggle to restore the child's normalcy. Two of them cared for their child alone but they showed continual intense psychotic symptoms requiring frequent re-hospitalization. Another two participants shared the caregiving role with their wives for nearly five years. They reported that the long-lasting and frequent recurrence of their child's symptoms always disturbed their family's normal life. They adjusted to restore their normal life rather than their child's life. They no longer tried to maintain medication adherence and stopped searching for the strategies to manage psychotic symptoms. One father separated himself from his daughter, though he was in the same household, while another one moved away to live in another place and came back to visit his son occasionally. These fathers just waited to take their children to the hospital when the psychotic symptoms became severe. One father said:

> *I had to go away to have a normal life and I left him to stay alone.  It was just like staying without peace. I eventually gave up. What happens, happens. He had never taken care of himself, no one could help him .... I came back to see him occasionally and give him some food. If his symptoms became severe, I just took him back to the hospital.*

## Discussion

While prior research has described the caregiving process in long-term care of schizophrena, the current study provided valuable data about the caregiving process in the early schizophrenia. Data analysis indicated that the children's unstable symptoms and the impacts of the illness were the basic psychosocial problems for their parents as caregivers.  As a result, struggling to restore normalcy emerged as the core category describing the complex process of Thai parents' adaptations to their caregiving role in early schizophrenia. The findings shared some common attributes with "pursuing normalcy" in a study among family caregivers of severe mental illness.[18] Although that study demonstrated normalcy as a family caregivers' coping response to a chronic mental illness, the current study adds to body of knowledge that normalcy is also the goal of caregiving in the early schizophrenia. It indicates that, for parents, independence and productivity of their children are their optimal needs, regardless of where they were in the illness experience.

The participants in this study struggled with difficulties in dealing with their child's psychotic symptoms both before and after the diagnosis. Before the diagnosis, they experienced struggling in trying to understand and deal with things that happened to their children and which was consistent with findings from prior studies,[11,16-17,33] where caregivers recognized the abnormalities of their relatives, but they were unable to define them.

After diagnosis and treatment for schizophrenia, the participants struggled to restore normalcy for their children. Because of their lack of experience and caregiving skills, they experienced agony in controlling the unstable psychotic symptoms, especially in maintaining medication adherence, managing symptoms, and preventing the exacerbation and relapse of psychotic symptoms. This is similar to other studies,[16,18-19] where the researchers reported that caregivers experienced a cycle of instability and recurrent crises of care recipients' symptoms and they became aware of the chronic trajectory through the cycle of exacerbations and relapses.

Unlike findings of studies focusing on caregiving over a long-term period in which caregivers achieved mastery in caregiving,[10, 18-19,25-27] the participants in this study still struggled with uncertainty and wondered how to appropriately respond to the unstable and unpredictable nature of their child's symptoms. Previous studies supported that caregivers took a long time in adjusting themselves to living with and caring for people with schizophrenia.[10,15] Hence, it was impossible for them to reach a state of stability in caring for the early phase of schizophrenia. They still had to learn through trial and error to control unstable psychotic symptoms and the impacts of the illness.

It is evident that struggling to control psychotic symptoms and to deal with the impacts of the illness influenced participants' coping responses. These could be either adaptive or maladaptive. When a child's psychotic symptoms were controllable for some period of time, participants still had to maintain caregiving whilst developing new perspectives after accepting a new normal. This finding is consistent with other studies[17,22,34] where the researchers noted that most caregivers who experienced the positive side of caregiving usually were those who had hoped for improvement in their relative'condition. The caregivers' hopes and encouragement were maintained if their ill relatives had some signs of improvement or reciprocated their love. These encouraged the caregivers to continue their caregiving.

On the other hand, four fathers, whose children had never complied with medication and their psychotic symptoms had not improved, distanced themselves from caregiving. Two of them shared the caregiving role with their wives for nearly five years, while the others provided caregiving alone and their children showed continual intense psychotic symptoms requiring frequent re-hospitalization. This finding is consistent with previous studies[33,35-36] which noted that the caregivers responded in a negative way if they did not experience the recovery of their care recipients in long-term care. After they experienced failure in trying to control the psychotic symptoms, they felt exhaustion, boredom, and hopelessness. Another possible explanation for this issue concerns gender-specific behaviors associated with the Thai cultural values. Because Thai society expects women to be family caregivers,[23-24,26] these fathers might think that it was not their direct responsibility to be caregivers. A recent study supported that such thinking might be associated with family tradition that the main responsibility of child rearing and caregiving belonged to mothers.[37] Although they distanced themselves from caregiving, their wives still maintained a caregiving role. However, because of the limited number of fathers, it was not enough information to draw a conclusion and to compare with the mothers' experiences and this aspect of gendered caregiving needs further study.

The findings of the current study indicated that dealing with severe psychotic symptoms continuously is a barrier to the positive side of caregiving. Since the nature of psychotic symptoms in the early phase of illness is unstable, living with severe and unstable psychotic symptoms makes it very difficult for the participants to sustain their efforts to handle the illness over time. However, the majority of them could maintain caregiving because they perceived caregiving as an unavoidable role. It is a positive appraisal of the caregiving role which is in line with many studies in Asian culture.[22-23,26,32,34,36] This evidence suggests that caregiving is a strong cultural value and Thai culture and Buddhist principles have deeply influenced Thai caregivers and helped them to overcome distress in managing their children's conditions and their caregiving role.

## Limitations of the Study

Although the study included both mothers and fathers, which seemed to be a strength of the study, there were limited numbers of the fathers. In addition, the study findings were based on interview only. As such, interpretation and conclusion about the differences between mothers' and fathers' experiences which were gender-specific should be undertaken with care. Recruiting larger number of fathers and obtaining data from medical records would enhance variation and saturation of the theory. Survey research may help to extend study findings, as would be a triangulation approach to data collection.

## Conclusions

Our findings add to body of knowledge that normalcy is also the goal of parents in dealing with early schizophrenia. The experiences of caregivers provides more understanding to parents of children affected with schizophrenia, and to mental health care providers about the uniqueness of the caregiving in the early phase of the condition. It was a devastating experience for parents struggling to restore normalcy for their children. Caregiving in the early phase of schizophrenia has been demonstrated to be a critical period needing a high level of support from mental health care providers. In addition, Thai culture and Buddhist principles have deeply influenced Thai parents' responses to schizophrenia.

## Implications for Nursing Practice and Research

Information from this study has implications for the development of effective and supportive services for parents of children with schizophrenia. Given the importance of the caregiving role, parents should be provided with systematic education to help them to deal with multiple problems of caregiving. This educational and support program should be started soon after the first diagnosis, and include providing information about schizophrenia, its prognosis, the nature of its symptoms and management, as well as side effects of antipsychotic drugs and management. Parents should be trained in caregiving skills, typically for monitoring the symptoms, maintaining medication adherence, and dealing with delusions, hallucinations, and aggressive and violent behaviors. Based on the study findings, of particular concern are the needs of fathers who are providing care for their children alone or who are faced with continual psychotic symptoms. Skill training for dealing their children's symptoms is essential for them to prevent maladaptive coping responses. A program could be implemented in a group format to promote the parents' learning from the others' experiences and for mutual support.

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# การดิ้นรนต่อสู้เพื่อการกลับสู่ภาวะปกติ: ประสบการณ์ของบิดามารดาไทยในการเป็นผู้ดูแลบุตรโรคจิตเภทระยะแรก

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**บทคัดย่อ:** แม้ว่าการดูแลผู้ป่วยโรคจิตเภทระยะแรกจะซับซ้อนและยุ่งยาก ความรู้เรื่องกระบวนการดูแลในระยะนี้ยังมีจำกัด การวิจัยนี้จึงมุ่งศึกษากระบวนการดูแลบุตรโรคจิตเภทระยะแรก โดยการสัมภาษณ์เชิงลึกบิดามารดา 25 คนที่บุตรเป็นโรคจิตเภทได้รับการวินิจฉัยภายใน 5 ปีแรก ที่แผนกผู้ป่วยนอกและหอผู้ป่วยในของโรงพยาบาลจิตเวชแห่งหนึ่งในประเทศไทย วิเคราะห์ข้อมูลโดยการเปรียบเทียบข้อมูลอย่างต่อเนื่องตามวิธีวิจัยเชิงทฤษฎีพื้นฐานของสเตราส์

การดิ้นรนต่อสู้เพื่อการกลับสู่ภาวะปกติเป็นหัวข้อเรื่องหลัก ประกอบด้วย 6 หัวข้อย่อยคือ การรู้ว่าบุตรป่วยทางจิต การเผชิญกับฝันสลาย การดูแลเป็นบทบาทที่เลี่ยงไม่ได้ การพยายามควบคุมอาการทางจิต การจัดการผลกระทบของโรค และการยอมรับความเป็นปกติใหม่ หลังจากรู้ว่าบุตรป่วยทางจิต บิดามารดารู้สึกเหมือนกำลังเผชิญกับฝันสลาย จากการรับรู้ว่าการดูแลเป็นบทบาทที่เลี่ยงไม่ได้ จึงดิ้นรนต่อสู้ให้บุตรกลับมาเป็นปกติ โดยพยายามควบคุมอาการทางจิตที่ไม่คงที่ด้วยวิธีการต่างๆ ประกอบด้วย ดูแลให้ได้รับยาต่อเนื่อง เฝ้าระวังและจัดการกับอาการ และป้องกันการกำเริบและกลับเป็นซ้ำของอาการ อีกทั้งต้องจัดการกับผลกระทบของโรค ได้แก่ การตัดสินใจที่ไม่ดีของบุตร ตราบาปของโรค และความรู้สึกสูญเสียและความยุ่งยาก บิดามารดาค่อยๆยอมรับการรักษาไม่หายของโรคซึ่งเป็นความปกติใหม่ของบุตร

ผลการวิจัยเพิ่มองค์ความรู้ทางการพยาบาลเกี่ยวกับการดูแลบุตรในกลุ่มนี้ สามารถนำมาเป็นแนวทางพัฒนาโปรแกรมการช่วยเหลือบิดามารดาที่เป็นผู้ดูแล เพื่อให้ข้ามพ้นความยุ่งยากไปได้ การศึกษาต่อไปควรเปรียบเทียบประสบการณ์การดูแลบุตรโรคจิตเภทระยะแรกของบิดากับมารดา

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# Case Study: A Good Choice for Nursing and Midwifery Research

Case study is a qualitative research approach useful for exploring, explaining and describing complex issues in their real life, natural context.[1,2] As healthcare changes with advances in technology, treatments and demand, nursing practice has become increasingly complex. Contemporary use of case study in nursing and midwifery research has demonstrated its applicability as a unique and powerful approach to explore and understand these complexities.[3,4] For some researchers however, the variation in case study approaches can be confusing. Drawing on the ideas of two leading case study methodologists, Yin[2] and Stake[1,5] we present some of the fundamental steps that can enable a robust yet flexible research design.

**What is and why use case study?**

Case study research "explores a bounded system (a case) or multiple bounded systems (cases) over time through detailed, in-depth data collection involving multiple sources of information (e.g. observations, interviews, audio visual material, and documents and reports) and reports a case description and case-based themes."[8] The case therefore is the object of the study and commonly referred to as the unit of analysis.

Case study can be used to investigate a range of issues, however the essential requisite for employing case study is the impetus to explore, understand and describe the complexities of a situation or phenomena.[1,2,6,7] Case study research does not ascribe to one ontological, epistemological or methodological position.[6,9,10] This versatility presents the opportunity to design research that best addresses the complexity inherent in research problem.[2,5] Multiple methods can be used to inform the research, enabling a comprehensive, in depth investigation.

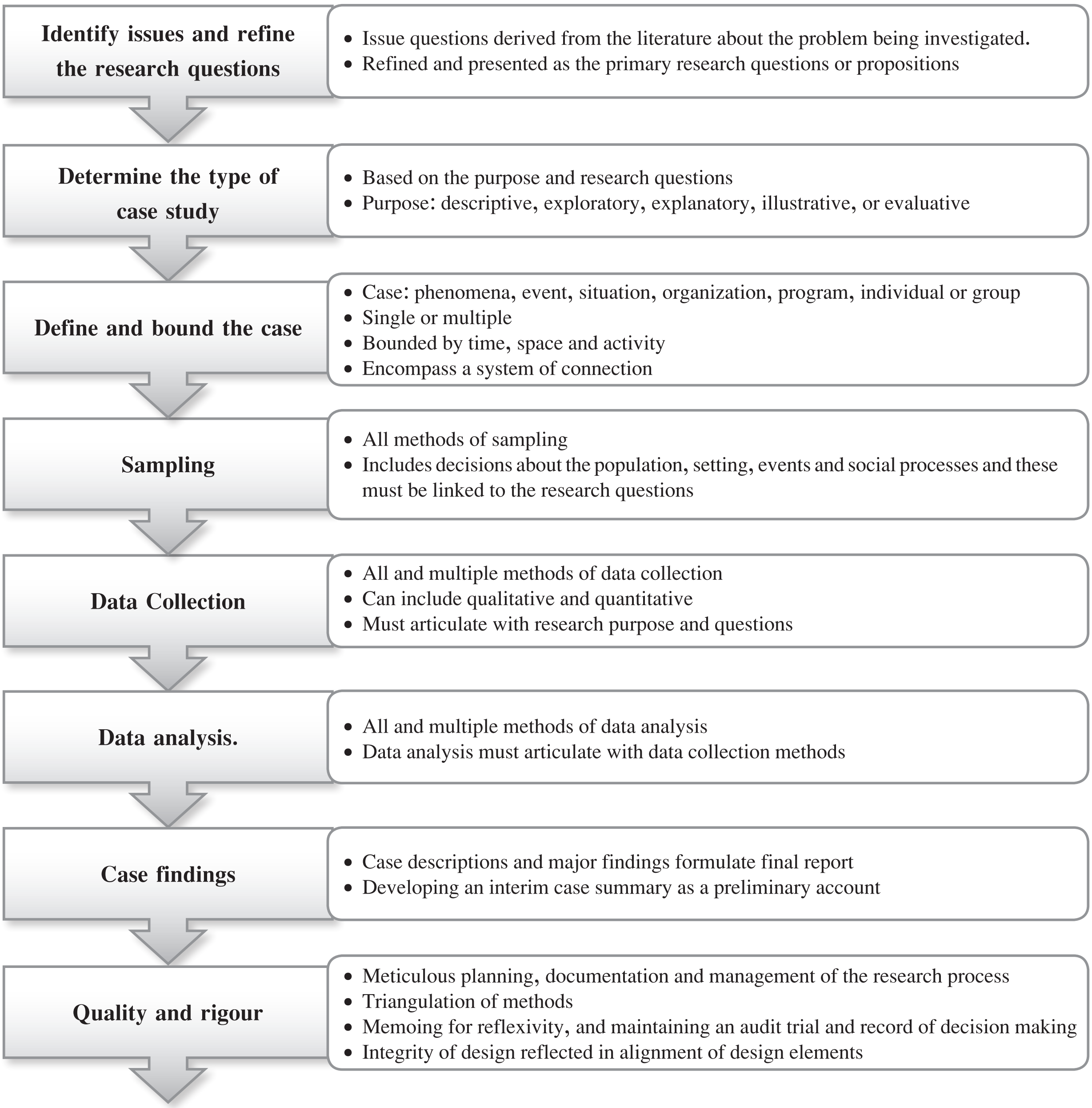
Yin[2] explains that determining when to use case study research and defining the type of case study, is primarily based on the purpose of research outlined in the research questions. Research questions are primarily focused on answering queries related to "what is" and "has happened" or explaining the "how and why" of a situation.[2] Data is collected in its natural setting thus context is a significant contributor to the case being studied and minimal control over variables and behavioural events is evident.[1,2] The context in which a nurse works can shape their clinical practice. Case study presents an approach that captures the influence of these elements for a more in-depth, holistic understanding of research problems related to nursing.

**Designing the research: Essential steps [Figure 1]**

Designing a case study begins with identifying the issues related to the research problem, defining the case and refining the research questions. Issue questions are derived from the literature about the problem being investigated. These help formulate the framework of the case study and are presented as the primary research questions or propositions.[1,2] These direct the data collection and analysis toward the addressing the underlying purpose of the study.[1,2,5]

**Determining the type of case study**

Varied types of case study exist for different purposes and include descriptive, exploratory, explanatory, illustrative, and evaluative.[2] The case study can also be single or multiple where a number of cases are examined collectively. Judicious choice is based on determining which type best addresses the purpose and research questions of the study.



**Identify issues and refine the research questions**
- Issue questions derived from the literature about the problem being investigated.
- Refined and presented as the primary research questions or propositions

**Determine the type of case study**
- Based on the purpose and research questions
- Purpose: descriptive, exploratory, explanatory, illustrative, or evaluative

**Define and bound the case**
- Case: phenomena, event, situation, organization, program, individual or group
- Single or multiple
- Bounded by time, space and activity
- Encompass a system of connection

**Sampling**
- All methods of sampling
- Includes decisions about the population, setting, events and social processes and these must be linked to the research questions

**Data Collection**
- All and multiple methods of data collection
- Can include qualitative and quantitative
- Must articulate with research purpose and questions

**Data analysis.**
- All and multiple methods of data analysis
- Data analysis must articulate with data collection methods

**Case findings**
- Case descriptions and major findings formulate final report
- Developing an interim case summary as a preliminary account

**Quality and rigour**
- Meticulous planning, documentation and management of the research process
- Triangulation of methods
- Memoing for reflexivity, and maintaining an audit trial and record of decision making
- Integrity of design reflected in alignment of design elements

Figure 1: Essential steps in designing case study research

### Define and bound the case

The case can be a phenomena, event, situation, organisation, program, individual or group.[1,2,6,7] The case must be bounded by time, space and activity and encompass a system of connection.[1,2] Boundaries vary according to the case and could be geographical, organisational and/or facility specific where a defined phenomenon occurs or a set criterion for an individual or group. Often the boundaries between the case and context can be blurred and take time to specify. Bounding the case applies a frame to focus the research process on the object of the study and manage contextual variables.

### Sampling

Sampling in case study includes decisions about the population, setting, events and social processes.[11] Refining these strengthens the boundaries of the case and is critical for data analysis. The sample operationalizes the research design to enable a reliable description and understanding of the case. All types of sampling methods can be applied, however they must be carefully linked to the research questions. An appropriate sampling framework adds external validity where case study conclusions can be more readily understood and applicable to a wider section of the population.[1,2]

### Data collection

Conducting site visits (fieldwork) is central to case study research where the researcher's field notes formulate part of the documented evidence for analysis. Conducting these visits relies on identifying a reliable contact person or 'gatekeeper' to facilitate access and data collection at the site.[1,2.5,10] The gatekeeper becomes the fulcrum within the study whereby their site knowledge provides essential guidance about approaches to disseminate study information, recruiting participants and special considerations that might be required.

A useful approach in developing knowledge about the site is to develop an initial overview of the case including location and specific contextual features. This can be refined as the study progresses and inform the final case description drawn from the findings of the study.

Data collection methods are chosen with specificity to address research questions. Multiple qualitative and quantitative methods can be employed to support a holistic, comprehensive investigation and understanding of the case.[1,2,5,7] Methods most commonly utilised in case study research include observation, interviews, focus groups, documentation and artefacts.

### Data analysis.

Similarly multiple methods can be used to analyse data, however how data is analysed must articulate with the method chosen for data collection.[1,2] This alignment is important to the integrity of the research design and validity of the research findings. Data analysis methods can include coding and categorizing of data, and thematic and content analysis.[1,2,11]

For multiple case studies, cross case analysis is the final step in the research process. Here each case is analysed and presented separately.[1,2] Findings are compared across cases to explore how different contexts and processes vary. Similarities, differences and unique findings are identified and the final product of the research is presented as a collective case description.

Methods of triangulation are valued and commonly used at different stages during data analysis to add depth and rigor to the findings.[2] Triangulation of data sources, researchers, methods (within and between) and/or theory can be combined, compared and contrasted within and across cases.[1,11]

### Quality and rigour

Memoing as a reflexive activity is valuable in case study research and constant and central to the research process. The aim of memos is to provide a record of decisions and an audit trail of the research process.[12] Memoing captures the researcher's thinking and focuses on writing up ideas separate to the data collection and analysis.

Meticulous planning, documentation and management of the case study are important to ensure rigor and quality.[2,10] Ensuring the overall approach articulates with the study's purpose is critical. A strong articulation contributes to the credibility and integrity of the final case study.[2,4,9]

### Case findings

Findings from the data collection and analysis are presented as case descriptions and key themes. Case descriptions can vary depending on the type of case study and approach used. These can be descriptive, illustrative or explanatory in nature.[1,2] Initially, developing an interim case summary that outlines a preliminary account of what is happening in the case can enable refinement of the final case description.[11] The case description and major findings are combined to formulate the final report.

### Conclusion

Case study research is a unique research approach capable of providing valuable insights into complex nursing phenomena. Understanding the essential steps in case study research can empower nursing and midwifery researchers to make significant contributions to nursing knowledge, clinical practice and health care. What is presented here is a brief and simplistic introduction to case study research approaches. Case study designs can be complex and need to be carefully considered and planned. Designing a robust case study takes time however the outcome is well worth the time and effort invested.

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# Psychological Distress of Family Members Caring for a Relative with First Episode Schizophrenia

*Suchanya Lohacheewa, Yajai Sitthimongkol*, Yupapin Sirapo-ngam, Chukiat Viwatwongkasem*

**Abstract:** The purpose of this study was to examine the pattern of relationships among factors related to psychological distress of family members caring for a relative with first episode schizophrenia. The conceptual model was built on Lazarus and Folkman's theory of stress and coping. A total of 210 family members providing care for a relative with first episode schizophrenia were recruited from outpatient departments of three different psychiatric hospitals located in Bangkok and the surrounding vicinity. The Behaviors and Symptom Perception Scale, Social Support Questionnaire, Experience of Caring Inventory, Revised Way of Coping Questionnaire, General Health Questionnaire, and a demographics questionnaire were used to collect the data. Data was analyzed by descriptive statistics and path analysis.

The results revealed that the modified model fitted the empirical data and explained 33% of the variance in the psychological distress. Appraisal of the stressful situation, and coping were associated with psychological distress of family members. Appraisal, both positive and negative perspectives, appeared to mediate the effects of the seriousness of illness and perceived social support on psychological distress. Coping was found to mediate the relationship between perceived social support and psychological distress. The results suggested that appraisal of the stressful situation and coping should be considered major influential factors when developing nursing interventions to attenuate psychological distress of family members caring for a relative with first episode schizophrenia. Psychiatric nurses should offer family members an opportunity to exchange information and share experiences with other family members so as to enable them to develop a positive appraisal, and strengthen the appropriate coping strategies to reduce their psychological distress.

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**Keywords:** Appraisal; Coping; Family; First episode schizophrenia; Path analysis; Perceived social support; Psychological distress; Serious illness; Stress; Thailand.

## Introduction

Schizophrenia is a chronic neurobiological disease and is a leading cause of disability worldwide.[1] It has the highest incidence among psychiatric illnesses with prevalence ranging from 0.5 to 1.5 cases per 100 population, and the annual incidence ranging from 5 to 50 cases per 100,000 population.[2] In Thailand, data available for 2014 suggests the incidence rate for schizophrenia was 82,838.[3] The first episode of schizophrenia typically occurs in the late teenage

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years or the early 20s.[4,5,6] In most cases, an individual with the first presentation of schizophrenia usually has a prodromal phase, which can include a variety of behavioral changes.[2,6] Common signs and symptoms of this disease include sleep disturbance, anxiety, anger/irritability, depressed mood, deterioration in functioning, social withdrawal, poor concentration, suspiciousness, loss of motivation, and low energy.[11] Patients typically suffer from disturbing symptoms, as well as side effects of the treatment itself, and they may have increased physical and psychological risks, including the risk of suicide. As such, the caregivers of patients newly diagnosed with schizophrenia are most commonly parents or other family members. There are indications that family members of patients with first episode psychosis report higher levels of distress than do family members of those with a more chronic illness.[7] Family members of patients with first-episode psychosis experience a range of different feelings and emotions as they attempt to understand and cope with the challenges associated with the psychotic symptoms in their relative.[8] The unpredictable and often severe symptoms of first-episode schizophrenia coupled with the social stigma associated with the disease can contribute to high levels of distress and reduced quality of life among caregivers.[9,10] Studies suggest that family caregivers of this population report health problems such as exhaustion, weakness, fatigue, headache, insomnia, low appetite, and lower food intake.[8] Mental health problems are also common including tension, stress, anxiety, resentment, depression with accompanying feelings of hopelessness and powerlessness, and a sense of entrapment.[7,13] A range of factors have been shown to be associated with distress among family members including behavioral change, the range and severity of psychotic symptoms,[6] lack of knowledge about the disease, diagnostic uncertainty,[7,12,13,14] changes in the roles and the responsibilities in the family structure,[15,10] and social stigma associated with mental illness.[16] However, in order to design a nursing intervention to reduce family distress, understanding how these factors work to influence family distress is crucial. Thus this study aimed to develop and test the model displaying the causal relationships among factors influencing psychological distress in family members caring for a relative with first-episode schizophrenia.

## Conceptual Framework and Literature Review

The conceptual model for this study was built on Lazarus and Folkman's theory of stress, appraisal and coping[17]. Their theory defined stress as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being"[17], Cognitive appraisal is a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being.[17] There is an evaluative process that reflects the individual's interpretation of the situation. Individuals' decisions are based on the cognitive appraisal that can be divided into two forms, primary and secondary appraisals. The coping process involves constantly changing cognitive and behavioral efforts that are made to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. This definition explains that coping as a cognitive process can be distinguished from other perspectives such as coping as a trait, defense mechanism, or automatic adaptive behavior that has been learned. There are two major coping functions: problem-focused coping function, and emotion-focused coping function. Finally adaptation outcomes that have immediate effects are physiological changes, positive or negative feeling, and quality of encounter outcome. The long-term effects focus on somatic health and illness, morale, and social functioning.[17] Stress, cognitive appraisal of stressful situations, and external resources can shape the coping, which has an effect on adaptation outcomes (psychological distress). In this study, stress (seriousness of illness), cognitive appraisal of stressful situations (negative and positive appraisal of the stressful situation), external resources available (perceived social support), and coping were selected to be included in the proposed model.

Research based on stress appraisal and coping models, has been a focus in this field. The literature suggests that caregivers' appraisal of the stressful situations associated with illness would inform which coping strategies the caregivers employ.[18] While caring for a relative with first-episode schizophrenia, family members experienced both negative and positive appraisals of the impact of the illness.[5,19] Previous studies found that caregivers of relatives with more severe negative symptoms had higher negative appraisal. However, some studies found that caregivers' psychological distress was not associated with psychotic symptoms.[7,19,10]

Poor coping in family members was associated with their distress.[7,19] Avoidance coping strategies were found to be associated with psychological distress.[20] Based on the stress and coping model, people will cope better when faced with stressful situations if they have social support.[21] Research findings revealed that there was a negative relationship between social support and psychological distress of family members of a relative with first-episode schizophrenia.[22,23]

To date, a few studies have examined factors - including seriousness of illness, appraisal, coping, and social support - affecting psychological distress in a family dealing with first-episode schizophrenia. No research in Thailand has focused on how appraisal, coping and psychological distress of family members caring for a relative with first episode schizophrenia. To address this gap in the literature, the overall purpose of this study was to develop and test the model displaying the causal relationships among factors including seriousness of illness, perceived social support, appraisal of the stressful situation, coping, influence psychological distress in family members caring for a relative with first-episode schizophrenia. The hypothesized model of this study is presented in Figure 1.

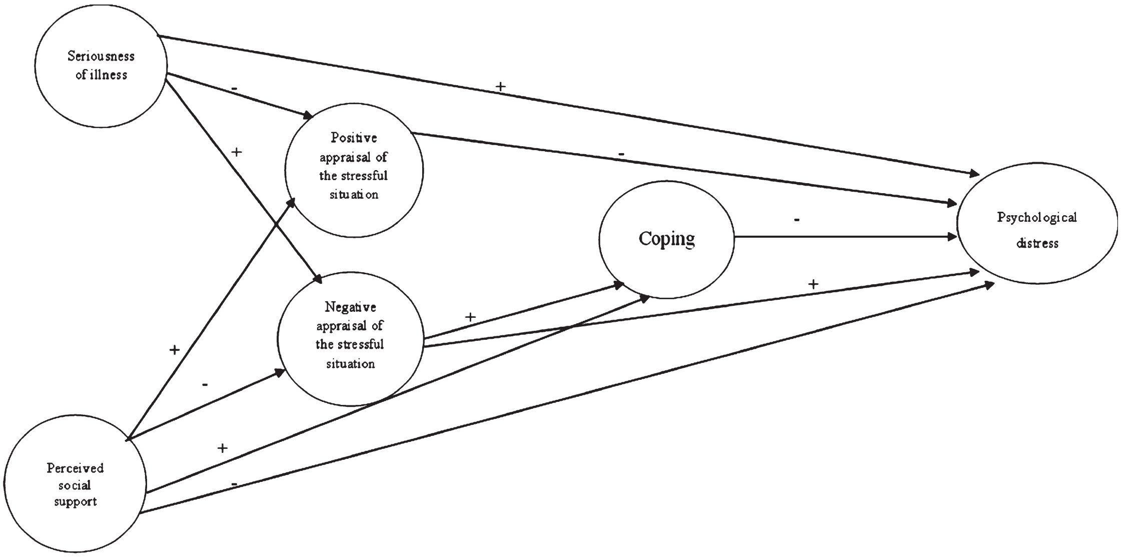


**Figure 1:** A hypothesized model of psychological distress in family members caring for a relative with first-episode schizophrenia

## Methods

**Design:** A descriptive cross-sectional design was used.

**Participants and setting:** Data were collected from family members caring for a relative with first-episode schizophrenia receiving treatment in the outpatient departments of three psychiatric hospitals located in Bangkok and the surrounding vicinity in Thailand. Two hundred and ten family members were recruited using purposive sampling from the three clinical settings. The inclusion criteria were: (1) Being the family member primarily responsible for the care of a relative with first-episode schizophrenia; (2) not receiving a salary or any monetary reward for this care; (3) age ≥ 18; and (4) being able to communicate in the Thai language. A total of 210 participants meet eligibility criteria based on medical chart review. The sample size for this study was determined by Cohen's statistical power analysis,[24] for an alpha of .05, a power of .80 and a medium effect size (.30).[25] Based on these criteria, at least 210 family members were required. Of those, 210 were approached for participation in the study and all agreed to participate.

**Ethical considerations:** Approval to conduct the study was obtained from the Ethics Committee on Human Rights Related to Research Involving Human Subjects of the Faculty of Nursing, Mahidol University, being approval No. IRB-NS2012/143.1510.

**Instruments:** Data were collected through the use of six questionnaires as follows:

**Demographics:** Data were obtained from family members and an individual with first-episode schizophrenia. Information obtained from family members included gender, age, education, marital status, occupation, average family income, relationship with patients, and duration of caregiving. Information obtained from an individual with first-episode schizophrenia comprised age, gender, educational level, marital status, and duration of illness.

**Seriousness of illness:** The Behaviors and Symptom Perception Scale (BSPS) was used to measure the extent to which caregivers' perceived the degree of each patient's behavior and symptom. The scale was developed by Pipatananond.[26] It comprises 27 items using a 4-point Likert scale from 0 (never) to 3 (always). Two examples of items are: "Taking inadequate care of him/herself such as lacking interest in cleaning body and clothes." and "Performing work or studying poorly". Possible scores range from 0-81. Higher scores indicated higher degrees of caregivers' perception of the seriousness of relative's illness. For the current study, the Cronbach's alpha coefficient was 0.81.

**Appraisal of the stressful situation:** The Experience of Caring Inventory (ECI) was used to measure appraisal of stressful situation. ECI was developed by Szmukler and Colleagues[27], to measure the experience of caring for a person suffering from severe mental illnesses such as schizophrenia. The Inventory was developed based on Lazarus and Folkman's[17] stress-appraisal-coping paradigms and comprises 66 items rated on a 5-point Likert scale. The main measures are negative and positive aspects of caregiving (e.g., "Feeling unable to tell anyone about this illness"). The back-translation technique was used to translate this instrument into Thai language. The content of the ECI Thai version was validated by a panel of three experts (psychiatrist, advanced psychiatric nurse, and psychiatric nurse instructor) who confirmed the clarity and appropriateness of the domain. The CVI of the ECI Thai version for this study was 0.87 and Cronbach's alpha coefficient was 0.78.

**Perceived social support:** The Social Support Questionnaire (SSQ) was used to measure social support. The Thai version of SSQ by Pipatananond was used.[26] The SSQ was originally developed by Schaefer, Coyne, and Lazarus.[21] It is a 35-item self-report instrument for measuring emotional, tangible, and information support from 5 resources: family, which includes the spouse, close friends, relatives, co-workers, neighbors, and supervisors, other providers in the community such as traditional doctors and priests, and health care providers. The SSQ asks the degree of support the participants received on a 5-point Likert scale ranging from 0 (not at all) to 4 (extremely). Participants were asked to rate each of the lists of 3 sources of social support including spouse, close friends, and relatives. Possible scores range from 0-84. The higher scores reflected a higher level of perceived social support. For the current study, the Cronbach's alpha coefficient was 0.96.

**Coping:** The Revised Way of Coping Questionnaire (WCQ) was used to measure coping. WCQ was developed by Lazarus and Folkman.[28] It was designed to measure thoughts and actions that individuals used to cope with the stressful encounters of everyday living. The back translation technique was used to translate WCQ into the Central Thai by Sitthimongkol, Pongthavornkamol, and Gasemgitvattana.[29] The WCQ comprises 66 items assessing eight coping sub-scales. The total score comes from only 50 items. The additional 16 items were included to maintain the flow of the questionnaire. The items of the WCQ were rated on a 4-point Likert scale ranging from 0 (does not apply/not used) to 3 (used a great deal). The range of possible scores of problem-focused coping is 0-36 and emotion-focused coping is 0-114, with higher scores indicating more frequently used strategies. Examples of items are: "Just concentrated on what I had to do next-the next step" and "Bargained or compromised to get something positive from the situation". For the current study, the reliability of this instrument was 0.88.

**Psychological distress:** The General Health Questionnaire (GHQ-12) Thai version was used to measure whether study participants had recently experienced symptoms of distress in the last 2-3 weeks.[30] The GHQ-12, originally developed by Goldberg, has been widely used. The GHQ-12 was translated into Thai by Nilchaikovit et al.[30] The scoring method for the GHQ-12, the value for the first two answers is 0 = positive and for the other two 1 = negative. Examples of items are: "Been able to concentrate on whatever you are doing?" and "Lost much sleep over worry?" Possible scores of GHQ range from 0-12, with the scores >2 indicating the presence of psychological distress. For the current study, the reliability of this instrument was 0.85.

**Data Collection Procedures:** Each participant received a verbal explanation of the study, including the duration of the interviews and written details to ensure their informed consent. Written consent was also obtained from both family members and patients. The purpose of the study and data collection procedure was also described to the directors of nursing of each study-site hospital, so as to attain access to potential participants.

**Data analysis:** The significance level was set at an alpha value of .05. Data was analyzed through use of descriptive statistics, Pearson's correlation coefficient and path analysis. Path analysis was used to test the hypothesized model through the Linear Structural Relationship (LISREL) program. The assumptions of path analysis including normality, linearity, homoscedasticity and multicollinearity were tested before data analysis.[31] The results revealed that normality was violated. To deal with non-normality, an estimation method with less restrictive distributional assumptions, robustness maximum likelihood estimation, was used to estimate the strength of relationship and assess how well each hypothesized model fit the empirical data.

## Results

**Participant Characteristics:** Table 1 displays the characteristics of the study sample. The sample comprised 144 females and 66 males, with ages ranging from from 18 to 78 years old. More than one-third of the participants were mothers. The duration of caregiving ranged from 1 month to 24 months, with the mean of 11.70 (SD = 6.99).

**Table 1** Characteristics of Family Members (N=210)

| Characteristics | Number | Percentage |
|---|---|---|
| **Gender** | | |
| Male | 66 | 31.40 |
| Female | 144 | 68.60 |
| **Age** (Year) Range 18 to 78 years Mean = 49.49 SD = 12.10 | | |
| < 40 years | 40 | 19.00 |
| 41 – 60 years | 132 | 62.90 |
| > 60 | 38 | 18.20 |
| **Education Level** | | |
| Elementary school | 36 | 17.10 |
| High school | 119 | 56.70 |
| Diploma | 20 | 9.50 |
| Bachelor degree | 31 | 14.80 |
| No formal education | 4 | 1.90 |
| **Religion** | | |
| Buddhism | 201 | 95.70 |
| Christianity | 1 | 0.50 |
| Muslim | 8 | 3.80 |
| **Marital Status** | | |
| Single | 28 | 13.30 |
| Married | 145 | 69.00 |
| Widowed, divorced or separated | 37 | 17.60 |
| **Occupation** | | |
| Employee | 140 | 66.70 |
| Unemployed | 70 | 33.30 |
| Retirement | 40 | 21.00 |
| Stop working due to taking care of patients | 26 | 12.40 |
| **Family Incomes (baht per month)** Range 3,000 to 47,000 baht per month Mean = 18,652.38 SD = 10,988.82 | | |
| < 20,000 | 164 | 78.10 |
| 20,001-40,000 | 32 | 15.30 |
| 40,001-50,000 | 12 | 5.70 |
| >50,001 | 2 | 1.00 |
| **Number of Members in Family** Range 2 to 8 Mean = 4.04 SD = 1.31 | | |
| 2-3 | 79 | 37.60 |
| 4-5 | 101 | 48.10 |
| 6-7 | 28 | 13.30 |
| >8 | 2 | 1.00 |

**Table 1** Characteristics of Family Members (N=210) (continued)

| Characteristics | Number | Percentage |
|---|---|---|
| **Relationship with person with schizophrenia** | | |
| Husband | 18 | 8.60 |
| Wife | 6 | 2.90 |
| Child | 2 | 1.00 |
| Father | 33 | 15.70 |
| Mother | 92 | 43.80 |
| Other (Grandmother, Grandfather) | 59 | 28.10 |
| **Duration of Caregiving (Months)** Range 1 to 24 months Mean = 11.70, SD = 6.99 | | |
| 1-6 | 67 | 31.90 |
| <6 – 12 | 45 | 21.40 |
| <12-18 | 42 | 20.00 |
| > 18 | 56 | 26.70 |

**Characteristics of participants with first-episode schizophrenia:** The mean age of these participants was 30 years old. More than half were male. Almost three quarters of the participants had graduated from high school. The mean of duration of treatment was 11.7 months.

**Study variables' characteristics:** The family members perceived a low level of seriousness of the illness and higher level of perceived social support. They had less negative and positive appraisal of the stressful situation, and did not use coping strategies very often. The family members reported their psychological distress as being at a low level. Details of each variable is shown in Tables 2 and 3.

*Model testing*: The results revealed that the hypothesized model did not fit the data ($\chi^2$ = 81.03, df = 4, $\chi^2$/ df = 16.24, p = 0.00, RMSEA= 0.305, GFI = 0.88, AGFI= 0.38). Therefore, the model was modified following the modification indices of the LISREL program. The final Model fitted the data ($\chi^2$ = 0.042, *df* =1, $\chi^2/df$ = 0.042, *p*= 0.838, RMSEA = 0.00, GFI= 1.00, AGFI= 1.00). The model explained 33% of psychological distress in family members of a relative with first-episode schizophrenia. The results of model testing are presented in Figure 2 and Table 3.

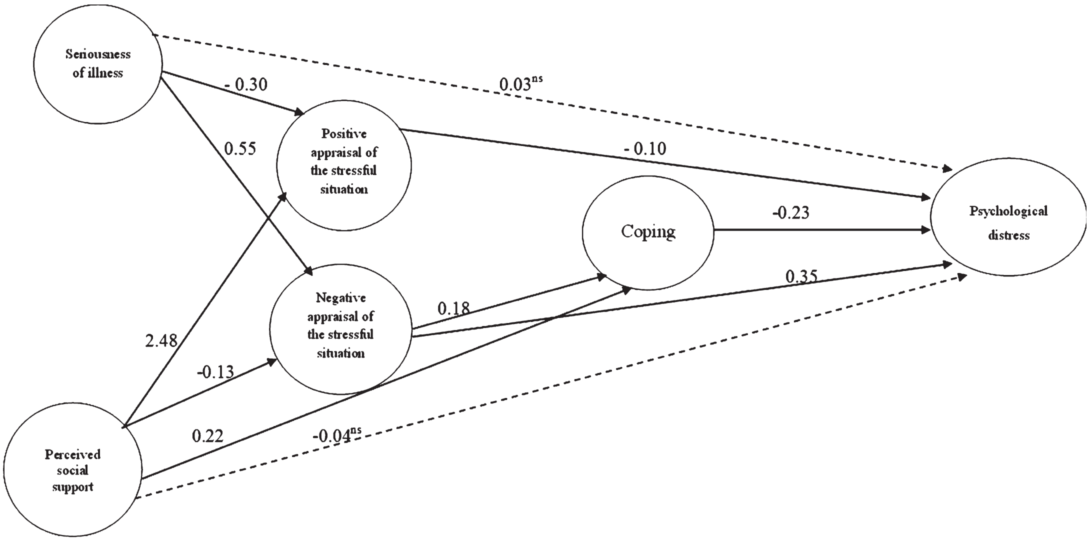
**Table 2** Descriptive Statistics of Independent and Dependent Variables (N = 210)

| Variable | Possible Range | Actual Range | Mean | SD |
|---|---|---|---|---|
| Psychological distress | 0-12 | 0-10 | 2.03 | 2.52 |
| Seriousness of illness | 0-81 | 0-40 | 8.79 | 7.46 |
| Perceived social support | 0-84 | 0-77 | 46.51 | 15.35 |
| Negative appraisal of the stressful situation | 0-208 | 1-90 | 29.49 | 16.51 |
| Positive appraisal of the stressful situation | 0-56 | 2-54 | 22.15 | 10.98 |
| Coping | 0-150 | 11-130 | 66.24 | 27.50 |

**Table 3** Direct Effect, Indirect Effect and Total Effect of Study Variables in the Final Model

| | The Final Model | | |
|---|---|---|---|
| **Causal Variables** | **DE** | **IE** | **TE** |
| SER → PAPP | -0.30 | - | -0.30 |
| SER → NAPP | 0.55 | - | 0.55 |
| SER → COPE | - | 0.10 | 0.10 |
| SER → PSY | 0.03 | 0.20 | 0.23 |
| SS → PAPP | 2.48 | - | 2.48 |
| SS → NAPP | -0.13 | - | -0.13 |
| SS → COPE | 0.22 | -0.03 | 0.19 |
| SS → PSY | -0.04 | -0.34 | -0.38 |
| PAPP → PSY | -0.10 | - | -0.10 |
| NAPP → COPE | 0.18 | - | 0.18 |
| NAPP → PSY | 0.35 | -0.04 | 0.31 |
| COPE → PSY | -0.23 | - | -0.23 |

**Note** *p<.05, **p<.01, ns=not significance
DE=Direct effect, IE=Indirect effect, TE= Total effect,
SER = Seriousness of illness, SS = Perceived social support, NAPP = Negative appraisal of the stressful situation; PAPP = Positive appraisal of the stressful situation, COPE = Coping; PSY = Psychological distress



$\chi^2 = 0.042$, $df = 1$, $\chi^2/df = 0.042$, $p = 0.838$, RMSEA= 0.00, GFI= 1.00, AGFI= 1.00

**Figure 2:** The modified model of psychological distress in family members caring for a relative with first-episode schizophrenia

## Discussion

The results partly supported the use of the Lazarus and Folkman's stress and coping theory in that appraisal, positive and negative perspectives of the stressful situation were a mediator between seriousness of illness and psychological distress. Previous studies found that psychotic symptoms were associated with negative appraisal.[7] As mentioned cognitive appraisal is an evaluative process that reflects the individual's interpretation of the situation.[17] The finding of positive appraisal can be explained by the fact that more than two-thirds of the participants (68.60%) were females who were the mothers or siblings so they had bonding and attachment with their relative. Furthermore, they were Buddhists. The participants, thus, consisted of those who were considerably tolerant to stress as they could rely on their love for their relative as well as the Buddhist principle that taught them to lead their life on the 'middle path' to help them encounter the stressful situation and eventually develop positive appraisal.

The finding that positive appraisal of the stressful situation acts as a mediator between perceived social support and psychological distress indicates that, regardless of the extent of perceived social support of family members, if they had negative appraisal, the level of their psychological distress would remain high. This may be due to the newness or novelty of the stressful situation. According to the concept proposed by Lazarus and Folkman,[17] novelty of situation factors influences appraisal. It is one of the factors that causes stress due to individuals' lack of previous experience. In this study, schizophrenia took place for the first time, and the family members had never had such experience before, so they appraised the situation negatively, which led to their psychological distress. In addition, when the family members had a high level of perceived social support, they would have a positive appraisal of the stressful situation. Findings of the present study also revealed that positive appraisal was important as it could help reduce the psychological distress of family members caring for a relative with first-episode schizophrenia. This study also found that family members employed social support to help them cope with problems and to reduce psychological distress that had taken place. As such, perceived social support acted as a coping resource. This finding reflected the notion that coping acts as a mediator that links perceived social support and psychological distress of family members. Thus, perceived social support enabled the family to understand the stressful situation that had resulted from the psychotic symptoms of their relative. When family members received social support they should be better able to analyze their problems, develop more self-pride, and come up with more appropriate coping strategies, hence more appropriate coping and solutions to problems, which in turn lead to a reduction in psychological distress.

The finding that a negative appraisal of the stressful situation had a positive direct effect on psychological distress, indicating that family members with a high negative appraisal had a higher level of psychological distress. Previous studies have found that family's ability to cope with stress could reduce psychological distress.[20,9,10] According to the Stress, Appraisal, Coping, and Adaptation Theory, the coping process is constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.[17] The coping process is an important mediator of stressful person-environment relationships and their adaptation outcomes.[17] However, the findings of this study did not support this statement. It could be explained that family members' appraisal of the stressful situation had an influence on the mental suffering of family members. This was because family members had to cope with first-episode schizophrenia which was the first mental illness experienced in the family so, as it was a new situation, family members were unable to predict how it would turn out.[7,13,14] Family members may not have received sufficient information and emotional support because they did not dare ask for information or request assistance from others. Previous studies have shown that caregiving families of individuals diagnosed with schizophrenia felt a lack of connectedness with healthcare professionals. The families felt embarrassment and fear of disclosure of the patients' mental condition. It was also possible that they did not know where they could seek resources.[33,34,35,8] As a result, the family appraised the stressful situation negatively, hence there was a direct effect on psychological distress. Thus, it can be assumed that family members who lack resources are unable to apply appropriate coping strategies to reduce their psychological distress.

However, if family members appraised the stressful situation in a positive way, such appraisal would promote close relationships between family members and peers.[36] The family members' acceptance of their own role to provide care, lead to open discussion with other family members. This made family members ready to look for positive aspects amidst the stressful situation that had already taken place. The experience made every member feel that the situation was something that all the family members should be accountable for and should help find solutions. In addition, family members did not feel ashamed to reveal the patients' symptoms to other family members, to seek for necessary information[37,34,16,8] and to refer patients to appropriate care. It has been documented that if patients receive appropriate and continuous treatment within the first two years after the onset of schizophrenia, they would have no symptom expression and become less dependent on other family members. Such a condition of the patients can result in the well-being of the family. Therefore, a positive appraisal could prevent or relieve psychological distress in family members.

## Limitations

This study used convenience sampling to recruit the study participants from only three settings, which were outpatient units of three hospitals located in an urban area, thus generalizability is limited. Next, although the powerful analytical method of path analysis was employed in the present study so as to establish the association among the study variables, this study used a cross-sectional descriptive research design that allowed examination of the causality of a specific time point or a single occasion snapshot of a system of variables. Thus inferring causal relationships among the study variables must be cautious.

## Conclusions and recommendation

This study found that appraisal of the stressful situation and coping acts as a mediator between seriousness of illness and psychological distress and between perceived social support and psychological distress. Therefore, further studies should be conducted to develop a program that promotes positive appraisal and coping skills of family members caring for a relative with first-episode schizophrenia to help reduce their psychological distress. In addition, studies should be carried out to determine the effectiveness of programs to exchange knowledge and learning among family members caring for a relative with first-episode schizophrenia, so that they will have a chance to learn from different perspectives of benefits of utilization of various sources of social support so that they will be able to provide care to an individual with first-schizophrenia in their family efficiently and effectively.

Regarding implications for nursing practice, psychiatric nurses should promote increased knowledge and understanding of family members caring for a relative with first-episode schizophrenia so that they would realize the significance of positive appraisal. Moreover, nurses should offer them the opportunity to learn about positive perspectives of access to and utilization of various sources of social support to ensure effective coping and caregiving for an individual with first episode schizophrenia.

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# ภาวะกดดันทางจิตใจของสมาชิกครอบครัวที่ดูแลญาติที่มีการเจ็บป่วยด้วยโรคจิตเภทครั้งแรก

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**บทคัดย่อ**: วัตถุประสงค์ของการวิจัยครั้งนี้เพื่อหารูปแบบความสัมพันธ์ของปัจจัยที่เกี่ยวข้องกับภาวะกดดันด้านจิตใจของสมาชิกครอบครัวที่ดูแลญาติที่มีการเจ็บป่วยด้วยโรคจิตเภทครั้งแรกโดยใช้ทฤษฎีความเครียดและการเผชิญความเครียดของลาซาลัสและโฟร์คแมน เก็บข้อมูลโดยการสัมภาษณ์ร่วมกับการตอบแบบสอบถามของครอบครัวผู้ดูแลผู้ป่วยโรคจิตเภทที่มีการเจ็บป่วยครั้งแรก 210 คนที่พาผู้ป่วยมาตรวจที่แผนกผู้ป่วยนอกของโรงพยาบาลจิตเวชในกรุงเทพมหานคร และปริมณฑล แบบสอบถามที่ใช้ในการเก็บข้อมูลได้แก่ การรับรู้ความรุนแรงของอาการทางจิต แหล่งสนับสนุนทางสังคม ประสบการณ์การดูแล การเผชิญความเครียด และ แบบสอบถามสุขภาพทั่วไป วิเคราะห์ข้อมูลโดยใช้สถิติขั้นพื้นฐานและการวิเคราะห์เส้นทาง

ผลการศึกษาพบว่าแบบจำลองสุดท้ายที่ปรับให้มีความสอดคล้องกับข้อมูลเชิงประจักษ์ สามารถทำนายความผันแปรของภาวะกดดันด้านจิตใจของสมาชิกครอบครัวที่ดูแลญาติที่มีการเจ็บป่วยด้วยโรคจิตเภทครั้งแรกได้ ร้อยละ 33 โดยพบว่าการประเมินสถานการณ์และการเผชิญความเครียดมีอิทธิพลโดยตรงต่อภาวะกดดันทางจิตใจของครอบครัวผู้ดูแลผู้ป่วยโรคจิตเภท การประเมินสถานการณ์ทั้งทางด้านบวกและด้านลบเป็นตัวกลางที่มีอิทธิพลต่อความสัมพันธ์ระหว่างการรับรู้อาการทางจิต การรับรู้แหล่งสนับสนุนทางสังคม กับภาวะกดดันด้านจิตใจ การเผชิญความเครียดเป็นตัวกลางที่มีอิทธิพลต่อความสัมพันธ์ระหว่างการรับรู้แหล่งสนับสนุนทางสังคมการประเมินสถานการณ์ทางลบกับภาวะกดดันด้านจิตใจ ผลการวิจัยสนับสนุนว่า การประเมินสถานการณ์และการเผชิญความเครียดเป็นปัจจัยสำคัญที่ควรนำมาพิจารณาในการพัฒนาโปรแกรมการพยาบาลเพื่อบรรเทาภาวะกดดันทางจิตใจของสมาชิกครอบครัวที่ดูแลญาติที่มีการเจ็บป่วยด้วยโรคจิตเภทครั้งแรก พยาบาลจิตเวชควรเปิดโอกาสให้มีการแลกเปลี่ยนประสบการณ์ระหว่างสมาชิกครอบครัวของผู้ป่วย เพื่อส่งเสริมการประเมินสถานการณ์ในทางบวกมากขึ้น และใช้วิธีการเผชิญความเครียดที่เหมาะสม

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**คำสำคัญ:** การประเมินสถานการณ์ความเครียด การเผชิญความเครียด สมาชิกครอบครัว การเจ็บป่วยด้วยโรคจิตเภทครั้งแรก การวิเคราะห์เส้นทาง การรับรู้ความรุนแรงของอาการทางจิต การรับรู้แหล่งสนับสนุนทางสังคม ภาวะกดดันด้านจิตใจ ประเทศไทย

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# Effects of the Community–Based Breastfeeding Promotion Program for Working Mothers: A Quasi–experimental Study

*Benjamas Thussanasupap, Punyarat Lapvongwatana, Surintorn Kalampakorn, Diane Lynn Spatz*

**Abstract:** This quasi-experimental study tested the effectiveness of the Community-based Breastfeeding Promotion Program for working mothers. The purposive sample of 52 working mothers living in Chonburi Province, Thailand were divided into comparison and intervention groups. Before implementing the Program, the first 26 dyads were assigned to the comparison group and received the usual activity. Seven months later, the Program was implemented in the district and another 26 dyads were assigned to the intervention groups. The Program was developed from the situation analysis phase, a literature review, and self-efficacy theory. Its effectiveness was measured and breastfeeding knowledge, breastfeeding self-efficacy, perceived breastfeeding support from family, and breastfeeding behavior of the intervention group were significantly higher than in the comparison group. The exclusive breastfeeding duration of the intervention group was significantly longer than the comparison group. Further, 69.23% of the intervention group exclusively breastfed for 6 months and 53.85% continued to breastfeed for 1 year whereas none of the participant of the comparison group exclusively breastfed for 6 months and continued to breastfeed for 1 year. It can be concluded that this Program bridged the gap of breastfeeding support in the health care system to encourage working mothers to continue breastfeeding after hospital discharge.

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**Keywords:** Breastfeeding; Breastfeeding Program; Exclusive Breastfeeding; Self-efficacy theory

## Introduction

"Breastfeeding is the cornerstone of childhood nutrition,"[1] and is a key global public health issue.[2] The advantages of breastfeeding for the family, the economy, national health care costs, employers' costs, and also environmental benefits have been described explicitly.[2-5] The benefits of breastfeeding and the risks of not breastfeeding are well documented.[4-5] An estimated 1.30-1.45 million child deaths could be prevented each year with improved breastfeeding practices.[6] Global efforts have focused on increasing breastfeeding initiation and duration to reach the

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Millennium Development Goal (MDG), which aims to reduce mortality among children under five by two-thirds.[7] Despite the fact that World Health Organization (WHO) and the American Academy of Pediatrics (AAP) have recommended that mothers exclusively breastfeed for 6 months, and continue breastfeeding for at least one year or longer,[4,8] breastfeeding rates in Thailand and worldwide are of concern.

In Thailand, a national target has been set for 30% of infants to be exclusively breastfed for six months. In 2006, a national survey found that only 5.4 % of Thai children were exclusively breastfed at the first six months after birth.[9] Thailand has one of the lowest national rates of exclusive breastfeeding in the world.[10] To address this crisis issue, the Family Bonding with Love Project has been developed to raise awareness of breastfeeding promotion across the country, and also emphasize healthy childhood development.[11] This effort led to an increase in exclusive breastfeeding rate at six months of 12.3 % in 2012; however, still well below the national target.[12]

The influence of maternal employment on breastfeeding is a public health and global health issue. The proportion of working women with young children has increased in several countries of the world. Continuing breastfeeding after returning to work is challenging.[18] The barriers related to early weaning among working mothers include low milk supply, insufficient information on breastmilk expression method and feeding, lack of preparation for breastfeeding after returning to work, struggling to maintain milk supply, regarding breastfeeding support in the workplace, and lack of support from family members.[18,27,39] Some evidence suggested heath care providers in communities should provide breastfeeding support continuously and follow up working mothers especially from 2-4 weeks before returning to work and from 2-4 weeks after returning to work, until 6 months after delivery or longer.[27]

Therefore, the Community-based Breastfeeding Promotion Program (CBPP) for working mothers was developed from the earlier situation analysis phase, literature review, and self-efficacy theory to be beneficial. This study aimed to examine the effectiveness of the CBPP regarding breastfeeding knowledge, breastfeeding self-efficacy, perceived breastfeeding support from family, breastfeeding behavior and breastfeeding duration.

## Review of Literature

Many factors influence women choosing not to breastfeed or stop breastfeeding too early. Research has indicated that "return to work" strongly affects breastfeeding duration - an earlier return to work results in a shorter breastfeeding duration.[16-18] The balance between employment and breastfeeding is often perceived as incompatible; the workplace may not accommodate the needs of breastfeeding mothers.[20] Most workplaces in Thailand do not have breastfeeding facilities to support mothers who have returned to work (inflexible work hours, no clean and safe child care, no breaks to express milk, and no breastfeeding room/space).[21-22]

Besides lack of breastfeeding support in the workplace, breastfeeding is usually promoted only in the short period during hospital stay after delivery. This is the salient gap of breastfeeding support service. Breastfeeding mothers then have to sustain breastfeeding by themselves at home. Thai working mothers plan in advance to stop breastfeeding and bring their baby to be cared for by someone else at another place rather than learn about how to combine breastfeeding and working.[22] Maternal breastfeeding intention and knowledge alone are not sufficient to overcome breastfeeding barriers and difficulties; therefore, efforts at promoting breastfeeding must go beyond the individual level to the family and community levels. Involving family members, community leaders, social support networks, the health sector, and community members in breastfeeding promotion can be justified on the grounds not only of effective breastfeeding behavior change, but also of women's empowerment and community development.[23-24]

The majority of the studies from our literature review revealed significant differences in duration rate of mothers receiving a variety of interventions ranging from prenatal lactation education, in-hospital support, postpartum home visits by professionals, and peer support.[13-15] However, few intervention studies achieved significant differences of the exclusive breastfeeding rate for 6 months. Despite the fact that working mothers are less likely to continue breastfeeding,[16-18] few intervention studies focused only on working mothers. In addition, little research has been directly focused on breastfeeding promotion in the community, especially in Thailand. Breastfeeding promotion must move beyond the short period during hospital stay after delivery to after discharge/home/community environment.[19] Therefore, the CBPP for working mothers may bridge the gap of breastfeeding support following hospital discharge. This Program involved the stakeholders, the community members to collaboratively provide breastfeeding support in the communities.

## Method

***Design:*** A quasi-experimental was employed in this study.

***Ethical Considerations:*** Approval was obtained from the Ethical Committee of Mahidol University, before data collection. Informed consent was obtained from all participants. Participants were given written information explaining the purpose of the study, procedures, confidentiality and anonymity preserved. They were also informed about their right to withdraw from the study at any time without losing any benefits of their health care service.

***Setting and sample:*** The study was conducted in a community unit in a hospital and the mothers' homes in Chonburi Province, Thailand from March 2013 to January 2015. The sample size calculation according to Twisk[25], suggested that when the significant criterion is .05 with the power of 80%, the sample size should comprise at least 20 cases. The principal researcher considered using 26 dyads for the comparison group and 26 dyads for the intervention group as the sample size in this study. The extra 6 participants of each group (30% of the total subjects) were added to offset any missing subjects. All participants meeting the inclusion criteria were included and while others were excluded following the exclusion criteria. For each group, after completely enrolling 26 participants, the researcher stopped immediately to prevent selection bias. The inclusion criteria were: (1) age >18 years, (2) intention to breastfeed their infant, (3) no factor that could significantly interfere with breastfeeding and (4) able to be contacted by telephone. Exclusion criteria were (1) during the study both mother and infant had a complication that could be contraindication to breastfeed the infant and (2) planning to send her infant to be cared for by someone else in another province before 1 month after delivery.

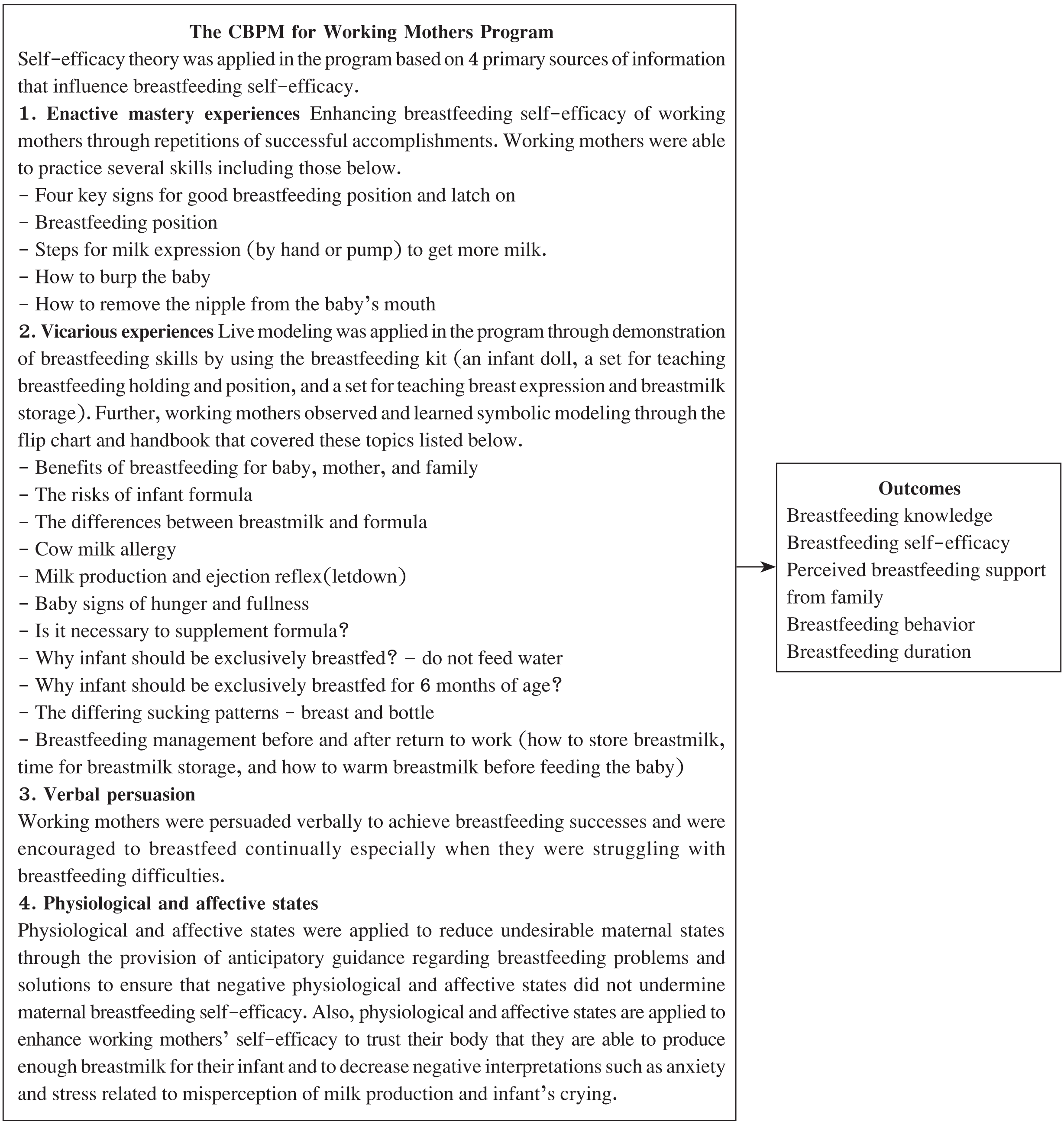
## Procedure and Data Collection:

The results presenting in this study comprise 3 phases: (1) situation analysis, (2) model preparation and development, and (3) model implementation and evaluation. Before implementing the CBPP, the first 26 dyads were assigned to the comparison group and received the usual activities/services of public health nurses. In general, they received single home visits within 1-2 weeks after delivery without specific breastfeeding knowledge/support for working mothers. The researcher recruited the participants following the inclusion criteria and collected data while they visited the community medical unit. Seven months later, the CBPP was implemented in the district (the duration of phase 1 and 2 was 7 months) and another 26 dyads were assigned to the intervention group. Therefore, the comparison and intervention groups were not contaminated.

**The Community-based Breastfeeding Promotion Program (CBPP) for Working Mothers**

***Preparing Working Mother and Family (0 - 7 days after delivery).***

The CBPP (Figure 1), delivered by health volunteers and public health nurses as the breastfeeding support team in the communities, aimed to increase the breastfeeding self-efficacy of working mothers. The Program of 90 minutes was developed based on literature review, information from the situation analysis phase, and the 4 primary sources of information of Bandura's self-efficacy theory including (1) enactive mastery experiences, (2) vicarious experiences, (3) verbal persuasions, and (4) physiological and affective states. The content validity of the program was examined by 5 experts. Contents of the CBPP are listed in Table 1. The breastfeeding support team used the breastfeeding kit including (1) a flip chart for teaching mothers and family, (2) a baby doll, (3) a set for demonstrating how to hold the baby to latch on, (4) an artificial breast, (5) and breastmilk bag and bottle for demonstrating how to keep breastmilk safely and (6) a cup for teaching cup-feeding technique. Further, the participants received a handbook of breastfeeding for working mothers. This handbook included the content of a CBPP for working mothers in brief. All contents and photographs in a handbook were congruent with the program and the flip chart, used by the breastfeeding support team for easy memorization and review.



**The CBPM for Working Mothers Program**

Self-efficacy theory was applied in the program based on 4 primary sources of information that influence breastfeeding self-efficacy.

**1. Enactive mastery experiences** Enhancing breastfeeding self-efficacy of working mothers through repetitions of successful accomplishments. Working mothers were able to practice several skills including those below.

- Four key signs for good breastfeeding position and latch on
- Breastfeeding position
- Steps for milk expression (by hand or pump) to get more milk.
- How to burp the baby
- How to remove the nipple from the baby's mouth

**2. Vicarious experiences** Live modeling was applied in the program through demonstration of breastfeeding skills by using the breastfeeding kit (an infant doll, a set for teaching breastfeeding holding and position, and a set for teaching breast expression and breastmilk storage). Further, working mothers observed and learned symbolic modeling through the flip chart and handbook that covered these topics listed below.

- Benefits of breastfeeding for baby, mother, and family
- The risks of infant formula
- The differences between breastmilk and formula
- Cow milk allergy
- Milk production and ejection reflex(letdown)
- Baby signs of hunger and fullness
- Is it necessary to supplement formula?
- Why infant should be exclusively breastfed? - do not feed water
- Why infant should be exclusively breastfed for 6 months of age?
- The differing sucking patterns - breast and bottle
- Breastfeeding management before and after return to work (how to store breastmilk, time for breastmilk storage, and how to warm breastmilk before feeding the baby)

**3. Verbal persuasion**

Working mothers were persuaded verbally to achieve breastfeeding successes and were encouraged to breastfeed continually especially when they were struggling with breastfeeding difficulties.

**4. Physiological and affective states**

Physiological and affective states were applied to reduce undesirable maternal states through the provision of anticipatory guidance regarding breastfeeding problems and solutions to ensure that negative physiological and affective states did not undermine maternal breastfeeding self-efficacy. Also, physiological and affective states are applied to enhance working mothers' self-efficacy to trust their body that they are able to produce enough breastmilk for their infant and to decrease negative interpretations such as anxiety and stress related to misperception of milk production and infant's crying.

**Outcomes**

Breastfeeding knowledge
Breastfeeding self-efficacy
Perceived breastfeeding support from family
Breastfeeding behavior
Breastfeeding duration

**Figure 1** Conceptualization of the CBPP for Working Mothers Program

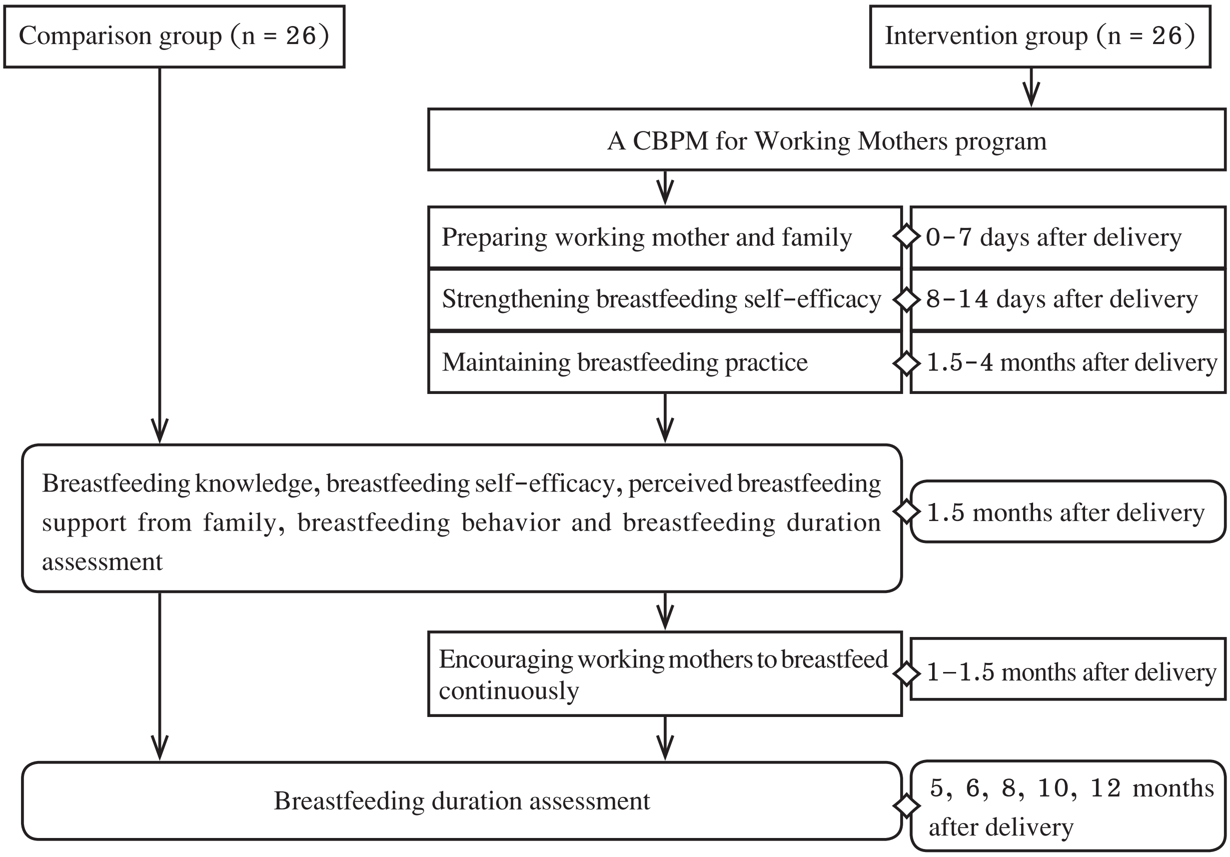


**Figure 2** Flow chart of procedure

***Strengthening Breastfeeding Self-efficacy (8-14 days after delivery).***

The breastfeeding support team visited the working mothers at home aiming to strengthen their breastfeeding self-efficacy by reassuring them on their breastfeeding choice and following up their breastfeeding self-efficacy. The team also discussed with working mothers and families about their breastfeeding plan and management when mothers resumed work, and investigated any breastfeeding difficulties to find solutions with working mothers and family members.

***Maintaining Breastfeeding Practice (1-1.5 months after delivery)***

The breastfeeding support team visited working mothers at home proposing to maintain maternal breastfeeding practice through the involvement of family member roles in breastfeeding support.

***Encouraging Working Mothers to Breastfeed Continuously (1.5-4 months after delivery)***

The breastfeeding support team focused on investigating the breastfeeding difficulties regarding combining breastfeeding and employment and mutually explored strategies to support working mothers to breastfeed continuously with the support of family members.

## Instruments:

The instruments for data collection were 6 questionnaires. Before collecting data, all research instruments were assessed for content validity and language appropriateness by 5 experts included 2 obstetrics and gynecological nursing instructors, 1 public health nursing instructor, 1 public health instructor, and 1 lactation nurse. Then the researcher adjusted the instruments according to the experts' recommendations and comments for improving content validity and language appropriateness before using in this study.

*The Breastfeeding Knowledge of Working Mother Questionnaire* was developed by the researcher from the CBPP for working mother lesson plans and the Handbook of Breastfeeding for Working Mothers. The questionnaire consisted of 30 items. Participants were required to respond to all of the items by answering true or false (answer wrong = 0, answer correct = 1). The score ranged from 0 to 30, with higher scores indicating higher breastfeeding knowledge. Tested for reliability, the Kuder-Richardson Formula 20 was 0.71.

*The Breastfeeding Self-efficacy of Working Mothers Questionnaire* was adapted by the researcher from the Thai version of the Breastfeeding Self-efficacy Scale - Short Form (BSES-SF: Thai version) of Thussanasupap.[35] The original BSES-SF was developed based on the self-efficacy theory to measure maternal breastfeeding confidence by Dennis.[36] For this study, the Questionnaire consisted of 20 self-administered items, arranged in a 5-point Likert-type scale, ranging from 1 (not at all confident) to 5 (very confident) that assessed breastfeeding self-efficacy expectancies among working mothers. The total scores ranged from 20 to 100, with higher scores indicating higher levels of self-efficacy. The Cronbach's alpha coefficient was 0.93.

*The Perceived Breastfeeding Support from Family Questionnaire (PBSF)* was adapted from the PBSF of Suriyakhan.[37] The PBSF consists of 20 self-administered items, arranged in a 4-point Likert-type scale, ranging from 0 (never) to 3 (usually, 6-7 times/week). The total scores range from 0 to 60, with higher scores indicating higher perceived breastfeeding support from family members. The Cronbach's alpha coefficient was 0.85.

*The Breastfeeding Behavior of Working Mothers Questionnaire* was adapted from the questionnaire developed by Rungreang.[38] It consists of 20 items, arranged in a 3-point Likert-type scale, ranging from 0 (never) to 2 (every time). The scores range from 0 to 40, with higher scores indicating higher breastfeeding behavior. The Cronbach's alpha coefficient was 0.90.

*The Breastfeeding Duration Form* was developed by the researcher to record breastfeeding duration and exclusivity of breastfeeding among working mothers. This form was also used to monitor the type of food that infants received including breastmilk, water, formula, and complementary food. A question consisting of 7 choices for selecting only one choice which best explained the feeding that the infant received in the 24 hours before the interview such as breastmilk only or breastmilk and formula.

*The Demographic Data Questionnaire of Working Mothers* elicited basic personal data consisting of 5 main parts (1) personal information (such as age, education level, income), (2) family information and support from family members, (3) the history of pregnancy and delivery, (4) breastfeeding information and experience, and (5) information of employment and workplace.

## Data Analysis:

General characteristics of working mothers were compared and analyzed by grouped t-test, Mann-Whitney U test, and Chi-square test. The Mann-Whitney U test was used to determine any differences between the intervention and comparison groups.

## Results

***The characteristics of the intervention and comparison groups***

Findings showed no significant differences among the demographic characteristics between both groups (Table 1). Similarly, all characteristics of the participants between the 2 groups demonstrated no significant differences (Table 2).

**Table 1** Comparison of the Characteristics of the Participants by Grouped t-Test and Mann-Whitney U test

| Characteristics | Intervention group (n = 26) | | Comparison group (n = 26) | | Mann-Whitney U | $z$ | $p$-value |
|---|---|---|---|---|---|---|---|
| | n | % | n | % | | | |
| **Age (years)** | | | | | | | |
| 20 - 29 | 18 | 69.2 | 14 | 53.9 | | | |
| 30 - 39 | 8 | 30.8 | 11 | 42.3 | | | |
| > 39 | 0 | 0.0 | 1 | 3.8 | | | |
| $\bar{X}$ ± SD; | 26.31 ± 4.70 | | 29.35 ± 5.59 | | 233.5 | 1.921 | 0.555 |
| **Parity** | | | | | | | |
| Primiparous | 13 | 50.0 | 12 | 46.2 | | | |
| Multiparous | | | | | | | |
| 2 children | 10 | 38.5 | 12 | 46.2 | | | |
| 3 children | 3 | 11.5 | 2 | 7.6 | | | |
| $\bar{X}$ ± SD; | 1.62 ± 0.70 | | 1.62 ± 0.64 | | 333.0 | 0.102 | 0.919 |
| **Exclusive breastfeeding duration of last child (days)**$^{(a)}$ | *n = 13* | | *n = 14* | | | | |
| < 30 | 2 | 15.4 | 1 | 7.1 | | | |
| 30 - 59 | 5 | 38.4 | 2 | 14.3 | | | |
| 60 - 119 | 2 | 15.4 | 5 | 35.7 | | | |
| > 120 | 4 | 30.8 | 6 | 42.9 | | | |
| $\bar{X}$ ± SD; | 73.15 ± 62.65 | | 91.57 ± 53.18 | | 0.826$^{(b)}$ | - | 0.417 |
| **Income (baht/month)** | | | | | | | |
| < 10,000 | 7 | 26.9 | 7 | 26.9 | | | |
| 10,000 - 19,999 | 15 | 57.7 | 15 | 57.7 | | | |
| 20,000 – 29,999 | 4 | 15.4 | 2 | 7.7 | | | |
| > 30,000 | 0 | 0.00 | 2 | 7.7 | | | |
| $\bar{X}$ ± SD; | 12,538.46 ± 5,398.01 | | 13,646.15 ± 7,316.68 | | 323.0 | 0.276 | 0.783 |
| **Total of working days/weeks (days)** | | | | | | | |
| 5 | 2 | 7.7 | 4 | 15.4 | | | |
| 6 | 14 | 53.8 | 15 | 57.7 | | | |
| 7 | 10 | 38.5 | 7 | 26.9 | | | |
| $\bar{X}$ ± SD; | 6.31 ± 0.62 | | 6.12 ± 0.65 | | 286.0 | 1.070 | 0.284 |
| **Total working hours/days (hours)** | | | | | | | |
| 8 | 1 | 3.9 | 5 | 19.2 | | | |
| 9 | 16 | 61.5 | 14 | 53.9 | | | |
| 10 | 3 | 11.5 | 3 | 11.6 | | | |
| 11 | 0 | 0.0 | 1 | 3.8 | | | |
| 12 | 3 | 11.6 | 0 | 0.0 | | | |
| 13 | 0 | 0.0 | 1 | 3.8 | | | |
| 14 | 3 | 11.5 | 2 | 7.7 | | | |
| $\bar{X}$ ± SD; | 10.00 ± 1.79 | | 9.54 ± 1.68 | | 276.0 | 1.265 | 0.206 |
| **Break time duration/time (minutes)** | | | | | | | |
| 0 (no break) | 22 | 84.6 | 18 | 69.2 | | | |
| 10 | 4 | 15.4 | 8 | 30.8 | | | |
| $\bar{X}$ ± SD; | 1.54 ± 3.68 | | 3.08 ± 4.71 | | 286.0 | 1.304 | 0.192 |

a = grouped t-test, b = $t$-value

**Table 2** Comparison of the Characteristics of the Participants by Chi-Square

| Characteristics | Intervention group (n = 26) |  | Comparison group (n = 26) |  | $\chi^2$ | *p*-value |
|---|---|---|---|---|---|---|
|  | n | % | n | % |  |  |
| **Educational level** |  |  |  |  |  |  |
| Primary school | 2 | 7.7 | 1 | 3.8 | 4.092 | 0.536 |
| Junior high school | 5 | 19.2 | 10 | 38.5 |  |  |
| Senior high school | 8 | 30.8 | 5 | 19.2 |  |  |
| Primary vocational certificate | 1 | 3.8 | 1 | 3.8 |  |  |
| High vocational certificate | 4 | 15.4 | 6 | 23.1 |  |  |
| Bachelor degree | 6 | 23.1 | 3 | 11.5 |  |  |
| **Type of delivery** |  |  |  |  |  |  |
| Normal | 15 | 57.7 | 15 | 57.7 | 1.048 | 0.592 |
| Vacuum | 1 | 3.8 | 0 | 0.00 |  |  |
| Cesarean section | 10 | 38.5 | 11 | 42.3 |  |  |
| **Time to first start breastfeeding** |  |  |  |  |  |  |
| Within 30 minutes after delivery | 9 | 34.6 | 14 | 53.8 | 1.950 | 0.377 |
| Within 60 minutes after delivery | 7 | 26.9 | 5 | 19.2 |  |  |
| Longer than 1 hour after birth | 10 | 38.5 | 7 | 26.9 |  |  |
| **Type of feeding during hospital stay** |  |  |  |  |  |  |
| Exclusive breastfeeding | 15 | 57.7 | 14 | 53.8 | 0.078 | 0.780 |
| Mixed feeding | 11 | 42.3 | 12 | 46.2 |  |  |
| **Occupation** |  |  |  |  |  |  |
| Formal sector | 16 | 61.5 | 18 | 69.2 | 0.340 | 0.560 |
| Informal sector | 10 | 38.5 | 8 | 30.8 |  |  |
| **Working characteristic** |  |  |  |  |  |  |
| Formal fulltime | 22 | 84.6 | 17 | 65.4 | 2.564 | 0.109 |
| Shift work | 4 | 15.4 | 9 | 34.6 |  |  |

**1. Breastfeeding knowledge of working mothers**

The breastfeeding knowledge of working mothers score of the intervention group (mean rank = 39.50) was significantly higher than the comparison group (mean rank = 13.50), $U = 351.0$, $z = 6.381$, $p < .001$.

**2. Breastfeeding self-efficacy of working mothers**

The breastfeeding self-efficacy of working mothers score of the intervention group (mean rank = 38.87) was significantly higher than the comparison group (mean rank = 14.13), $U = 16.5$, $z = 5.907$, $p < .001$.

**3. Perceived breastfeeding support from family**

The perceived breastfeeding support from family score of the intervention group (mean rank = 35.62) was significantly higher than the comparison group (mean rank = 17.38), $U = 101.0$, $z = 4.349$, $p < .001$.

**4. Breastfeeding behavior of working mothers**

The breastfeeding behavior of working mothers score of the intervention group (mean rank = 36.65) was significantly higher than the comparison group (mean rank = 16.35), $U = 74.0$, $z = 4.838$, $p < .001$.

### 5. Breastfeeding duration

The exclusive breastfeeding duration of the intervention group (mean rank = 38.96) was significantly longer than the comparison group (mean rank = 14.04), $U = 14.0$, $z = 6.059$, $p < .001$. As shown in Table 5, 18 participants (69.23%) of the intervention group exclusively breastfed for 6 months and 14 participants (53.85 %) continued to breastfeed at 1 year whereas none of the participants of the comparison group exclusively breastfed for 6 months and continued to breastfeed for 1 year.

**Table 3** Comparison of the Outcomes Between the Intervention and Comparison Groups by Mann-Whitney U Test

| The outcomes | Intervention group (n = 26) | | Comparison group (n = 26) | | Mann-Whitney U | $z$ | $p$-value |
|---|---|---|---|---|---|---|---|
| | $\overline{X}$ | SD | $\overline{X}$ | SD | | | |
| 1. Breastfeeding knowledge of working mother | 29.77 | 0.43 | 21.85 | 3.22 | | | |
| Mean Rank | 39.50 | | 13.50 | | 351.0 | 6.381 | 0.000*** |
| Range | 29 - 30 | | 14 - 26 | | | | |
| 2. Breastfeeding self-efficacy of working mother | 94.77 | 6.61 | 65.85 | 16.05 | | | |
| Mean Rank | 38.87 | | 14.13 | | 16.5 | 5.907 | 0.000*** |
| Range | 80 - 100 | | 30 - 92 | | | | |
| 3. Perceived breastfeeding support from family | 71.73 | 9.06 | 58.42 | 8.73 | | | |
| Mean Rank | 35.62 | | 17.38 | | 101.0 | 4.349 | 0.000*** |
| Range | 50 - 80 | | 37 - 73 | | | | |
| 4. Breastfeeding behavior of working mother | 33.31 | 7.97 | 18.2 | 9.75 | | | |
| Mean Rank | 36.65 | | 16.35 | | 74.0 | 4.838 | 0.000*** |
| Range | 14 - 40 | | 1 - 38 | | | | |
| 5. Exclusive breastfeeding duration | 154.04 | 44.16 | 29.88 | 25.14 | | | |
| Mean Rank | 38.96 | | 14.04 | | 14.0 | 6.059 | 0.000*** |
| Range | 51 - 180 | | 0 - 75 | | | | |

*** $p < .001$

**Table 4** Comparison of the Exclusive Breastfeeding for 6 Months and Continued Breastfeeding for 1 Year Between the Intervention and Comparison Groups

| The outcome | Intervention group (n = 26) | | Comparison group (n = 26) | |
|---|---|---|---|---|
| | n | % | n | % |
| Exclusive breastfeeding for 6 months | 18 | 69.23 | 0 | 0.0 |
| Continued breastfeeding for 1 year | 14 | 53.85 | 0 | 0.0 |

## Discussion

After hospital discharge, many mothers experience difficulty finding and receiving breastfeeding support: they may need continued breastfeeding support from health professionals - not only from their family members.[2]

Further, pressures of employment influence working mothers to reduce or stop breastfeeding too early.[16-21] Continuing to breastfeed after returning to work presents significant challenges for working mothers, and they often face several difficulties.[15] This study revealed that the effect of CBPP could improve several outcomes such as breastfeeding knowledge, breastfeeding self-efficacy, perceived breastfeeding support from family members, breastfeeding behavior, and breastfeeding duration that are discussed below.

***Breastfeeding knowledge of working mothers***

The finding of this study revealed that the breastfeeding knowledge scores of the intervention group was significantly higher than the comparison group. Lack of breastfeeding knowledge regarding breastfeeding preparation before returning to work, the method of breastmilk expression, and breastfeeding management during work was identified as the barrier to successful exclusive breastfeeding among working mothers.[27] Breastfeeding knowledge and skills were important for working mothers to continue breastfeeding after returning to work. An explanation of this study's results indicate that the CBPP for working mothers (Figure 1) including the necessary breastfeeding knowledge for working mothers may have increased breastfeeding knowledge of working mothers. The breastfeeding kit, flip chart, and handbook were useful for the mothers to understand more easily.

***Breastfeeding self-efficacy of working mothers***

The breastfeeding self-efficacy scores of the intervention group was significantly higher than the comparison group. This led to the conclusion that the CBPP had a positive effect on the breastfeeding self-efficacy of working mothers. Mothers' breastfeeding self-efficacy has a direct influence on performance accomplishments of breastfeeding. The significance of maternal breastfeeding self-efficacy has been demonstrated frequently to be predictive of breastfeeding outcomes. It constitutes a salient variable in breastfeeding performance as it predicts (a) whether a mother chooses to breastfeed, (b) how much effort she will expend if she does, (c) whether she will have self-enhancing or self-defeating thought patterns, and (d) how she will emotionally respond to breastfeeding difficulties.[28] Breastfeeding self-efficacy is influenced by 4 main sources of information including enactive mastery experiences, vicarious experiences, verbal persuasion, and physiological and affective states. As such, the intervention of this study was devised based on self-efficacy theory and was expected to increase mothers' confidence in their ability to breastfeed by adjusting 4 main sources of self-efficacy information in the Program.

Further, the provision anticipatory guidance in the Program and the breastfeeding handbook were very helpful when the mothers had breastfeeding problems or concerns. For example, common problems including nipple pain, cracked nipples, breast engorgement, pain, and insufficient milk supply were frequently cited as breastfeeding problems after hospital discharge and mothers who faced these problems were less likely to continue to breastfeed. The Program and the breastfeeding handbook provided guidelines to prevent and to solve such problems.

***Perceived breastfeeding support from family***

The perceived breastfeeding support from family scores of the intervention group were significantly higher than the comparison group. We believe that engaging family members to learn about the breastfeeding program encouraged the family to provide breastfeeding support for the working mothers. Family members play a vital role in breastfeeding support[29] and influence breastfeeding practice. [30] Komkham[31] reported that although Thai mothers received appropriate advice from healthcare professionals and mothers desired to follow those recommendations, they may eventually give formula or supplementary food to their infant because of the influence of their own mother. Moreover, the infant's grandmother and the father of the infant have been identified as crucial roles in influencing mothers in their intention to continue to breastfeed after returning to work.[32] In this study, family members participated in the program to receive all breastfeeding information as working mothers received and also participated in planning and managing breastfeeding when mothers resumed work. Family members cooperated with working mothers and the breastfeeding support team to explore strategies that encouraged working mothers to breastfeed their infant continuously after returning to work with the support of family members.

***Breastfeeding behavior of working mothers***

The breastfeeding behavior of working mothers' scores of the intervention group was significantly higher than the comparison group. The qualitative study of Tangsuksan & Ratinthorn[27] revealed that the hospital did not provide enough breastfeeding information for working mothers such as the details of how to store, and to handle expressed milk, and the breastfeeding management plan for working mothers. Lacking breastfeeding information that was needed to understand and to practice in daily life led working mothers to not practice breastfeeding continuously after returning work, resulting in insufficient breastmilk problems.[27] In this study, 0-7 days after delivery, participants received a CBPP which provided full breastfeeding information about hand expression and pumping techniques, storing and handling expressed milk, milk storage and breastfeeding management, and preparation before returning to work. They directly experienced how to express breastmilk by hand and how to use the pump correctly by practice and rehearsal. Further, 8-14 days after delivery, they were reassured and followed up regarding their breastfeeding practice by the breastfeeding support team. From 1 - 1.5 months after delivery, they were followed up to maintain breastfeeding practice and reassured that they had already prepared the infant's caregiver to provide breastmilk while they worked. From 1.5 - 4 months after delivery, they were followed up to encourage their breastfeeding practice continuously after returning to work. Therefore, working mothers were able to maintain breastfeeding behavior after they returned to work. In this study, 2 infants had hyperbilirubinemia and needed phototherapy treatment. However, working mothers still practiced exclusive breastfeeding even when the hospital did not allow mothers to take the infants out of the phototherapy incubator because they learned from the breastfeeding support team that the infant with hyperbilirubinemia needed breastmilk rather than formula to increase the releasing of bilirubin.

***Breastfeeding duration***

The current study found that the exclusive breastfeeding duration at 6 months of the intervention group was significantly longer than the comparison group. Further, 18 participants (69.23%) of the intervention group exclusively breastfed for 6 months and 14 participants (53.85 %) continued to breastfeed for 1 year whereas none of the comparison group exclusively breastfed for 6 months and continued to breastfeed for 1 year. This led to the conclusion that the CBPP had an effect on the breastfeeding duration of working mothers.

The results of this study could be used to explain that the CBPP, that increased breastfeeding knowledge, breastfeeding self-efficacy, perceived breastfeeding support from family and breastfeeding behavior, resulted in the exclusive breastfeeding rate for 6 months and the breastfeeding rate for 1 year. The prospective survey of Blyth et al.[33] reported that low self-efficacy was related to bottle-feeding at 1 week postpartum ($p <.001$). Mothers with higher breastfeeding self-efficacy scores were significantly more likely to continue to breastfeed to four months postpartum and did so exclusively more than mothers with lower scores ($p <.001$). This is congruent with a randomized controlled trial of Olenick,[34] demonstrating that breastfeeding confidence was associated with higher rates of full breastfeeding at weeks 1, 6, and 12. High breastfeeding confidence was associated with longer mean duration of breastfeeding (10 weeks) versus lower scores (5 weeks) ($p < .0001$).

## Limitations

The working mothers who participated in this study stayed with their infants. Therefore, working mothers who have to send their infants to stay in their hometown may need extra support and strategies.

## Conclusion and Recommendation

The finding showed that the CBPP was an effective program to improve breastfeeding knowledge, breastfeeding self-efficacy, perceived breastfeeding support from family, breastfeeding behavior, and breastfeeding duration of working mothers. Both public health nurses and health volunteers as the breastfeeding support team in Thailand work almost exclusively in community settings, and thus, serve as the connector between the birth hospital and the community to provide breastfeeding support for working mothers. This model should be implemented in other areas to increase the exclusive breastfeeding rate of mothers, resulting in increasing the exclusive breastfeeding rate of the country. Future research is needed to explore strategies for the working mothers who had to separate from their infants after returning to work.

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# ผลของโปรแกรมส่งเสริมการเลี้ยงลูกด้วยนมแม่ในชุมชนสำหรับแม่ทำงาน: การวิจัยกึ่งทดลอง

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**บทคัดย่อ:** การวิจัยกึ่งทดลองเพื่อทดสอบผลของโปรแกรมส่งเสริมการเลี้ยงลูกด้วยนมแม่ในชุมชนสำหรับแม่ทำงาน กลุ่มตัวอย่างประกอบด้วยแม่ทำงานที่อาศัยอยู่ในอำเภอบ้านบึง จังหวัดชลบุรี จำนวนทั้งหมด 52 ราย ผู้วิจัยกลุ่มตัวอย่างออกเป็นกลุ่มควบคุมและกลุ่มทดลอง ก่อนหน้าที่จะดำเนินการตามโปรแกรมส่งเสริมการเลี้ยงลูกด้วยนมแม่ในชุมชนสำหรับแม่ทำงาน ผู้ร่วมวิจัย 26 รายแรกถูกจัดอยู่ในกลุ่มควบคุมและได้รับกิจกรรมตามปกติ หลังจากนั้น 7 เดือนต่อมา จึงดำเนินการตามโปรแกรมส่งเสริมการเลี้ยงลูกด้วยนมแม่ในชุมชนสำหรับแม่ทำงานในอำเภอบ้านบึง และผู้ร่วมวิจัยอีก 26 รายต่อมาถูกจัดให้อยู่ในกลุ่มทดลอง รูปแบบโปรแกรมดังกล่าวพัฒนามาจากข้อมูลที่รวบรวมได้จากระยะวิเคราะห์สถานการณ์ก่อนหน้านี้ การทบทวนวรรณกรรม และทฤษฎีสมรรถนะแห่งตน

ผลการวัดประสิทธิภาพของโปรแกรมส่งเสริมการเลี้ยงลูกด้วยนมแม่ในชุมชนสำหรับแม่ทำงานพบว่า กลุ่มแม่ทำงานในกลุ่มทดลองมีคะแนนเหล่านี้สูงขึ้นอย่างมีนัยสำคัญทางสถิติเมื่อเปรียบเทียบกับกลุ่มควบคุม ($p < .001$) ได้แก่ (1) ความรู้เกี่ยวกับการเลี้ยงลูกด้วยนมแม่ (2) สมรรถนะแห่งตนในการให้นมบุตร (3) การรับรู้เกี่ยวกับการได้รับการสนับสนุนส่งเสริมเรื่องการเลี้ยงลูกด้วยนมแม่จากครอบครัว และ (4) พฤติกรรมการเลี้ยงลูกด้วยนมแม่ ระยะเวลาการเลี้ยงลูกด้วยนมแม่อย่างเดียวในกลุ่มทดลองยาวนานกว่ากลุ่มควบคุมอย่างมีนัยสำคัญทางสถิติ mean rank = 14.04, $U = 14.0$, $z = 6.059$, $p < .001$ นอกจากนี้พบว่า ผู้ร่วมวิจัยในกลุ่มทดลอง จำนวน 18 ราย (69.23%) สามารถเลี้ยงลูกด้วยนมแม่อย่างเดียวนาน 6 เดือน และมี 14 ราย (53.85 %) ที่สามารถเลี้ยงลูกด้วยนมแม่ต่อเนื่องได้ถึง 1 ปี ในขณะที่ไม่มีผู้ร่วมวิจัยรายใดในกลุ่มควบคุมที่สามารถเลี้ยงลูกด้วยนมแม่อย่างเดียวนาน 6 เดือน และสามารถเลี้ยงลูกด้วยนมแม่ต่อเนื่องได้ถึง 1 ปี จากผลการทดลองจึงสรุปได้ว่า โปรแกรมส่งเสริมการเลี้ยงลูกด้วยนมแม่ในชุมชนสำหรับแม่ทำงานนี้สามารถช่วยประสานช่องว่างของระบบการดูแลสุขภาพในเรื่องของการสนับสนุนการเลี้ยงลูกด้วยนมแม่ โดยส่งเสริมให้แม่ทำงานสามารถเลี้ยงลูกด้วยนมแม่ได้อย่างต่อเนื่องภายหลังออกจากโรงพยาบาล

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**คำสำคัญ:** โปรแกรมส่งเสริมการเลี้ยงลูกด้วยนมแม่ แม่ทำงาน ทฤษฎีสมรรถนะแห่งตน

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# Influences of Mothers' Stressors, Maternal Depression and Parenting on Conduct Problems among Thai Preschoolers

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**Abstract:** The purpose of this study was to examine the influence of mothers' stressors, maternal depression, and disrupted parenting on Thai preschoolers' conduct problems. One hundred ninety-eight mother-child dyads were recruited from 8 schools under the supervision of Bangkok Metropolitan Administration. Data were collected from October 2012 to May 2013. There were two main steps in the data collecting process: screening and collecting data. The participants were screened based on the children's conduct-problems score. Data were collected via eight self-administered questionnaires; 1) Demographic data form, 2) Strength and Difficulties Questionnaire, 3) Everyday Stressors Index, 4) Locke-Wallace Marital Adjustment Test, 5) Difficult Child Questionnaire, 6) Center for Epidemiologic Studies Depression Scale, 7) Parenting Scale, and 8) Eyberg Child Behavior Inventory and then analyzed using path analysis.

There were significant indirect effects of the mothers' stressors (i.e. daily hassles, marital satisfaction, and child difficult temperament) on child conduct problems through maternal depression and disrupted parenting. In addition, maternal depression and disrupted parenting independently affected child conduct problems. Thus interventions to reduce maternal depression and to improve effective parenting are essential to reduce conduct problems in preschool-aged children.

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**Keywords:** Conduct problems, Maternal depression, Parenting, Preschooler, Thailand

## Introduction

Childhood conduct problems refer to a broad spectrum of oppositional or antisocial behaviors in childhood such as delinquency, disobedience, lying, fighting, and stealing.[1] Conduct problems represent the most common mental health disorders of childhood.[1] In the United States approximately 1.4% of children aged 3-5 years have received a diagnosis of conduct disorders.[2] Prevalence rates for conduct problems among preschoolers are unavailable in Thailand; however, among children and adolescents aged 5-16 years of age the reported incidence of conduct problems is 18.3%.[3] Untreated, childhood conduct problems

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may result in negative short and long-term psycho-social sequelae for individual children and their families.[1,4-6] Persistence of childhood conduct problems can increase risks for early adult depression.[4] A 25-year longitudinal study in New Zealand examining the association between conduct problems at ages 7-9 years and later adjustment in young adulthood aged 21-25 years showed that individuals with a history of childhood conduct problems were 1.5-1.9 times more likely to have committed a crime, engaged in risky substance use and sexual activities, and had poor mental health outcomes compared to those individuals without such histories.[5] Further, the follow-up studies from years 7 through years 13 showed that additional public costs involving educational, health, and social services for children with conduct disorders were almost $70,000 higher than those for the children with no problems.[6] Given the far-reaching personal, family, and societal costs, childhood conduct problems are a significant public health concern. Additional research is needed in Thailand to better understand the risk and protective factors for the development of childhood conduct problems and to inform the development of early intervention and prevention approaches.

## Conceptual Framework and Literature Review

The conceptual model of how stressors affect parenting attitudes and parent-child interactions proposed by Webster-Stratton[7] was used to guide the development of the current study. According to Webster-Stratton,[7] various risk factors related to child conduct problems are explained in terms of family stressors (i.e. extra-familial, inter-parental and child stressors). All these stressors could affect child conduct problems through maternal depression and disrupted parenting. Mothers confronting multiple sources of family stressors require more coping skills. If the mothers cannot cope with their stressors effectively, these stressors may disrupt the quality of parenting. In the Webster-Stratton model,[7] various factors decrease mothers' coping skills, including parents' psychological or substance problems and social isolation. Maternal depression has been identified for its strong negative effect on the quality of parenting.[8] Influenced by depressive symptoms like pessimism, irritability, indecisiveness as well as loss of their drive and interest,[9] depressive symptoms can decrease mothers' ability to cope with their stressors and to provide their child with optimal parenting.[10] Depressed mothers are more likely to deal with their stressor in unconstructive ways as well as have negative perception of and interactions with their child. Thus, the children, whose mothers have high levels of stress, depression and disrupted parenting, have a higher risk to develop conduct problems.

The extant literature identifies a myriad of risk factors associated with childhood conduct problems.[1] These risk factors can be categorized into three main groups: child factors such as temperament,[11] family factors such as daily hassles,[12] marital problems,[13] maternal depression,[10] parenting practices,[14] and contextual factors such as neighborhood risks, economic disadvantage.[10] Family risk factors have been accepted as the most proximal determinants of early conduct problems, and several studies in Western world consistently indicated the mothers' effects on childhood conduct problems.[10,15] The mothers' stressors, daily hassles, marital problems and difficult child temperament, have been confirmed for their significant effects on both maternal depression[16-17] and disrupted parenting.[18-19] In Thailand as well as in other countries around the world, women play a central role in child rearing. In comparing maternal and paternal effects on the risk for child behavior problems, this has been shown to be higher if mothers, rather than fathers, are experiencing dysfunction.[8,20] For example, Ramchandani and others[20] found that children were at 2.05 times the risk for conduct problems if their mothers had depression and 1.84 times the risk for such problems if their fathers had depression. Disrupted parenting practices are the hypothesized mechanism by which maternal depression influences child conduct problems.

There is no research reporting how mothers' stressors influence conduct problems among Thai preschoolers. Since differences in cultural beliefs and norms can result in variations in maternal adjustment, parenting approaches and child outcomes,[21] additional research is warranted to replicate these findings in the Thai context. Moreover, in Thailand, existing tools used to identify children with conduct problems are available. However, the prevention or intervention of conduct problems among preschoolers in Thailand remains inadequately developed due to deficient understanding of the pathway of early development of conduct problems among Thai preschoolers. To fill the gap, the overall purpose of this study was to examine the causal relationships among mothers' stressors, maternal depression, disrupted parenting, and preschoolers' conduct problems in the context of Thai culture. According to Webster-Stratton,[7] three variables including daily hassles (extra-familial stressors), marital dissatisfaction (inter-parental stressors), and child temperament (child stressors) were identified as mothers' stressors. Also, maternal depression and disrupted parenting were selected as mediators in the relationship between mothers' stressors and preschoolers' conduct problems. The hypothesized model depicting the causal relationships among variables is shown in Figure 1.

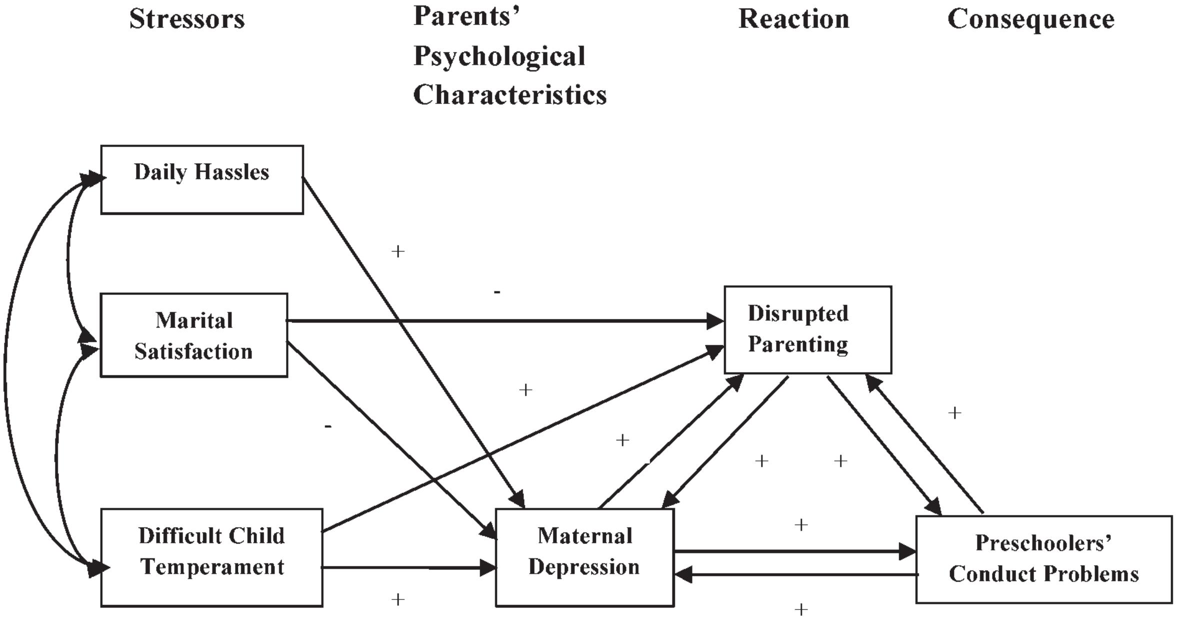


**Figure 1** Conceptual framework of the current study

## Methods

**Design:** The current study was cross-sectional in design.

**Participants and Setting:** Data were collected from the mothers of children who showed signs of conduct problems in school-based settings. Mother-child dyads were recruited from eight schools under the supervision of Bangkok Metropolitan Administration (BMA). With government support, the schools under BMA aim to enhance the opportunity for elementary education for Thai children living in Bangkok.

Because it is a free educational service, students in the BMA schools are mostly low-income children who are characterized as having a higher risk of child conduct problems.[10] There were 428 schools under BMA located in six geographical areas of Bangkok eligible for inclusion. Multistage cluster sampling method was used in the current study and schools were selected.

The calculation of the sample size was based on structural equation modeling (SEM). A minimum sample size in SEM required that the ratio of the sample size to the number of estimated parameters ratio be 10:1.[22] In this study, there were 17 estimated parameters, therefore, the calculated sample size was equal to 170. Then, the researcher oversampled 15% higher than the calculated sample size in anticipation of missing data.[23] Finally, the approximate sample size for the current study was 196 (170 x 15)/100 = 195.5).

There were 198 mother-child dyads enrolled in this study. Both the mothers and their children needed to meet the following inclusion criteria: for the preschoolers: 1) having no problems of physical disability or history of developmental disorder, 2) not taking medication for behavioral problems, and 3) obtaining scores of 4 or higher on the conduct problem subscale of the Strength and Difficulties Questionnaire (SDQ)[24] rated by either mothers or class teachers. For the mothers, the inclusion criteria were: 1) being a primary caregiver of the child, 2) having an intact family, 3) not receiving treatment for psychological problems and 4) being able to read and communicate in Thai.

**Ethical considerations**: Approval to conduct the study was obtained from the Ethics Committee on Human Rights Related to Research Involving Human Subjects of the Faculty of Nursing, Mahidol University (No. IRB-NS2012/139.2409), and from the BMA. Invitation letters were distributed to all mothers of preschoolers in each selected school. The mothers who were willing to participate were provided with sealed envelopes containing informed consent and screening questionnaires. The researcher approached eligible mothers individually, invited them to participate in the study. The mothers were informed that their participation was voluntary and assured of confidentially and anonymity in the use of data. Written informed consent was obtained from everyone.

**Instruments**: Eight self-administered questionnaires were used to obtain data: the Demographic data form (DDF); the Strength and Difficulties Questionnaire (SDQ);[24] Everyday Stressors Index (ESI);[25] Locke-Wallace Marital Adjustment Test (L-WMAT);[26] Difficult Child Questionnaire (DCQ); Center for Epidemiologic Studies Depression Scale (CES-D scale);[27] Parenting Scale (PS);[28] and Eyberg Child Behavior Inventory (ECBI).[29] The ESI, the PS, and the ECBI were translated into Thai by using the back-translation technique with permission from the instrument developers.[25,29-30] The Thai version of the SDQ[31], L-WMAT[32] and CES-D scale[33] were used with the permissions.

**The DDF** was used to obtain the standard demographic information of the mother and the child and to screen the mother-child dyads who met the inclusion criteria, for the preschoolers, information included gender, age, and medical history, for the mothers, information included age, marital status, number of children, education level, income, financial status and medical history.

**The SDQ**, a questionnaire for brief behavioral screening, was developed by Goodman.[24] It was used to identify children who show signs of conduct problems. The 25-item of the SDQ is divided into five subscales including hyperactivity, conduct, peer and emotional problems and pro-social behavior. There are two versions of the SDQ: parents and teachers. The items in both versions ask the parents and teachers with the same statements. The children's behaviors are assessed on 3-point rating scales ranging from 0 (not true), to 1 (somewhat true) and 2 (certainly true).

Each subscale contains five items, thus the total possible score of each subscale ranging from 0 to 10 and the score ≥ 4 are in abnormal range indicating higher risk of conduct problems. Children obtaining scores on conduct problems subscale ≥ 4, from either mothers or teachers, were recruited in this study. An example of item in conduct problems subscale is: "Often loses temper". The Cronbach's alphas in this study for the mothers' and teachers' rates were .62 and .74 respectively.

**The ESI:** is a 20-item questionnaire, developed by Hall[25] and used to measure daily hassles. The mothers rated how each problem bothered them from day to day on a 4-point scale ranging from 1 (not bothered at all) to 4 (bothered a great deal). The total possible scores range from 20 to 80, where higher scores indicate higher stress. An example of items is: "Having too many responsibilities". A previous study reported internal consistency using Cronbach's alpha of ESI at .86.[12] For this study, the Cronbach's alpha of the ESI in pilot and main studies were .79 and .81 respectively.

**The L-WMAT:** a 15-item self-administered questionnaire, was developed by Locke and Wallace[26] and used to measure marital satisfaction. This study used the L-WMAT Thai version translated by Pornthip Wongvisetsirikul.[32] The response tasks of this tool include rating scale and multiple choices. The score for assessing each part is not consistent across questions. For the rating scale, mothers rated their degree of happiness on a 7-point scale ranging from 0 (very unhappy) to 35 (perfectly happy) and also rated their degree of agreement on a 5-point scale varying between 0 (always disagree) and 15 (always agree). For multiple choices, mothers answered which situation that best express their couple lives; the scores vary between 0-15. The total possible scores range from 2-158. The total sum scores were used for data analysis in this study. The higher scores indicate higher marital satisfaction. An example of items for rating scale is: "Handling family finances". The internal consistency reliability testing among Thai spouses was .80. In this study, the Cronbach's alpha of the L-WMAT in pilot and main studies were .80 and .82 respectively.

**The DCQ:** was used to measure difficult child temperament, and was developed by the first and third researchers based on a literature review about child temperament.[34-35] It is an 18-item questionnaire with 5-point rating scale ranging from 1 (strongly disagree) to 5 (strongly agree) assessing the mother's perception of their child's difficulty in the features of activity level, rhythmicity, approach/withdrawal, adaptability, intensity, and mood. The total possible scores range from 18-90 in which higher scores mean greater difficulty for preschoolers as perceived by mothers. An example of item is: "Your child is hyperactive and tends to walk, run, climb or play all the time".

The newly developed DCQ was assessed for its content validity by three experts from pediatric and psychiatric fields. The concurrent validity of the DCQ was assessed using the CES-D scale. A previous study has indicated a significant correlation between maternal depression and difficult child temperament.[17] Therefore, the CES-D scale, which is a standard measurement, was selected as the criterion measure for testing the validity of the SDQ. For this study, the Pearson correlation coefficient between the DCQ and the CES-D of .50 ($p < .01$), suggested a moderate level of concurrent validity in this study. The Cronbach's alpha of the DCQ in pilot and main studies were .80 and .64 respectively.

**The CES-D scale:** is a 20-item self-report instrument, developed by Radloff[27] and used to measure maternal depression. Mothers rated how often the symptoms of depression occurred to themselves during the previous week on a scale ranging from 0 (rarely or none of the time), to 3 (most or all of the time). The total possible score ranges from 0-60; scores of 16 or higher are a cut-off point indicating depression. The total scores were used for data analysis in this study. An example of item is: "I was bothered by things that usually don't bother me". This study used the CES-D Thai-version translated by Umaporn Trangkasombat.[33] In this study, the Cronbach's alpha of the CES-D in pilot and main studies were .82 and .85 respectively.

**The PS:** is used to measure disrupted parenting. The PS[28] is a 26-item questionnaire modified from the original version developed by Arnold, O'Leary, Wolff and Acker[30] upon the factor analysis. A mother rates her tendency to use a particular discipline in response to the child's behavior. Each item is anchored a 7-point Likert scale, on which (7) indicates the uses of dysfunctional discipline strategies and (1) indicates the uses of effective discipline strategies. The total possible score ranges from 26-182, and higher scores indicate more dysfunctional parenting. The total scores were used for data analysis in this study. An example of item is: "When my child misbehaves I do something right away (1) or I do something about it later (7)". Cronbach's alpha coefficients of the modified PS ranged from .86 - .89 in the previous studies.[14,28] In this study, the Cronbach' s alpha of the PS in pilot and main studies were .60 and .64 respectively.

**The ECBI:** is a 36-item questionnaire, developed by Eyberg and Ross[29] and used to measure child conduct problems. The ECBI consists of two dimensions; a problem scale and an intensity scale. Only the intensity scale measuring how often behavior problems occur was used in this study. The scores range from 1 (never) to 7 (always) and the total possible scores range from 36 – 252. The cut-off scores of 131 or higher indicate the high frequency of the problems' occurrence. In this study, the total scores were used for the data analysis. An item example is: "Dawdles in getting dressed". Cronbach's alpha coefficients of the ECBI reported in the previous study was .87.[14] In this study, the Cronbach's alpha of the ECBI in pilot and main studies were .88 and .87 respectively.

**Data Collection Procedures:** The data collection was divided into three main phases: recruitment, screening and data collection. In the recruitment phase, the researcher approached the school teachers for their cooperation and to inform them about the entire process of data collection in the study. The total number of preschoolers in eight selected schools was 2,528; therefore, 2,528 invitation letters were distributed to all mothers of preschoolers in each selected school. In the screening phase, 891 mothers (35.3%) who were interested in the study were sent sealed envelopes containing an information sheet, informed consent form and screening questionnaires (Demographic Data form and the SDQ). Of the mothers interested in the study, 622 (69.8%) completed the screening questionnaires. Also, 95 class teachers were given the SDQ to check if these 891 children were at risk for conduct problems; and 841 children were finally rated (94.4 %). Of 891 mother-child dyads, based on the SDQ score and the other inclusion criteria, 289 were eligible to participate in the study. The researcher could not contact 91 mothers who met inclusion criteria. Finally, there were 198 mother-child dyads who participated in this study. From all of the preschooler samples (N = 198) obtaining conduct problems scores of the SDQ $\geq$ 4, 133 (67.2%) were rated by their mothers, 38 (19.2%) by the class teachers and 27 (13.6%) by both mothers and class teachers as having conduct problems. The average score of the SDQ rated by the mothers (M = 4.28, *SD* = 1.45) was higher than that rated by the teachers (M= 2.62, *SD* = 2.12). In data collection phase, the researcher contacted potential study participants and made an appointment for completing the set of questionnaires. The data were collected at school or at home according to the participants' availability. A small gift was presented to each participant after completing the data. Finally, there were 198 (68.5 %) of the eligible mothers who completed all of the questionnaires. A diagram of sampling flow is shown in Figure 2.

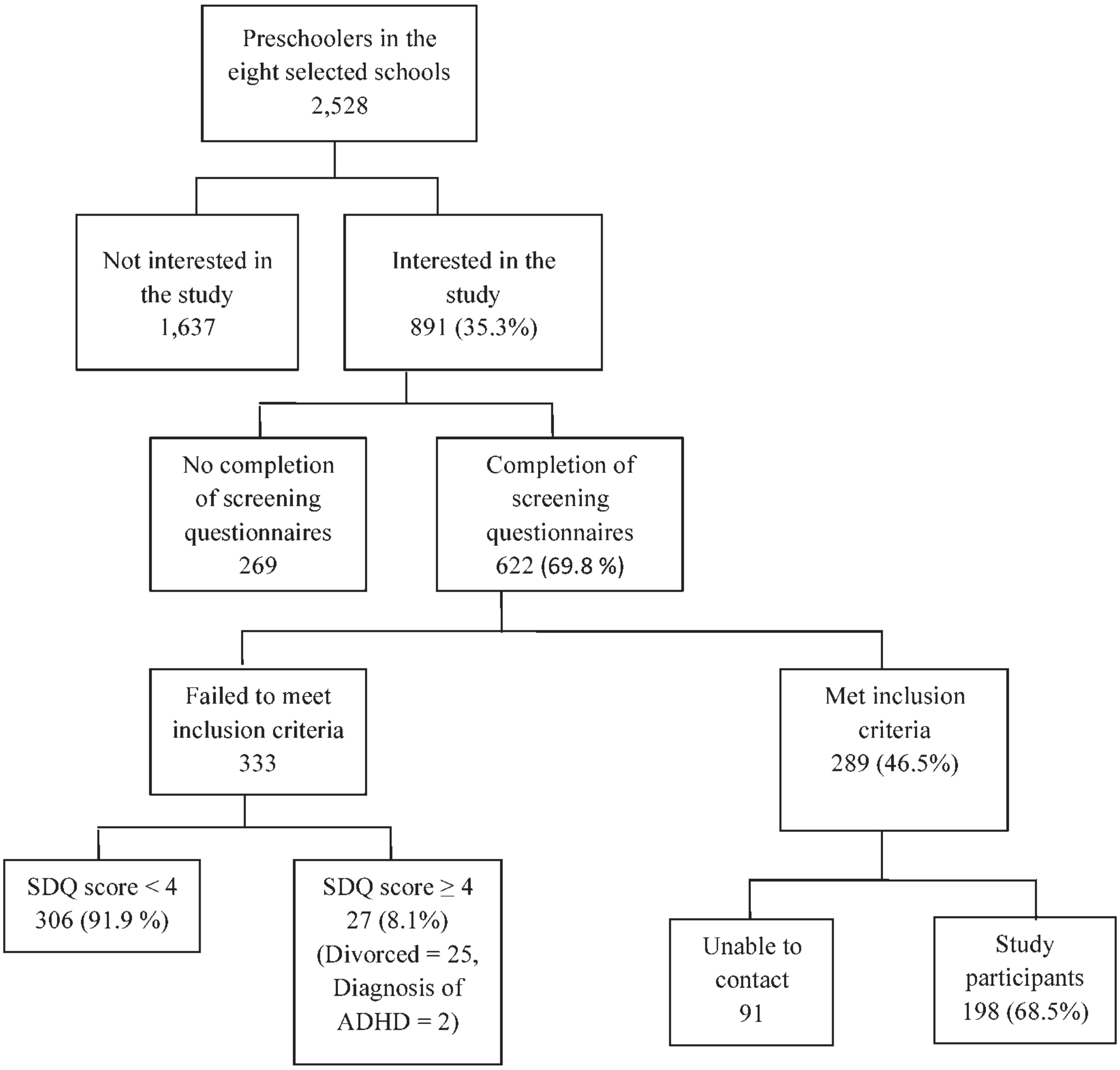


**Figure 2** Diagram of sampling flow for the study participants

**Data analysis:** Data were analyzed using computer software for statistical analysis. First, the research instruments were examined for reliability. Before testing the model, the descriptive statistics of participants' characteristics including frequency, percentages, mean, standard deviation, and range of score were examined. After examining the assumptions of path analysis including normality, multicollinearity, linearity and homoscedasticity, the model was tested by using LISREL 9.10 (STUDENT, Scientific Software International. Chicago, IL, USA).

## Results

**Demographic characteristics:** The demographic characteristics of the mothers and the children are shown in Table 1. The mothers' average age was 34.3 years (*SD* = 7.24, ranging between 20 - 52 years). The number of their children ranged from 1- 8 children (mode = 2). Two-thirds of the mothers (73.8%) completed primary and high-school education. The majority of the mothers (83.3%) were employed and most of the mothers' incomes (70.2%) ranged between

5,000 and 15,000 baht/month. For children, the average age was 5.45 years (*SD* = .76, ranging between 4 - 7 years), and nearly two-thirds (64.6%) were males.

**Table 1** Demographic Characteristics of the Mother-child Dyads (N = 198)

| Variables | categories | n (%) |
|---|---|---|
| Mothers | | |
| Age (years old) (*M* = 34.03, *SD* = 7.24) | 20 - 35 | 121 (61.1) |
| | 36 - 44 | 56 (28.3) |
| | 45 - 52 | 21 (10.6) |
| Number of children *Mdn* = 2, mode = 2 | 1 - 2 | 142 (71.7) |
| | 3 - 4 | 52 (26.3) |
| | > 4 | 4 (2.0) |
| Education | No school attendance | 3 (1.5) |
| | Primary school | 71 (35.9) |
| | High school | 75 (37.9) |
| | Technical school | 27 (13.6) |
| | Bachelor degree | 22 (11.1) |
| Occupation | None | 33 (16.7) |
| | Merchant | 42 (21.2) |
| | Government | 4 (2.0) |
| | Employee | 110 (55.6) |
| | Other | 9 (4.5) |
| Income | None | 19 (9.6) |
| | < 5,000 | 21 (10.6) |
| | 5,000 - 9,999 | 81 (40.9) |
| | 10,000-15,000 | 58 (29.3) |
| | > 15,000 | 19 (9.6) |
| Sufficiency of family income | Sufficient | 94 (47.5) |
| | Insufficient | 104 (52.5) |
| Children | | |
| Gender | Male | 128 (64.6) |
| | Female | 70 (35.4) |
| Age (years old) (*M* = 5.45, *SD* = .76) | 4 - 5 | 105 (53.0) |
| | 6 - 7 | 93 (47.0) |

**Characteristics of study variables:** As shown in Table 2, the average scores of child conduct problems reported by the mothers (M = 125.23, SD = 29.08) was lower than the ECBI cut-off score of 131 where 131 or higher indicates a high frequency of conduct problems. Concerning maternal depression, the average score of depressive symptoms rated by the mothers (M = 15.41, SD = 8.25) was close to the cut-off score of 16 indicating clinically depressive symptoms.

**Table 2** Descriptive Statistics of the Study Variables. (n=198)

| Variables | Possible Range | Actual Range | Mean | Median | *SD* | CV (%) |
|---|---|---|---|---|---|---|
| DH | 20-80 | 20-68 | 37.97 | 37.00 | 8.58 | 22.60 |
| MS | 2-158 | 7-158 | 97.05 | 103.00 | 30.90 | 31.84 |
| DCT | 18-90 | 29-83 | 51.47 | 51.00 | 8.50 | 16.51 |
| MD | 0-60 | 1-48 | 15.41 | 15.00 | 8.25 | 53.54 |
| DP | 26-182 | 55-152 | 96.72 | 97.50 | 15.64 | 16.17 |
| CCP | 36-252 | 47-198 | 125.23 | 121.00 | 29.08 | 23.22 |

DH=Daily Hassles, MS=Marital Satisfaction, DCT=Difficult Child Temperament, MD=Maternal Depression, DP=Disrupted Parenting, CCP=Child Conduct Problems, CV=Coefficient of Variation

**Model Testing:** The hypothesized model was tested by using LISREL 9.10 (STUDENT). The data of the study variables met all the assumptions for path analysis (multicollinearity, linearity, homocedasticity), except normality distribution. Weighted least squares (WLS), an asymptotically distribution-free test, was used as an estimator for analyzing non-normality of data in the current study.[36] The hypothesized model showed a good fit to the data at $\chi^2$ = 3.39 (*df* = 4, *p*-value = .50), $\chi^2$ / *df* = .85, *GFI* = .99, *AGFI* = .97 *RMSEA* = 0.00, and *SRMR* = .02. However, it yielded four path coefficients with incorrect signs that indicated a non-sensible solution for the model and should be rejected.[23] The improperly hypothesized model was modified by using both of the modification indices in the LISREL program and the supports from theoretical basis as the direction. Upon modification, the three reverse signs in feedback loop were cut. The final recursively modified data fitted well to the empirical data at $\chi^2$ = 5.06 (*df* = 5, *p*-value = .41), $\chi^2$/ *df* = 1.01, *GFI* = .99, *AGFI* = .97 *RMSEA* = 0.00, and *SRMR* = .03. The causal relationships among mothers' stressors, maternal depression and disrupted jointly accounted for 15% of the variance explained in child conduct problems. Explained variances in maternal depression and disrupted parenting were 31% and 20% respectively. Maternal depression and disrupted parenting mediated the relationship between stressors and preschoolers' conduct problems; however, disrupted parenting did not mediate the relationship between maternal depression and preschoolers' conduct problems. The results of the model testing are shown in Figure 3 and Table 3.

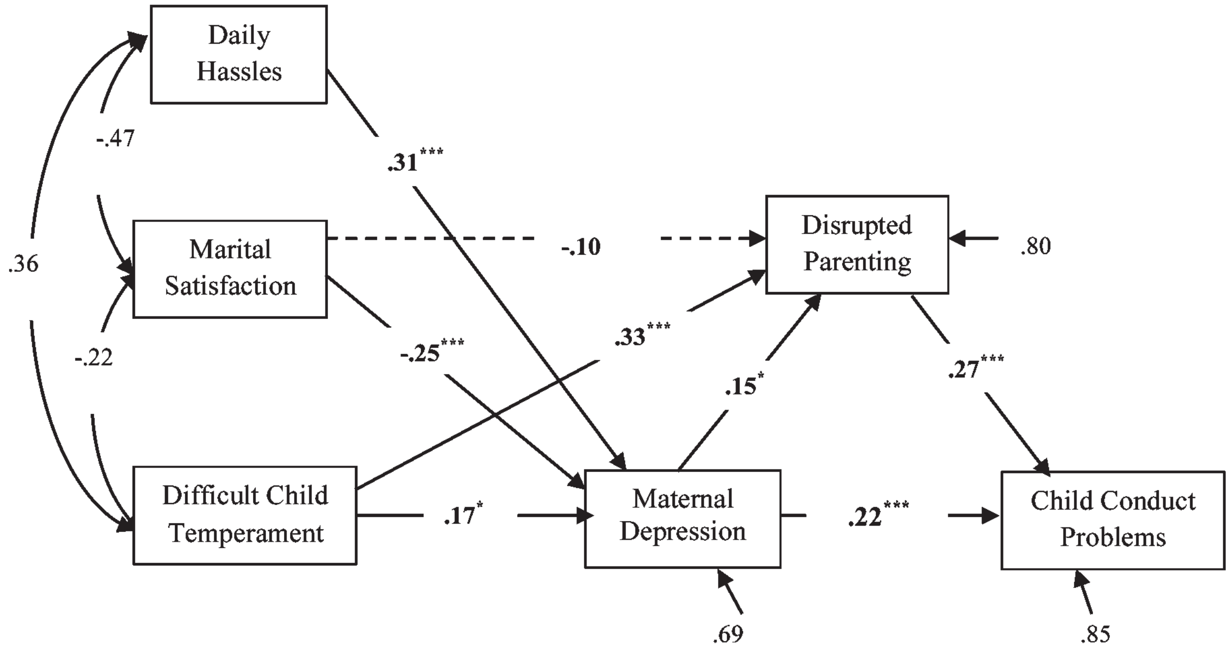
**Table 3** Total Indirect and Direct Effects of the Final Model. (N = 198)

| Causal variables | MD | | | DP | | | CCP | | |
|---|---|---|---|---|---|---|---|---|---|
| | TE | IE | DE | TE | IE | DE | TE | IE | DE |
| DH | .31*** | - | .31*** | .05$^{ns}$ | .05$^{ns}$ | - | .08** | .08** | - |
| MS | -.25*** | - | -.25*** | -.13* | -.04* | -.09$^{ns}$ | -.09** | -.09** | - |
| DCT | .17* | - | .17* | .36*** | .02$^{ns}$ | .34*** | .13** | .13** | - |
| MD | - | - | - | .15* | - | .15* | .26*** | .04$^{ns}$ | .22*** |
| DP | - | - | - | - | - | - | .27*** | - | .27*** |
| Statistics $\chi^2$ = 5.06, *df* = 5, *p* = .41, *GFI* = .99, *AGFI* = .97, *SRMR* = .03, *RMSEA* = 0.000 | | | | | | | | | |
| Variables | CCP | DP | MD | | | | | | |
| $R^2$ | 15% | 20% | 31% | | | | | | |

TE = Total Effect, IE = Indirect Effect, DE = Direct Effect

*$p$ <.05, **$p$ <.05, ***$p$ <.001, *ns* = not significant

DH=Daily Hassles, MS=Marital Satisfaction, DCT=Difficult Child Temperament, MD=Maternal Depression, DP=Disrupted Parenting, CCP=Child Conduct Problems, CV=Coefficient of Variation



$\chi^2 = 5.06$, $df = 5$, $\chi^2/df = 1.01$, $p = .41$, $GFI = .99$, $AGFI = .97$, $RMSEA = 0.000$, $SRMR = .03$

All paths shown are statistically significant (*$p < .05$, **$p < .05$, ***$p < .001$) except the dash line indicating a non-significant path.

**Figure 3** Final model

## Discussion

The modified model fitted the empirical data suggesting that the relationships among the factors and mediators in the developed model were congruent with and capable of explaining the phenomenon of conduct problems in this Thai preschooler population. In the model, mothers' stressors, daily hassles, marital problems and difficult child temperament, had significant direct effect on maternal depression. Besides, difficult child temperament had a significant direct effect on disrupted parenting, whereas marital satisfaction had a significant indirect effect on disrupted parenting through maternal depression. The results partly supported the Webster-Stratton's model,[7] and were consistent with previous studies.[12,17-19] Stressors, depressive symptoms and ineffective parenting were typically found among mothers whose children had conduct problems.[10] Generally, mothers of young children experience stress caused by their routine parenting. For the mothers in our sample, they confronted more complicated situations dealing with their several sources of stressors including rearing their difficult children, marital problems and daily hassles. The combination effects of stressors from various parts of their lives might overwhelm them and decrease their ability to cope with their stressors effectively. According to Webster-Stratton,[7] those stressors the mothers were not able to handle tend to be judged as harmful or threatening in which prolonged effects could deteriorate the mothers' psychological well-being as well as disrupt the quality of parenting. The results were both maternal depression and disrupted parenting, which in turn accounts for increased child conduct problems.

In addition, there were significant mediating effects of both maternal depression and disrupted parenting in the relationship between stressors and preschoolers' conduct problems. The result was consistent with Webster-Stratton[7] in that the effects of mothers' stressors on child conduct problems could be transferred by maternal depression and disrupted parenting. According to Webster-Stratton,[7] the effects of stressors on child conduct problems depend on how mothers appraise their stressful situations. If mothers perceive their stressors as trivial matters that were not beyond their capability, they would gain more confidence and power to overcome their difficulties. Influenced by the symptoms of depression such as loss of interest, decreased energy, poor concentration and difficulty in making decision,[9] the mothers' daily functions would be impaired and negative appraisals of themselves and others would be induced too. Previous studies indicated the effect of maternal depression in predicting low maternal self-competence, high levels of both child conduct behaviors and dysfunctional parenting (laxness and over reactivity).[10,37] It is difficult for depressed mothers to manage their stressors effectively as well as to provide their children with optimal parenting. Therefore, through maternal depressive symptoms, stressors could have indirect effects on preschoolers' conduct problems.

Concerning disrupted parenting, those stressors with which the mothers could not cope would also disrupt the quality of parenting. When parenting is disrupted, it decreases maternal ability to balance between responsiveness and demands, thereby resulting in higher use of laxness or overreactivity in response to their children's needs. For the mothers in our sample confronting stressors from several sources, they might feel overwhelmed with their stressors and became less tolerant, more conflicted and frustrated with their difficult children, thereby resulting in responses to them marked by laxness and overreactivity. Through mothers' uses of laxness and overreactivity, the children were unintentionally reinforced in their misbehaviors and modeled to react hostilely and cruelly. Children's misbehaviors such as yelling, temper tantrums and disobedience if reinforced might develop into more serious behaviors such as child conduct problems violating the rights and rules of others in the form of fighting, bullying, lying and thieving. Positive association between the two forms of dysfunctional parenting, namely, laxness and overreactivity, with conduct problems in young children.[14,37] Thus, there were indirect effects of stressors on preschoolers' conduct problems through disrupted parenting.

Unexpectedly, there was no significant indirect effect of maternal depression on preschoolers' conduct problems through disrupted parenting. This result was inconsistent with Webster-Stratton.[7] Two possible explanations of this finding are related to Thai culture. First, Thai mothers are more likely to punish less for their young children's misbehaviors like hitting or losing their temper. They perceive these misbehaviors as normal behaviors in young children that would disappear when the children grow up.[38] Second, most of Thai mothers use punitive methods as common discipline for young children.[38-39] Because of raising the children in the same cultural context and beliefs, either depressed or non-depressed mothers might tend to engage in similar child disciplines. Therefore, there was no mediating effect of disrupted parenting found in this study.

However, the results showed significant direct effects of the two mediators on child outcome, which is congruent with a meta-analytic study reporting that maternal depression had strong effects on child behavioral problems, including conduct problems.[15] In addition, the strong effects of both laxness and over reactivity on child conduct problems have been supported by several studies[14,37] Therefore, the findings of the current study indicated that both maternal depression and disrupted parenting independently affect child conduct problems.

## Limitations

There are some limitations in the current study. The first is related to low reliability of the instruments, the PS and the DCQ. The Parenting Scale (the PS) measuring disrupted parenting had rather low reliability as compared to previous studies reporting the acceptable internal consistency coefficient.[14,28] The low reliability of the instrument may have been due to the homogeneity of the sample.[40] In the current study, the homogeneous data for the difficult child temperament variable ($M$ = 51.47, $SD$ = 8.50, CV = 16.51%) and the disrupted parenting variable ($M$ = 96.72, $SD$ =15.64, CV = 16.17%) were found to be capable of affecting the reliability. Thus, the findings of this study must be interpreted with caution. Second, caution must also be taken about generalizing the findings to mothers of middle or high socioeconomic status, since the current study recruited the study samples from low socioeconomic background. The mothers in our sample reported their high levels of stress related to their several socioeconomic disadvantages which might be different from those recruited from higher socioeconomic status. In the future, we will require the model to be tested with different samples in various regions of Thailand.

## Conclusions and Recommendation

The results support the theoretical model, proposed by Webster-Stratton,[7] that maternal depression and disrupted parenting act as mediators between mothers' stressors and Thai preschoolers' conduct problems. As suggested by the findings, the significances of depression in mothers and quality of parenting should be considered in preventing new cases of preschoolers' conduct problems. Further research should develop an intervention to prevent conduct problems in preschool-aged children by focusing on reducing maternal depression and increasing effective parenting skills. However, as the model accounted for only 15% of outcome variables there is a need for further studies to explore other mediating factors such as low social support and mothers with substance use and antisocial personality[7] in order to strengthen relationships between mothers' stressors and preschoolers' conduct problems. In addition, the homogeneous data of the current study could have led to the low reliability of the DCQ and the PS. Future studies should increase the heterogeneity of the data by increasing the sample size. As well, adjusting the semantic differential scale of the PS by increasing directionality for respondents' responses like assigning a set of numerical values in future studies might be able to help decrease random errors with the instruments.

The results also provide empirical evidence that can be used to guide nursing practices. Depressive symptoms in mothers could present during the ante-, peri- and postnatal periods in which the effects on their children could persist.[10,13] Thus, preventing preschoolers' conduct problems involve multiple areas of clinical nursing practices, including psychiatric, obstetric, pediatric and community aspects. Nurses in involved areas should work co-operatively so that some initial preventing programs can be developed and implemented, for instance, early screening for depression in every pregnant woman and careful monitoring for mothers who are in the period of child development. Psychiatric nurses should provide the knowledge of how maternal depression and disrupted parenting affect children's behaviors for other nurses working with mothers and children. An educational group can be set for pregnant women or mothers of young children to encourage them to be alert to the early signs of depressive symptoms and their children's conduct behaviors.

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# อิทธิพลของสิ่งก่อเครียด ภาวะซึมเศร้า และการเลี้ยงดูของมารดาต่อพฤติกรรมเกเรของเด็กไทยวัยก่อนเรียน

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**บทคัดย่อ:** จุดประสงค์ของการศึกษาครั้งนี้ เพื่อตรวจสอบอิทธิพลของสิ่งก่อเครียดของมารดา ภาวะซึมเศร้าของมารดา การเลี้ยงดู ที่มีต่อพฤติกรรมเกเรของเด็กไทยวัยก่อนเรียน มารดาและบุตรวัยก่อนเรียนจำนวน 198 คนได้รับการคัดเลือกจากโรงเรียนในสังกัดกรุงเทพมหานครจำนวน 8 โรงเรียน ข้อมูลถูกเก็บช่วงเดือนตุลาคม 2555 ถึง เดือนพฤษภาคม 2556 การเก็บข้อมูลแบ่งเป็น 2 ขั้นตอนหลัก คือ ขั้นคัดกรอง และ ขั้นเก็บรวบรวมข้อมูล กลุ่มตัวอย่างถูกคัดกรองโดยใช้คะแนนพฤติกรรมเกเร เก็บข้อมูลโดยใช้แบบสอบถามจำนวน 8 ฉบับ; 1) แบบสอบถามข้อมูลทั่วไป 2) แบบประเมินจุดแข็งจุดอ่อน 3) ดัชนีวัดความเครียดในชีวิตประจำวัน 4) แบบวัดสัมพันธภาพระหว่างคู่สมรส 5)แบบสอบถามพื้นอารมณ์เด็ก 6) แบบคัดกรองภาวะซึมเศร้า 7) แบบประเมินการเลี้ยงดูบุตร และ 8) แบบวัดพฤติกรรมเกเรในเด็ก และวิเคราะห์ข้อมูลโดยใช้ สถิติการวิเคราะห์เส้นทาง

ผลการศึกษาพบอิทธิพลทางอ้อมของสิ่งก่อเครียดของมารดา (ความเครียดในชีวิตประจำวัน สัมพันธภาพระหว่างคู่สมรส พื้นฐานอารมณ์ความเป็นเด็กเลี้ยงยาก) ที่มีต่อพฤติกรรมเกเรของเด็กวัยก่อนเรียนโดยผ่านภาวะซึมเศร้าและการเลี้ยงดูของมารดา นอกจากนี้พบว่า ภาวะซึมเศร้าของมารดา และการเลี้ยงดูของมารดาทั้งคู่ต่างก็มีอิทธิพลต่อพฤติกรรมเกเรของเด็กอย่างเป็นอิสระต่อกัน ดังนั้นโปรแกรมที่ลดภาวะซึมเศร้าของมารดาและส่งเสริมการเลี้ยงดูอย่างมีประสิทธิภาพจึงมีความสำคัญในการลดปัญหาพฤติกรรมเกเรของเด็กในวัยก่อนเรียน

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# Factors Associated with the Retention in Care After Delivery among Thai Mothers with HIV

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**Abstract:** The objectives of this retrospective cross-sectional study were to investigate the prevalence and predictive factors in retention of care during the first year after delivery among Thai mothers with HIV. The sample consisted of 185 mothers with HIV infection who gave birth at a public hospital from January 2010 to December 2012. Recruitment and enrollment took place from March - July 2014. Data were collected through self-administered questionnaires and telephone interviews by using 5 questionnaires: the Personal Information, Access to Health Care, Receiving HIV Care, Attitudes toward Health Care Providers, and Short Form-HIV Stigma Scale. Data were analyzed using descriptive statistics and logistic regression analyses.

Results showed that 77.3% of the participants were retained in care at the HIV clinics with 46.5% at obstetric and gynecology clinics. The results of logistic regression analysis revealed that the predictive factors of retention in care at HIV clinics explained 80% of the variance. The factors predictive of retention in care at obsetetric and gynecology clinics were official referral and disclosure of HIV status. These factors explained 14% of the variance of retention in care at these clinics.

The results suggest that health care providers should have an effective system to refer patients to their registered hospital and improve benefits of health coverage to be relevant to patients' need. In addition, the management of HIV care should address the individual patient's self-disclosure.

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**Keywords:** HIV, Post-partum period, Pregnant women, Retention in care, Thailand

## Introduction

In Thailand, the prevalence of newly-identified HIV cases is approximately 1% of all individuals screened.[1] Recent data suggest that the greatest number of HIV detections is in pregnant women when compared with other populations with HIV screening. From 2011 to 2013, the average nationwide prevalence rates for HIV infection among pregnant women stabilized at about 0.57 percent,

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while the prevalence rates in Bangkok ranged from a low of 0.61% in 2008 to a high of 0.94% in 2012.[1] Previous studies have shown that CD4 counts decrease during the postpartum period. Low immunity level is a strong risk factor for morbidity or opportunistic infections and frequent hospitalizations. As such, the compromised health of postpartum mothers HIV positive (HIV+) has important consequences for the long-term health of both mothers and babies. Further, targeting the needs of women HIV+ in the postpartum period has important implications for containing health care costs by improving HIV-specific health outcomes and reducing emergency department visits and hospitalizations. As such, the postpartum period represents a critical time frame for engaging or retaining mothers in HIV treatment.

To date, the majority of research among pregnant women HIV+ has been aimed at reducing the rate of mother-to-child transmission. Comparatively fewer studies have focused on engaging and retaining women HIV+ in the postpartum period in HIV-related care. For postpartum mothers with HIV, referral between obstetric and gynecology (OB & GYN) and HIV care clinics is an important opportunity to engage these mothers in care for continued monitoring of their health. Engagement in HIV-specific health care includes both treatment initiation and long-term follow-up and monitoring and is critical the management of this chronic illness. For example, among women without antiretroviral therapy (ART) indications, continuous monitoring every 6 months is needed to detect changes in viral load, CD4 counts and the development of opportunistic infections.[2] For mothers on ART, engagement in health care services is needed to prevent medication interruptions, maintain immunologic levels,[3] prevent HIV drug resistance, and monitor the effects of therapy.[4]

To date, there have been only two studies that report specifically on postnatal check-ups to assess the health status of Thai mothers with HIV. Chalermpichai and colleagues[5] studied the prevalence of loss to postpartum follow-up in mothers with HIV. They found that approximately 61% of mothers who delivered at a large public hospital in Bangkok returned to the postpartum clinic at 6 weeks after giving birth. A second study conducted by Kongyu[6] focused on provinces outside of Bangkok and reported that only 38.5% of the mothers with HIV had regular interval check-ups during the two years after delivery. Therefore, this study was launched to study the prevalence and predictive factors of retention in care at the first year after delivery among Thai mothers with HIV.

## Literature Review and Conceptual Framework

Based on the extant literature, retention in care has been shown or hypothesized to be influenced by factors associated with the health service system[7] and personal-level factors.[8] Health service system factors include health coverage, access to health care, receiving HIV care, and referral.

Access to health coverage has been shown to facilitate engagement in HIV care and treatment.[9] Many kinds of Thai health coverage cover the different costs of HIV care and the receipt of health services varies according to that health coverage.[10] Access to health care means a person's personal care experiences with medical care services (affordability, availability, convenience, and access to specialists)[11] such as costs of HIV treatment, distance between home and the health care setting, a lack of HIV specialists, and substandard health service provision.[12] Therefore, access to health care factors is associated with retention in care. Regarding receiving HIV care meant that people received holistic care, especially health education and consultation, antiretroviral (ARV) drug provision, and medical appointment by coordinating nurse.[13] Referral means a healthcare process that results in the transfer of patient care from a referring provider to a secondary service or provider, and transfer back when and if appropriate.[14]

Several patient factors have been identified as facilitators of and barriers to retention in care in mothers with HIV including attitudes toward HCPs, stigma, disclosure of HIV status, and perceived health status. Attitudes toward HCPs are the assessment and interpretation of patients on their environment and on their interactions with their HCPs.[15] These concepts include professionalism and emotional support that are influenced by personal beliefs and experiences from prior health service utilization. Negative attitudes are considered as a barrier to the use of health services while positive attitudes have been significantly related to greater out-patient appointment attendance at HIV clinics.[16]

Stigma refers to individual perceptions about societal attitudes toward people with HIV and their self-awareness of being infected with HIV. Stigma has been accepted widely as a serious obstacle to the success of HIV/AIDS prevention programs such as the prevention of mother-to-child transmission (PMTCT) service. It is associated with violations and deprivations of several rights including the right to health and treatment.[17] Although studies in Nigeria[18] and Zimbabwe,[19] show trends toward more accepting attitudes towards people living with HIV/AIDS (PLHA), in Thailand stigma is still a barrier to retention in care because of fear of exposure and personal or family humiliation.[20] Therefore, stigma might be associated with retention in care of mothers with HIV.

Disclosure of HIV status is sharing information about patients' HIV status to partner, parents, or relatives. Disclosure of HIV status might bring more difficulties to the patients' lives and to their infants because they fear rejection and discrimination. On the other hand, disclosure may be helpful to get HIV treatment and retention in care.[21] Perceived health status is an individual patient's assessment of her general health. Most Thai mothers with HIV have asymptomatic infection, and perceive themselves to be in good health, thus decreasing the likelihood of engaging in care after delivery.[22] In summary, the literature review was synthesized into a conceptual framework, which depicted the relationships among the health service system, personal-level factors, and retention in care as shown in Figure 1.

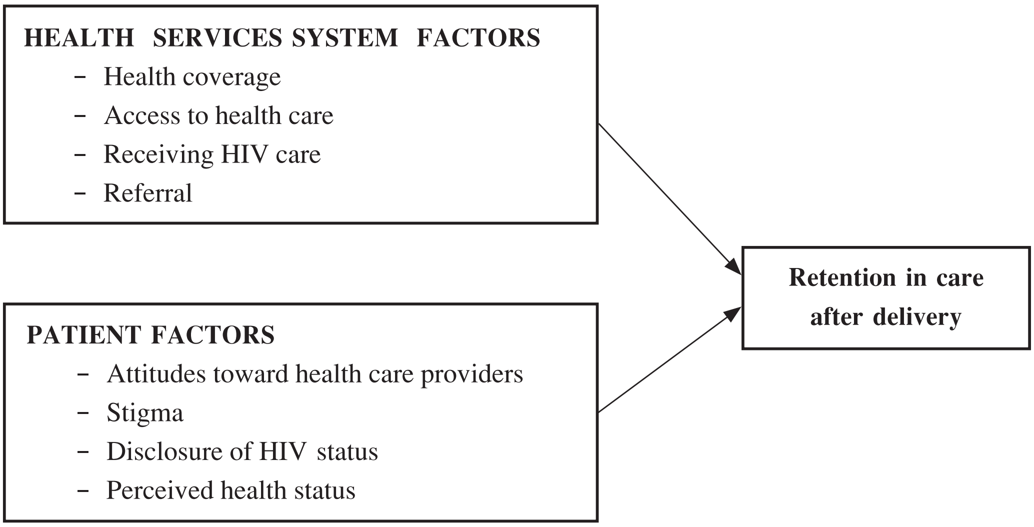

**Figure 1.** Research framework of the study

## Study Aim

Retention in care among Thai mothers with HIV infection is an important public health issue. However, little is known about the predictors of retention in care among this vulnerable and underserved population. To address this gap in the literature, the aim of the current study were to examine rates and predictors (health service system and patient factors) of retention in HIV-specific treatment among Thai mothers during the first year following delivery.

## Methods

***Study Design:*** This was a retrospective cross-sectional study.

***Setting:*** The study was conducted at a Thai tertiary care university hospital which has implemented a PMTCT program according to the National Guidelines on the Care and Treatment.[23] Service provision for pregnant women with HIV is provided by collaboration between the OB & GYN and HIV out-patient clinics. The OB & GYN clinic provides fetal health monitoring and sexually transmitted disease screening. At the HIV clinic, the physician specialized in infectious disease provides HIV physical examination, health monitoring, and ARV drugs prescription. After delivery, the mothers are referred to a HIV clinic according to their health coverage or registered hospital–primary or secondary care, public or private hospital in central and regional province–to continue health follow-up. The OB & GYN staff passed mothers' personal and medical history to the HIV clinic, if the patients were referred within this hospital.

***Sample Size Estimation:*** The sample size was calculated by an epidemiological formula[24] using the proportion of retention in care in postpartum mothers with HIV from a prior study, 38.5%.[5] The actual probability of a Type I error is expected to fall between .03 and .07 at the nominal level of $\alpha$ of .05. The significance level (1-a or Type I error) equal to .07 and power of testing (1-b or Type II error) equal to .70 was determined. Therefore, 185 mothers with HIV were needed to participate in the study.

***Populations & Sample:*** 283 mothers with HIV who had given birth in a large university hospital in Bangkok from January 1, 2010 to December 31, 2012 were eligible for the study. Ninety-eight eligible mothers did not participate in this study: 90 mothers were not able to be approached due to an unavailable phone number, 5 refused to participate, and 3 had died. Study inclusion criteria were: 1) aged 18 years and older, 2) knew their HIV+ status, 3) able to listen, speak, read, and write Thai language, and 4) agreed to participate voluntarily. Finally 185 mothers with HIV were recruited to the study.

***Measures:***

**Demographic** and background characteristics of study participants were obtained including age, marital status, educational level, occupation, family income, a number of family members, health coverage, average cost spent per each visit, disclosure of HIV status, referral, and retention in care.

**Access to health care** was measured with the *Access to Health Care Questionnaire* (AHCQ).[25] It has subjective ratings of affordability (1 item), availability (3 items), convenience (1 item), and access to specialists (1 item). Each item is rated on a 5-point Likert scale ranging from 1 (strongly agree) to 6 (strongly disagree). Scores range between 6-30 points with higher scores indicating better access to care. An example of access to health care is "Places where I can get medical care are very conveniently located." The AHCQ was back translated to investigate the equivalence of meaning between English and Thai languages. Three HIV experts validated content of the Thai language version using a 4-point rating scale: (1) not relevant, (2) somewhat relevant, (3) quite relevant, and (4) very relevant.[26] Any discrepant items were discussed and revised until at least 2 of the 3 HIV experts agreed on the content. In this study, the Cronbach's alpha was 0.62.

**Receiving HIV care** was measured with the *Receiving HIV Care Questionnaire* (RHCQ) developed by the researcher based on a literature review, observation, and interviews with two nurses; one at OB & GYN and the other at HIV out-patient clinics. The instrument has 2 sets of questions including 5 items for assessment mothers' receipt of services provided by HIV nurses working at OB & GYN clinics and 5 items HIV nurses working at HIV clinics. The questionnaire assesses receiving HIV care including assessment of health problems, provision of individual counseling and health education, management of medical appointments, and coordination between clinics and other health units. A sample item is "Nurse contacted you to inquire about the reasons for missing an appointment and reschedule for the new appointment." Each item consists of yes or no response (Answer: Yes = 1, No = 0). A higher score indicates more services received from the HIV nurse. In this study, the Kuder-Richardson method obtained for the measure was 0.92.

**Attitudes toward health care providers** was measured with the 19-item *Attitudes toward HCPs* (AHHCP) developed by Bodenlos and colleagues.[15] The extent of agreement with different attitudes toward the medical team is assessed with a 6-point Likert scale that have both positive and negative questions. For positive items, rating scores were ranged from 1 (strongly disagree) to 6 (strongly agree); conversely, the scale is arranged from 1 (strongly agree) to 6 (strongly disgree) for negative items. Scores range between 19-114 points with the higher scores indicating more positive attitudes. The AHHCP was back translated according to Maneesriwongul's guideline[26] by 3 HIV experts. An item example is "My medical team puts an effort into my treatment." In this study, the Cronbach's alpha was 0.95.

**Stigma** was measured with the *Short Form-HIV Stigma Scale* (SF-HIVSS) of Maneesriwongul.[27] It has 8-items that measure an individual's perception of society toward people with HIV and personal knowledge of being infected with HIV. A sample item is "I am very careful whom I tell that I have HIV." Each item is measured on a 4-point Likert scale ranging from 1 strongly disagree to 4 strongly agree. The total scores range from 8 to 32 with a higher score representing a higher level of perceived stigma. Cronbach's alpha in this study was 0.86.

**Health status** was assessed with a 100 millimeter horizontal line (visual analogue scale) with end-point of 100 (healthy) and 0 (unhealthy). Respondents identify a point on the scale at a position which best represents their current perceived health status with a question "How do you feel about your health status for HIV/AIDS?" The visual analogue scale was transformed linearly to a 0 to 10 scores, where 0 represents unhealthy, and 10 represents healthy.

**Retention in care** referred to continued attendance at any hospital for care and treatment at HIV and/or OB & GYN out-patient clinics during the first year after delivery. In each clinic, retention in care was evaluated per the match between the number of patients' clinic visits and frequency of medical schedule appointment. The participants were categorized as "retention" if they attended the clinic visit within 4 weeks of the scheduled appointment; "non-retention" if they did not come for a scheduled appointment or came later than 4 weeks after appointment.

The content validity index (CVI) of all measures was 0.90. Any discrepant item was discussed and revised till there was agreement with at least 2 of 3 experts.

***Ethical Considerations:*** The study was reviewed by the Ethical Committee of Siriraj Institutional Review Board and approved to waive attainment of written consent (Protocol No. 727/2556). In order to maintain the participants' confidentiality, a staff of each clinic who could access medical data was requested to be research assistants. The research assistants initiated contact with the potential participants to explain the research project, and asked for their voluntary participation in the study and permission to introduce the researcher. The researcher gave the participants the clinic's address and telephone number to call back if they had doubts about the study. Participants' information was kept confidential.

***Data Collection Procedures:*** The participants who attended the clinic could complete the questionnaire at that clinic or made an appointment to conduct a phone interview. For the participants who did not attend, the research assistant first called them to describe the characteristics of project; ask for consent before participation in the study and disclosure of their HIV status to the researcher. All participants who were willing to be contacted by phone were given a secret code for the next contact to increase personal identification accuracy. Data were collected by self-administered questionnaire (71 mothers) and telephone interview (114 mothers) between March 1 and July 31, 2014. It took each participant approximately 18-35 minutes to complete the questionnaires.

***Data Analysis:*** **Data were analyzed using descriptive statistics and logistic regression.** Descriptive statistics including frequencies, percentages, and means used to describe demographic data of the participants. Prior to the univariate logistic regression, the data of four variables (health coverage, referral, disclosure of HIV status, and retention in care) were coded and categorized into 2 groups. Health coverage included self-payment and able to be reimbursed for costs of care and treatment. Referral included official referral and non-referral. Disclosure of HIV status included disclosure and non-disclosure. Retention in care included retention and non-retention. Univariate logistic regression analyses were used to examine the association between the eight potential predictors and retention in care and multivariate logistic regression analyses were used to determine the predictors of retention in care.

## Results

### Sample Characteristics

The characteristics of study sample (N = 185). The ages of the mothers ranged from 18 to 44 years with the mean age of 31.30 years (SD = 6.07). More than half (52.4%) of the mothers were aged between 31-40 years old. The majority (80%) cohabited with their partners. In terms of educational level, about 34.1% of the mothers completed junior high school, whereas 21.6 percent graduated from senior high school, while 29.7% of the mothers were housewives and a similar number were laborers (27.6%). Twenty-seven percent of the mothers had family income of between 9,001 - 15,000 baht. More than three quarters (77.3%) of the participants had retention in care at HIV clinics while only 46.5% had retention in care at OB & GYN clinics.

The participants who were retained in care at HIV clinics had higher percent of health coverage (96.5%), received official referral (88.8%), and disclosure of their HIV status (86.0%) than those with non-retention in care. On the other hand, at OB & GYN clinics, most participants (92.9%) who had health coverage were not retained in care at a OB & GYN clinic. The percentage of receiving official referral in the participants who were retained in care at OB & GYN clinics had higher than those with non-retention in care. The percentage of disclosure of HIV status in the participants who were retained in care at OB & GYN clinics had slightly higher than those with non-retention in care, as shown in Table 1. At the HIV clinics, the mean scores for access to health care, receiving HIV care, attitudes toward health care providers (AHHCP), and perceived health status were higher among the participants who had retention at the clinic than those with non-retention in care. The mean score for stigma among the participants who were not retained in care at HIV clinics was higher than those with retention in care. At the OB & GYN clinics, the mean scores for access to health care, receiving HIV care, AHHCP, and stigma were similar among the participants who had retention as participants who were retained at the HIV clinics. However, the participants who were retained at the OB & GYN clinics had the same perceived health status scores as those who were not retained in care (Table 2.).

**Table 1.** Frequency and Percentage of Study Variables (N=185)

| Variables | HIV clinics | | | | OB&GYN clinics | | | |
|---|---|---|---|---|---|---|---|---|
| | Retention (n=143) | | Non-retention (n=42) | | Retention (n=86) | | Non-retention (n=99) | |
| | N | % | N | % | N | % | N | % |
| Health coverage | | | | | | | | |
| - Health coverage | 138 | 96.5 | 36 | 85.7 | 49 | 57.0 | 92 | 92.9 |
| - Self-payment | 5 | 3.5 | 6 | 14.3 | 37 | 43.0 | 7 | 7.1 |
| Referral | | | | | | | | |
| - Referral | 127 | 88.8 | 7 | 16.7 | 74 | 86.0 | 60 | 60.6 |
| - Non-referral | 16 | 11.2 | 35 | 83.3 | 12 | 14.0 | 39 | 39.4 |
| Disclosure of HIV status | | | | | | | | |
| - Disclosure | 123 | 86.0 | 29 | 69.0 | 77 | 89.5 | 75 | 75.8 |
| - Non-disclosure | 20 | 14.0 | 13 | 31.0 | 9 | 10.5 | 24 | 24.2 |

**Table 2.** Mean and Standard Deviation of Study Variables (N=185)

| **Variables** | **HIV clinics** | | | | **OB & GYN clinics** | | | |
|---|---|---|---|---|---|---|---|---|
| | **Retention** | | **Non-retention** | | **Retention** | | **Non-retention** | |
| | $\overline{X}$ | **SD** | $\overline{X}$ | **SD** | $\overline{X}$ | **SD** | $\overline{X}$ | **SD** |
| Access to Health Care | 22.29 | 4.02 | 19.76 | 3.59 | 22.28 | 4.14 | 21.23 | 3.94 |
| Receiving HIV Care | 8.68 | 2.38 | 6.83 | 3.98 | 8.70 | 2.41 | 7.88 | 3.26 |
| AHHCP | 99.66 | 14.11 | 99.50 | 14.25 | 100.47 | 13.26 | 98.90 | 14.83 |
| Stigma | 24.48 | 5.38 | 25.48 | 5.44 | 24.57 | 5.45 | 24.83 | 5.38 |
| Perceived Health Status | 8.34 | 1.50 | 7.71 | 1.97 | 8.20 | 1.44 | 8.20 | 1.79 |

AHHCP=Attitudes toward health care providers

At HIV clinics, univariable logistic regression analyses revealed that six out of eight important factors were significantly associated with retention in care including health care coverage, referral, disclosure of HIV status, access to health care, receiving HIV care, and perceived health status. However, at the OB & GYN clinics, only two out of eight factors were significantly associated with retention in care, referral and disclosure of HIV status. Only significant variables from univariate logistic regression analyses were entered to multivariate analyses.

At HIV clinics, the result revealed that three factors (health coverage, referral, and perceived health status) could predict retention in care at HIV clinics, as shown in Table 3. The results also indicated that after controlling for the effect of other variables, the odds of retention in care at HIV clinics for mothers who had reimbursement of health coverage as a ratio to the odds for the mothers with self-payment equaled 46.32. Regarding referral, the odds of retention in care at HIV clinics for mothers who were referred to another HIV clinic, as a ratio to the odds for the mothers who were not referred, equaled 8.90. In regard to perceived health status, the findings indicated that every one unit of increased perceived health status increased the odds of retention in care at HIV clinics by 50%. These three significant factors could present the variance of retention in care at HIV clinics during the first year after delivery at 80%.

**Table 3.** Multivariate Logistic Regression Analysis of Predictive Model of Retention in Care at HIV Clinics (N=185)

| Factors | b | S.E. | Wald | *p* | Exp(B) | 95%CI |
|---|---|---|---|---|---|---|
| Health care coverage | 3.84 | 0.79 | 23.60 | <.001 | 46.32 | 9.86-217.71 |
| Referral | 2.19 | 0.66 | 10.99 | <.01 | 8.90 | 2.44-32.44 |
| Disclosure of HIV status | 0.74 | 0.76 | 0.93 | >.05 | 2.09 | 0.47-9.35 |
| Access to health care | 0.03 | 0.08 | 0.14 | >.05 | 1.03 | 0.88-1.21 |
| Receiving HIV care | -.008 | 0.11 | 0.005 | >.05 | 0.99 | 0.80-1.23 |
| Perceived health status | 0.40 | 0.19 | 4.62 | <.05 | 1.50 | 1.04-2.17 |
| Constant | -6.97 | 2.23 | | | | |

-2LL = 85.94, Nagelkerke's $R^2$ = 0.80

At OB & GYN clinics, two factors (referral and disclosure of HIV status) could predict retention in care at OB & GYN clinics, as shown in Table 4. The results also indicated that after controlling for the effect of other variables, the odds of retention in care at OB & GYN clinics for the mothers who were not referred was equal to 3.80. In regard to disclosure of HIV status, the finding indicated that the odds of retention in care at OB & GYN clinics for mothers who had disclosed their HIV status as a ratio to the odds for the mothers who had not was equal 2.46. These two significant factors could present the variance of retention in care at OB & GYN clinics during the first year after delivery at equal to 14%.

**Table 4.** Multivariate Logistic Regression Analysis of Predictive Model of Retention in Care at OB & GYN Clinics (N=185)

| Factors | b | S.E. | Wald | *p* | Exp(B) | 95%CI |
|---|---|---|---|---|---|---|
| Referral | 1.33 | 0.38 | 12.51 | <.001 | 3.80 | 1.81-7.95 |
| Disclosure of HIV status | 0.90 | 0.44 | 4.21 | <.05 | 2.46 | 1.04-5.80 |
| Constant | -1.89 | 0.49 | | | | |

-2LL = 235.46, Nagelkerke's $R^2$ = 0.14

## Discussion

In this study, approximately 77% of the mothers had retention in care at HIV clinics while only 46.5% had retention in care at OB & GYN clinics. Rates of retention in care was higher than those reported in prior studies conducted in Thailand[5, 6] and the United States.[28] Moreover, retention in care was higher at the HIV clinics than at the OB & GYN clinics, especially retention at the university hospital, because most mothers received financial support from the research project for HIV treatment and travel expenses.

Several factors were associated with the retention in care after delivery. First, one of the key predictors of retention in care for both clinic types was official referral. Most mothers had health care coverage at other hospitals therefore they needed to receive official referral in order to be retained in care. This result is consistent with a study in Kenya[29] where direct referral from clinic-to-clinic before patients' discharge increased clinical retention. Second, two predictors, health care coverage and perceived health status, significantly predicted retention in care at the HIV clinics, but did not significantly predict retention in care at the OB &

GYN clinics. In regard to health care coverage, more than 90% of participants had health care coverage. The available health care coverage schemes covers free HIV treatment, but did not cover the cost of a Pap smear. At present, a person who is HIV+ and has universal health coverage can transfer their benefits to any hospital for HIV treatment only by consent of the transferring hospital.[30] However, at OB & GYN clinics, most mothers could not take advantage of their health care coverage for Pap smear screening because their registered hospitals charged for this. However, 20% of the participants were willing to pay by themselves to facilitate retention in care at OB & GYN clinic. The mothers who could not pay this cost were not retained in care at the OB & GYN clinics. Therefore, the provision of a free service system contributed to higher patient retention in care at HIV clinic but not at OB & GYN clinic.

Regarding perceived health status, findings from this study differ from several previous studies. Although mothers perceived good health, they were retained at HIV clinics because of their perceptions of the necessity for treatment.[31] On the other hand, most mothers were not aware of the higher risk of cervical cancer in persons with HIV; pathological changes of the cervix are detected by cervical screening only.[32] Therefore, if the patients considered themselves at low risk for this disease, they would not screen for cervical cancer or be retained in health care.[33] Third, disclosure did not significantly predict retention in care at the HIV clinics because health care coverage and official referral were two greatly influential variables in the prediction equation of multivariate analysis at HIV clinics as aforementioned.

Fourth, four factors did not significantly predict retention in care at either the HIV or the OB & GYN clinics: access to health care, receiving HIV care, AHHCP, and stigma. Regarding access to health care, this finding is different from a study in sub-Saharan Africa.[34] In this study, access to health care measured perceived problems with access of the mothers when they became sick during the first year after delivery. Most mothers were never sick or had only minor illness such as headache. Thus, they used health service at clinics near their home or treated those symptoms by themselves. In regard to receiving HIV care and retention at HIV clinics, this result is not congruent with studies in several countries such as Taiwan[35] and Japan,[36] in which their health care systems provide comprehensive care by several HCPs who work together as a multidisciplinary team. In this study, some mothers received ANC at a hospital, but were referred to another hospital only for delivery. These women met a nurse only for a short period of time at the postpartum ward before being discharged, which was not enough time to increase retention in care after delivery.[37] In addition, during ANC, the mothers received HIV care from different clinics that meant a difference in the process of HIV care. Regarding AHHCP, findings from this study are inconsistent with several studies.[37, 38] Attitudes in this study were derived from the experience of the women in contacting health care providers during antenatal to postpartum care. It does not affect retention in long-term care after giving birth. Relating to stigma, this finding is also inconsistent with several studies.[30, 34,] Although, most mothers experienced high levels of social stigma, this may motivate individuals to seek support from their health care providers and thus be retained in care.[39]

## Limitations

The limitations of this study are related to data collection which might lead to three types of bias[40] as follows. Firstly, there is the potential for recall bias. Several mothers had given birth in the past two or three years, so they could not fully recall the situation during that period. Their answers might have deviated from the actual circumstances through recall bias. Secondly, there is potential response bias. The registered nurses or health care providers of the clinics who were familiar with the patients introduced them to the research project and the researcher. This might have resulted in overestimated scores of receiving HIV care and AHHCP. Moreover, during data collection at the HIV clinic, the university hospital where the research project was conducted provided free laboratory testing and ARV drugs for the patients. This might have affected the number of patients who were retained at the hospital. Therefore, the prevalence rate of retention in care is more likely to have been overestimated. Finally, there is potential non-response bias. This research was based on convenience sampling; non-respondents (34.6% of population) may have differed from those who responded and their exclusion could have led to non-response bias.

The measure of access to health care is another limitation as the internal consistency (Cronbach's alpha) in this study was 0.62. This instrument was developed to use for AIDS-advanced stage patients who were in urgent need of care. Therefore, it might not have been an appropriate for measure in asymptomatic patients. Finally, the research findings might have limitation in generalization. In addition, the data were collected only the setting that had research program to improve retention in care among asymptomatic mothers with HIV.

## Conclusions and Implications for Health Care Policy and Nursing Practice

This study fills a significant gap in the extant literature by examining factors associated with retention in care after delivery among Thai mothers with HIV. Three factors were predictive of retention in care at HIV clinics: official referral, health coverage, and perceived health status. Two factors were predictive of retention in care at OB & GYN clinics: referral and disclosure of HIV status.

Based on the findings of this study, policy makers should pay greater attention to having a roadmap to construct an effective referral system and linkage to HIV health service for enhancement of retention in HIV care. Mothers who use a social security scheme or universal coverage should have a chance to determine their registered hospital by themselves so they can have ease of access. Moreover, policy makers might consider the possibility of improving health benefits of health care coverage to be more relevant to individuals' needs. The health care policy should also determine a framework for monitoring the health coverage operational management of health care facilities in accordance with the HIV treatment guidelines to reduce barriers to patients' health service utilization, especially in private hospital. Moreover, the health care policy should provide equally proactive care for both HIV symptomatic and asymptomatic patients.

In regard to nursing practices, nurses should emphasise the importance of retention in care after delivery during postpartum period; the possibility of retention in care at registered hospitals under their health care coverage or other health facilities; their registered hospital according to their census registration; the treatment plans for mobile workers who have their registered hospital in a rural area; and asking for permission to provide a formal transfer letter to another health facility. Moreover, nurses should help the individual mothers plan for their disclosure. This should include discussing and thinking about what needs to be considered prior to disclosure, developing communication and language skills applicable to disclosure, and preparing for potential reactions and outcomes to disclosure.

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# ปัจจัยที่เกี่ยวข้องกับการคงอยู่ในการดูแลสุขภาพของมารดาหลังคลอดที่ติดเชื้อเอชไอวี

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**บทคัดย่อ:** การวิจัยครั้งนี้เป็นการศึกษาย้อนหลังแบบภาคตัดขวาง มีวัตถุประสงค์เพื่อศึกษาความชุกของการคงอยู่ในการดูแลสุขภาพ และทดสอบปัจจัยทำนายการคงอยู่ในการดูแลสุขภาพในช่วงหนึ่งปีแรกหลังคลอดบุตรของมารดาที่ติดเชื้อเอชไอวี กลุ่มตัวอย่างที่ใช้ในการศึกษาครั้งนี้คือ มารดาติดเชื้อเอชไอวีที่คลอดบุตรที่โรงพยาบาลของรัฐแห่งหนึ่ง ระหว่างวันที่ 1 มกราคม พ.ศ. 2553 ถึง 31 ธันวาคม พ.ศ. 2555 จำนวน 185 ราย เก็บข้อมูลระหว่างวันที่ 1 มีนาคม - 31 กรกฎาคม พ.ศ. 2557 โดยการตอบแบบสอบถามด้วยตนเองและการสัมภาษณ์ผ่านทางโทรศัพท์โดยใช้ 5 แบบสอบถาม ได้แก่ แบบสอบถามข้อมูลส่วนบุคคล การเข้าถึงการดูแลสุขภาพ การได้รับการดูแลทางด้านเอชไอวี ทัศนคติที่มีต่อผู้ให้การดูแลสุขภาพ การรับรู้ตราบาปเกี่ยวกับเอชไอวีฉบับย่อ วิเคราะห์ข้อมูลโดยใช้สถิติเชิงบรรยาย และการวิเคราะห์ถดถอยลอจิสติก

ผลการวิจัยพบว่า 77.3% ของแม่ที่ติดเชื้อเอชไอวีคงอยู่ในการดูแลสุขภาพที่คลินิกเอชไอวี ขณะที่ 46.5% ของแม่ที่ติดเชื้อเอชไอวีคงอยู่ในการดูแลสุขภาพที่คลินิกสูติศาสตร์-นรีเวชวิทยา ผลการวิเคราะห์ถดถอยลอจิสติกพบว่า ปัจจัยที่สามารถร่วมทำนายการคงอยู่ในการดูแลสุขภาพของมารดาที่คลินิกเอชไอวี ได้แก่ หลักประกันทางสุขภาพ การส่งต่อแบบเป็นทางการ และการรับรู้สภาวะสุขภาพ โดยทั้งสามปัจจัยร่วมกันอธิบายโอกาสในการคงอยู่ในการดูแลสุขภาพของมารดาที่คลินิกเอชไอวีได้ร้อยละ 80 ปัจจัยที่สามารถทำนายการคงอยู่ในการดูแลสุขภาพของมารดาที่คลินิกสูติศาสตร์-นรีเวชวิทยา คือ การส่งต่อแบบเป็นทางการ และการเปิดเผยการติดเชื้อเอชไอวี โดยทั้งสองปัจจัยร่วมกันอธิบายโอกาสในการคงอยู่ในการดูแลสุขภาพของมารดาที่คลินิกสูติศาสตร์-นรีเวชวิทยา ได้ร้อยละ 14

ข้อเสนอแนะจากงานวิจัย ผู้ให้การดูแลสุขภาพควรจัดให้มีระบบการส่งต่อผู้ป่วยที่มีประสิทธิภาพไปยังสถานบริการพยาบาลที่ผู้ป่วยมีสิทธิหลักประกันสุขภาพ และปรับปรุงบริการของสิทธิประโยชน์ชนิดต่างๆ ให้สอดคล้องกับความจำเป็นในการใช้บริการของผู้ป่วยโดยรวมอย่างแท้จริง นอกจากนี้การจัดการดูแลผู้ติดเชื้อเอชไอวีควรคำนึงถึงการเปิดเผยตนเองของมารดาแต่ละรายด้วย

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# Experiences of People with Advanced Cancer in Home-Based Palliative Care

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**Abstract:** People with advanced cancer who are receiving palliative care at home has increased dramatically in Thailand. The aims of this study were to explore the experiences of people with advanced cancer in home-based palliative care and to study and inform caregiving for them. A qualitative approach was employed using a phenomenological investigation of people with advanced cancer with data gathered from 2011 to 2012. There were seven participants engaged through multiple in-depth interviews. In addition, their family caregivers, and five public health nurses provided perspectives on caregiving through focus group discussions. Three main themes emerged: 1). 'State of being', experience facing the end of life. 2). 'Quality of life', experience of life satisfaction and satisfaction with care; and 3) 'Compassionate care in the Buddhist view', a holistic approach through caregiver assistance, resources and supplies. Palliative care experiences served to enhance the quality of life for people with advanced cancer through a culturally-appropriate, holistic approach of family and nursing care.

This study shows how persons with cancer and their relatives faced end of life crises while fighting to maintain peace and dignity. Sufferers' life experiences and how caregivers helped people with advanced cancer deal with their cancer, suffering, and enabled them to have a better quality of life.

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**Keywords:** Advanced cancer, Home-based care, Palliative care, Phenomenology

## Introduction

Global trends have created a better understanding of useful concepts for comprehensive practice patterns, both direct and indirect, with positive and appropriate responses to the needs and problems of people with advanced cancer (PAC) in maintaining optimal health and quality of life (QOL). However, PAC and their families can manage chronic care through the stages

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of the cancer pathway to a good ending, death with dignity. Early discharge from hospital necessitates setting up and implementing a continuing care plan in the home, in order to reduce what otherwise would balloon national health care debt.[1,2] Current hospital policies aim to reduce hospital stays. In Thailand, public health service policy has established and extended this national strategy to practice through home care for chronic illness, often ending with dying at home.[3]

Severe illnesses, like cancer, require ongoing, comprehensive palliative care during a person's last stages of life. Patients often prefer to be at home during these times but the required active and holistic care is rarely available, causing family caregivers (FC) to bear the burden of care. Recently, new home palliative care strategies for pain relief, symptom control, and spiritual healing have been developed.[4] Palliative care for PAC aims to reduce institutional burdens and increase the possibility of dying at home instead of in a hospital or health care institutions.[5] However, translating knowledge into policy and practice can be limited due to lack of planning, human resource preparedness and effective utilization.

Home-based care necessitates essential continuing care from hospital to home and this requires a natural extension of the roles and function of public health and community nurses. The Bangkok Metropolitan Administration Health Department has provided home care delivery for all kinds of illnesses for Thai patients at home since 1974,[6] including taking care of patients with cancer.

Cancer was the third leading cause of death in Thailand in 2014.[7] The Health Information Unit, Bureau of Health Policy and Strategy[4], reported that one of the major challenges facing the health service system is cancer. The National Cancer Institute report of 2014 stated that the number of patients with cancer was 2,955 per 100,000 population[2] and more than one fifth of people with cancer live in Metropolitan Bangkok.[7]

Moreover, in the case of advanced cancer, Walshe and Luker[8] indicated that PAC have a wide range of problems and needs; resulting in anxiety and uncertain conditions not only in daily activities, but also from a complexity of signs and symptoms which impedes responding with effective psychological and spiritual care. Structural support is needed for effectively coping with fear and reducing the fear of suffering. There are few comprehensive studies of dying patients in home-based care in Thailand,[9] especially regarding psychosocial and spiritual healing. Yet, home-based care must provide continual care with reference to patients' needs.[10] Although a few international studies on palliative care at home from foreign countries have revealed special needs of patients and relatives, nurses need a deep understanding of the cultural context in their own country for meeting home care needs.

In Thai culture, people want to die at home, in a familiar environment and surrounded by family and friends. Older people may be reluctant to live at home during the last stage of life due to fear and uncertainty.[11] PAC are dependent on others to meet common living conditions and require care by their family/relatives and/or a visiting nurse. Home-based palliative care leads to the extension of the roles and function of Public Health Nurses (PHN) to be responsible for informing palliative care by FC.[12] However, most PHN are not well prepared to provide chronic care to clients at home. There is very scant knowledge and training regarding palliative home-based care in Thailand.

Public health care system policies in Thailand need to embrace home-based care, especially regarding the home health care concept. PHN have the opportunity to provide benefits in terms of both psychological and palliative care[5] through support of FC by providing information and building relationships. PAC would then have more options to live the rest of their lives at home surrounded by family.

This study provided insights into home-based care for PAC; home-based care affects families and relatives' emotional, social, physical, and spiritual well-being more than in any other setting.[6]

## Review of Literature

Palliative care is based on pain relief, addressing symptoms and providing emotional and spiritual support for the patient and their family members.[6] Palliative care is multi-level care and with various methods of care provided by PHN and formal and informal caregivers. Palliative care addresses the relief of suffering and healing help directed at improved QOL and a good death. A good death in cancer care is composed of physical and psychological comfort, dying in a favorite place, a good relationship with medical staff, maintaining hope and pleasure, and dignity in terms of not being a burden to others. Santina and Bernstein[13] stated that a good death is one:

> *That is free from avoidable distress and suffering for people, families and caregivers; in general, according with patients' and families' wishes for peace and dignity; a good death has been described as one that is pain free, where dying is acknowledged and preferably occurs at home in the presence of family and friends, with the patient aware and alert so the unresolved business of life can be accomplished.*

Human experiences are reflected as phenomena, as lived realities. Based on the purpose of this study, the researcher applied the phenomenological approach outlined by Martin Heidegger. Phenomenology can be understood as a process of discovering the objects of attention in one's 'life-world', revealing oneself as 'those to whom things appear'. So it is potentially a rich source of experience, revealing subjective meanings.[14, 15] Heidegger argues that his phenomenology is based on the concept of "dasein", in German, meaning "there being", an expression of being in the world; this is a specific understanding in which lived expression always comes to be understood as something performing an important function, as performing a type or state of being, and is found in the human experience by analyzing relationships and lived experiences.[16]

According to previous studies, there are many accounts about people with cancer who have had both positive experiences, appreciating their families, and negative experiences,[17]extreme feelings of suffering and uncertainty.[18,19] PAC frequently have existential experiences about the severity of physical disease and spiritual distress. [20] The best way to understand them is to examine their experiences and relationships in order to deal with advanced cancer and life-threatening diseases, through translating this experience to serve nursing care practice.[21, 22]

## Study Aims

1. To explore lived experiences of PAC in home-based palliative care.
2. To study and inform caring for PAC in the home.

## Method

This study utilized a qualitative approach to explore the experiences of PAC. Using purposive selection, researchers selected individuals for study participation based on their experiences of the phenomenon for the purpose of sharing that experience.[23] Experiences were shared through in-depth interviews from PAC, cared for at a pain control clinic, home care clinic of the National Cancer Institute, or those staying in their homes in Metropolitan Bangkok. Select FC and PHNs provided context and insight to PAC experiences through focus group discussions.

The inclusion criteria for the participants were people diagnosed with advanced cancer, located in Metropolitan Bangkok and surrounding vicinities who could communicate effectively with the researcher, and consented to participate in the study.

*Data collection:* In-depth interviews using open-ended dialogue were used for in-depth interviews with PAC which were tape recorded, reviewed and confirmed in follow-up interviewing. Interviews were carried out in participants' homes. During 2011 and 2012, two or three interviews were conducted per study participant. The 18 in-depth interviews each averaging 40 minutes were conducted over six months (see table 1). Field notes were recorded immediately after each interview.

Guidelines for questions in each interview were designed to elicit information about lived experiences such as; "Could you please describe your experience living with your disease? "What is your life like?" and "Please tell me about your care and how you feel about it?" Sub-questions or probing questions were sometimes used to elicit feelings about needs: "What needs/cares are most important to you?"

*Focus group discussions:* Focus group discussions were held at health centers with PHN who cared for PAC, had focus groups averaging one hour at mini-health centers at their convenience. A total of two focus groups were held with each FC group; the first with FC1-4, the second with FC 5-7, and there was one focus group discussion with PHN. The focus group settings were prepared in advance by the researcher for privacy and to ensure useful interviews.

A standard questionnaire was used in the focus group discussions with the seven FC and five PHN about the care for PAC. Focus group questions included such questions as, "What kind of care did you provide?" "How has this impacted your life?" Follow-up questions included, "Please tell me how you felt when you discovered that" and "So what happened next?"

*Credibility and Trustworthiness*: The researcher was familiar with home health care concepts and the care of those with chronic illness in families of the Thai culture. The researcher had an understanding of participants' culture, dialects and their social values as well as general home care practice, all useful throughout the interview process. Research analysis relied on narrative data and personal accounts of human experiences.[20] A variety of alternatives have been suggested to evaluate analytical research.[21] In this study, reliability checks were undertaken regarding the themes derived within completed interviews and related themes by two members of the research team. High levels of agreement were expected while any minor differences were resolved by consensus. The validity of information was verified and clarified with each participant over the course of their interviews.

*Data analysis:* The phenomenological approach of Martin Heidegger was used to study aspects of experience of the participants.[14,15] Field notes and researcher observations were recorded and transcribed for content analysis. Kvale[20] explained this method as follows: "the researcher begins the process after the first interview by listening to the audiotapes, performing verbatim transcription, and reading the extracted transcripts to understand the hidden meanings in the text. The researcher re-examines the text with a back and forth movement of both the whole text and parts of the text to gain deeper comprehension of the emerging themes." The thoughts, daily life activities and actions of the participants related to palliative care were presented through their life story, social values, feelings and emotions, and language based on Thai custom in their home and community. Through this process, insights were gained about the beliefs, practices, and lived experiences of PAC. FC and nurse practices and roles were among the topics discussed. The optimum content from interviews was achieved when data analysis reached a point of saturation of themes from PAC's experience.

*Ethical approval* was provided by the Institutional Review Board of Mahidol University (Coding; MUPH 2011-075), and the Ethics Committee of the National Cancer Institute of Thailand (Coding; EC 251/2011). All participants gave their consent and were informed that they could withdraw from the project at anytime they wanted without any consequences. PAC interviews were suspended and rescheduled if the participants became sick or upset in relating their personal experience. Confidentiality of all data was explained to participants and all tape recordings of interviews and focus groups were destroyed once the project was finished.

## Results

The participants with advanced cancer had a mean age of 59 with a range of 37-84 years. Five of seven had received home-based care from both PHN and FC, and two only from FC. Three participants were male and four were female. Four of seven participants were married and their spouses were their caregivers. Two participants had brain cancer, two had stomach cancer and the others had colorectal, lung and cervical cancer. Five of them had access to universal health coverage insurance and the other two had government welfare or social security. The characteristics of the PAC are given in Table 1:

**Table 1** Thedemographic Characteristics of the PAC.

| No/ code | Age Gender | Marital status | Prior occupation | Level of education | Site of cancer | No of In-depth interview | FC | PHN*** caring |
|---|---|---|---|---|---|---|---|---|
| M1 | 68 M* | married | small trade | Elementary | stomach | 3 times | wife FC1 | PHN1 |
| M2 | 58 M | married | wage workers | Elementary | Lung | 2 times | wife FC2 | PHN2 |
| W3 | 58 W* | married | housewife | Elementary | stomach | 3 times | husband FC3 | PHN3 |
| W4 | 53 W | widow | housewife | Elementary | brain | 2 times | daughter FC4 | PHN4 |
| W5 | 84 W | widow | none | Literacy | brain | 3 times | daughter in-law FC5 | PHN5 |
| W6 | 55 W | widow | housewife | Elementary | Cervical | 2 times | Sister in-law FC6 | No one |
| M7 | 37 M | married | employee | Bachelor | Colorectal | 3 times | wife FC7 | No one |

Note; M= Male; W= Female;

The FC participants had a mean age of 42 with a range of 26-58 years. Six of seven FC were female. Four of seven were spouses, two were siblings, and another sister in-law. Most of them had an elementary education. The five female PHN participants had a mean age of 35 with a range of 32-56 years. All of them had a bachelor degree in nursing science.

Three themes emerged from PAC interviews and caregiver focus groups: State of being, Compassionate care in the Buddhist view, and QOL. Two themes emerged from PAC through in-depth interviews: State of being and QOL. The other theme emerged from PHN and FC in the focus groups: Compassionate care in the Buddhist view. In the text, participant quotes are used to illustrate the results presented in Table 2.

**Table 2**: The Experiences of PAC

| Main Theme 1: **State of being** | | | |
|---|---|---|---|
| Theme | Suffering in dying process | End of life | |
| Subtheme | Physical, emotional and mental, Psychosocial and Spirituality function | Deterioration of Physical cognitive, Psychosocial, and Spirituality changed | |
| Main Theme 2: **Compassionate care in the Buddhist view** | | | |
| Theme | Holistic approach | Caregiver care | Resources and materials |
| Subtheme | Goal and vision sharing, Clients' problem-orientated decision making, decision making, Relationship, Communication, and trust | bereavement care and respite care | Information and equipment, materials for home health care |
| Main Theme 3:**Quality of life** | | | |
| Theme | Satisfaction in caring | Life-Satisfaction | |
| Subtheme | Caring meet the need, Competences, Continuity of health care providers, adjustment | Alleviated pain, surrounding their loved ones, dignity/not restrained, Religious practice, and touch in calm and peaceful *(decent leave all behind)* | |

## State of being

PAC experiencing suffering in dying process when approaching the end of life and often expressed their suffering in four dimensions: in physical, emotional/mental, psychosocial, and spiritual dimensions as revealed through the process of their decline. The end of life themes was crucial to the predicaments of change and decline in physical health, and psychosocial and spiritual circumstances of the PAC.

**Suffering in dying process:**

> *"I have been suffering from the side effects of treatment, I still have diarrhea and nausea, so I have increased weakness and am disheartened, but I still have relief from tension due to my daughter staying with me all the time, and also the presence of my niece. I feel happy whenever my children are around."* (W5)

W5 spoke in a whisper with a weak voice, saying it was important to maintain normal activities and be engaged even when dependent on others. The physical and emotional distress of people dying from cancer and its treatment has a significant impact on peoples' lives which can lead to difficulties in doing daily activities until the end of one's life. Severe illness affects the life of people as participants explained their physical circumstances and how these handicaps resulted in pessimistic perceptions developing. Due to family inter-relationship, one PAC expressed the wish to see her niece grow up to adulthood, so she hoped to live although she knew she could die at any time.

Likewise, negative points of view when coping with cancer progression can lead to psychosocial conditions which made two PAC feel angry like they were being punished and wished to die as expressed below:

> *"I feel anxious as if it (the drug) is a poison running into my body via the infusion of a venous solution"* (W3)

**End of life:** People with advanced cancer often encounter physical, psychosocial and spiritual decline. "When your days depend greatly on others, you are valueless" said one interviewee, M7, who is the head of his family. His wife (FC7) who provided constant care for him, confirmed he wishes to regain his independence and life. On the other hand W6, who has faced declines from physical and psychosocial changes, wished to die as soon as possible as he explained:

> *"What should I do? You know what; I would love to die to get away from this suffering?"*

When the severity of the illness increased and moved one closer to the end of life, the PAC had deteriorating physical conditions. Among those who considered they had received decent care and clear communication from caregivers, there was a spiritual change in their acceptance in leaving all behind, calmly countering fear and accepting the end of life. This means that they wish to died naturally. The two participants explained:

> *"I need my wife (FC1) to help me to explain to the doctor that I don't want the operation (tracheotomy). I don't want anything else. It is all the best for me"* (M1)

In a positive view, he expressed that:

> *"I've always decided the true situation for deciding the best direction on matters relating to my life, but treatment has changed that, and it is only my luck that I have a caring spouse who can now meet my needs."* (M7)

## Quality of life

QOL is perceived differently for everyone. The main thing is the ability to enjoy what one has in life. QOL for PAC derived from good care provided to them. This was revealed through two themes: Satisfaction in caring and Life satisfaction. The Satisfaction in caring theme consists of knowing that PAC needs for health care are being met through continuity of care and provision of competent care. The Life satisfaction theme consists of PAC having their pain alleviated, being surrounded by loved ones, having one's human dignity maintained without restraint, having freedom of religious practice, and touch that calms and brings peace.

**Satisfaction in caring:** This should be considered to be one of the most desirable outcomes of care, even as an element of one's health status (state of being). When the severity of illness brings one close to the end of life, the last stage, PAC in this study had deteriorating experiences. Two received close care from their caregivers, very supportive care, even when they had great suffering from their health conditions. Satisfaction in caring was reflected in the following experience:

> *"...now that it is more serious, I'm ready, knowing that it (severity of complications and health conditions) are close and coming. It will soon arise after all. It is what we as human beings have to face. I am satisfied with the dedicated care my family members have given me."* (W5)

> *"She (PHN) has provided proper care, particularly when my relative has emergency signs or severe pain and becomes uncertain; when I can't make a decision by myself...I ask her even outside office hours...I feel confident in her caring for my relative."* (FC2)

**Life satisfaction:** This was reflected in their state of being and favorable attitudes, and expressed through alleviation of pain, being surrounding by loved ones, dignified, unrestrained care, freedom of religious practice, and gentle treatment with a calm and peaceful touch.

> *"I feel good to be with my close siblings"*(W5)

PAC and FC described continuity of health care at home as follows:

> *"...I've been taking care of my relative and the nurse visits our house regularly,...I feel appreciated, get good advice, even outside office hours..."* (FC1)

One theme emerged from the focus groups with PHN and FC:

**Compassionate care in the Buddhist view:** Caring for PAC from the perspective of formal and informal caregivers had numerous meanings and some differences. The PHN and FC care for PAC, who had experiences suffering during the dying process and at the end of life, expressed compassionate care through three subthemes in focus group discussions: the Holistic approach, Caregiver care, and Resources and materials.

**Holistic approach:**

Total holistic care, physical, emotional, psycho-social, and spiritual, was expressed by PAC and caregivers as below:

One PAC expressed relationships at end of life as follows:

> *"... due to my dreadful sickness, I cannot have daily life activities by myself. I need someone to help and understand me."* (M7)

One PAC explained their dilemma in receiving care as follows:

> *"Because I did not eat anything for a long time, and I threw up and had diarrhea and anorexia, the result was that my bodyweight dropped by over 10 Kg. and I nearly had cachexia. I required my wife to take care of me and stay with me all the time. Unfortunately, she cannot... she is the only source of money for my family."* (M2)

The care which one FC gave to their loved one is shown as follows:

> *"I took care of him providing all kinds of food as he asked, cleaned his body ... as I could, because sometimes I had to work, anyway I tried to let him know that this is his destiny*

> *or fate and we would pass this critical period with our faith in Buddhist ritual, alms, chanting and especially by releasing sin through freeing birds or fish; believing that this merit will bring balance to his spiritual life."* (FC7)

Among the PHN, three of five explained palliative care through a holistic approach as consisting of physical, psycho-social and spiritual care, assisting with functional aspects of life, and social and family care. They expressed great importance for palliative care that home-based nurses are prepared to integrate palliative care into their practice:

> *"Caring for people in the last stage of life is very complex. Holistic care is required at all times... to deal with physical symptoms of the disease, such as the side effects of treatment.... Therefore, I am concerned with the needs of the patients and holistic care, making me unsure I can provide the extensive care for these patients; sometime I feel unsure that I am prepared to provide end stage of life care."* (PHN4)

> *"We care by understanding our client's belief and value in the doctrines of Buddhism, and faithfulness, and having rituals for care with our clients. Some of them give alms in the morning or chant praises, some have careful consideration of their breathing in and out like in meditation, some have a little Buddha image pendant or amulet laying under their pillow"* (PHN 5)

> *"I took care of her comfort, and she didn't need anything more. I tried to ask for my brother (her son) to be a monk one time, because my mom had a great expectation to see her son temporarily become a monk as merit, as is Buddhist tradition."* (FC4)

The trusting relationship of PAC, their family and PHN in home-based care is revealed in these PAC experiences:

> *"She (FC4) came to my room and looked at me for a long time, she touched me to make me calm and told me to care for myself and ... I felt serene and confident."* (W4)

Family relationships and information are the most important for those being supported in home-based palliative care by PHN as one FC explains:

> *"I was given useful information about my life and health from the PHN at my times of need. I felt generosity when I ask for her idea...I could contact them (the nurses) to get help from PHN at the time I needed."* (W3)

**Caregiver care**: Bereavement care is considered a normal response to death and loss which is a universal human experience. It was reported that this care can help with sleep and other physical symptoms and includes using prayer and meditation.

> *"The FC do need bereavement care from my experience; some have high sorrow and are extremely upset."* (PHN5)

Respite care is the provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home. The respite care subtheme emerged from PHN's views as below:

> *"I suggested the main caregiver to leave for her own enjoyment to be replaced by friends/neighbors/relatives/health volunteers."* (PHN4)

**Resources and materials**: In PAC, resources are essential elements for support through palliative home-based care. Resources and materials include experiences with three subthemes: information, equipment, and meeting demands on time and at the right place. One caregiver explained:

> *"Some health materials and instruments are very expensive. We cannot afford tubes and disposable pampers which are not covered...I always receive useful information from the PHN about these needed items."* (FC1)

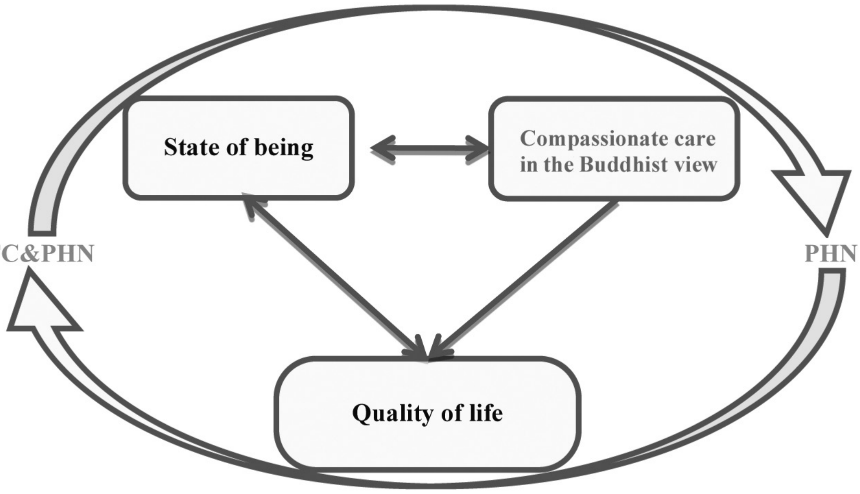

**Figure**1. The major themes of experiences of PAC and caregivers are state of being, compassionate care in the Buddhist view, and quality of life.

In order to present the data more clearly for readers above, the researcher first presented only the data in each theme and subtheme that came from PAC life experience, and then from information of caregivers and the researcher's observations. This draws on the three themes: state of being, compassionate care in the Buddhist view and QOL. The state of being directly interacts with compassionate care in the Buddhist view and QOL, while compassionate care in the Buddhist view directly affects one's QOL. In the same way, the effect of caring and support from PHN and FC increases QOL. Finally, caring and its consequences for PAC weresummarized and the constitutive patterns of the three main themes emerge as state of being, compassionate care, and QOL.

## Discussion

The results from considering the experiences of PAC and caregivers views brought forward three themes. State of being and QOL were revealed by PAC. Compassionate care in the Buddhist view grew more out of caregiver discussions in the focus groups. In this study, PAC, FC and PHN had two to three sessions (in-depth or focus group), which provided enough time for the researcher to consider the themes emerging from these encounters, and to confirm them in subsequent sessions. This resulted in prolonged engagement and the establishment of trust.[21,22] During the data collection processes the researcher observed the participant's behaviours, expressions and the surrounding environment. These observations were recorded in field notes at the end of each session. This technique achieved credible, persistent observation.[19] The twice conducted in-depth interviews and focus sessions provided an opportunity for the researcher to clarify important points from the previous sessions that may have been unclear. Multiple interviews of PAC served as a way to achieve trustworthiness in providing shared experiences. State of being and QOL revealed by PAC are discussed below:

For the participants in this study suffering in the dying process was evident in the sub-themes of physical and cognitive, psychosocial, and spiritual function. Most PAC talked of the dying process consisting of two areas: deteriorated physical and cognitive function, and psychosocial and spiritual changes.

The functions in state of being in the results are consistent with the comprehensive assessment of the end of life, which Emanuel[24] stated in four dimensions. Although the content of results look like the comprehensive assessment that Emanuel stated, in some ways they are not the same.

Suffering in dying process as to physical and cognitive function of PAC changed overtime due to the severity of cancer progression and the effect of treatment. PAC were alert to and awakened to declines, perceived in suffering from changes in level of consciousness. In home-based care, PAC usually chose alternative or comprehensive forms of healing[11] such as acupuncture or herbs. However, PAC did not choose to eat "Kong-slang" (meaning injurious food) such as pickled fish that they felt compromised their physical condition, in order to maintain a better QOL.[11] The optimum challenge for PAC, FC, and PHN was to share their experiences, needs, and values with each other.

The meanings among PAC varied from hope in the sense of acceptance to die to a hope for death to a refusal to die based on addressing their beliefs and values in Buddhist religious doctrines.

Life satisfaction was seen when PAC had their pain alleviated through being surrounded by their loved ones. PAC, who choose not to be restrained or have an operation, sometimes seemed to retain their power and autonomy. Touch to bring calm and peace can be important in the end of life stage. The result is congruence with a good death, as stated by many educators and researchers, and as mentioned by the Institute of Medicine's committee on the end of life care.[25]

Some research provides different viewpoints regarding the dimensions of QOL. Wyatt & Friedman[26, 27] identified various views of QOL; most researchers generally agree that QOL is multidimensional, subjective, and related to a state of physical, psychosocial, and spiritual well-being.[28] However, FC sometimes expressed QOL in other ways, such as in the positive satisfaction in meeting care needs for PAC. Furthermore, some nurse researchers use QOL together with life satisfaction, adaptation, health, and caring for PAC and their FC.[29]

Regarding the theme compassionate care in the Buddhist view, nurses are concerned to improve FC behavior by teaching and demonstration, application, new knowledge and sharing experiences with them.[30] In the case of a new FC, nurses have to coach and counsel about the dying process and end of life challenges.

Nurses' responsibilities include appropriate cultural care, support for maintaining a safe physical and psychosocial environment, and enhancing the education of FC to identify and coordinate care to protect each patient's human rights.

FC and those with advanced cancer do need information resulting in support to face existential circumstances. FC took care of their PAC relatives mostly through providing physical and spiritual care, but also gave emotional and social support. This study was based on the research methods of Martin Heidegger.[15, 31] He investigated themes in his works focusing on man's ability to face existential anxiety, guilt and death.

Caregiver care sub-themes included respite care with different views among nurses, caregivers and PAC. This sub-theme is clear in the actions of PHN5 who encouraged other family members, health volunteers, and neighbors to have time away from caregiving. This is particularly useful for increased FC morale and is congruent with Froggatt, and Parker[32] who emphasized that caregivers need respite care, the time for themselves away from the care setting and for pleasure. They also often lack sufficient time to relax and sleep.[33] Families have to find alternative caregivers when the primary, existing caregiver is too exhausted to continue.[34]

The experience of one who has lost a relative and has depression, propels the concept of family role after a loss. PHN must provide bereavement care to surviving family. In Thai culture and the Buddhist religion, after the loss of a loved one, there are many complex and busy rituals; in the morning of the first seven days, family members will give alms and invite monks and priests to pray for the dead.[11] The forty-ninth day and the one-hundredth day, they also give alms and invite monks and priests to pray again, to heal emotional grief and sorrow from the recent experience of the end of life struggle with their relative. Thais′ beliefs and rituals like mental and spiritual support from family members' gratitude help to bring PAC to peace and dignity.

In the West, respite care and bereavement care is commonly provided by nurses[32], but in Thailand PAC always expect care and compassion from their relatives more than from nurses.[6] The care for PAC can be a fragile matter due to the beliefs and faith of PAC; it cannot be viewed as a rigid construct of caring for every PAC through just one model of caring.

The relationships among the three themes are reciprocal. Starting from QOL, one might see positive or negative experience derived from compassionate care and state of being. From another direction, compassionate care interacts with state of being and has a direct effect on QOL. The goal of palliative care is a QOL for PAC and their families.[27,34] This view is consistent with that seen in the study by Tornoe, Danbolt, Vigne, and Sorlie[35] who proposed that QOL is composed of well-being in physical, psychosocial, and spiritual function. The result of their study confirms previous studies and research. Suree Lemongkol[36] also mentions nurses' roles in palliative care with consequences for QOL. The functions of state of being in the results of this study are congruent with a comprehensive assessment at one's end of life, Emanuel's statement of the four dimensions as physical, psychological, social, and spiritual. [11, 24, 37, 38]

## Limitations of this study

The PAC in this study were compromised, dependent individuals and their experiences must be understood with sensitivity to human rights and the culture of Thailand. Researchers doing further study in this area should consider this a challenge and opportunity. This study has provided valuable results for nursing practice in palliative care. Future studies are needed to gain a better understanding of the ways nurses can aid those with advanced cancer and their caregivers in the home care environment and to include multidisciplinary health care professionals who are involved in caring for them. For these people want to have social interaction and support from friends and familiar relatives. In the limited focus group discussions, we had a great deal of verbal and nonverbal data which was challenging to confirm and summarize and which should be investigated further. Future studies are needed to gain a better understanding of the ways nurses can aid those with advanced cancer and their caregivers in the home care environment.

### Conclusions and Implications for Nursing Practice

The PAC who stays at home usually receives some on-going domestic health care services provided by PHN of local health centers and/or ambulatory services. However, not all PAC have access to such care. Some may only receive care from FC. PAC and their FC need more health care services such as palliative care. So the improvement of community and home-based programs to include palliative care services is needed. Insights from people's experiences with palliative care at home inform nursing practice.[33] Experiences of PAC in this study support palliative care services since PHN can better understand the dynamic nature of providing effective palliative care to individuals and families in their communities. It is important to understand the complexity of distress facing people at the end of life to inform an appreciation for every life. Compassionate care is a fragile balance between acknowledging the beliefs and faith of people confronting multiple human needs. It is difficult to assess and takes an ongoing and critical investigation for improvement.

**Conflict of Interests**

The authors declare no conflicts of interest in this research.

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# ประสบการณ์ของผู้เป็นมะเร็งระยะลุกลามที่ได้รับการดูแลแบบประคับประคองที่บ้าน

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**บทคัดย่อ:**ผู้เป็นมะเร็งระยะลุกลามที่ได้รับการดูแลแบบประคับประคองที่บ้านมีจำนวนเพิ่มขึ้นอย่างมากในประเทศไทย การศึกษานี้มีวัตถุประสงค์ เพื่อศึกษาประสบการณ์ของผู้เป็นมะเร็งระยะลุกลามที่ได้รับการดูแลแบบประคับประคองที่บ้าน และการดูแลสำหรับผู้เป็นมะเร็งระยะลุกลามการวิจัยนี้เป็นการศึกษาเชิงปรากฏการณ์วิทยาเก็บรวบรวมข้อมูลในปี พ.ศ. 2554-2555 ผู้ให้ข้อมูลคือผู้เป็นมะเร็งระยะลุกลาม จำนวน 7 ราย โดยการสัมภาษณ์แบบเจาะลึก สำหรับผู้ดูแลในครอบครัว จำนวน 7 ราย และพยาบาลสาธารณสุข จำนวน 5 รายโดยการอภิปรายกลุ่มย่อย การศึกษาพบว่าผู้เป็นมะเร็งระยะลุกลามให้ความหมายชุดรูปแบบ 3 ชุด คือ 1)สภาวะความเป็นอยู่ประกอบด้วย กระบวนการใกล้ตายและระยะท้ายของชีวิต 2) คุณภาพชีวิต เป็นความพึงพอใจในชีวิต และความพึงพอใจในการดูแลที่ได้รับและ 3) การดูแลด้วยความเมตตากรุณาในมุมมองพุทธศาสนา เป็นการดูแลแบบองค์รวมการดูแลช่วยเหลือผู้ดูแลการสนับสนุนทรัพยากรด้านวัสดุอุปกรณ์ การดูแลแบบประคับประคองสามารถส่งเสริมคุณภาพชีวิตของผู้ที่เป็นมะเร็งระยะลุกลามด้วยการดูแลแบบองค์รวม ท่ามกลางวัฒนธรรมที่เหมาะสมจากครอบครัวและพยาบาล

ผลการวิจัยครั้งนี้พบว่าผู้เป็นมะเร็งและญาติสามารถเผชิญกับภาวะวิกฤตอย่างสงบและมีศักดิ์ศรีประสบการณ์ของผู้เป็นมะเร็งระยะลุกลาม การดูแลจากพยาบาลและผู้ดูแลช่วยให้ผู้เป็นมะเร็งระยะลุกลามบรรเทาอาการทุกข์ทรมานและมีคุณภาพชีวิต

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**คำสำคัญ:** มะเร็งระยะลุกลามการดูแลที่บ้านการดูแลแบบประคับประคองปรากฏการณ์วิทยา

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# An Ethnography: How does Buddhist Doctrine, A Local Wisdom, Affect Older Thai Villagers' Well-being?

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**Abstract:** In line with global trends, Thailand has an increasingly aged society. Generally, Thai elderly from rural lowlands in the central area are committed to Buddhism. Accordingly, many use the wisdom of their understanding of Buddhist teachings about facing death to maintain their well-being. Thai local wisdom involves accumulated knowledge, skills, behavior, and beliefs integrated and absorbed from generation to generation. Thus, local wisdom is part of local culture.

This article reports on an ethnographic study that aimed to gain understanding of the local wisdom of Buddhist doctrine with reference to facing death, and the relationship of that understanding to the elders' maintenance of health among Central Thai villagers. Twenty elderly key informants and nineteen general informants were recruited by using snowball technique. Participant-observation began while the principal investigator (first author) was establishing rapport and trust with villagers and continued for two years of fieldwork. In-depth interviews were conducted after securing informed consent. Data were analyzed by thematic analysis. In the larger project of which this was a part, facing death as guided by Buddhist doctrine emerged as the central theme. The study reported here identifies two approaches to facing death peacefully were having deep awareness about death; and preparing for a peaceful death.

Incorporating this local wisdom will help elderly face death peacefully. Health care providers can use this information to understand how wellbeing can be experienced by patients approaching death.

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## Introduction

Local wisdom is culturally constructed, and different parts of a country present different interpretations of local wisdom. In Thailand, there are four geographical regions, namely Northern, North-Eastern, Southern, and Central. Each region has its own historical and social background, which reflects each region's local wisdom. Central Thailand has been a fertile source of local wisdom about health.[1, 2]

Data for the study reported in this paper were gathered in a rural village of Suphan Buri Province of the Central Thai region. Therefore, Central Thai local wisdom refers to knowledge, skills, behavior, and belief or attitude resulting from accumulative experiences as transferred from generation within the specific Central Thai community of the primary author's fieldwork.

In Thailand, the elderly are living longer than ever before; also life expectancies continue to increase. More people are living into old age and facing fear about death and the prospect of long term illness associated with aging. As a consequence of the aging process and health decline in later ages, generally, deterioration in physical health, normal aging development leads to structure and functional decline, but does not cause disease directly.[3] However, literature states that Thai villagers often live with chronic illness.[4] The literature reports that the fear of death declines during middle adulthood but does not continue to decline through old age. Rather, increasing age and frailty render them ever more vulnerable to death, such that fear of death is greater among the older people. Moreover, since some research has found that physical and mental health problems predict higher levels of death anxiety. Generally the death of a human being too often catches the elder unprepared emotionally spiritually and practically. Cicirelli's work suggests that living with conscious awareness of death, when you are young and healthy, and have a clearer understanding of religious teaching, helps one in advanced age have less fear of death and to be ready to bdie peacefully.[5]

In facing death peacefully, one issue of concern regards spiritual health, the meaning of which varies based on the local culture and spiritual belief system.[6] An older person generally understands the nature of life as being born, aging and dying, which is a natural process, and accepts the facts of death and dying in later age. Understanding about facing death will help people prepare for and cope better in later year. As with religious belief, such wisdom is a buffer against the fear of death and dying in aging people, it not only provides help in time of suffering, but offers a promise of life after death. Elders who are firm and consistent in their religious practice beliefs and practices will develop strong abilities to facing death peacefully.[7] Also traditional forms of religious may be supportive such as church or temple attendance, allowing people to learn and share and support the elderly to encounter death. For example, Buddhism teaches the elderly about death and dying so that we can talk about it and we can deal with the topic of death with a peaceful mind. Encouraging such reflections to deal with death based upon facing death peacefully means the elders learn to accept the truth of life, to accept the natural law and let things go.

Feelings of a peaceful death among older people can function as a protective factor for well-being.[8] People from diverse cultures face death differently.[6] In the neighboring countries of Burma, Laos, Cambodia, and Sri Lanka, Buddhist influence is pervasive. However, most Thai Buddhists tend to believe that how they perceive a peaceful death may differ due to three attributes, namely sociocultural norms, personal experiences, and continued process with one's life cycle, and that these may make a difference in their health regarding a peaceful death.[6] One study found older persons who had had personal experiences related to facing death helped them prepare for and cope with dying and death better.[9]

According to Buddhist doctrine that influences older people's beliefs, the Three Universal Characteristics (Trilakkhana) are impermanence (anicca), suffering (dukkha), and insubstantiality (anatta). These guide older people to accept deterioration in aging as a natural development and to prepare them to face death and dying with peacefulness.[10] Contemplation of death is one of the Buddhist methods by which to develop mindfulness, to think good thoughts, and do good deeds. This benefits older people in their present and also helps them build wisdom from their life experiences.[11] Kongsuwan and Touhy[12] conducted a descriptive qualitative study in which they found that Buddhist principles guided older Thai in their awareness of death aiming to prepare them for a peaceful death by conducting good deeds for themselves and for others. Looking across studies, they found that death preparation was an important process as it could help older people to accept the last stage of life. These researchers also mentioned that family members should be partners in the anticipation of death as doing so could help them become familiar with the process of death as well. Buddhist doctrine has been found to enhance positive psychological health among older people.[12] However, there have been few studies seeking an empirical association between facing death through Buddhist doctrine, and maintaining elders' health. Therefore this topic needs further exploration.

## Study Aim

The purpose of this study was to explore local understanding of Buddhist doctrine with reference to facing death, and the relationship of that understanding to the elders' maintenance of health among Central Thai villagers. This help nurses to understand the way of life of elderly villagers with a conscious awareness of beliefs and cultural knowledge in nursing care for maintaining their holistic health.

## Methods

### Study design

The study was conducted using an ethnographic approach. A fundamental purpose of ethnography is to identify shared meanings. By identifying those that are associated with a specific behavior or event, such as facing death, understanding of the socially constructed meaning of deliberatively facing death can be made explicit.[13,14] Older villagers' interpretations of Buddhist doctrine as a component of local wisdom were explored in terms of their role in maintaining health by coming to terms with their mortality and approaching death.

### Sample and Setting

Ethnographic methods are used when the researcher and the informants interact in the informants' natural venues. The researcher introduced herself as a doctoral student in the research setting. Suphan Buri province of Central Thailand was selected as the site for this study as it was in the central region so relevant to the people living in the Choa Praya River basin, and Buddhism was the dominant faith. Thirty-nine participants lived in a village of Makamlom sub-district. All of them self-identified as Buddhist.

Participant observation and interviews were conducted at the participants' homes or in Buddhist temples, wherever was most convenient for them. Some participants were uncomfortable during a formal interview. The ethnographic method encourages use of informal interviews and they were also undertaken. As some participants were comfortable talking in a group setting as it helped them with memory recall, talking in groups was also undertaken.

Both purposive sampling and snowball sampling were used to select key informants and general informants.[15] Key informants, both female and male, were selected by the following criteria: aged 60 years and over; born and residing in a community in Suphan Buri province; able to do their daily activities as judged by the Chula Activity Daily Living Index (The Chula ADL index); mentally healthy as judged by Mini Mental State Examination (MMSE); able to communicate in Thai language; and willing to provide rich information about their experiences in maintaining elderly health. Their willingness to participate was shown through their written informed consent. General informants were family members, healthcare providers, community leaders, and village health volunteers who had experience maintaining elderly health using Central Thai local wisdom.

### Participant characteristics.

There were twenty key informants, just over half were male (n=11), with mean age of all being

75 years (age range: 62-88 years). The majority were married (n=11) followed by widowed (n=7), divorced (n=1) and single (n=1). The nineteen general informants were people who had experience related to maintaining elderly health using Central Thai local wisdom including community leaders (monks and municipal officers) (n=6 ), family members (n=5), village health volunteers (n=5) and healthcare providers (n=3 ).

## Ethical Considerations

Study approval was obtained from the Institutional Review Board of Chiang Mai University. In addition, permission to collect data was received from the Suphan Buri Public Health Office. The participant consent form contained the study purpose, confidentiality procedures, and the rights of study volunteers. In addition, it outlined the benefits including the statement that there would be no direct benefit to the participant, the potential risks involved in participation, and contact information if follow-up referrals were needed. The researcher was conscious of the researcher-informant relationship and tried not to interrupt or disturb the informants while they were conducting their activities. Also codes were used in this paper to preserve the anonymity of informants. Finally, the researcher reassured the participants about confidentiality and anonymity throughout the research and presentation of findings.

## Data Collection

Data were collected from June 2013 to May 2014, and from March 2015 to May 2015. Multiple collection methods were used until data were saturated: including participant observation, in-depth interview, focus group discussion, field notes, reflective note, and document-related sources. Data were collected and analyzed using the six steps as described by Braun and Clark (2006) as mentioned below.[16] Data collection commenced following initial participant observation and initial discussions with the participants, and continued during subsequent interviews. Participant observation guidelines were used. The observations occurred in the places where the elderly participated in various situations such as Buddhist practice at temple, the participant's home, or community meetings. The researcher visited these places and undertook activities with informants such as eating, group chat, and cooking. After trust and rapport were established the researcher interviewed informants to try and understand their perspectives on elderly wisdom in maintaining health. All interviews were tape recorded with each participant's permission, and transcribed verbatim for data analysis, tapes recorder were erased when the author's dissertation was approved. The interviews began with the researcher asking general questions and inviting the participants to share their experience about their health and lifestyle. The data were collected iteratively with data analysis.

## Data Analysis

Recordings of the indepth interviews and focus group discussions were transcribed verbatim and captured data were analyzed using qualitative thematic analysis as described by Braun and Clark (2006).[16] This is composed of six phases, namely becoming familiar with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Becoming familiar with the data process enables the researcher to become immersed and familiar with all aspects of the data, and look for meanings related to maintaining elder's health with local wisdom. To generate initial codes, the researcher organized the data into meaningful groups. The codes identified a feature of data that included latent or semantic content in relation to the research questions. Codes were linked in order to identify the theme, and following this the researcher approached the data with specific questions in mind. After collating the relevant data, themes were compiled and prioritized by the researcher. Themes were revised by looking at the relevance between the coded extracts of the compiled themes and by taking into account the overall information presented in the data. After the themes were identified a meeting was held with the first researcher's advisory committee to seek agreement on the purpose of the study and relevance between the themes and the codes. After studying the analysis display and the specifics of each theme, defining and naming the themes was completed. The researcher then clarified the definitions and specifics of each theme.

**Trustworthiness**

Four criteria for trustworthiness were considered: credibility, transferability, dependability, and conformability, according to Guba and Lincoln.[13] To achieve credibility, prolonged periods of time were spent conducting fieldwork, participant observation, peer debriefing, member checking, and triangulation. To achieve transferability, in-depth descriptions and verbatim quotations of phenomenon were developed. To achieve dependability, the researcher provided sufficient information that allowed the advisory committee members to reach similar conclusions by using raw data, and analytical evidence. To achieve conformability, data were analyzed, discussed, and checked for accuracy with the research team's advisory committee, experts in local wisdom in maintaining elder's health, and the informants.

## Results

The data focused on the recognition of facing death through Buddhist doctrine. The theme emerged from two categories, having deep awareness about death and preparing for a peaceful death. These are presented below (also see Table 1).

**Table 1** Theme and its Respective Categories and Sub-categories

| **Theme** | Recognize facing death through Buddhist doctrine | | | |
|---|---|---|---|---|
| **Categories** | 1. having deep awareness about death | | 2. Preparing for a peaceful death | |
| | Meaning | Practice | Meaning | Practice |
| **Sub-Categories** | (1) death is unescapable | Directed learning near death experience | Preparing for peaceful death based on Buddhist | (1) Preparing for peaceful death in the empirical world |
| | (2) death is a transition from one form to another | Indirect learning by experiencing of death of another person | | (2) Preparing for peaceful death in a Dharma world |
| | (3) death is the universal truth | | | |

**Table 2** Characteristics of 20 Key Informants

| Case | Sex | Age | Education | Religion | Marital status | Occupation | Living with | Health problem |
|---|---|---|---|---|---|---|---|---|
| 1. | M1 | 84 | Elementary | Buddhism | Windowed | No | Child | Asthma |
| 2. | M2 | 77 | Elementary | Buddhism | Married | No | Spouse | CA Colon |
| 3. | M3 | 79 | Elementary | Buddhism | Windowed | No | Child | - |
| 4. | M4 | 79 | Elementary | Buddhism | Married | No | Spouse | HTN |
| 5. | M5 | 87 | Elementary | Buddhism | Married | No | Spouse | - |
| 6. | M6 | 63 | High school | Buddhism | Divorced | Farmer | Child | HTN |
| 7. | M7 | 87 | Bachelor | Buddhism | Married | No | Spouse | - |
| 8. | M8 | 61 | Elementary | Buddhism | Married | Farmer | Spouse | - |
| 9. | M9 | 69 | Elementary | Buddhism | Married | Traditional healer | Spouse | HTN, Gout |

**Table 2** Characteristics of 20 Key Informants (continued)

| Case | Sex | Age | Education | Religion | Marital status | Occupation | Living with | Health problem |
|---|---|---|---|---|---|---|---|---|
| 10. | M10 | 80 | Elementary | Buddhism | Married | Traditional healer | Spouse | - |
| 11. | M11 | 79 | Elementary | Buddhism | Married | Traditional healer | Spouse | Gout |
| 12. | F1 | 68 | Elementary | Buddhism | Married | Farmer | Spouse | - |
| 13. | F2 | 83 | Elementary | Buddhism | Windowed | No | Relative | - |
| 14. | F3 | 77 | Elementary | Buddhism | Windowed | Trade | Relative | - |
| 15. | F4 | 86 | Elementary | Buddhism | Windowed | No | oneself | - |
| 16. | F5 | 88 | Elementary | Buddhism | Married | No | Child | - |
| 17. | F6 | 84 | Elementary | Buddhism | Single | No | Relative | Knee pain |
| 18. | F7 | 75 | Elementary | Buddhism | Married | No | Spouse | - |
| 19. | F8 | 80 | Elementary | Buddhism | Married | Traditional healer | Spouse | - |
| 20. | F9 | 73 | Elementary | Buddhism | Windowed | Traditional healer | Child | Low back pain |

## Recognizing facing death through Buddhist doctrine

All of the informants identified themselves as Buddhist, and believed that life's circumstances of birth, aging, illness, and dying, were natural processes. They understood and accepted that human beings have the nature to change, and they understood that life is impermanent; that suffering loss and change can be an unbearable feeling to live with; and the insubstantiality of self, or non-self (Anatta). As consistent with popular Buddhism in Thailand, most informants believed in life after death. All humans have to die and can die anytime without any foresight, and therefore they need to be prepared to die in part by doing good deeds. In Buddhism, this is called "contemplation of death" (มรณานุสติ) for example:

> *Contemplation of death is a significant Dharma principle that the elderly should consider at all times. Suffering was caused by birth as a human being, if a person takes account of the truth of suffering they can steer away from it. They can then be content; birth and death occurs with all humans. We must be ready to die by being aware that we will die. Also, we need to prepare to be ready for any unforeseen event, and then one will not feel in trouble. What we have to do is accumulate good deeds when we are alive* (79 year-old male: M3).

> *Contemplation of death as unsteady volition or impermanence of the body (สังขารไม่เที่ยง), monks have said that humans experience birth, aging, illness, and death. Death is an issue that humans should be aware of, people who have no illness have a halo. This depends on the laws of Karma, if one does good deeds, merit will protect them from evil or hell. To be ready to die in peace you must make merit in this world at this time* (77 year-old male: M2).

Most informants went to a temple often, learned and practiced the Buddha's teachings. Most of them believed that facing death is an integral part of life. Social gatherings at funeral ceremonies allowed for villagers to help in this activity. It enabled older people to learn and share thoughts and feelings about death and dying through customs within community.

**Meaning: Having deep awareness about death through Buddhist doctrine**

According to informants' understanding, death, recognizing and facing death is a natural process which they accept. This is due to their deep understanding of death, which they learned through Buddhist doctrine. Three subcategories formed deep awareness about death namely: death is unescapable; death is a transition from one form to another; and death is the universal truth.

**Death is unescapable**: This refers to informants' thoughts, understanding, and perception of the truth of death as a natural process that cannot be escaped.

> *Practicing the Dharma doctrine can guide knowledge of birth, aging, suffering, and death, which are unavoidable... If we truly understand this we will see that we cannot escape death. If you accept this, you will not worry when death comes* (79 year-old male: M3).

**Death is a transition**: This refers to informants' belief about death and transition after death. This belief is based upon the Buddhist principle which proposes life and reincarnation. Learning this can lead to an understanding and deep awareness about death.

> *Death in Buddhist principles refers to a journey from one life to another. Any positive, virtuous actions (profitable state) we make in this life will be the provision for the next life* (79 year-old male: T5M11).

He was a spiritual guide or lay leader of a congregation.

**Death is the universal truth**: This refers to informants' belief about the truth of death and that it occurs with all living beings.

> *For the death of my wife, I realized that it was her time to leave. Indeed, when my time comes, I will have to go. I realize that death is the truth.... When the end of life comes, we all have to leave all beloved ones -- parents die, children pass away—it is called separation by death. It is the universal truth of life* (77 year- old male: M2).

**Practicing: Having deep awareness about death through Buddhist doctrine**

According to the informants' point of view, their life experiences grew from their practice and understanding of the Buddhist doctrine. This category was derived from two sub-categories: Direct learning near death experience and indirect learning by experiencing of deaths of other person.

**Direct learning near death experience**: This refers to the lessons learned from the life circumstance that humans are born, grow old, get sick, and die. When facing degeneration in advanced aged, changes in health status occur which can lead them to see these changes as being due to their awareness of death and virtual death. In addition, some informants had a near death experience (NDE).

> *First, all human beings are born with disease, no one never got sick. Therefore if we consider every day that we have to get sick, this will make us conscious to find a solution, and not to be careless, that is, not abandon maintaining health. Second, when we get ill we think about death. Therefore, when we consider that we have to die, we will not fear death, but we will get a heightened consciousness and know what we have to do by undertaking good deeds.* (Monk, Wat Bost).

Some elderly had faced a NDE. One recounted an experience of a home robbery: she was hit on the head with a piece of wood and was unconscious for one night, subsequently called herself *"resurrected"*.

> *When I was unconscious, I saw a beautiful place like paradise. God or goodness allowed me to select which place I would love to stay. At that time I decided back to the earth. I think I was dead, but I was resurrected as the result of accumulated good deeds. Every day for over 50 years I prepared myself for death and dying by always practicing the dharma, mindfulness, and be a folk healer and do good deeds by helping others. Auntie [I] felt when I was hurt, when I was attacked, I felt he would hit me until I died. But I did not die. I am still alive, I will do good deeds by healing other people and chanting and meditation. After I recovered,*

> *my memory recalled about the robber, I know him well, he was a money borrower. I forgave him for the assault, I think of the Laws of Kharma.* (80 year-old female: T3F8).

**Indirect learning by experiencing of deaths of other person**: This refers to informants' lessons learned from the loss and grief of loved ones, and lessons learned through a sermon, for example at funeral ceremonies.

> *When uncle died, auntie's [my] mind took a long time to recover ...auntie [I] overcame the feelings of loss and stopped thinking about it or put it out of mind. I thought that he went to meet his precepts, his merit. I am still alive, I have to pay attention and perform good deeds and live to earn merit. I practice consciousness so when I die I will have mindfulness and not be careless in life and I make merit* (73 year-old female: T4F9).

Two key informants passionately shared what they have indirectly learned from the loss by considering attending a funeral ceremony and funeral prayers.

> *Attending the funeral, the Buddhist metaphysical prayers* (Abhidhamma-pitaka/extra doctrine: บทสวดพระอภิธรรม) *for funeral, Buddhist metaphysics* (พระอภิธรรม 7 คัมภีร์) taught that Kusala-dhamma (Skillful), *A kusala-dhamma* (Unskillful), *Abyakata -dhamma* (The indeterminate; neither good-nor-bad thing), *means any righteousness or unrighteousness, or things that are a merit and not merit, or any things that are neither merit nor demerit. These things can exist and end. Whatever exists will deteriorate or end. We should not depend on it. Our life and body deteriorates with date and time. Sometimes, it ends before deterioration. Attending funerals reminds people that the body exists and ends. We will also die. Therefore, we should not be careless in doing merit-making good deeds*, (79 year-old male: M3).

### Meaning: Preparing for peaceful death

The second category described the essence of recognizing facing death, the informants felt they needed to understand death as peaceful, and this needs preparation. Most informants perceived the meaning of preparing for a peaceful death based on their respective Buddhist beliefs. This process was a consequence of their deep awareness about death. If the informant has an awareness of death and reflects on their understanding of life and death, then they has begun preparation for death.

**Preparing for peaceful death based on Buddhist doctrine**: Almost all informants respected the Buddhist principles that their beliefs can lead their consciousness to a peacefull end. They thought about death deliberatively, were preparing to give up their self or ego, and were purposefully doing good deeds.

> *We have to practice preparing to deal with death consciously and regularly, until we are accustomed to it. If we are not well prepared, when the time of death is coming we cannot control our consciousness*, (80 year-old female: T3F8).
>
> *Do not be careless in the moment of life, but do things to accumulate merit, is the way of preparing consciousness of death*, (73 year-old female: T4F9).

### Practicing: Preparing for a peaceful death

Preparing for a peaceful death category emerged from two sub-categories one preparing in the empirical world, and the other, preparing in the Dhamma world.

***Practice of preparing for a peaceful death in the empirical world***: This refers to responsibilities that the elderly should undertake before they die, its purpose is to not burden their family after they pass away. This is the one of social tasks they should tend to before death.

> *The problem nowadays is the elderly die suddenly without any preparations. How do*

> *their descendants then live? The big issues are always about dividing the property such as farmland and other assets, this can sometimes lead to legal battles. Therefore, to prevent this problem, the elderly should plan for the life after death by disclosing their wishes to their descendants and making inheritance arrangements* (87 year-old male: M7).

***Practice of preparing for a peaceful death in a Dharma world***: This refers to practices that help one recognize facing death as a natural part of life. This can be a conscious action, by performing good deeds, and a precautionary action, by releasing oneself from attachments to others and the empirical world. To accumulate goodness is a treasure that will be with oneself even after death.

> *Death is inevitable... Uncle is* [I am] *building good deeds by being the leader of all ceremonies in the village and passing on his knowledge to the next generations. Being a temple officiator or merit leader at the temple makes him* [me] *feel happy --merit is happiness and pleasure,* (79 year-old male: T5M11).

Some informants reported undertaking good deeds or merit making. This refers to informants' thoughts or behaviors that should be beneficial to others or the community. Somewhat ironically, they believed that "selfless actions" will prepare them for a peaceful death by gaining merit for their journey to the next life

> *Preparation without doing merit means dying without any merit or virtue with you. Therefore you will not have anything to support you when you die or transfer from one life to the next life* (called Tay La Ka Mai Me: ตายหล้าข้าไม่มี ), (80 year-old traditional female: T3F8).

Some informants reported releasing themselves from attachments. Specifically, releasing and relaxing their minds meant to be free from external binding factors and unexpected external factors. Death is certain; however, when we die is uncertain. Everything in our body and other people can be transformed all the time.

> *Auntie* [I] *prepare for death by releasing her* [my] *need for things. Not creating demerit is not creating attachments.* [For instance] *feeling that it is alright if my descendants do or don't pay attention to me, take it easy, let it be,* (86 year-old female: F4).

> *Releasing is a death preparation doctrine... everyone will feel comfortable if they can comfortably let things go. Knowing that oneself is old, being satisfied with everything, such as not being envious, puts one's mind at peace. Let things go, just let things go when anyone says anything. We are already at this age, just let it go* (ช่างเขาเถอะ) (an 80 year-old female traditional healer: T3F8).

## Discussion

An older person's health comprises physical, mental, social, and spiritual elements, which may be in holistic balance. Individual elders may perceive their health differently, based upon personal and cultural norms and values and the informants' health status includes both positive health as well as health problems. Although physical health in the elderly often declines, psychological health can be promoted and strengthened. Positive psychological health can be a protective barrier in later life, especially when faced with death and dying.[17,18]

Maintaining elders' health refers to the practice of effectively preserving health as perceived and practiced by older people themselves. Different ways of doing this are reported in the literature. Integrating different health care systems together in a dialectic fashion to promote holistic health is called medical pluralism and is one way to actively maintain health.[17,19,20] Several studies report finding that older people utilize a variety of health resources to maintain their health, including biomedical healthcare, traditional or folk healthcare, indigenous self-care, or a combination of these. Older people may choose to use traditional means or local wisdom for logical reasons such as being compatible with tradition, cultural belief and lifestyle, as for reasons of convenience such as keeping healthcare cost low, accessibility, and supporting health holistically.[17, 19-24]

Maintaining elders' health by using Klienman's cultural care system involves three sectors, popular, folk, and professional. For instance, families using diet for healing would be in the popular sector; seeking help from sharmans would be in the folk sector; and requesting modern scientific interventions would be in the professional sector.[19] Several studies found that using all three sectors helped maintain elder health. In addition, researchers found that Buddhist doctrine influences elders' belief and behavior.[18,23,25] Considering elders' behavior in terms of the cultural care system indicates that they utilize the popular sector and prefer traditional medicine. The folk sector, which refers to local wisdom or tradition, is another way to maintain elders' health.

Local wisdom about elder health refers to knowledge, skills, behaviors, and beliefs or attitudes resulting from accumulated experiences transferred from generation to generation within a Thai community.[26] Several studies consistently reported that traditional local wisdom and culture are significant in maintaining holistic health among the elderly in a Thai context. One study explored ways of healthy aging in a Northern Thai village. The study found that both biomedical care and local wisdom were prevalent.[21] Two studies both taking a qualitative approach, conducted in the North-East region of Thailand, found that applying local wisdom to promote health meant to value the life experience of older people, and helped to promote positive health among them.[27, 28]

Buddhism offers Thai elders the local wisdom to maintain holistic health in line with cultural context. This is grounded in the Three Universal Characteristics (Trilakkana); Anicca refers to things both living and non-living having the nature to change. Dukkha can be seen among those who do not understand natural rules, so believe that all things have permanence. When they experience loss or a change in social position, they might become depressed and suffer. If older people are able to understand impermanence, they can understand suffering as they are similar. Anatta or selflessness means that all things have no permanent entity. Everything exists under the cause and effect law, nothing belongs to anyone. Human beings misunderstand that things belong to them and become attached to them. When there is attachment, suffering will follow.[10, 29] These Buddhist doctrines influence elders' beliefs, knowledge, and behavior, all of which can influence elders' health.

When older people in Central Thailand recognize and face death according to Buddhist doctrine, they are using local wisdom that helps maintain their health in accordance with cultural beliefs. Buddhist principles are dominant factors in their beliefs, behavior, lifestyle, and their readiness for the end of life are regarded as the basics that Buddhists should know and understand. If older people apprehend the Three Universal Characteristics, they understand the Buddhist teachings regarding the natural law and change in later life. If they accept deterioration as part of later life, they may be prepared to face death peacefully.[21] Older people must cope with losses in their health and independence. Preparing for peaceful death is a significant task and requires a deep understanding of life and death. Practice through Buddhist principles has guided older people to be mindful in facing death peacefully.

According to this study most informants apply Buddhist doctrine such the Three Universal Characteristics and contemplation of death to understand about death and dying, and these were a doctrinal guide to lifestyle. There were two challenging issues having deep awareness about death and preparing for a peaceful death that emerged in the recognition of facing death through Buddhist doctrine.

The learning process contributed to the informants' understanding and awareness about death through both direct and indirect learning. The literature suggests that learning to face one's own mortality with equanimity can also be learned through the media.[11] However, in the researchers′ view, the present social culture talking about death is not encouraged or wanted as it is considered depressing. There is also the view that living, dying, and grieving are separable. Consequently, this may mean that there is less opportunity for people to learn and become familiar with death and for it to become part of living.[11]

From the Thai Buddhist perspective, peaceful death is promoted by family members when they are co-providers in the attainment of peaceful death. We recommend that family members should try and accept death, be at peace, and participate in a family member's dying process. Consequently, if a person is intimately engaged in the process of death and dying, they then might be able to help a person to accept death as a natural process.[12] Buddhist principles that actively support preparation to encounter death include meditation and contemplation of death while attending others' funerals. This enabled the participants to learn and understand about the process of death and dying, be aware and not fear death nor be careless in life. In addition, they should be living in the present time, have a strong mind, be generous, kind, tender, and be committed to merit making, and abstain from sinful behaviors.[8]

One previous study found older people (60-74 years) who had religious beliefs, and practiced Dharma every day by chanting, reflected a high level of behavior for preparing to cope with dying and death. Rongsikosai et al. reported that older people who experienced anxiety surrounding death at a high level, had poor behavior in terms of preparing for death.[9] The findings in the study reported in this paper are consistent with these authors.

## Limitations and recommendations

The results of this research study has limitations due to the fairly homogenous context of a study of a specific age cohort based in a Buddhist village in Central Thailand. Furthermore, the research was conducted in only into four settings which were Kokko, Sakeayangmoo, Wat Bost, and MeaTaLum in the sub-district of Bang Pla Ma, Suphun Buri province, due to the limited time and resources available for researcher. Consequently, the study findings about maintaining elder's health and well-being might not represent the influence of the sociocultural context in other provinces in Thailand. However, the rich findings enhance nursing knowledge about this important issue, both in Thailand and elsewhere.

Suggestion for future studies focus on issues relating to the use of Central Thai Local Wisdom, regarding health, should include a longitudinal study of older people in order to compare outcomes of preparations for facing death with how family members say the participants experienced dying and death. This would provide evidence of the effectiveness of Buddhist-informed local wisdom for preparing for a peaceful death, as well as for maintaining health in old age.

## Conclusion

The findings of this ethnographic study highlight the value of local wisdom that the elderly apply in maintaining elderly health with reference to facing death by practicing Buddhist teaching as a doctrinal guideline. It was simple way of life among older villagers with congruence to their beliefs and culture. This local knowledge was significant to them in later age, it helped them to accept facing death by understanding that death is natural process that all human beings will face and cannot escape. This means they are living having awareness about death, thus they are preparing for a peaceful death by doing good deeds and mind training practicing through Buddhist doctrine, according to their beliefs which accumulative good deeds and well mind preparing will support them to face death peacefully. Recognizing and facing death as natural was an important task for the informants, and if they accepted facing death with peace of mind and let their mind be free from the fear of death associated with the deterioration of life's circumstance, this would lead to the state of health at present moment.

The research findings will help nurses to understand the health practice of the elderly from rural based beliefs and culture regarding facing death as part of maintenance of health, so they can try to incorporate this knowledge with conventional health care service to support people's needs. These findings contribute to be understanding of local wisdom as part of local knowledge of the care of older people in Central Thailand.

## Implications for Nursing Practice and Research

This study of maintaining holistic health by using Central Thai Local wisdom purposefully included only rural elders. Comparisons between older people in urban and rural area would be useful to help identify the role of place in generating the content of local wisdom and cultural context. Understanding that seniors in a society might have local wisdom about maintaining their health could help nursing care providers, health care policy makers, and organizations, that work with older people to take account of elders' local wisdom in their work, and to perceive elderly adherents to local wisdom as pillars of their communities. This could help enhance elders' psychological health and well-being. In the case reported here, local wisdom was paramount in the older peoples' constructive facing of their approaching death, and in maintaining their health. Moreover, strengthening spiritual health and the local wisdom of the understanding of Buddhist doctrine, in particular the aspects of facing their own death and maintaining optimum health, promoted healthier lifestyles among the participants in the study village

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# การศึกษาเชิงชาติพันธุ์วรรณา:การปฏิบัติตามความเชื่อทางพุทธศาสนาส่งผลต่อสุขภาพผู้สูงอายุชนบทอย่างไร ภายใต้วิถีการดูแลสุขภาพโดยใช้ภูมิปัญญาพื้นบ้านไทย

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บทคัดย่อ: การเข้าสู่สังคมผู้สูงอายุ เป็นสิ่งที่เกิดในประเทศไทยเช่นเดียวกับในระดับสากล ผู้สูงอายุชนบทไทยภาคกลางนับถือศาสนาพุทธเป็นส่วนใหญ่ และนำหลักคำสอนทางพระพุทธศาสนาเกี่ยวกับการเผชิญความตายซึ่งถือเป็นภูมิปัญญามาเป็นแนวปฏิบัติในการดำรงไว้ซึ่งสุขภาวะดี ภูมิปัญญาพื้นบ้านเป็น องค์ความรู้ ทักษะ พฤติกรรม และความเชื่อ ที่สั่งสมและถ่ายทอดสืบต่อกันมาจากรุ่นสู่รุ่น โดยถือเป็นส่วนของวัฒนธรรมพื้นบ้าน รายงานการวิจัยฉบับนี้เป็นส่วนหนึ่งของวิทยานิพนธ์ มุ่งศึกษาประสบการณ์การใช้ภูมิปัญญาพื้นบ้านของผู้สูงอายุชนบทไทยภาคกลางในการดำรงสุขภาพในมิติการเผชิญความตาย คัดเลือกผู้ให้ข้อมูลแบบลูกโซ่ โดยมีผู้ให้ข้อมูลหลัก 20 คน และผู้ให้ข้อมูลทั่วไป 19 คน เก็บรวบรวมข้อมูลโดยการสังเกต การสัมภาษณ์แบบเจาะลึก เริ่มหลังสร้างสัมพันธภาพจนได้รับความไว้วางใจจากผู้ให้ข้อมูล โดยผู้วิจัยเข้าอยู่ในชุมชนสองปี วิเคราะห์ข้อมูลด้วยแก่นสาระ ผลการศึกษาพบว่าการเผชิญความตายอย่างสงบมีที่มาสองแนวทางคือ ผู้สูงอายุตระหนักถึงความตายและมีการเตรียมความพร้อมตนเองในการเผชิญความตายอย่างสงบ

ความรู้ที่ได้จากการวิจัยนี้จะช่วยให้ผู้สูงอายุเผชิญความตายอย่างสงบ และช่วยให้บุคคลกรด้านสุขภาพเข้าใจวิธีการปฏิบัติเพื่อเกิดสุขภาวะในภาวะใกล้ตาย

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**คำสำคัญ:** พุทธศาสนา การศึกษาเชิงชาติพันธุ์วรรณา การเผชิญความตาย ไทยภาคกลาง

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# Ethical Issues in Research on Children

One of the most common ethical concerns in research is related to the dilemma of using children as subjects, because young children are one of the most vulnerable groups who are open to exploitation by adults.[1] It is imperative that nurse researchers appraise themselves of their research obligations when considering the ethical issues of their subjects or participants, whether adults, adolescents or children. Importantly, nurses and other health professionals should always consider the additional issues and research requirements involved in gaining consent or involving children or adolescents in their studies. This editorial will explore some issues related to ethical principles and practice about this to help avoid research misconduct with children.

Historically, research in children before and during the World War II was marked by unethical practices in Europe and Asia. For example, in a study at Kobe Medical School in Japan in 1958, infants were used as "objects" in clinical experiments, without parental consent, to identify the best density of lactose in artificial milk. A small gastric plastic tube was inserted into the infants' gastrointestinal tract to analyze the gastric content along the tract after feeding with various milk formulas. A number of babies in the study suffered from high fever, diarrhea, and vomiting[2]. In another example, in 1952 infants of the Nagoya City Infant Nursery in Japan were inoculated with coliform bacillus, resulting in severe diarrhea among the babies, and death.[2] During WWII, twin children in Nazi concentration camps were subjected to cruel experimental studies, e.g. injection of different dyes into eyes to change the color of their eyes.[3,4] In the Nazi Neuengamme Camp in Germany, children were deliberately infected with tuberculosis and later killed after the experiment.[3] Therefore, following the Nuremberg Trials after the WWII, some of the medical researchers involved were punished and the world medical community urged for ethical principles for research. Ethical research among children was also reinforced.

Gradually in a number of countries, a paradigm shift began to occur, where children became viewed as "subjects" rather than "objects" in research. However today, ethical issues still exist in many countries,[5] including Thailand, where ethical review committees (or institutional review boards) for human research are not established in many places across the country, and there is a dearth of both experts with experience and knowledge in both adult and child research ethics. However, Thailand is now in the final process to enact a new law requiring all human research to be approved by standard Ethical Review Committee.[6]

There have been a number of statements of ethical principles produced over the years for example, The Declaration of Helsinki[7] and The Belmont Report[8]. In 1964, The World Medical Association developed a set of ethical principles for medical research, The Declaration of Helsinki, consisting of 32 items, and which has become the foundation of human ethics for research across the world.[7] This Declaration recognizes the vital significance of medical research to advance understanding and development of medical interventions. But it is the researcher's duty to promote and safeguard the health, wellbeing and human rights of their human subjects. It is therefore important to weigh up and evaluate the potential risks, burden or benefit of the research to the subjects. Only if the benefit(s) of a study is greater than the risks, it is acceptable.[7]

Later in 1977, the National Commission of the Protection of Human Subjects of Biomedical Behavioral Research in the USA produced the Belmont Report, which had three core principles: a) respect of persons (autonomy protection), b) beneficence (do no harm and maximize benefit), and c) justice (no bias for risk and benefit).[8] These three principles can apply to research in both adults and children.

1. **Respect for persons.** The two requirements are that the researcher should a) respect the autonomy of subjects, and b) protect those with diminished autonomy. In respect of autonomy, it is required that any subject needs to enter into any investigation process voluntarily and with adequate information from the researcher. Parental consent/permission for children aged below 18 to participate in any research is also required. Children aged 7-18 are able to provide their assent in research participation.[1]

2. **Beneficence.** It is the obligation of the researcher to secure the health and wellbeing of the subjects by: a) doing no harm and b) maximizing possible benefits and minimizing possible harms. Throughout the research, the researcher should have carefully thought in advance of any possible risk or discomfort that might occur and plan ahead to prevent them. Emergency care or alleviating measures should be planned in advance. In most clinical trials trying to find effective treatments for pediatric illnesses, the subjects themselves may not directly gain benefit from the experimental research, but hopefully this will further benefit the future advancement of knowledge for treating illness in the future.[1,9]

3. **Justice.** – Questions to ask in terms of this are: Who will gain benefit and who bear the risk/burden? Why are the children subjects? Why not adults? What are reasons to justify the need for study? Are the subjects treated equally? It is critical that the burdens and benefits should be equally distributed with respect to the merit of a study.[9]

Children's autonomy and the assent form

The autonomy of subjects can be better ensured by providing informed consent and informing them they can withdraw from the study without any negative consequences from the researchers. Parents and caregivers are important persons for researchers to involve, for they need to grant permission for studies on their children. The researcher needs to try to gain children's *active* agreement using an assent form and *passive* agreement using a consent form signed parent(s) or caregiver(s). For passive agreement or permission, the researchers should provide parents with clear and understandable information about their research in order to try to gain truly *informed consent.* Older children are able to actively explore the information provided by the researchers and express their wish as to whether to participate.[9] The child and adolescent permission form, the so-called *assent form,* is used among children aged 12 and above, as their normal cognitive ability is at formal operational stage.

The process of getting assent from children needs to include:

1. Giving content about the research activities, offering information as appropriate to their age and reading ability.
2. Avoiding medical/technical terms that unfamiliar to them. Pictures and user-friendly language for explanation is recommended.
3. Providing in writing the necessary information about research background, process, risk and benefit of the study and persons to contact (addresses and telephone numbers of both researchers and a contact person within the ethical review committee should be given).
4. Avoiding coercion and informing them that if they want, they can withdraw from the study at any time without negative effect on their usual service such as health care or education processes.
5. Allowing sufficient time for parent(s) or caregiver(s), and children to make a decision as to whether to join the study.

6. Inviting any questions before, during, and after the study period.

7. Inviting parents to stay with children when administering drugs or other interventions.

8. When children understand and are willing to participate, with the permission of their parents, they are invited to sign their name.[1,10,11]

Parental permission or informed consent can be *waived* in cases of research:

1. Involving child protection, such as dealing with child abuse, child neglect, and domestic violence; or

2. Where, the privacy of the child or adolescent can be violated.[11] For example, when parents are asked to give permission in studies about drug use or sexual behaviors in adolescents, most parents will scrutinize their child's behaviors. This can cause a violation of privacy and make adolescents feel uncomfortable and not provide the truth about the topic to the researcher.

Ethical issues in research designs

Various research situations/designs may raise concerns in research on children. For example:

*Clinical trials*: When children are subjects of invasive treatment, researchers should carefully consider the risks of such treatment. For example, what is a safe dose for a new drug experiment? How much blood can be taken from children? According to Howie in the WHO Bulletin, the maximum allowable blood volume in healthy children is 0.8-4.0 ml./kg. of body weight within 24 hour and less than 8 ml./kg. within 4-8 weeks. In sick children, it is <3 ml./kg. within 24 hour.[12,13]

*Cohort study*: In most descriptive and experimental studies among children, parents provide their informed consent and children provide their informed assent just once before data collection. However, when children are subjects in birth cohort or other cohort studies, renewal of their assent is required at different stages. It is recommended that researchers consider gaining re-assent in children when they reach 7, 13, and 18 years old, as at the time that they are contacted periodically as subjects in cohort studies.[12,14,15]

*Participatory Action Research*: There may be additional research ethics issues when children are participants within this research design, because of the nature of direct contact between researchers and children during study processes. Carefully designed approaches in communicating and data gathering with children are essential. For example, the researcher must consider questions like: What are the research topics to be studied?; What methods of communication will be used? (For example, drawing, writing, and oral interview); and How can children take part in data interpretation?[5,8]

Conclusion

All ethical principles for conducting research in adult subjects must also be applied to children. When children are subjects, special consideration includes four major issues. Firstly, a child's cognitive ability is usually aged-related and so appropriate assent forms should be used for those aged 7-18 years old. Secondly, children need special attention in research projects because they may be vulnerable to exploitation. Therefore, researchers are obligated to protect their health and well-being during and after the studies, and to protect their human rights at all times. Thirdly, parental permission is legally pertinent. Parents or guardians should be given adequate information and provided with informed consent forms prior to the beginning of the study. Lastly, when children grow older in a longitudinal study, it is recommended to renew their assent/consent at various important stages.

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# Primary Brain Tumors in Thais: Symptom Experience and Predicting Factors.

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**Abstract:** This longitudinal repeated-measure study aimed to evaluate the occurrence, severity, and interference of the common symptoms and their predicting factors of Thais with primary brain tumors before, during, and at the end of radiotherapy. One hundred and sixteen adult and older participants were recruited from three hospitals residing in the metropolitan area of Bangkok. The measures used were a demographic and medical record form, the Mini-Mental State Examination and the M.D Anderson Symptom Inventory-Brain Tumor.

Results revealed that the most common symptoms found in various occurrence and severity dimensions were: fatigue, drowsiness, sleep disturbances, difficulty remembering, and change in appearance. Fatigue and sleep disturbance were the most common symptoms occurring and their severity existed from the beginning to end of radiotherapy. The type of radiotherapy predicted the occurrence and the severity of fatigue, sleep disturbance, difficulty remembering, change in appearance, and feeling upset. Tumor laterality predicted the severity of fatigue, difficulty remembering, change in appearance, pain, and feeling upset, whereas, tumor location predicted only the severity of drowsiness, difficulty remembering and visual impairment. Tumor type predicted the severity of most common symptoms. It is recommended that nurses should be aware of these symptoms in order to facilitate patients to obtain smooth transition during radiotherapy. Nurses who work in radiotherapy clinics and in wards with patients with brain tumours receiving this treatment, should be trained and encouraged to use the scales to assess patients' symptoms. A nursing practice guideline needs to be developed to care for patients receiving radiotherapy, emphasizing symptom assessment and management, and follow up care as well as evaluating patients' clinical outcomes.

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## Introduction

Patients with primary brain tumors (PBTs) are faced with physical, emotional, and cognitive symptoms.[1, 2] These symptoms vary according to different factors such as patients' age, gender, prognosis, type and location of tumor and treatment responses.[1-3] In particular, after receiving radiotherapy (RT), including intensity-modulated radiotherapy (IMRT), X-Knife,

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and CyberKnife as the initial treatment or after surgical resection[3], patients usually suffer more with various symptoms. The symptoms can occur in the early or late phase after receiving RT. Early symptoms include nausea, vomiting, dizziness, or headache. The severity of symptoms depended on treatment location, target volume, tumor factors, and radiation techniques.[4] Thus, persons with PBT experience symptoms from both the disease itself and from RT. Many of them can not resume their previous work and roles due to deterioration of physical functions, cognitive functions and social functions. These may eventually affect their quality of life and disrupt the continuity of treatment that would decrease the chance of control of the tumor growth. In order to control or minimize the symptom experiences, it is necessary to understand their occurrence and pattern of change over time as well as predicting factors from the beginning through the end of RT. However, most studies from the USA and European countries have focused on the late side effects of RT[5, 6] at one point in time, and no prospective studies in regard to acute effects on patients with PBTs can be located.[7] In Thailand, there are no reports of studies concerning the common symptoms of patients with PBTs receiving RT so scientific knowledge to support best practice in this group of patients is very limited. Thus, a study to explore patients' symptom experiences, symptom response and how it may change over time was warranted.

## Conceptual Framework and Review of Literature

The Symptom Management Model (SMM)[8] was used as a framework to guide this study. The SMM is based on the interrelation of three concepts: symptom experience, management strategies, and outcomes. Symptom experience refers to the subjective experience of a person who interprets changes in bio-psychosocial function, sensation or cognitive function.[9] Symptom experience consists of one's perception of a symptom, evaluation of the meaning of a symptom and response to a symptom. Symptom management refers to the actions that begin with judgment of the symptom experience from the individual's perspective in order to prevent or delay a negative outcome or minimize the symptom experience. Symptom outcomes are the consequences of symptom experiences and symptom management strategies, including functional status, emotional status, self-care, cost, quality of life, morbidity, and mortality.[8, 9] These concepts are framed within the person, health/illness, and environmental dimensions of nursing science. However, this study focused only on symptom experience and its influencing factors which fall into the dimension of nursing science.

Symptoms may be a result of the characteristics of a tumor, and locations of brain tumors can cause different symptoms. A tumor located in a cavernous sinus may compress the visual pathway leading to visual loss.[10] The brain laterality also be affected with symptoms, for example, a left frontal tumor is related to impaired decision-making in persons with low-grade gliomas (LGG).[11] Several studies have described tumor characteristics as predictors of symptom experience in patients with PBTs.[11, 12]

The current modalities of radiation treatment of benign and malignant brain tumors are stereotactic radiotherapy (SRT) and stereotactic radiosurgery (SRS).[3] IMRT is an example method of RT, while X-Knife and CyberKnife are the types of radiosurgery. These three methods use a Linear Accelerator, the delivery device of therapeutic X-ray that can give high radiation doses to fit the target point guided by the actual image acquired before treatment.[13] All of these methods are called RT. Even though the types and regimens of RT have been found to be related to symptom experiences, previous studies have explored RT-related symptoms at a late stage after completion of RT, i.e., 6 months to more than 1 year.[2] None of those studies focused on the early stage effects of RT, which might affect patients' experiences.

## Aims and Objectives

This study aimed to explore symptoms in their occurrence and severity dimensions and their pattern of changes, as well as life interference in Thai adults with PBTs before, during, and at the end of RT and their predicting factors. The specific objectives were to:

1. Describe the occurrence and patterns of the most common symptoms in occurrence and severity dimensions throughout the period of RT regimen from the initial phase until the completion of RT, and
2. Determine the extent to which tumor factors (laterality, location, and type) and type of RT predicted the most common symptoms in occurrence, severity dimensions and life interference over time.

## Methods

### *Design:*

A longitudinal repeated-measure design was used to obtain data prior, during, and at the end of RT in persons with PBTs.

### *Sample and Setting:*

The sample comprised participants with PBTs who received RT at the outpatient clinics of three tertiary care hospitals in Bangkok, Thailand. Two sites were university hospitals and the other was a cancer institute. The following inclusion criteria were set for sampling selection: diagnosis with PBTs according to the World Health Organization grading system or histological tumor confirmation[5], age above 18 years and receiving primary RT. Exclusion criteria were four-fold: persons with other cancers; having had RT previously; having a severe cognitive impairment; or being unable to pass the Mini-Mental State Examination (MMSE).

The sample size was based on the work of Hedeker et al.[13] who estimated the sample size for a longitudinal repeated-measure research design. The attrition rate was expected to be 10% at two time points. Accordingly, the final sample size required was 113 participants. A total number of 130 adults with PBTs were initially approached. One refused to participate and four had other cancers while five had a history of previous RT. Therefore, 120 participants with PBTs participated in the study. At time 1, after receiving cognitive impairment screening, four participants who had a severe cognitive impairment were excluded yielded the final sample of 116 participants. Throughout the data collection period, which included time 2 and time 3, all 116 participants, passed the MMSE test.

### *Ethical Considerations:*

Ethics approval was obtained from the Research Ethics Committee of Faculty of Medicine Ramathibodi and Siriraj Hospital, Mahidol University, and the National Cancer Institute, Thailand. Each participant received essential information about the purposes, research activities, the utility outcome, and the option to withdraw at any time with no effect on their treatment before signing the consent form. The participants were assured of privacy and confidentiality and a code number was assigned to each questionnaire instead of using their real name.

### *Instruments:*

***The Mini-Mental State Examination***, developed by Tombaugh and McIntyre[14], was used to screen cognitive status. The Thai version of this test was developed after translation by the Institute of Geriatric Medicine, Ministry of Public Health.[15] The MMSE contains 11 questions grouped into seven categories. Each category represents a different cognitive domain. Scoring of each domain is assigned to: orientation to time (5 points), orientation to place (5 points), registration of three words (3 points), attention and calculation (5 points), recall of three words (3 points), language (8 points), and visual construction (1 point).

Scores range from 0 to 30. The cutoff levels classify the severity of cognitive impairment: score 24-30 = normal, score 18-23 = mild, and score 0-17 = severe.[14] The screening of cognitive status for the 116 participants in this study showed that 100 participants had normal cognitive status while 16 had mild cognitive impairment.

***The Demographic and Medical Record Form*** was developed by the principal investigator. It included the participants' ages, type of PBTs, stage of disease, tumor laterality and location, type of RT, dose/ fraction, and total dose of RT.

***The MD Anderson Symptom Inventory-Brain Tumor Module*** (MDASI-BT) was used to measure both neurologic and cancer-related symptoms. This was developed by Armstrong et al.[16] and consists of 22 symptoms and 6 interference items to specify the presence of a particular symptom in the last 24 hours. The following are examples of questions: How severe are your symptom? Your pain at its worst? Your fatigue (tiredness) at its worst? The author received the permission to use the Thai-version of MDASI-BT from the MD Anderson Institute. Symptom occurrence was coded as binary data (0 = no symptom and 1 = had a symptom). In total, a high score denotes the higher occurrence of a symptom. Symptom severity and symptom interference were coded as ordinal data (0 = not present to 10 = as bad as you can imagine). Scoring the severity of each symptom is achieved by summing and averaging. The authors referred to the reference of Armstrong et al.[17] to cluster symptom interference from six interfered items. A higher mean score refers to the higher symptom interference. The Cronbach's alpha from the initial phase to the end of RT for symptom severity was .701 (time 1 or T1), .756 (time 2 or T2), and .763 (time 3 or T3) respectively, whereas the Cronbach's alpha from the initial phase to the end of RT for symptom interference was .776 (T1), .790 (T2), and .794 (T3) respectively.

***Data Collection:*** After informed consent was obtained, participants received explanations about how to answer the questionnaire. Approximately 1 week before starting RT (T1) participants were asked to complete the demographic questionnaire and the test for neurocognitive status (MMSE) and complete a self-report on their symptom experiences (MDASI-BT). After receiving RT 8-10 Gy (T2) and at the completion of RT (T3), the cognitive status of the participants was evaluated and those who had normal or mild cognitive impairment were retained to complete the MDASI-BT.

***Data Analysis:*** Descriptive statistics were used to analyze the participants' characteristics, the most common symptoms, and life interference. A line graph was created to evaluate the pattern of symptoms in which time is assumed as categorical variables. The generalized estimating equation (GEE) was used to examine the factors predicting symptoms in the severity and symptom interference, while the logistic GEE was used to evaluate the occurrence (binary scale). Before carrying out a GEE analysis, the choice for selection model and correlation structure was based on the smallest value of the scale parameter and the highest value of a Wald test. Tumor factors (tumor laterality, location, and type) and type of RT were coded as a categorical scale. Time was added to the model as a continuous variable.

## Results

***Demographics:***

The mean age of participants was 48.4 years. The majority presented with meningiomas. Approximately 43.1% of the tumors were situated in the right laterality, while 55.2% of the tumors were located in the middle skull base. Of these, the majority (36.2%) received IMRT with a fractional dose of 1.8- 2.5 Gy up to an accumulated mode dose of 54 Gy. (Table 1).

**Table 1** Demographic Characteristics of the Participants (n = 116)

| Characteristic | N (%) | Characteristic | N (%) |
|---|---|---|---|
| **Age** (range 22-78 years) | Mean 48.4 | | |
| | SD 10.0 | | |
| **Type** | | **Grade** | |
| Meningiomas | 71 (61.2) | WHO I | 84 (72.4) |
| Pituitary adenomas | 20 (17.2) | WHO II | 14 (12.1) |
| Schwannoma | 14 (12.1) | WHO III | 3 (2.6) |
| HGG | 5 (4.3) | WHO IV | 4 (3.4) |
| LGG | 4 (3.4) | No pathological report | 11 (9.5) |
| Other tumors | 2 (1.7) | | |
| **Laterality** | | **Tumor location/origin** | |
| Left side | 33 (28.4) | Frontal lobe | 17 (14.7) |
| Right side | 50 (43.1) | Middle skull base | 64 (55.2) |
| Both sides | 11 (9.5) | Posterior skull base | 29 (25.0) |
| Central part | 22 (19.0) | Multiple sites | 6 (5.2) |

| Type of RT | N (%) | Dose/fraction | | Total dose | |
|---|---|---|---|---|---|
| | | Range | Mode | Range | Mode |
| IMRT | 42 (36.2) | 1.8-2.50 | 2.0 | 30.50-69.96 | 54 |
| X-Knife | 34 (29.3) | 1.8-3.00 | 1.8 | 30.00-50.40 | 45 |
| CyberKnife | 40 (34.5) | 4.0-6.75 | 5.0 | 20.00-33.75 | 25 |

***The Most Common Symptoms:***

The top five symptoms most frequently presented over 50% at 3 time points were: visual impairment, difficulty remembering, feeling upset, drowsiness, pain, fatigue, and sleep disturbance. The top five of the most severe symptoms at 3 time points included visual impairment, feeling upset, difficulty remembering, drowsiness, fatigue, sleep disturbance and change in appearance. Visual impairment was the most occurrence and severity symptom at three time points. The new symptoms occurring during T2 to T3 were fatigue and sleep disturbances. Over 45% of participants reported symptom interference in regard to their walking, work, mood, general activity and enjoyment of life at 3 time points. Relations with other people had the lowest score of symptoms interfered with daily life at three time points.

***Patterns of the Most Common Symptoms:***

Fatigue and feeling drowsy more frequently occurred from T1 to T2 and less frequently occurred from T2 to T3 (Table 2, 3, Figure 1). In contrast, their severity increased over time (Tables 2 and 3, Figure 1).

**Table 2** Change in Most Common Symptom Experience at three time points (n=116)

| Variable | Time1 | N | % | Time2 | N | % | Time3 | N | % |
|---|---|---|---|---|---|---|---|---|---|
| **Symptom Occurrence** | Vision | 88 | 75.9 | Vision | 91 | 78.4 | Vision | 88 | 75.9 |
| | Upset | 65 | 56.0 | Fatigue | 83 | 75.5 | Fatigue | 80 | 69.0 |
| | Remember | 65 | 56.0 | Drowsy | 81 | 69.8 | Remember | 77 | 66.4 |
| | Drowsy | 60 | 52.7 | Remember | 72 | 62.1 | Drowsy | 77 | 66.4 |
| | Pain | 60 | 51.7 | Sleep | 70 | 60.3 | Sleep | 73 | 62.9 |

**Table 2** Change in Most Common Symptom Experience at three time points(n=116) (Cont.)

| | **Time 1** | **M (SD)** | **Time 2** | **M (SD)** | **Time 3** | **M (SD)** |
|---|---|---|---|---|---|---|
| **Symptom Severity** | Vision | 4.22 (3.08) | Vision | 4.39 (3.04) | Vision | 4.07 (3.03) |
| | Upset | 2.41 (2.70) | Drowsy | 3.04 (2.50) | Appearance | 3.52 (3.54) |
| | Appearance | 2.31 (3.07) | Fatigue | 2.91 (2.28) | Drowsy | 3.24 (2.84) |
| | Remember | 2.22 (2.53) | Sleep | 2.72 (2.57) | Fatigue | 3.19 (2.72) |
| | Drowsy | 2.17 (2.49) | Remember | 2.56 (2.48) | Sleep | 3.01 (2.78) |
| | **Time 1** | **M (SD)** | **Time 2** | **M (SD)** | **Time 3** | **M (SD)** |
| **Symptom Interfere** | Work | 3.90 (3.02) | Walking | 4.45 (2.89) | Work | 4.08 (2.86) |
| | Walking | 3.79 (3.08) | Work | 4.03 (2.92) | Mood | 3.92 (2.92) |
| | Mood | 3.54 (2.94) | Mood | 3.86 (2.59) | Activity | 3.75 (2.82) |
| | Activity | 3.36 (2.96) | Activity | 3.76 (2.66) | Walking | 3.74 (2.99) |
| | Enjoyment | 1.91 (2.58) | Enjoyment | 2.32 (2.64) | Enjoyment | 2.09 (2.69) |
| | Relation | 1.86 (2.67) | Relation | 2.11 (2.78) | Relation | 2.09 (2.72) |

**Table 3** Predictors of Symptom Occurrence and Severity over Time

| **Variable** | **Symptom Occurrence** | | | **Symptom Severity** | |
|---|---|---|---|---|---|
| | **Coef.** | **Odds Ratio** | **CI** | **Coef.** | **CI** |
| ***Fatigue*** | | | | | |
| **Time** | 0.83 *** | 2.29 | 1.76-2.96 | 0.93*** | 0.65-1.21 |
| **Type of RT**: IMRT | | | | | |
| X-knife | -0.26 | 0.77 | 0.33-1.79 | -0.31 | -0.96-0.34 |
| CyberKnife | -1.18** | 0.31 | 0.13-0.71 | -1.30*** | -1.93-(-0.67) |
| **Laterality**: Left side | | | | | |
| Right side | 0.21 | 1.24 | 0.59-2.60 | -0.41 | -0.71-0.42 |
| Both sides | -0.45 | 0.66 | 0.19-2.34 | -0.29 | -1.27-0.69 |
| Central part | -9.92 | 4.92 | 8.88e-68-2.73e+58 | -3.02** | -5.13-(-0.91) |
| **Location**: Frontal lobe | | | | | |
| Middle skull | 0.12 | 1.13 | 0.34-3.78 | 0.36 | -0.54-4.85 |
| Posterior skull | -0.03 | 0.97 | 0.25-3.79 | 0.33 | -0.71-1.37 |
| Multiple sites | 0.76 | 2.15 | 0.31-14.75 | 1.03 | -0.41-2.46 |
| **Type**: Meningiomas | | | | | |
| Pituitary | 10.29 | 29423.55 | 5.31e-59-1.63e+67 | 2.75* | 0.65-4.85 |
| Schwannoma | 0.76 | 2.15 | 0.65-7.13 | 0.71 | -0.22-1.64 |
| HGG | 29.98 | 1.04e+13 | 0 | 2.63*** | 1.33-3.94 |
| LGG | 1.78 | 5.95 | 0.45-77.99 | 1.52* | -0.06-3.00 |
| Other tumors | 39.63 | 1.62e+17 | 0 | 4.18*** | 2.11-6.25 |

* = p < .05, ** = p < .01, *** = P < .001

**Table 3** Predictors of Symptom Occurrence and Severity over Time (Cont.)

| Variable | Symptom Occurrence | | | Symptom Severity | |
|---|---|---|---|---|---|
| | Coef. | Odds Ratio | CI | Coef. | CI |
| *Drowsy* | | | | | |
| **Time** | 0.35 *** | 1.41 | 1.17-1.71 | 0.53** | 0.21-0.85 |
| **Type of RT**: IMRT | | | | | |
| X-knife | -0.48 | 0.62 | 0.24-1.59 | -0.23 | -0.98-0.51 |
| CyberKnife | 0.12 | 1.03 | 0.42-2.79 | -0.26 | -0.98-0.47 |
| **Laterality**: Left side | | | | | |
| Right side | 0.24 | 1.27 | 0.45-2.86 | 0.41 | -0.24-1.06 |
| Both sides | -0.13 | 0.88 | 0.22-3.50 | 0.27 | 0.86-1.40 |
| Central part | -22.52 | 1.65e-10 | 0 | -1.90 | -4.33-0.53 |
| **Location**: Frontal lobe | | | | | |
| Middle skull | 0.79 | 2.19 | 0.59-8.15 | 1.13* | 0.09-2.16 |
| Posterior skull | 0.26 | 1.30 | 0.30-5.68 | 0.97 | -0.23-2.17 |
| Multiple sites | -0.22 | 0.80 | 0.11-5.92 | 0.06 | -1.60-1.71 |
| **Type**: Meningiomas | | | | | |
| Pituitary | 22.62 | 6.68e+09 | 0 | 1.77 | -0.64-4.20 |
| Schwannoma | -0.80 | 0.45 | 0.12-1.66 | -1.06 | -2.13-0.01 |
| HGG | 1.91 | 6.78 | 0.45-103.24 | 2.42** | 0.92-3.93 |
| LGG | 0.10 | 1.11 | 0.15-8.44 | 1.24 | -0.45-2.93 |
| Other tumors | 22.03 | 3.71e+09 | 0. | 3.27** | 0.89-5.66 |
| *Sleepy* | | | | | |
| **Time** | 0.55 *** | 1.73 | 1.40- 2.12 | 0.56** | 0.23-0.88 |
| **Type of RT**: IMRT | | | | | |
| X-knife | -0.47 | 0.63 | 0.25-1.58 | -0.07 | -0.84-0.69 |
| CyberKnife | -1.05** | 0.35 | 0.14-0.86 | -0.76* | -1.50-(-0.02) |
| **Laterality**: Left side | | | | | |
| Right side | 0.49 | 1.63 | 0.74-3.61 | 0.54 | -0.13-1.20 |
| Both sides | 0.39 | 1.47 | 0.38-5.75 | 0.68 | -0.47-1.83 |
| Central part | 0.20 | 1.22 | 0.07-22.51 | -0.02 | -2.50-2.46 |
| **Location**: Frontal lobe | | | | | |
| Middle skull | 0.78 | 2.19 | .61-7.92 | 0.81 | -0.25-1.87 |
| Posterior skull | 0.74 | 2.10 | .49-9.02 | 0.79 | -0.44-2.01 |
| Multiple sites | -0.20 | 0.82 | .11-5.84 | -0.44 | -2.13-1.25 |
| **Type**: Meningiomas | | | | | |
| Pituitary | -1.35 | 0.25 | 0.01-4.78 | -1.36 | -3.83-1.12 |
| Schwannoma | -0.72 | 0.49 | 0.14-1.74 | -1.01 | -2.11-0.08 |
| HGG | 0.99 | 2.60 | 0.32-22.85 | 1.61* | 0.08-3.15 |
| LGG | -1.67 | 0.18 | 0.02-1.72 | -1.53 | -3.26-0.20 |
| Other tumors | -0.71 | 0.49 | 0.03-8.57 | -0.61 | -3.04-1.83 |

* = P < .05, ** = P < .01, and *** = P < .001

**Table 3** Predictors of Symptom Occurrence and Severity over Time (Cont.)

| **Variable** | **Symptom Occurrence** | | | **Symptom Severity** | |
|---|---|---|---|---|---|
| | **Coef.** | **Odds Ratio** | **CI** | **Coef.** | **CI** |
| ***Remember*** | | | | | |
| **Time** | 0.27** | 1.31 | 1.11-1.54 | 0.30* | 0.01-0.59 |
| **Type of RT**: IMRT | | | | | |
| X-knife | -0.90 | 0.41 | 0.14-1.20 | -0.48 | -1.16-0.20 |
| CyberKnife | -1.14* | 0.31 | 0.11-0.91 | -1.16** | -1.81-(-0.50) |
| **Laterality**: Left side | | | | | |
| Right side | 0.51 | 1.66 | 0.67-4.15 | 0.36 | -0.23-0.95 |
| Both sides | 0.03 | 1.03 | 0.22-4.79 | 0.98 | -0.05-2.01 |
| Central part | -30.76 | 4.37e-14 | 0 | -3.20** | -5.41-0.99 |
| **Location**:Frontal lobe | | | | | |
| Middle skull | 0.34 | 1.41 | 0.33-5.97 | -0.34 | -1.28-0.60 |
| Posterior skull | -0.82 | 0.44 | 0.09-2.24 | -1.68** | -2.77-(-0.59) |
| Multiple sites | -0.45 | 0.63 | 0.07-6.06 | -1.50* | -3.00-0.00 |
| **Type**: Meningiomas | | | | | |
| Pituitary | 31.55 | 5.08e+13 | 0 | 3.28** | 1.08-5.48 |
| Schwannoma | -0.28 | 0.76 | 0.18-3.24 | -0.43 | -1.40-0.55 |
| HGG | -0.25 | 0.78 | 0.09-6.82 | 0.85 | -0.51-2.22 |
| LGG | 2.50 | 12.12 | 0.06-2538.70 | -0.04 | -1.58-1.49 |
| Other tumors | 15.07 | 3499547 | 0 | 1.64 | -0.53-3.81 |
| ***Appearance*** | | | | | |
| **Time** | 0.36*** | 1.43 | 1.21-1.69 | 0.60** | 0.23-0.98 |
| **Type of RT**: IMRT | | | | | |
| X-knife | -0.25 | 0.78 | 0.29-2.10 | -0.22 | -1.10-0.67 |
| CyberKnife | -1.33** | 0.26 | 0.10-0.72 | -1.86*** | -2.72-(-1.01) |
| **Laterality**: Left side | | | | | |
| Right side | -0.19 | 0.82 | 0.35-1.94 | -0.31 | -1.07-0.46 |
| Both sides | -1.02 | 0.36 | 0.08-1.72 | -1.53* | -2.86-(-0.19) |
| Central part | -30.09 | 8.57e-14 | 0 | -3.73* | -6.59-(-0.87) |
| **Location**:Frontal lobe | | | | | |
| Middle skull | 0.74 | 2.11 | 0.51- 8.75 | 0.30 | -0.92-(1.52) |
| Posterior skull | 0.92 | 2.50 | 0.49-12.83 | 0.70 | -0.71-2.10 |
| Multiple sites | 1.76 | 5.81 | 0.55-61.27 | 1.61 | -0.34-3.55 |
| **Type**: Meningiomas | | | | | |
| Pituitary | 28.76 | 3.10e+12 | 0 | 2.08 | -0.77-4.93 |
| Schwannoma | -0.08 | 0.92 | 0.22-3.78 | -1.01 | -2.27-0.26 |
| HGG | 2.00 | 7.38 | 0.51-107.46 | 2.79** | 1.03-4.56 |
| LGG | 0.14 | 1.15 | 0.13-10.04 | -0.34 | -2.33-1.65 |
| Other tumors | 14.80 | 2689614 | 0 | 1.63 | -1.18-4.44 |

* = p < .05, ** = p < .01, *** = P < .001

**Table 3** Predictors of Symptom Occurrence and Severity over Time (Cont.)

| **Variable** | **Symptom Occurrence** | | | **Symptom Severity** | |
|---|---|---|---|---|---|
| | **Coef.** | **Odds Ratio** | **CI** | **Coef.** | **CI** |
| ***Vision*** | | | | | |
| **Time** | -5.55e-17 | 1 | 0.88- 1.14 | -0.08 | -0.45-0.29 |
| **Type of RT**: IMRT | | | | | |
| X-knife | 0.33 | 1.39 | 0.39-4.96 | -0.14 | -1.01-0.73 |
| CyberKnife | 0.11 | 1.10 | 0.34-3.61 | -0.09 | -0.93-0.75 |
| **Laterality**: Left side | | | | | |
| Right side | 0.45 | 1.58 | 0.53- 4.70 | 0.45 | -0.31-1.20 |
| Both sides | -0.57 | 0.57 | 0.09- 3.50 | 0.28 | -1.03-1.59 |
| Central part | 15.07 | 3507081 | 0 | -2.06 | -4.88-0.76 |
| **Location**:Frontal lobe | | | | | |
| Middle skull | 0.18 | 1.19 | 0.19- 7.63 | 1.29* | 0.08-2.49 |
| Posterior skull | -1.50 | 0.22 | 0.03- 1.60 | -0.33 | -1.72-1.07 |
| Multiple sites | 0.33 | 1.39 | 0.07-27.63 | 0.51 | -1.41-2.42 |
| **Type**: Meningiomas | | | | | |
| Pituitary | -16.00 | 1.12e-07 | 0 | 1.31 | -1.50-4.12 |
| Schwannoma | 0.24 | 1.27 | 0.28-5.69 | -0.93 | -2.18-0.31 |
| HGG | -1.51 | 0.22 | 0.02-2.13 | -1.01 | -2.76-0.73 |
| LGG | -1.05 | 0.35 | 0.03-4.70 | -1.12 | -3.09-0.84 |
| Other tumors | 2.74 | 15.53 | .0008-269122.4 | 2.97* | 0.20-5.74 |
| ***Pain*** | | | | | |
| **Time** | 0.08 | 1.08 | 0.88-1.31 | 0.06 | -0.21-0.34 |
| **Type of RT**: IMRT | | | | | |
| X-knife | 0.51 | 1.67 | 0.71-3.91 | 1.09** | 0.45-1.73 |
| CyberKnife | 0.68 | 1.97 | 0.85- 4.55 | 0.71* | 0.10-1.33 |
| **Laterality**: Left side | | | | | |
| Right side | -0.31 | 0.73 | 0.34-1.55 | -0.39 | -0.94-0.17 |
| Both sides | -0.34 | 0.71 | 0.19-2.70 | -0.40 | -1.36-0.57 |
| Central part | 0.12 | 1.12 | 0.04-33.37 | -2.67* | -4.75-(-0.60) |
| **Location**:Frontal lobe | | | | | |
| Middle skull | 0.03 | 1.03 | 0.32-3.36 | -0.01 | -0.89-0.87 |
| Posterior skull | -0.03 | 0.97 | 0.25-3.82 | -0.18 | -1.20-0.85 |
| Multiple sites | -1.37 | 0.25 | 0.03-2.29 | -0.58 | -1.99-0.83 |
| **Type**: Meningiomas | | | | | |
| Pituitary | -0.31 | 0.73 | 0.02-22.05 | 1.89 | -0.18-3.95 |
| Schwannoma | 0.25 | 1.28 | 0.37- 4.41 | 0.62 | -0.30-1.53 |
| HGG | 0.98 | 2.61 | 0.45-15.15 | 1.32 * | 0.04-2.60 |
| LGG | -0.55 | 0.58 | 0.08- 4.18 | -0.60 | -2.04-0.84 |
| Other tumors | 39.35 | 1.23e+17 | . | 3.64*** | 1.61-5.68 |

* = P < .05, ** = P < .01, *** = P < .001

**Table 3** Predictors of Symptom Occurrence and Severity over Time (Cont.)

| Variable | Symptom Occurrence | | | Symptom Severity | |
|---|---|---|---|---|---|
| | Coef. | Odds Ratio | CI | Coef. | CI |
| *Upset* | | | | | |
| **Time** | -0.09 | 0.91 | 0.76- 1.09 | -0.08 | -0.41-0.24 |
| **Type of RT**: IMRT | | | | | |
| X-knife | -0.45 | 0.64 | 0.25-1.59 | 0.11 | -0.66-0.87 |
| CyberKnife | -1.16* | 0.31 | 0.13-0.77 | -1.14** | -1.88-(-.40) |
| **Laterality**: Left side | | | | | |
| Right side | -0.33 | 0.72 | 0.33-1.57 | -0.23 | -0.89-0.43 |
| Both sides | -0.84 | 0.43 | 0.11-1.68 | -0.43 | -1.58-0.73 |
| Central part | -0.84 | 0.43 | 0.02-7.99 | -2.67* | -5.14-(-0.19) |
| **Location**:Frontal lobe | | | | | |
| Middle skull | 0.40 | 1.48 | 0.42-5.21 | -0.09 | -1.14-0.96 |
| Posterior skull | 0.03 | 1.03 | 0.24-4.41 | -0.12 | -1.34-1.10 |
| Multiple sites | 0.00 | 1.00 | 0.14-7.11 | 0.04 | -1.64-1.72 |
| **Type**: Meningiomas | | | | | |
| Pituitary | 0.07 | 1.07 | 0.06-19.55 | 1.86 | -0.60-4.32 |
| Schwannoma | 0.71 | 2.04 | 0.56- 7.48 | 0.10 | -0.99-1.19 |
| HGG | -0.16 | 0.85 | 0.14- 5.14 | -0.35 | -1.88-1.18 |
| LGG | -0.59 | 0.55 | 0.08- 4.04 | -0.89 | -2.61-0.83 |
| Other tumors | 0.95 | 2.59 | 0.11-59.67 | 2.37 | -0.05-4.80 |

* = P < .05, ** = P < .01, and *** = P < .001

**Table 4** Predictors of Symptom Interference over Time

| Variable | Symptom Interference | |
|---|---|---|
| | Coef. | CI |
| Time | 0.11 | 0.13-0.34 |
| **Type of RT**: IMRT | | |
| X-knife | -0.03 | -0.58-0.52 |
| CyberKnife | -0.54* | -1.07-(-0.01) |
| **Laterality**: Left side | | |
| Right side | -0.05 | -0.52-0.43 |
| Both sides | 0.29 | -0.54-1.12 |
| Central part | -2.13* | -3.92-(-0.35) |
| **Location**: Frontal lobe | | |
| Middle skull | -0.29 | -1.05-0.47 |
| Posterior skull | 0.07 | -0.81-0.95 |
| Multiple sites | -1.14 | -2.35-0.07 |
| **Type**: Meningiomas | | |
| Pituitary | 1.78* | 0.01-3.56 |
| Schwannoma | 0.49 | -0.30-1.27 |
| HGG | 1.45* | 0.35-2.55 |
| LGG | -2.11** | -3.35-(-0.87) |
| Other tumors | 2.57** | 0.82-4.32 |

* = P < .05, ** = P < .01, and *** = P < .001

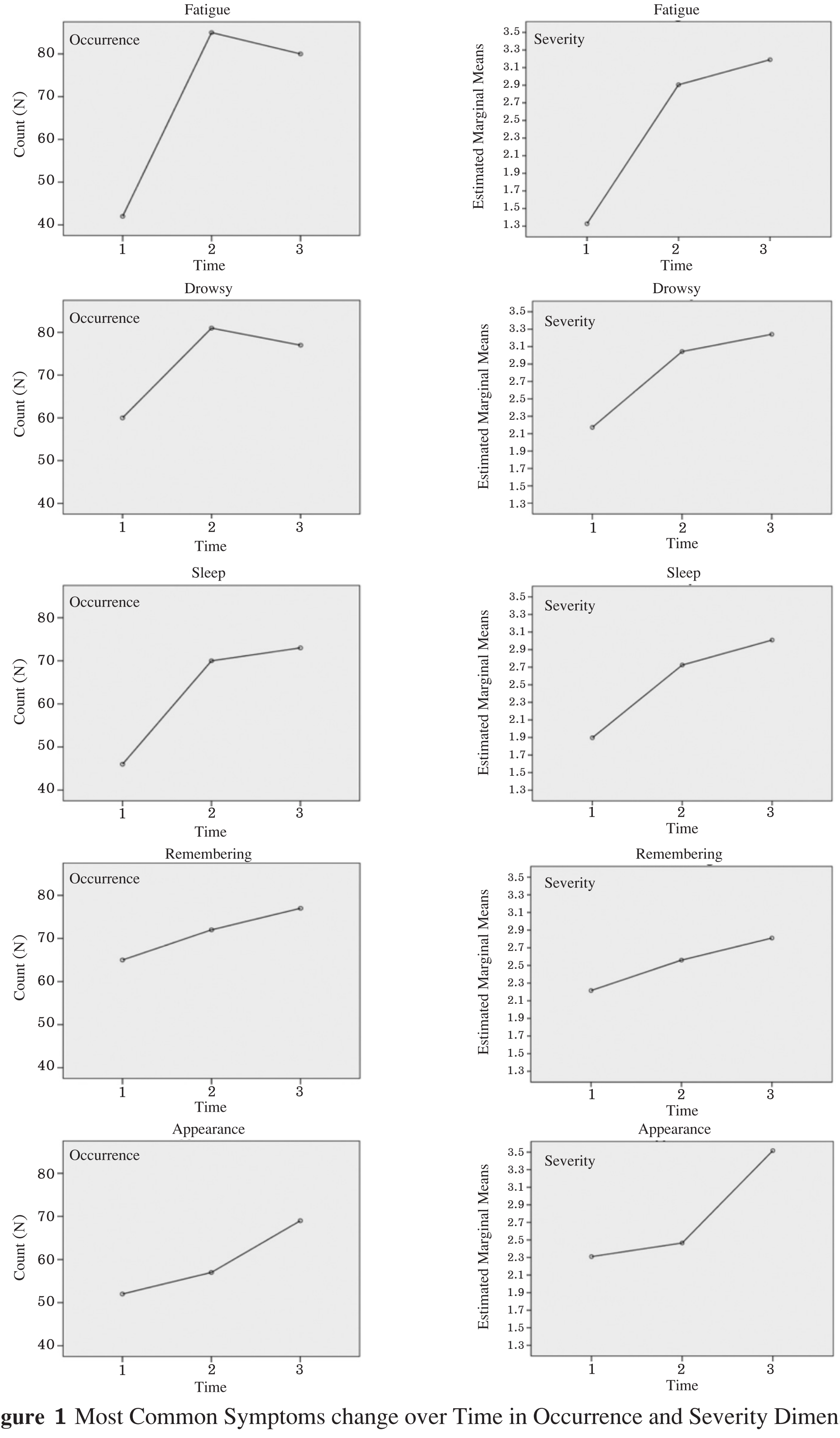

**Figure 1** Most Common Symptoms change over Time in Occurrence and Severity Dimensions

Disturbed sleep, problems with remembering, and change in appearance more frequently occurred from baseline to the end of RT (Table 2, 3, Figure 1). Their severity also increased over time (Tables 2, 3, Figure 1).

***Factors predicted the Most Common Symptoms:***

**Type of RT**: the occurrence of fatigue, disturbed sleep, difficulty remembering, change in appearance, and feeling upset in participants receiving CyberKnife was less than those receiving IMRT 0.31 times (CI = .13-.71), 0.35 times (CI = .14-.86), 0.31 times (CI = .11-.91), 0.26 times (CI = .10-.72), and 0.31 times (CI = .13-.77), respectively. For the severity dimension, participants receiving CyberKnife reported less severity of fatigue, disturbed sleep, difficulty remembering, change in appearance, and feeling upset than those with IMRT 1.30 times ($p < .001$), 0.76 times ($p < .05$), 1.16 times ($p < .01$), 1.86 times ($p < .001$), 1.14 times ($p < .01$), respectively. Participants receiving CyberKnife and X-knife reported more severe pain than those with IMRT .71 times (p < 05) and 1.09 times ($p < .01$), respectively.

**Tumor laterality**: participants with central area tumor rated severity of fatigue, difficulty remembering, change in appearance, pain, and feeling upset less than those with left side tumor 3.02 times ($p < .01$), 3.20 times ($p < .01$), 3.73 times ($p < .05$), 2.67 times ($p < .05$), and 2.67 times ($p < .05$), respectively. Participants with bilateral tumor rated severity of change in appearance less than those with a left sided tumor 1.53 times ($p < .05$).

**Tumor location**: participants with a middle skull base tumor felt more severe drowsiness and visual impairment than those with a frontal lobe tumor 1.13 times ($p < .05$) and 1.29 times ($p < .05$), respectively. However, participants with a posterior skull base tumor reported less severe difficulty remembering than those with a frontal lobe tumor 1.68 times ($p < .01$).

**Tumor type**: participants with a high grade glioma (HGG) had more severe fatigue, feelings of drowsiness, disturbed sleep, changed appearance, and pain than those with a meningioma, 2.63 times ($p < .001$), 2.42 times ($p < .01$), 1.61 times ($p < .05$), 2.79 times ($p < .01$), and 1.32 times ($p < .05$) respectively. Participants with a pituitary tumor had more severe fatigue and difficulty remembering than those with a meningioma, 2.75 times ($p < .05$) and 3.28 times ($p < .01$), respectively. Participants with a pineocytoma or endolymphatic tumor experienced more severe fatigue, feeling drowsy, visual impairment and pain than those with a meningioma, 4.18 times ($p < .001$), 3.27 times ($p < .01$), 2.97 times ($p < .05$) and 3.64 times ($p < .001$), respectively. Participants with a low grade glioma (LGG) experienced more severe fatigue than those with a meningioma, 1.52 times ($p < .05$).

However, the tumor laterality, tumor location, tumor type were not significant in predicting the occurrence of common symptoms over time.

## Discussion

**Patterns of the Most Common Symptoms:**

The most common symptoms in their frequency and severity can be grouped into four separate patterns. First, the frequency of fatigue and feeling drowsy increased from T1 to T2 and decreased from T2 to T3. Second, the severity of fatigue, feeling drowsy, and disturbed sleep increased over time. These two patterns indicated that a number of participants recovered from fatigue and feeling drowsy, whereas others reported fatigue and feeling drowsy more severely, with the highest peak at the end of RT. A possible explanation is that after RT, the blood brain barrier breakdown may occur in the early phase after RT, resulting in frequency and severity of symptoms. Brain edema leads to increased intracranial pressure and makes symptoms worse.[14] Some studies defined the relationship of fatigue, feeling drowsy, and disturbed sleep as an effect of brain radiation in term of somnolence syndrome. This syndrome occurs during the first phase in the second week of RT and symptoms resolve, then recur again after the fifth week of RT.[15] This is consistent with the study of Powell et al.[16] who reported that patients with PBTs receiving RT experience somnolence at baseline and reached its peak at 6 weeks of RT. The pattern of fatigue and disturbed sleep as well as drowsiness in this study when undergoing RT, is congruent with previous studies in PBTs and other cancers.[17, 18]

The third pattern, the frequency and severity of changes in appearance, increased over time. Our study found that participants changed in their appearance before RT. They experienced facial palsy due to the tumor lesion, skull bone deformity due to surgery, and proptosis or ptosis due to the progression of disease. However, changes in appearance occurred again at the end of RT due to toxicity of radiation, including hair loss and skin erythema. This is similar to a previous study reporting that the most common acute reaction with brain radiation includes hair loss and skin erythema.[19]

The last pattern, the frequency and severity of difficulty in remembering, increased over time. Difficulty in remembering occurred in the early acute phase from the tumor itself and from the side effect of RT. This is consistent with a study of patients with LGG, who reported difficulty remembering in the early phase of RT.[20] However, some previous research found that difficulty in remembering occurred 6 months to 1 year after receiving RT, a late delayed effect.[17]

The frequency and severity of visual impairment, pain, and feeling upset did not change over time in our participants, which is similar to a study in patients with HGG receiving fractionated IMRT.[21] We found that visual impairment was the most frequent symptom with high severity, and this was possibly due to the majority of participants who presented with meningiomas with different lesions that affected the visual pathway. The growth of a visual pathway meningioma can affect visual dysfunction. This finding is consistent with that of Maclean et al.[22] who found that visual deficit was a common clinical problem in patients with meningiomas.

Pain was the most common symptom that occurred at baseline before RT. Similarly Macartney et al. reported that pain was the most common symptom in pediatric brain tumor survivors.[23] In the severity dimension, Armstrong et al.[24] evaluated patients with PBTs and found that pain, fatigue, sleepiness, distress, and difficulty remembering were the most common symptoms presenting in moderate to severe level.

In this study, participants reported that feeling upset was the top of 5 symptoms before receiving RT, possibly due to the complex investigation procedure, the process of preparing for RT, and the suffering from various other symptoms, especially trouble remembering. Consistently Henzel et al.[25] studied people with meningioma and found a high psychological strain before RT, probably due to the primary diagnosis. In our study the participants reported difficulty remembering and this symptom significantly increased over time, while being upset did not significantly change. This result indicates that participants' upset did not contribute to their remembering. Likewise, patients with pituitary adenoma receiving radiosurgery demonstrated that memory loss was not causally related to levels of distress.[26]

**Pattern of Symptom Interference:**

Symptom interference did not change over time. Work, walking, and mood were ranked as having high interference scores at three time points, while relations with other people was the lowest interference score over time. Likewise Armstrong et al.[27] reported interference scores between 24-hour and 7-day recall period in patients with PBTs, the 24-hour recall similar to 7-day rating. The majority of studies about interference severity conducted with a cross sectional design[28] demonstrate change over time in this dimension limited, and this should be further explored in Thailand.

**Factors Predicting the Most Common Symptoms:**

The type of RT predicted the most common symptoms in their occurrence and severity dimensions. Our results indicated that participants receiving CyberKnife showed the occurrence and severity of fatigue, disturbed sleep, difficulty remembering, change in appearance, and feeling upset at a lower level than those receiving IMRT. This indicates that symptom occurrence and symptom severity differed for various types of RT. Fatigue had the most common acute and mildly transient toxicity in persons with meningiomas treated with neither fractionated SRT nor IMRT.[29] The mechanisms of RT-related fatigue and sleep disturbance are unclear, but several studies have supported increased cytokine due to the body using energy to repair normal tissue surrounding the tumor site.[30] In opposition to this, Welzel et al.[31] found that patients treated with radiosurgery demonstrated the strongest decline in memory function. Patients treated with IMRT experienced hair loss and skin irritation more than those who treated with CyberKnife. Hair loss depended on the dose and method of RT. One explanation is that IMRT and Cyberknife effectively beam to target tumor and lessen destroy normal tissue, however CyberKnife is more accurate, using for smaller tumor, and total volume less than those with IMRT. So that areas including hair follicles effect by IMRT more widely than those with CyberKnife.[32] Soldà et al.[33] examined 222 patients with benign intracranial meningiomas receiving stereotactic radiotherapy (type of radiotherapy). The result showed that treatment was associated with mild (rating of severity) transient acute toxicity such as alopecia. There was a limited study comparing the occurrence and severity of disturbed sleep and feeling upset with various types of RT.[4-7] Patients treated with CyberKnife and X-Knife had more severe pain than those who receiving IMRT. Inconsistently, Henzel et al.[25] found that patients with meningioma receiving SRT had a low pain level.

Tumor laterality significantly predicted severity of the most common symptoms over time. Participants with a central brain tumor reported less severe fatigue, difficulty remembering, change in appearance, pain, and feeling upset than those with a left-sided tumor. Participants with a bilateral brain tumor rated their change in appearance less severe than those with left-sided tumor. This indicates that the severity of symptoms might be the result of the tumor laterality. For example, patients with a left-sided tumor demonstrate significantly worse memory function than those with right-sided tumor.[34] This is consistent with Klein[20] who proposed that early neurocognitive dysfunction, including a problem with remembering in patients with LGG, should be attributed to the tumor and/or radiotherapy that occurred in acute phase. However, further studies are needed to confirm this finding because there are very limited studies about this.

Tumor location can also predict the severity of the most common symptoms over time. Participants with a middle skull base tumor reported feeling drowsy and had visual impairment more severely than those with a frontal lobe tumor. This is similar to patients with a middle skull base tumor who also experienced asthenia and drowsiness.[15] Participants with posterior skull base tumor reported difficulty in remembering less severe than those with a frontal lobe tumor. One explanation is that memory function in patients with cerebral tumor decreases due to disturbance of frontal lobe functioning.[35] This result reveals that a frontal lobe tumor seems to have a more severe effect on memory function.

Tumor type can predict the most common symptoms over time. Our results indicated that participants with HGG had more severe fatigue, felt more drowsy, had more disturbed sleep and changes in appearance and pain than those with meningioma. This is similar to patients with HGG treated with IMRT and temozolomide who experienced severe drowsiness after receiving RT 1.5 monthly and had severe pain at baseline to the end of RT.[22] Patients with HGG receiving RT demonstrate dermatological side effects such as dermatitis and alopecia which may take several months to reverse.[36] One explanation is that patients with HGG always receive high doses of radiation therapy, which may lead to more damage to normal brain tissue, disturbances in sleep pattern,[30] affecting hair loss and skin irritation. Participants with a pituitary tumor in the present study had more severe fatigue and difficulty remembering than those with meningioma, however a previous study found that fatigue was the most common acute toxicity, and was not significantly different between those with meningiomas and pituitary adenoma.[10]

Our participants with pineocytoma or endolymphatic tumor experienced more severe fatigue, visual impairment and pain and felt more drowsy than those with meningioma. Participants with LGG had more severe fatigue than those with meningioma, and the severity of fatigue during RT was found in participants with all types of tumor with the exception of schwannoma. In addition, participants with HGG reported more severe various symptoms than the other tumors. In contrast, LGG affected only fatigue severity.

**Factors Predicting Symptom Interference:**

Type of RT, tumor laterality, and tumor type predicted symptom interference over time. Our findings demonstrate that patients with LGG had interferences with daily activities at a lower rate than those with meningiomas, while patients with HGG had more interference with daily activities than those with meningiomas. Clinically significant changes were hardly seen as factors affecting symptom interference over time in persons with PBTs. Recent, in a cross-sectional study of Armstrong et al. used symptom interference to predict tumor recurrence and tumor progression in patients with PBTs.[24]

## Limitations

In this study, we did not determine cut points for the severity of symptoms to support the severity level because of the limited studies that support cut points for cognitive symptoms in patients with PBTs. In addition, we did not distinguish the severity of symptoms between participants with a recurrent tumor and those with a progressive tumor.

## Conclusions and implications for nursing practice

With respect to symptom occurrence and severity dimensions, symptoms significantly worsening over time from the beginning until the end of RT were observed including disturbed sleep, difficulty remembering, and change in appearance. Some symptoms significantly worsening over time in the severity dimension were observed as fatigue and feeling drowsy. However, in the occurrence dimension, fatigue and feeling drowsy decreased from the initial RT to the end of RT. No significant change from baseline to the end of RT were observed in visual impairment, pain and feeling upset. Any alteration of a person's symptoms depends on the type of RT, tumor type, tumor laterality, and tumor location that they have. This finding supports a definitive scope of nursing practice in that in order to facilitate patients obtaining a smooth transition during the early phase of radiation therapy, nurses should be aware of these variables. Patients who have HGG, a left laterality tumor, and who receive IMRT, should be closely monitored throughout the period of radiation therapy. Nurses who work in RT clinics and in wards with patients receiving this radiotherapy for brain cancer should be trained to use the scales to assess patients' symptoms. Nursing leaders are encouraged to work with staff to develop a nursing practice guideline to care for patients receiving RT and implement and evaluate this in clinical practice. This guideline should emphasize symptom assessment, symptom management and follow up care to evaluate patients' clinical outcomes. Further studies should also be conducted to evaluate the effectiveness of the practice guidelines on symptom outcomes.

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# เนื้องอกสมองปฐมภูมิในคนไทย: ประสบการณ์การเกิดอาการและปัจจัยทำนาย

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**บทคัดย่อ:** การศึกษานี้มีวัตถุประสงค์เพื่อสำรวจ อาการแสดงที่เกิดขึ้น ความรุนแรงของอาการ และการรบกวนที่เกิดจากอาการของผู้ป่วยเนื้องอกสมองปฐมภูมิ ใน 3 ช่วงเวลา คือ ตั้งแต่เริ่มให้การรักษาด้วยรังสี ระหว่างการรักษา และเมื่อสิ้นสุดการรักษา และศึกษาว่ามีปัจจัยใดบ้างที่ทำนายอาการแสดงที่พบบ่อยตามระยะเวลาที่เปลี่ยนแปลงไป กลุ่มตัวอย่างเป็นผู้ป่วยจำนวน 116 คน ซึ่งมีคุณสมบัติตามเกณฑ์ที่กำหนด และได้รับรังสีรักษาจากโรงพยาบาล 3 แห่งในกรุงเทพมหานคร เครื่องมือที่ใช้ในการวิจัย ประกอบด้วย แบบบันทึกข้อมูลส่วนบุคคล โรค และการรักษา แบบทดสอบสภาพสมองเบื้องต้น และแบบวัดอาการเนื้องอกสมองของนายแพทย์แอนเดอร์สัน

ผลการศึกษาพบว่า อาการแสดงที่เปลี่ยนแปลงทั้งจำนวนการเกิดและความรุนแรงตลอดทั้ง 3 ช่วงเวลาใน 5 อันดับแรก ได้แก่ ความเหนื่อยล้า ความรู้สึกสะลึมสะลือ อาการนอนไม่หลับ อาการหลงลืม และการเปลี่ยนแปลงของภาพลักษณ์ ในขณะที่ความผิดปกติของสายตา ความเจ็บปวด และความรู้สึกไม่สบายใจไม่มีการเปลี่ยนแปลงตลอดทั้ง 3 ช่วงเวลา สำหรับอาการที่พบระหว่างการให้รังสีรักษา คือ ความเหนื่อยล้าและอาการนอนไม่หลับ ชนิดของรังสีรักษา ประเภทเนื้องอกสมอง ซีกสมองด้านที่มีรอยโรค และตำแหน่งเนื้องอกสมอง มีผลต่อจำนวนการเกิดอาการและความรุนแรงของอาการที่เกิดขึ้นกับผู้ป่วย ชนิดของรังสีรักษาเป็นปัจจัยทำนายจำนวนครั้งและความรุนแรงของความรุนแรงของความเหนื่อยล้า การนอนไม่หลับ อาการหลงลืม การเปลี่ยนแปลงของภาพลักษณ์ และความรู้สึกไม่สบายใจ ซีกสมองที่มีรอยโรคมีอิทธิพลต่อความรุนแรงของความเหนื่อยล้า อาการหลงลืม การเปลี่ยนแปลงของภาพลักษณ์ ความปวดและความรู้สึกไม่สบายใจ ตำแหน่งเนื้องอกสมองมีอิทธิพลต่อความรุนแรงของความรู้สึกสะลึมสะลือและอาการหลงลืม ประเภทเนื้องอกสมองเป็นปัจจัยทำนายความรุนแรงของความเหนื่อยล้า ความรู้สึกสะลึมสะลือ อาการนอนไม่หลับ อาการหลงลืม การเปลี่ยนแปลงของภาพลักษณ์ ความผิดปกติของสายตา และความเจ็บปวด จากผลการศึกษาผู้วิจัยมีข้อเสนอแนะว่า พยาบาลควรมีความเข้าใจและตระหนักถึงแบบแผนของอาการที่เกิดขึ้นในผู้ป่วยเนื้องอกสมองปฐมภูมิที่ได้รับการรักษาด้วยรังสีรักษา ตั้งแต่ระยะแรกเมื่อเริ่มรับการรักษาจนสิ้นสุดการรักษา โดยการประเมินอาการและอาการแสดงที่เกิดขึ้นกับผู้ป่วยอย่างต่อเนื่อง ติดตาม เฝ้าระวังและส่งต่ออาการ ตลอดจนพัฒนาแนวทางในการควบคุมและจัดการกับอาการที่เกิดขึ้นอย่างมีประสิทธิภาพ

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# Development and Psychometric Testing of the Safer Sex Behavior for Thai Women Scale

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**Abstract:** This study used a mixed method sequential explanatory design to develop and test the psychometric properties of the Safer Sex Behavior for Thai Women Scale. The conceptual model and content domains were derived from a comprehensive literature review. Five domains and 70 items of safer sex behaviors for Thai women were generated through in-depth interviews from 20 Thai women. The first draft instrument was verified for content validity by 7 experts and examined for the clarity by 6 Thai women. Out of 70 items, 53 items remained.

The construct validity of the revised scale was tested by exploratory factor analysis and confirmatory factor analysis. The participants were 298 and 354 Thai women, respectively. The results revealed that scale was composed of 9 factors and accounted for 50.17 % of the variances. Confirmatory factor analysis revealed that only 8 factors (42 items) fitted the empirical data, namely: avoiding having sex with a partner who has multiple-partners; negotiating with partners for condom use; avoiding alcohol drinking and drug use; avoiding having sex with a partner who has sexual transmitted infection; protecting when partner has sexual transmitted infections; using condom; avoiding having sexual intercourse; and reducing sexual risk behavior. The Cronbach's alpha coefficient of the overall scale was 0.89. Thus the instrument has good construct validity and reliability. This instrument has potential to monitor and evaluate a nursing intervention to promote safer sex behavior among Thai women.

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**Keywords:** Behavior, Instrument development, Psychometric testing, Safe sex, Thailand, Women

## Introduction

In Thailand, sexually transmitted infections (STIs) are significant women health problems, with the overall prevalence of 37.2 cases per 100,000 populations (MOPH, 2011).[1] The prevalence tends to increase between 15 and 44 years, and might be a result of unsafe sexual behaviors, such as not using a condom or having sex with multiple partners.[2]

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Promoting safer sex practice is necessary for women to reduce the risk of STIs. Safer sex is the practice that reduces the risk of STIs and limits body fluid exchange by using barrier devices.[3] For example, using condoms has been shown to decrease the risk of STIs about 20 fold; choosing insertive fellatio rather than insertive anal sex can reduce 13 fold the risk of HIV infection; and choosing a partner who has no sexual risk behavior can reduce 4.7 fold the relative risk of HIV transmission.[3-4] Although safer sex practice is an excellent way for HIV prevention. However, it has not been successfully implemented among Thai women.[5] Such behavior in Thai women is quite complex, as it is under the influence of biological- physiological, intra-psychic, interpersonal, and socio-cultural domains,[6] making it difficult to be promoted, practiced and monitored.

In the biological-physiological domain, female sexual organs and the soft tissue of the reproductive tract make women more vulnerable to infections than men. Thus, strategies used for safer sex practice are different by gender. In the socio-cultural domain, Thai social and cultural norms have treated females as inferior to males, and women have to keep silent surrounding sexuality. Thai culture dictates that good women are expected to be ignorant about sexual behavior and should be passive in sexual interactions. This has affected the interpersonal domain which involves women's ability to interact with partners. It is more difficult for Thai women to become informed about sexual risk reduction. Even when they are well informed, it is still difficult for them to be proactive in negotiating for safer sex.[7] In the intra-psychic domain, personality mediators and cognitive processes are involved in decision making regarding sexual risk-taking for STIs. Thai women are unable to make decisions about safer sex independently, as using or not using condoms mostly depends on a male partner's decision.[8] Moreover, the belief that condoms must always be used with commercial sex workers (CSWs)[9] has negative influences on the safer sex behavior of Thai women, and increases risk of HIV transmission from their steady partners.[10] Thus, these four domains must be taken into considerations in promoting safer sex behavior among Thai women.

When promoting safer sex behavior among Thai women, valid and reliable measures that more specific to the Thai context are needed. Although, there are several existing instruments, they do not represent all domains, as none of them specifically concern gender differences. As seen in a study by Dilorio and colleagues,[11] the Safer Sex Behavior Questionnaire (SSBQ) was used in both men and women; it was found that women responded with scores of half those of men in terms of risk. The researchers suggested that any tool measuring safer sex behavior should be gender specific. Moreover, safer sex has involved various methods: abstinence, monogamy, a couple's mutual fidelity, and a couple's condom use.[7] However, existing instruments used to measure safer sex behavior focus mostly on consistent condom use. These instruments could reveal information about women's safer sex behavior because other safer sex methods aside from condom use have also been employed.[12]

In addition, sexually-related instruments developed in target countries should be more sensitive and better able to capture concepts than those developed in other countries,[13] minimizing measurement errors and increasing validity. Thus, this study aimed to develop and test the psychometric properties of the Safer Sex Behavior for Thai Women Instrument (SSBTW), which can be used to assess, monitor and evaluate the effectiveness of an intervention program.

## Conceptual Framework

Sexuality is a natural part of life and an integral aspect in the quality of life, but it lacks theoretical definition, and this has complicated efforts to develop measures that clearly operationalize the construct of human sexuality.[14] However, Wilmoth [15] suggested that if researchers have to develop a measurement for sexuality, the concept of human sexuality and resultant sexual behavior should measure all biological-physiological, intra-personal, interpersonal, and socio-cultural domains so that an instrument will provide a high degree of construct validity.[15] Safer sex behavior for Thai woman can be measured in terms of behavioral intention and actual behavior. The behavioral intention has been a good proxy measure for predicting of actual safer sex behavior.[16-17]

In the biological-physiological domain, safer sex behavior involves practices to limit body fluid exchange and use barrier devices appropriately for routes of sexual actions. For the intra-personal domain, women should use a decision-making process to reduce risk behavior for STIs. This process involves several psychosocial factors such as personal knowledge, attitude, self-efficacy of safer sex, and perceived risk of HIV/STIs which affect the practice of safe sex behavior.[18] In the interpersonal domain, women successfully have safer sex behavior when they have adequate communication skills to negotiate with their partners for the use of barrier devices, and to refuse unsafe sex.[19-20] In the socio-cultural domain, women have to be concerned about values and social norms within their own context about the intention to avoid risk behavior of HIV and STIs and safer sex practices.[7]

The characteristics of safer sex behavior were synthesized from a review literature under the influence of four domains. They were used to guide the development of the Safer Sex Behavior for Thai Women Scale (SSBTWS). Safer sex behaviors are: a) sexual practices to limit bodily fluid exchange such as abstinence and the practice of monogamy and faithfulness; b) using barrier devices appropriately within the route of sexual activity, such as condom; c) practicing to reduce risk behaviors of STIs including reducing the number of partners, avoidance of alcohol and drug use; and d) negotiating skills for safer sex behavior.

## Methods

***Design:*** A sequential mixed method design was used to develop an instrument in two phases:. The first, scale development, began with Step 1-3 to develop the SSBTWS. The second phase, (Step 4-5) was conducted to test psychometric properties of newly developed instrument. (Figure 1)

***Ethical Considerations:***

Prior to data collection, this study was approved by the Research Ethical Committee, Faculty of Medicine Ramathibodi Hospital, the Research Ethics Committee, Ayutthaya Hospital and Sena Hospital. Before collecting data, information describing the research objectives, potential risks/benefits, confidentiality and anonymity was provided to the participants. The women gave informed consent to participate in the study, and received 300 Thai baht in compensation for their time spent during in-depth interview, and 50 baht in compensation for their time spent on completing a questionnaire.

***Settings and participants:***

In the scale development (Phase I, Step 1), 20 women were recruited for an in-depth interview. Fourteen women with high-risk sexual behaviors were recruited at obstetric and gynecology clinics (OGC), whereas 6 women with lower-risk sexual behaviors were recruited at family planning clinics (FPC). The high-risk women were purposively recruited based on the following inclusion criteria: 1) aged 18-49 years; 2) sexually active; and 3) having a history of STIs; while, the inclusion criteria of the low-risk woman were similar, except for no history of STIs. The average age of the high-risk women was 25.83 years (SD = 4.50) ranging from 20 to 34 years, and the average age of low-risk women was 28.5 years (SD = 6.20) ranging from 20 to 40 years, respectively. Women with high-risk sexual behaviors had HIV (n=4), candida alblican (n=3), pelvic inflammatory disease (n=3), tichomoniasis (n=1), chalamydia (n=1), herpes simplex (n=1), and genital warts (n=1).

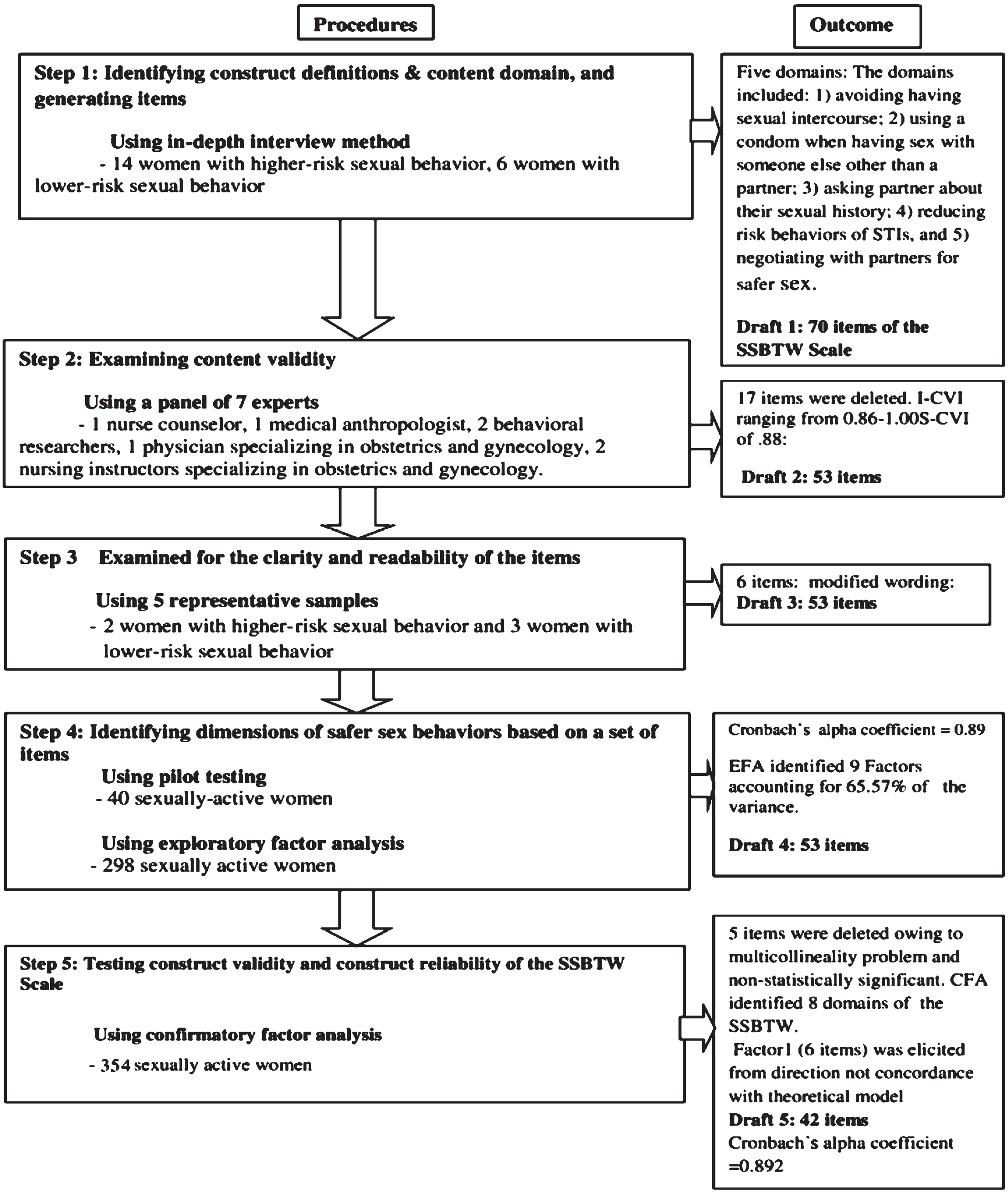

**Figure 1** Process of developing the Safer Sex Behavior for Thai Women Scale

In Step 2, seven experts assessed content validity. In Step 3, three women with high-risk sexual behaviors and two women with low-risk sexual behaviors were asked to assess clarity and readability of the first draft.

The second phase of the study involved testing of the psychometric properties of newly-developed instrument (Steps 4-5). These steps involved different consecutive samples of women of reproductive age working in the industrial sector. The inclusion criteria were: 1) aged 18-49 years; 2) sexually active; 3) able to read Thai; and 4) willing to participate in the study.

In Step 4, a pilot study with 40 sexually-active women was conducted prior to testing psychometric properties by exploratory factor analysis (EFA). For a study using EFA, a sample size is calculated using 5 participants per item;[21-22] thus, 53 items multiplied by 5 equals 265. An additional 30% of participants was added to compensate for incomplete respondents and/or respondents[23] with no sexual intercourse. Actually, 345 sexually-active women participated, but 47 reported never having sex. Finally, data from 298 participants was used for the EFA. The average age of the women was 32.58 years (SD = 7.00) ranging from 20-49 years. Most were married (77.8%) and 11.4% had sex with more than one partner. Nearly 10% of their partners had sex with other women (9.4%), with commercial sex workers (CSWs) (1.3%), and with other men (1.3%). The participants reported that they and their partners used to have a symptom of STIs (12.4% and 1.7 %, respectively).

For confirmatory factor analysis (CFA) (Step 5), the same calculation was conducted with the same 53 items.[21-22] However, the principal investigator (PI) used an addition of 40% to compensate for incomplete responses and those who reported no sexual experience. There were 371 participants, and 17 reported no sexual experience and/or gave an incomplete response. Finally, data from 354 participants were used for CFA. The average age of the women was 32.05 years (SD = 7.68), ranging from 20-49 years, and they were predominantly married (68.7%). They reported sexual risks as they had sexual intercourse with more than one partner (21.5%), their partner having sex with someone else (14.4%), and their partner had symptoms of STIs (1.4 %).

## Data Collection and Data Analysis

***Phase I***: The scale development phase comprised three steps: identifying construct definition, constructing content domain, and generating items (Step 1); examining content validity (Step 2); and assessing the clarity and readability of the instrument (Step 3).

***Step I: Identifying construct definition, constructing content domain, and generating items.*** Each participant was interviewed for 40-60 minutes in a private area. The PI asked permission to have audio-recording during the interviews, and after finishing the interviews, immediately wrote field notes to be used in analysis of the data.

The verbatim reports from in-depth interview were analyzed using content analysis. There were three interpretive strategies[24]: 1) data reduction: data was the consideration of the particular texts from the interviews relevant to the safer sex behavior and selected into table, 2) data display: the text was linked together and condensed to create sub-categories and themes, and 3) making conclusions and drawing verification: The meaning unit, sub-categories and themes were summarized and confirmed by the interview participants. Themes emerging from the interview content were used in item generation of each domain. The wording or phrases on meaning unit and sub-categories with a high frequency were utilized to generate scale items. There were 70 items generated in Draft 1 with five domains (Figure 1).

***Step 2: Examining content validity***: Draft 1 was examined for content validity by a panel of 7 experts with consideration as to whether the items taken together adequately provided the full nuance of the construct. The panel comprised a physician specializing in obstetrics and gynecology, a medical anthropologist, two behavioral researchers, a nurse counselor, and two nursing instructors specializing in obstetrics and gynecology. Seventeen items with an I-CVI less than 0.86 were discarded.[25] Subsequently, the 53 items on Draft 2 of the SSBTWS have I-CVIs ranging from 0.86 to 1.00 with an S-CVI of 0.88.

***Step 3: Assessing the clarity and readability***

Draft 2 of the Scale was examined for the clarity and readability of the items by 5 participants: 3 women with high risk sexual behavior and 2 women with low-risk sexual behavior. They were asked to comment about words or phrases that they were unable to understand or were unclear to them. Six items were revised to improve semantic content of the SSBTWS (Draft 3).

***Phase II***: The testing of psychometric properties of the Scale included 2 steps: identifying dimensions of safer sex behaviors based on a set of items (Step 4, Draft 3), and testing construct validity and construct reliability (Step 5, Draft 4).

***Step 4: Identifying dimensions of safer sex behaviors***

After getting permission from the manager of a private company, recruitment information was posted on an information board in front of an infirmary room. Those women who were interested in participating were given details about the objectives of the study. They received a questionnaire and a consent form contained in an envelope. Those who volunteered to participate signed a consent form, completed the questionnaire, sealed the envelope and returned it directly to the PI. They took about 30-40 minutes to complete the questionnaire.

Demographic data and responding scores of the SSBTWS were analyzed by descriptive statistics. A pilot study of Draft 3, with 40 women revealed a Cronbach's alpha co-efficient of 0.89. Subsequently, this draft was tested by EFA to identify dimension of safer sex behavior for Thai women. The assumptions of EFA were examined including Kaiser-Mayer-Olkin measure of sampling adequacy test (KMO), Bartlett's test of sphericity, and bivariate distributions among variables. KMO was equal to 0.85. Bartlett's test of 53 items was statistically significant ($\chi^2 = 7977.60$, df = 1378, $p < 0.001$). The initial factor analysis was conducted using the principal component analysis (PCA) and orthogonal rotation to summarize the number of underlying dimensions. The criteria set for analyzing and interpreting items were an eigenvalue greater than 1.00, and items loading above 0.30 on each factor.[26]

***Step 5: Testing construct validity and construct reliability***

In Step 5, Draft 4 was tested by CFA using the LISREL program version 8.80 student edition. Prior to CFA, the assumptions were tested including multicollinearity, univariate and multivariate normality, and the linearity of the relationship. The CFA was used to evaluate the goodness-of-fit of a statistical model of safer sex behavior on individual subscale and overall measurement models of the SSBTW Scale. The goodness-of-fit was evaluated by following guidelines for goodness-of-fit-indices, including: 1) non-significant chi-square; 2) relative or norm chi-square ($\chi^2$/df) less than 2; 3) GFI and AGFI values > 0.90: and 4) SRMR and RMSEA values <0.05.[26] The observed variables were estimated by t-values that exceeded the critical values of ±1.96 at the 0.05 significant levels. The squared multiple correlation ($R^2$) or variance extracted was used to assess reliability of the measured variable representing a latent construct. $R^2$ was used to detect the item construct reliability with the acceptable suggestion at the threshold level of 0.50 or higher.[26]

Next, overall measurement models of the SSBTWS were tested for construct validity and reliability. The summed score of each factor on the SSBTWS model was calculated by using a factor score. The summed score of each factor were then analyzed by CFA using the same criterion. Lastly, the Cronbach's alpha coefficient was calculated.

## Results

EFA explored the data in terms of how many factors were needed to best represent the data from statistics, not from theory. EFA was tested prior to CFA. The findings from EFA initially suggested 13 factors, with factor loadings that were greater than or equal to 0.30. According to Hair[26] each factor should have at least 3 observed variables. However, there were 4 factors with 1-2 items, including Factors 9, 10, 11 and 12. Items on these factors were conceptually adjusted and re-loaded on Factors 4, 5, and 6. Finally, the SSBTW Instrument retained 9 factors (**Table 1**). Most items had communalities of greater than 0.50. Although the cut of point factor loading was above 0.3, there were 52 items with factor loadings greater than 0.40. The factor extractions of the SSBTWS can explain 50.17% of the variance.

**Table 1** Factor loadings and communalities of the SSBTW Scale

| Items | Items | Factor Loadings | Communalities ($h^2$) |
|---|---|---|---|
| | **Factor 1: Asking partner about their sexual history (ASKPAR): 7 items** | | |
| 16 | Prior to making a decision to have sex with your partner, you ask him about his STIs history. | .722 | .596 |
| 17 | Prior to making a decision to have sex with your partner, you ask him about having sexual intercourse with other women in the past. | .824 | .680 |
| 18 | Prior to making a decision to have sex with your partner, you ask him about having sexual intercourse with CSWs in the past. | .845 | .714 |
| 19 | Prior to making a decision to have sex with your partner, you ask him about using a condom when having sexual intercourse with CSWs in the past. | .824 | .679 |
| 20 | Prior to making a decision to have sex with your partner, you ask him about using a condom when have sexual intercourse with other women in the past. | .805 | .648 |
| 21 | Prior to making a decision to live with spouse, you ask him about using condom when having sexual intercourse with other women. | .827 | .684 |
| 22 | If you do not know partner's entire sexual history, you will not have sex with him. | .657 | .432 |
| | Percentage of explained variance = 8.36% | | |
| | **Factor 2: Reducing sexual risk behavior (RISKBEH): 11 items** | | |
| 26 | At the present time, you have multi-partners. | .773 | .597 |
| 27 | Prior to making a decision to live with this partner, you had sexual intercourse with other men in the past. | .729 | .531 |
| 28 | After you live with your partner, you have sex with other men. | 797 | .635 |
| 29 | You have sexual intercourse with commercial sex worker (CSWs) | .465 | .216 |
| 30 | You have sexual intercourse frequently with your partner, you have bleeding per vagina, lower abdominal pain dysuria and hematuria after having sexual intercourse. | .655 | .429 |
| 31 | You have violent sexual intercourse with your partner, as a result of feeling pain. | .610 | .372 |
| 32 | During the menstruation period, you have a sexual intercourse with your partner. | .575 | .330 |
| 35 | You make love to have an orgasm without penetration. | .483 | .233 |
| 36 | You have sex by withdrawal method without penetration. | .534 | .285 |
| 37 | You have oral sex with your partner. | .703 | .494 |
| 38 | You have anal sex with your partner. | .708 | .502 |
| | Percentage of explained variance = 8.72% | | |
| | **Factor 3: Using condom (CONUSE): 5 items** | | |
| 7 | You have prepared condoms for having sexual intercourse with men. | .846 | .716 |
| 8 | In the past, your partners have made a decision about using or not using a condom. | .753 | .567 |
| 9 | You will get all of partner using a condom if they want to have sex with you. | .798 | .636 |
| 10 | If you will have sex with other temporary partners, you insist on them using a condom when having sex with you. | .678 | .459 |
| 13 | You have symptoms of STIs such as an itching vagina or leucorrhoea; therefore, you get your partner to use a condom when he has sex with you. | .686 | .470 |
| | Percentage of explained variance = 5.38% | | |

**Table 1** Factor loadings and communalities of the SSBTW Scale (Cont.)

| Items | Items | Factor Loadings | Communalities ($h^2$) |
|---|---|---|---|
| | **Factor 4: Avoiding having sexual intercourse (AVIOD): 7 items** | | |
| 1 | You will not have sex with your partner if he had sex with CSWs. | .843 | .711 |
| 2 | Even if your partner did not use a condom with CSWs, you are still having sex with him as usual. | .322 | .104 |
| 5 | Even though you have symptoms of STIs such as leucorrhoea, itchiness or fungi, you are still having sex with your partner. | .146 | .021 |
| 44 | You can refuse sexual intercourse with partner if you do not want to have sex. | .506 | .256 |
| 47 | You can refuse sexual intercourse with partner if he has STIs such as syphilis, gonorrhoea or AIDS. | .847 | .718 |
| 52 | You can persuade your partner not to visit CSWs. | .799 | .639 |
| 53 | You can persuade partner not to have sex with other women. | .568 | .323 |
| | Percentage of explained variance = 5.14% | | |
| | **Factor 5: Avoiding alcohol drinking and drug use (USEALCOH): 5 items** | | |
| 39 | You have drunk alcohol before having sex. | .719 | .516 |
| 40 | You have drunk alcohol and had sexual intercourse without condom use. | .755 | .601 |
| 41 | You have drunk alcohol, you have sexual intercourse with other men without condom use. | .697 | .485 |
| 42 | You had used illicit drugs before having sex. | .837 | .700 |
| 43 | You had used illicit drugs before having sex with your partner, so you did not use a condom. | .825 | .680 |
| | Percentage of explained variance = 5.62% | | |
| | **Factor 6: Negotiating with partners for condom use (NEGOTI): 6 items** | | |
| 11 | You know that your partner had sex with CSWs. You did not get him using condoms when he has sex with you. | .780 | .608 |
| 45 | You cannot persuade your partner to use a condom with you when he has sex with you. | .457 | .209 |
| 46 | You cannot persuade your partner to use condom, when he had sex with other women. | .733 | .538 |
| 48 | You cannot negotiate with your partner for using a condom even though he had sex with CSWs. | .507 | .257 |
| 49 | Even though your partner has sex with other women, you cannot negotiate with him for using a condom when he has sex with you. | .768 | .590 |
| 51 | You do not dare ask partner to use condom because of being afraid of arguing with him. | .627 | .393 |
| | Percentage of explained variance = 4.90% | | |
| | **Factor 7: Avoiding having sex with a partner who has STIs (PARSTI) : 3 items** | | |
| 4 | You will have sex with your partner as usual, even if your partner has STIs, such as a blister pus or discharge from his penis. | .732 | .536 |
| 33 | In the past, your partner had a symptom of STIs such as dysuria, pus from tip of penis. | .843 | .711 |
| 34 | In the past, your partner had STIs such as herpes, gonorrhoea or syphilis. | .858 | .736 |
| | Percentage of explained variance = 3.74% | | |
| | **Factor 8: Protecting when partner has STIs (PROTECT ): 5 items** | | |
| 3 | You will not have sex with your partner as usual, even though he had sex with CSWs and used a condom. | .668 | .446 |
| 12 | If your partner has symptoms of STIs, such as a blister pus discharge from his penis, you get your partner to wear a condom | .717 | .514 |
| 14 | You will get your partner to use condom with you if he has STIs such as syphilis, gonorrhoea or AIDS. | .735 | .540 |
| 15 | Although your partner had STIs, you did not get him using a condom. | .702 | .493 |

**Table 1** Factor loadings and communalities of the SSBTW Scale (Cont.)

| Items | Items | Factor Loadings | Communalities ($h^2$) |
|---|---|---|---|
| 50 | You persuade your partner to use a condom by helping him put it on. | .669 | .448 |
| | Percentage of explained variance = 4.60% | | |
| | **Factor 9: Avoiding having sex with a partner who has multi-partners (MULTIPAR): 4 items** | | |
| 6 | If you know that your partner has sex with other women, you are still having sex with him as usual. | .669 | .448 |
| 23 | Even though your partner lives with you, he had sex with other women. | .770 | .593 |
| 24 | Even though your partner lives with you, he had sex with CSWs | .763 | .582 |
| 25 | Even though your partner lives with you, he had sex with men. | .590 | .348 |
| | Percentage of explained variance = 3.71% | | |

Subsequently, CEA was used to finalize and confirm a theoretical factor structure and test for the variance of the factor structure over multiple data sets, and the assumptions of the CFA statistics were tested. There was a pair of items which had a correlation coefficient >0.85 (Item 20 "Prior to making a decision to have sex with your partner, you ask him about using condoms when having sexual intercourse with other women in the past"; and Item 21 "Prior to making a decision to live with a spouse, you ask your partner about using condoms when having sexual intercourse with other women"). This indicates the presence of multicollinearity.[27] Thus, Item 20 was eliminated. The remaining 52 items of the SSBTWS were further tested for psychometric properties by CFA. All variables violated the assumption as they were not distributed by multivariate normal distribution. When the data were not normally distributed, the robust maximum likelihood estimation (RML) was used.[28]

The 52 items of the SSBTW Model were tested to confirm 9 individual measurement models. Four items not statistically significant (Items 2, 29, 42, and 50) were deleted. Nine factors (48 items) were re-analyzed by using CFA. The results of CFA confirmed that each factor (1-9) fitted the empirical data and that they had construct validity (**Table 2**).

**Table 2** Fit statistics of an individual measurement models (n = 354)

| variables | $\chi^2$ | df | $\chi^2$/ df | *p* | GFI | AGFI | CFI | RMSEA | SRMR |
|---|---|---|---|---|---|---|---|---|---|
| 1. ASKPAR | 5.144 | 3 | 1.714 | .162 | .993 | .954 | .999 | .045 | .011 |
| 2. RISKBEH | 16.634 | 19 | .875 | .615 | .987 | .963 | 1.000 | .000 | .029 |
| 3. CONUSE | 1.164 | 5 | .232 | .948 | .998 | .993 | 1.000 | .000 | .011 |
| 4. AVOID | 2.315 | 3 | .771 | .510 | .997 | .982 | 1.000 | .000 | .017 |
| 5. USEALCOH | .062 | 1 | .062 | .804 | 1.00 | .998 | 1.000 | .000 | .003 |
| 6. NEGOTI | 5.740 | 6 | .956 | .452 | .991 | .969 | 1.000 | .000 | .026 |
| 7. PARSTI | 1.421 | 1 | 1.421 | .233 | .994 | .965 | .997 | .034 | .038 |
| 8. PROTECT | .167 | 1 | .167 | .683 | 1.00 | .997 | 1.000 | .000 | .006 |
| 9. MULTIPAR | 1.820 | 2 | .910 | .403 | .995 | .976 | 1.000 | .000 | .022 |

**Note:** Asking partner about their sexual history (ASKPAR), Reducing sexual risk behavior (RISKBEH), Using condom (CONUSE), Avoiding having sexual intercourse (AVOID), Avoiding alcohol drinking and drug use (USEALCOH), Negotiating with partners for condom use (NEGOTI), Avoiding having sex with a partner who has STIs (PARSTI), Protecting when partner has STIs, Avoiding having sex with a partner who has multiple-partners (MULTIPAR).

Measurement model of the SSBTW fitted to the empirical data (Satorra - Bentler $\chi^2$ = 12.368, df = 8, $\chi^2$/d f = 1.546, p = 0.136, GFI = 0.988, AGFI = 0.933, CFI= 0.966, RMSEA = 0.0393 and SRMR = 0.031). Surprisingly, Factor 1 "Asking partner about their sexual history" had a negative direction with the SSBTW model (standardized factor loading = -.150) and be considered not to be a practical indicator for the theoretical model. Thus, Factor 1 was eliminated. Finally, the SSBTWS retained 8 factors with 42 items. It was re-analyzed and we found that the measurement model of the SSBTWS fitted with empirical data (Satorra - Bentler $\chi^2$ = 6.326, df = 8, $\chi^2$/df = 0.790, p = 0.611, AGFI = 0.966, GFI= 0.993 CFI= 1.000, RMSEA = 0.021 and SRMR = .000) (**Figure 2**).

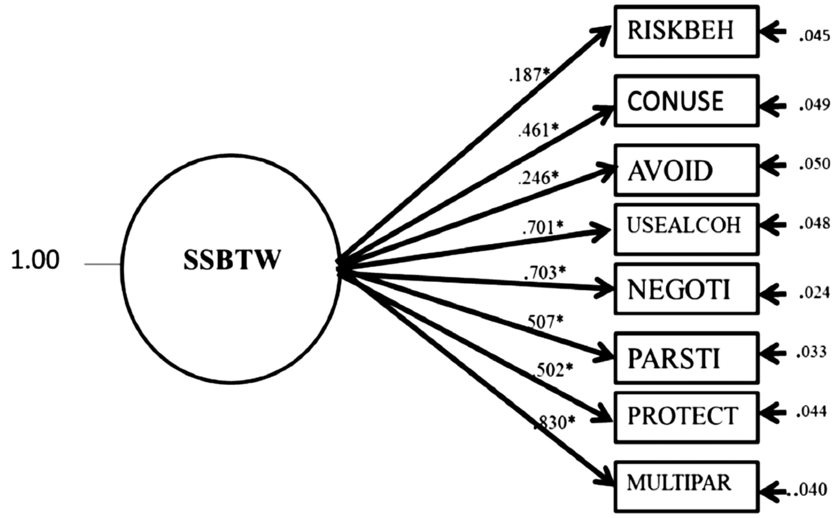

**Figure 2** Standardized factor loadings and measurement errors for indicators of the SSBTW model

$\chi^2$= 6.326, df = 8, $\chi^2$/df = 0.790, p = 0.611, AGFI = 0.966, GFI= 0.993 CFI= 1.000, RMSEA = 0.021, SRMR = 0.00.

Note: 1) chi-square goodness of fit ($\chi^2$); 2) a ratio of the chi-square/degree of freedom ($\chi^2$/df); 3) the goodness of fit index (GFI); 4) adjusted goodness of fit index (AGFI); 5) comparative fit index (CFI); 6) root mean square error of approximation (RMSEA); and 7) standardized root mean square residual (SRMR).

The standardized factor loadings ranged from 0.187 to 0.830 (***Table 4***). The standardized factor loadings of 42 items were in the range of 0.149 - 0.912. Square multiple correlations ($R^2$) were in the range of 0.049 - 0.832. The most important indicator of the SSBTW model was Factor 9: Avoiding having sex with a partner who has multiple-partners (MULTIPAR), followed by Factor 6: Negotiating with partners for condom use (NEGOTI), Factor 5: Avoiding alcohol drinking and drug use (USEALCOH), Factor 7: Avoiding having sex with a partner who has STI(s) (PARSTI), Factor 8: Protecting when partner has STIs (PROTECT), Factor 3: Using a condom (CONUSE), Factor 4: Avoiding having sexual intercourse (AVOID), and Factor 2: Reducing sexual risk behavior (RISKBEH), respectively. In terms of internal consistency, Cronbach's alpha coefficients ($\alpha$) of the overall Scale was 0.892 (42 items). The alphas for subscales were .75 for RISKBEH, .79 for CONUSE, .66 for AVOID, .71 for USEALCOH, .74 for NEGOTI, .61 for PARSTI, .73 for PROTECT, and .66 for MULTIPAR subscale (**Table 4**).

**Table 3** Standardized factor loading and construct reliabilities of observes in SSBTW measurement model (n=354)

| Variable | Factor Loadings | | | | | Factor Score |
|---|---|---|---|---|---|---|
| | b | B | SE(b) | t | $R^2$ | Regression |
| Measurement model of SSBTW | | | | | | |
| RISKBEH | .141* | .187* | .045 | 3.161 | .035 | .021 |
| CONUSE | .417* | .461* | .049 | 8.504 | .213 | .085 |
| AVOID | .220* | .246* | .050 | 4.366 | .060 | .002 |
| USEALCOH | .580* | .701* | .048 | 12.017 | .491 | .244 |
| NEGOTI | .344* | .703* | .024 | 14.378 | .494 | .481 |
| PARSTI | .215* | .507* | .033 | 6.437 | .257 | .266 |
| PROTECT | .496* | .502* | .044 | 11.270 | .252 | .106 |
| MULTIPAR | .738* | .830* | .040 | 18.682 | .689 | .508 |

Note: b = Unstandardized factor loading, B = Standardized factor loading, SE (b) = Standard error,

$R^2$ = construct reliability, $*p < 0.05$. Asking partner about their sexual history (ASKPAR), Reducing sexual risk behavior (RISKBEH), Using condom (CONUSE), Avoiding having sexual intercourse (AVOID), Avoiding alcohol drinking and drug use (USEALCOH), Negotiating with partners for condom use (NEGOTI), Avoiding having sex with a partner who has STIs (PARSTI), Protecting when partner has STIs, Avoiding having sex with a partner who has multiple-partners (MULTIPAR).

**Table 4** Cronbach's alpha of observed variables in SSBTW Scale (n=354)

| variable | A number of items | Cronbach's alpha |
|---|---|---|
| RISKBEH | 10 | .759 |
| CONUSE | 5 | .796 |
| AVOID | 6 | .660 |
| USEALCOH | 4 | .711 |
| NEGOTI | 6 | .749 |
| PARSTI | 3 | .616 |
| PROTECT | 4 | .731 |
| MULTIPAR | 4 | .668 |
| Overall | 42 | .892 |

Note: Asking partner about their sexual history (ASKPAR), Reducing sexual risk behavior (RISKBEH), Using condom (CONUSE), Avoiding having sexual intercourse (AVOID), Avoiding alcohol drinking and drug use (USEALCOH), Negotiating with partners for condom use (NEGOTI), Avoiding having sex with a partner who has STIs (PARSTI), Protecting when partner has STIs, Avoiding having sex with a partner who has multiple-partners (MULTIPAR).

## Discussion

The SSBTWS is a newly-developed instrument to measure safer sex behavior in Thai women. It measures both actual safer sex behaviors and the intention to practice safer sex and was developed by using a quantitative method in accordance with the conceptual framework. This reflects that it can capture the targeted construct accurately and support validity of the Scale. The initial items were generated from open-ended interviews of Thai women with higher and lower sexual risk behaviors. Item generation from the population of interest was able to provide insights into construct definition and measurement. Thus, these enhance the validity of the instrument.[22]

The SSBTWS is composed of 9 subscales. There are 4 subscales similar to existing instruments measuring sexual behaviors: Factor 1: Asking partner about their sexual history, Factor 2: Reducing sexual risk behavior, Factor 6: "Negotiating with partners for condom use", and Factor 5: "Avoiding alcohol drinking and drug use". Five new subscales are: "Protecting when partner has STIs", "Avoiding having sex with a partner who has multiple partners", "Avoiding having sexual intercourse" and "Avoiding having sex with partner who has STIs". The new subscales were derived from this study from this study are also essential components of safer sex in women. The most important indicator of the SSBTW model is Factor 9 "Avoiding having sex with a partner who has multiple-partners". However, this factor has not been included in any other existing instruments measuring sexual risk behavior. This subscale is essential to evaluate whether women protect themselves when their partner has multiple partners because men may have premarital sex with girlfriends and/or their acquaintance, and do not protect themselves with permanent partner. Factor 6, "Negotiating with partners for condom use", is an important skill to reduce sexual risk for women. They can protect themselves from STIs by negotiating with their partner to reduce sexual risk for example by using a condom. Most Thai women have sexual risk behavior because of their partners. [29] Thus, success in safer sex depends on their negotiating skills.[30] Negotiating with partners for safer sex is an essential component of successful safer sex behavior for Thai women. The "Using condom" subscale of the SSBTWS has added items to assess about: women's decision making for condom use (Item 7) and availability of condoms (Item 8) which have strong direct effects on condom use. [30]

The item content about condom use was in accordance with the Thai context. Next, Factor 5 "Avoiding alcohol drinking and drug use" is similar to items in a "mode of risk sexual behaviors" in some existing instruments such as the SSBQ and the **Behavioral Surveillance Survey (BSS)**. The SSBTWS has 2 additional items about the use of methamphetamine since it is commonly-used among female drug users in Thailand.[31] Lastly, Factor 8 "Protecting when partner has STIs" is a subscale that will add benefit to measuring women's protection when their partner has STIs.

The SSBTWS was tested for psychometric properties by EFA. Most items on the 9 factors had communalities of 0.50 or better. This was a reasonable estimation of communality. It represents the proportion of variance of observed variables able to account for substantial variance on all factors. Most items had factor loadings greater than 0.30 which indicated fair measure of the subscales. The index for the overall solution explained 50.17% of the total variance. When total variance explained was >50%, it was accepted as an accounting variance in social science.[21-22]

The SSBTWS has good construct validity and reliability of the overall SSBTW model by CFA. Nevertheless, the final model retained 8 factors. Factor 1, "Asking partner about their sexual intercourse" was deleted due to negative variance in the SSBTW model. It is not a good indicator of safer sex behavior among Thai women, since "Asking partner about sexual intercourse" is not common among them. In Thai society, a culture of silence surrounding sexuality dictates that good women are expected to be ignorant about sexual behavior and passive in sexual interaction.[32] Asking partner about sexual intercourse will affect relationships between partners. Respondents' scores for items on Factor 1 are low (not do = 45-50%, sometimes 15-30%) causing low variability leading to a negative estimated parameter.[33] These unexpected results may occur due to sampling homogeneity, low random variability, and violation of regression assumption. For this study, a negative variance might resulted from a homogeneous sample and low random variability.[33-34]

The overall Cronbach's alpha coefficient of the SSBTWS was 0.89, which is acceptable for a newly-developed instrument.[35] Five subscales had coefficients >0.70 which is acceptable for preliminary research,[22,35] while 3 subscales had coefficients <0.70 including: "Avoiding having sexual intercourse", "Avoid sex with partner who has STIs", and "Avoid having sex with a partner who has multiple partners". This might be due to having only 3-4 items in each subscale.[27] Some items on these subscales, "Asking about sexual risk behaviors of partners" which the respondents may not know accurately, may cause measurement errors, for example, Item 2 "Even though your partner did not use a condom with CSWs, you are still having sex with him as usual?". Some participants did not know whether their partners visit CSWs, thus they might not be sure of the answer.

Items on some subscales need to be modified to improve semantic wording and enhance construct reliability and construct validity. The revised version of the SSBTWS needs to be re-tested for psychometric properties in a more heterogeneous samples of women. However, the Scale will be useful in both nursing practice and research. The SSBTW model presented "Negotiating with partners for condom use" in second order significant next to "Avoiding having sex with a partner who has multiple-partners". In case of not being able to avoid several sexual risks, women's negotiation skills are an important predictor of a partner's condom use.[36] Negotiation skills can help women decrease STIs, thus it should be promoted in Thai women to achieve safer sex behavior. The SSBTW model and Scale can be used in research to assess nursing intervention for promoting safer sex behavior among Thai women. Finally, this instrument should be tested and used with different population which have similar cultures, and interpreted safer sex behavior. It may also have applicability in other Asian cultures.

## Limitations and Future Research

The samples used in this study were recruited using non-probability sampling. All participants were female factory workers from only one setting. Using homogenous samples might not offer adequate information to generalize to all Thai women in general. Thus, the SSBTWS has fair generalizability. However, probability sampling is needed for model testing to enhance its psychometric properties and individual items should also be further ameliorated to improve the psychometric properties.

*Implications for nursing practice*

The SSBTWS will be useful for measuring and assessing safer sex behaviors among Thai women in general as well as women who have sexual risks. It has the potential to assess these women before and after giving them information. Health professionals can use it to assess and screen women whose partner had symptoms in the past, and it will help health professionals plan appropriate advice on safer sex. When Thai women know that their partner has a risk of STIs, they will increase self-protection consistently.[7, 36]

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# การพัฒนาและทดสอบคุณสมบัติทางจิตมิติของเครื่องมือวัดพฤติกรรมการมีเพศสัมพันธ์ที่ปลอดภัยในผู้หญิงไทย

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**บทคัดย่อ:** การศึกษานี้มีวัตถุประสงค์เพื่อพัฒนาและทดสอบคุณสมบัติทางจิตมิติของเครื่องมือวัดพฤติกรรมการมีเพศสัมพันธ์ที่ปลอดภัยในผู้หญิงไทย โดยใช้การวิจัยแบบผสมผสาน กรอบแนวคิดของเครื่องมือได้มาจากการทบทวนวรรณกรรม ข้อคำถามถูกสร้างจากข้อมูลการสัมภาษณ์เชิงลึกผู้หญิงไทยจำนวน 20 คน ผลการวิเคราะห์เนื้อหาพบว่าพฤติกรรมการมีเพศสัมพันธ์ที่ปลอดภัยสำหรับผู้หญิงไทยมี 5 มิติ สร้างข้อคำถามทั้งหมด 70 ข้อ ข้อคำถามถูกตรวจสอบความตรงเชิงเนื้อหาโดยผู้เชี่ยวชาญ 7 ท่าน ผลการตรวจสอบความชัดเจนของคำถามโดยผู้เข้าร่วมการวิจัย 6 ท่าน พบว่าความตรงเชิงเนื้อหาจากข้อคำถามจำนวน 53 ข้อ มีค่า I-CVI อยู่ระหว่าง 0.86-1.00 และ S-CVI = 0.88

การตรวจสอบความตรงเชิงโครงสร้างของเครื่องมือทำโดยใช้การวิเคราะห์องค์ประกอบเชิงสำรวจในกลุ่มตัวอย่าง 298 คน และวิเคราะห์องค์ประกอบเชิงยืนยันในกลุ่มตัวอย่าง 354 คน ผลการวิเคราะห์องค์ประกอบเชิงสำรวจ พบว่าพฤติกรรมการมีเพศสัมพันธ์ที่ปลอดภัยในผู้หญิงไทยประกอบด้วย 9 องค์ประกอบร่วม มีร้อยละความแปรปรวนสะสมเท่ากับ 50.17 ผลการวิเคราะห์องค์ประกอบเชิงยืนยัน พบว่าโมเดลมีความตรงเชิงโครงสร้างเพียง 8 องค์ประกอบหลัก (42 ข้อ) ที่สอดคล้องกลมกลืนกับข้อมูลเชิงประจักษ์ คือ การหลีกเลี่ยงการมีเพศสัมพันธ์กับคู่ที่มีเพศสัมพันธ์กับหลายคน การเจรจากับคู่เพื่อให้ใช้ถุงยางอนามัย การหลีกเลี่ยงการดื่มสุราและการใช้สารเสพติด การหลีกเลี่ยงมีเพศสัมพันธ์กับคู่ที่เป็นโรคติดต่อทางเพศสัมพันธ์ การป้องกันตนเองเมื่อคู่มีโรคติดต่อทางเพศสัมพันธ์ การใช้ถุงยางอนามัย การหลีกเลี่ยงการมีเพศสัมพันธ์ และการลดพฤติกรรมเสี่ยงทางเพศ เครื่องมือมีค่าสัมประสิทธิ์แอลฟาของ ครอนบาค 0.89 คุณสมบัติการวัดด้านความตรงและความเที่ยงเชิงโครงสร้างของเครื่องมืออยู่ในเกณฑ์ดี สามารถนำไปใช้ในการติดตามและประเมินผลการให้กิจกรรมทางการพยาบาลเพื่อส่งเสริมการมีเพศสัมพันธ์ที่ปลอดภัยในผู้หญิงไทย

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# Factors Associated with Kidney Damage among Thais with Lupus Nephritis

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**Abstract :** Kidney damage is a serious, irreversible, adverse change to the kidney, including anatomical, physiological, or functional damage. Thus, screening for and management of factors associated with kidney damage are necessary to initiate early intervention to prevent or minimize permanent damage to the kidneys. This descriptive cross-sectional study investigated the factors associated with kidney damage among Thais with lupus nephritis. Data collection took place between July 2012 and June 2013 at the auto-immunology, allergy, and rheumatology clinic of a large university hospital located in Bangkok, Thailand. The participants consisted of 140 persons with lupus nephritis. Data were obtained through a Personal Data Form, the Disease Activity Record, the Thai Depression Inventory, the Self-Management Questionnaire, and a Clinical Data Form and were analyzed by descriptive statistics; t-test and Cohen's *d* effect size and chi-square. Findings indicated that disease duration, depression, disease activity, and self-management are associated with kidney damage among Thais with lupus nephritis, significantly. Cohen's *d* effect size indicated that disease activity had the largest effect, followed by self-management, depression and disease duration, respectively. In terms of self-management, Cohen's *d* indicated that nutrition had the largest effect, then avoiding risk factors such as fatigue, sun, stress, and infection. Disease activity and depression could be diminished by good self-management. Thus, nurses should provide self-management support emphasising a balanced diet, and minimizing exposure to risk factors, which will delay kidney damage.

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**Keywords:** Disease Activity, Kidney Damage, Lupus Nephritis, Self-Management, Thailand

## Introduction

Lupus nephritis (LN) is an inflammation of the kidney caused by systemic lupus erythematosus (SLE), and can be very grave, often requiring immediate medical treatment to prevent permanent damage. The principal goal of therapy in lupus nephritis is to normalize renal function or, at least, to prevent the progressive loss of renal function, which is a costly

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condition to treat. The average hospitalization charge among person with SLE was greater for lupus nephritis compared to those without lupus nephritis ($US43,100 versus $US28,500) especially for lupus nephritis with kidney failure, transplant, and end-stage kidney disease.[1] In many cases, treatment is effective in completely or partially controlling lupus nephritis, resulting in fewer complications. Up to 60% of adults with SLE suffer from varying degrees of renal involvement, and severe lupus nephritis (World Health Organization class III and above) progresses to end-stage kidney disease (ESRD) within 15 years of diagnosis in 10% to 30% of people with lupus nephritis develop kidney failure necessitating hemodialysis or kidney transplant.[2] When lupus attacks the kidneys, the damage can be life-threatening. Kidney damage is a key predictor of mortality in lupus nephritis[3]; however, little is known about the factors associated with kidney damage among this population. In order to provide effective intervention, knowing associated factors related to kidney damage are necessary.

## Review of Literature

The mechanisms underlying kidney damage in lupus nephritis are not completely understood. However, autoimmune disease is under genetic control, so organ resistance to damage indicates the need to personalize therapeutic strategies in the treatment of lupus nephritis to minimize side effects and prevention of flares in the maintenance phase of the disease become more important.[4] Kidney damage is an irreversible abnormal kidney structure or function persisting greater than 3 months, initially without decreased GFR, which over time can lead to decreased GFR. Proteinuria is an early and sensitive marker of kidney damage in many types of chronic kidney disease. Other markers may include evidence of pathologic abnormality which detected by renal biopsy and structural abnormalities which shown on imaging studies.[4] The extant literature outside of Thailand suggests that multiple factors including disease duration[5,6], disease activity[7], depression[9,10] and self-management[12,13,14] have been shown to influence the development of kidney damage in persons with lupus nephritis.

Disease duration: The individuals with long term disease duration may have long-term scars in their kidneys and have received more treatments which affect their kidney functions. The cumulative damage assessed by Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SDI) was increased at a rate of 0.13 per year.[5] The cumulative incidence of end stage renal disease after 1, 5, and 10 years was 3.5%, 15%, and 17%, respectively.[6] In addition, the extent of kidney damage depends on the disease activity.

Disease activity is the exacerbation of the disease after remission. The more exacerbated, the more likely to cause kidney damage. This exacerbation is determined by 10 symptoms: neurological disorder, renal disorder, vasculitis, haemolysis thrombocytopenia, myositis, arthritis, mucocutaneous disorder, serositis, fever/fatigue, and leucopenia/lymphopenia.[7] The higher the frequency of symptoms, the higher disease activity or "active disease". There is a highly significant correlation of high disease activity with cumulative kidney damage particularly in those with the first years of lupus nephritis are an active critical period which can lead to severe damage[8], this highlights the necessity of aggressive treatment, tight-organized follow-ups and more patient compliance with the physician orders. Due to the possible rapid deterioration of the disease and the restrictions of lifestyle restrictions to manage their illness, they significantly impact on the social functioning, leading to anxiety and depression, preventing ability to cope, and adjustment.[8]

Depression is a common mental disorder that presents with depressed mood, loss of interest or pleasure, decreased energy, feelings of guilt or low self-worth, disturbed sleep or appetite, and poor concentration.[9] These problems can become chronic or recurrent and lead to substantial impairments in an individual's ability to take care of his or her everyday responsibilities.[10] In some cases, depression is a result of the emotional drain of coping with a chronic medical condition that requires a wide range of adjustments and sacrifices. In other cases, lupus medication, especially steroid medications like prednisolone, and other physiological factors, can trigger depression.[11,12] Some people with lupus have mild but noticeable changes in behavior such as unusual feelings of fear or lack of fear, or loss of interest or curiosity. More commonly, the fatigue and pain of lupus is draining to the point that a person changes his or her outlook on life. Individuals with lupus nephritis are overwhelmed with having a disease and require a targeted, sensitive, and flexible approach for self-managing their conditions.

Self-management represents an ideological shift away from patients as passive recipients of treatment to empowered individuals who are partners in the effective management of their health.[13] They do this by performing a range of activities they consider to enhance their health and well-being. From this perspective self-management also involves the tasks people do to navigate health services and to take an active part in their treatment planning such as shared decision-making.[14] Self-management in person with lupus nephritis involves monitoring fluid retention, managing medications and modifying diet, exercise and fluid habits. Effective self-management improves health outcomes, slows disease progression and delays renal replacement therapy.[15] A prospective randomized controlled trial found that there were fewer hospitalization events for a self-management group than non-self-management group.[16]

There are both physical and psychological factors that might affect the deterioration of lupus nephritis to kidney damage. However, there is no single report reviewing factors associated with kidney damage among Thais with lupus nephritis. To address this gap, we examined the clinical (disease duration, disease activity), psychological (depression), and self-management factors associated with kidney damage among Thais with lupus nephritis. Study findings may help to inform clinical management and patient education approaches to reduce the prevalence of this preventable lupus nephritis co-morbidity.

## Methods

*Design*

A descriptive cross-sectional design was used to investigate the factors associated with the development of kidney damage among people with lupus nephritis. Data collection was carried out in the autoimmunology, allergy, and rheumatology clinic of a large university hospital located in Bangkok, Thailand. Data collection took place between July 2012 to June 2013.

*Ethical consideration*

Ethical Considerations: Approval to conduct the study was obtained from the Committee on Human Rights related to Research involving Human Subjects, Faculty of Medicine Ramathibodi Hospital, Mahidol University, ethical clearance number MURA 2011/547. Each potential participants received an information sheet describing: the purpose of the study; what would be involved in participating; confidentiality and anonymity issues; and that involvement was voluntary. Participants could withdraw at any time without repercussions, and still receive regular treatment from the hospital. Individuals consenting to take part in the study were asked to sign a consent form.

*Sample and Setting*

Potential participants were identified via a review of the medical records of patients with lupus nephritis. Inclusion criteria were: aged 15 to 60 years old; confirmed diagnosis of lupus nephritis by rheumatologists for ≥ 1 year; able to speak Thai; and able to provide informed consent. Those requiring renal replacement therapy were excluded. A total of

160 potential participants meeting eligibility criteria based on medical chart review and 140 (87.50%) agreed to participate. Reasons for non-participation were: lack of interest, not enough time to complete the survey, and health status.

The sample size was determined according to Yamane[17], as this was necessary for a given combination of precision, confidence levels, and variability. The prevalence of lupus nephritis in Thailand has never been studied. Based on a study on the epidemiology of systemic lupus erythematosus in Asia, the prevalence rates usually fall within 30-50/100,000 population[18] and lupus nephritis affects more than 60% of people with systemic lupus erythematosus.[19] Based on these data, it was estimated that there are currently 200,339 people with lupus nephritis in Thailand. The sample size for ±10% precision levels where confidence level was 95% and p=.5 is 100 respondents. However, the sample size of this study was increased to 140 in case of incomplete questionnaire responses.

*Study Measures*

Measures used in this study were *Demographic characteristics, Kidney damage, Disease duration, Disease Activity, Depression and Self-Management.*

*Demographic characteristics:* Demographic questions were used to obtain participant's age, education, occupation, income, and method of payment for medical services.

*Kidney Damage:* A chart review was conducted to obtain laboratory results of urinalysis. Proteinuria persisting more than three months prior to this study was determined as kidney damage.

*Disease duration:* was measured in full months from the time the patient was diagnosed with lupus nephritis until when data was obtained.

*Disease Activity*: This was measured by the frequency of abnormal symptoms recorded in the preceding 12 months by the physician in the progress note of the medical record. It contained 10-main clinical symptoms: neurological disorder, renal disorder, vasculitis, haemolysis thrombocytopenia, myositis, arthritis, mucocutaneous disorder, serositis, fever/fatigue, and leucopenia/lymphopenia.[7] This record produced a picture of disease activity in the past year, with higher frequency representing higher disease activity.

*Depression:* The Thai Depression Inventory (TDI) is a self-rated instrument used for measuring the severity of depressive symptoms in the past 14 days. The TDI contains 20 items such as "How much is your hopelessness?", with each item score ranging from none (0) to extremely (3), therefore the total score ranges from 0-60. The internal reliability and concurrent validity in a previous study were good (Cronbach alpha = 0.858; r=0.72).[20] The Cronbach's $\alpha$ coefficient of the Thai Depression Inventory in this study was 0.857.

*Self-Management*: The Self-Management Questionnaire (SMQ) represents all daily decisions a person makes to attain the greatest possible physical functioning and mental outlook to positively manage his/her chronic illness. The SMQ was adapted from the Self-care Behavior Questionnaire by Tantisak[21], the Relapse Prevention Behavior Questionnaire by Urairat et al.[22], with copyright permission and through information obtained from a literature review. The SMQ is a 42-item, 4-point Likert scale from 1 (never) to 4 (routinely), with score ranged from 42-168, the higher score indicated higher self-management. A score between 42-104 indicates poor self-management, 105-147 moderate self-management, and between 148-168 good self-management. This questionnaire includes six dimensions: health communication, nutrition, stress reduction, physical activity, managing medications, and avoiding risk factor. A sample item is "See doctor if had abnormal sign," Content validity was evaluated by 3 experts, 2 who are nurse instructors, and a registered nurse working more than 20 years with people diagnosed with SLE. The Content Validity Index (CVI) of the overall questionnaire was .89. A CVI was calculated for each dimension:

health communication (.90), nutrition (.96), stress reduction (.90), physical activity (.78), managing medications (.80), and avoiding risk factor (.89). The reliability of the SMQ was tested on 30 participants with lupus nephritis. The coefficient alpha of the 42-items of the questionnaire was 0.977, while the actual study was 0.92. The coefficient-alpha of each dimension was: health communication (.896), nutrition (.884), stress reduction (.930), physical activity (.907), managing medications (.818), and avoiding risk factor (.879).

## Data Collection

Prior to data collection, permission was obtained from the hospital director to approach potential participants located in the outpatient clinics. The head nurse and staff in the relevant clinics were informed about the goals and procedures associated with the research study. The medical records for patients on the daily appointment rosters were searched by the principal investigator (PI) for eligibility. The potential participants were then individually approached at the time of their scheduled medical appointment. Prior to data collection, the PI approached and informed them about the study goals, procedures and potential risks associated with the study. Those who agreed to participate then completed an informed consent form. Data collection took place via the self-administered questionnaire in a private room located in the outpatient clinic waiting area. Survey completion took approximately 40 minutes. Following data collection, participants were given a small gift as a token of appreciation.

## Data Analysis

Descriptive statistics were used to analyze characteristics of the participants and examine the distribution of demographic variables. T-tests were used to examine the differences in the disease duration, disease activity, depression, and self-management dimensions between lupus nephritis participants with and without kidney damage. The effect size of the independent variable was examined by using Cohen's d. The significant level of the hypothesis testing was at .05. Chi-square test was conducted to examine the differences of self-management in six dimensions between lupus nephritis participants with and without kidney damage. The effect size of each self-management item was examined by using Cramer's V.

## Results

*Demographic characteristics*

There were 140 participants with lupus nephritis. Of these, 97 (69.3%) were diagnosed with kidney damage and 43 without kidney damage (30.7%). As shown in Table 1, participants with and without kidney damage differed on the type of residence, household income, lupus nephritis class, and frequency of hospital admissions. Participants with kidney damage living outside Bangkok had lower household monthly income, were more likely to be categorized in lupus nephritis class IV, and were admitted to the hospital 2-3 times during last 1 year. Participants without kidney damage living in Bangkok and suburbs had higher income, were more likely to be in Lupus nephritis class II, and rarely were admitted to the hospital. There were no different characteristics of marital status and health care utility in both groups and most participants were single and had health cover under the Universal Coverage Scheme.

*Factors associated with kidney damage among participants with lupus nephritis*

As shown in Table 2, there were statistically significant differences in disease duration, disease activity, depression, and self-management scores among individuals with and without kidney damage. Individuals with kidney damage had a longer disease duration ($t = 5.917$), higher depression scores ($t =$

6.748), more disease activity (t = 13.669), and a lower self-management score (t = -7.598) than those without kidney damage.

Cohen's d was used to examine which independent variables had the most significant effect on kidney damage, results indicated that disease activity, depression, and self-management had a moderate significant effect on kidney damage. Disease activity had the largest effect size (Cohen's d = 2.319), followed by self-management (Cohen's d = 1.289), depression (Cohen's d = 1.145), and disease duration (Cohen's d = 1.004), respectively.

**Table 1** Comparison of demographic and clinical characteristics between participants with and without kidney damage. (N=140).

| Characteristics | | Kidney damage | | p -value |
|---|---|---|---|---|
| | | Yes n (%) | No n (%) | |
| Total | | 97 (100.0) | 43 (100.0) | |
| Residence | Bangkok and suburbs | 32 (33.0) | 34 (79.1) | .000* |
| | Other | 65 (67.0) | 9 (20.9) | |
| Marital status | Single | 62 (63.9) | 23 (53.5) | .328 |
| | Married | 35 (36.1) | 20 (46.5) | |
| Educational level | Primary school | 8 (08.2) | 0 (00.0) | n.a. |
| | High/Vocational school | 32 (33.0) | 18 (41.9) | |
| | Bachelor degree | 57 (58.8) | 22 (51.2) | |
| | Higher than bachelor degree | 0 (00.0) | 3 (07.0) | |
| Lupus nephritis | LN class 2 | 5 (05.2) | 33 (76.7) | .000* |
| | LN class 3 | 42 (43.3) | 10 (23.3) | |
| | LN class 4 | 50 (51.5) | 0 (00.0) | |
| Admission | Never | 31 (32.0) | 41 (95.3) | .000* |
| (Per year) | 1 time | 28 (28.9) | 2 (04.7) | |
| | 2-3 times | 38 (39.2) | 0 (00.00) | |

* p<.05

n.a. = not applicable

**Table 2** The differences and effect size of related variables among individuals diagnosed with lupus nephritis with and without kidney damage.

| Characteristics | Kidney amage | N | Mean | S.D. | t | Sig. (2-tailed) | Cohen's *d* |
|---|---|---|---|---|---|---|---|
| Disease duration (month) | yes | 97 | 84.96 | 73.684 | 5.917 | .000** | 1.004 |
| | No | 43 | 36.98 | 20.523 | | | |
| Disease activity | Yes | 97 | 4.81 | 3.238 | 13.669 | .000** | 2.319 |
| | No | 43 | 0.23 | 0.427 | | | |
| Depression | Yes | 97 | 19.93 | 4.438 | 6.748 | .000** | 1.145 |
| | No | 43 | 16.26 | 2.001 | | | |
| Self-management | Yes | 97 | 122.38 | 10.404 | -7.598 | .000** | 1.289 |
| | No | 43 | 135.47 | 6.548 | | | |

** p<.05

*Self-management*

There were statistically significant differences in all six dimensions of self-management among the participants with and without kidney damage: health communication (t = -2.948, p<.05); nutrition (t = -14.712, p<.05); physical activity (t = -2.058, p<.05); stress reduction (t = -4.763, p<.05); managing medications (t = -3.188, p<.05); and avoiding risk factor (t = -8.046, p<.05). A Cohen's d indicated that the degree of all six dimensions of self-management among those with kidney damage was lower than those without damage. Cohen's d indicated that nutrition had the largest effect size (Cohen's d = 2.496) followed by avoiding risk factors (Cohen's d = 1.365), and both had a moderate effect on kidney damage. Particularly, Cohen's d indicated that stress reduction (Cohen's d = 0.808), managing medications (Cohen's d = 0.541), and health communication (Cohen's d = 0.500), respectively had an effect size at a significant level, while physical activity (Cohen's d = 0.349) had the lowest effect size.

**Table 3** Differences and effect size of self-management score among individuals diagnosed with lupus nephritis with and without kidney damage.

| **Characteristics** | **Kidney damage** | | | | **t** | **Sig. (2-tailed)** | **Cohen's *d*** |
|---|---|---|---|---|---|---|---|
| | **Yes (N = 97)** | | **No (N = 43)** | | | | |
| | **Mean** | **S.D.** | **Mean** | **S.D.** | | | |
| (a) Health communication | 29.80 | 3.115 | 31.40 | 2.518 | -2.948 | .004** | 0.500 |
| (b) Nutrition | 24.98 | 2.217 | 29.35 | 1.270 | -14.712 | .000** | 2.496 |
| (c) Physical activity | 8.92 | 1.412 | 9.42 | 1.118 | -2.058 | .042** | 0.349 |
| (d) Stress reduction | 25.53 | 4.146 | 28.86 | 2.949 | -4.763 | .000** | 0.808 |
| (e) Managing medications | 17.28 | 1.718 | 18.21 | 1.264 | -3.188 | .002** | 0.541 |
| (f) Avoiding risk factor | 15.88 | 1.900 | 18.23 | 1.445 | -8.046 | .000** | 1.365 |

**p<.05

## Discussion

The rate of kidney damage among individuals with lupus nephritis in this study was 69.3%. Most participants with kidney damage were in lupus nephritis class IV, while most participants without kidney damage were in class II. This finding is congruent with the Classification of Glomerulonephritis in Systemic Lupus Erythematosus Revisited[23] in that lupus nephritis class IV are focal proliferative nephritis, while lupus nephritis class II is based on a finding of mesangial proliferative.

Our study found that factors associated significantly with kidney damage are disease duration, depression, disease activity, and self-management. Participants with kidney damage had longer disease duration, higher depression score, more disease activity, and a lower score of self-management than those without kidney damage.

*Disease duration:* Individuals with kidney damage had longer disease duration (mean 86.96 months or about 7 years) than those without kidney damage (mean 36.98 months or about 3 years). Chambers et al.[24] followed 232 patients for at least 10 years and found that 90% did not have damage at year 1 post-diagnosis. However, by year 10, 50% had accrued some damage. Urowitz et al.[25] conducted research to describe the course of disease activity and the development of damage during the first 5 years of SLE. Their results indicated that damage accumulation occurred slowly among individuals with SLE; and those who accumulated damage within the first year of disease were at an increased mortality risk. Therefore, the longer time since onset allowed comorbidities to appear due to the disease itself or possible adverse effects of treatments during its progression. After the long disease duration, most patients presented deteriorated disease damage.

*Disease activity:* Within 12 months the frequency of symptoms ranged from 0-12. Individuals with kidney damage had more frequent disease activity (mean =4.81) or active disease than those without kidney damage (mean=0.23). Active disease activity can occur in different organs especially kidneys where it can cause serious damage. If the disease course become aggressive and unresponsive to established therapies such as corticosteroids, azathioprine and cyclophosphamide, toxicity associated with prolonged use of these drugs can contribute to increased kidney damage.[26] Parikh et al.[27] found that renal activity may be an independent predictor of incident and progressive chronic kidney disease (CKD).

*Depression:* Participants in the kidney damage group had a higher score of depression (mean=19.93, with 31% mild to moderate depression) than those without damage (mean=16.26 and 2% of mild to moderate depression). Individuals with kidney damage had to undergo lifestyle and dietary restrictions to manage their illness which impacted on their social functioning, leading to anxiety and depression, decreasing ability to cope, and adjustment. Beckerman et al.[28] found that the more chronic the symptoms, the more likely depression would arise, and the more frequent the disease activity, the more intense the emotional distress.

*Self-management*: Self-management scores of participants in both groups were at a moderate level (mean = 122.38-135.47 [range 42-168], respectively). Participants with kidney damage had a lower score of self-management (mean=122.38) than those without damage (mean=135.47). Among individuals with lupus nephritis a diet with moderate protein and salt restriction is the major nutrition issue which can reduce the burden on kidneys, promote a beneficial protective effect against tissue damage, and suppress inflammatory activity. As a major concern, this is followed by avoiding risk factors, especially sun protection. Similar findings have been reported by Sohng[29] who found that it is important in self-management to reduce fatigue and depression, and improve coping skills and self-efficacy in persons with systemic lupus erythematosus. Individuals with lupus nephritis experience various changes in physical and emotional functions because of the unpredictability of symptoms, the effects of the treatment, and the uncertain prognosis. Daily life activities of patients are often impaired; thus self-management is important to prevent active disease and kidney damage.[29]

There were statistically significant differences in all six dimensions of self-management among participants with and without kidney damage. Cohen's d indicated that nutrition and avoiding risk factors had a moderate effect on kidney damage. Particularly, nutrition had the larger effect size, follow by avoiding risk factors, stress reduction, managing medications, and health communication. When participants were asked what the most important activity in self-management they should do, frequent answers were what they could eat and what they should avoid. Actually, all participants responses were similar. They all knew what they should do and what they should avoid; however, the important question was "Can they really do this?". In addition, emotion was an important factor affecting participants' clinical status such as problems from husband, and stress from work. In interviews, it was found that when participants tried to do appropriate self-management, sometimes the disease still attacked.

## Limitations

The study included a small sample of the target population from only one institution and this may limit the generalization of all patients with lupus nephritis in different contexts. In addition, collecting data from medical record retrospectively is particularly problematic because it needs to rely on others for accurate recordkeeping.

## Conclusions and Implications for Nursing Practice

The results found associations between disease duration, disease activity, depression, self-management and kidney damage in participants with lupus nephritis. Among the associated factors, disease duration is the factor that we cannot control, while disease activity and depression can be diminished by good self-management. The key to living a good life for those with lupus nephritis is knowledge about the condition, understanding what the limitations are and making the absolute most of what they have. Health care providers and family members should encourage and support individuals with lupus nephritis, enabling them to perform the appropriate self-management to prevent kidney damage.

Nurses should provide information that enables individuals to expand their health knowledge to influence their self-management. Nursing support can range from advice on the use of sun protection when undertaking outdoor activity or scheduling outdoor activities for early morning, late afternoon or early evening to avoid peak sun exposure. Other interventions such as offering advice on a balanced diet, smoking cessation, and adequate exercise and rest, all help to manage disease activity. Especially, food is very important for the individual with lupus nephritis, they should eat a high protein, low salt diet, which is very difficult to do, especially for those who do not cook at home by themselves, since Thai food always contains salt in its ingredient. Nurses should reiterate that adherence to treatment is necessary to delay progression; however, minimizing exposure to precipitating factors such as fatigue, sun, stress, and infection, will become more important. During exacerbation, individuals will become abruptly ill. Nurses should detect and record the abnormal symptoms and response to therapy. Depression may occur in the trap of feeling tired, worried and overwhelmed. Nurses should become competent in the use of various stress reduction techniques and relaxation programs to help people overcome depression and stress.

Further studies are required, especially longitudinal studies of individuals that track the changes correlated with kidney damage among lupus nephritis.

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# ปัจจัยที่มีความสัมพันธ์กับความเสียหายของไตในผู้ป่วยโรคไตอักเสบลูปัส

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**บทคัดย่อ:** การทำลายของไต คือ การที่ไตเกิดการเปลี่ยนแปลงอย่างถาวรทั้งกายวิภาค สรีรวิทยา และการทำหน้าที่ การค้นหาและจัดการปัจจัยที่ทำให้เกิดการทำลายของไต จึงมีความจำเป็นสำหรับบุคลากรทางสาธารณสุขที่ควรตระหนักและให้การช่วยเหลือเพื่อป้องกันและลดการทำลายของไต การศึกษาครั้งนี้มีวัตถุประสงค์เพื่อหาปัจจัยที่มีความสัมพันธ์กับการทำลายของไตในคนไทยที่มีไตอักเสบลูปัส ทำการวิจัยระหว่างเดือนกรกฎาคม 2555 – เดือนมิถุนายน 2556 ณ คลินิกผู้ป่วยนอกโรคภูมิคุ้มกัน ภูมิแพ้ และโรคข้อ ในโรงพยาบาลมหาวิทยาลัยแห่งหนึ่งในกรุงเทพมหานคร กลุ่มตัวอย่างเป็นผู้ที่ได้รับการวินิจฉัยว่ามีไตอักเสบลูปัส จำนวน 140 คน เก็บรวบรวมข้อมูลโดยใช้แบบสอบถามข้อมูลส่วนบุคคล, แบบบันทึกความถี่ของอาการกำเริบ, แบบวัดภาวะซึมเศร้า, แบบสอบถามการจัดการตนเอง และแบบบันทึกข้อมูลทางคลินิก ทำการวิเคราะห์ข้อมูลด้วยสถิติพรรณนา การทดสอบที การทดสอบไคแสควร์ และขนาดอิทธิพลโคเฮ็น ผลการวิจัยพบว่าระยะเวลาการดำเนินโรค ภาวะซึมเศร้า Disease activity และการจัดการตนเองมีความสัมพันธ์กับการทำลายของไต ในผู้ที่ได้รับการวินิจฉัยว่ามีไตอักเสบลูปัส โดยพบว่า Disease activity มีขนาดอิทธิพลต่อการเกิดความเสียหายของไตมากที่สุด รองลงมา คือ การจัดการตนเอง ภาวะซึมเศร้า และระยะเวลาการดำเนินโรค ตามลำดับ ในด้านการจัดการตนเอง พบว่าโภชนาการมีขนาดอิทธิพลสูงที่สุด รองลงมา คือ การหลีกเลี่ยงปัจจัยเสี่ยง เช่น ความอ่อนล้า แสงแดด และการติดเชื้อ ซึ่ง Disease activity และภาวะซึมเศร้าสามารถลดลงได้ด้วยการจัดการตนเองที่ดี ดังนั้นพยาบาลควรสนับสนุนให้มีการจัดการตนเอง โดยเน้นการรับประทานอาหารที่เหมาะสม และลดการสัมผัสกับปัจจัยกระตุ้น ซึ่งจะช่วยชะลอการทำลายของไตได้

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**คำสำคัญ :** ความเสียหายของไต ไตอักเสบลูปัส การจัดการตนเอง

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# Effectiveness of Self–Management Enhancement Program for Thais with CKD at Pre–dialysis Stages: A Randomized Controlled Trial

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**Abstract:** This randomized controlled trial aimed to examine the effects of a nurse-led, self-management, enhancement program used as an intervention for self-management behaviors, disease control, and quality of life among Thais with chronic kidney disease, pre-dialysis. Purposive sampling was used to recruit 120 participants, of whom 60 were equally diagnosed with chronic kidney disease at stages 3 and 4. Participants were randomly assigned to either the experimental (n=60) or control group (n=60). The experimental group received the 6-week intervention in addition to usual care, while the control group received only usual care. Outcome variables included self-management behaviors, systolic blood pressure, diastolic blood pressure, $HbA_{1c}$, serum creatinine, and quality of life. Data were collected through self-reported questionnaires, blood pressure measurements, and laboratory procedures, at baseline, 4 weeks, 12 weeks, and 24 weeks after participation in the program. Data were analyzed using descriptive statistics, paired t-test, and independent t-test. Results revealed that after program completion and compared to the control group, at 4 weeks the experimental group had significantly better self-management behaviors; at 12 weeks, lower systolic blood pressure, diastolic blood pressure, and $HbA_{1c}$; and, at 24 weeks, better quality of life. However, there was no significant difference in serum creatinine between groups at 24 weeks. Findings indicate the program improved health outcomes. Hence, self-management enhancement should be incorporated into nursing practice for individuals with chronic kidney disease at pre-dialysis stage.

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**Keywords:** Chronic Kidney Disease, Disease Control, Intervention Program, Pre-dialysis Stage, Quality of Life, Self-Management Behaviors, Self-Management Enhancement Program.

## Introduction

In Thailand, chronic kidney disease (CKD) is becoming a major public health concern since its incidence is increasing alarmingly.[1] Hypertension (HT) and Diabetes (DM) have been well–established as the underlying risk factors of CKD.[2] Thus, living with CKD usually involves management of CKD itself and both HT and DM. Moreover, it has been consistently reported that individuals with CKD stage

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3 and stage 4 often confront the profound impacts of disease on physical, psychological, and social dimensions as well as economic burden.[3-5] In other words, all dimensions of quality of life (QOL) of those with CKD at pre-dialysis stage are subject to impairment and deterioration due to the presence of CKD-related symptoms, complications, and CKD progression.[6] QOL, an important marker of disease burden, refers to the subjective perception of the effects of disease or its treatment on one's health.[7] Having progressive CKD with co-existing conditions implies impaired QOL, and therefore both CKD and its co-existing conditions, particularly HT and DM, should be controlled.

With a particular focus on disease control, it should be emphasized that individuals with CKD pre-dialysis should be enabled to maintain their clinical stability of disease as indicated by the normal or near-normal range of certain clinical markers. There are three practical strategies for achieving disease control. First, controlling high BP to the particular target BP of less than 140/80 mmHg is recommended.[8] Second, controlling high blood glucose to near normal level or $HbA_{1c}$ of less than 7.0 % is considered optimal glycemic control.[9] Third, controlling proteinuria to the normal range of 30-300 mg/24 hours is shown to be associated with slowed CKD progression.[10] To achieve these, daily performance of key self-management behaviors including adherence to medications, diet modifications, BP and blood glucose monitoring, regular exercise, avoidance of nephro-toxins and smoking cessation are necessarily.[11-12] However, in previous studies, self-management behaviors in terms of medical management in this population were reported to be low and insufficient in association with the presence of co-morbid diseases.[13-14]

Enhancing self-management helps individuals with CKD pre-dialysis to perform day-to-day activities needed to manage their chronic conditions by altering behaviors to optimize health outcomes.[15] Skills that are necessary to self-manage CKD in daily living include: goal selection; information collection; information procession and evaluation; problem solving; decision making; resource utilization; patient-provider relationship; action taking; and self-reaction.[15-16] To successfully train individuals with these skills, self-efficacy is found to be the most influential predictor by having the direct positive effect on self-management behaviors.[13-14] Hence, self-efficacy enhancement should be included in skills training.[17] Additionally, informational support has been shown to be associated with increased self-management behaviors.[14] Thus, knowledge is an essential prerequisite for self-management adoption. Individuals with CKD pre-dialysis who are provided with these elements are expected to address their health problems via medical, emotional, and role management in achieving desirable health outcomes.

However, few studies pertaining to self-management intervention conducted in Thais with CKD pre-dialysis were found.[18-20] Moreover, these studies were heterogeneous with respect to theory-based, intervention components, and outcome measures. Also, it is noted that all studies lacked rigorous design with large sample sizes and inclusion of QOL as an outcome. Besides, little is known about the effectiveness of theory-based self-management enhancement program in Thais with CKD pre-dialysis. This indicates the necessity of developing and conducting programs and testing its efficacy in this population.

## Review of Literature and Conceptual Framework

CKD education may increase both objective and perceived kidney disease knowledge and improve a range of outcomes across the CKD spectrum among individuals with CKD.[11]However, education alone is not sufficient to promote and sustain healthy behavior change, particularly where there is such a complex regimen.[8] Provision of education appears to be regarded as necessary but not a sufficient contributor to behavior change. However, when education is supplemented with ongoing self-management skills training, regardless of type of chronic diseases, significantly greater improvements in a variety of health outcomes are observed.[21-23] With the acquisition and adoption of effective self-management, it is required that individuals with chronic disease are trained with specific skills of self-management needed to handle medical, emotional, and role consequences.[24]

Given the necessary processes and skills of self-management that are imperative for individuals with CKD at stages 3 and 4 to deal with their existing conditions,[25-26] there are six self-management processes to be achieved: goal selection, information collection, information evaluation and processing, decision-making, action, and self-reaction.[16]These considered suitable for those with CKD pre-dialysis to engage in behavioral change that controls and reduces the impact of CKD. These six self-management processes seem to be more practical and applicable when are integrated with five skills of self-management which include problem-solving, decision-making, resource utilization, patient-provider relationship and, action taking.[15] Within the training of integrated processes and skills of self-management, the primary tasks that are vital to success of self-management are threefold 1) medical management, examples of which include taking medication, adhering to special diet, or using medical devices, 2) emotional management, such as adjusting to situation-induced emotions including anger, fear, sadness, depression, or grief, and 3) role management which refers to maintaining, changing, and creating new meaningful behaviors and life roles.[15,24] However, self-management skills training alone combined with knowledge provision might not be adequate to influence ones' self-management behaviors unless cognitive processes to change behaviors, for example increase in self-efficacy, are involved.[27] To be successful, enhancing perceived self-efficacy should also be incorporated into the process of training for self-management skills. Perceived self-efficacy can be developed and influenced through four main sources including 1) mastery experiences by performing an activity, 2) vicarious experience by observing others who are successful in performing an activity, 3) verbal persuasion by using reinforcing and encouraging words, and 4) emotional arousal by promoting positive feedback.[17]

There is a variety of studies that have proved the positive association between perceived self-efficacy and self-management behaviors in individuals with CKD.[13-14,28-29] Moreover, self-management programs based on self-efficacy theory have been shown to be effective and efficient in the care of persons with chronic illness.[17] Interventions that are delivered using face-to-face education within a group format have also yielded promising results.[26,30] There is strong evidence across studies in individuals with CKD at pre-dialysis stage of the beneficial effect on physiological outcomes including BP control,[19-20,31-32] glycemic control,[18-19,31-32] CKD progression control,[34] adherence to therapeutic regimens,[33] self-management behaviors,[18-20,32,35-36] psychological outcomes including knowledge,[18,34-35] self-efficacy,[33,37] and QOL.[32-33] Therefore, self-management intervention that is tailored to such individuals should primarily include initiating informational support in the form of group-based knowledge provision, training processes and skills of self-management, and enhancing perceived self-efficacy.

QOL is regarded as one of evaluation indicator for successful self-management intervention in CKD.[21] However, it has been reported that QOL decreases in the early stages of CKD in association with an impaired glomerular filtration rate (GFR).[6] Some reports suggest that the presence of co-morbidities is a major determinant of a decline in QOL.[7-8] Therefore, self-management interventions that focus on controlling co-morbidities of CKD would improve QOL in individuals with CKD at pre-dialysis stages.

One of the most important parts of CKD treatment is about controlling the disease to prevent

CKD progression.[8] Keeping BP less than 140/90 mmHg, $HbA_{1c}$ lower than 7%, and proteinuria 30-300mg/24 hours is considered the optimal disease control that not only slows CKD progression but also increases QOL.[8-10] However, to optimize disease control, self-management skills are required to deal with medical, emotional, and role aspect.

It is clear that Thais with CKD at pre-dialysis stage lack sufficient self-management behaviors particularly regarding medical management.[14] Prior studies have indicated that inadequate self-management behaviors were associated with suboptimal disease control which in turn led to impaired QOL.[6,21,36] It is therefore important to initiate a theory-based approach to involve individuals with CKD taking a central role in alterations to their lifestyle to promote disease control and improve QOL. Nonetheless, it is noteworthy that no integrated theory-based studies have been conducted in Thailand with this population to evaluate their self-management behaviors, disease control, and QOL. Hence, this study aimed to test the effects of the strategy to enhance self-management through providing knowledge, training self-management skills and increasing perceived self-efficacy on self-management behaviors, disease control, and QOL. It was conceptually hypothesized that compared to individuals with receiving usual care, those with CKD pre-dialysis receiving a 6-week self-management enhancement program would at 4 weeks have better self-management behaviors, at 12 weeks better disease control in terms of risk factors control, and at 24 weeks better CKD progression control and QOL than baseline.

## Methods

***Design:*** This study used a randomized control trial.

***Sample and Sampling:*** The samples were Thais who were diagnosed with stage 3 or 4 CKD. Purposive sampling was used to recruit the 120 eligible participants. Inclusion criteria were: 1) aged 50-70 years; 2) having underlying both DM and HT; 3) able to read and write in Thai; and 4) willing to participate in the study. Exclusion criteria were: 1) having severe complications associated with underlying diseases and CKD; and 2) expected to undergo renal replacement therapy (RRT) in the period of next six months. Discontinuation criterion was that participants did not complete at least one session of the intervention that participants.

The sample size was determined based on three components of power analysis including: 1) $\alpha$ of .05 (one-tailed probability test); 2) statistical power of 0.8; and 3) effect size of 0.5 which is usually the minimum effect size considered acceptable in RCT.[41] The sample size was estimated using a calculating formula for comparisons of two groups at single time point. As a result, the required numbers of participants were 100. Twenty percent of estimated sample size was further added to overcome the attrition rate. Therefore, the actual total numbers of participants were 120 persons, 60 per group.

In this study, initially, 148 potential participants with CKD at pre-dialysis stages were approached, of whom, 28 refused to participate in the program due to: being far away from the setting (12 persons); lack of caregivers to accompany them to the setting (10 persons); and lack of interest in the program (6 persons). One hundred and twenty (120) eligible participants were stratified into CKD stage 3 and stage 4 with 60 participants for each stage. The participants with both stages were randomized into the experimental and control group with 30 participants per group of each stage. All participants completed 4 weeks, 12 weeks, and 24 weeks follow-up

***Randomization:*** After obtaining informed consent, the PI proceeded to allocate the participants to the experimental or control group using simple randomization. With randomization method, initially, stratified randomization was made using CKD stage as a stratum. As a result, the participants were divided in to CKD stage 3 and stage 4. Subsequently, the PI made two slips of paper with "E" is the experimental group and "C" is the control group and drew out a slip from a box. The participants of each stage were assigned to either "E" or "C" as stated in chosen slip (Figure 1).

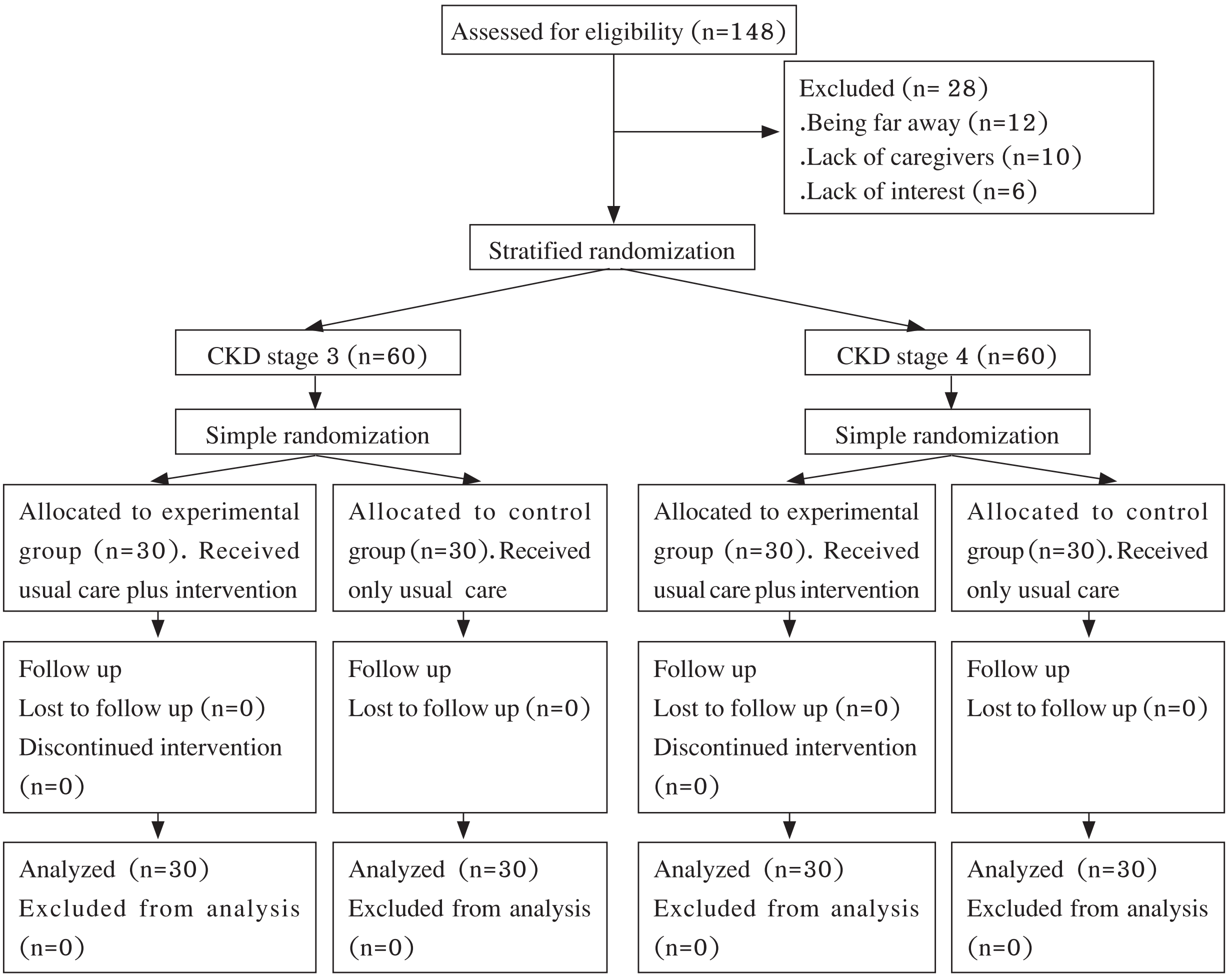

**Figure 1.** Flow chart of the participants throughout the trial

***Setting:*** The study was conducted from August 2014-March 2015 at one tertiary care hospital in Songkhla Province, southern Thailand. The PI implemented intervention sessions at one nursing college adjacent to the setting, and all follow-ups were implemented at that setting.

***Ethical Consideration:*** Study approval was given by the Research Ethics Review Committee of the Faculty of Nursing, Chiang Mai University and the study setting. All potential participants were informed about: study's objectives; procedures; potential risks and benefits; voluntary participation; and protection of confidentiality and rights to withdraw at any point in the study without consequence on current treatment or hospital service. Prior to signing the informed consent form, participants were assured of confidentiality and anonymity and had enough time to ask questions about the study.

***Training and Preparing Research Assistants:*** There were two research assistants (RAs) in this study who assisted in collecting data by administering the questionnaires. They were introduced to a full description of the study, procedures, data collection method, questionnaire administration, protection of human rights, and informed consent, and given time to ask questions about these processes. They were trained in how to complete questionnaires and spent time collecting data at baseline and follow-ups with ten individuals with CKD at pre-dialysis stages under the close supervision of the PI. Problems that emerged from training were discussed and solved to reach mutual understanding. With preparing and training, the RAs were fully qualified to assist the PI with their practical experience.

***Procedures:*** After obtaining study approval, the eligible participants were randomly assigned into the experimental group and the control group. The RAs helped to collect data using questionnaires, and BP was measured by the PI according to the Seventh Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure(JNC7) guideline, indicating the accurate measurement of BP that included sitting quietly at least 5 minutes, and avoiding caffeine, exercise, and smoking for at least 30 minutes prior to measurement. In addition, an appropriately sized cuff and at least two readings 5 minutes apart with average record were recommended.[42] $HbA_{1c}$ and serum creatinine were tested by the laboratory staff of the study setting at baseline. The experimental group received a 6-week intervention in addition to usual care, while the control group received only usual care. For follow-up, an appointment was made with the participants after program completion for assessment of outcomes: 4 weeks for self-management behaviors; 12 weeks for BP and $HbA_{1c}$; and 24 weeks for serum creatinine and QOL. These different times of outcome measures were supported by the previous evidences that self-management intervention had positive effects on theses outcomes in respective time points of measurement.[19,34,37]

## Instruments

*The Demographic Data Recording Form* was developed to obtain participants' personal data of age, gender, marital status, education level, occupation, income, payment scheme, living arrangements, duration of having CKD, co-morbid diseases, smoking status, alcohol drinking status, exercise, and participation in other CKD education courses.

*The Self-Management Behavior Questionnaire* (SMBQ) was used to measure self-management behaviors. This self-reported questionnaire, translated into Thai and modified by Sritarapipat,[14] was originally developed by Curtin.[13] The SMBQ is a 37-item instrument consisting of five dimensions of self-management behaviors, including: communication with health care providers (8 items); partnership in care (7 items); self-care activities (11 items); self-advocacy behaviors (10 items); and, medication adherence behavior (1 item). Examples of an item from two different dimensions are: "During the past six months, how often have you kept track of blood glucose (sugar) levels?" (self-care activities); and, "In the past six months, how often have you used additional treatments other than what your doctor prescribed?" (medication adherence behavior). Possible responses to each item range from 1 = "never" to 5 = "all of the time." A total score, which could range from 37 to 185, is obtained by summing the response values across all items. The total score indicates the level of self-management behaviors, whereby a score of 37 to 85.9 = low; 86 to 135.9 = moderate; and, 136-185 = high.[14]The SMBQ in the pilot study was tested for reliability using Cronbach' alpha coefficient of internal consistency with 15 participants who had the same characteristics as study sample, revealing the value of 0.88, while the value of actual study was 0.92.

*The Kidney Disease Quality of Life -36 Questionnaire* (KDQOL-36) was used to assess CKD-related QOL and translated into Thai by Thaweethamcharoen.[38]The instrument was originally developed by RAND Health Organization, University of Arizona for individuals with CKD and on dialysis and has been translated into several languages. The KDQOL-36, a self-reported measure, consists of 1) SF-12 (12 items) which measure physical functioning (physical component summary [PCS]) and mental functioning (mental component summary [MCS]), burden of kidney disease subscale (4 items), symptoms and problems subscale (12 items), and effects of kidney disease on daily subscale (8 items). However, in this study, one dialysis specific question in the symptoms and problems subscale concerning dialysis was excluded because the participants did not have enough severe kidney disease to require dialysis. Thus the total number of items was 35. Examples of items are: "During the past four weeks, were you limited in the kind of work or other activities?" (PCS); and, " To what extent were you bothered by shortness of breath?"(burden of kidney disease).The possible response to each item varies with its response scale. Response to items include: 1= "not at all" to 5= "extremely". The scores of the KDQOL-36 are transformed into 0 to 100, with higher scores indicating better QOL.[38]This instrument was tested for reliability using Cronbach' alpha coefficient of internal consistency, indicating the value of 0.92 in the pilot study and 0.95 in the main study.

*Biological measures:* A mercury sphygmomanometer, the Hemoglobin A1C Measurement-DCA 2000 Analyzer, and the Beckman Coulter AU Analyzer were instruments measuring BP, $HbA_{1c}$, and serum creatinine, respectively. The accuracy and precision of these instruments were verified using the calibration done by quality control section of the study setting.

***Intervention Program***

The Instruction Manual for Enhancing Self-Management of Pre-dialysis CKD Patients (IMESM) was developed by the PI and was used as guideline for implementing the intervention. This manual primarily includes six sessions for enhancing self-efficacy and training self-management skills.

The *VDO media* regarding CKD knowledge was downloaded from the Nephrology Society of Thailand website.[43] The VDO was delivered in the form of the animated cartoons with sound, lasting about 30 minutes. The content featured in the VDO included cause of CKD, risk factors, signs and symptoms, complications, medical treatment, nutritional management, and medication use.

The Participants' Personal Booklet, *Living a Healthy Life with Chronic Kidney Disease*, was developed based on a literature review and used as guiding manual for participants with CKD at pre-dialysis to initiate self-learning at home. This booklet includes information and knowledge necessary to self-management in dealing with medical, emotional, and role management.

In order to ensure the participants' readiness to perform their self-management behaviors, the following specific monitoring tool was used. The *Personal Written Action Plan* (PWAP) was developed for the participants recording their health data and specifying activities they wanted to perform in managing day to day CKD-related problems. With the participants' intention of undertaking selected activities, the *Motivation and Self-efficacy Rating Scale,* a part of the PWAP, was employed rating the strength of their efficacy belief on a 10-point scale, ranging in 1 unit intervals from 0 ("Cannot do"); through intermediate degrees of assurance, 5 ("Moderately certain, can do"); to complete assurance, 10 ("Highly certain, can do").

The *Perceived Self-Management Self-Efficacy Questionnaire* (PSMSEQ) was first developed by Curtin[13] and translated into Thai by Sritarapipat.[14] This instrument consists of 12 self-reported items regarding confidence to perform three subcategories of self-management including medical management, emotional management, role management, and overall CKD self-management. The response of items is on a five-point Likert scale ranging from 1 = Not at all confident to 5 = Very confident. Possible total scores of the PSMSEQ range from 12 to 60. For the purpose of description, the total score was classified into three equal levels including low self-efficacy (12 – 27.9), moderate self-efficacy (28 – 43.9), and high self-efficacy (44 - 60). Higher scores indicate higher levels of perceived self-efficacy of self-management. This scaling was specific for pre-dialysis CKD-related self-efficacy and used to monitor level of participants' self-efficacy after completion of intervention to ensure that they had enough self-efficacy levels in performing self-management behaviors. They needed to gain a score of at least 44.

The IMESM, PWAP, and Participants' Personal Booklet were reviewed for content validity by a panel of five experts in nephrology, and nephrological nursing. In addition, the booklet was confirmed from five individuals with CKD to evaluate the readability and understandability. Some words lacking clarity or were ambiguous were corrected and modified before distribution. The VDO media and the PSMSEQ were not validated because these two instruments were unmodified and standardized.

***Intervention implementation***

The intervention was a nurse-led, self-management, enhancement program that aimed to train the participants with nine skills of self-management, to enhance the participants' perceived self-efficacy and, to provide the participants with information regarding CKD and self-management concept. The participants with CKD stage 3 and stage 4 were further divided into four groups, with 15 participants per group. See **Table 1**.

**Table 1.** Summary of six sessions of self-management skills training

| Sessions | Self-management skills training | Self-efficacy enhancement strategy | Method |
|---|---|---|---|
| Week 1 | Program introduction, health education, health problems identification, and formulation of personal action plan | - Verbal persuasion | - Group-based discussion<br>- Education<br>- Demonstration |
| Week 2 | Skills of 1) goal selection, 2) information collection and 3) information procession and evaluation | - Verbal persuasion | - Group-based discussion |
| Week 3 | Skills of 4) problem solving, 5) decision making, 6) action taking, and 7) self-reaction | - Verbal persuasion | - Group-based discussion<br>- Group support |
| Week 4 | Skills of 8) resource utilization, and 9) patient-provider relationship | - Vicarious experience<br>- Verbal persuasion | - Group-based discussion<br>- Group support |
| Week 5 | Review of all nine self-management skills, emotional, stress, and role management, and exercise training | - Skill mastery<br>- Vicarious experience<br>- Verbal persuasion<br>- Emotional arousal | - Group-based discussion<br>- Group support<br>- Demonstration |
| Week 6 | Repeated review of all nine self-management skills, program summary, and follow up plan | - Skill mastery<br>- Vicarious experience<br>- Verbal persuasion<br>- Emotional arousal | - Group-based discussion<br>- Group support<br>- Return-demonstration |

Each session lasted about 2.5-3.0 hours with 2 intermittent breaks during session in progress, held once a week for 6 consecutive weeks. In session 4 and 5, the participants were assessed for perceived self-efficacy level using motivation and self-efficacy rating scale as specified in personal action plan. It was found that the participants' self-efficacy score was higher than 7 scores. This indicated that they had high perceived self-efficacy levels in completing tasks they chose. Moreover, in session 6, participants' perceived self-efficacy level was assessed using the PSMSEQ. It revealed that all participants had high level of perceived self-efficacy with scores more than 44. In addition, all six sessions of self-management skills training were designed to be highly interactive, flexible and motivated with an emphasis on self-efficacy enhancement. Peer support occurred automatically and naturally through group-based discussion. The participants were allowed to share their successful experience in self-management to the others during group based session.

***Usual care:*** Refers to a broad range of typical medical services provided to the individuals with CKD stages 3 and 4 who regularly attend the CKD clinic at medical outpatient department of the study setting.

***Data Analysis:*** Descriptive statistics, the Chi-square, Fisher's Exact, and t-test were used for analyzing the demographic data. The assumptions of normal distribution and homogeneity of variances were tested prior to data analysis, indicating normal distribution and homogeneity of variances of dependent variables. Thus, the use of t-test was allowed. The paired t-test was used to test the difference in all dependent variables between baseline and post-test of both the experimental and control groups. The independent t-test was employed to test the difference in all dependent variables between the experimental and control groups at post-test.

## Results

All participants were those diagnosed with CKD stages 3 and 4 with an equal number of 60 in the control and experimental groups. Both groups were similar in all demographic characteristics at baseline in terms of age, gender, marital status, educational level, occupation, income, payment scheme, living arrangement, duration of having CKD, co-morbidities, smoking and alcohol consumption status, and exercise. Also, participation in other CKD education courses was similar (Table 2). Likewise, all dependent variables of both groups were similar at baseline (Table 3).

**Table 2.** Demographic characteristics of the participants in the control and experimental groups

| Characteristics | Control (n=60) | | Experiment (n=60) | | Statistic test value | p-value |
|---|---|---|---|---|---|---|
| | n | % | n | % | | |
| Age | | | | | | |
| $\overline{X}$ ± SD | 59.75 ± 6.38 | | 59.48 ± 6.41 | | $-.228^{t}$ | .820 |
| (Range) | 50-70 | | 50-70 | | | |
| 50-59 | 33 | 55.0 | 33 | 55.0 | $1.000^{b}$ | .573 |
| 60-70 | 27 | 45.0 | 27 | 45.0 | | |
| Gender | | | | | | |
| Male | 21 | 35.0 | 23 | 38.3 | $.850^{b}$ | .425 |
| Female | 39 | 65.0 | 37 | 61.6 | | |
| Marital status | | | | | | |
| Single | 5 | 8.3 | 6 | 10.0 | $.862^{a}$ | .835 |
| Married | 35 | 58.3 | 38 | 63.3 | | |
| Widowed | 11 | 18.3 | 10 | 16.6 | | |
| Divorced/separated | 9 | 15.0 | 6 | 10.0 | | |
| Educational level | | | | | | |
| Elementary school | 39 | 65.0 | 33 | 55.0 | $2.710^{a}$ | .607 |
| Secondary school | 9 | 15.0 | 9 | 15.0 | | |
| High school/vocational certificate | 6 | 10.0 | 7 | 11.6 | | |
| Diploma/high vocational certificate | 5 | 8.3 | 7 | 11.6 | | |

**Table 2.** Demographic characteristics of the participants in the control and experimental groups (cont.)

| Characteristics | Control (n=60) | | Experiment (n=60) | | Statistic test value | p-value |
|---|---|---|---|---|---|---|
| | n | % | n | % | | |
| Occupation | | | | | | |
| Unemployed | 26 | 43.3 | 20 | 33.3 | $8.953^{a}$ | .176 |
| Grocer/business owner | 14 | 23.3 | 13 | 21.6 | | |
| Agriculturist | 12 | 20.0 | 8 | 13.3 | | |
| Private employee | 7 | 11.6 | 11 | 18.3 | | |
| Retired government officer | 1 | 1.6 | 8 | 13.3 | | |

| Demographic characteristics | Control (n=30) | | Experiment (n=30) | | Statistic test value | p-value |
|---|---|---|---|---|---|---|
| | n | % | n | % | | |
| Household income (Baht/month) | | | | | | |
| $\overline{X}$ ± SD | 9,566 ± 4,336 | | 10,866 ± 5,703 | | $.994^{t}$ | .324 |
| (Range) | 5,000-20,000 | | 5,000-30,000 | | | |
| < 10,000 | 24 | 40.0 | 25 | 41.6 | $1.135^{a}$ | .567 |
| 10,000-15,000 | 23 | 38.3 | 20 | 33.3 | | |
| > 15,000 | 13 | 21.6 | 15 | 25.0 | | |
| Payment scheme | | | | | | |
| Universal healthcare coverage | 36 | 60.0 | 31 | 51.6 | $1.336^{a}$ | .513 |
| Social insurance | 13 | 21.6 | 14 | 23.3 | | |
| Medical expense reimbursement | 11 | 18.3 | 15 | 25.0 | | |
| Living arrangement | | | | | | |
| With spouse | 19 | 31.6 | 18 | 30.0 | $.695^{a}$ | .952 |
| With family members | 33 | 55.0 | 33 | 55.0 | | |
| Duration of CKD | | | | | | |
| 1-2 years | 9 | 15.0 | 6 | 10.0 | $2.303^{a}$ | .941 |
| 3-4 years | 44 | 73.3 | 46 | 76.6 | | |
| > 4 years | 7 | 11.6 | 8 | 13.3 | | |
| Co-morbid diseases (both HT and DM) | 60 | 100 | 60 | 100 | | |
| Smoking status | | | | | | |
| Never | 43 | 71.6 | 46 | 76.6 | $1.336^{a}$ | .513 |
| Have quit smoking | 17 | 28.3 | 14 | 23.3 | | |

| Demographic characteristics | Control (n=60) | | Experiment (n=60) | | Statistic test value | p-value |
|---|---|---|---|---|---|---|
| | n | % | n | % | | |
| Alcohol consumption status | | | | | | |
| Never | 48 | 80.0 | 52 | 86.6 | $.436^{b}$ | .232 |
| Seldom | 12 | 20.0 | 8 | 13.3 | | |
| Exercise | | | | | | |
| Never | 49 | 81.6 | 51 | 85.0 | $1.210^{a}$ | .546 |
| Sometimes | 11 | 18.3 | 9 | 15.0 | | |
| Participation in other CKD education courses | | | | | | |
| Never | 22 | 36.6 | 18 | 30.0 | $2.400^{a}$ | .301 |

**Table 2.** Demographic characteristics of the participants in the control and experimental groups (cont.)

| Demographic characteristics | Control (n=60) | | Experiment (n=60) | | Statistic test value | p-value |
|---|---|---|---|---|---|---|
| | n | % | n | % | | |
| Having participated at | | | | | | |
| Hospital | 36 | 60.0 | 36 | 60.0 | | |
| Sub-district health promoting hospital | 2 | 3.3 | 6 | 10.0 | | |

*Note.* $^{a}$ = Chi-square test; $^{b}$ = Fisher's Exact test; $^{t}$ = t-test

**Table 3.** Comparison of Differences in Dependent Variables of the Sample at Baseline (n=120)

| Dependent variables | Experimental group (n = 60) | | Control group (n = 60) | | t-test | p-value |
|---|---|---|---|---|---|---|
| | $\bar{X}$ | SD | $\bar{X}$ | SD | | |
| Self-management behaviors | 87.45 | 5.16 | 88.95 | 4.47 | -1.70 | .092 |
| Systolic BP | 154.43 | 10.27 | 154.60 | 9.50 | -0.92 | .927 |
| Diastolic BP | 87.07 | 6.86 | 86.30 | 6.67 | .620 | .536 |
| HbA$_{1c}$ | 8.33 | .713 | 8.33 | .744 | .006 | .995 |
| Serum creatinine | 2.40 | .613 | 2.41 | .587 | -.064 | .949 |
| Quality of life | 50.24 | 7.33 | 48.34 | 10.12 | 1.17 | .241 |

Regarding the hypotheses, as shown in Table 4, at post-test, the experimental group was found to have significantly higher mean score of self-management behaviors (4 weeks after receiving the program), lower mean systolic BP, diastolic BP, HbA$_{1c}$ (12 weeks after receiving the program), lower mean serum creatinine and higher mean score of QOL (24 weeks after receiving the program) than baseline. Thus, these hypotheses were totally supported.

As shown in Table 5, at post-test, the experimental group was found to have significantly higher mean score of self-management behaviors (4 weeks after receiving the program), lower mean systolic BP, diastolic BP, HbA$_{1c}$ (12 weeks after receiving the program), and higher mean score of QOL (24 weeks after receiving the program) than the control group. However, there was no significant difference in serum creatinine between groups. It is important to note that although all dependent variables were significantly different between groups, except that of serum creatinine, some clinical outcomes including systolic BP and HbA$_{1c}$ did not meet normal limit and standard level (< 140 mmHg and < 7.0 %, respectively). Hence, these hypotheses were partially supported.

**Table 4.** Comparison of Dependent variables between Baseline and Post-test (n=120) in Each Group

| Dependent variables | Experimental Group (n = 60) | | | Control group (n = 60) | | |
|---|---|---|---|---|---|---|
| | Baseline $\bar{X}$ ± SD | Post-test $\bar{X}$ ± SD | t-test | Baseline $\bar{X}$ ± SD | Post-test $\bar{X}$ ± SD | t-test |
| Self-management behaviors | 87.45 ± 5.16 | 138.95 ± 4.19 | 69.33$^{**}$ | 88.95 ± 4.47 | 90.05 ± 4.84 | -1.66$^{ns}$ |
| Systolic BP | 154.43 ± 10.27 | 150.00 ± 9.39 | -7.56$^{**}$ | 154.60 ± 9.50 | 157.67 ± 8.55 | -6.46$^{**}$ |
| Diastolic BP | 87.07 ± 6.86 | 82.50 ± 6.18 | -7.13$^{**}$ | 86.30 ± 6.67 | 86.03 ± 4.76 | .419$^{ns}$ |
| HbA$_{1c}$ | 8.33 ± .713 | 7.97 ± .732 | 13.99$^{**}$ | 8.33 ± .744 | 8.53 ± .738 | -9.19$^{**}$ |
| Serum creatinine | 2.40 ± .613 | 2.38 ± .618 | -4.68$^{**}$ | 2.41 ± .587 | 2.42 ± .588 | -5.15$^{**}$ |
| Quality of life | 50.24 ± 7.33 | 67.70 ± 5.32 | 16.77$^{**}$ | 48.34 ± 10.12 | 52.27 ± 9.81 | -2.65$^{*}$ |

Note. * = $p < .05$, ** = $p < .001$, $^{ns}$ = not significant

**Table 5.** Comparison of Dependent variables between the Experimental and Control Groups at Post-test (n=120)

| Dependent variables | Experimental group (n = 60) | Control group (n = 60) | t-test | p-value |
|---|---|---|---|---|
| | $\overline{X} \pm SD$ | $\overline{X} \pm SD$ | | |
| Self-management behaviors | 138.95 ± 4.19 | 90.05 ± 4.84 | 59.12 | .000 |
| Systolic BP | 150.00 ± 9.39 | 157.67 ± 8.55 | -4.67 | .000 |
| Diastolic BP | 82.50 ± 6.18 | 86.03 ± 4.76 | -3.50 | .001 |
| $HbA_{1c}$ | 7.97 ± .732 | 8.53 ± .738 | -4.13 | .000 |
| Serum creatinine | 2.38 ± .618 | 2.42 ± .588 | -.374 | .709 |
| Quality of life | 67.70 ± 5.32 | 52.27 ± 9.81 | 10.70 | .000 |

## Discussion

Overall, the findings from this study indicated that self-management enhancement program was effective in improving self-management behaviors, reducing systolic BP, diastolic BP, $HbA_{1c}$, and improving QOL among Thais with CKD at pre-dialysis stages, focusing on stage 3 and stage 4. Furthermore, these improved outcomes were clinically significant. The main findings basically supported the majority of proposed hypotheses and conceptual framework that self-management enhancement program leads to increased self-management behaviors which promote disease control, thereby increasing QOL.

The significant increase in self-management behaviors which were at high level may be due to the program component characteristics that incorporated several combined methods into the intervention. Firstly, the development of this program was fundamentally based on the assumption that self-management behaviors are directly influenced by increased perceived self-efficacy. Thus, enhancing the participants' perceived self-efficacy was thought to induce behavioral change following the participation in self-management enhancement program. In this study, four main sources of self-efficacy including skill mastery, vicarious experience, verbal persuasion, and emotional arousal were enhanced in conjunction with training self-management skills. These findings were consistent with previous studies that showed that increased self-management behaviors were associated with increased self-efficacy levels.[13-14]

Secondly, the participants' increased self-management behaviors are also explained by training self-management skills with the formulation of action plan. The necessary nine skills as generated by the integration between Creer's six self-management processes[16] and Lorig's five self-management skills,[15] taught with face-to-face, group-based training. After training, the participants had the ability to set realistic goals that were achieved by a range of activities as they chose and identified in their personal action plan. The aim of self-management skills training was to enable the participants to self-manage the daily tasks encompassing medical, emotional, and role management.[16] Furthermore, a personal action plan served as an essential tool for enhancing not only perceived self-efficacy, but also self-management behaviors.[23]

Thirdly, another explanation was that increased self-management behaviors might be because of informational support. Knowledge provision in the form of the VDO presentation regarding CKD was delivered together with self-management booklet entitled "Living a Healthy Life with CKD" in the first session of intervention. Informational support was shown to be a key determinant in increasing self-management behaviors and was inextricably linked to the improved health outcomes in CKD.[18-20]

Disease control in terms of risk factors control as indicated by systolic BP, diastolic BP, and $HbA_{1c}$ was significantly improved as a direct result of increased self-management behaviors. By controlling disease, the participants' self-management behaviors were used to adopt lifestyle modifications as specified in their personal action plan. CKD-related lifestyle modifications involved the participants altering long-term habits, typically of eating or physical activity, and maintaining the new behaviors for months, which were consistently reported in personal action plan. Having been exposed to skills training, the participants also gained skills in performing self-monitoring blood pressure (SMBP) and self-monitoring blood glucose (SMBG) at home. Both SMBP and SMBG helped them lower their earlier BP and blood glucose levels by reminding them to continue self-management practice. This in turn resulted in BP control and glycemic control. These findings were congruent with previous studies of Thais with CKD pre-dialysis that showed significant improvements in BP control and glycemic control following participation in self-management intervention.[18-19] However, CKD progression control as represented by serum creatinine was not significantly different between groups. Possible reasons to support insignificant findings were that the presence of co-morbidities and advanced age are the major factors impairing kidney function.[39] Obviously, in this study, the most participants were older adults having both HT and DM as co-morbid disease which are the modifiable factors accelerating CKD progression.[2] Also, too early a time of data collection for serum creatinine at post-test might be difficult to prove a change in serum creatinine within 24 weeks after completing the program. This finding was found in contrast to a previous similar study that demonstrated the significant reduction in serum creatinine levels during 12 month follow up after a self-management intervention.[37] The supported explanation is that the participants of the previous study had a longer time to perform ongoing self-management behaviors in retarding the deterioration of kidney function than those of present study. Moreover, all participants were those with CKD stages 3 and 4 which has a certain degree of renal reserve. Hence, serum creatinine level may not be changed within 24 weeks until more than half of kidney function has been improved.[8]

QOL was significantly improved due to the presence of disease control, particularly risk factors control. It was possible that the participants may have felt better with improved disease control which eventually resulted in the perception of better QOL. Also, the participants' ability to keep both BP and blood glucose under control helped them reduce CKD-related complications which might affect physical function and limit functional status. This indicated that the participants felt more capable of dealing with disease-related symptoms and experienced better QOL than those who did not. However, it is important to consider that the participants in the control group had significantly greater QOL ($p < .05$) than at baseline (Table 4). This may be due in part to the acquisition of usual care that was routinely provided to individuals with CKD at pre-dialysis in the study setting. From receiving usual care, the participants in the control group might have better subjective perception of QOL as a result of emotional and peer support during participation in class of usual care. These findings were consistent with that of the previous studies that demonstrated the significant increase in QOL in individuals with CKD at pre-dialysis stages after participation in self-management enhancement program.[40]

## Limitations

First, the posttest measure of self-management behaviors overlapped with that of the pretest measure. The participants' self-management behaviors as assessed by the SMBQ might not correspond consistently with program effects since the SMBQ asked the participants to rate self-management behaviors over the past 24 weeks. Second, BP was measured by only the PI at both baseline and post-test, which might induce the expectation bias. Third, the intervention was conducted at only one setting that might limit the generalizability of results

## Conclusion, Contributions to Nursing Science and Practice, and Recommendations

As the study had limitations, the findings of this study should be used with caution. The intervention program was shown to be effective in improving self-management behaviors, reducing systolic BP, diastolic BP, and $HbA_{1c}$, and improving QOL. Thus, the findings of this study make concept of self-management clearer, better understood and complement the existing body of knowledge regarding self-management. Additionally, this effective program can be used as nursing intervention to optimize health outcomes in individuals with CKD at pre-dialysis stages. Further studies should be undertaken, using RCT with a double-blinded design to eliminate the potential sources of bias. Also, as this study met with little success in determining CKD progression control as indicated by serum creatinine at 24 weeks after completing the program, an assessment of serum creatinine over a longer period of time is recommended.

## Acknowledgements

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# ประสิทธิผลของโปรแกรมการส่งเสริมการจัดการตนเองสำหรับผู้เป็นโรคไตเรื้อรังระยะก่อนการบำบัดทดแทนไต: การวิจัยเชิงทดลองแบบสุ่ม

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**บทคัดย่อ:** การศึกษาครั้งนี้มีวัตถุประสงค์เพื่อทดสอบผลของโปรแกรมการส่งเสริมการจัดการตนเองต่อพฤติกรรมการจัดการตนเอง การควบคุมโรคและคุณภาพชีวิตในผู้ที่เป็นโรคไตเรื้อรังระยะก่อนการบำบัดทดแทนไต กลุ่มตัวอย่างได้มาจากการคัดเลือกแบบเฉพาะเจาะจง จำนวน 120 คน โดยได้รับการวินิจฉัยเป็นโรคไตเรื้อรังระยะที่ 3 จำนวน 60 คน และระยะที่ 4 จำนวน 60 คน กลุ่มตัวอย่างได้รับการสุ่มเข้ากลุ่มทดลองและกลุ่มควบคุม กลุ่มละ 60 คน กลุ่มทดลองได้รับโปรแกรมในเวลา 6 สัปดาห์เพิ่มเติมจากการดูแลตามปกติ ขณะที่กลุ่มควบคุมได้รับการดูแลตามปกติเพียงอย่างเดียว ตัวแปรผลลัพธ์ประกอบด้วย พฤติกรรมการจัดการตนเอง ความดันซิสโตลิก ความดันไดแอสโตลิก ค่าน้ำตาลเฉลี่ยสะสม ซีรั่มครีเอตินิน และคุณภาพชีวิต รวบรวมข้อมูลก่อนและที่ระยะเวลา 4, 12, 24 สัปดาห์หลังการเข้าร่วมโปรแกรม โดยใช้แบบรายงานด้วยตนเอง การวัดความดันโลหิตและวิธีการทางห้องปฏิบัติการ วิเคราะห์ข้อมูลโดยใช้สถิติบรรยาย สถิติทีคู่และสถิติทีอิสระ ผลการวิจัยพบว่ากลุ่มทดลองมีพฤติกรรมการจัดการตนเองหลังสิ้นสุดโปรแกรม 4 สัปดาห์ ดีกว่ากลุ่มควบคุม มีความดันซิสโตลิค ความดันไดแอสโตลิคและน้ำตาลเฉลี่ยสะสม หลังสิ้นสุดโปรแกรม 12 สัปดาห์ ต่ำกว่ากลุ่มควบคุม และมีคุณภาพชีวิตหลังสิ้นสุดโปรแกรม 24 สัปดาห์ดีกว่ากลุ่มควบคุม อย่างไรก็ตามพบว่าไม่มีความแตกต่างอย่างมีนัยสำคัญของซีรั่มครีเอตินินระหว่างกลุ่ม ผลการวิจัยแสดงให้เห็นว่าโปรแกรมมีความสัมพันธ์กับผลลัพธ์ที่ดีขึ้น ดังนั้นจึงควรนำการส่งเสริมการจัดการตนเองไปใช้ในการปฏิบัติการพยาบาลสำหรับผู้ที่เป็นโรคไตเรื้อรังระยะก่อนการบำบัดทดแทนไต

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คำสำคัญ: โรคไตเรื้อรังระยะก่อนการบำบัดทดแทนไตการควบคุมโรค คุณภาพชีวิต พฤติกรรมการจัดการตนเอง โปรแกรมการส่งเสริมการจัดการตนเอง

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# Expressed Emotion among Family Caregivers of Persons with Schizophrenia: A Causal Model Study

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**Abstract:** The purpose of this cross-sectional correlational study was to test the Model of Expressed Emotion among Family Caregivers of Persons with Schizophrenia. A hypothesized casual model was developed based on Lazarus and Folkman's theory of stress and coping, and empirical evidence from a literature review. Relevant factors integrated into the Model included severity of illness, mental health status of the family caregiver, caregiving burden, family functioning, and stigma. The study participants, recruited by means of purposive sampling, consisted of 385 primary family caregivers of adults with schizophrenia who had been followed up at outpatient units of two major psychiatric hospitals in central Thailand. Data were collected using the Thai Expressed Emotion Scale, the Behavior and Symptom Perception Scale, the Thai General Health Questionnaire-28: the Caregiving Burden Scale, the Chulalongkorn Family Inventory, and the Perceived Stigma Questionnaire. Structural equation modeling was used to test the hypothesized model.

The study findings revealed that the modified model fitted the data and could explain 57% of variance of expressed emotion. In addition, severity of illness, mental health status, caregiving burden, and family functioning had a direct effect on expressed emotion. Meanwhile, stigma had an indirect effect on expressed emotion, mediated through caregiving burden and mental health status of the family caregiver. The Model can be used as a guideline for developing nursing interventions to reduce caregiving burden, as well as promote mental health status and family functioning among family caregivers of persons with schizophrenia.

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**Keywords:** Caregiving burden, Causal modeling, Expressed emotion, Family caregivers, Schizophrenia

## Introduction

Schizophrenia is a severe and chronic mental illness, identified by profound disturbances of thinking, perception, affect, and social behavior[1,2] that often reduces a person's ability to function well in daily life, their occupation, and their social activity. Schizophrenia is ranked among the top ten causes of disability-adjusted

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life years (DALYs) globally[3], with a prevalence rate of approximately 1.5%-3% worldwide, and affecting around 24 million people.[4] In Thailand, the number of patients diagnosed with schizophrenia is more than twice the number of patients diagnosed with mood disorder, the second most common mental illness.[5] Moreover, schizophrenia is a costly disease. For example, the overall direct cost of schizophrenia has been estimated at THB 87,000 (USD 2600) per person and THB 31,000 million (USD 925 million) for the entire population with schizophrenia.[6] Unemployment of both patients and families is a major indirect cost, resulting in more than half (61%) of the total economic burden of schizophrenia.[6] In addition, the consequences of schizophrenia interrupt almost every aspect of a person's life,[1,2] since it is a dependent chronic condition that requires a high demand for care by family caregivers. Internationally, family caregivers continue to play a significant and expanding role in the care of persons with schizophrenia. Globally health and social services systems, including those in Thailand, tend to conform to the current trend of mental health care policy[5] that focuses on shortening the hospitalization period and returning persons with schizophrenia and other mental illnesses to live with their families in the community as soon as possible. Therefore, family caregivers are significant persons because they supplement conventional medical treatment, give reassurance, and help reduce the recurrence of the illness. Caregivers may care for people with schizophrenia, as well as other family members. As a result, overwhelming tasks and struggles to balance their daily life and responsibilities often cause them to perceive more stress and difficulties in several areas in their life, reflecting a high level of burden.[7] These experiences lead family caregivers to have high expressed emotion (HEE), which in turn increases the risk of relapse in schizophrenia in the person they are caring for.[8]

Expressed emotion (EE) is defined as an attitude, feeling, or behavior of the family caregiver in response to and reaction towards the person with schizophrenia.[9,10] It is composed of five key aspects: criticism or critical comments (CC); hostile, emotional over-involvement (EOI); and positive remarks and warmth[9,10,11]; emotional under-involvement; and emotional regulation, the last two of which are additional aspects particularly found in the Thai culture.[12] EE is manifested in traits of low expressed emotion (LEE) or HEE. LEE family caregivers are usually characterized as tolerant, non-intrusive, and sensitive to patient needs.[9,10,11] On the contrary, HEE is described as patterns of CC, hostility or marked EOI[9,10,11] which manifest as rejection, irritability, ignorance, blaming, overprotection, self-sacrifice, or being over-intrusive.[11,13] Such reactions of HEE family caregivers may create a negative emotional atmosphere,[9,11,13] causing persons with schizophrenia to have more stress that can potentially precipitate a relapse.[8,9,14]

High and low EE family caregivers obviously differ from each other. However, many aspects of the EE concept, especially its mechanism, are not clearly understood.[11,14] Therefore, it is important to know why some family caregivers react differently to events associated with the illness, or why some family caregivers have HEE while the others do not. Several studies have found that the meaningful factors associated with EE are severity of illness,[15,16,17,18] mental health status of the family caregiver,[15,18] caregiving burden,[14,18] family functioning,[19] and stigma.[20] Whilst emerging studies have pointed to only those individual variables that might have the direct effect on EE, a more comprehensive, multivariate model of contributors to EE has not been tested. Therefore, this study was undertaken with the hope to better understand EE among family caregivers of persons with schizophrenia. The study aimed to test the developed Model of Expressed Emotion among Family Caregivers of Persons with Schizophrenia in an attempt to describe how multiple factors influence EE.

## Conceptual Framework

The conceptual model of this study was based on Lazarus and Folkman's theory of stress and coping[19] and a literature review. The cognitive appraisal process was used to describe the relationship pattern of how five selected factors—severity of illness, mental health status of the family caregiver, caregiving burden, family functioning, and stigma—worked to influence EE.

According to Lazarus and Folkman's theory of stress and coping[19], there are two types of cognitive appraisal, primary and secondary. Primary appraisal is a person's consideration whether the encountered situations have meaning or influence in their life. Such evaluation can be summed up as irrelevant (this is not important), benign-positive (this is good), or stressful. Stressful appraisals can be classified into three typical forms: 1) harm/loss (damage or loss that has already happened); 2) threat (the anticipation of harm that may be imminent); and 3) challenge (potential for gain and growth inherent in an encounter). Secondary appraisal is used to evaluate personal effort or competence as well as social support available in coping or handling stress. When the caregivers primarily appraise the caregiving situation as threatening they may overestimate the situation, however in secondary appraisal their ability to cope is often underestimation. Consequently, the emerging stress will affect their adaptation in a dysfunctional fashion, or by producing unhealthy outcomes.

In this study, EE was considered as the adaptation outcome, and presented as the attitude, feeling, or behavior with which the family caregivers frequently reacted to their family members with schizophrenia. EE was influenced by the stress of caring activities through primary appraisal. The severity of illness, considered in terms of the frequency or degree of patients' schizophrenic symptoms and behavior, was evaluated by the family caregivers as worsening symptoms or disturbing behaviors including annoyance, aversion, and troublesomeness.[20] Meanwhile, stigma was defined in this study as the family caregivers' consideration about the frequency of their encountering negative responses of other persons in the society about their family member who was diagnosed with schizophrenia. It was also evaluated as something that caused discomfort or difficulty for family caregivers when contacting others due to social rejection.[21] For this reason, both severity of illness and stigma were primarily appraised as the hardship of care that tended to be problematic for caregivers and caused difficulty in their life. These factors caused family caregivers to have negative attitudes and reactions toward the person with schizophrenia that could be explained with the HEE style.[15,16,17]

Caregiving burden in this study was conceptualized as a secondary appraisal in which overwhelming tasks exceeded family caregivers' abilities and available resources to cope.[22] Caregiving burden could also cause family caregivers to have negative views of their family members with schizophrenia, threatening disruption of their lives, and, as a result, leading family caregivers to choose a negative response style that reflected their HEE.[23]

The mental health status of family caregivers and family functioning was conceptualized in this study in terms of the inadequate resources that did not help them manage high demands of caregiving tasks. Internal resources such as mental health status were evaluated as the frequency of signs of psychological dysfunction, such as insufficient strength or inadequate coping capabilities. In addition, family functioning was illustrated as the external resource for the entire family about the degree of family tasks and efforts to maintain family balance and adaption, so as to continue healthy and normal of the family after a member had been diagnosed with schizophrenia. In this regard, family functioning was appraised as proper or adequate resources that enabled caregivers to deal with a high demand in caring situations.[20] So, in the body of inadequate resources that family caregivers had when dealing with stressful situations,[24] they may develop chronic stress that results in negative responses including rejection, overprotection, or being over-intrusive, all of which reflect their HEE.[22,25] The conceptual framework is explained in hypothesized model in Figure 1.

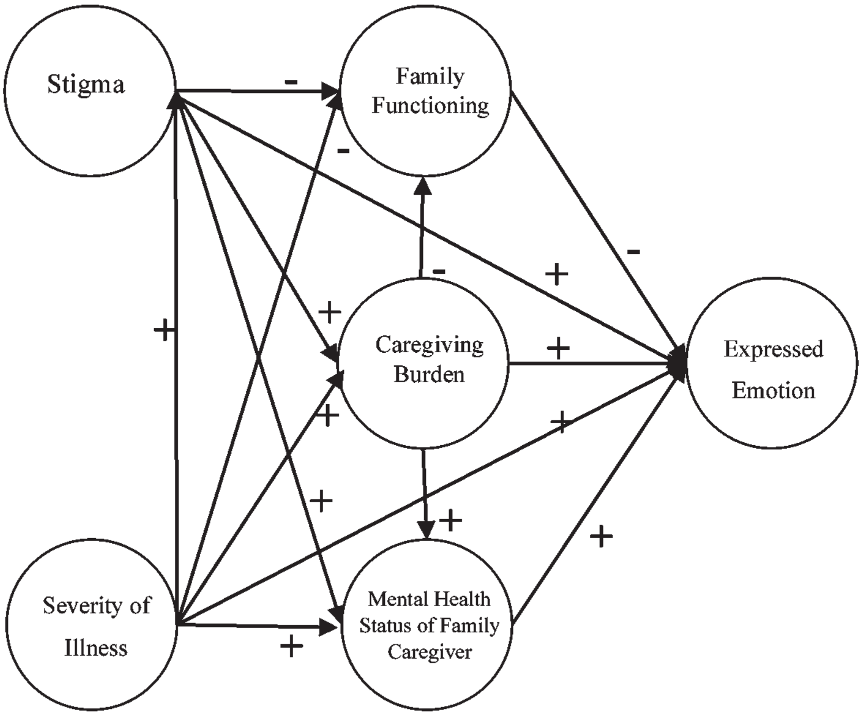


**Figure 1:** The hypothesized model illustrating the influence of severity of illness, mental health status of family caregivers, caregiving burden, family functioning, and stigma on EE among family caregivers of persons with schizophrenia

## Method

**Design:** A cross-sectional, correlational research design was employed to test the developed causal model of EE among family caregivers of persons with schizophrenia.

**Sample and setting:** Data were obtained from 385 family caregivers of adults who had been diagnosed with schizophrenia for at least six months and who were being followed up at outpatient units of two major psychiatric hospitals in central Thailand. The caregivers were referred by nurses using purposive sampling based on the inclusion criteria as follows: (1) living with a person with schizophrenia for whom they had been primary caregivers for at least six months; (2) able to read and verbally communicate in Thai; and (3) at least 18 old. The sample size was determined based on the rule of thumb, with the sample size-to-parameters ratio of 10:1.[26] The 35 estimated parameters (21 loadings and 14 between construct correlation estimates) were used to estimate the sample size, a minimum of 350 participants. However, an additional 10% or 35 participants were added into the calculated sample size,[27] in case of attrition,so the final number of participants was 385.

**Ethical Considerations:** This study was approved by the Research Ethics Committee of the Faculty of Nursing, Chiang Mai University and the hospital used as the study site. Verbal and written explanations of the study objectives, procedures, and participant rights were clearly stated to potential participants, and written informed consent was obtained from those willing to participate in the study before data collection commenced.

**Instruments:** Data were obtained using the six questionnaires as follows:

*The Thai Expressed Emotion Scale (TEES)* was developed by Sunpaweravong[28] to assess EE among family caregivers of relatives with schizophrenia in the Thai context. It consists of 49 items with seven subscales including CC (seven items), Hostility (eight items), EOI (five items), Warmth (seven items), Positive Remarks (seven items), Emotion Regulation (seven items), and Emotional Under-involvement (eight items). An example of an item is "I feel ashamed of his/her behavior." The items were arranged in a 4-point rating scale ranging from 1 (strongly disagree) to 4 (strongly agree), except for the positive items under the positive subscales of Warmth, Positive Remarks, and Emotion Regulation, for which reverse scoring was used. A total score is obtained by summing the scores of all items, and possible total scores ranged from 49 to 196 points, with higher scores reflecting more negative attitudes or behaviors of family caregivers, hence a higher level of HEE, and vice versa.[28] In this study, regarding the reliability of the instrument, the Cronbach's alpha coefficient was 0.84.

*The Behavior and Symptom Perception Scale (BSPS)* was developed by Pipatananond[29] to measure the extent to which family caregivers' perceived the degree of each behavior and symptom caused by schizophrenia impairment. An item example is "Inadequate care of him/herself." The BSPS consists of 29 items with a 4-point Likert scale ranging from 0 (never) to 3 (always). Possible total scores range from 0 to 87 points, with higher scores indicating a greater perception of severity of the patient's illness.[29] As for reliability in this study, the Cronbach's alpha coefficient was 0.77.

*The Thai General Health Questionnaire (Thai GHQ-28)* was translated from English into the Thai language and modified by Nilchaikovit, Sukying, and Silpakit.[30] It has been widely used to assess common mental health problems amongst Thais. The Questionnaire contains 28 items classified into four subscales of Somatic Symptoms, Anxiety and Insomnia, Social Dysfunction, and Severe Depression. An item example is "Have you recently lost much sleep over worry?" Each item is rated on a 4-point response scale ranging from a = not at all/better than usual, to d = much more than usual/much worse than usual. Scoring is undertaken using the bi-modal method (0-0-1-1) in which the value of the first two types of positive answers is 0, and for the two others, 1 is for the negative answers. The possible total scores ranges from 0 to 28 points. A high total scores reflects greater perception of having more mental health problems. Cronbach's alpha coefficient in this study was 0.82.

*The Psychiatric Caregiver Burden Scale (PCBS)* was originally developed by Oberst & Hughes (1990) and was modified by Pipatananond to assess burden of caregivers of persons with schizophrenia in the Thai culture.[31] The Scale is composed of 18 items divided into two subscales of Demand and Difficulty. The items are arranged in a 5-point Likert scale ranging from 1 (none) to 5 (a great deal). The Demand subscale assesses the caregivers' perception of the scope of the task or activity required by persons with schizophrenia, and the Difficulty subscale evaluates caregivers' perception of the degree to which the activity is seen as difficult or troublesome. An item example is "Seeking help in crisis situations or in home care." Each subscale has a possible score ranging from 18 to 90 points. Half of the total scores in both subscales reflect a caregiver's perception of the caregiving burden they are facing, with higher scores indicating greater perception of caregiving burden and vice versa.[31] As for reliability, in this study, the PCBS achieved a Cronbach's alpha coefficient of 0.85.

*The Chulalongkorn Family Inventory (CFI)* was originally developed by Trangkasombat[32] in Thai to measure family functioning. It is comprised of seven subscales. Six of the seven subscales were developed based on the McMaster model of family functioning developed by Epstein and Bishop (1973), Problem Solving (six items), Communication (five items), Roles (four items), Affective Responsiveness, (five items), Affective Involvement (five items), and Behavior Control (four items). The remaining subscale was developed specifically to assess general functioning of the family. In this study, the participants were asked to rate only 28 items of the six subscales. An item example is: "Our family is able to solve daily problems that happen within our family." The items are arranged in a 4-point rating scale ranging from 1 (strongly disagree) to 4 (strongly agree). The total scores are obtained by summing the scores of all items, including those of the nine negative items for which reverse scoring is used. Possible total scores range from 28 to 112 points, with higher scores indicating greater perception of well family functioning and vice versa. As for reliability of the instrument, in this study, Cronbach's alpha coefficient was 0.83.

*The Perceived Stigma Questionnaire (PAQ)* was developed by Khumhom[33] based on the questionnaire originally developed by Wahl (1999) to measure stigma experienced by family caregivers. It is composed of two components: Stigma (nine items) and Discrimination (eight items), each of which is arranged on a 6-point Likert scale ranging from 0 (never) to 5 (always), except for four items that are statements regarding positive experiences and for which reverse scoring is used. An item example is "You avoid telling anyone that you have a family member who has a psychiatric problem." Higher scores reflect a greater perception of higher stigma and vice versa.[33] As for reliability of the questionnaire, in this study, Cronbach's alpha coefficient was 0.86.

**Data collection:** The participants were asked to complete the seven self-administered questionnaires in a private place at the study site. Data collection lasted approximately 60-80 minutes, with a break time of 10-15 minutes.

**Data analysis:** Descriptive statistics were used to describe the demographic characteristics of the study participants and selected study variables. Statistical assumptions underlying structural equation modeling (SEM), including normality, linearity, homoscedasticity, and multicollinearity, were tested. Then, the hypothesized model was tested using SEM conducted with the SPSS version 16.0 and the Linear Structural Relationship Modelling (LISREL 8.52) program. The maximum likelihood method was used to estimate the strength of the relationships that existed among the study variables.

## Findings

The 385 participants ranged in age from 22 to 70 years (mean = 45.35, SD = 11.73). Almost three quarters were female (70.9%, n = 273), and almost half were married (41.5%, n = 160). Most participants were Buddhists (86.2 %, n = 332), more than one-third completed elementary education (39.5%, n = 152), and almost one-third worked as wage earners (32.2%, n = 124). Furthermore, the largest group of participants were parents of adults with schizophrenia (34.8%, n = 134), and they lived in an extended family (69.1%, n = 266). Nearly half of participants perceived they had sufficient family income for living but not for saving (44.7%, n = 172), with their average income ranging from THB 8,700 (USD 247.19) to THB 50,000 (USD 1,420.66) per month (mean = THB 21,887.35 or USD 621.89, SD = 9,703.24).

Findings regarding the study variables are shown in Table 1. Regarding EE scores, the mean score of EE was higher than half of the possible range. Likewise, more than half of the participants, or 53.77% (n = 207), rated that they had a higher score than the mean. This indicates that the majority of the participants experienced an infrequent HEE. In terms of severity of illness, the mean score of severity of illness was slightly higher than 75% of the possible range. Moreover, the mean score of mental health status based on the Thai-GHQ28 was 6.50 (SD = 1.13) with the prevalence elevated risk of mental health problem of 81.04% (n = 312), owing to their total scores being higher than 23 points. Finally, other variables such caregiving burden, family functioning, and stigma had the mean score higher than half of the possible range.

**Table 1** Descriptive Statistics of Study Variables (N = 385)

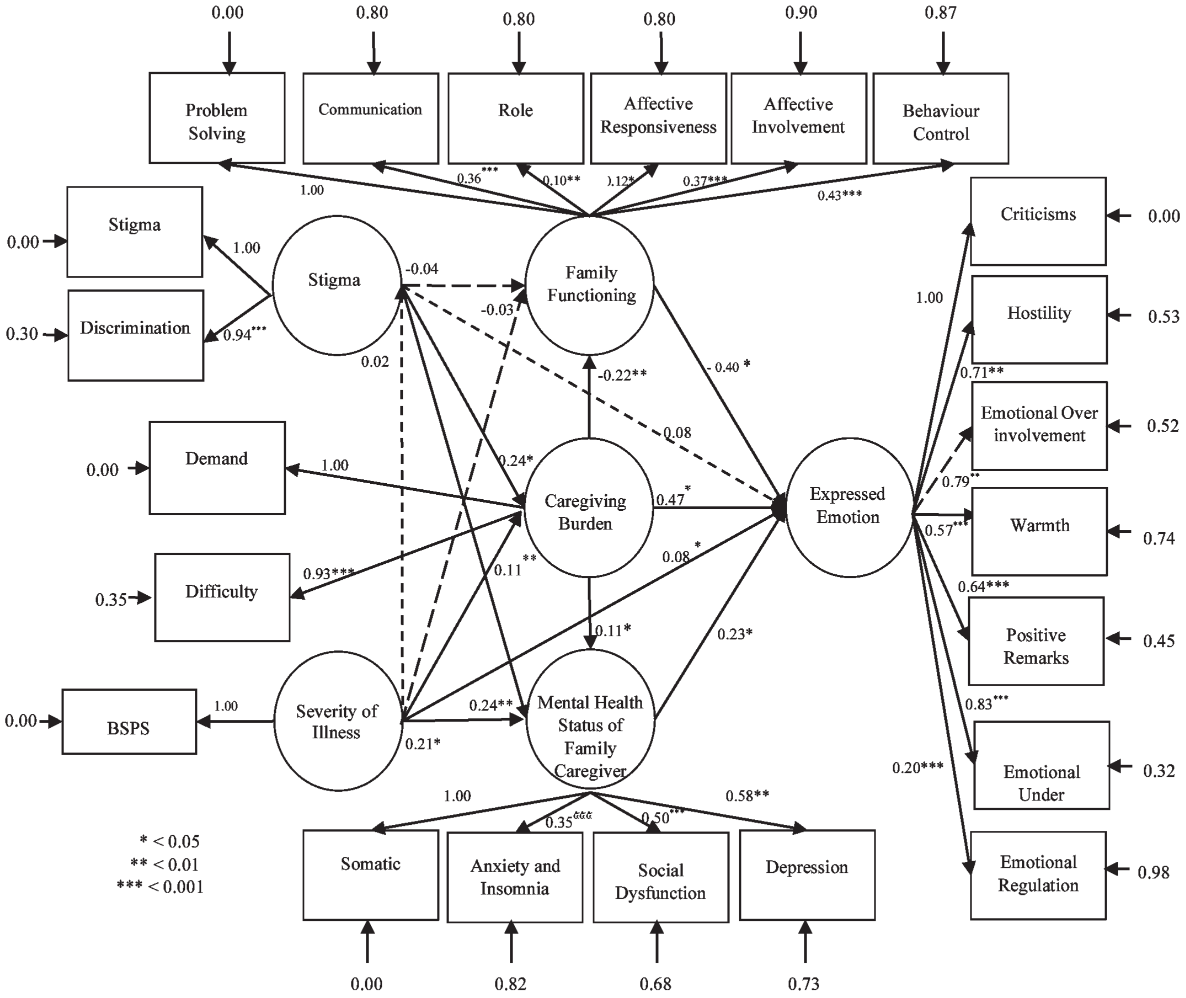
| Variables | Possible Score | Actual Score | Mean | SD |
|---|---|---|---|---|
| Expressed Emotion | 49-196 | 104-159 | 130.94 | 7.29 |
| Severity of Illness | 0-87 | 54-73 | 65.56 | 3.31 |
| Mental Health Status | 0-28 | 4-9 | 6.50 | 1.13 |
| Caregiving Burden | 18-90 | 38.50-65.50 | 54.71 | 4.89 |
| Family Functioning | 28-112 | 44-82 | 63.39 | 5.91 |
| Stigma | 0-85 | 25-69 | 50.44 | 6.02 |

During model testing, it was found that the hypothesized model did not fit the actual data. Therefore, modification of the model was performed based on both reasonability of statistical findings until it fitted the data well ($\chi^2$ = 245.26, p = 0.10, df = 199, GFI = 0.95, AGFI = 0.93, CFI = 0.95, RMSEA = 0.02, SRMR = 0.05). The final model could explain 57% of variance in EE among family caregivers of persons with schizophrenia. Stigma had an indirect effect on EE and was mediated through caregiving burden and mental health status of the family caregivers. In addition, severity of illness had a direct effect on EE and also indirect effects through caregiving burden and mental health of the family caregiver. Caregiving burden had the strongest significant positive direct effect on EE and a significant indirect effect through mental health status and family functioning. Moreover, mental health of the family caregivers had a direct effect on EE, and family functioning had the strongest significant negative direct effect on EE. The results of hypothesized model testing are presented in Figure 2 and Table 3 that follow.

**Table 2** Direct, Indirect, and Total Effect of Study Variables in the Final Model

| Causal Variables | Affected Variables | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Caregiving Burden | | | Mental Health Status | | | Family Functioning | | | Expressed Emotion | | |
| | TE | IE | DE | TE | IE | DE | TE | IE | DE | TE | IE | DE |
| Severity of Illness | $0.12^{**}$ | 0.01 | $0.11^{**}$ | $0.23^{*}$ | 0.02 | $0.21^{*}$ | -0.06 | -0.03 | -0.03 | $0.31^{*}$ | $0.13^{*}$ | $0.18^{*}$ |
| Stigma | $0.24^{*}$ | - | $0.24^{*}$ | $0.27^{**}$ | 0.03 | $0.24^{**}$ | -0.09 | -0.05 | -0.04 | $0.29^{*}$ | $0.21^{*}$ | 0.08 |
| Caregiving Burden | - | - | - | $0.11^{*}$ | - | $0.11^{*}$ | $-0.22^{**}$ | - | $-0.22^{**}$ | $0.58^{*}$ | $0.11^{*}$ | $0.47^{*}$ |
| Mental Health Status | - | - | - | - | - | - | - | - | - | $0.23^{*}$ | - | $0.23^{*}$ |
| Family Functioning | - | - | - | - | - | - | - | - | - | $-0.40^{*}$ | - | $-0.40^{*}$ |
| Structural Equation | $R^2$ = 0.18 | | | $R^2$ = 0.36 | | | $R^2$ = 0.23 | | | $R^2$ = 0.57 | | |

**Note**: * = p < 0.05, ** = p < 0.01, *** = p < 0.001
TE = total effect, IE = indirect effect, DE = direct effect



$\chi^2 = 245.26$, $p = 0.10$, $df = 199$, GFI = 0.95, AGFI = 0.93, CFI = 0.95, RMSEA = 0.02, SRMR = 0.05

**Figure 2:** The modified model of EE among family caregivers of persons with schizophrenia

## Discussion

This study has produced a model of factors that leads to better understanding of EE among family caregivers of persons with schizophrenia. The findings indicate that the final modified model fitted the data well and could explain 57% of the variance in EE. Overall, the findings support Lazarus and Folkman's stress and coping theory that emphasizes the important role of cognitive appraisal when encountering a difficult situation and mediating between that situation and the outcomes.[19]

It is worth noting that the findings of the present study were not always consistent with previous studies. For instance, it was found in this study that stigma had an indirect effect on EE. Phillip et al. found there was a small predictive power of stigma on EE even though it should have had greater power to explain EE when it had the mediated effect.[21] Likewise, this study found that stigma could explain EE through the mediating effect of caregiving burden and mental health status of family caregivers. However, although the links among the four variables – EE, stigma, caregiving burden, and mental health status of the family caregivers - were not explored in the previous study, they could still be explained within the framework of the cognitive appraisal process of Lazarus and Folkman's theory and the related literature review. For example, similar findings can be found in the study of Phillip et al. which revealed the relationships among stigma, caregiving burden, and EE.[21] Generally, stigma often has direct effect towards the person with schizophrenia in the form of rejection, and this makes them uncomfortable in contacting someone outside their family. As a result, they may isolate themselves from non-family members and thus depend more on family caregivers. In such cases, family caregivers need to evaluate how their life has been disrupted by stigma. Thus, the adverse effect of negative emotions can lead to caregiving burden, which, in turn, increases HEE.[23] It is noteworthy that the mediator effect of the mental health status of family caregivers between sigma and EE has not been thoroughly explored in existing literature. However, the findings of the present study are consistent with another study result that stigma is associated with the mental health status of family caregivers.[34] In this study, perceived stigma was evaluated as a difficult and painful experience for family caregivers as it eventually induced negative responses such as distress, depression, and anxiety[35,36] This is reflected in a mental health status leading to the development of more pronounced EE attitudes.[37,38]

In addition, severity of illness had a direct influence on EE, in that family caregivers who perceived more severity of the schizophrenia had a higher level of EE. This finding is also consistent with previous studies[15,17,39] in that family caregivers and their family members with schizophrenia are not in control of the severity of illness. Thus, sufferers of schizophrenia may not be able to carry out daily activities by themselves and turn back to depend more on their caregivers. As a consequence, family caregivers are likely to evaluate their life as being interrupted.[18] This belief of the family caregivers about their own inability to manage severe symptoms might make them encounter repetitious long-term stress, causing them to have the reactions or behaviours found in the HEE style.[22,25]

In addition, our findings demonstrated that the severity of illness had indirect effects on EE through caregiving burden and mental health of the family caregivers. This is congruent with a previous study indicating that family caregivers who perceived a patient's illness as being more severe, had greater caregiving burden and a poorer mental health status, and thus a higher level of HEE.[34] According to the cognitive appraisal process in Lazarus and Folkman's theory, severity of illness is often overestimated as hardships requiring more caregiving demand and which generate the caregiving burden.[7,38] The negative effects of caregiving burden have been described as the suffering of body pains, a decrease in vitality, development of depressive and anxiety disorders, and restrictions in physical role and social function.[37,38]

The deviated mental health status due to severity of illness and caregiving burden was appraised as the inadequate resource for the family caregivers in managing the stress from the caring situation. This could cause the family caregivers to react to their family members with schizophrenia in a negative way, hence HEE. Moreover, the finding that caregiving burden had a direct effect on EE is consistent with a previous study which indicated that family caregivers with caregiving burden had HEE.[39] Their caregiving tasks were secondarily appraised by caregivers as being more than their ability to control. This belief about their inability to control caregiving burden could cause long-term stress among family caregivers. Consequently, they may develop a negative response style reflecting HEE.

Our findings also revealed that caregiving burden had an indirect effect on EE through the mental health of the family caregivers and family functioning. Related literature supports the mediator effect of mental health of the family caregivers between caregiving burden and EE in that family caregivers who have burden and poor mental health status have HEE.[34] In general, burden of care for persons with schizophrenia generates negative effects including depression, anxiety, grief, and somatic complaints. These reflect the poor mental health status of family caregivers, and in turn lead to the development of high EE attitudes.[37,38] Caregiving burden is also identified as the disruption of family functioning because of the inability to overcome the demand of care. Consequently, family caregivers cannot fulfill the expectations of the family members with schizophrenia, and also other family members.[40,41] This contributes to dissatisfaction and excessive stress for both the person with schizophrenia and the family, and might generate negative emotions that are associated with impaired family functioning.[40],[41]

Our finding that mental health status of caregivers and family functioning had direct effects on EE in this study is similar to that described by Boger et al.[41] Together these were appraised as inadequate resources preventing caregivers from performing behaviors to fulfill the instrumental and affective needs of the family members that made them less able to solve caregiving task problems. Thus, family caregivers might respond negatively to persons with schizophrenia such as commenting on their behavior, rejecting them, having exaggerated emotional responses, being overprotective, doing self-sacrificing, or being over-intrusive, all of which reflect their HEE.

## Limitations

This study may have limited generalizability given that the participants and their caregivers were referred from only two major psychiatric hospitals in central Thailand. Next, as the research design was cross-sectional, the interpretation of causal relationships must be done with caution. Preferably a longitudinal study should be undertaken to verify the credibility of the study findings. Additional studies are also needed to explore the stability of the Model with other populations of family caregivers of persons with schizophrenia. Ultimately, a nursing intervention to promote a reappraisal process for balancing the estimation between perceived threatening situations and the caregivers' coping ability should be developed and tested.

## Conclusion and Implications for Nursing Practices

The findings of this study have provided more understanding of the role of cognitive appraisal and the adaptation outcomes among family caregivers of persons with schizophrenia. Such findings can be used as a guideline for screening vulnerable family caregivers who have more influential factors of EE, especially caregiving burden, mental health status, as well as family functioning. It is hoped that the Model will ultimately assist nurses to develop and conduct nursing interventions to promote the capability of family caregivers to reappraise their situations and experiences, so that they can more effectively manage the stress of caregiving situations of their family members with schizophrenia. Finally, it is anticipated that the findings of the present study would eventually be utilized to bring about a reduction in a negative atmosphere in families where there is person with schizophrenia, such as EE.

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# การแสดงออกทางอารมณ์ของผู้ดูแลในครอบครัวผู้ที่เป็นโรคจิตเภท: แบบจำลองเชิงสาเหตุ

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**บทคัดย่อ:** การศึกษาครั้งนี้ เป็นการวิจัยแบบภาคตัดขวาง เพื่อทดสอบแบบจำลองเชิงสาเหตุของการแสดงออกทางอารมณ์ของผู้ดูแลในครอบครัวผู้ที่เป็นโรคจิตเภท ซึ่งพัฒนาโดยใช้กรอบทฤษฎีความเครียดและการเผชิญกับปัญหาของลาซารัสและโฟล์คแมนร่วมกับการประมวลความรู้จากหลักฐานเชิงประจักษ์ที่บ่งบอกถึงความสัมพันธ์ระหว่างปัจจัย ได้แก่ การรับรู้ความรุนแรงของโรค ภาวะสุขภาพจิต การรับรู้ภาระในการดูแล การทำหน้าที่ของครอบครัว และการรับรู้ตราบาป กับ การแสดงออกทางอารมณ์ของผู้ดูแลในครอบครัวผู้ที่เป็นโรคจิตเภท กลุ่มตัวอย่างจำนวน 385 คน คือ ผู้ดูแลในครอบครัวของผู้ใหญ่ที่ได้รับการวินิจฉัยว่าเป็นโรคจิตเภท ที่รับการรักษาในแผนกผู้ป่วยนอกของโรงพยาบาลจิตเวช ในเขตภาคกลาง ประเทศไทย เก็บข้อมูลโดยใช้แบบสอบถามจำนวน 6 ฉบับ ได้แก่ แบบวัดการแสดงออกทางอารมณ์ในญาติผู้ดูแล แบบวัดการรับรู้ความรุนแรงของโรค พฤติกรรมและอาการทางจิต แบบประเมินสุขภาพจิต แบบวัดภาระของผู้ดูแล แบบประเมินการทำหน้าที่ของครอบครัว และแบบสอบถามการรับรู้ตราบาปของผู้ดูแล วิเคราะห์ผลการวิจัยโดยใช้สถิติทดสอบแบบจำลองสมการเชิงโครงสร้าง

ผลการศึกษา พบว่า โมเดลสมมติฐานการวิจัยมีความสอดคล้องกับข้อมูลเชิงประจักษ์และสามารถ อธิบายความแปรปรวนของการแสดงออกทางอารมณ์ของผู้ดูแลในครอบครัวผู้ที่เป็นโรคจิตเภทได้ร้อยละ 57 โดยพบว่า การรับรู้ความรุนแรงของโรค ภาวะสุขภาพจิต การรับรู้ภาระในการดูแล และการทำหน้าที่ของครอบครัว มีอิทธิพลทางตรงกับการแสดงออกทางอารมณ์ของผู้ดูแลในครอบครัว ส่วนการรับรู้ตราบาปมีอิทธิพลทางอ้อมต่อการแสดงออกทางอารมณ์ของผู้ดูแลในครอบครัว โดยส่งผ่านทางการรับรู้ภาระในการดูแล และสภาวะทางสุขภาพจิต ซึ่งผลการวิจัยนี้ สามารถนำไปพัฒนากิจกรรมการพยาบาลที่จะช่วยส่งเสริมศักยภาพของผู้ดูแลในครอบครัวให้สามารถลดการรับรู้ภาระในการดูแล ลดปัญหาสุขภาพจิต เพื่อลดระดับของการแสดงออกทางอารมณ์ของผู้ดูแลในครอบครัวต่อไป

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# Culturally–sensitive Maternity Care Needs of Muslim Mothers in a Rural Community of the Southernmost Province in Thailand

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**Abstract:** This study was conducted to better understand culturally-sensitive maternity care needs assessment for Muslim mothers. It was conducted in a rural community of the southernmost province in Thailand from May-December 2013. Community-based participatory research was used as the research methodology and involved three groups of participants: 1) 26 Muslim mothers (15-49 years old with at least one child under age three) and 17 of their husbands, 2) 14 community and religious leaders, and 3) 14 health care providers including village health volunteers and traditional birth attendants. Qualitative data were collected through focus group discussions, in-depth interviews, and participative observations. Data were analyzed using content analysis.

The results indicated that the culturally-sensitive maternity care needs for Muslim mothers comprised five themes: respecting the way of life, practicing religious and local traditional belief, harmonizing cultural care from traditional birth attendants, supporting mothers and families, and enhancing cultural competence among health care providers, and village health volunteers. The findings illustrate the elements of culturally-sensitive maternity care needs for Muslim mothers which can be a guide for appropriate community care.

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**Keywords:** Community-based participatory research, Cultural care, Cultural sensitivity, Needs assessment, Maternity care, Muslim mothers, Rural community, Thailand

## Introduction

Maternal and child health problems are a major health concern in the southernmost provinces of Thailand. The maternal mortality ratio (MMR) and infant mortality rate (IMR) in this area are very high, at 17.6 per 100,000 live births and 6.8 per 1,000 live births respectively.[1] Compared with the

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national level, the MMR in the southernmost provinces is more than three times higher (59.4).[2]

Postpartum hemorrhage (PPH) is a major cause of maternal death in the southernmost provinces.[2] There are several causes of PPH including atonic uterus which results in uterine inertia from prolonged labor.[3] The direct cause of atonic uterus is anemia which is associated with fatigue. Pregnant women with anemia may succumb more quickly to any subsequent blood loss.[3] Pregnant women with very severe anemia are a medical emergency due to the risk of congestive heart failure and maternal death.[4]

Many factors affect maternal health. Islamic perspectives on maternal health are associated with maternal age, fertility, family size preferences, contraceptive use, and TBAs.[5, 6] Maternal age, both for teens and older women increase the risk of adverse pregnancy outcomes.[7] Early and late pregnancy may put the life of the mother and fetus at risk and contributes to higher mortality rates.

The fertility rate of Muslim mothers is higher than that of non-Muslim mothers. While the fertility rate in all regions of Thailand has sharply declined to below replacement level, it has only slightly declined in area where Muslims are predominant.[8] In the southernmost provinces of Thailand, the birth rate is higher than both the southern region and national average.[1]

Family size preferences are significantly associated with the desire to have more children and result in the low contraceptive use among Muslims.[5] Most Muslim respondents said that whatever number of children God gave them was appropriate. This surrendering to God about family size before mentioning one's personal preference indicates a strong belief inspired by Islam.[5]

Islamic teaching forbids any form of family planning using contraception and sterilization. Conservative Muslims view contraception as a sin and accept as many children as God provides. Consequently, Malay-speaking Muslims in the south demonstrate higher fertility preferences and lower contraceptive use than Thai speakers.[5] Thus, religion and region are associated with the attitude and behaviors of Muslims in fertility and contraceptive use.

TBAs are still favored in the southernmost provinces.[6] According to Teeraworn's study in 2002, infant mortality was higher among women those attending antenatal care and being delivered by a TBA at home. Over half of deliveries were practiced by a TBA and more than 60% of deliveries occurred at home. It was observed that women at the beginning and end of their reproductive life mostly prefer to give birth with TBAs. Women aged 15-20 years are too young to make an independent decision for delivery, and most likely accede to family norms, and use traditional services. Women with past experience of childbirths (aged 35-49 years), may feel more comfortable with TBAs as they are an integral part of the religious practice. Typically, the TBAs can speak the local language, too.[6]

Gender sensitivity and the language barriers in the southernmost provinces where Muslims are the majority, make utilization of primary health-care difficult. They need modesty and privacy, and the appropriate use of touch.[9] Muslim women prefer female providers who respect their need to not expose intimate parts of their bodies to non-related males.[10] However, their preferences are often overlooked or not accommodated due to a lack of female staff.

Language barriers obstruct mothers' access health care, as well as the ability of HCPs to work effectively.[11] Muslim women who can speak Thai are more likely to utilize antenatal care (ANC), deliver at a health facility, and be attended at birth by a trained health worker, than those who cannot speak Thai.[6]

Healthcare in mainstream Thailand is seen as a universal right that draws closely from the Western paradigm. However, this Western bias is not very applicable to groups with distinct cultures and belief systems, such as Muslims, that need the tailor-made attention of health care providers. To achieve the Millennium Development Goals (MDGs) for improving maternal health in the southernmost provinces, specific strategies and strong health care services are needed. Health care service leaders need to analyze the majority of maternal deaths that could be avoided by basic maternity care.[12] In Pattani Province in the deep south, only 70.2% of pregnant women utilize the ANC service.[2] Women who do not use ANC services believe that ANC is not necessary.[13] The under-utilization of maternity care service exists predominantly in the social context, which creates barriers to accessing health care services.

The utilization of all maternity care services — antenatal care, intrapartum care, and postpartum care — are lowest in the southernmost provinces of Thailand.[14] There women view pregnancy as a natural process and thus, there is no need to seek medical care. The complexities of religion and culture, as well as gender, modesty and language (inability to speak Thai), can limit accessibility to health services.[6,15] These may be intrinsically linked to negative attitudes, which in turn, cause barriers to access.

Although 47% of HCPs are Muslims in the southern provinces, it is unclear how religious and cultural concepts have been applied in the health care system.[16] Some HCPs do not understand the Islamic principles and are uninformed about the maternity needs of Muslim women, particularly those related to religious needs, such as fasting safety during pregnancy.

Existing maternity care is inadequate in meeting the desires of Muslim mothers. It was observed that Muslim mothers who received ANC at health care services came rather for treatment of complications during pregnancy, rather than for routine checkups. Thus the delay in deciding to seek, reach or receive obstetric care and delay in transferring to an appropriate birth center, both of which relate to maternal death, need to be further analyzed to find ways to reduce the MMR in this area.[17, 18] To improve the quality of maternity care, the most appropriate approach to respond to cultural constrains is to establish in-depth understanding of Islamic culture. To contribute to this process, it is crucial to assess culturally-sensitive maternity care needs in order to meet the needs of Muslim mothers in a rural community of the southern most province, Thailand.

## Conceptual Framework

The concepts of cultural care and cultural competence, and critical social theory (CST) were used as theoretical frameworks to guide the methodology in this study in order to assess culturally-sensitive maternity care needs for Muslim mothers. Cultural care refers to subjectively and objectively learned and transmitted values, beliefs, and patterned way of life that assists, supports, facilitates, or enable another individual or group to maintain well-being and health, to improve the human condition and way of life, or to deal with illness, handicaps, and death.[19]

*Cultural competence* is "awareness of and sensitivity to cultural differences; knowledge of cultural values, beliefs, and behaviors; and skill in working with culturally-diverse populations".[20] Cultural competence aims to create a health care system and workforce that are capable of delivering the highest quality care to every patient regardless of race, ethnicity, culture, or language proficiency.

The purpose of CST is to view phenomena with an open condition, unconstrained by communication and to strengthen or empower participants to encounter their problems by themselves.[21] Community members seek to move the public health fields forward by generating new knowledge, identifying the factors associated with intervention success, and determining actions that will effect social and behavioral change in order to eliminate health disparity.[22]

Community-based participatory research (CBPR) is rooted in CST, and is a focal point to power, cultural diversity, and equity.[22] CBPR facilitates a direct interaction between researcher and community. It gives the researcher a better understanding of community needs, concerns, and capacities; and it opens new doors for exploration of community resources.[23] The equal participation process with this research approach encourages the enhancement of cultural context, promotes co-learner and capacity building, changes in community norms, and constructs a network that supports the sense of belonging and sustainability of the program.[24,25] Thus, a CBPR process facilitates a connection, where cultural and linguistic gaps between researcher and community exist, and was considered most appropriate for this study in the Muslim southernmost provinces.

## Study aim

The purpose of this study is to assess culturally-sensitive maternity care needs for Muslim mothers in Pattani Province.

## Methods

***Design:*** CBPR was used as an approach in order to assess culturally-sensitive community needs for Muslim mothers.

***Study setting:*** Pattani Province, a border province in the deep south of Thailand, was used as the research setting. Data were collected from May-December 2013. Pattani was chosen because of high incidence of MMR. Pattani has a large (80.3%) population of Muslims[27] who mainly speak the local language, Yawee, in daily life.

***Sample:*** Three groups of research participants were involved:

Muslim mothers and their husbands: 26 Muslim mothers, aged between 15-49 years, who had at least one child under aged three and living in the community setting were invited to this study, 10 for participating in in-depth interviews and 16 for two focus group discussions. There were two focus groups discussion with 17 their husbands, who take care of or are responsible for the women in the study.

Community leaders including community religious leaders: 14 community members/community leaders in the study area were encouraged to participate in two focus groups. They included five assistant village headmen, three religious leaders and six community members from eight villages.

HCPs: 14 HCPs comprised 2 nurses and a director of the primary health service who worked at health promoting hospital, three traditional birth attendants (TBAs) and eight village health volunteers (VHVs).

The researchers were prepared with knowledge and skills on CBPR regarding health culture and community. The open-ended questions of the interview guides were developed by the researcher's team and were pilot-tested with Thai and Yawee-speaking individuals. An observation guide and tape-recorders was used for in-depth interviews, focus groups discussion, group meeting, and project activities.

***Rigor and Trustworthiness:*** Procedures to establish trustworthiness, credibility and confirmability were used.[27, 28] Credibility was achieved through a triangulation method including observation, focus group discussion, and interviews. To achieve confirmability, the transcript, field notes, as well as data analysis were checked and rechecked, and findings were shared with research team according to four steps of research procedures.

***Data Collection:*** Qualitative data was collected through in-depth interviews of 10 mothers, three TBAs, three HCPs, eight VHVs. Six focus group discussions (FGDs) were conducted with 26 mothers, 17 of their husbands and 14 community and religious leaders. Each group consisted of eight to nine people. Participative observations was conducted about the contexts and activity of participants.

***Preparing local researchers***: Three local researchers (one VHV and two nurses) were prepared with knowledge and skills on the research process of CBPR through training by researcher (including ethical considerations) for one week in order to enhance their research ability.

## Research Procedures

The researchers used the CBPR approach in the phase of situation analysis to *assess culturally-sensitive maternity care needs* through community collaboration along the following four steps:

***Step 1: Establishing community collaboration***

For building trust and establishing a collaborative relationship with the study community the researcher informally and formally contacted key informants who were the community gatekeepers including the sub-district chief, the village headman, and the chief executive of the sub-district administrative organization (SAO).They were informed about the study, its objectives, process, and potential benefit to the community in order to obtain their permission to conduct it.

The local researchers, as co-researchers, spoke Yawee and were recruited and trained in doing research along with promoting sustainability and creating a sense of belonging to the project from the beginning. For *establishing mutual trust and respect*, the researchers always participated in special events, and acted in an appropriate cultural manner. This step achieved good social relationships in *working partnerships.*

***Step 2: Assessing culturally-sensitive community needs of maternity care***

Community members as core working group consisted of three VHVs, three community leaders, and three HCPs who co-operated in the design of needs assessment by providing community-specific information on maternity care and patterns as well as providing insights into cultural issues that proved relevant in the design of the cultural maternity needs assessment. They were involved in raising knowledge and awareness, and gaining commitment in action and research. They helped by identifying maternal health problems and gathering preliminary data from the community with collaboration of its members, as well as suggesting potential strategies and feasible approaches for maternity care.

The maternal health problems were discussed during three meetings of stakeholders, in which they were free to provide suggestions and emancipator knowledge. The commitment to action and research was gained by the community members. The researchers' team conducted six focus group discussion (two groups of Muslim mothers, two groups of husbands, and two groups of community members/ religious leaders). In-depth interviews were conducted with 10 mothers, three TBAs, three HCPs, and eight VHVs.

***Step 3: Analyzing and interpreting the data***

All data was transcribed verbatim by the team. The problems related to maternal health were analyzed and interpreted using content analysis[29] and summarized. Content analysis began on the first day after interview, listening to the recording then later reading the transcripts line by line and considering for potential concerns and needs of culturally-sensitive maternity care. The themes were defined by categorizing and coding the transcripts.

***Step 4: Reflecting and sharing the findings***

The core working group (VHVs, HCPs, and community leaders) illustrated the pictures of activities during the process by organizing a community forum to reflect and share the assessment findings and to solicit community response validation of the findings. The reflection on concerns and needs regarding cultural maternity care was focused. The participants were asked to provide critical analysis of assessment results and members were encouraged to make additional suggestions and comments through open group discussion.

**Data Analysis:** The data were analyzed during the research process through content analysis.[29] The analysis began by reading the transcripts of each qualitative data and looking for potential concerns and needs regarding to culturally-sensitive maternity care. Themes were categorized and coded in the transcription line by line.

**Ethical considerations:** The study was approved by the Human Subjects Review Board of Chiang Mai University. All participants gave written informed consent, after explanation of their rights and a description of the study was given.

## Results

Participants were 71 Muslim mothers, families, community members or leader, and HCPs/VHVs/TBAs. As shown in **Table 1**, the majority of the participants were: aged between 20-35 years of age; with 1 to 11 children; and primary school education. Five themes of culturally-sensitive maternity care needs of Muslim mothers were identified as follows: respecting the way of life, practicing religious and local traditional belief, harmonizing cultural care from TBAs, supporting mothers and families, and enhancing cultural competence of HCPs and VHVs. Each need is elaborated below:

**Table 1** Demographic background sheet

| **Characteristics** | **Muslim mothers** n=26 (%) | **Husbands** n=17(%) | **Community members/leaders** n=14 (%) | **HCPs/ VHVs/TBAs** n=14 (%) |
|---|---|---|---|---|
| Age (yrs.) | | | | |
| < 20 | 3(11.54) | 1(5.88) | 0(0) | 1(7.14) |
| 20-35 | 15(57.69) | 9(52.94) | 6(42.86) | 2(14.29) |
| 36-50 | 8(30.77) | 5(29.41) | 5(35.71) | 5(35.71) |
| >50 | 0(0) | 2(11.77) | 3(21.43) | 6(42.86) |
| Gender | | | | |
| Male | 0(0) | 17(100) | 14(100) | 4(28.57) |
| Female | 26(100) | 0(0) | 0(0) | 10(71.43) |
| Marital status | | | | |
| Single | 0(0) | 0(0) | 1(7.14) | 1(7.14) |
| Married | 26(100) | 17(100) | 13(92.86) | 12(85.71) |
| Widow/Divorcée | 0(0) | 0(0) | 0(0) | 1(7.14) |
| Number of children (average) | 1-11(4.46) | 1-6(2.58) | 1-9(5.14) | 0-7(3.42) |
| Education | | | | |
| No formal schooling | 1(3.85) | 0(0) | 0(0) | 3(21.43) |
| Primary school | 7(26.92) | 4(23.53) | 2(14.29) | 3(21.43) |
| Secondary school | 10(38.46) | 10(58.82) | 6(23.07) | 2(14.29) |
| Certificate (vocational) | 6(23.08) | 1(5.88) | 1(7.14) | 2(14.29) |
| Undergraduate | 2(7.69) | 2(11.77) | 5(35.71) | 4(28.57) |
| Occupation | | | | |
| Agriculture | 3(11.54) | 3(17.65) | 2(14.29) | 1(7.14) |
| Vendor | 7(26.92) | 4(23.53) | 2(14.29) | 2(14.29) |
| Worker | 5(19.23) | 2(11.77) | 3(21.43) | 2(14.29) |
| Entrepreneur | 5(19.23) | 7(41.17) | 5(35.71) | 2(14.29) |
| Civil servant | 2(7.69) | 1(5.88) | 2(14.29) | 3(21.43) |
| Housework | 4(15.38) | 0(0) | 0(0) | 4(28.57) |
| Family income per month (bath) | | | | |
| < 3,000 | 1(3.85) | 0(0) | 0(0) | 2(14.29) |
| 3,000-6,000 | 6(23.08) | 5(29.41) | 4(28.57) | 1(7.14) |
| 6,001-9,000 | 15(57.69) | 9(52.94) | 5(35.71) | 7(50.00) |
| > 9,000 | 4(15.38) | 3(17.65) | 5(35.71) | 4(28.57) |

***1. Respecting the way of life;*** Muslim mothers have experiences of being a multi-para with normal labor at home. Giving birth at home with TBAs is considered normal among Muslim mothers in this community. They viewed pregnancy and childbirth as natural processes and the determination of God. Thus, they felt that pregnant women do not need to seek medical care. They believed that it is their way of life under Islamic doctrine. Therefore, pregnant Muslim women need HCPs to respect their spiritual beliefs. They do not want HCPs to judge them through the eyes of modern Western, using loud voices and disrespect. They feel stigmatized by others, as if people perceive their ways of life as incorrect or wrong. They feel loss of choice and control when they leave their community to give birth at the hospital. One Muslim mother described her voice in the hospital as a silent voice. Nobody heard it:

> *When we arrived at the hospital, they* (HCPs) *do what they want to do. If we spoke or requested something more, they would be looking disapprovingly. Any more, they would be doing badly to us. That's why we did not talk, and just waited quietly. The hospital is their place, not ours. In the hospital, health care providers are big, we are small. When I went there, I was just endured quietly when I felt pain. When I felt more back pain or felt stiff, I just had to tolerate it.* (Muslim mother 1, in-depth interview)

> *Firstly, it should be accepted as they are. What do they want in the whole? They want respect of their way of life, the number of children they have and being delivered by a toa be-dae* (TBA). *These are the main parts of life here. Health care providers don't judge about whether to have more children, or, the age at which they get pregnant. The women feel bad if they are judged* (by the HCPs). *That can lead them to avoid delivering at the hospital.* (Community leader 1, FGD)

***2. Practicing religious and local traditional beliefs.*** The participants reflected on their needs for spiritual care that they mostly performed. Two types of spiritual care were manifest and discussed below. Note that while the first one is based on Islamic faith, the other rituals discussed are local traditions unrelated to Islam but inherited through generations.

*2.1Pray and recite the Holy Quran.* While pregnant, Muslim mothers and their husband would pray more than they usually do to receive blessings from God. They also spend more time to recite the *Holy Quran*. In addition, pregnant women prayed to express *zhukor* (to give thanks to God) for blessing them with a child. Every day after prayer, the women (and/or husbands) prayed at dawn and dusk. Before giving birth, the *Quran*, especially the *surah* (chapter) *baqarah* (the cow), *lugman* (a wise man), and *Maryam* (Arabic name) were read to the women. It is believed that such action would bring to parents a good and attractive baby. According to them, the prayer and the *Quran* reading would also help ease the painful process of delivery. As two Muslim mothers explained during FGDs:

> *After prayer, we recited the Quran all day. And then after the makrib* (dawn prayer) *we recited surah, baqarah, lugman and Maryam for a pretty and handsome child and for easy birthing were important. The surah lugman prays for intelligence, and we recited that by ourselves.* (Muslim mother 2, FGD)

> *When I asked the doctor about my pregnancy he was quiet so I was nervous. The day before, he asked me if I was diabetic and on the third day I had to check blood sugar. I was scared and thought that there was a threat to my baby's life. I feared that the child would be disabled. We prayed hayat* (seeking for God blessing and to get rid of bad things) *to be far from that possibility.* (Muslim mother 3, FGD)

*2.2 Nae-Ngae worship and Sama-ngat worship:* this ritual is one of the traditional beliefs in the study area, not based on Islamic principle. Although there are fewer formalities, the ritual remains a tradition in the setting, performed by TBAs. Generally, the TBAs conduct the worship when the pregnancy is at seven months (thus no risk for abortion). The purposes are to ease the delivery and to predict the baby's sex. In the *nae-ngae* (forecast) ritual, the TBAs used a half of a peeled coconut and then put it on the abdomen of pregnant woman. For the *sama-ngat* (hearten) worship, three-color rice and sticky rice are used in the ceremony.

> *Nae-ngae ritual depends on the TBAs. The TBAs cut the coconut and ordered us to lay down. Later, the TBAs ordered me to kick the coconut as far as I can, and then she would peel and cut it on our abdomen to predict the sex of the baby.* (Muslim mother 4, FGD)

> *A small coconut was used representing a little baby's head, believed to ease the birthing process. Somebody formulated the sama-ngat together with some homemade colors rice and sticky rice.* (Husband 1, FGD)

***3. Harmonizing cultural care from TBAs:*** Muslim mothers in this community need to harmonize care from TBAs in the antenatal, intrapartum, and postpartum periods. For traditional antenatal care, TBAs implement worship at seven months to hearten soon-to-be mothers. Receiving warm and close care with gentle touch on her abdomen most satisfies the pregnant women before and during giving birth. After giving birth, mothers receive the TBAs' herbal body massage for three days. The herbal healing comforts them and helps them to be relaxed. Moreover, TBAs also perform a ceremony for mothers to eliminate bad things in order to prevent them from seizures.

> *In the labor room, the nurse midwife was so busy with her documents. She always bends her head over her working desk. ...not attending to us. That is different from the behavior of the toe-be dae* (TBAs)*....they are always attending to us...touching our abdomen...making a dua* (beg God for something) *for easier birthing... We felt good. But at the hospital, the nurse midwife is sitting far away.* (Muslim mother 5, in-depth interview)

As mentioned earlier, concerns about gender, experiences and religion of HCPs are the main underlying reasons for Muslim mothers' preference to give birth at home with TBAs who are female, experienced, and Muslim. Plus, TBAs also speak the local language and this helped Muslim mothers to express how they felt. In addition, because of not receiving ANC from the hospital, Muslim mothers are not familiar with HCPs staff. This further discourages them from seeking delivery services at the district hospital.

An important reason for giving birth at home is the desire to respond to Islamic traditions. As especially expressed among husbands of the participants, they prefer their wives to give birth at home because they desire that their child's first sound to hear is the *athan* (the call to prayer) in the name of God, not the noise of nurse midwives talking to each other.

The participants would use postpartum care from the hospital only to take the medication to heal the wound from giving birth, though they also use the herbal remedy from TBAs. However, according to our participants, the after-birth medicines they received from the hospital were not sufficient. They need not only medicines from hospital, but also herbal fire, pills, and herbal medicines prepared by TBAs. In their words, what a mother needs is beyond healing or cure, and is a harmonized care for physical and mental health, a caring care that integrates modern health services with culture and belief.

***4. Supporting mothers and families:*** It is clear from our study that Muslim mothers and their husbands need cultural and psychosocial support for both psychological and physical health. Psychologically, there is a need to keep mothers' spirits strong during pregnancy. Muslims need the right knowledge about performing religious practices, such as the recommended chapters of *Quran* to be recited during pregnancy. They may need an *ustaz* (religious teacher) to teach them. They may also need an *ulama* (an expert in Islamic knowledge) to *fatwa* (judge) some practices whether they have the religious indication such as birth spacing. For physical health, participants mentioned the need for *halal* (Islamic approved consumption) food appropriate during pregnancy.

> *When I was pregnant, I kind of needed someone to help me, especially during my first pregnancy. I was worried that either I or my baby wouldn't make it. I performed dua* (prayer) *from Allah but sometimes I wasn't sure how to do it properly, so I asked a ustaz* (Islamic teacher) *to teach me some chapters from the Quran.* (Muslim mother 6, in-depth interview)

> *While pregnant, there were many things that I wanted to eat. It's like eating a useful food, as well as halal. I needed someone to advise me about which halal food in order to make my baby a good life.* (Muslim mother 7, in-depth interview)

In everyday life, pregnant Muslim women need care from their families, especially care from their husband, physically, mentally, and economically. They need their husband to be available to care for the elder children and to bring them to ANC. Lack of care experienced by Muslim mothers in this setting was exacerbated by a husband's migration to work in Malaysia. We also found that some husbands did not provide care or assistance to their pregnant wife but were concerned about the pregnancy. Thus, some husbands actually felt that care should be performed by health personnel.

> *Well, I don't know. We don't know about this. I am a man, and I don't know about pregnancy issues. She should go to the public health center for ANC. The doctors know best, they know how to take care of it. I can't help much.* (Husband 2, FGD)

> *Perhaps it is the father* (husband) *who will take care of our baby... by trying to hold the baby ... to watch over them. If he's around... Yor* (he; baby) *and the baby was not silent.* (Muslim mother 8, in-depth interview)

> *Most of the problem is that her husband is not home. The husband has to work remotely* (Malaysia). *For those whose husband is at home, it is not a problem.* (Muslim mother 9, in-depth interview)

> *No one brought me to the hospital for antenatal care. It seemed....* (Shaking her head)*... Bae* (followed by husband's name) *gave some massage, legs massage* (laughs). (Muslim mother 10, in-depth interview)

***5. Enhancing cultural competence of health care providers and village health volunteers.*** All HCPs and VHVs in this area are Muslims. Three of HCPs and eight of VHVs responded that they were unsure how religious and cultural concepts could be utilized in health care services. As they do not have depth understanding of the Islamic principles, and they do not really know how the pregnant woman inform about the maternity needs relating to religion such as fasting safety during pregnancy. Therefore, HCPs need to upgrade VHVs to a new category of practice called Maternal care volunteers (MCVs) who can provide Muslim mothers with cultural care.

> *Although we are Muslim. We learned science. Sometimes, we don't know. It seems that the religious beliefs are stronger than science. We don't know how to fast safely during the fasting period and what is permitted or prohibited. We would have to be trained to better understand those concepts. Training on culture and religious beliefs are needed in addition to training as a volunteer.* (HCP 1, in-depth interview)

## Discussion

Results from this study revealed that Muslim mothers in this particular setting need culturally-sensitive maternity care which mainly relies on Islamic beliefs. Five needs regarding culturally-sensitive maternity care for Muslim mothers were identified.

The participants strongly desired more respect for the way of life as they live it. They did not want HCPs to judge them because they did not follow modern medical procedures as in an earlier study.[30,36] Prejudice from HCPs was an obstacle to participation among members and groups from non-dominant cultures.[31] Knowledge of this opens dialogue and encourages HCPs to be thoughtful as they work in the broader community. The importance of treating women with respect has been underscored in previous studies.[30,32] Respecting their culture by HCPs in this study was different from many studies that focus on the cultural differences between HCPs and clients. Health care services are more attuned to cultural care in this area of Thailand's deep south. Most HCPs in the study were Muslim, just like their clients. In this area, Muslims are not the minority population, but rather, they are the majority.

In this setting, fertility is high and contraceptive use is low. Pregnancy at an advanced age is a reason which prevents women from utilizing ANC. In our study, there was a pregnant woman aged 45 years with 11 children. Women with many children who became pregnant were too embarrassed to go to the hospital.

Women who avoid ANC and give birth at home without trained attendants have a greatly increased risk of perinatal and maternal death.[30] Promoting Muslim mothers to utilize maternity care, especially ANC at early pregnancy is a real challenge for primary HCPs and VHVs. Early ANC can prevent maternal complications including those related to anemia, common among Muslim mothers in this area. Maternal anemia is a predisposing factor which increases the risk of postpartum hemorrhage, infection delivery and low birth weight.[3, 33]

In fact, health practices can be merged with worshipping. Hence, to increase access to maternity care among Muslims, health care services should provide cultural care in an environment that allows Muslim mothers and their family to comfortably perform religious practice. Female public health midwifes must be trained to address modesty and gender preference, and respect needs in practicing religious and local traditional belief.

Participants believed that TBAs offer harmonizing cultural care for Muslim mothers at all stages maternity care. Accordingly, Muslim mothers prefer to give birth at home by a TBA. This is contradictory to the Thailand's government policy of encouraging all women to give birth in the hospital. [2] However, existing maternity care services are fragmented. While ANC and postpartum care are provided at health promoting hospitals at sub district level, but intrapartum care is provided at the district hospital, which is unfamiliar and unknown to Muslim mothers. Moreover, at a hospital, mothers cannot choose with whom they will deliver their baby, being unable to choose creates more stress.

The findings indicate that Muslim mothers still needed services from TBAs and HCPs in the community in which similar to previous study [6, 10] which found that Muslims mothers in Pattani Province used mixed care from HCPs and TBAs for ANC and postpartum care. TBAs provided traditional care for ANC using body massaging and herbal healing for postpartum care.

The need for cultural care during maternity among Muslim mothers has not yet been achieved in the formal health care service setting. Improvement is thus needed. For example, there should be better linkages and referral system/information between the health promoting hospital and district hospitals. Integrating traditional practices such as herbal healing and TBAs massage in the hospital should be allowed, encouraged, and facilitated.

Cultural and psychosocial support for Muslim mothers and their families is needed. In the high fertility context, Muslim mothers are in need of a caregiver for their other young children and themselves during pregnancy. The common view of the community, however, is that maternity care is the responsibility of the individual or their families, and not a public concern. In fact, Islam view mothers as the "greater one", which we need to support in all aspects in order to promote a good *ummah* (nation). Motherhood is a great responsibility, not only for mothers and their family, but also for all community members, especially community leaders and community religious leaders. Therefore, collaborative supports for mothers and their family from all levels and networks within and outside the community are needed.

Health personnel need Islamic knowledge and skills to provide culturally-sensitive maternity care for Muslim mothers. Our study shows that although HCPs and VHVs are Muslim, they do not always know how to adapt Islamic beliefs to their routine care. This is similar to Muslim HCPs concerns in USA and Scotland[36, 37] as none of the available approaches has been shown to overcome the problems of providing culturally- appropriate care.[38, 39] The knowledge and understanding of these cultural practices and beliefs helps HCPs provide cultural care for Muslim mothers in this area.[35] HCPs and VHVs should acquire cultural competence through training and education in maternity care from the Islamic perspective. This should be a collaborative effort among health care services, community religious leaders, and community leaders, and the nursing education institutes. One of the outcomes of this effort should be a guideline for cultural care for Muslim mothers.

Assessment activities played a critical role in building capacity of collaboratively partnerships, creating a sense of ownership, and ensuring its sustainability, fulfilling its mission to collaboratively promote maternal health and systematic change in the formal and informal health care system. In fact, the result of this collaborative effort should serve the goal of maternal care in the study community, which is declared by community members' goal as *"Salamat ibu, salamat anokku, salamat kapong* (save mothers, save children, and save community)".

It is important to raise the awareness of how underserved groups of Muslim mothers contribute to high maternal complications and high MMR. To effectively address the many issues affecting maternal health of Muslim women, culture and belief must be included. The achievement of needs regarding cultural maternity care for Muslim mothers as an underserved group requires concerted effort.

Better understanding of the needs for cultural maternity care among Muslims is crucial for improving maternity care that realizes the needs of Muslim mothers in this setting. Strengthening the capacity of the community to actively participate is a crucial strategy for establishing an appropriate cultural-based care for Muslim mothers that contributes to enhance cultural sensitivity of maternity care in the southernmost provinces of Thailand.

## Conclusions, Limitations and Recommendations

The CST and cultural care concept provides in-depth understanding of Muslim maternity care needs regarding their cultural contexts in the Muslim community. The four steps, establishing community collaboration, assessing cultural community needs of maternity care, analyzing and interpreting data, and reflecting and sharing the findings, illustrated needs on cultural maternity care among Muslim mothers through CBPR process.

The results highlight five themes of needs regarding culturally-sensitive maternity care for Muslim mothers: respecting the way of life, practicing religious and local traditional belief, harmonizing cultural care from TBAs, supporting mothers and families, and enhancing cultural competence of HCPs and VHVs.

The findings are able to explain specific phenomena covering only this rural community with a specific culture and belief in an area of civil unrest. Recommendations for future research include increasing the involvement of religious leaders in *Pondok* (traditional Islamic school) and HCPs in hospital. For nursing and midwifery practice, it is important to make care services more efficient safe, and culturally-appropriate in the Muslim community as well as in the health system at-large. Emphasis should be placed on maternity care competencies for preservice and in-service education.

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# ความต้องการการดูแลเชิงวัฒนธรรมสำหรับมารดามุสลิมในชุมชนชนบทของจังหวัดชายแดนใต้ในประเทศไทย

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**บทคัดย่อ:** การวิจัยครั้งนี้มีวัตถุประสงค์เพื่อประเมินความต้องการเชิงวัฒนธรรมในการดูแลมารดามุสลิมในชุมชนชนบทของจังหวัดชายแดนใต้ในประเทศไทย จากเดือนพฤษภาคม-ธันวาคม พ.ศ. 2556 ใช้วิธีวิจัยเชิงปฏิบัติการชุมชนมีส่วนร่วมโดยศึกษาใน 3 กลุ่มของ 1) *มารดามุสลิม* (อายุ 15-49 ปี และมีลูกที่มีอายุน้อยกว่า 3 ปีอย่างน้อย 1 คน) จำนวน 26 คน และสามี จำนวน 71 คน 2) *ผู้นำชุมชนและผู้นำศาสนา* จำนวน 14 คน และ 3) *บุคลากรทางสุขภาพ* รวมทั้งอาสาสมัครสาธารณสุขหมู่บ้านและผดุงครรภ์แผนโบราณ จำนวน 14 คน เก็บรวบรวมข้อมูลเชิงคุณภาพ ด้วยการสนทนากลุ่ม การสัมภาษณ์เชิงลึก และการสังเกตอย่างมีส่วนร่วม ใช้การวิเคราะห์ข้อมูลเชิงเนื้อหา

ผลการวิจัยพบว่า ความต้องการเชิงวัฒนธรรมในการดูแลมารดามุสลิม มี 5 ประเด็นดังนี้ 1) การยอมรับในวิถีชีวิต 2) การปฏิบัติศาสนกิจและการปฏิบัติตามความเชื่อของประเพณีในท้องถิ่น 3) การดูแลเชิงวัฒนธรรมอย่างกลมกลืนจากผดุงครรภ์แผนโบราณ 4) การสนับสนุนแม่และครอบครัว และ 5) การพัฒนาศักยภาพด้านวัฒนธรรมสำหรับบุคลากรสุขภาพและอาสาสมัครสาธารณสุขหมู่บ้าน ผลการศึกษาแสดงให้เห็นถึงความต้องการการดูแลเชิงวัฒนธรรมสำหรับมารดามุสลิม เป็นแนวทางในการให้การดูแลเชิงวัฒนธรรมสำหรับมารดามุสลิมในชุมชนได้อย่างเหมาะสม

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**คำสำคัญ:** วิจัยเชิงปฏิบัติการชุมชนมีส่วนร่วม การดูแลเชิงวัฒนธรรม ความไวเชิงวัฒนธรรม การประเมินความต้องการ มารดามุสลิม ชุมชนชนบท ประเทศไทย

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