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IN THIS ISSUE

EDITORIALS

RESEARCH ARTICLES

REVIEWS AND DISCUSSION PAPERS

The *Australian Journal of Advanced Nursing* is the peer-reviewed scholarly journal of the Australian Nursing and Midwifery Federation (ANMF). The Mission of *AJAN* is to provide a forum to showcase and promote a wide variety of original research and scholarly work to inform and empower nurses, midwives, and other healthcare professionals to improve the health and wellbeing of all communities and to be prepared for the future.

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EDITORIALS

Relaunching the *Australian Journal of Advanced Nursing* (AJAN)

It gives us great pleasure to introduce the new-look *Australian Journal of Advanced Nursing* (*AJAN*) to our Australian Nursing and Midwifery Federation (ANMF) members and local and international readers. As we enter 2020, the World Health Organization (WHO)-designated Year of the Nurse and Midwife, there is no better time to relaunch *AJAN*; the scholarly, peer-reviewed sister-publication to the *Australian Nursing and Midwifery Journal* (*ANMJ*), with a revised mission and scope, revitalised look, and updated policies and processes.

First of all, we would like to offer our sincerest thanks to the ANMF staff (particularly Anne Willsher who for so long sat at the journal's helm), who have dedicated their time, effort, ideas, and energy to both running *AJAN* over many years and to contributing strongly to its renewal and relaunch. An immense amount of work goes on in the background of running a journal and without our dedicated team's input, *AJAN* may have quietly faded away. We also wish to thank our authors and readers. Despite being a very small journal, we were gratified to see the numbers of individuals who navigated to the *AJAN*'s website, and we continue to be impressed and informed by the many submissions *AJAN* has continued to receive, even during its brief hiatus while renovations were taking place this last year.

As mentioned, the new *AJAN* has a revised mission and scope that builds on and extends upon the journal's previous character and aligns and advances the ANMF's overall strategic objectives as Australia's largest union and professional nursing and midwifery organisation. The ANMF's diverse and dispersed membership works in many sectors including but not limited to public and private health, aged care, schools, tertiary education, research, the community, and disability care across a wide variety of metropolitan, regional, and remote locations. Accordingly, *AJAN* will seek to showcase and promote a wide variety of original research and scholarly work to inform and empower nurses, midwives, and other healthcare professionals to improve the health and wellbeing of all communities and be prepared for the future.

In an increasingly interconnected world, where health, social, and political issues and influences traverse borders as frequently as nurses and others, we proudly remain the *Australian Journal of Advanced Nursing*, but also look beyond national borders and will cover issues that affect the regional and global community. Only recently we are hearing that pneumonic plague has been identified in two patients being treated in Beijing, and already concern is growing regarding the risks of a global pandemic similar to H1N1 ('swine flu')/ H5N1 ('bird flu'). Nations and their health systems cannot ignore international developments and incidents and it is vital that nursing and midwifery are at the forefront in terms of being informed, prepared, and ready with the latest best evidence, skills, and knowledge to meet future challenges head on.

The *Australian Journal of Advanced Nursing* will be a source of rigorously conducted and reported research and analysis that, beyond nursing and midwifery, is also relevant for other health professions, health workforce experts, health services researchers, economists, and policy researchers. As users and producers of rigorous evidence, nurses and midwives are leaders in clinical and maternity care and research. Evidence enables them to influence and test policy and practice across a variety of health and social issues. With high-quality evidence, nurses and midwives will also be better supported to advocate for and advance improved health, maternity, and aged care, better and safer workplace conditions, and speak with a stronger voice for nursing and midwifery wherever there is debate and decision making at local, national, and international levels.

We will seek to publish a variety of original research, review articles, practice guidelines, and commentaries relevant to nursing and midwifery practice, health- maternity- and aged- care delivery, public health, healthcare policy and funding, nursing and midwifery education, regulation, management, economics, ethics, and research methodology. We also hope to publish personal narratives that convey the art and spirit of nursing and midwifery as unique but often undervalued professions.

We hope that you enjoy reading the articles in this, the first revitalised issue of *AJAN*, and in the issues to come. As we enter 2020 – the WHO Year of the Nurse and Midwife, this issue's guest editorial has been written by Professor Emeritus Jill White AM – Western Pacific Member of the Nursing Now Campaign Board. Professor White calls on nurses and midwives to use their significant electoral and political power and look beyond the professions to demonstrate evidence for their contributions to national and global health. Professor White also urges us to commit to establishing a National Nursing Strategy by the end of 2020, as a necessary and powerful tool for change.

Nurses can be central to the initiation of treatment summaries and care plans in the context of cancer survivorship. With an increasing number and proportion of people living longer after a cancer diagnosis, supportive care is becoming tremendously important. The first paper in this issue identifies the barriers and enablers to initiating treatment summaries with people who have been affected by cancer and provides lessons for addressing system-level and practical challenges to implementing survivorship care.

A second paper examines patient experience of 'hospital at home' treatment for multiple sclerosis. Patient-centred care is widely recognised to be best-practice and nurses are instrumental in advocating for and delivering interventions that reduce known burdens and often distressing circumstances for patients. Treatment at home can be more convenient and cost-effective for patients, and keeping people out of hospital and in the community can reduce bed-block as well as the risk of hospital-acquired infection.

Nurses and midwives play a critical role in regional and remote health delivery. In this issue you will read an integrative review which provides new and valuable, evidence-based insight into the role of registered nurses in particular and offers suggestions to policy makers for expanding these roles. As we know, rural and remote Australians have more limited access to healthcare than their metropolitan counterparts and also face an increased burden of disease and a different array of health risk factors and social determinants of health. Nurses and midwives can be central to addressing this challenge.

We look forward to working with authors, readers and the Board to enhance the reach, readership, and profile of *AJAN*. Throughout 2020, the journal will continue to evolve and grow as we establish a full editorial board, new author guidelines, and continue to add new features and content to the journal website. This year we will be publishing a series of guest editorials, inviting submissions on current and pressing topics, and also hope to develop helpful training resources for prospective peer-reviewers. We would like to conclude this editorial and introduction to the new *AJAN* by extending an invitation to the researchers and authors across nursing, midwifery, and healthcare to support *AJAN* by submitting their work for publication and by engaging in peer-review.

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EDITORIALS

2020 – A National Nursing Strategy: it's time

Happy 2020 International Year of the Nurse and Midwife. This will be an important year for nurses and midwives around the world, with a focus on us and our work in a way that has never before been experienced. The World Health Organization (WHO) has declared many years as focus years but always this has been a focus on a health problem. It has never been a focus on any health professional group. It signals the importance the Director-General (DG), the Executive Board, and the Member States place on nursing and midwifery's contributions to enabling people everywhere to have equitable access to healthcare without being financially crippled by the interaction or, as WHO calls it: universal health coverage.

This is an extraordinary recognition but one that did not happen by accident or by the DG just deciding it might be a good idea. Months of hard talking, discussion, lobbying, and organising happened behind the scenes. This was led by Nursing Now and Lord Crisp, the Nursing Now co-chair, in particular. It demonstrates the planning, networking and highly skilled political workings that are behind most seemingly simple initiatives, and it is this strategic political working that I want to highlight at this beginning of our focus year. Such an opportunity to influence may not come again and we must not squander it.

The Nursing Now campaign, as so many of you know, is a three-year *HEALTH* campaign highlighting the important contribution nurses can make to health access and outcomes. It is *NOT* a Nursing campaign, despite what it may have at times appeared to be. The campaign was designed to highlight the fact that globally, nurses are undervalued and underutilised. It was, of course, necessary for nurses to know and understand the campaign and the report from which it arose – the Triple Impact Report from the United Kingdom – and to do their internal professional housekeeping,[1] but it is also an essential part of the campaign to engage influential non-nurses to take forward the message of the barriers to our greater potential contribution and to help forge a path to redress this. Nursing Now is about engaging with politicians of all political persuasion to demonstrate the evidence of our potential contribution and also to educate the media and community about a contemporary understanding of nursing and the benefits of broader engagement of nurses in health services and in health policy. In these areas outside the nursing bubble we have not made as much ground in Australia as hoped. But it's not too late! We still have 2020, so let's look at how we can best make use of this year of focus.

In Australia we have some stellar nursing organisations led by committed Boards and Chief Executive Officers (or equivalent in title) and in the Australian Nursing and Midwifery Federation (ANMF), we have the largest union in the country, organised and well-led. Together we represent enormous potential electoral/political power. Why then are we not more politically influential? One of the reasons, I believe, is that we don't have a unified, collaborative plan – a National Nursing Strategy – that is agreed by all stakeholders, including the community and to which all key nursing organisations are committed to do their part as that part aligns with their mission. This is not a piece of work to be directed by government or by government chief nurses. It is not their role. It is a professional responsibility, and, I would say, a requirement for any self-regulating profession to have a map of how they can meet their society's mandate in the most effective way and to be working towards this. Such a strategy enables a consensus response to approaches such as the recent National Nursing Education Review,[2] or to proactively approach politicians pre-election or pre-budget and seek their public commitment to our policy positions for health and social care.

The year 2020 will be a time for celebration – no doubt – a time for a spotlight on our professions. Our responsibility is to be ready to make this more than just a party. Let us commit to have a National Nursing Strategy by the end of 2020 so the public, the community organisations, the other health professional groups, and the whole of government knows what we offer, the evidence base for our claim, the priorities we see for healthcare, and our inclusion in this such that Australia has better healthcare equity and access and so no-one is left behind or impoverished by becoming sick.

The ANMF is the oldest and largest of our professional organisations and is the facilitator of the Coalition of National Nursing and Midwifery Organisations (CoNNMO) to which all other organisations are invited to participate. You have the talent, you have the commitment, you have the opportunity, and you have the mandate. If we manage to end the year with such a National Strategy, as well as raising the profile of the profession, demonstrating that it has been undervalued and underutilised, we will also have a plan for redressing this and making our appropriate contribution to health and healthcare in Australia.

I do not underestimate the challenge of this seemingly simple initiative – like most seemingly simple initiatives, it will require enormous commitment, political savvy, funding, data and evidence gathering, networking, self-reflection, and unselfishness. But no-one else will or should do it for us.

As the famous, old slogan goes "It's time".

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RESEARCH ARTICLES

A quality improvement pilot to initiate treatment summaries and survivorship care plans in oncology services in South Australia

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ABSTRACT

Aim: To review, test and refine standardised tools for nurses to initiate treatment summaries and care plans, and identify barriers and enablers to providing them.

Background: This paper reports on a pilot study informed by the development of a Survivorship Framework in South Australia.

Methods: Expression of interest was sought for adult medical oncology services to pilot standardised tools within existing services and resources. A quality improvement approach was used over three months with nurse practitioners and nurse practitioner candidates to obtain feedback, refine tools and resources, and identify barriers and enablers. Quantitative and qualitative data was recorded at each site using spreadsheets, at fortnightly meetings, and at a final debriefing. Content analysis was used to identify key themes in the context of barriers and enablers.

Findings: Four medical oncology clinics in South Australia participated (three metropolitan, one regional). Forty-three consultations were delivered at three sites. Barriers included time to complete documentation, perceived knowledge and skills, re-orientation of clinics and referral pathways, competing service priorities and lack of administrative support. Enablers included interrelationships within and between pilot teams, supporting resources, and increased familiarity with tools.

Discussion and conclusion: There is potential for nurses to initiate treatment summaries and care plans in the treatment setting with the use of standardised tools. Further refinements are needed to make the process less time burdensome, additional specialised training is needed to improve confidence of nurses to work in a wellness model, and numerous system challenges need to be overcome to improve overall feasibility of using standardised tools to provide survivorship support to patients. Lack of systems to populate information, and lack of referral processes to support survivorship discussions with patients are likely to limit the initiation of survivorship care in treatment settings in South Australia. Further nurse-led development of tools for treatment summaries and care plans should occur in parallel with translational research designed to address system challenges.

Key words: Survivorship; care plans; treatment summary; implementation; medical oncology; South Australia

What is already known about the topic?

Structured survivorship care is recommended to facilitate the individual follow-up needs, health and wellness of people treated for cancer.

Many health services are grappling with the challenge of delivering survivorship care in a sustainable way. It is clear that embedding survivorship care routinely and at scale presents a significant implementation challenge for oncology services.

What this paper adds:

Nurses are well placed to lead the initiation of treatment summaries and care plans, however, this pilot provides real-world insight into the system and practical challenges that need to be addressed to provide essential components of survivorship care in South Australia.

BACKGROUND

As more people are living longer following cancer treatment, health services must address how to best manage the consequences of cancer and its treatment in coordination with other care providers.[1] The structured delivery of information that includes a summary of the treatment received (treatment summary, TS) and a plan for follow-up care (care plan, CP) has been recommended to support care coordination and facilitate transition from regular contact with the treatment team to follow-up care that can be delivered by other health professionals within and external to the treatment setting.[1-3] The initiation of a TS and CP led by nurses within the treatment setting is the focus of the present paper.

Although our understanding of the efficacy and effectiveness of TSs and CPs is still emerging [4,5] many organisations and professional bodies in the United States, Europe and Australia recommend that TS and CPs are initiated in the treatment setting. [6-12] Despite endorsement to do so, there exists a gap between recommendations and uptake of TSs and CPs into practice [13,14] due to issues such as organisational support, funding and resources, and expertise of staff. [3,15,16] Educational sessions with a specialist nurse are amongst the models that have been evaluated in research settings but there is little understanding of the tools required to assist nurses with this task in routine care across diverse settings.[17] The development of appropriate tools and identification of barriers and enablers to delivery are therefore important in building the evidence to enable the design and scale up of survivorship care in local contexts.

To progress the delivery of survivorship care in South Australia (SA), the National Cancer Expert Reference Group commissioned the SA Cancer Service (SACS) responsible for statewide cancer service planning to develop and pilot the SA Cancer Survivorship Framework (Framework). South Australia has a population of 1.7 million, mostly concentrated around the capital city, Adelaide. Cancer care is delivered across public cancer services as well as through the private sector. Approximately 61,000 South Australians were living with cancer in 2014.[18] The SACS facilitates and supports the coordination of cancer care and alignment of service planning with the SA Cancer Control Plan across public cancer services.

The Framework was developed to identify and recommend the minimum level of care cancer survivors should receive following completion of treatment. Key components of the Framework include the provision of a cancer TS and the development of a CP (informed by a needs assessment). The Framework and standardised templates of the key components were developed following a review of the literature regarding survivorship care elements, standards, and implementation; national guidelines [2,19]; several years of survivorship care experience at an established site in SA, and refinement via stakeholder consultation.[20]

The objective of this paper is to report on the lessons learned from a pilot project with a particular focus on the barriers and enablers to documenting TSs and CPs and to identify key issues and strategies that could be used for future implementation. An existing nurse-led model initiating survivorship care was considered the most appropriate and likely to be successful based on a successful model established at one site in SA and support by survivors for the involvement of nurse practitioners in follow-up care.[21] The aims of the pilot were:

1. To review, adapt, and refine the standardised tools for TS and CP to provide support to survivors to transition to primary care services
2. To identify barriers and enablers to implementation of the TS and CP within existing services and resources via a once-off, nurse-led survivorship consultation

METHODS

CONTEXT

This paper reports on a pilot study undertaken as part of a larger project to develop a state-wide Survivorship Framework. The project activities were based on a strategy for translating evidence into practice developed at John Hopkins University [22], which includes four stages: (1) summarising the evidence, (2) identifying local barriers to implementation, (3) selecting measures of performance, and (4) implementing the evidence. The pilot presented in this paper addresses stage 2.

A multi-disciplinary Survivorship Steering Group including cancer survivors, clinicians and researchers was established to oversee the project and review the literature to identify best practice guidelines to survivorship care, chronic disease management and relevant state-wide and national policies and reforms. The literature was presented to a diverse range of stakeholders at an initial forum in 2015 with a focus on the newly developed Model of Wellness for Survivorship Care by the Clinical Oncology Society of Australia (COSA) and to adapt the model within the SA context. The forum explored current practice in SA including the barriers, enablers and gaps to delivering best practice survivorship care. Subsequent to the forum smaller working groups were convened to closely examine the core components of survivorship care outlined within the COSA Model with consideration to the barriers and enablers identified at the forum.

This led to the development of a theoretical Framework that captured the delivery of three core components including a cancer TS, needs assessment and survivorship CP. Standards, principles and templates were developed for each component. Implementation principles were also developed with consideration to challenges expressed during stakeholder consultation. A health economic analysis of the theoretical Framework was also conducted that made recommendations for measuring the effectiveness of the proposed Framework once implemented.

Four self-selected teams consisting of a nurse practitioner (Site D)/nurse practitioner candidate (Sites A, B and C) and a medical oncologist participated in the pilot study to identify local barriers and enablers to implementation. The aim was to have multiple sites but there were no inclusion criteria regarding patient demographics or cancer type. The teams represented three metropolitan hospitals (Sites A, C, and D) and a regional hospital (Site B) (Table 1). There were two large comprehensive cancer centres (Sites A and D), one smaller centre with lower volume but full casemix (Site C), and one rural centre with more limited services (Site B). The pilot was undertaken over three-months (February–May). Each site delivered a once-off survivorship consultation for cancer survivors completing treatment or adjuvant therapy with a senior physician providing support. Pilot teams worked with

TABLE 1: CHARACTERISTICS OF PILOT SITES

	Site A	Site B	Site C	Site D
Population serviced	Adults	Adults	Adults	Adults
Service location	Metropolitan	Regional	Metropolitan	Metropolitan
Survivorship clinic already established	✓	✓	✕	✕
Experience prior to pilot				
TS, CP	✓	✓	✕	✕
NA	✓	✓	✓	✓
Change in practice with pilots	Replaced existing TS & CP with pilot templates within survivorship clinic	Replaced existing TS & CP with pilot templates within survivorship clinic	Created survivorship clinic and adopted TS & CP pilot templates	Created survivorship clinic and adopted TS & CP pilot templates
TS/CP developed by	Nurse practitioner candidate	Nurse practitioner candidate	Nurse practitioner candidate	Nurse practitioner

Note: ✓= existed prior to pilot; ✕ = did not exist prior to pilot
CP = Care Plan, NA = Needs Assessment, TS = Treatment Summary

their local teams to establish the flow of work. The model was based on the Survivorship Framework. Two sites (Sites A and B) were already providing a once-off survivorship consultation prior to the pre-implementation pilot and replaced existing templates with study templates (ie. developed by the American Society for Clinical Oncology.[23] The remaining two sites re-oriented services by creating clinics to incorporate survivorship consultations. Participant nurses from the experienced sites were those that worked in the existing model. All nurses were experienced cancer nurses. All sites had support from the SA Cancer Service and local site management.

FRAMEWORK TOOLS

The survivorship consultation involved the development and provision of a cancer TS and CP in partnership with the cancer survivor using standardised tools. Templates for the tools were modelled on the IOM recommendations, COSA Model, established approaches to chronic disease self-management [24], and the inclusion of goals in care plans.

The TS template was designed to record information relating to cancer type, diagnosis, stage, pathology findings, treatment, and complications. The CP template was designed to record surveillance and monitoring requirements, side effect management, problems reported by the survivor, other health problems; recommended wellness and health promotion activities (eg. screening practices, dietary and lifestyle modification) and any other concerns (eg. financial, relationship concerns). The CP template was designed to be underpinned by principles of chronic disease self-management and include goals to support transferability into the primary healthcare setting and become a 'living' document.[24,25]

The National Clinical Cancer Network (NCCN) Distress Thermometer and Problem Checklist was utilised during individual consultations with the survivor to identify key needs and priorities and establish goals to address these within the CP.[26] The goals were to be developed in accordance with the chronic disease management approach based on the Flinders Program of Chronic Disease Management (https://www.flindersprogram.com.au) and were expected to be specific, measurable, achievable, realistic and time specific (SMART). This CP was designed to facilitate the delivery of ongoing care provided by other healthcare and service providers and reengagement with specialist cancer services where indicated, but this aspect was beyond the scope of the current intervention.

Completed TS/CP exemplars, instructions to utilise templates within the current electronic medical health record system (where available), a generic letter template to the survivor's general practitioner (GP), and a spreadsheet to record information related to process and outcomes measures were also provided. Each team was required to use the standard templates but could adapt to best fit the respective service. Each site was to determine its own system of identifying patients at completion of treatment or adjuvant therapy and to deliver a once-off survivorship consultation, using a toolkit provided. Example materials are available on the SA Health website.[27] There were no eligibility criteria applied to the recruitment of survivors and all cancer types were included, and no differences in the criteria applied at each site.

A copy of the TS and CP was provided to the survivor and their GP upon completion.

STUDY DESIGN

A continuous quality improvement design was used to trial, adapt, and collect feedback on the design and delivery of the TS and CP.[28] The project was coordinated by a Senior Projects Officer from SA Cancer Service. A pragmatic approach was adopted for data collection. Fortnightly debriefing meetings were held to collect data on process and outcomes and to provide support and ongoing contact with other pilot teams (nurses and specialists). Meetings enabled participants to receive informal training on using the tools and templates. A final debrief with each site also took place. The meetings were used to review processes, collate and review information recorded in spreadsheets, develop new strategies, processes and improvements as required. An actions and outcomes log was used to track common issues. De-identified TSs and CPs were collected and analysed by an independent reviewer using a pre-defined scoring process to assess the quality and level of detail in the information documented. Feedback from survivors was sought via a survey. A summary of the data collected and methods for collection and analysis are provided in Table 2. The findings related to quality and survivor feedback are presented in a separate paper.

MEASURES

The following measures were reported on:

1. Time to deliver the TS and CP including preparation, consultation, follow-up and finalisation.
2. Barriers and enablers to implementation and differences in approaches adopted across sites. This information was collected at the fortnightly debriefing meetings, final debrief, and on the data collection spreadsheets.

ANALYSIS

Qualitative data were analysed using content analysis and quantitative data were analysed using descriptive statistics. For the content analysis, text from the spreadsheets and hand-written field notes from the fortnightly meetings and a final debriefing for each site were copied into Excel. The text was then coded inductively to identify key themes. The coding was undertaken by the Senior Project Officer and the interpretation was verified by all participants. This method was considered appropriate given the project context, nature of the information, and depth of analysis required.[29]

TABLE 2: DEMOGRAPHICS OF CANCER SURVIVORS

	Site A	**Site B**	**Site C**	**Site D**	**Total sites A-C**
Consultations (N)	34	6	3	0	43
Age range (years)	39–80	32–75	53–71	0	32–80
Median age (years)	59	58.5	59	0	59
Gender (N, %)					
Male	7 (16%)	1 (17%)	0	0	7 (16%)
Female	36 (84%)	5 (83%)	3 (100%)	0	36 (84%)
Tumour type					
Breast	23 (67%)	6 (100%)	3 (100%)	0	32 (74%)
Other[a]	11 (33%)	0	0	0	7 (16%)

[a] Other included 7 colorectal cases and individual cases of ovarian, tonsil SCC, testicular, and cholangiocarcinoma.

ETHICAL CONSIDERATIONS

Submission to one of the Local Health Network (LHN) Human Research Ethics Committee was made for approval to collect data during the implementation pilots. The pilots were deemed a quality improvement initiative, and approval was granted with mutual acceptance agreed across all LHNs involved (R20160104).

RESULTS

STUDY OF THE INTERVENTION

During the early stages of the pilots, nurses requested that de-identified TS and CP be shared to check consistency, develop ideas to support completion, build confidence in content related to goal setting, and identify credible support resources. They indicated that the sharing of experiences across sites helped in the development of 'response templates' to address common clinical problems to help to improve the efficiency of preparing and developing the CP. They identified the need to have access to a list of credible resources that were available and could be recommended to survivors in supporting their understanding and ability to self-manage. Survivorship Care Plans developed during the early phase of the pilots were used to start identifying relevant resources. A Framework Companion Document – Resources was developed by the end of the pilot. The CP template was revised to list resources at the bottom with reference to relevant websites.

As a result of early discussions at the debrief sessions, a list of key phrases and examples for common issues being identified within CP were developed. These included examples of SMART goals and action-based strategies.

Terminology that catered for various health literacy levels to enhance understanding and meaning for cancer survivors was included. Feedback was sought from consumer representatives on the Survivorship Steering Group following to ensure readability and user friendliness.

As the pilot progressed, nurses reported reduction in time and improvements in efficiency as a result of improved familiarity with the tools. The sites that had replaced existing templates reported improved time efficiency due to the more simplified and less content rich detail required.

There was agreement that the survivorship consultation would be held three to six months following completion of treatment to ensure toxicities and effects of treatment had subsided.

NUMBER OF CONSULTATIONS AND SURVIVOR DEMOGRAPHICS

Forty-three survivorship consultations were held across three sites (A, B, and C) over the three months (Table 3). There were no consultations in site D. In total, 74% (n=32) of survivors had been treated for breast cancer, 84% (n= 36) were female and median age was 59 years.

TIME TO IMPLEMENT TREATMENT SUMMARIES AND CARE PLANS

The average time to prepare, develop, follow-up and finalise the TS and CP was 154 minutes (median 165 minutes) per person. The time breakdown included: preparation (compilation of medical records and commencing pre-population of the TS; 20–90 mins, median 50 mins), appointment (discussing treatment, completing the needs assessment and translating areas identified onto the CP; 45–90 mins, median 60 mins) and finalisation (completion of TS and CP, delivery to survivors, letter to GPs; 30–75 mins, median 50 mins).

BARRIERS AND ENABLERS

Compiling the information

Implementation time, particularly in the preparation phase was affected by: location of medical records and files (in some instances across multiple sites), access to original documentation (eg. pathology reports), and compiling

TABLE 3: DEMOGRAPHICS OF CANCER SURVIVORS

	Site A	Site B	Site C	Site D	Total sites A-C
Consultations (N)	34	6	3	0	43
Age range (years)	39–80	32–75	53–71	0	32–80
Median age (years)	59	58.5	59	0	59
Gender (N, %)					
Male	7 (16%)	1 (17%)	0	0	7 (16%)
Female	36 (84%)	5 (83%)	3 (100%)	0	36 (84%)
Tumour type					
Breast	23 (67%)	6 (100%)	3 (100%)	0	32 (74%)
Other[a]	11 (33%)	0	0	0	11 (16%)

[a] Other included 7 colorectal cases and individual cases of ovarian, tonsil SCC, testicular, and cholangiocarcinoma.

information of treatment, particularly if survivors received services across both the public and private sectors, and complexity of treatment, management and/or risk of complications of cancer and its treatment as well as other co-morbidities.

Although electronic templates were available, there was a preference for handwriting the TS and CP to maintain rapport and the flow of conversation during the consultation and formalising after the appointment using the computer-based patient record summary system or computer-generated word file. This resulted in duplication of processes and additional time. Nurses suggested that the progressive development of a TS commencing at the point of diagnosis, and documented by the relevant treating team, could be an enabler by improving the efficiency of collating and accurately summarise the treatment received.

Providers

Nurses reported that it was challenging to transition from a medical, acute model of care, to one of wellness, and from a directive approach to one that promoted/facilitated self-management. They felt they had limited training and experience in developing and setting suitable goals and strategies with survivors; limited awareness of other service providers available and referral processes to link survivors of cancer with support beyond the acute cancer setting. Concerns were also expressed regarding preparedness of cancer survivors to engage in a model of wellness and discussions in relation to their needs; and how to intervene when items nurses thought were important were not identified as priorities by the survivor. Switching the focus to wellness was challenging if the survivorship consultation was held too early because toxicities and effects of treatment were still evident and therefore most salient to the survivor.

Nurses identified existing and potential enablers to overcome these challenges. These included: further training and education particularly in the area of motivational interviewing and goal setting; forwarding a pre-appointment information pack to survivors to encourage thinking about health and wellness needs and goals; and having specialists discussing with and preparing survivors for post-treatment care including the survivorship consultation.

System readiness for innovation

System barriers included competing demands on nurses' time and lack of explicit process to identify survivors. It was not possible to determine the number of patients eligible for consultations as this information was not captured within any system at the sites. The sites were reliant on specialists for referrals to the survivorship consultation which was ad hoc and mostly included patients with breast cancer. Referral pathways were reported to be dependent upon specialists and their preferences for follow-up care and perceived value of survivorship care. Site A who produced the largest number of TS and CP expressed concerns of capacity if all cancer survivors were referred to the survivorship clinic. It was recognised that the competing demands and other priorities toward the end of treatment for both survivors and their specialists may have had an impact on discussing and referring to survivorship consultation. Another challenge related to administrative support for coordinating appointments and disseminating the finalised documents. When administrative support was unavailable or limited, the process of coordinating appointments and disseminating the completed documents was more time consuming, and in some instances delayed. The pilot sites had limited levels of administrative support for finalisation and timely distribution of the documents.

Contextual elements and unexpected outcomes

In the case of Site D, major service changes (upcoming move to a new hospital location) made it difficult to mobilise resources for the pilot and engage specialists outside the pilot team and these were insurmountable barriers to referral despite good will and intentions of the pilot team. A possible lesson is that innovations in survivorship practices should be tested during periods of service stability.

DISCUSSION AND CONCLUSION

This paper reports on a quality improvement study undertaken as part of a larger project to develop a South Australian Survivorship Framework. The study was a pilot in four oncology settings designed to initiate the development of treatment summaries (TS) and survivorship care plans (SC) by nurse practitioners/nurse practitioner candidates to (1) test and refine the core components of the Survivorship Framework and (2) determine local barriers and enablers to implementation. In relation to aim 1, several improvements to the TS/CP templates were made to improve the ease and efficiency of the documentation templates. In relation to aim 2, several barriers to delivering TS and CPs were identified including challenges associated with manual data extraction required for the TS and the skills required to construct the goals and strategies in the CP. There were system constraints that made it difficult for teams to set up survivorship consultations and referral pathways, including lack of system infrastructure to identify patients coming to the completion of treatment. The opportunities for sharing learnings, development of supporting resources, and increased familiarity with the resources, were key enablers.

Our findings are consistent with other research. Organisational resources including time and having adequately trained personnel are often cited as barriers to the use and uptake of survivorship care plans [13,30-33] including at sites with established survivorship clinics [34] and even when there is buy-in from clinicians.[35] Lack of systems to populate information and for systematic referral have also been reported as barriers to use and uptake.[30] A lack of training in survivorship care and rehabilitation amongst health professionals is thought to be a barrier to referral to appropriate services.[36] In our pilot, a lack of system infrastructure to support referrals for cancer survivors proved difficult to overcome when there were competing service priorities and when engagement beyond the pilot teams and the rest of the cancer team was required. There was no unifying system across sites to identify people coming to completion of treatment, and therefore identification of cancer survivors was ad hoc and largely reliant on clinicians in the pilot teams.

The strategies that participants identified to address these barriers have also been suggested by others. For example, populating the TS from diagnosis is an approach used by Macmillan Cancer Support.[9] Training in survivorship is thought to assist health professionals to provide survivorship care activities [33] and to encourage referral to relevant survivorship services.[36] The use of electronic records or other systems to auto-populate information is thought to be a way of addressing efficiencies in production of TSs and CPs.[37] A flexible approach aligned to the preferences of survivors for brief or detailed information is also recommended.[38]

The documentation process for TS/CP improved with increased familiarity but was nevertheless time consuming and cumbersome, requiring manual and often challenging data extraction from medical records to populate. In the CP, translation of needs and problem areas into SMART goals and provider strategies were challenging to construct. Whilst additional training could be provided to assist with the development of skills required to develop goals and strategies, this may not be feasible in all settings and by staff with varied training and expertise.

Future implementation of survivorship care in South Australia will require critical examination and addressing of the barriers to care delivery including systematic approaches to identification of eligible survivors, system changes to improve efficiency, and staff training and support. In addition, strategies will be required to improve perceptions of the value of providing TSs and CPs. Future work could explore whether re-framing the activity as an example of quality clinical handover, which is identified in the national safety and quality standards,[39] would be more meaningful to wider network of clinicians. There should be engagement with community services and ongoing evaluation of any implementation efforts.

The main strength of the study was its pragmatic quality improvement design. This approach recognises that the use of small pilots is an important strategy in large system change[40] and that innovations are more easily adopted when they can be trialed, readily adapted and refined.[41] By situating the pilot in the context of usual nursing practice, system barriers and potential solutions to the feasibility of initiating treatment summaries and care plans were readily identified.

The limitations of the study need to be considered. Most consultations were undertaken at site A that had an established clinic infrastructure, referral pathways, time to establish relationships with stakeholders, and was the only site to see survivors with diverse cancer albeit amongst a breast cancer majority. Although participants were operating within limited existing resources, they were motivated and engaged in survivorship and had unique qualifications to enable them to consider expanded roles. The findings may therefore moderately over-estimate the feasibility of delivering TS/CP. The barriers and enablers identified are relevant to the public sector setting and service providers and the experiences may not be generalisable across sector boundaries including community private providers and the community sector. Finally, the pragmatic nature of the project had some inherent methodological limitations such as reliance on field notes for data collection and analysis that did not allow an in-depth or nuanced analysis of the challenges encountered.

In conclusion, this pilot indicates that the standardised tools for treatment summaries and care plans outlined in the South Australian Survivorship Framework can assist nurses to structure a survivorship consultation with patients completing treatment. The tools appear to assist with streamlining the compilation of treatment information and developing strategies to align to patient needs and goals, although further specialised training skills may enhance confidence with the latter. By testing the templates in the context of a quality improvement project, we were able to identify that the establishment of referral processes and resourcing for survivorship specific activities are critical hurdle steps to enable TS/CP to be implemented in treatment settings.

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Patients' experiences of natalizumab treatment in a home environment: a qualitative study

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ABSTRACT

Objective: This study's objective was to understand the experiences and perspectives of people with multiple sclerosis who received infusions of natalizumab at home instead of the tertiary hospital day unit.

Background: Continually returning once every four weeks to an out-patient department to complete an intravenous infusion can be taxing for chronic disease patients. In Australia, acute care patients may be offered hospital in the home service. In-home services are delivered by highly qualified, trained nurses following the infusion protocols similar to that of the hospital. However, this service is not yet offered for chronic disease patients, such as those with relapsing remitting multiple sclerosis.

Study design and methods: An exploratory-descriptive study that incorporated face-to-face audio-recorded interviews of people with multiple sclerosis was undertaken as part of a larger study that trialled delivery of natalizumab at home instead of the hospital day unit. The interviews were conducted at the Ambulatory Care Day Unit of a hospital following a period of three natalizumab infusions in participants' homes. Twelve people with multiple sclerosis (two males and 10 females) aged between 18–56 years participated in this study.

Results: A main theme of 'patient-centredness' that describes the positive contribution of having patients at the centre of care when delivering home infusions emerged. This encompassed three subthemes: 'in the comfort of their own home', 'convenience for patients and their families' and 'saving time and money'. Patient-centred care was an important part of the model of care because it provided flexibility for the participants in managing their home and work-life commitments.

Discussion: Although home infusion therapy requires a healthcare team approach, this study's findings demonstrated that delivering patient-centred home infusions provided satisfaction for people with multiple sclerosis. This enabled natalizumab to be delivered at patients' preferred time in the convenience of their own home.

Conclusion: If models of care are to be truly patient-centred, the convenience of the location of the delivery of safe treatment must be a consideration into the future design of services for those with long term health issues such as multiple sclerosis.

Implications for research, policy, and practice: Patients should play a role in the planning of their care and infusion nurses should be flexible in negotiating and delivering appropriate care. Future research could consider the experiences of the home infusion team.

Key words: Multiple sclerosis, model of care, patient-centred, home infusion, hospital infusion

What is already known about the topic?
People with multiple sclerosis come to hospital on a four-weekly basis to receive natalizumab infusions via an out-patient department service.

Home infusion programs have been established to stem the increasing demand for acute care hospital beds.

What this paper adds:
Home natalizumab infusions were accepted by the participants, particularly because of the convenience involved.

The study contributes to patient-centredness of home infusions, which may improve the health and wellbeing of people with multiple sclerosis.

INTRODUCTION

Out-patient intravenous therapy service is well established and is considered to be a standard of care for antimicrobial therapy.[1] However, improved care for chronic disease patients who receive regular intravenous therapy should emphasise minimising and avoiding out-patient hospital admissions, so that patients do not miss work or other activities on the day of their infusion therapy.[2] Around 2.5 million people have been diagnosed with multiple sclerosis (MS) worldwide, including over 23,000 people in Australia.[3, 4] One of the first targeted disease-modifying therapies approved for the treatment of adults with Relapsing Remitting Multiple Sclerosis (RRMS) is natalizumab.[5–8]

BACKGROUND

Internationally, home infusion treatment programs have been established to stem the increasing demand for acute care hospital beds, decrease the risk of infections and control costs.[9] From the patient's perspective, the convenience that comes with having therapy in the home is an essential benefit. Patients who received treatment through such programs reported that it is far more convenient compared to the hospital and that people with chronic health conditions experience benefits while receiving care in their own home.[10] Others emphasised that the calmness of the home environment and good home coordination provided a lesser impact on patients' lives that resulted in a positive patient experience.[2, 11] This 'convenience' links to patients' acceptance of home infusions.[12] In the Australian healthcare system, acute care patients may be offered 'hospital in the home' (HITH) service.[13] However, this service is not yet offered for chronic disease patients such as those with RRMS. In other countries, this practice is accepted for other monoclonal antibody agents, such as infliximab therapy, with clear advantages in terms of safety, satisfaction and cost.[14] Other recent international studies have published abstracts for natalizumab home infusions. In the United Kingdom, a pilot study concluded significantly higher levels of satisfaction with home infusion service on 10 MS patients.[15] Although natalizumab was well-tolerated with a positive safety profile, less serious adverse events, such as elevated temperature, were well-documented. Another study in Australia has documented the first at-home natalizumab infusion service in which 34 patients received nearly 494 doses in total at home.[16] This study concluded that participants' satisfaction was achieved without compromising their safety; while this is an important finding due to the potential for adverse events early in natalizumab treatment, further detail about participants' experiences is unknown.

However, patients receiving natalizumab therapy have the risk of developing progressive multifocal leukoencephalopathy (PML), which is an infectious disease caused by the John Cunningham virus that causes progressive damage or inflammation of leukocytes within the central nervous system.[17] Despite the chance of developing PML, natalizumab is a favourable treatment option for adults with highly active RRMS.[5–7, 18] The potential benefits of decreasing the progression of disability, stabilising the neurological symptom and increasing the quality of life must be weighed against the risk associated with PML.

Offering in-home natalizumab infusion could improve the quality of life, enhance patient centredness, and allow people with RRMS to fulfil basic daily activities. Having the patient at the centre of care should be beneficial in meeting their needs. Patient-centred care is defined as 'providing care that is respectful of, and responsive to, individual patient preferences, needs and friends, and values, and ensuring that patient values guide all clinical decisions'.[19] One North American study used phenomenological methodology to investigate the experiences of patients diagnosed with RRMS receiving natalizumab infusions in clinical settings.[18] The study showed that participants felt that natalizumab treatment improved their quality of life. However, no previous report has focused on patients' experiences having the natalizumab infusion at their own home. In order to explore and describe the participants' experiences and perspectives of home infusion, the research question: 'What are the patients' experiences of natalizumab treatment in a home environment?' guided the study.

METHOD

This paper presents the qualitative component of a larger study on the safety and clinical effectiveness, acceptability and cost effectiveness of home infusions of natalizumab for people with multiple sclerosis.[20, 21] An exploratory, descriptive approach to explore the patients' experiences of receiving treatment at home and to generate a descriptive understanding of this phenomenon was used. A descriptive understanding in the qualitative study is the exploration of human experiences to either investigate new ideas or increase knowledge of a phenomena. Schneider explained this context as 'an 'overarching' process whereby researchers do not adopt a traditional philosophical or theoretical methodological stance but, instead, use a 'free form' approach that adopts general principles of qualitative process, such as common data collection and data analysis styles'.[22]

SETTING AND PARTICIPANTS

The study was based in an Ambulatory Care Day Unit (ACDU), an 11 bed out-patient unit of a major metropolitan hospital in Adelaide, Australia, catering to approximately 26 out-patients per day. Ethical approval was provided by the Royal Adelaide Hospital Ethics Committee (HREC/16/RAH/192). Using convenience sampling 12 participants were selected from 37 consenting participants from the larger study, recruited using the following inclusion criteria:

- Adult MS patients (≥ 18 years)
- Medically stable
- Have been risk assessed as safe for the flexible infusion delivery program by the prescribing Neurologist
- The patient has had a minimum of six natalizumab infusions
- John Cunningham Virus negative
- Comply with other vigilance requirements – Tests such as, MRI are done to identify the disease activity. In addition to clinical signs and symptoms, new lesions found in MRI indicate relapse and disability progression.[23]
- Have completed three natalizumab infusions at home as part of the larger study

DATA COLLECTION/ANALYSIS

A semi-structured interview was carried out during the participants' natalizumab infusions at ACDU, as this was a convenient location for participants to be interviewed. The interviews took between 20 and 60 minutes and were audiotaped. While most interviews were carried out within two months of the participants' last home infusion, a few interviews occurred more than two months after the last in-home infusion, due to the participants' appointment times and the researcher's availability. The recordings were transcribed and the transcripts were analysed using Braun and Clarke's approach to identify, analyse and report the main findings. In other words, the researcher focused on the content of the transcripts, then identified common themes.[24] This approach involved grouping of concepts, supported with quotes from the participants' interviews. The transcripts were also reviewed and themed by a second researcher to build in a trustworthiness measure.

FINDINGS

DEMOGRAPHICS CHARACTERISTICS

Twelve multiple sclerosis patients participated in the face-to-face interview. Most participants were female (n=10), married, and aged 36–45 years (Table 1).

TABLE 1: DEMOGRAPHIC CHARACTERISTICS OF 12 INTERVIEW PARTICIPANTS

Characteristics		Number
Gender	Male	2
	Female	10
Age range	18–25	1
	26–35	2
	36–45	6
	>46	3
Marital status	Single	3
	Married	7
	Divorced	2
	Widow	0
Work status	Yes	5 (Part time)
	No	7

THEMATIC ANALYSIS

A main theme of 'patient-centredness' emerged. This described the participants' overall experience of natalizumab infusion at home instead of the tertiary hospital. This encompassed three subthemes; in the comfort of their own home, convenience for patients and their families and saving time and money.

Main theme: Patient-centredness

All participants acknowledged that it was a positive experience not only for themselves but also for their family members. The nursing care was responsive to them as an individual and not just the treatment of the condition. Priorities were focused on patients' and their families' needs and acknowledgement of patient autonomy and involvement in determining the timing and location of their care.

Subtheme one: In the comfort of their own home

This sub-theme explains what it means for participants to have natalizumab as an option of care at home. Participants expressed the advantages of being comfortable during treatment at home because it fitted in with their daily routine such as having family around.

> *'Yeah, in my favourite chair, with my feet up, with a cup of coffee and kids – my daughter was making coffee, and my granddaughter was just playing with her toys.'* (ID 11)

All of the participants expressed that they had a more pleasant experience receiving natalizumab infusion at home. Participants were very appreciative of having this model of care as an option, as one participant mentions:

> *'It has been a really pleasurable experience, so thank you for including me. Yeah, definitely, it's been a great experience for me.'* (ID 34)

Although the participants identified advantages of having the infusion at home, one particular participant mentioned that there was a benefit of having the treatment at hospital, which allowed the participant to separate their MS condition from their home life:

> *'…at the moment having it at the hospital, I come to the hospital and I think about MS when I'm at the hospital but when I go home I don't have to think about it anymore.'* (ID 5)

One of the consistent feelings expressed by participants was of being less stressed while having treatment at home. This was because attending hospital for an appointment and then returning home did have particular anxieties for some participants that caused them to feel stressed:

> *'At home, it's less stressful. I suppose it's just you're in an environment that you know. So up here [hospital], it's not so much the stress once you get here, it's the stress of getting here and then getting home too.'* (ID 46)

When exploring the benefits of the home model of care, participants indicated that being at home was less stressful because they felt more relaxed and calmer.

> *'It was just nice and relaxed. I could just get up. I could have my water,…prepare myself. I didn't feel nauseous or anything.'* (ID 12)

Another participant mentioned that access to the medication was more important than travelling to the hospital for the natalizumab infusion:

> *'Because I love the drug so much and that is my ultimate priority, as long as I get it I don't care where I get it, … that is the ultimate goal. As far as location, it really doesn't matter because …. coming here is really a no-brainer.'* (ID 21)

Subtheme two: Convenience for patients and their families

The convenience felt by the participants was a result of ease in managing appointments which benefited them and their family members. The convenience of home infusions reduced the difficulties associated with natalizumab treatment in a hospital setting.

Participants' indicated that home infusions gave them a sense of control and autonomy over the appointment time for their therapy. Upholding dignity and integrity through decisional autonomy provides participants a sense of control over appointment times that fit into their routine, whether that be their work or home lives:

> *'I think I would just say it's easier to work, especially if the nurses are prepared to come later in the day, and you have your infusion before dinner or whatever, it's more convenient for your work.'* (ID 3)

To some extent, managing appointments fundamentally helped participants to maintain a sense of control over their lifestyle:

> *'Having it in a time that I can manage and help manage my family life is important. Yeah, so I can make the treatment fit in with my life, rather than my life fitting in around my treatment.'* (ID 34)

It is clear from participants' experience that having home infusions benefits everyone. Some participants viewed home care as freeing up space at the hospital for people who are acutely ill.

> *'It benefits, I think, everyone. It benefits the patients, but it also benefits the hospital because there's three or four people that – in a day, I suppose, I don't know how many would come up on the same day. But it just frees up that space as well.'* (ID 46)

Another participant highlighted the benefits at workplace.

> *'As I said about [my work], I didn't have to leave early and disappoint the [students], or get a reliever or anything like that.'* (ID 5)

Others mentioned that having home infusions was suitable for their family commitment, as they could continue with their usual daily activities in their own environment.

> *'…You probably get the same from everybody. It was really convenient with my lifestyle, with work and kids and everything.'* (ID 20)

Subtheme three: Saving time and money

Although a natalizumab infusion only takes an hour in a hospital setting, most of the participants claimed that it is almost a day spent in hospital. Some participants or their family members need to take a day off work to accommodate the treatment. This will then impact on them having to make up the day lost or have lesser pay. Others have to spend extra money to have their children looked after by a carer during treatments. This subtheme documents the participants' perceptions of home infusions in terms of the saving time and money.

Most of the participants reported that they felt that the infusion went 'quicker' compared to the hospital service.

> *'So yeah, I think it – it went fairly quickly anyway but I think it went quicker because I wasn't sort of aware of it as much.'* (ID 34)

Travelling time represents the participants' experience of travelling to and from the hospital for their appointment, which was an issue that all participants verbalised. Most of the participants were also concerned about parking their car, the level of traffic on the inner city roads, and rushing to the hospital to be on time for appointments. Participants indicated that one of the main benefits of the home model of care was eliminating the need to travel to and from the hospital:

> *'…You don't have to worry about the time it takes to travel in and to travel home. I much prefer it at home.'* (ID 11)

Saving money is one of the benefits identified from receiving home infusions. Participants mentioned that staying at home was beneficial as they do not have additional costs for petrol, parking, television rental and food.

> *'You're spending less money on petrol and parking, which is a big drama.'* (ID 3)

In addition, they also mentioned that they did not need to take time 'off' from work, which also related to cost-effectiveness.

> *'I think that – so it didn't cost me anything to be able to have it at home.'* (ID 5)

DISCUSSION

Patients' perspectives and evaluation of service delivery within the healthcare system should be focused on what they find important.[2, 25] Ducharme, Pelletier and Zacharias have reported that 'restrictions' and 'inefficient care' leads to inconvenience for patients.[26] Trialling a model of care for home infusions of natalizumab, which was the focus of the larger study, was in response to the changing expectations of patients' as well as the evidence of the safe infusion of natalizumab in the community away from the acute health service. The findings from this study aided the understanding of how people with MS appreciated and benefited from the care provided. This was supported by the participants' interviews and their aspiration of having a permanent home infusion delivery. Overall, the study indicated that being at home while receiving natalizumab infusions supported a patient-centred care approach by offering convenience for patients with RRMS and their family members. In addition, this provides a valuable insight for nurses delivering in-home treatment. Given the pivotal role of nurses within an in-home service, further qualitative study exploring their experiences with the concept of patient-centred model of care would be beneficial.

PATIENT-CENTREDNESS

In our study, the flexibility and ease in which the participants could arrange their appointments' was highlighted. They were able to make re-bookings easily by messaging the infusion nurse and having their natalizumab treatment at an agreed time and place. One of the dimensions of the MS relapse management scale to measure patient care is 'access to care'.[2] During the participants' home infusions, they mentioned that they had their four-weekly infusions in a time and place that suits them, as the home infusion team upheld flexibility with the appointments. Also, they noticed that the infusion went quicker compared to the ones at the hospital. This may be due to the 1:1 ratio of patient-nurse in the home, therefore enabling the immediate and total attention of the nurse, where the main focus was patients' safety and comfort. The home treatment was more physically and emotionally comfortable. This finding is supported by international studies, which found that because of the initial impression of comfort, the majority of participants elected to change to in-home infusions.[2, 10–12]

The second dimension of the MS relapse management scale is 'coordination of care', which relates to this study's subthemes 'in the comfort of their own home', which emphasised the advantages of participants being more comfortable and less stressed in their own home during the treatment. This is consistent with findings from other home therapy survey studies. In Italy, a survey of adults receiving enzyme replacement therapy for lysosomal storage disease found that the majority of participants favoured in-home therapy, indicating that they experienced less stress, increased comfort and less impact on family life during the treatment.[27] Given the relationship between stress (at work or life events) and relapse for people with MS,[28] reduced stress may reduce the risk of relapse, which is very important to patients with MS.

Acknowledging patients' comfort and empowering patients' and family members' involvement with the plan of care can lead to a higher level of patient compliance with their treatment.[29] Consistent with the trends in other in-home treatment models, convenience for patients and their families made a significant difference to their experiences of infusion therapy in the home setting. A number of studies have demonstrated that receiving IV therapy at home will increase patient compliance with their treatment.[11, 29–31] Being in hospital for infusions presents obstacles for MS patients, which may be addressed by providing alternative services, such as infusion therapy at home.

LIMITATIONS

The participants of this study consisted of RRMS patients who were currently receiving infusions at a single, metropolitan, tertiary hospital. The results may not be generalisable to other groups of patients and other MS patients at other hospitals and countries due to geographic and social differences.

CONCLUSION

This is the first research on the experiences of people with MS receiving natalizumab in the home environment. This study supports health services to consider different models of delivering care for patients with chronic conditions, such as MS, requiring regular infusions. Delivering the infusion in an environment of the patient's choice does enhance their wellbeing, physically, emotionally and financially. The convenience, comfort and saving time and money of in-home treatment were the most important parts of the experience that contributed to a patient-centred approach. Therefore, this study encourages adopting in-home infusion therapy as an ongoing model of care to support MS patients' health and wellbeing within their own familiar environment, ensuring their lifestyle remains as routine as possible.

RECOMMENDATIONS

To ensure patient-centredness, the infusion nurses and the support team should discuss the patients' and families' needs when receiving infusions in the home. Depending on the situation, patients should play a role in the planning of their care and infusion nurses should be flexible in planning and delivering the care. The study recommends important areas for future research, including:

As patients only were included, in future studies it would be useful to understand the experiences and opinions of their family members, including their involvement in care, using in-depth interview tools.

It would be beneficial to further explore if there are any additional benefits of home care to supporting the broader family unit.

It would also be useful to consider the experiences of the in-home infusion team during the period of in-home infusions.

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REVIEWS & DISCUSSION PAPERS

Roles of rural and remote registered nurses in Australia: an integrative review

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ABSTRACT

Objective: The aim of this review is to explore the multifaceted roles of registered nursing practice in rural and remote areas of Australia.

Background: People in rural and remote Australia have less access to healthcare than their metropolitan counterparts. They are also burdened with higher rates of chronic disease and premature mortality. These areas also have less doctors and allied health professionals than metropolitan areas, with the core workforce being registered nurses. One strategy to address the health workforce disparities, is to promote registered nurses to work to their full scope and in advanced generalist roles. An understanding of the current roles of the registered nurse is therefore required to assist in determining how their scope could be extended, and to inform appropriate educational planning.

Study design and methods: An integrative review of literature was used to obtain articles from online databases relevant to nursing from 1995 to 2017. Data was quality appraised, extracted, and thematically analysed.

Results: Registered nurses in rural and remote Australia work in diverse contexts that have a major influence on the roles they undertake. They are already required to be multi-skilled and to practice at an advanced level, including undertaking some aspects of the health professional role traditionally the domain of medical practitioners. These registered nurses often feel unprepared for the breadth and complexity of this role.

Discussion: To enable registered nurses to be adequately prepared for rural and remote practice, educational programs need to be flexible, accessible and affordable. The registered nurse's existing experience and expertise should be recognised, and educational pathways structured to enable the nurse to expand their practice according to the context in which they work and the needs of the community.

Conclusion: Registered nurses in rural and remote areas function as advanced generalists. Greater understanding these roles is necessary to inform the development of 'fit for purpose' educational models.

Implications for research, policy and practice: Future research is needed to focus on evaluation of existing models of rural and remote nursing practice and in particular the role of the nurse as doctor substitute. The findings of this study highlight the potential expanded contribution of registered nurses in these areas, which is an important factor for consideration by policy makers. In practice, supportive frameworks are required to ensure registered nurses are able to function to their full capacity in their unique context.

Key words: Educational models, rural nursing, nurse role, remote area nurse

What is already known about the topic?

People living in rural and remote areas are subjected to inequities in respect of health and access to healthcare services

Registered nurses working in rural and remote areas are essential for addressing healthcare needs that would otherwise be unmet

Nurses practicing in these areas require an advanced skills-set in order to function effectively in their role

What this paper adds

This paper examines the multifaceted role of the registered nurse working in rural and remote areas of Australia as described in the literature

Four main themes were identified: roles shaped by context; doctor substitute; multi-skilled and advanced practice; and feeling unprepared

Understanding the complexity of the registered nurse role in rural and remote areas enables the development of policy, practice and educational approaches to support nurses in functioning to their full capacity

INTRODUCTION

Approximately 30% of the Australian population live outside of metropolitan areas, with 11% living in outer regional, remote or very remote areas.[1] Additionally, a large proportion of Aboriginal and Torres Strait Islander people (Australia's Indigenous population) live in remote areas (21%) and comprise around 45% of the population living in very remote Australia.[2]

The health of rural and remote people in Australia is poorer than those residing in major cities, with higher rates of chronic disease, injury and premature mortality.[3] Furthermore, as the distance from cities and regional areas increases, so to do disease risk factors and levels of illness.[4] The poorer health and reduced life expectancy of Aboriginal and Torres Strait Islander people, as compared to non-Indigenous people, is well established,[3] with their health status also deteriorating the more remotely they live.[2]

In addition to having poorer health, rural and remote people have less access to healthcare than their city counterparts.[3] Health services in rural and remote areas have smaller facilities, less infrastructure, less access to specialist services, and are tasked with delivering services to a diverse population.[4] Furthermore, these areas have less doctors and allied health staff than metropolitan areas and experience a higher turnover of registered nurses (RNs).[5]

The Australian Government acknowledges the health disparities of rural and remote people, and a primary goal of the 'National Strategic Framework for Rural and Remote Health',[4] is for equal access to healthcare for everyone, regardless of the geographical location. This goal includes access to an "appropriate, skilled and well supported health workforce".[4(np)] To build an appropriate workforce, an objective of the Framework includes exploring flexibility in the scope of practice of health professionals, improved access to training and continuing professional development, and promotion of advanced skill roles for nurses and general practitioners.[4] Consistent with this objective, the review presented in this paper promotes greater understanding the roles of rural and remote RNs undertake. This understanding will inform the development of 'fit for purpose' educational models.

Queensland, a state which boasts a significant proportion of the rural and remote population in Australia,[1] sees 'rural generalist' health professionals as being central for sustainability and capability of rural and remote healthcare.[6] In their 2017–20 workforce strategy, the Queensland Government proposed a structured 'fit for purpose' rural and remote (generalist) model for RNs be developed, enabling them to practice to their full (and expanded) scope within appropriate clinical governance arrangements.[6]

One initiative to address workforce capability in rural and remote areas in Australia, is the rural and isolated practice registered nurse (RIPRN) qualification. The RIPRN qualification equips RNs with skills in assessment and diagnosis relevant to rural and remote primary care. RIPRN qualified RNs are authorised by state or territory legislation to initiate medicines, such as antimicrobials and immunisations, a process supported by context specific clinical guidelines.[7] The RIPRN qualification, however, only encompasses some facets of the rural and remote RN's role. It is therefore timely to consider the unique needs of rural and remote communities and how RNs working in these areas contribute to meeting these needs.

METHOD

AIMS

This review aims to examine the multifaceted role of the RN working in rural and remote areas of Australia as described in the literature. Consideration will be given as to how appropriate preparation for the role can be ensured. The review question is 'What are the roles of rural and remote registered nurses in the Australian context?'

DESIGN

An integrative review methodology was used to allow for inclusion of diverse methodologies, theoretical and empirical literature.[8] This method was selected over other review methods as early searches indicated practice literature and qualitative studies were most prominent in the topic. Prior to conducting the review, planning was performed based on the principles of the PRISMA-P-2015 checklist.[9] An *a priori* protocol was not developed. The review process involved retrieval of relevant literature using a transparent and reproducible search methodology; assessment of quality using a structured critical appraisal process; and the resulting data analysed and synthesised.[10]

SEARCH METHODS

Online databases relevant to nursing and healthcare were searched. These included CINAHL, Scopus, Medline (Ovid), Informit Health Databases, PsycINFO (ProQuest), Joanna Briggs Institute (Ovid) and Cochrane Library. Trove was searched for Australian Masters and PhD dissertations/theses, and the educational databases ERIC (Education Resources Information Centre, [ProQuest]) and Informit A+ Education were perused for educational studies related to the topic.

Key search words included: rural, remote, registered nurses, Australia and roles. Alternate key words, Boolean terms (AND and OR), subject heading suggestions and MeSH terms were used to broaden or narrow the search as required. Appendix A (see Supplementary Material) provides an example of the search strategy performed for Scopus.

Search limits included the English language, full text, and dating from 1995 to 2017. Preliminary searches identified a seminal review by Hegney that is frequently cited in more recent literature and therefore older papers were considered worthwhile exploring.[11] Reference lists of relevant articles were also hand searched for additional papers that may have been missed in the database searches. The final search was performed in October 2017.

During the search process, each article was assessed against predetermined inclusion and exclusion criteria as presented in Box 1. Slight modifications were made to these criteria as the search evolved. Community and practice nursing were excluded to ensure the review was focused on roles rather than areas or specialisations of nursing. Practice literature was added as several practice literature papers relevant to the review question were located during the search, while there were limited research papers. Practice literature are published non-research articles "written by practitioners about their field of expertise" and could include (for example) "expert opinion, discussion papers, debate, (and) ethical arguments".[12(p45)]

Inclusion criteria	Exclusion criteria
Registered nurses Roles Rural and remote Australia Qualitative, quantitative and mixed method research methodology Practice literature	Nurse practitioner Enrolled nurse Practice nursing Community nursing Other professions/people (e.g. doctors, health workers, allied health, farmers) Other aspects of rural and remote nursing not related to roles (e.g. stress) Countries other than Australia (e.g. Canada) Grey literature

BOX 1: INCLUSION AND EXCLUSION CRITERIA

Endnote was used for record keeping of each database search result and as a repository for articles found. This program was also used to facilitate removal of duplicate publications.

SEARCH OUTCOMES

A total of 496 articles were retrieved from the online database search, and a further 19 through hand searching reference lists. The database retrieved articles were initially reviewed for relevance by title only, resulting in 445 being excluded. Duplicates were removed from the 70 remaining articles, leaving 51. These were reviewed by title and abstract against the inclusion and exclusion criteria, resulting in an additional 14 being excluded. The full text of the remaining 37 articles were reviewed and 19 were excluded due to not meeting inclusion criteria. Of the excluded articles, three were literature reviews related to the roles of rural and remote RNs.[13–15] These were examined to ensure that this review was not duplicating work already published. Two articles which met the inclusion criteria were excluded – one as it was a duplication of a research study by the same author,[16] and another as only an incomplete version of the article was accessible.[17]

QUALITY APPRAISAL

Fit for purpose tools were used to complete a comprehensive systematic appraisal of the remaining 16 papers.[12] The Critical Appraisal Skills Programme (CASP) qualitative checklist, as suggested by the Cochrane Collaboration,[18] was used to analyse the qualitative research studies. The AACODS (Authority, Accuracy, Coverage, Objectivity, Date, Significance) checklist, a generic appraisal tool developed by Tyndall,[19] was used for the practice literature.

Two articles were excluded during the quality appraisal process. Rosenberg and Canning was removed due to low quality (a lack of clarity in the research aim, research methodology and rationale for recruitment of participants; no discussion of ethics approval, the consent process or anonymity; and thematic analysis and themes extracted from qualitative data not clearly described).[20] A paper by Bagg was excluded as it was limited to the experience and views of a single person, and the credibility and qualifications of the author could not be established.[21]

Of the remaining 14 papers, eight were qualitative research articles. Through appraisal using CASP, it was determined all had clear aims and used qualitative research methodology appropriately to meet the objectives of the research. Five were assessed as having an appropriate recruitment strategy. Of the other three, the recruitment strategy was unclear,[22] had a limited description,[23] or the justification did not appear to meet the aims of the research.[24] Seven studies described appropriate data collection for the study design, and one was limited in the description.[24] The relationship between the researcher and participants was unclear in most papers, with only three addressing reflexivity appropriately.[25–27] This omission may have resulted in a bias in the studies, and therefore reduced the reliability of the study outcomes. Six studies included a thorough description of ethical issues, with the remaining two only providing a moderate description.[27, 28] All studies described rigorous data analysis, provided clear statements of findings, and articulated value of the research. They were therefore deemed of satisfactory quality to include in the review, with appropriate rigor applied in particular to methodology and analysis of data. Appraisal of the remaining six practice literature papers using the AACODS tool resulted all being considered of adequate quality for inclusion in the review. A summary of the appraisal of the research articles included in the review is presented in Appendix B and practice literature in Appendix C (see Supplementary Material). A total of 14 articles were therefore included in the literature review, comprising eight research studies, and six practice literature papers. A summary of these papers is presented in Table 1.

The Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) flow chart has been used to illustrate transparency of the search processes,[29] (Figure 1). The lead author performed the search and quality appraisal of the papers.

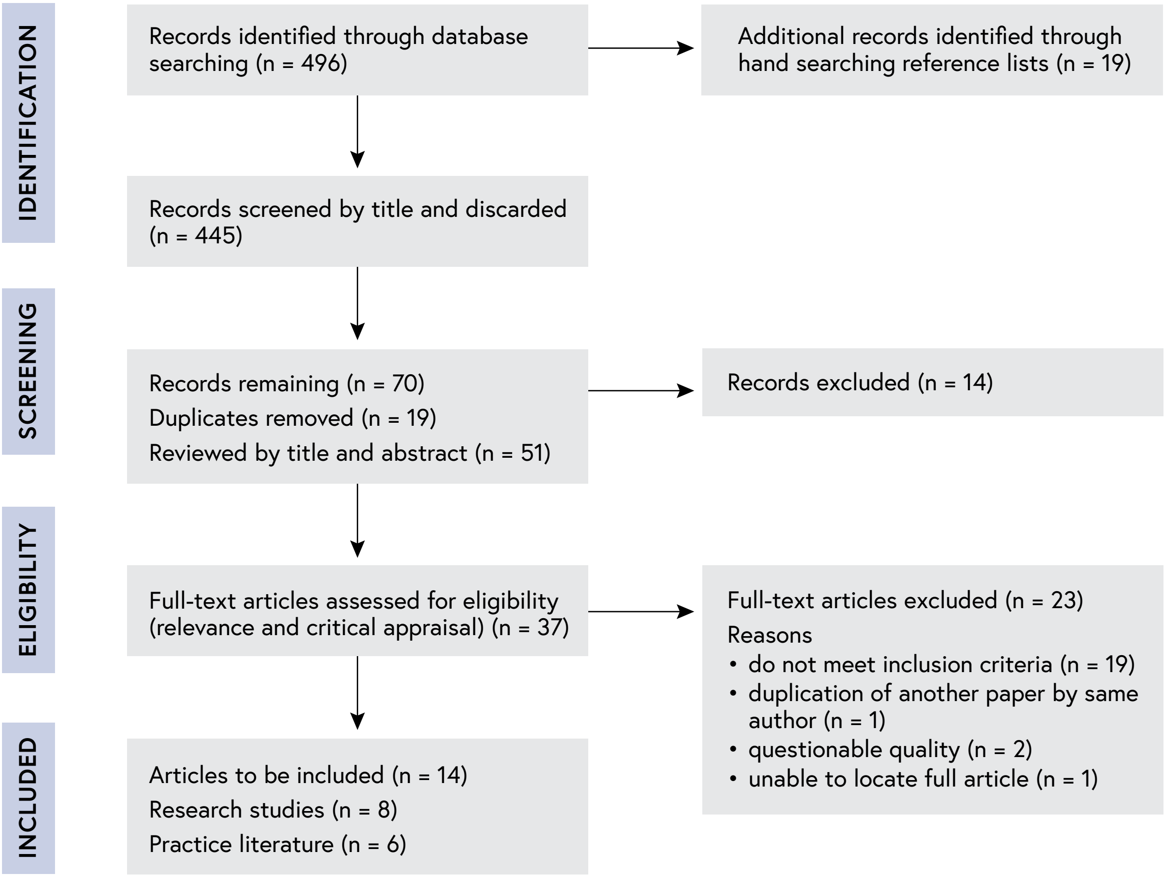

FIGURE 1: PRISMA FLOW DIAGRAM

TABLE 1: SUMMARY OF INCLUDED ARTICLES

Study	Title	Setting/context	Method	Sample	Main findings (summary)	Comments/ recommendations
Research literature						
Al-Motlaq, Mills, Birks, and Francis (2010)	How nurses address the burden of disease in remote or isolated areas in Queensland (Qld)	Remote and isolated Queensland No Medical Officer (MO) on site	Multiple case study – interviews, focus groups Part of a larger study of role of nurses working in remote or isolated areas of Qld	35 Registered nurses (RNs)	Role varies according to place of practice Felt underprepared/time poor for primary healthcare – focused on emergency/acute care RNs deal with chronic disease, mental health, dental problems, infections, accidents, trauma, abuse disorders	Require a paradigm shift to promote stronger primary healthcare approach to practice
Birks et al. (2010)	Models of healthcare delivery in remote or isolated Qld	Remote and isolated Qld No MO on site	Multiple case study – interviews, focus groups part of a larger study of role of nurses working in remote or isolated areas of Qld	35 RNs	RN seen as substitute for GP Torres Strait Model of care – RNs coach and are a clinical resource for Indigenous Health Workers; on call Health service prioritise primary healthcare, but RNs provide more of a bandaid service (acute care)	Need to develop model with more emphasis on primary healthcare
Courtney, Yacopetti, James, Walsh, and Finlayson (2002)	Comparison of roles and professional development needs of nurse executives	Qld (all) Remote was defined as a centre with a population < 5000 Rural – an urban centre with a population from 5000 – 25000	Cross sectional self-report descriptive study Questionnaire survey tool	All (n=281) Director of Nursing (DON), Assistant Director of Nursing (ADON) employed in Qld public health service, with min 12 months experience	DONs reported more diverse roles the further from cities to remote – more clinical management Clinical management most frequent role for remote respondents, including 'general nursing role'	Response rate of 52% (limitation) Noted also, that perceptions of geographical area or work may have been interpreted differently by participants and limit findings
Cramer (1998)	Nursing practice in a remote area: An ethnographic study	Remote Aboriginal community in Western Australian (WA) Central Desert No MO on site	Qualitative Ethnographic study Interviewing and participant observation	Purposive sampling - RNs employed at remote area clinic in WA desert over a one-year period (n=19)	Themes – Detachment, diffusion, beyond the nursing domain Not prepared well for role Expected to use treatment manual, which assumes a diagnosis is made, but not trained in medical diagnosis Suddenly expected to do things outside of normal nursing role (e.g. medical diagnosis) Skills different from hospitals Role like Nurse Practitioner Many clinical skills required	First research study providing detailed description of remote area nursing in Australia

TABLE 1: SUMMARY OF INCLUDED ARTICLES (CONTINUED)

Study	Title	Setting/context	Method	Sample	Main findings (summary)	Comments/ recommendations
Crossland (2011)	Perceptions of roles and skills of primary health professionals – rural	Rural Remote Four communities in North Qld Non-Indigenous communities	Collective case study methodology; narrative approaches, organisational change theory	One nurse from one remote community Multidisciplinary from other communities	Where no doctor on site, patients see nurses as doing everything a doctor does – community does not perceive GP as 'essential' healthcare professional (note reference to practice nurses' meaning RNs, and RIPERNs working in primary healthcare settings (meets inclusion criteria) RIPERNs akin to advanced nurse practitioners RNs called themselves generalist, regardless of service model worked in	As communities' value non GP led services, should be supported as a service model in its own right - further research to define flexibility of roles Only one nurse sample for the RIPERN
Josif, Kruske, Kildea, and Barclay (2017)	Quality of health services to remote dwelling infants	Two Northern Territory remote area Aboriginal communities	Qualitative Semi structured interviews, observation	24 multidisciplinary clinicians managing child health services – RNs n=4	Some misunderstanding of the primary health role by RANs Saw acute as being more relevant to their practice (even though most presentations were related to primary healthcare) RANs were immunising and running baby clinics, often unprepared	Need better preparation for roles; better service design Urgently need better management practices for better quality care
Hegney, McCarthy, and Pearson (1999)	Effects of size of health service on scope of rural nursing practice (analysis of the activities of rural nurses from a national audit in 1996)	Australia wide Rural defined in study as taking place in a rural environment where there are no full time on site medical and allied health practitioners/often no support from MO or allied health	Qualitative Nurses observed over 24-hour period - all activities undertaken recorded	Random sample of 129 health services and 362 nurses employed in the health services (p. 22)	Size of health service influences staffing type and ratio Jack of all trades/multi-skilled Flexible (25%) Increased level of responsibility No support in emergency situations Concern of legal issues associated with extended role Non-nursing duties Three categories of health service identified – varying roles depending on size of health service – smaller health service = broader range of skills	Further research into impact of skill mix and patient acuity Extended role needs to be recognised
Smith and Jones, (2007)	Remote x-ray operator radiography: a case study in inter-professional rural clinical practice	NSW – All remote x-ray operators i.e. where a radiographer not available	Qualitative case study Semi structured in depth interviews –	Multidisciplinary clinicians, including 10 RNs Purposeful sampling	RNs taking on x-ray role in areas where radiographers not available - upper limb, shoulder, chest, lower limb, pelvis Radiographers feel the quality is below standards; RNs impinging on their role General acceptance that if no one else to do it, then it is ok for RNs, regardless of quality to meet community needs	Better communication and collaboration needed Cross disciplinary education required

TABLE 1: SUMMARY OF INCLUDED ARTICLES (CONTINUED)

Study	Title	Setting/context	Method	Sample
Practice literature/Other				
Greene and Burley (2006)	The changing role of bush nurses in East Gippsland, Victoria	Five bush nursing centres in Victoria Single nurse posts No doctor or pharmacist Non Indigenous	Discussion based on research study by authors	24 hour primary health service Traditional roles broadening in response to community needs and advances in nursing practice (specific roles detailed in paper)
Hegney (1996)	The status of rural nursing in Australia: A review	Focus on rural rather than remote RN Non indigenous	Narrative review	Rural nurses – Rural hospitals, community health settings, nursing homes (defines remote as more Aboriginal and Torres Strait Islander primary healthcare services). Work beyond legal boundaries Extended into doctor and allied health roles Context impacts on role (e.g. location, population density, community needs High responsibility On call Multi-skilled – (skills defined in paper) Work beyond legal boundaries Autonomous
Hegney (1997)	Extended, expanded, multi-skilled or advanced practice? Rural nurses in Australia, 1991–1994	Rural settings in all Australian states (except NT which is 98% remote) p.23	Uses Foucault's framework to examine public and workplace discourses of rural nursing 1991–1994 In addition, 30 RNs Purposive sampling	Extended role to fill the gap, otherwise the service would not exist Size of rural facility and type of support impacts on scope of practice (Smaller = more autonomous and expected to do more) Proposes that advanced rural nursing practice be used to refer to the generalist scope
NRHA, (2005)	Advanced nursing practice in rural and remote areas	Rural and remote (broadly)	Position paper	Many experienced registered nurses in rural and remote areas are already practicing in advanced levels but are not nurse practitioners. They need to be recognised Remote nurses work in indigenous communities, islands, tourist centres, mining, pastoral, fishing communities, jails, refugee camps, emergency retrieval services Remote Area Nurses (RAN) – care across the lifespan Non-clinical roles, e.g. vehicle maintenance
Taylor, Usher, and McDermott (2013)	Diabetes in Torres Strait Islanders: Challenges and opportunities for remote area nurses	Torres Strait Islands, Remote Qld	Discussion paper	RANs in remote primary healthcare centres in Torres Strait Islands (21 Primary Healthcare Centres) Nurses have role to: Manage, educate, screen, assist with new models of care related to diabetes (need to not just focus on acute care, but also primary care)
Timmings (2006)	Rural and Isolated Practice Registered Nurse (RIPRN) – emergency nurses of the Qld 'bush'.	Discussion on how nurses in rural areas in Qld can gain an endorsement as a RIPRN to enable more autonomous practice	Expert opinion	RIPRN nurses administer and supply medicines legally, using the Primary Clinical Care Manual; Able to do assessment, diagnose and manage with or without doctor

DATA ANALYSIS

Data was extracted into a table using pre-determined headers of specific criteria. Headers included: the purpose of the paper or study, focus, analysis, methodology, context/setting, sample details, findings, and gaps identified for future research.

As the papers were either qualitative research or practice literature, a thematic analysis was used. A thematic analysis is also appropriate for a systematic narrative synthesis of the literature, such as this paper provides.[30] The analysis was completed manually and included familiarising and reviewing the findings of each research paper by reading, re-reading, and highlighting important or recurring themes.[12] Evolving themes were tabulated to visualise results and enable comparisons to each paper. Themes of prominence were then able to be identified.[12, 30] Thematic analysis was performed by the lead author, with the second author verifying the analysis to assist in reducing bias.[31]

Initial analysis of the papers established six were focused on remote areas, five on rural areas, and three on rural and remote areas. The parameters around what constitutes rural and remote has some variation within the papers. For the purposes of this review, 'rural and remote' will not be defined further, and rather will be referred to as presented by the author/s of each publication.

RESULTS

Four main themes were identified: roles shaped by context; doctor substitute; multi-skilled and advanced practice; and feeling unprepared.

ROLES SHAPED BY CONTEXT

Two subthemes were identified within this theme in relation to the influence context has on the role of the rural and remote RN: the size of the health service and the needs of the community.

Many authors agree the smaller the facility the more generalised the role of the RN becomes.[24, 26, 28, 32] In a report of a larger study in the 1990s, Hegney et al. analysed activities undertaken by 362 RNs from a random sample of 129 rural health services across Australia.[26] The services were categorised by the number of acute (inpatient) beds in the service. Hegney et al. revealed that there was a significant difference in the activities of RNs in relation to the size of the health service in which they worked, with RNs from the smaller services requiring a broader range of knowledge and skills.[26] This was reflective of the findings of an examination of discourses of rural nursing from 1991–1994 by Hegney,[32] who concluded that the smaller the facility, the less access and support from medical and allied health staff, and therefore the more extended the role of the RN became in order to "fill the gap".[32(p27)]

Later studies report similar findings. Using a collective case study design, Crossland investigated the perceptions of the roles of health professionals in four rural and remote north Queensland communities.[24] The findings suggest that RNs in single nurse posts undertake much broader roles than RNs in communities with additional health professionals on the ground.[24] Similarly, in a study of the roles of nurse executives across Queensland, Courtney et al. reported Directors of Nursing roles became much broader and more clinically focused the further away from cities they worked.[28]

The needs of the community were also shown to impact on the roles of rural and remote RNs. Rural and remote RNs service a diverse range of communities, for example, "islands, tourist centres, mine(s), pastoral (and) fishing communities ... jails, refugee camps ... emergency retrieval services".[33(p8)] and Aboriginal and Torres Strait Islander communities.[23, 25, 27, 34]

Several authors indicated that the RN's role requires flexibility to be able to respond to community needs.[22, 25, 27, 34, 35] Greene and Burley,[35] for example, discussed how the practice of RNs in bush nursing centres in Victoria is shaped by an ageing population, increasing mental health needs, and the health needs of farmers and their families.

The social determinants of health and disease patterns in Aboriginal and Torres Strait Islander communities further influence the roles required of rural and remote RNs.[22, 25, 27, 34] RNs in these communities are required to undertake a range of health promotion and prevention activities and management of chronic diseases.[22, 25, 27, 34] Taylor et al. for example argued that significantly high rates of diabetes in people living on the outer islands of the Torres Straits presented an enormous challenge for the RNs working in that area.[34] Similarly, Al-Motlaq et al. explored how remote or isolated RNs addressed the burden of chronic disease.[22] Using a multiple case study approach, the authors reported that RNs from a non-Indigenous community prioritised acute care and trauma services, whereas RNs from the Aboriginal communities saw diabetes management and teaching chronic disease self-management as a core focus of their work.[22] In the same vein, Josif et al. reported that the significant amount of malnutrition, anaemia and acute illnesses in children in two Northern Territory remote area Aboriginal communities required RNs to incorporate a child health focus to their role.[27]

DOCTOR SUBSTITUTE

A number of authors revealed that rural and remote RNs often acted as substitutes for general practitioners (GPs).[11, 23–25, 32, 33, 35, 36] The substitute GP role is reportedly undertaken in rural areas when the doctor is off site, and the RN becomes the first point of care for patient presentations.[11, 32, 33, 36] As the health facility becomes more remote it becomes usual practice for RNs to take on the GP substitute role in its entirety, while collaborating with GPs, nurse practitioners and other experts via distance communication strategies, or during periodic community visits.[22–25, 33, 35]

Cramer exemplified the medical role of remote area RNs in her research in a remote Western Australian Aboriginal community.[25] The community had a population of 515 people, with a health centre staffed by three RNs, and a doctor off site. Cramer observed 19 RNs while living in the community for 12 months.[25] She concluded it was normal practice for RNs to undertake medical histories and physical examinations, order pathology tests, and make medical diagnoses. There was also an expectation from doctors and management that the RNs would perform these roles.[25]

Crossland reported similar findings in her study of rural and remote communities in North Queensland.[24] In one community, with a population of 200 people, the primary healthcare clinic had no doctor on site and was staffed by a RN with the RIPRN qualification. Crossland found that the community perceived the service provided by RNs with the RIPRN qualification as being no different to a GP service, with many patients not concerned about the lack of a GP on site.[24] Of note, Crossland only included one RIPRN qualified RN in her research and did not differentiate between the roles of a RN without this qualification in a similar context, or to that of a nurse practitioner.[24]

Birks et al. reported that RNs with the RIPRN qualification were more likely to take on a GP role than other RNs, because of the added authority to initiate medicines.[23] Other studies reported that community members generally accept RNs providing primary care and have an expectation that RNs will assume a GP role when doctors are not available.[11, 33, 35]

Some authors noted that RNs working in rural and remote areas are also sometimes required to assume allied health roles, such as taking x-rays, pharmacy dispensing, and being the ambulance first responder.[11, 24, 25, 32, 33, 37]

MULTI-SKILLED AND ADVANCED PRACTICE

The majority of authors agree that rural and remote RNs are required to be multi-skilled, and often practice at an advanced level.[11, 24–26, 32, 33, 35, 36] Rural RNs may adopt a generalist or specialist role, depending on the setting,[33] with Hegney suggesting a typical day for a generalist rural RN could include working across an array of areas, such as paediatrics, medical and surgical, midwifery, aged care, operating theatre, and emergency.[11]

Remote area RNs conversely have much broader roles.[33] The National Rural Health Alliance (NRHA) argue that it is essential for all remote area RNs to practice at an advanced level in a generalist role.[33] Remote area RNs are required to deliver care across the lifespan, including "maternal, infant and child health, adolescent health, mental health, women's and men's health, aged care, palliative care, emergency care, retrieval and transfer, and public health … including … communicable diseases and chronic illness management".[33(p9)]

All authors identified multiple clinical roles undertaken by rural and remote RNs. These roles are summarised in Table 2.

In addition to clinical roles, an array of non-clinical roles are often undertaken by rural and remote RNs, for example, domestic/general cleaning,[25, 26, 33] food preparation, repairs, general maintenance, security checking,[26] maintaining records and files,[25] reception and administrative work,[24, 35] vehicle maintenance, and animal health.[33]

FEELING UNPREPARED

The final theme identified, was that rural and remote RNs often report feeling unprepared for their extended roles, yet they still perform the roles in order to meet community needs.[11, 22, 25–27, 32, 33] The authors of two papers have suggested that the quality of care in the remote Aboriginal communities they studied is often dependant on the experience and expertise of the RNs who were commonly employed straight from acute hospital settings.[25,27] Both authors expressed significant concerns about the quality of care provided to Aboriginal people by RNs who lacked context specific expertise.[25, 27] For example, Josif et al. purposively interviewed four RNs, who were providing child health services to two remote Aboriginal communities in the Northern Territory.[27] The RNs generally reported feeling unprepared for this role, however voiced concerns that it was an employer expectation to perform these roles regardless.[27] One RN said, "you're expected to do the job without the background, without the knowledge",[27(p7)] and "we're all trained in accident and emergency or … coronary care or intensive care but it is primary healthcare here so we really do need more training".[27(p6)] It is noteworthy that one third of presentations to the health services were for child health or non-acute service provision.[27]

Similarly, Cramer found that new RNs felt 'thrown in' to the remote Western Australian community of her study.[25] RNs reportedly were expected to use a practice manual to guide practice, albeit unprepared, as the manual assumed competence in medical diagnosis, which the nurses lacked.[25] Table 3 maps the themes to each paper.

TABLE 2: SUMMARY OF CLINICAL SKILLS AND ROLES

Clinical skills/roles	Rural	Remote	Source
Sexually transmitted infections diagnosis and treatment		✓	Al-Motlaq et al., 2010; Cramer, 1998
Women's health/family planning	✓	✓	Cramer, 1998; Greene and Burley, 2006; Hegney, 1997; NRHA, 2005
Men's health		✓	NRHA, 2005
Renal disease management		✓	Cramer, 1998
Diabetes		✓	Taylor et al., 2013
Initiating medicines	✓	✓	Birks et al., 2010; Cramer, 1998; Crossland, 2011; NRHA, 2005; Timmings, 2006
Emergency care	✓	✓	Al-Motlaq et al., 2010; Birks et al., 2010 ; Cramer, 1998; Crossland, 2011; Hegney et al., 1999; Josif et al., 2017; NRHA, 2005
Midwifery/antenatal care	✓	✓	(Cramer, 1998; Hegney, 1996; NRHA, 2005)
Paediatrics/child health	✓	✓	Cramer, 1998; Josif et al., 2017; NRHA, 2005
General medical, surgical, perioperative	✓		Hegney, 1996
Acute care	✓	✓	Al-Motlaq et al., 2010; Birks et al., 2010; Cramer, 1998; Crossland, 2011; Greene and Burley, 2006; Hegney, 1996; Josif et al., 2017; Timmings, 2006
Chronic disease		✓	Al-Motlaq et al., 2010; Birks et al., 2010; NRHA, 2005
Mental health		✓	Al-Motlaq et al., 2010; Greene and Burley, 2006; NRHA, 2005
Dental problems		✓	Al-Motlaq et al., 2010
Infections (e.g. skin, gastroenteritis, ears, nose throat)		✓	Al-Motlaq et al., 2010
Trauma/pre-hospital trauma		✓	Crossland, 2011
Abuse disorders		✓	Cramer, 1998
Ambulance/first responder		✓	Crossland, 2011
Immunisation		✓	Cramer, 1998; Greene and Burley, 2006; Josif et al., 2017
Health promotion		✓	Al-Motlaq et al., 2010; Birks et al., 2010; Crossland, 2011; Greene and Burley, 2006; Josif et al., 2017; Taylor et al., 2013
Palliative care		✓	Greene and Burley, 2006; NRHA, 2005
Aged care	✓		Hegney, 1996; NRHA, 2005
Order pathology tests		✓	Cramer, 1998
Medical diagnosis	✓	✓	Birks et al., 2010; Cramer, 1998; Crossland, 2011; Greene and Burley, 2006; Hegney, 1996, 1997; NRHA, 2005; Timmings, 2006
Aboriginal and Torres Strait Islander health related conditions		✓	Al-Motlaq et al., 2010; Birks et al., 2010; Cramer, 1998; Josif et al., 2017; NRHA, 2005; Taylor et al., 2013
Suturing	✓	✓	Cramer, 1998; Crossland, 2011; Hegney, 1997; Timmings, 2006
Plastering		✓	Crossland, 2011
Intraosseous insertion		✓	Cramer, 1998
Storage, dispensing medicines	✓	✓	Birks et al., 2010; Cramer, 1998; Hegney, 1997
X-rays	✓	✓	Crossland, 2011; Hegney, 1996; Smith and Jones, 2007

TABLE 3: THEMES MAPPED TO PUBLICATION

Theme	Articles
Roles shaped by context	
Subtheme 1 - Size of health service	Courtney, Yacopetti, James, Walsh and Finlayson, 2002; Cramer, 1998; Crossland, 2011; Hegney, 1996, 1997; Hegney, McCarthy and Pearson, 1999
Subtheme 2 – Needs of the community	Al-Motlaq, Mills, Birks and Francis, 2010; Cramer, 1998; Greene and Burley, 2006; Josif, Kruske, Kildea and Barclay, 2017; NRHA, 2005; Taylor, Usher and McDermott, 2013
Doctor substitute	Birks et al., 2010; Cramer, 1998; Crossland, 2011; Hegney, 1996, 1997; NRHA, 2005; Timmings, 2006
Multi-skilled and advanced practice	Al-Motlaq et al., 2010; Birks et al., 2010; Cramer, 1998; Crossland, 2011; Greene and Burley, 2006; Hegney, 1996, 1997; Josif et al., 2017; Smith and Jones, 2007; Timmings, 2006
Feeling unprepared	Al-Motlaq et al., 2010; Cramer, 1998; Greene and Burley, 2006; Hegney, 1996, 1997; Hegney et al., 1999; Josif et al., 2017

There is consensus amongst many authors that if rural and remote RNs are to continue to practice in an extended role, then they need structured, affordable and accessible education to build their skill level appropriate to the community and health service needs.[11, 22, 32, 33, 35]

DISCUSSION

This literature review aimed to investigate the multifaceted role of the RNs working in rural and remote areas of Australia. From a chronological perspective, the findings of the more recent papers were not dissimilar to those of the older papers reviewed, suggesting that the role of the rural and remote RN has not changed significantly in the past 20 years.

The findings of this review indicate that the most significant influence on the roles of rural and remote RNs lies within the context in which they practice, including the size of the health service and the needs of the community. This is similar to reports by Lenthall and Smith,[38] and Whitehead et al.,[39] who identified a number of factors that characterise healthcare in rural and remote practice, including the relationship with the community, workforce supply, available resources and the need to work as part of an interdisciplinary team.

The distribution of health professionals across Australia is geographically disproportionate, particularly in respect of doctors.[40] As has been found in this review, Lenthall and Smith also reiterate that RNs are consequently required to undertake activities that would normally be the domain of doctors in less isolated contexts.[38] In a scoping review, Burrows, Calleja and Cook similarly report that rural nurses felt they needed more recognition of these extended roles, particularly as they are often working alone with a high degree of autonomy with minimal resources.[41]

In addition to stepping up to "fill the gap" by assuming the roles of other healthcare professionals,[32(p23)] Lenthall and Smith also report RNs in rural and remote areas may be required to demonstrate an extended knowledge and skills base from within their own discipline to enable them to meet the healthcare needs of their diverse populations.[38]

This review has reinforced the concept of the advanced generalist role in rural and remote areas. Lenthall and Smith,[38] in discussing the unique context of non-metropolitan healthcare, also identify the need for a breadth of understanding of diverse content areas. These content areas include discipline specific knowledge, such as those identified in this review (Table 2) as well as context specific skills in areas such as tele-health, cross-cultural communication and Indigenous health.[38] As is evidenced by this work, the requirement to possess such a broad, adaptable skill set, often in the context of isolated practice, can leave RNs feeling unprepared for this role, or lacking in expertise needed to address the community's health priorities.

A key strategy in ensuring that RNs working in rural and remote areas are adequately prepared for their role is the development of educational programs that are tailored to address the complexity of nursing in this unique context. Educational pathways need to consider the diversity of these roles and acknowledge that acting in the stead of a medical practitioner is often a normal part of the RNs practice. The RN's existing experience and expertise should be considered, along with the impact of the high turnover of RNs in these areas.[5] Whitehead et al. highlight that unnecessary barriers to practice such as mandating credentialling of rural and remote nurses should be avoided, however agree that accessibility to education for rural and remote nursing needs to increase.[39]

An example of a suggested model for addressing education considerations is presented in Figure 2. This model addresses the distinction, albeit sometimes blurred, between rural and remote nursing as suggested in the papers reviewed. These distinctions impact on the education needs of RNs working in each location. As established in this review, a 'one size fits all' approach would not be appropriate, but rather education pathways should be flexible and be offered along a continuum. Approaches such as micro-credentialling or programs with multiple entry and exit points that meet an individual's educational needs are more likely to ensure timely preparedness for practice in a given context. Flexibility such as this may be better suited to rural and remote RNs who generally stay in positions for shorter periods than metropolitan RNs.[5]

The scarcity of recent research around the roles of rural and remote RNs highlights the need for more work in this area. Future research could include an evaluation of existing models of practice in rural and remote areas. Other research should evaluate the skills required by rural and remote RNs who are often required to substitute for doctors. How these nurses currently prepare for and are supported in this role; the quality of care provided by RNs who undertake medical diagnoses; and how this contributes to meeting community needs warrants specific consideration.

LIMITATIONS

The lack of contemporary research that was located examining rural and remote RN roles could be a limitation to this review, with nine of the 14 papers reviewed published 10 years or more ago. This may indicate that little research has been completed on the roles of rural and remote RNs within the last decade. Another limitation of this review may be the exclusion of grey literature, for example policy or government documents and position descriptions,[12] which may have added valuable insight into the role of rural and remote RNs. The lack of consistency around what constitutes rural and remote regarding the RNs roles may also be a limitation to the findings.

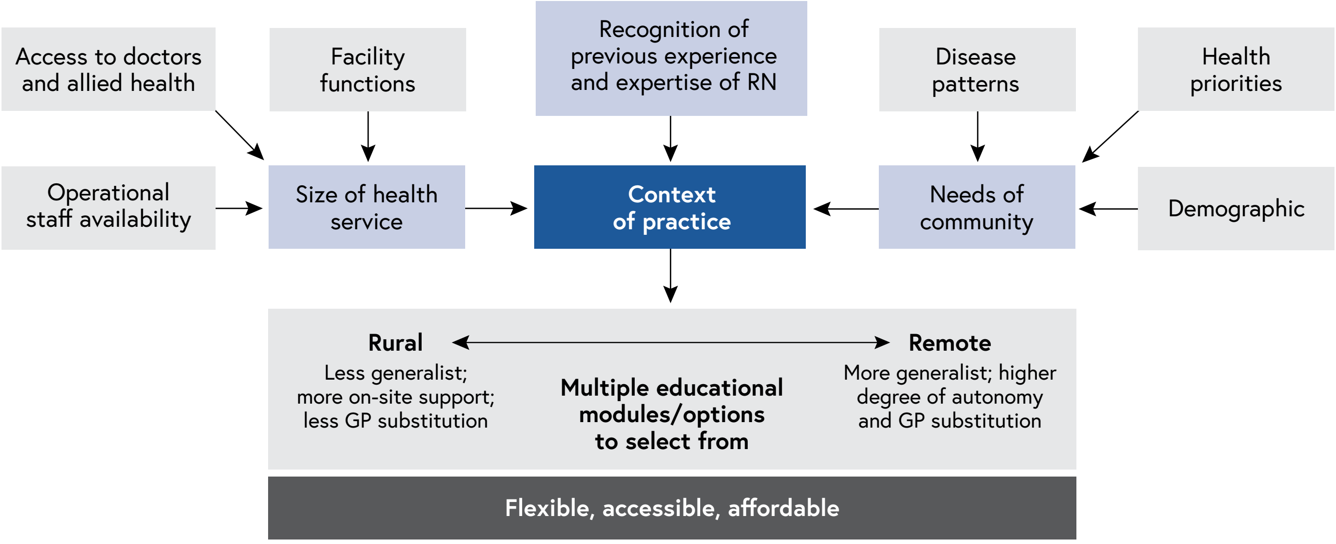

FIGURE 2: CONSIDERATIONS FOR EDUCATIONAL PLANNING

As with any review process, there are limitations to note in respect of this review. Of the literature found, there were no quantitative studies. While the qualitative studies located were assessed as being of good quality, the generation of themes from qualitative studies can be subjective, and be dependent on the authors insight[12]. Bias may have been introduced into the review process through a slight amendment of the inclusion criteria after the review had commenced, and the review process being led by a single author with a second author verifying the process and findings.

CONCLUSION

With the findings of this review in mind, strategic planning to improve rural and remote health access should acknowledge that rural and remote RNs are already practicing in extended and advanced generalist roles and have been for some time. Nursing and medical leaders need to appreciate that rural and remote RNs diagnose as a normal part of their role and need to be educationally prepared and supported accordingly. Development of models for rural and remote practice should prioritise the development of a supportive framework for existing and novice rural and remote RNs, which differentiates and defines their roles according to context, integrates appropriate clinical governance, and enables flexible educational pathways.

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Supplementary Material for:

Muirhead S, Birks M. Roles of Rural and Remote Registered Nurses in Australia: an Integrative Review. *Aust J Adv Nurs.* 37(1):21-33.

Page 2:	**Appendix A:** Example of search strategy for Scopus database
Page 3:	**Appendix B:** Appraisal of qualitative research papers using the Critical Appraisal Skills Programme (CASP) qualitative check list -
Page 4:	**Appendix C:** Appraisal of practice literature using AACODS (Authority, Accuracy, Coverage, Objectivity, Date, Significance) checklist

Appendix A: Example of search strategy for Scopus database

Limits: English language; full text; date range: 1995 to 2017

“Rural health services” “rural nursing” “rural health nursing” isolated
RN, nurs* registered nurs* “remote area nurse” RAN
Australian Capital Territory, ACT, New South Wales, NSW, Northern Territory, NT, Queensland, QLD, South Australia, SA, Tasmania, Tas, Victoria, Vic, Western Australia, WA, Australia*
Role* function, work, skill*

Appendix B: Appraisal of qualitative research papers using the Critical Appraisal Skills Programme (CASP) qualitative check list

	Q.1	Q.2	Q.3	Q.4	Q.5	Q.6	Q.7	Q.8	Q.9	Q.10
Al-Motlaq et al. (2010)	✓	✓	✓	unclear	✓	unclear	✓	✓	✓	✓
Birks et al. (2010)	✓	✓	✓	limited description	✓	unclear	✓	✓	✓	✓
Courtney et al. (2002)	✓	✓	✓	✓	✓	unclear	moderate description	✓	✓	✓
Cramer (1998)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Crossland (2011)	✓	✓	✓	limited justification	limited	unclear	✓	✓	✓	✓
Josif et al. (2017)	✓	✓	✓	✓	✓	✓	moderate description	✓	✓	✓
Hegney et al. (1999)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Smith and Jones (2007)	✓	✓	✓	✓	✓	unclear	✓	✓	✓	✓

CASP checklist questions

Screening questions

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aim of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?
10. How valuable is the research?

http://www.casp-uk.net/

Appendix C: Appraisal of practice literature using AACODS (Authority, Accuracy, Coverage, Objectivity, Date, Significance) checklist

	Authority	Accuracy	Coverage	Objectivity	Date	Significance
Greene and Burley (2006)	✓	✓	✓	✓	✓	✓
Hegney (1996)	✓	✓	✓	✓	✓	✓
Hegney (1997)	✓	✓	✓	✓	✓	✓
Taylor, Usher, and McDermott (2013)	✓	✓	✓	✓	✓	✓
Timmings (2006)	unclear	some inaccuracies	✓	✓	✓	✓
NRHA (2005)	✓	✓	✓	✓	✓	✓

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IN THIS ISSUE

EDITORIAL

RESEARCH ARTICLES

REVIEWS AND DISCUSSION PAPERS

The *Australian Journal of Advanced Nursing* is the peer-reviewed scholarly journal of the Australian Nursing and Midwifery Federation (ANMF). The Mission of *AJAN* is to provide a forum to showcase and promote a wide variety of original research and scholarly work to inform and empower nurses, midwives, and other healthcare professionals to improve the health and wellbeing of all communities and to be prepared for the future.

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EDITORIAL

COVID-19 – nurses and midwives impact on global security

In the year of the nurse and midwife, a global pandemic is not what we signed up for. Nor were we to predict how the world would be turned upside down with grief and devastation across the globe coupled with lethal economic impact. At the commencement of 2020 the World Health Organization (WHO) designated this year as the Year of the Nurse and Midwife in recognition of the contribution nurses and midwives make to peoples lives everyday. Nurses and midwives are the very fabric of healthcare and now we have learnt in real-time that health is an essential component to global security and economic stability. The value that nurses and midwives bring is health security; without them we would see fragile systems dangerously vulnerable to collapse, in the shadow of this global crisis. Now there is extraordinary recognition, but in ways we would have never predicted.

The widespread havoc, catastrophe, and insecurity has left the world scrambling for essential supplies, workforce, equipment, health resources, medical breakthroughs, and economic solutions. Whilst the pandemic is set to near wipe out the world's economy, many low-resourced countries are still fighting major outbreaks of other infectious diseases such as Ebola, and controllable infectious diseases like measles are making a vicious return. Cholera, a disease of the Middle Ages, continues to strike and bring devastation to millions across low resourced countries. What have we learnt? It is distressing to know that these diseases exist when we know how to prevent them and the importance of public health systems in maintaining our global health security. Whilst Australia is in the grip of the SARS-CoV-2 (COVID-19) crisis, there is no doubt it should be taken seriously, our best defense at present is strong public health messaging regarding behaviour change, coupled with a resilient and well-resourced health workforce. Across every facet of the health crisis are committed nurses and midwives who are mission critical to communities' health outcomes.

What's past is prologue; it's fair to say that the impact of COVID-19 was not something the health system had prepared for. The impact the pandemic has had and will continue to have on our health system and every day lives will change the future and our way of living for years to come. While the world battles the pandemic on all fronts, mental health is currently the great sleeper issue. The blast zone of this pandemic will be its psychosocial impact. When we do emerge from isolation, businesses start again and life begins to resemble something like normal – whenever that may be – other areas may take much longer. The warning that more people will suffer from anxiety, fear, and post-traumatic stress will take a significant toll on the community for years to come. Preparedness is focused on the here and now, and perhaps even the next six months, but we must also be planning now for two, five and ten years time as the impact will be wide ranging and hidden if we do not seek it out. One in five Australians already battle a mental illness and there is no doubt this number will increase. Connectedness and support is a critical consideration for the future. Preparing the health workforce to support the community and for the community to support the health workforce as the days ahead will be long and hard is the challenge we now need to equip ourselves for, and translate innovative opportunities for long-lasting benefit.

However, I would argue there are some positives emerging. The relentless impact of COVID-19 has resulted in the speed we have witnessed change, for example the evolution of the adoption of technology, government policy, and legislation, which in the past may linger for months or years. It has been refreshing to not be bombarded by media-fueled populist politics and stalemates in policy decision-making driven by bureaucracy. The bickering over the cost of public healthcare and job losses. The vacuum created by our relatively safe and prosperous world has disappeared. The opportunity to enact creative thinking by necessity has resulted in a new way of working, rapid access to health equipment, increased production to meet demand in certain areas and in amongst all of this has been a spotlight on the incredible work nurses and midwives do every day. On the front line there is no doubt that nurses, midwives, medical, allied health and other hospital staff have a massive challenge ahead of them and it is an investment we all need to support.

It has been said we face an enemy without a flag or a face. In response, public trust and societal stability has been tested. This was demonstrated by panic buying, disappearance of medical supplies, and for many a feeling and sense of deep loss, sadness, loneliness, isolation fatigue, fear, and the unknown. We know the pandemic will resolve, but it is the ability to cope, in the here and now and the wake of destruction that is unknown. It is happening and we need to work out how to proceed. Deep in this uncertainty are nurses and midwives working to ensure care is delivered to those who need it every day, now deployed to COVID-19 clinics and managing infectious clinics, tending to those diagnosed with COVID-19. Challenged by having to wear protective clothing all shift and then to walk out from the shift, returning to their family, knowing they must go back tomorrow, all the while wondering if (or when) they will contract the illness. Some

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have now chosen to distance themselves from their family, and their friends are, understandably, not taking the risk to see them. Such behaviours are indicative of a challenge bigger than any of us as individuals, so as a society we must respond.

So how do we weather the storm and where do we find the silver lining, together, in this twin crisis? A global health pandemic, and an economic crisis the likes the world has not seen since the Great Depression. These uncertain times provide opportunities to re-evaluate operations and lower former obstacles such as utilisation of innovative technology resulting in the optimisation of telehealth and mobile technology, expedite access to data, utilisation of registries, cloud-based platforms, the value of clinical research networks, artificial intelligence for health initiatives, health algorithms changing how we work and where we work enabling reach to where it is needed. The awareness and crucial role nurses and midwives are having on our health system is paramount. The results behavioural change at a population level can achieve to 'flatten the curve' when we stand together is immense. Noting that distancing is having one of the greatest impacts, rapid change sees growth and opportunity such as the importance to pull together as a nation.

April 7, 2020 was World Health Day and deliberately coincided with the release of the first publication of the WHO The State of the World's Nursing Report to mark The Year of the Nurse and Midwife. This report provides us with a detailed snapshot of the nursing workforce globally. The focus is to build our future workforce, continue to foster leadership, quality care and drive policy. Leadership that is greater than a role and title but is responsive, engaged, drives innovation, and has the will to act.

It is not by coincidence the WHO theme for 2020, *Nurses: A Voice to Lead – Nursing the World to Health* was decided, with many stories of true altruism, heroic leadership, delivering quality care to those at greatest need across the world, in a world where there is fear and uncertainty, Nurses and midwives continue to provide hope and quality care. Whilst there has not been the fanfare and celebrations that nurses and midwives may have hoped for in the Year of the Nurse and Midwife, what has emerged in the wake of this COVID-19 crisis is the worldwide awareness of the critical role nurses and midwives play to global security – a message that no coordinated media campaign could have achieved.

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RESEARCH ARTICLES

The organisational socialisation of new graduate nurses and midwives within three months of their entrance into the health workforce

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ABSTRACT

Objective: To investigate if the current onboarding process influences the organisational socialisation of new graduate nurses and midwives into the workforce.

Background: Positive organisational socialisation experience for new graduate nurses and midwives during their entry into the healthcare environment is an important contributor when building an organisation's ability to increase workforce capacity. However, few studies have investigated the onboarding processes to promote their organisational socialisation.

Study design and methods: A quantitative, descriptive, cross-sectional study design was conducted at a large Local Health District that provides health services to almost one million people in metropolitan, rural and remote locations. Participants were 170 new graduate nurses and midwives who commenced their transition program at 21 acute and community healthcare settings within the District in January and February 2017. Data was collected through a document review of current onboarding processes and by an online survey of new graduates. Data sets were analysed using descriptive statistics and content analysis.

Results: The survey response rate was 47% (n= 80). Findings highlight that the onboarding process provided by the District was useful for the new graduate's transition into the workplace. The findings also indicated that the onboarding process was inconsistent across different contexts in the District and required more relevant and practical components. In addition, the current onboarding did not adequately provide strategies to build relationships for new graduates within their work environments.

Discussion: This study provides valuable insight into current onboarding practices in both metropolitan and rural contexts and highlights gaps in this process across the health District. The findings of the study provide insights and future direction for improvements by addressing the inconsistency in the structure and content of orientation programs. The need for more accessible and consistent organisational information and a more structured

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framework for the organisational wide onboarding process was also identified.

Conclusion: Re-design of an onboarding process that is relevant, consistent and enhances relationship-building is imperative to meeting both the professional and organisational needs of new graduate nurses and midwives.

Implications for research, policy and practice: The findings of the study imply a need to streamline the onboarding process to provide greater opportunity for new graduates to develop and sustain professional networks and associated workplace relationships regardless of their locations. They also signal a need to develop policies practice and future research to assist a better organisational socialisation, in particular, the allocation of resources, better utilisation of time spent on education and workplace support in the transition into their clinical workplaces.

What is already known about the topic?
- Supporting new graduate nurses and midwives in their first year is important for their transition into the workforce and to increase their retention in the profession.
- Onboarding processes for new graduates during their transition into the workplace enhances their professional knowledge and confidence, which increases their capacity to provide safe quality healthcare.
- Few studies have investigated the relationship between the onboarding process and the promotion of organisational socialisation within the first three months of entering the health workforce.

What this paper adds:
- Findings identify the need to improve the onboarding process to better meet the complex needs of the new graduates.
- Implementation of a tailored onboarding process, especially in rural and specialty areas improves organisational socialisation.

Key words: Onboarding; orientation; personal support; transitioning to practice

INTRODUCTION

Organisational socialisation is critical for new employees as it is a learning and adjustment process that enables an individual to assume an organisational role that fits both organisational and individual needs.[1] Further, organisational socialisation is emphasised in the literature as crucial and necessary to assist new employees with the capability to transit into the workforce.[2,3] This is because organisational socialisation provides opportunity to gain organisational knowledge and increases the new employees understanding of organisational expectations, and its culture in their particular profession.[2,4] Hence, organisational socialisation assists new employees to assimilate into their new work community with reduced uncertainty because of access to organisational information such as policies and procedures and introduction to ways of working and building relationships.[2] Organisational socialisation also assists new employees to develop relationships with others, while learning the social norms and how the organisation operates.[3–5]

Organisational socialisation is a dynamic and complex concept and an important step is 'onboarding'.[1,2] Onboarding is defined as the process of helping new employees adjust to social and performance aspects of their new jobs.[2] Health organisations provide an onboarding for new graduate nurses and midwives (NG) aimed at facilitating their organisational socialisation in the initial period of employment. A positive organisational socialisation experience for NGs during their transition and entry into the healthcare environment is an important contributor to building an organisation's ability to retain staff and increase workforce capacity.[4]

The onboarding process is recognised as an important priority for policy makers, administrators and educators working within healthcare environments,[4,6] a number of aspects to the onboarding process for NGs are identified in the literature. These include structured or non-structured orientation programs, preceptorship/mentorship programs, supernumerary time, and professional education opportunities.[7–9] Orientation programs have been used as an onboarding strategy to assist NGs to gain organisational knowledge and skills so they can assimilate and perform in the workplace.[2,10] Support through preceptorship and/or mentorship, including supernumerary time, and providing education and training is also recognised as essential during the transition of NGs into clinical practice.[11–13]

It has been identified that some NGs feel inadequately prepared through their university studies to work in healthcare work environments.[13,14] In fact, the transition of NGs into healthcare work environments is described frequently as stressful.[15] Some authors described expectations that NGs need to 'hit the ground running'.[16] If NGs are not provided with clear direction and mentorship in the first few months of practice they are known to develop role ambiguity, characterised by coping poorly, anxiety and a lack of confidence.[3,4] Similarly, an Australian mixed method

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cross-sectional study exploring the experiences of NGs in their first year of employment indicated there was a lack of evaluation of onboarding processes for NGs in health services in New South Wales (NSW), one of the largest states in Australia.[17] In particular, there is a lack of information on the NGs perspectives about their experiences in both rural and metropolitan health service settings.[17] Addressing the NGs' needs through a substantial and relevant onboarding process may be beneficial in improving their performance, job satisfaction and long term retention.[18,19] This aspect of organisational socialisation may be pivotal for the retention of the Australian nursing and midwifery workforce, experiencing long term workforce shortages.[20]

The District involved in this study has experienced an increase in NG recruitment of 33% across a ten year period (171 NGs in 2008 to 228 NGs in 2018),[21] paralleling with increasing intakes of nursing students in surrounding universities. Therefore, it is timely for the District to explore the effectiveness of its onboarding processes in meeting the socialisation needs of those NGs. This aligns with the NSW State Health Plan that emphasises support and development of NGs into their clinical roles.[22] As the initial onboarding experience is known to improve job performance and job satisfaction and reduce unwanted turnover,[2] it is therefore important that organisations optimise their onboarding processes. The study presented in this paper aims to provide a deeper understanding of the onboarding process of NGs, its impact on them, and to identify key priority areas in the onboarding process for healthcare organisations employing NGs.

STUDY DESIGN AND METHODS

DESIGN

This study used a quantitative, descriptive, cross-sectional study design.

SETTING

The setting was a large health district (the District) in New South Wales, Australia, providing health services to almost one million people in metropolitan, rural and remote locations. The District consists of three tertiary referral hospitals, four rural referral hospitals, 22 district and community hospitals, 70 multipurpose services and community health services, three mental health facilities and one residential aged care facility spread across 25 local government areas (geographically about 133,000 square kilometres in size).

PARTICIPANTS

One hundred and seventy NGs who commenced their transition program in the health District in January and February 2017 across 21 acute and community healthcare settings.

DATA COLLECTION

Phase one: A review of current onboarding processes was undertaken through examination of current programs and related documents, specifically reviewing orientation programs and induction, supernumerary days, personal support offered, and NGs information sources.

Phase two: An online survey containing 41 items was circulated via work email to the 170 NGs at four to six weeks after commencement of employment. The survey was opened for six weeks with a reminder sent half way through at three weeks.

DEVELOPMENT OF SURVEY

The survey was developed based on key constructs identified in an extensive literature review and modifications made from a previously validated survey used by Parker et al.[17] by adding questions specifically related to the onboarding process. The survey collected information on NG demographics, prior nursing/midwifery work experience, program structure and content relevance along with locations and NG satisfaction with the onboarding process. The survey also included a total of 19 items that explored future education topics; four items about organisational information, seven items about ways of working and eight items related to coping skills. Content validity was ensured through consultation with seven nursing and midwifery leaders, including clinical educators and NG coordinators who reviewed the survey and provided feedback.[23]

Survey questions were structured as either multiple choice questions or as a Likert scale where respondents were asked to choose an option from 1 (strongly disagree) to 5 (strongly agree). The respondents were provided with free text fields on some questions so that they could make additional comments.

DATA ANALYSIS

Quantitative data were analysed using descriptive statistics and frequency distribution and additional free text comments were analysed using content analysis as described.[24] All text was analysed by taking the following steps: read and re-read the texts, condense into meaningful units, formulate codes, develop codes into categories and create themes.

ETHICAL STATEMENT

Approval to conduct this study was granted by the District Ethics Committee (HNEHREC Reference No: 16/12/14/5.14). Completion of the online survey implied consent. NGs were informed that participation was voluntary and all information obtained during the course of the study was de-identified to ensure anonymity.

RESULTS

PHASE ONE: REVIEW OF THE CURRENT ONBOARDING PROCESS WITHIN THE DISTRICT

New graduates were expected to participate in the following four orientation components in a face-to-face mode across the District: 1) Corporate orientation: a two-day program which included organisation information (eg. clinical governance, ethics, staff health and security) and mandatory education (manual handling, infection control, fire safety, roles and expectation of nurses/midwives); 2) NG specific orientation, where the information provided focused on the perceived needs of new graduate nurses and midwives; 3) Ward induction, focused on specific ward information; 4) Supernumerary days, allowing the NG to not have a patient load. Wide-ranging variations were identified in these four orientation components. Further review identified that the length and content of each component of the program varied depending on location, facility resources and the needs of speciality areas. An acute care hospital in a metropolitan environment allocated a minimum of three days for orientation, whereas an acute care setting in a rural area provided a total of five days orientation. In addition, new graduates in rural or remote areas and speciality areas such as mental health or critical care were more likely to participate in a longer orientation period, as much as two weeks. Depending on the facilities, the length of orientation and education topics were varied. For example, medication safety was included in all orientation programs, but the length of the sessions ranged from 30 minutes in one facility to 120 minutes in another facility, and a medication safety competency assessment was only included in two facilities. In addition, NGs from all facilities were provided with a site-specific NG Handbook that guided them in their first year of clinical practice. The content and extent of this information varied, with much duplication of information in the handbooks. The District, in collaboration with NSW Health, was working towards providing greater capacity for staff to undertake online courses including specific modules for NGs, however there was limited uptake of online courses included in the onboarding process, with a greater reliance on nursing/midwifery educators.

PHASE TWO: SURVEY RESULTS

The survey yielded a 47% response rate (n=80). The characteristics of respondents were similar with the cohort of NGs who commenced their work, except there was less representation of male respondents in the survey (see Table 1). The majority of respondents (66%, n=53) were aged 20-29 years and 75% (n=60) reported having had prior nursing and/or midwifery experiences before recruitment to the NG program. The respondents were almost equally located between metropolitan facilities and rural/remote facilities, and 34% (n=27) needed to relocate to take up their employment. Overall, all except one (98.8%) of the respondents stated they were happy to commence their work at the District.

ORIENTATION, WARD INDUCTION AND SUPERNUMERARY TIME

All NGs attended either Corporate Orientation or New Graduate Orientation with orientation periods varying from one day to two weeks. Over 30% of respondents (n=25) identified that they did not participate in a ward induction, but the rest attended one to two days ward induction. All except six NGs had supernumerary days, which varied from one day up to two weeks.

Further, 82% (n=66) of respondents agreed that 'the orientation program was beneficial to a new employee' in their transition period. The following comments reflect the NGs satisfaction with the orientation program:

TABLE 1: CHARACTERISTICS OF RESPONDENTS

		All NGs (N=170)	Respondents (N=80)
Age	20–29 years old	73% (125)	66% (53)
	30–39 years old	18% (30)	24% (19)
	40–49 years old	6% (10)	8% (6)
	≥50 years old	3% (5)	2% (2)
Gender	Male	12% (20)	2% (2)
	Female	88% (150)	98% (78)
Location	Metropolitan	65% (111)	54% (43)
	Rural	35% (59)	46% (37)
Prior nursing and/or midwifery experience †	Yes	70% (119)	75% (40)
	No	30% (51)	25% (20)
The duration of your experience	≤ 12 months	30% (35)	31% (19)
	>12 months	70% (135)	69% (41)

† Some respondents had worked more than one job.

> *'It was great. I felt very supported and welcomed. Coming from out of area it was a great introduction to the XX Hospital and made an enormous difference in my transition into the workplace. I would definitely continue it for future New Grads.'* (Metropolitan area)

> *'It has been great so far and I really have enjoyed my overall time here at XX Hospital.'* (Rural area)

Respondents (n=53) also made comments suggesting areas for improvement in the orientation process such as need for relevance, practicality and redesign of supernumerary days. Ten comments related to the relevance of the content in meeting NGs particular workplace needs. They pointed out that some information was redundant, for example, topics that had previously been covered by their university study or NGs previously employed in a different capacity at the District were required to re-attend the orientation program. Two respondents highlighted the need for more localisation of content of the orientation program.

> '(The orientation program) *feels like a one-size fits all process.'* (Rural area)

> *'I went to XX Hospital for my orientation and I am working a Y Hospital, and the orientation at XX Hospital was very site specific and not relevant to me.'* (Rural area)

Eleven comments were about the need for orientation topics to be more practical to assist with familiarising NGs to the clinical practice environment.

> *'Introduction to all the programs that nurses use on the wards, what they are for, and how they are used would be helpful. They are hard to navigate and use when in the first few weeks of the first rotation.'* (Metropolitan area)

> *'Include education on expectations of documentation e.g. falls risk, Waterlow score, and explanation of CPD points, how it works, how to document points etc.'* (Rural area)

Some respondents asked for demonstrations of certain procedures to enhance their skill in areas that are relevant and important to the organisation, such as the use of computer system procedures for leave requests, and how to manage rosters and source policies. Another element highlighted for improvement in the orientation program was the lack of information available about Aboriginal health and staff health and lack of guidance or support in developing the competency levels they needed to achieve.

A further eight comments related to supernumerary days, and indicated a lack of clarity about the role and responsibilities of preceptors and NGs, and a lack of transparency about the goals of supernumerary days.

> *'I was allocated three booking in visits on my first day without a proper supernumerary day. I found this scenario to be extremely challenging.'* (Metropolitan area)

> *'We need to have more appropriate supernumerary buddies. Educate nurses on being supernumerary buddies so they know what to do and how to support new grads. My buddy gave me two of her patients without an introduction to the ward and sat at the desk for most of the day. She also only worked one day a week on that ward. Not an appropriate buddy.'* (Rural area)

PERSONAL SUPPORT

Respondents were asked to rate the types of personal support they were being offered during the first month of their employment. The majority indicated that all types of personal support were beneficial (Table 2). In particular, 94% of respondents agreed that the benefit of support from a clinical mentor/preceptor or clinical educators in the initial part of their working life as new nurses or midwives was most beneficial. Some respondents were not sure how beneficial regular meetings with managers and clinical supervisors were, but they felt there was a need for them.

Twenty percent of respondents (n=16) made comments about the importance of personal support and the lack of access and consistency of access to personal support.

> *'Having XX as an educator has been my survival line. XX really helps the transition and also to be there to help explain things on the ward and help us'* (Rural area)

> *'Having a mentor on the ward has been amazing to bounce questions off and know that they are okay with that rather than burdened by it. Regularly seeing the educators has also been so good to chat about different situations and get a helping hand. …*(with) *a skill I was not confident with on my own but now feel confident following supervision and guidance from the educators.'* (Metropolitan area)

> *'Different wards provided differing levels of support. I found to have a lot of support in Medical 1 was brilliant and so helpful and I found to have very minimal support in Surgical 2 which was really hard and not fair as it has a heavy workload and is a difficult ward to work in as a new grad RN.'* (Rural area)

TABLE 2: TYPE OF PERSONAL SUPPORT YOU FEEL WOULD BE BENEFICIAL TO YOU DURING THE TRANSITION PROGRAM

	(Strongly) Disagree	Neutral/Don't know	(Strongly) Agree
Clinical Mentor/Preceptor	1.25% (1)	4 5% (4)	93.75% (75)
Regular meeting with Nursing/Midwifery Unit Manager	10% (8)	17.5% (14)	72.5% (58)
Regular meeting with Clinical Educator	0% (0)	6.25% (5)	93.75% (75)
Clinical Supervision	3.75% (3)	21.25% (17)	75% (60)

FUTURE EDUCATION NEEDS

Respondents were provided with a list of topics grouped into three categories; organisational information (OI), ways of working (WOW) and coping skills (CS). The Phase one of the review of current onboarding processes identified these to be the topics of education days throughout the year, rather than during the initial onboarding period. They were asked to rate the importance of each topic to their future educational needs. Table 3 demonstrates that respondents rated all three categories highly. In addition, more than 95% of the respondents strongly agreed or agreed that some educational topics should be addressed at the beginning of their transition period, for example, knowing roles and responsibilities, patient assessment, prioritising and planning, time management and introductions to other new graduates.

DISCUSSION

This study provides valuable insight into current onboarding practices in both metropolitan and rural contexts and highlights gaps in this process in a District where 170 NGs commenced their professional practice together. Thirty percent of this cohort were mature aged NGs, following a trend identified by Kenny et al.[16] Study findings are similar to those in a study of NGs in NSW public sector,[17] with almost 70% of NGs having more than 12 months prior nursing and midwifery experience. These characteristics impact on a NGs socialisation into the organisation as their life and work experiences are factors that need to be taken into account when planning onboarding processes.[3]

The District's efforts to enhance socialisation were accepted well by the NGs, with almost all respondents identifying that they accessed a variety of onboarding processes such as corporate orientation, new graduate orientation sessions, and supernumerary days. They found that these onboarding processes were useful for their organisational socialisation in the beginning of their professional practice. However, more than 30% of respondents reported not having a ward specific induction. The District where this study was conducted uses the ward induction as an opportunity for NGs to familiarise themselves with their immediate working environment and identify the people they work with. This could be a critical limitation of the onboarding process as relationship building is key in organisational socialisation of NGs and a challenge for NGs.[4]

TABLE 3: FUTURE EDUCATION TOPICS

		(Strongly) Disagree	Neutral/Don't know	(Strongly) Agree
OI	An overview of the organisation	3.75% (3)	13.75% (11)	82.5% (66)
	Your rights and responsibilities as a nurse/midwife	1.25% (1)	5% (4)	93.75% (75)
	Incident reporting	1.25% (1)	10% (8)	88.75% (71)
	Education management system	1.25% (1)	8.75% (7)	90% (72)
WOW	Patient assessment	1.25% (1)	2.5% (2)	95% (76)
	Documentation	2.5% (2)	11.25% (9)	86.25% (69)
	Cultural awareness	3.75% (3)	8.75% (7)	87.5% (70)
	Essential of care §	2.5% (2)	10% (8)	87.5% (70)
	Excellence*	5% (4)	10% (8)	82.5% (66)
	Work health and safety	3.75% (3)	13.75% (11)	82.5% (66)
	Infection control	5% (4)	12.5% (10)	82.5% (66)
CS	Prioritisation and planning	0% (0)	3.75% (3)	96.25% (77)
	Time management	2.5% (2)	2.5% (2)	95% (76)
	Stress management as a new employee	2.5% (2)	8.75% (7)	88.75% (71)
	Communication strategies	5% (4)	12.5% (10)	82.5% (66)
	Conflict resolution strategies	3.75% (3)	7.5% (6)	88.75% (71)
	How to deal with discrimination/racism/bullying	6.25% (5)	6.25% (5)	87.5% (70)
	Network building	2.5% (2)	12.5% (10)	85% (68)
	Introduced to other new starters	2.5% (2)	5% (4)	92.5% (74)

§ Essentials of care: a model of care.[25]

*Excellence includes Hourly patient rounding, Bedside clinical handover, Patient care board, and Follow up phone calls.[25]

Based on the findings of this study, the authors are calling for improvements in addressing the inconsistency in the structure and content of the orientation programs, and the quality of supernumerary time and levels of support across facilities and even at ward level. In addition, the respondents asked for more practical and relevant information to support them through their initial transition into the workforce. Suggestions covered more information about the organisation, ways of working and coping skills. Further, some respondents described parts of the onboarding process as repetitive and unnecessary. A number of respondents were required to complete six mandatory education modules, which they had previously completed as part of their clinical placements. Respondents who previously worked in the District as enrolled nurses or as assistants in nursing prior to being employed as NGs, felt they did not need to attend another corporate orientation. However, attending orientation again as a NG may be useful as the content of the program may differ from previous orientation programs, particularly if they were located in a different facility/ward as the localised content would differ. This point is particularly relevant for respondents in rural and remote locations, who at times felt geographically isolated. NG respondents employed in small rural locations needed to attend their orientation program in a larger facility, but found the content of this orientation not particularly relevant to their smaller facilities.

The importance of a clinical mentor/preceptor and supportive manager in the transition is well established in the organisational socialisation.[4,11,17,26] Personal support was seen as an important element of the onboarding process by NGs, who agreed that it helped them with learning coping skills such as relationship building and time/priority management skills in their initial six weeks of employment. However, at the same time, NG respondents reported that personal support, especially with availability and accessibility was not adequate at times. The provision of personal support assists the NGs' ability to learn workplace cultural norms, to build relationships with colleagues, and confidence,[13,27] and is therefore identified as one of the key aspects that requires improvement in the current onboarding process in this District.

The findings from this study highlight an onboarding process that needs to be more tailored to the individual's needs to make it more meaningful, relevant, and engaging. It calls for a District level open discussion about sustainable and practical onboarding strategies that better meet the needs of individual NGs. Similar to findings in the study by Parker et al.,[17] the need for better provision of consistent organisational information and a structured framework for an organisational onboarding process is required. An exploration of the feasibility of alternative models, such as a centralised internet based repository of relevant information for NGs that links to policy documents, organisational information and clinical practice may be a solution to address the lack of access to information. This could be especially useful for the District which now employs more than 220 NGs annually in geographically dispersed healthcare settings. A successful onboarding process to maximise organisational socialisation of NGs will enhance job satisfaction and retention, and potentially achieve the provision of quality healthcare by an adequately skilled nursing and midwifery health workforce.

LIMITATIONS OF THE STUDY

The study focused on an investigation of a small number of NGs' and reflected the onboarding experiences following a period of three months from commencement of employment in one District only. Results of this study may not be generalisable to other health areas, states and countries. Further investigations about how the onboarding process would impact socialisation across a longer term would be useful, and how it relates to the competence of NGs' to deliver evidence-based, safe patient care.

CONCLUSION

Onboarding processes for NGs are important to provide a smooth and meaningful transition experience into health organisations and clinical practice environments to ensure a more positive experience and increase employee engagement. This is critical, especially for health services which often experience high vacancy rates. This study has been instrumental in facilitating open discussion about the level and type of organisational support required for NGs. It has also been the driver for the exploration of sustainable strategies to meet NGs' needs. Re-designing the onboarding process to make it more relevant and consistent will enhance relationship-building and employee socialisation which are imperatives when trying to meet both the NGs professional needs and those of the organisation.

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RESEARCH ARTICLES

Registered nurses as role models for healthy lifestyles

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ABSTRACT

Objective: The aim of this paper is to report on registered nurses' adherence to current Australian health behaviour recommendations. Barriers and facilitators to healthy lifestyles, and their attitudes towards being role models and promoting healthy lifestyles to their patients.

Background: It is widely accepted that a healthy diet, limiting alcohol consumption, abstinence from smoking and regular physical exercise are important components of healthy lifestyles and play a significant role in preventing chronic diseases. Nurses are well situated to contribute to providing health and patient education regarding modifiable health risk factors, however their own adherence to health behaviours may impact this.

Study design and methods: The research is a mixed methods study of 123 registered nurses from both public and private organisations in regional Queensland. Data for this paper were generated from an online survey which is the first of two phases in the broader study.

Results: Four health risk factors were examined; diet, smoking, physical exercise and alcohol consumption. BMI was also calculated and considered as a fifth risk factor. Of this sample, 13% of participants met the guidelines for fruit and vegetable intake, 5.2% smoked, and only 24.2% exercised enough to be classed sufficiently active for their health. Of the 93.62% of participants whom consumed alcohol, 69.3% consumed more than two standard drinks/day. The most common barriers to adhering to healthy lifestyles were shift work, long working hours and family commitments.

Conclusion: Many nurses are not adhering to healthy lifestyle recommendations. It is recommended that the health and wellbeing of our health professionals, especially nurses be considered. Providing support and resources to enable them to care for themselves, may in turn allow them to better care for patients.

Implications for research, policy, and practice: Research is needed into strategies to enable registered nurses' better work/life balance. To make a real difference to health outcomes, nurses own health and health education needs to be made a priority that is supported and implemented at multiple points: by policymakers, within nursing practice, nursing curriculum, and in healthcare institutions. Nurses need to be supported to provide health education to their patients with better resources, education, and time allocation. Future research should include studies conducted in different regions or ideally a large nationally representative sample.

Key words: lifestyle risk factors, health behaviour, physical exercise, patient education

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What is already known about this topic?

- Healthy diet, limiting alcohol consumption, not smoking and regular physical exercise are important for healthy lifestyles.
- Nurses are seen as role models for patients and the community.

What this paper adds:

- Insight into nurse's adherence to health guidelines.
- Nurses beliefs of how their own behaviours impact their role model status and the health education they provide to people they care for.

OBJECTIVE

It is widely accepted that a healthy diet, limiting alcohol consumption, abstinence from smoking and regular physical exercise are important components of healthy lifestyles and play a significant role in preventing chronic diseases.[1] There is a lack of adherence to healthy lifestyles, at a population level, that has contributed to the increasing prevalence of obesity and smoking related illnesses.[2] This phenomenon has attracted significant attention at both national and global levels. Nurses are well positioned to contribute to providing health and patient education regarding modifiable health risk factors.[3] However, some studies report that nurse's personal adherence to healthy lifestyle recommendations is decreasing.[4–6] Furthermore, nurses' own behaviours and values are believed to impact on the quality and amount of health education they provide to their patients.[3,7]

This paper presents the findings of an exploratory research project that considered the role of registered nurses (RNs) in promoting healthy lifestyles. Underpinning the research is the premise that whilst health education is a recognised standard for practice for Australian RNs,[8] the reality of nursing practice is significantly restricting the ability of nurses to adequately meet this competency expectation.[9] Furthermore, nurses' own health behaviours may be an inhibiting factor in nurses effectively promoting healthy lifestyles to others.

BACKGROUND

In Australia, the Standards for Practice require that the role of the RN includes the promotion and maintenance of health and prevention of illness for individuals.[8] Standard 2.4 states RNs are to 'provide support and direct people to resources to optimise health-related decisions' whilst standard 3 mandates that RNs must ensure their own health and wellbeing as well as 'provide information and education to enable people to make decisions and take action in relation to their health'.[8] However, sometimes there is a dissonance between what nurses educate their patients on in regard to healthy lifestyles, and their own health behaviour.[10,11]

When RNs personally engage in behaviours that are detrimental to their own health, they not only put the profession in a negative light,[12] but their health behaviour may negatively impact on the behaviour of others through behaviour modelling.[13] Research is being undertaken to identify the cause of dissonance between what nurses say and what they do, and the rationale behind what prevents some nurses from adhering to the health behaviour they are expected to teach and model.[5] In Australia, with increased attention on preventing and decreasing lifestyle-related diseases, nurses are anticipated to be behavioural role models for their patients, families and the wider community.[14] When nurses adhere to healthy lifestyles it not only enhances their own health but also increases their credibility as health educators and role models. The focus of the work to date has been on the four modifiable health behaviours most commonly reported by the World Health Organization (WHO): smoking, unbalanced diet, excessive alcohol consumption and lack of physical activity.[1] Little is currently known of the personal dietary and exercise patterns of the RN workforce from an Australian perspective. One cross-sectional Australian study by Perry and colleagues found that even though nurses perceive they have good health, almost half indicated they had chronic disease and other health risk behaviours.[12] Other worldwide studies have tended to concentrate on health behaviours in nursing students,[13] obesity in healthcare workers,[15,16] and the impact of shift patterns on the health of nurses,[17,12] and health and chronic diseases.[5] However, research into actual excess weight and associated health behaviours in nurses is limited.[18] Of the studies conducted on nurses, most have identified prevalence rates of health risk factors amongst nurses at least equivalent to, or greater than general population levels.[5,12]

The relationship between nurse's personal health behaviours and nurse's counselling of patients about health issues has been examined in several studies. Researchers have found that nurses who practised positive healthy behaviours were more likely to advise patients in relation to these and reported that compliance of health promoting behaviours in patients had been influenced by the behaviours of those nurses caring for them.[7]

The Australian guidelines for adults' state: 'Guideline 1 - drinking no more than two standard drinks on any day reduces the lifetime risk of harm from alcohol-related disease or injury'.[19] The guidelines also recommend that to reduce the risk of injury on a single occasion ofdrinking, adults should drink 'no more than four standard drinks on a single occasion' (Guideline 2).[19] Australian dietary guidelines recommend a daily intake of five servings of vegetables and two servings of fruit.[20] The recommended national guidelines for physical activity are exercise at least five days per week, with 150 minutes or more being classed as sufficiently active and less than 150 minutes per week or less than five sessions a week classified as 'insufficiently active' to maintain health.[21]

There have been no studies identified that focus on RNs in regional Australia, where the general population are found to have higher rates of smoking and alcohol consumption, and lower rates of meeting physical activity and fruit and vegetable consumption than urban populations.[22] This paper focuses on the first phase of a larger exploratory, sequential mixed methods study. This research aimed to measure the prevalence of modifiable risk factors in RNs within a regional Queensland area and to explore the perceptions of nurses towards promoting healthy lifestyles to their patients.

METHOD

A cross-sectional, online (SurveyMonkey®) anonymous survey of RNs in the region was conducted (n = 123).

DATA COLLECTION

The survey instrument was developed using core items from the National Health Survey (NHS) and National Nutrition and Physical Activity Survey (NNPAS).[21,24] Full details of the survey design and measurements are available on the ABS website.[21] The instruments were adapted for this study by selecting scales or questions of direct relevance to the research aim. Questions were included that related to the health risk factors of tobacco smoking, dietary behaviours (fruit and vegetable intake), physical activity, alcohol consumption, height, weight as well as self-rated health and weight status. Self-rated health is a commonly used health outcome measure and has been found to be valid and reliable in a wide range of populations.[25] The survey also included open-ended questions relating to: barriers RNs face in adopting and maintaining healthy behaviours themselves; and suggested strategies to overcome these barriers, and whether they believed that nurses who engage in unhealthy behaviours are less likely to counsel their patients on these behaviours. As the tool utilised a variety of formats in the question designs, Cronbachs alpha was unable to be used for validity.[26] A copy of the final survey is available from the corresponding author on request.

PARTICIPANTS

Convenience sampling was utilised and data collected via an online survey, hosted on SurveyMonkey®. The explanatory letter on the first page of the survey outlined the research project and reminded participants of the inclusion criteria, that is, RNs who lived in the study region. The survey was posted to social media accounts; that being the researchers' personal Facebook page and the local nurses Facebook group via hyperlink, asking RNs to share on their own pages and also a URL to share via email with those that did not have access to Facebook. To reduce the effects of selection bias within the limits of the study, the survey was anonymous, and nurses were asked to share as broadly as possible with colleagues.

DATA ANALYSIS

The data was downloaded from SurveyMonkey® into Microsoft Excel for checking and cleaning before being uploaded to SPSS v22 for statistical analyses.[27] Frequencies and descriptive statistics were generated and checked for each variable and any statistical outliers were identified. The open-ended question data from the individual responses were analysed using both content and thematic analyses identifying key words, frequencies and themes. Content analysis was used to code the responses to the first three open-ended questions as the responses were only short.[28] An inductive categorisation method was utilised in which recurring factors found in the responses were identified.[29] The final open-ended question was analysed using thematic analysis as participants had responded in short paragraphs allowing emergent themes to evolve from the data.

ETHICS

The project received approval by the Human Ethics Research Review Panel at CQUniversity (PROJECT H14/07-167). Participant consent to take part in the study was indicated upon their completion and submission of the survey.

RESULTS

In total 123 responses were received of which 101 had complete data and were subsequently analysed. The estimated population of RNs in the region is 600, according to Human Resource records from Qld Health and the private healthcare facilities. Therefore, the response rate was estimated to be approximately 20.5% of RN population.

The age distribution (23-65 years, average 47 years) of the sample is relatively consistent with the RN population of Australia, which is 44.4 years.[30] The distribution of gender in this sample was 90% females and 10% males. All participants were qualified RNs working: part-time (51%); full-time (46%); or currently unemployed (3%). The average years of experience were 17.16 years (SD 12.435).

SELF-RATED HEALTH AND WEIGHT

Participants rated their health on a standard five-point scale from excellent to poor with the majority rating their health as being good (42%). Participants self-rated their weight status although when their Body Mass Index (BMI) was calculated using their self-reported height and weight, estimations of weight classification were consistently inaccurate (see Table 1). When asked had their weight altered in the last twelve months, 22.7% reported an increase while 25.7% reported a decrease; 51.5% reported their weight had stayed the same.

TABLE 1: COMPARISON OF PARTICIPANTS' SELF-RATED WEIGHT VS. CALCULATED BMI

Weight status	Self-Rated (%)	BMI* (calculated)	Australian general population (%)
Overweight* for BMI includes Overweight and Obese	57.84%	70.21%	63.4
Healthy Weight	39.22%	29.79%	35.0
Underweight	0.98%	Not calculated	1.6
Currently pregnant	1.96%	Not calculated	n/a

Total N=102

HEALTH BEHAVIOURS

Only 5.2% of participants identified that they currently smoke (4.2% daily smokers; 1% less than daily). Of those participants who responded that they did not currently smoke, 55.6% identified as ex-smokers and 15.7% as having never smoked.

Nearly all participants in this study (93.62%) reported having consumed alcohol in the last 12 months: less than weekly (56.82%); 1-2 days a week (17.05%); 3-4 days a week (12.5%); 5-6 days a week (7.95%); and every day (4.55%). On the occasions that they did drink alcohol in the last twelve months, 69.3% reported drinking more than the recommended two standard drinks on a single occasion,[19] and 39.7% reported drinking more than the recommended four standard drinks on a single occasion. The 55-64 year age group (N=16) most closely met the Australian guidelines for alcohol with 56.3% drinking within acceptable limits.[19] Over the last twelve months, 8.89% said their alcohol intake had increased, 21.11% said it had decreased and 70% said it had stayed about the same.

TABLE 2: PERCENTAGE OF PARTICIPANTS THAT MET ALCOHOL GUIDELINES

Age Groups	% of sample that met NHMRC guidelines for alcohol consumption		
	Guideline 1	Guideline 2	Both Guidelines
18-24	60.0	60.0	20.0
25-34	50.0	56.3	43.8
35-44	36.7	50.0	30.0
45-54	40.6	65.6	37.5
55-64	56.3	87.5	56.3
65-74	100.0	100.0	100.0

Only 18% of participants were meeting the Australian dietary guidelines' recommended intake of vegetables (five servings per day), but 61.7% were meeting the recommended daily intake of fruit (two servings per day).[20] When compared to the guidelines, 13% of participants met both the recommended daily guidelines for vegetables and fruit. The age group most likely to meet the dietary guidelines were between 45 and 54 years (30.8%). Those who worked part-time (15.7%) were also more likely to adhere to the dietary guidelines.

Physical activity was analysed based on whether participants met the recommended national guidelines.[21] Nearly all participants (N=99) responded to the questions regarding their physical activity. Table 3 shows that over half of the participants exercised less than 150 minutes per week and were classified as 'insufficiently active' to maintain their health. The age group that met the guidelines the most was 45-54 years (52.9%).

TABLE 3: COMPARISON OF PARTICIPANTS' PHYSICAL ACTIVITY TO THE RECOMMENDED GUIDELINES VS. THE AUSTRALIAN POPULATION

Recommended Guidelines	% of Participants	% of Australian general population
Sufficiently active: 150 mins or more and five sessions per week	24.2	55.5
Insufficiently active: 1-149 mins or less than five sessions/week	59.6	29.7
Inactive: 0 mins	16.2	14.8

ADDING UP THE LIFESTYLE RISK FACTORS

The prevalence of risk factors is frequently considered in isolation. However, there is increasing evidence that they also have an interactive and cumulative effect.[22,31] Figure 1 shows the six risk factors used in the analysis for this section.

RISK FACTOR	GUIDELINE IDENTIFIER
Smoking	Current daily smoking
Physical inactivity	Insufficient time and sessions
Low fruit consumption	Less than two serves
Low vegetable consumption	Less than five serves
Risky alcohol consumption	Over two standard drinks in any one day
Obesity	BMI of 30 or more

FIGURE 1: RISK FACTORS USED IN THE ANALYSIS FOR THIS SECTION

TABLE 4: PERCENTAGE OF MULTIPLE RISK FACTORS COMPARED TO AGE GROUPS

Age Groups	% of age group with multiple risk factors						
	0	1	2	3	4	5	6
18–24	0.0	0.0	20.0	60.0	20.0	0.0	0.0
25–34	0.0	6.3	37.5	25.0	25.0	0.0	6.3
35–44	3.3	3.3	6.7	40.0	40.0	6.7	0.0
45–54	3.1	3.1	12.5	50.0	18.8	9.4	3.1
55–64	0.0	12.5	31.3	31.3	18.8	6.3	0.0
65–74	0.0	0.0	0.0	0.0	100.0	0.0	0.0

Most participants (98%) had at least one of the six risk factors listed above (Figure 1), with the majority having two to four (85%) (Table 4). There was no significant difference in the distribution of risk factors according to gender or age. This may be attributed to the sample being mostly female and the median age 47 years.

BARRIERS AND STRATEGIES

These questions asked participants to elucidate on the barriers and strategies to adopting and maintaining healthy behaviours themselves. Participants identified two main issues regarding perceived barriers RNs face in adopting and maintaining healthy behaviours themselves. Shift work and working long hours were cited by many participants (61.5%), with time and family commitments also being cited by almost half (47.4%). The detrimental impact of shift work was described by one participant:

> *'Shift work and being on our feet all day, early starts, makes me tired, so I am more reluctant to go to the gym or go for a run. Doing shift work makes it hard to get into a good routine with diet sometimes also.'*

Whilst the lack of time was explained by another participant:

> *'Time poor. I go to work, long hours, then come home to family, kids, chores and it is often extremely difficult to find ten minutes to do a survey let alone find 30 minutes to walk around the block.'*

When considering strategies to overcome perceived barriers to adopting and maintaining healthy lifestyles, prioritising, planning and making time was reported as a potential strategy by 34.4% of participants, whilst 28% suggested better rostering and improved work-life balance as well as education and support. One participant outlines how planning could be a strategy:

> *'Taking the time to plan healthy meals ahead of time and ensure that healthy snacks are brought to work all the time so that the temptation of vending machine food is not there.'*

Whilst another discussed an improvement to rostering:

> *'If shift rotation must be done, do the shifts in blocks so that a routine for eating, sleeping and living can be established.'*

Over half of the participants believed that RNs who engage in unhealthy behaviour were less likely to counsel their patients on these behaviours. This is at odds with the belief held by the majority of participants that an RN has an important role in the provision of health education. While there was no statistically significant relationship, there was a slight tendency towards not providing health education by those not engaging in the healthy behaviours and that they saw this in terms of hypocrisy, credibility and self-efficacy.

The feeling of hypocrisy was highlighted by one participant:

> *'It's easy to give education on healthy behaviours, however, up until I quit smoking six months ago I always felt like a hypocrite when advising others to quit smoking. I think people who are engaging in healthy behaviours would be more likely to provide education as people who don't would probably feel ashamed or feel like a hypocrite.'*

Another participant emphasised the importance of credibility:

> *'If you aren't walking the walk you can't talk the talk. Nurses who are overweight, smoke, eat loads of takeaway do not portray healthy habits to patients and patients would be less likely to want to change if they see that in nurses who do the same as themselves.'*

Those who believed nurses' own health behaviours did not influence their health education practices saw health education as part of their job that was not reflective of their own lifestyle. One participant stated it is not taken into consideration:

> *'Because when it comes to looking after patients and providing education this is not really taken into consideration what we do in our own lives. It's like the saying do as I say, not as I do.'*

The participants reported that their knowledge and experiences made them more relatable and authentic and that they believed patients felt they could understand the challenges and barriers to achieving good health.

LIMITATIONS

The current study has a number of limitations that are worth highlighting. The study utilised a convenience sample conducted in a single regional area, which means the results are not generalisable to RNs nationally. The geographic restriction might also influence particular findings, for example comments on workload and staffing may be more reflective of conditions in that area. The sample size and question format limited the analysis able to be undertaken.

DISCUSSION

RNs working in regional Australia play a particularly important role in promoting healthy lifestyles to their patients and the community at large.[32] While this study has demonstrated some adherence to recommended guidelines, it has highlighted RNs in regional Queensland may not be adhering as closely to national guidelines around healthy behaviours and that this may be impacting on their willingness to provide advice around healthy lifestyles.

Self-rated health of the cohort in this study was lower than the Australian general population as reported by the ABS.[21] This could be reflective of the influence of the risk factors under investigation – whilst smoking rates were lower, and fruit and vegetable consumption were higher than the general population, alcohol consumption was higher, physical activity was lower than the general population and there were higher rates of overweight and obesity.[21] These findings are consistent with another study by Perry and colleagues,[23] of nurses in New South Wales, although smoking rates were twice as high in their cohort, fruit and vegetable intake, low physical activity and risky drinking were common. When considering self-rated weight however, the opposite effect of under reporting occurred. This is unsurprising given previous findings around the under estimation of self-reported weight in general.[33]

The prevalence of risk behaviours is of concern both in terms of the RN's health outcomes but also the influence on providing health education. From a chronic disease perspective, as the numbers of risk factors increase, so does the likelihood of developing health problems.[22,34,35] In addition to the prevalence of chronic disease rates, with the ageing of the RN workforce in Australia (current average age of 44.3 years),[22] reductions in overall health also put them at higher risk of injury and emotional disease through compromised work performance.[5,18]

Even though we know that adherence to healthy lifestyles directly reduces the incidence of chronic diseases and work-related injuries as well as increasing wellbeing, there are barriers to this adherence. The high frequency of shift work was cited as a barrier in this study and this is consistent with findings from other studies.[17,22] The present study identified that RNs working part-time were more likely to meet dietary guidelines, suggesting the influence of the time pressures around full-time work may have a negative influence.

However, a study by West and colleagues,[36] which critically analysed findings from two previous studies, claim the opposite and assert that nurses who do shift work have more time to engage in activities such as going to the gym or exercise classes and that nurses are aware of the need to maintain health. The author's claimed that nurses can develop a shift work tolerance and use it to negotiate a more manageable work/life balance. It is important to highlight that these findings were from mid-life nurses, which is consistent with some findings within the present study. In the present study RN's in the older age brackets were also more likely to meet guidelines. Whether this is because they were less likely to have younger children creating additional demands on their time or because they have developed shift work tolerance is an issue for future investigation.

The strategies suggested by participants for assisting them to achieve health behaviour guidelines were very broad. Two of the suggestions were directed at themselves, highlighting a perceived need to prioritise, plan and make time for healthier meals and physical activity, and the desire for a better work life balance. The findings of the current study illustrated that nurses who had achieved success in certain areas such as losing weight, increasing physical activity and/or stopping smoking felt more motivated to adhere to the recommended guidelines and confident as role models for good health. They were also more likely to feel confident in educating patients on the behaviours they had success in achieving. Whereas those who smoked or were overweight were less confident in providing education and more likely to feel hypocritical and avoid these topics with patients. Other researchers have found similar results reporting that nurses felt patients would heed advice given by healthy role models and that this would add credibility and validity to the health education they gave whilst also reflecting well on the organisation where they work.[13,37] Confidence and self-efficacy in overcoming barriers and providing regular health education would then in turn improve patient care.[13]

Some participants in the current study believed that their own health did not impact on the care and education they provided to patients and that the fact they were not seen as 'perfect' would allow patients to feel less threatened and that they understood the same challenges. These beliefs were also reported in other studies, with some believing that if nurses' own health behaviours were seen as those of a real person, patients would connect more and that unhealthy nurses were able to provide better care as they have a greater capacity to empathise with patients as they suffer the same conditions.[38] With the rising incidence of non-communicable diseases, many researchers are arguing that nurses are crucial as healthy role models and are uniquely placed to support the delivery of government and international health policy.[23,39] For RNs to make a real difference to health outcomes, nurses own health and health education needs to be made a priority that is supported and implemented at multiple points: by policymakers, within nursing practice, within nursing curriculum, and in healthcare institutions. [23,37,40]

As mentioned earlier, this paper reports the results of the first stage of the research. These informed the development of interview questions used in phase two which delves more deeply into the value placed on health education, personal beliefs, and perceived patient perceptions around nurse credibility and patient readiness to accept education.

CONCLUSION

The International Council of Nurses[41] issued a call to action for nurses everywhere to lead the fight against chronic disease; to act as healthy role models for their families, their patients and their communities. Nurses need to be physically and mentally healthy to reliably focus on providing the best care for themselves and others. The results of this study highlight the dissonance between the health behaviours of RN's for this regional area and the national guidelines as well as the perceived influence of shift work, long working hours and family commitments on them. Whilst this was a small exploratory study, it identifies some individual and systematic challenges to RN's meeting health behaviour guidelines.

IMPLICATIONS FOR FURTHER RESEARCH, POLICY, AND PRACTICE

Facilities need to implement more strategies to enable nurses' better work/life balance especially around rostering. Nurses need to be supported to provide health education to their patients with better resources, education and time allocation. Future research should include studies conducted in different regions or ideally a large nationally representative sample.

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RESEARCH ARTICLES

Nurses' documentation of falls prevention in a patient centred care plan in a medical ward

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ABSTRACT

Objective: To evaluate the consistency of nurses' documentation in the falls prevention assessment tool, and to ascertain whether patients identified as high risk of falling had falls preventative strategies implemented.

Background: Falls are one of the leading causes of adverse events for patients in the hospital setting. The current practice of implementing falls prevention strategies for patients has not been able to be sustained, which remains a challenge for healthcare providers. Among the falls prevention strategies, falls risk assessment tools have been identified as a crucial element in falls prevention so as the number of falls are minimised.

Study design and methods: A retrospective chart audit, with the auditing of falls assessment documentation on the Patient Centred Care Plan.

Results: The Patient Centred Care Plan audit revealed that 60.8% of patients (n=508) were identified as high risk of falls by the principal investigator. For the cohort of patients identified by the nurses as having a high risk of falling (53.4%), 53.7% of patients had falls prevention strategies implemented, and only 17.5% of patients were engaged with their falls prevention plan. The strategies that were documented by the nurses on the care plan for the high-risk cohort were not implemented for 16.8% of the patients, and 29.5% of high risk of falls patients did not have documentation on the plan indicating their falls status.

Discussion: The findings show that there is a significant gap in the identification of high falls risk patients and the documentation and implementation of falls prevention strategies, between nursing staff records on the Patient Centred Care Plan and the audit conducted by the principal investigator for patients who are identified as high falls risk. As part of the audit patient engagement in their falls prevention plan revealed that patients were not informed of their falls risk status by the nursing staff.

Conclusion: The outcome from this audit signifies that not all high falls risk patients were identified as a high falls risk, and most of the high falls risk patients were not engaged in their falls prevention plan.

Implications for research, policy and practice: Understanding the current practices of falls prevention and raising nursing staff awareness of

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variance in the implementation of falls prevention strategies will improve the quality, efficiency of healthcare and patient safety.

Key words: Patient falls, assessment, implementation of strategies, patient engagement, health education

What is already known about the topic?

- Nurses' do not always document patient assessment and associated nursing care.
- There are multiple factors which impact on nurses' documenting assessment findings and implementation of nursing care.

What this paper adds:

- At times nurses rely on a falls risk assessment made on the previous day when not able to conduct a current falls assessment.
- Patients are not engaged in their falls prevention plan, even though they are identified as being of risk of falls.
- Patients are not aware of the implemented falls prevention strategies which are part of their care.

INTRODUCTION

Falls are multifactorial and there are several factors which may contribute to implementation of falls prevention strategy. These may include nursing staffs' knowledge, belief, attitudes, workloads and staff culture on the ward, environmental factors and access to required resources.[1] Falls assessment tools have been documented to be effective in reducing falls rates and serious injuries amongst inpatients.[1] Falls assessment tools help identify high falls risk patients, so that timely interventions can be put in place.[2]

The 6-PACK (STRATIFY) falls prevention tool was developed in the UK,[3] and has been studied and implemented in Australian, Canadian and European acute care hospitals.[4] The 6-PACK falls prevention tool is a nurse led assessment tool designed for acute care settings. As the tool is an accurate predictor of falls risk it has been recommended for use in best practice guidelines to prevent patient falls.[4] Aranda-Gallardo and colleague's (2015) longitudinal study of the STRATIFY falls prevention tool, highlights that this tool maintains validity and accuracy as a predictor of falls risk.[5]

PATIENT CENTRED CARE PLAN

In 2002, the hospital in this study implemented the nurse led 6-PACK falls prevention tool, as part of the Patient Centred Care Plan (PCCP). The PCCP is a patient's daily plan of care which is completed by nursing staff and updated each shift and is located in the patient's medical record. The falls prevention strategies documented on the falls prevention tool are: the placement of falls alert signs above the patients' bed, use of high low beds, establishment of a toileting regime, supervision of patients whilst in the bathroom, use of bed/chair alarms, ensuring walking aid is within reach, and patient engagement/education in falls prevention plan. The implementation of the 'Alert Sign' with one or more falls prevention strategies specified in the PCCP are deemed as correct implementation of the falls prevention plan. As part of the implementation of the tool, the new nursing staff are provided training on their falls prevention risk assessment tool as part of the orientation to the hospital. Ward-based training was delivered by the injury prevention champions of the designated wards, so as to prepare and engage nursing staff in providing falls prevention assessment and interventions. The injury prevention champions of the ward conducted monthly audits of the falls prevention assessment tool, and in response to the audit results feedback was provided to the nursing staff team each shift. The nursing staff were encouraged to instil the education provided to the next shift to improve the assessment, documentation and implementation of the documented falls prevention strategies. Also, during ward handover/huddles the location of the high falls risk patients is reinforced by the nurse in charge to increase nursing staff awareness.

In 2002, as part of the introduction of the falls prevention tool in the hospital that is the focus of this study a nine-year observational evaluation study demonstrated >80% compliance with falls prevention documentation.[6] Barker and colleagues reported a 25% reduction in falls rates over an initial 12 month period and in the second year of implementation, a 50% reduction.[6] There continued to be a sustained decrease in the number of falls for five years post implementation with use of this tool in the hospital setting.[4]

The hospital has continued to use the falls prevention tool as part of its falls prevention program. Falls incidents were also classified according to an Incident Severity Rating (ISR): 'A score of 1, 2, 3 or 4 that measures the severity of the impact caused to the person affected following an incident, ISR 1 being the highest or most severe and ISR 4 a near miss'.[7]

Despite ongoing use of the tool, in the 2015 to 2016 period, there was a 16% increase (Table 1) in the overall number of the reported falls (ie. 147 to 170), consisting predominantly of an increase in no harm/near miss events (ISR-4) and with an increase in the number of serious injuries (ISR-2) in the medical ward. The PI abstracted the data from RiskMan, which is the hospital's information management system. In response to the increased incidence of patient falls in 2015-2016, an audit was instigated to determine the factors that have influenced this increase as the falls prevention tool has been a consistent component of the hospital's fall prevention strategy.

TABLE 1: FALLS INCIDENT SEVERITY RATING (ISR) 1 TO 4 AND THE TOTAL NUMBER OF FALLS FROM JAN 2015 TO DEC 2016

Falls Severity Level 1–4	Total Number of Falls		Change
	Jan-Dec 2015	Jan-Dec 2016	%
Incident Severity Rating 1: Severe (death)	1	1	0
Incident Severity Rating 2: Moderate (head injury, subdural haematoma, fracture)	2	5	↑150
Incident Severity Rating 3: Mild (graze, abrasion, cuts)	47	46	↓2
Incident Severity Rating 4: No harm/near miss	97	118	↑21
Total number of falls 2015–2016	**147**	**170**	**↑16**

The aim of the present study was to determine the number of patients admitted to the medical ward identified by nurses as high falls risk, measure the consistency of nurses' documentation of the identified falls prevention strategies using the falls prevention tool, and assess whether preventative falls prevention strategies were implemented for these patients.

METHODS AND METHODOLOGY

Quantitative data collection consisted of RiskMan falls data and PCCP Audit. RiskMan is an information management system used by hospitals to report in-house incidents. The data obtained from RiskMan is the basis for the instigation of quality improvement projects at the hospital. The PCCP Audit facilitated a comparison between the principal investigator (PI) and nursing staff identifying the patients as high risk of falls and the data was aggregated statistically.[8] RiskMan data results are presented as total number of falls and percentages. The results demonstrated different patterns in the identification, assessment and documentation of implemented falls prevention strategies.[9]

ETHICAL CONSIDERATIONS

The audit is part of the Doctor of Philosophy research study, and the rights of patients and nursing staff were upheld. The data (patient medical records and RiskMan data) was initially collected in an identifiable format but once the datasets had been linked, the data was de-identified. Verbal and written consent was obtained from nursing staff. The approval for the research study was given by the Ethics Committee of Austin Hospital HREC Project Number: HREC17 Austin27 and Victoria University Ethics Committee.

PARTICIPANTS

The principal investigator (PI) is a registered nurse and worked as an Injury Prevention Coordinator in the hospital for two years where the study was conducted. The Injury Prevention Coordinator role was responsible for the continuing education of nursing staff in providing safe patient focussed nursing care. Part of this continuing education involved the documentation and implementation of the falls prevention risk assessment tool. The nurses were registered nurses who provided nursing care to the patients in the medical ward. The ward staff consisted of graduate nursing staff, registered nurses, clinical nurse specialist, associate nurse unit manager and the nurse unit manager. Nurses on the ward use a team approach when providing patient care and there is a strong culture for collaboration. After the monthly auditing of the falls prevention assessment tool, targeted education sessions were conducted by the injury prevention champions of the ward.

AUDIT SITE

A point prevalence audit of the PCCP was conducted by the PI from 20 July 2017 to 30 November 2017 in the 28-bed medical ward at a major hospital in Melbourne. The ward has the allocation of 16 dementia and four renal dialysis beds. The audit was conducted each Wednesday for twenty weeks of the PCCP.

DATA COLLECTION

The audit was undertaken in the afternoon by the PI so as the nursing staff on the morning shift has adequate time to complete the falls prevention risk assessment tool. Given that the same patient could be audited more than once, the audit results are presented in the unit of patient beds. The PI audited the falls prevention risk assessment tool documentation by the nursing staff, and also used the same falls prevention risk assessment tool to rate the patient's falls risk. The PCCP audit results provided information on the nursing assessment of the patient, documentation and implementation of targeted strategies to prevent falls on the medical ward. Furthermore, the audit provided a comparison between the nursing staff and PI identifying the patients falls risk score and patient engagement in their falls prevention plan. As per the hospital's falls prevention policy, identified high falls risk patients are required to be engaged in their falls prevention management plan by nursing staff, as falls prevention is part of a high falls risk patient's daily management plan. The nursing staff are required to discuss the patient's falls risk, implement falls prevention strategies and highlight the falls prevention patient brochure with the patient and clarify/answer any questions a patient or significant other may have in regard to their falls prevention plan. Once the education session is completed the date and who the education was provided by is documented on the PCCP to indicate to other nursing staff that falls education was provided.

DATA ANALYSIS

Descriptive analysis was conducted to provide an indication of the falls risk assessment tool completion and the falls risk minimisation methods utilised and in practice for each patient. Chi-squared test and Fishers' exact tests were used to test for differences between the registered nurses and the principal investigator, while continuous variables were assessed for normality, with the appropriate parametric (Student's t-test) and/or non-parametric (Man-Whitney) tests applied. All analyses were conducted using STATA statistical analyses software, version 15.1 (StataCorp, College Station, TX, USA), with a two-sided p-value of less than 0.05 indicating statistical significance. The number of statistical tests have been kept to a minimum to reduce the likelihood of false positive results, and to avoid any adjustment for multiple comparisons, such as a Bonferroni adjustment.[14]

RESULTS

From a review of nurse-documented falls assessment as indicated in Table 2, the documentation compliance of entering a RiskMan number on the PCCP was only 60% (n=18).

Of the 508 patient beds audited, 271 were identified as a high falls risk by nursing staff with an additional 38 patients identified as high falls risk by the PI (p=0.016). Sixty-one percent of the patients admitted to the medical ward over the audit period were identified as having a high risk of falls. The differences between the nursing staff and PI's assessment of patients being a high risk of falls was statistically significant (p=0.016). Of the 60.8% of high-risk falls patients, only 53.7% had falls preventative strategies implemented as part of their nursing care (Classification of strategies implemented: Alert sign and one or more strategies implemented is deemed accurate). Seventeen percent of strategies documented on the PCCP were not implemented and 29.5% of high risk of falls patients had no documentation on PCCP as indicated in Table 2.

As shown in Table 2, of the 309 patients identified as high falls risk by the PI, only 17.5% were provided with Falls Prevention Brochures, which indicates that 83% of patients were not engaged in their Falls Prevention Plan. Out of 309 patients identified as high falls risk, 2.6% were confused, and 2.6% were non-English-speaking background.

TABLE 2: PCCP AUDIT RESULTS OF RISKMAN NUMBER DOCUMENTATION, IDENTIFICATION OF PATIENTS' FALLS RISK SCORE AND ENGAGEMENT

Criteria/Questions	Number	Total Occupied Beds	%
Falls this admission	30	508	5.9%
RiskMan No. documented on PCCP	18	30	60%
Staff identified patient as high risk of falls	271	508	53.4%
PI identified patient as high risk of falls	309	508	60.8%
Falls preventions strategies implemented	166	309	53.7%
Falls prevention not documented in PCCP	91		29.5%
Falls prevention not implemented	52		16.8%
Falls prevention brochure provided	54	309	17.5%
Falls prevention brochure not provided	255		82.5%
Risk and strategies discussed with patient	14		25.9%
Risk and strategies not discussed with patient	40		74.1%
Patient confused	8		2.6%
Patient NESB	8		2.6%

Table 3 provides an indication of which falls prevention strategies were implemented and not implemented. Of the 309 patients with falls risk 58% of patients had 'Alert Signs' as a falls risk displayed above their beds, whilst 28% of patients did not have falls risk documentation in their PCCP. In relation to the intervention of a hi-low bed as part of a risk of falls patient's care, 71% of patients did not have the intervention of a 'high low bed' documented or implemented. Of the 86% of high falls risk patients requiring a 'gait aid', only 25% of these patients had their walking aids within reach. Only 2% of 'toileting regimes' and 43% of high falls risk patient's 'bathroom supervision' were documented as implemented on the PCCP. For the 14 patient beds with an alarm in-situ, 64% of the patient 'alarms' were not connected correctly.

TABLE 3: IMPLEMENTED/NOT IMPLEMENTED 6-PACK FALLS PREVENTION STRATEGIES IDENTIFIED ON THE PCCP

Alert sign	**Number**	**Total No. of High-Risk Patients**	**%**
Alert sign documented on PCCP as implemented	178	309	58%
Alert sign not implemented	43		14%
No documentation in PCCP	88		28%
Low bed			
Low bed documented on PCCP as implemented	90	309	29%
If so, is it in lowest position	68		76%
No documentation and no implementation on PCCP	219		71%
Gait aid			
Total no. of high risk patient require gait aid	267	309	86%
Gait aid provided	63	267	24%
If so, is it close to patient	43	63	68%
Toileting regime			
Toileting regime documented on PCCP as commenced	5	309	2%
Toileting regime not commenced	210		68%
No documentation on PCCP	94		30%
Bathroom			
Supervise bathroom documented	133	309	43%
Supervise bathroom not documented	114		37%
No documentation in PCCP	59		19%
Alarm insitu			
Total no. of high-risk patient requires alarm	128	309	41%
Alarm insitu	14	128	11%
If so, is it connected correctly	5		36%
Documented PCCP but not implemented	9		64%

DISCUSSION

This study identified variability between patients being identified as high falls risk when comparing nursing staff records on PCCP and the audit conducted by the PI.

Beauchet and colleagues similarly found that 13.5% of patients that were audited to be a high risk of falls were not identified as risk of falling.[10] Accurate documentation and the reporting of falls is crucial in improving the quality of patient care. The findings suggest that there is a significant gap in the identification of high falls risk patients and the documentation and implementation of falls prevention strategies, along with patient engagement in their falls prevention plan. Knowing that many falls occur in bathrooms due to toileting, which could potentially result in serious injuries,[2] the barriers of not documenting high falls risk patient's toileting regime in the PCCP needs to be identified to improve patient outcomes. Some of the barriers that impact upon nurses' adherence to documentation may have been due to demands of patient care requirements (dementia, confused, delirium, and renal impairment). Also, the patient requirements may not always correlate with staff capacity due to workloads, complex patient care needs, staff allocation and skill mix.

Not displaying the 'alert signs' for high falls risk patients above their beds will hinder strategies to reduce falls rates. The allocation of alert signs increases the awareness of a patient's risk of falling to everyone who encounters the patient's surroundings, including the multidisciplinary team of nurses, doctors and visitors, and even the tea person. Radecki and Reynolds (2018) found that it was important that the patient was also aware of their falls risk, so that the patient could be an active participant in the falls prevention interventions.[11] It is imperative to document that a patient falls prevention brochure is provided to ensure that patients are engaged in their falls prevention plan.

Ensuring a patient's walking aid is within their reach allows the patient to stabilise their posture/mobility which in turn minimises their risk of falling. The use of bed and chair alarms for cognitively impaired patients play a crucial role in the minimisation of falls, as the alarms alerts healthcare professionals of movement when a patient is attempting to ambulate without any supervision. From the patient perspective, Radecki and Reynold found that patients' considered alarms to be part of the falls risk strategy.[11] In a medical ward where 16 dementia specific beds are located, having alarms not connected correctly can result in a serious injury due to a fall. Upon investigation for the reasons why there were a high number of alarms not documented or connected correctly, it was highlighted by nursing staff that the documentation was copied from the day before.

Patient centred care or patient engagement is a fundamental care requirement of the healthcare system, and by involving the patient in their daily care plan, evidence suggests that this will decrease the number of falls.[11] As per National Safety and Quality Health Service Standards [NSQHS] criteria 10.9.1 patients and their carers are required to be informed of their identified falls risk and engaged in their falls prevention strategies and management plan.[12] Patients' cognitive impairment or language barriers at times can hinder the patient education process.[13] As per the hospital's policy the nursing staff are required to provide a falls prevention brochure and discuss the strategies implemented with the high falls risk patient. The falls prevention brochures are translated into multiple languages and available for nursing staff to print and provided to the non-English speaking patients. In a medical ward by not actively engaging high falls risk patients in their falls prevention plan, not only increases their risk of falling, but also, prevents patient awareness of their falls risk to undertake the targeted strategies implemented/required whilst in hospital or post discharge.[11]

Knowing that the 6-PACK interventions are utilised as part of patients' daily care to decrease the number of serious injuries, it is important to obtain nurses perceptions to understand what constitutes the implementation of targeted falls prevention strategies on the falls prevention tool. The results of this study were provided to nursing staff/nurse unit manager of the ward during focus group discussions and the hospital's Standard 10 falls prevention committee to improve local nursing practice.

CONCLUSION

Even though the falls risk assessment tool was feasible to implement and has previously reduced the fall and fall related serious injury rate at the current hospital, the falls rate and reported serious injuries appears to be a continuing problem. A possible explanation for serious injuries on the rise is the inconsistent implementation of the falls prevention strategies. This study indicates that the nurse's risk assessment and implementation of falls prevention strategies as documented in the falls assessment tool, was not being applied as it is intended, and may not be having the same effect of reducing the rate of falls as it did following its introduction to the hospital in 2002. It is imperative to identify the barriers and the enablers to further understand the reasons behind nurses' documentation and the apparent lack of implementation of the targeted strategies. While the above audit results provide an insight, further research is required to explore the nurses' and patients' perspectives on effectiveness of the current falls prevention plan is required. The next phase of this study will explore these views.

RECOMMENDATIONS

An analysis should be conducted to determine the long-term sustainability of the falls prevention program. As part of the analysis the identification of the barriers and enablers that impact upon nurses' documentation and implementation of targeted falls strategies, requires further examination. The further exploration of both nursing staff and patients' perspectives regarding the effectiveness of current falls prevention plan, will contribute the overall analysis.

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REVIEWS & DISCUSSION PAPERS

Skin cancer in regional, rural and remote Australia; opportunities for service improvement through technological advances and interdisciplinary care

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ABSTRACT

Age standardised skin cancers (melanoma and non-melanoma) continue to increase in Australia, although they are stabilising for those under age 40. People living in regional, rural and remote Australia have higher rates of skin cancer and challenges accessing care. Better targeting of skin protection measures and improved opportunistic screening have been promoted as ways to improve care for these populations as have increased use of information technology and upskilling of primary healthcare nurses. The Australian Government supports that Optimal Cancer Care Pathways for skin cancers be used as a key resource in exploring best practice models of care for skin cancer patients both for the development of digital platforms and face to face multidisciplinary teams (MDTs). Better use of technology has been a core recommendation of national health and skin cancer organisations for improving prevention and early detection of skin cancer. Skin cancers, as a primarily visual diagnosis are considered one of the prime areas for technological health interventions. The harnessing of artificial intelligence (AI) technology as a tool for early detection and disease management of skin cancers has great potential to reduce the burden of healthcare costs to the regional, rural and remote community and improve health outcomes.

Keywords: Skin cancer, rural, Australia, nursing, interdisciplinary, artificial intelligence

What is already known about the topic?

- People living in regional, rural and remote Australia have higher rates of skin cancer and challenges accessing care.
- Primary care practitioners - whether nurses or GPs in regional, rural and remote Australia are often the primary contact for skin queries or concerns.

What this paper adds:

- Skin cancers, as a primarily visual diagnosis are considered one of the prime areas for technological health interventions
- Nurses in regional, rural and remote Australia are well positioned to be at the forefront of delivering these emerging technologies

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INTRODUCTION

SKIN CANCER IN REGIONAL, RURAL AND REMOTE AUSTRALIA

Skin cancers (melanoma and non-melanoma) are a major public health issue in Australia with two out of three Australians being diagnosed with skin cancer by the age of 70.[1] The age-standardised incidence rate of melanoma has steadily increased since the 1980s and estimates of non-melanoma skin cancer (keratinocyte cancers, KCs) are extremely high when compared with overseas rates.[2] Skin cancer burden is higher among people in regional, rural and remote Australia.[3] Those outside of major metropolitan cities have the highest rates of melanoma skin cancer, while areas of remote Australia, have lower rates, most likely due to lower rates of skin cancer experienced in Aboriginal populations.[2] Geographical disparities have also been recently noted in KC with the highest rates in South Australia in agricultural and coastal areas.[4] This is not altogether surprising given that farmers and outdoor workers have anywhere from three to eight times higher ultraviolet (UV) exposure than indoor workers and sun-protection practices in these populations are noted to be sub-optimal with many reluctant to seek health advice, often waiting until they have a serious health concern.[5] The most common cited barriers to seeking help for skin cancer detection in rural Australia include; minimising the problem, a desire to be in control, reluctance to show emotion or complain, stoicism and concerns about privacy and waiting times to see a doctor.[6]

PREVENTION, EARLY DETECTION AND SCREENING

Skin cancer prevention activities for over 40 years in Australia have been credited with the recent stabilisation of melanoma and KC rates in younger populations <40 years of age. Prevention campaigns have evolved by agencies at both the state/territory and national level from whole of population SunSmart campaigns, to targeted campaigns such as those aimed at farmers; *Protect your farm's most important asset. You.*[7] Currently skin cancer prevention is primarily funded by State/Territory Governments and organisations, the last nationally funded campaign being from 2006-2010. Cancer Council Australia and Clinical Oncology Society of Australia (COSA) have recommended that the Australian Government fund and conduct an ongoing national mass media social marketing campaign to raise awareness of skin cancer risk and sun protection.[8]

A number of resources for skin cancer prevention and early detection tools have been developed for use by the general public including tools and apps such as those developed by SunSmart,[9] risk predictor online tools such as the Melanoma Risk Predictor,[10] Scan Your Skin[11] and daily ultraviolet index alerts by the Bureau of Meteorology.[12] However these SunSmart messages may fall short in regional and rural Australia.[5] In a review of skin protection and public health campaigns for agricultural workers, it has been suggested that increased use of information technology, promoting prevention and early detection at agricultural events and upskilling primary healthcare nurses and other healthcare workers could play an important role in prevention and early detection.[5] Moving in this direction, a new 2019 Commonwealth funded study, *Improving Melanoma and Skin Cancer Awareness in Regional and Rural Australia*, coordinated by Melanoma and Skin Cancer (MASC) Trials in collaboration with clinician and patient groups around Australia aims to guide the development and requirements for resources to support people in these areas.[13]

Currently in Australia, population-based screening for skin cancer is not performed due to a lack of evidence either for or against population-based screening.[14] However, opportunistic screening is common. The Royal Australian College of General Practitioners guidelines currently recommend opportunistic skin checks for people at moderately elevated risk, and skin checks every six to 12 months plus advice on skin self-examination for those at high risk.[15] Primary care practitioners- whether GPs or nurses in regional, rural and remote Australia are often the primary contact for skin queries or concerns. Skin complaints comprise approximately 15% of GP consultations, with about one-third of these involving the diagnosis and treatment of a benign or malignant neoplasm.[16] However, for regional, rural and remote practitioners who may already be stretched to capacity, competing healthcare needs may limit opportunistic skin checks when consideration is given to the time spent on skin examination, visual diagnosis and possible referral to a dermatologist. As 92% of dermatologists in Australia live and work in major metropolitan cities,[17] specialist visits are not easy for regional, rural and remote people, although advances in teledermatology has improved access.

Early detection of skin cancers, especially in the case of melanoma is crucial with survival high if acted upon early and localised. Melanoma rates in Australia have decreased by more than 30% from 2002-2016 for people aged less than 40 which suggest that 40 years of skin cancer prevention programs are having an effect.[2,18] Melanoma if caught early has a five year survival of 91%, yet in 2019 it is estimated that it will be the ninth most common cause of death from cancer.[19] Early diagnosis and treatment for all skin cancers decreases the need for invasive and potentially disfiguring surgery especially of the head and neck. It is believed that for older men in particular, the higher proportion of face, scalp and neck tumours could be related to occupational and lifelong sun exposure rather than intermittent extreme exposures.[20] While KCs mostly do not present a serious disease they are the second most costly cancer (after colorectal) and reflect a disproportionately high burden on the healthcare system.[21]

For some patients, skin cancer will require ongoing management. In the case of KC, due to the multiplicity of the disease, the incidence is eight times as high in patients who have had a prior history as for those who have not.[22] In South Australia, 40% of people treated for a KC will have another one treated within five years.[4] For regional, rural and remote practitioners, post-diagnosis skin cancer follow-ups present challenges with the following reasons being cited: (i) workload and time constraints for consultations (ii) GP support, resources and infrastructure (including access to dermatologists for the patient) and (iii) patient factors such as poor health literacy and motivation to attend follow-up.[23]

NATIONAL INQUIRY INTO SKIN CANCER

Public health recommendations for optimal approaches to the prevention, early detection and management of skin cancer have taken the form of national reports from government and non-government cancer control organisations such as the Department of Health, Australian Institute of Health and Welfare, Cancer Australia, Cancer Council Australia, and professional organisations such as Clinical Oncology Society of Australia. In 2015 The Standing Committee on Health made an Inquiry into Skin Cancer with 63 submissions received from government, non-government, professional organisations, consumers and private individuals.[8] Amongst the submissions received, a number addressed issues specific to regional, rural and remote health and noted the contribution of nurses and primary healthcare teams in the provision of prevention, opportunistic screening and early diagnosis of skin cancer and called for greater professional support and recognition of their services. These included submissions from the National Rural Health Alliance and the Royal Flying Doctor Service:[8]

Submission 9 exert, the National Rural Health Alliance: *Notwithstanding their serious mal-distribution, it remains the case that nurses, doctors and allied health professionals are at the heart of primary care, including for skin cancer. Because nurses are the largest and best-distributed health professionals in rural and remote areas, the best way to provide a workforce for skin cancer care in those areas is through continuing support for their recruitment, retention and professional support. Given the constraints on their time and energies in the vast areas they serve, GPs cannot provide cancer care alone. These local teams also have a key role to play in raising awareness about skin care. Providing more support for these health professionals is imperative to enable them to more effectively undertake the jobs for which they are qualified.*

Submission 34 exert, the Royal Flying Doctor Service (RFDS): *Skin cancer is a significant issue in rural and remote Australia, with high incidence rates due to a range of higher risk factors. There is also a persistent lack of services available in rural and remote areas. Difficulties in accessing appropriate local services often results in delayed detection and diagnosis and late treatment and requires patients to travel great distances for treatment services. The RFDS strongly recommends: Efforts to improve early diagnosis, treatment and management must take into account the significant lack of dermatology and other specialist services in rural and remote Australia. Recognise GPs and primary healthcare teams as the critical service providers in these areas. There should be a focus on enhancing and ensuring the knowledge and expertise of existing rural and remote service providers. Innovative service models, such as fly-in fly-out and telehealth services, should be considered to provide more dermatology and specialist services to rural and remote communities, in partnership with relevant rural health providers. Specific rural and remote community awareness-raising activities are needed that are appropriate, and targeted to rural populations, taking into account their unique lifestyle factors.*

The report from this Inquiry, *Skin Cancer in Australia: Our National Cancer,* was published in 2017 with 12 recommendations made by the Committee to improve the prevention and treatment of skin cancers in Australia.[24] Three recommendations are of particular relevance to nurses and primary healthcare workers working in regional, rural and remote Australia. These are:

- Recommendation 8 (part 2): Proficiency in the use of the dermatoscope be included in the practical component of all undergraduate medical courses and in rural nursing training courses.
- Recommendation 11: establish a virtual platform for the multidisciplinary treatment of skin cancer for patients located in regional and remote Australia; and
- further develop and implement best practice models for multidisciplinary care for the treatment of skin cancer patients.
- Recommendation 12: The Committee recommends that the Australian Government ensure that adequate funds are provided for the non-medical support services of skin cancer patients and their families, particularly support services for those rural patients who have to travel for treatment.

IMPROVING OPPORTUNISTIC SCREENING AND EARLY DETECTION THROUGH TECHNOLOGY AND NURSE-LED COLLABORATIVE ARRANGEMENTS IN REGIONAL, RURAL AND REMOTE COMMUNITIES

Currently the most prevalent tool for identifying skin cancers in general practice is by dermatoscopy. However this requires specialised training and when used by less experienced clinicians, the accuracy can be no better than visual inspection alone.[25] In 2004, in an effort to improve dermatological services to regional, rural and remote areas underserved by dermatologists, the Australian College of Rural and Remote Medicine introduced the Tele-Derm initiative, initially in Queensland and later expanding nationally. This free online consultation service requires the primary doctor to submit a clear resolution digital photograph to a dermatologist to provide advice. However barriers to doctors using the service have been cited as; lack of remuneration (not billable in the MBS), increasing their workload and too time consuming.[26]

The importance and role of multidisciplinary team (MDT) care in skin cancer is recognised as the best practice approach to providing evidence-based cancer care and is supported by the Council of Australian Governments (COAG) as reflected in the Optimal Care Pathways (OCP) for Melanoma and non-Melanoma skin cancers.[27] Nurses are key MDT members and recognised primary care providers in rural communities, having a broad scope of practice and working collaboratively in advanced and extended roles.[28] Within their scope of practice nurses have been engaged in preventative and nurse-led collaborative arrangements from skin cancer prevention through to early detection and management. Examples of nurse-led skin cancer assessment services in regional, rural and remote areas include initiatives by the Silver Chain organisation in Western Australia, the Skin Cancer Remote Service (SCARS) which provides nurse-led full body skin cancer screening with dermatoscopy and community education and upskilling of nurses.[29] Nurses have received training in dermatoscopy through training programs such as those offered through the National Professional Development Framework for Cancer Nursing (EdCaN). These learning resources can benefit health professionals not just specialising in cancer and include learning activities for individual nurses and nurse educators, including those for melanoma and current prevention and early detection campaigns. http://edcan.org.au/edcan-learning-resources/using-edcan-resources

Better use of technology has been a core recommendation of national health and skin cancer organisations for improving prevention and early detection of skin cancer. The Australasian College of Dermatologists actively promotes the adoption of telehealth in dermatology services to geographically diverse populations, noting the great potential for telehealth using smart devices for health prevention, education and rapid access to specialist opinion. Currently, practice guidelines for teledermatology are being developed collaboratively by the University of Queensland and the Australasian College of Dermatologists.[30]

Advances in dermatological imaging and improved communication systems will go a long way towards improving diagnostic accuracy and facilitating services to vast geographically diverse areas. New technologies such as surveillance photography, teledermatology, artificial intelligence, and apps to support patient self-examination and triage of clinical examinations also have the potential to reduce overtreatment or unnecessary treatment of some lesions detected in screening. These technologies have great potential to improve equity of access to dermatological services for people living in regional, rural and remote areas.[31] An emerging technology that is predicted to revolutionise these existing technologies is through artificial intelligence.

EMERGING TECHNOLOGIES: ARTIFICIAL INTELLIGENCE (AI)

Skin cancers, as a primarily visual diagnosis are considered one of the prime areas for technological health interventions. While there are existing smartphone apps for skin cancer detection, there is little evidence of clinical validation and poorly designed, inaccurate and/or misleading consumer applications may cause harm to patients and risk public safety.[32,33]

In 2017, in a letter to the prestigious science journal *Nature,* Esteva et al. described how artificial intelligence technology called convolutional neural networks (CNNs) matched or outperformed 21 board-certified dermatologist across three critical diagnostic tasks: keratinocyte carcinoma classification, melanoma classification and melanoma classification using dermatoscopy.[34] Following the publication of these findings, the international press was alight with headlines such as '*Man against machine, AI is better than dermatologist at diagnosing skin cancer*'. It was acknowledged that a dermatologist's clinical diagnosis is based on more than visual and dermatoscopic inspection of a lesion in isolation, however the ability to classify skin lesion images with the accuracy of a specialist has the potential to greatly expand access to skin cancer care.[34]

In a recent trial in dermatology clinics in seven UK hospitals, the study demonstrated that an AI algorithm using different camera types could detect melanoma with a similar accuracy as specialists. The authors concluded that the development of low-cost screening methods, such as artificial intelligence-based services, could transform patient diagnosis pathways, enabling greater efficiencies throughout the healthcare service.[32] Other specialities that will benefit from AI include radiology and pathology, with predictions that machine learning will soon displace most of this work.[35] At Memorial Sloan Kettering Cancer Centre in New York, AI is currently being used and further refined by cancer pathologists with results showing that machine-learning is approaching 100% sensitivity for biopsies for prostate, skin and breast cancer.[36]

There are still issues to overcome in AI technology with regards to early detection of skin cancers including different skin backgrounds (most have been tested on caucasian populations), varying camera angles and lighting. It has been recommended in a systematic review and in several other studies assessing CNN that to improve the robustness of the CNN classifier, establishment of an open-access, standardised, large skin tumour image dataset, which includes both rare tumours/subtypes and all ethnicities, is mandatory.[37,38] In Australia, the University of Queensland is part of the International Skin Imaging Collaboration (ISIC) Melanoma Project which is addressing issues concerning standards and technology and developing an open source public access archive of skin images.[39]

While an accurate history and assessment will always be as essential component of diagnosis and management, initial visual inspection and classification by AI will go a long way towards early detection in communities where access to GPs and specialist doctors are difficult such as in regional, rural and remote Australia. Smartphone applications do not currently incorporate AI technology; however, it is just a matter of time before the technology is readily available for GPs and nurses to make the best use of this technology through smartphones. In a thoughtful editorial regarding AI and melanoma by Associate Professor Mar of Monash University and Professor Soyer of Queensland University, it was noted that AI promises a more standardised level of diagnostic accuracy, such that all people, regardless of where they live or which doctor they see, will be able to access reliable diagnostic assessment.[40]

WHERE TO FROM HERE?

The harnessing of AI technology as a public health tool for early detection and disease management of melanoma and KC will differ in approach but has great potential to reduce the burden of healthcare costs to the community and improve health outcomes. The Australian Government supports that Optimal Cancer Care Pathways be used as a key resource in exploring best practice models of care for skin cancer patients both for the development of digital platforms and face to face MDTs.[27] Delivering healthcare to regional, rural and remote communities is challenging and nurses are increasingly called upon to work to the full scope of practice as well as working in advanced practice roles in Australian rural health services in response to workforce demands.[41] Nurses as primary healthcare providers in regional, rural and remote Australia are well positioned to be at the forefront of delivering these emerging technologies, whether working in advanced nursing practice roles and/or working collaboratively with GPs and dermatologists through established multidisciplinary organisations that focus on delivering services in regional, rural and remote areas.

As skin cancers are initially assessed on visual inspection and prompt action is likely to result in cure, opportunistic screening in high risk populations with AI has great promise by means of improving diagnostic accuracy and decreasing the high proportion of investigations of suspicious benign lesions. It has been noted that despite the benefits of telehealth technologies, the actual uptake and integration into mainstream practice has been slow and fragmented, with many pilot programs not migrating into sustained services.[42] The introduction of AI potentially could remove some of these telehealth barriers, such as the need for real-time consultations and administrative burden. In a systematic review of telehealth services in rural Australia, six factors were identified that influenced success and sustainability of telehealth services. These were: vision, ownership, adaptability, economics, efficiency and equipment. [42]

Translation into a real-world scenario with AI technology is not too distant in the future. Mobile app technology and repositories of public source images of different skin lesions are becoming available. AI for skin cancer early detection is a good technological alternative for which there is good evidence, and is likely to be well received, efficacious and cost effective. There is likely to be minimal training involved and with better support and utilisation of the existing primary care workforce the technology should be readily adaptable within existing services. Careful planning and collaboration between health services will be needed to ensure that best practice is applied in bringing these services to those in regional, rural and remote Australia. As a needed service that will be low cost, efficacious and has great potential for cost savings to the health system, the time is ripe for exploring opportunities to bring this emerging technology to those who will most benefit from it.

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REVIEWS & DISCUSSION PAPERS

Community respite service utilisation and dementia care: a review of literature

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ABSTRACT

Objective: To explore the detrimental effects of caregiver burden, in relation to caregivers of people with dementia, and highlight caregiver burden as an emerging healthcare problem. The purpose of the literature review is to inform healthcare professionals of the barriers to utilising community respite services by caregivers and discuss the significance of respite services to caregivers of people with dementia.

Background: Dementia is one of the leading contributors to burden of disease and disability. Increasing numbers of spouse and family caregivers play crucial roles in providing support for people with dementia enabling them to continue living in the community. Caregiver burden occurs in individuals when the demands of caregiving exceeds their resources. Community respite services are valuable resources which provide individuals a break from their caregiving role.

Study design and methods: The literature review will draw attention to caregivers of people living with dementia in the community and their utilisation of community respite services. The target audience are healthcare professionals in multidisciplinary community teams composed of clinicians, educators, managers, administrators, and researchers. Seven online databases were accessed to search the following terms of caregiver burden, dementia care and community respite along with specific inclusion criteria. As a result, 26 scholarly articles were reviewed for the purpose of this literature review.

Results: There are several community respite services, which help minimise the incidence of caregiver burden, available to caregivers of people with dementia but there are many barriers which affect utilisation of these services. Some of these barriers include accessibility of information on respite services, flexibility and affordability of respite services, and the caregiver's inability to recognise their need for respite services.

Discussion: Healthcare professionals could assist caregivers to better utilise community respite services by performing through assessments on both people with dementia and their caregivers. As a result of these assessments, potential barriers to community respite service utilisation could be identified.

Conclusion: Community respite services are essential to minimising the incidence of caregiver burden. Healthcare professionals should recognise these barriers to respite service use and implement strategies to increase service utilisation.

Implications for research, policy, and practice: Further research is required to investigate the specific types of respite service caregivers need and which respite services have been most successful

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for caregivers. This knowledge can assist healthcare professionals in improving utilisation rates of respite services and inform health systems on where to focus the funding of their community resources for people with dementia and their caregivers.

Key words: Caregiver burden, dementia, respite, community, literature review

What is already known about the topic?

- Dementia is an emerging healthcare problem leading to caregiver burden amongst caregivers.
- Community respite services help minimise the occurrence of caregiver burden.

What this paper adds:

- Contributes to the existing knowledge of caregiver burden amongst Australian healthcare professionals.
- Identifies several barriers to caregiver respite service utilisation.
- Emphasises the significance of respite services to caregivers of people with dementia.

INTRODUCTION

The Australian Institute of Health and Welfare[1] states Australia's profile of its older population is projected to change in the coming years. In 2017, more than half of older people (57%, or 2.2 million) were aged 65–74, one-third were aged 75–84 (30%, or 1.2 million), and 13% were aged 85 and over (497,000). By 2047, it is projected there will be just under 3.4 million people aged 65–74.[1] It is evident that the number of people over 65 years will continue to grow as the population ages. Dementia is the number one cause of disability in Australians aged 65 years and older and it is characterised by the gradual impairment of brain function where the skills commonly affected include memory, cognition and personality.[2] Dementia presents a significant challenge to health and aged care in Australia. More than 342,000 Australians are living with dementia and this number is expected to increase up to 400,000 in less than a decade.[3] Worldwide, at least 44 million people are living with dementia, making the disease a global health crisis that must be addressed.[3]

Dementia is one of the leading contributors to burden of disease and disability, and people with dementia (PWD) are frequent users of health and aged care services.[2] This progressive neurodegenerative disease is difficult for both healthcare professionals (HCPs) and family caregivers to manage.[4] There are increasing numbers of spouse and family caregivers playing critical roles in providing support to PWD which enables them to remain living in their own homes.[5–7] Caregivers are those who share responsibility for another person's health, wellbeing and safety over time.[8] They are also unpaid individuals who support or provide informal care to a person who is dependent due to long-term physical or mental illness or to age-related problems.[5] The care of PWD provided at home often involves longer hours and more intense care compared with amount of formal care provided by health services.[5,6] Caregiver burden can be described as the emotional, physical, social, and financial costs that results when the demands of caregiving exceeds one's resources.[8–12] This literature review highlights caregiver burden as an emerging healthcare problem as it explores the detrimental effects of caregiver burden. Furthermore, this paper aims to educate HCPs on the barriers to utilising community respite services by caregivers and discuss strategies to increase service utilisation in order to minimise caregiver burden.

METHODOLOGY

Scholarly articles were researched using the following databases CINAHL plus, Academic search complete, eBook collection, Health source – nursing/academic edition, PsycInfo, Psych articles, and Socio/index with full-text. The inclusion criteria are as follows full-text, published between 2000–2018, and peer-reviewed. Search terms used included caregiver burden, dementia care, community, respite, and Australia. The primary search strategy used the terms caregiver burden, dementia care, and community which yielded 143 articles and a total of 95 articles excluded. Research based in the United States, rural settings, and non-English speaking countries were omitted due to the unfamiliarity of the author with how community services are delivered in these areas. In addition, research based in residential care settings were omitted. The remaining 48 articles were reviewed and 30 articles were excluded as they described caregiver burden not in the context of dementia care and some articles were situated in rural communities. As a result, 18 articles were chosen for this literature review (Figure 1).

A secondary search strategy was conducted using the eight previously stated databases to capture articles based in Australia. The search terms used were caregiver burden, dementia care, community, respite, and Australia. This search yielded 26 articles and 14 articles were chosen as 12 were excluded due to lack of dementia care, non-Australian articles, and focused on a specific intervention (Figure 2). These 32 scholarly articles resulting from both searches were

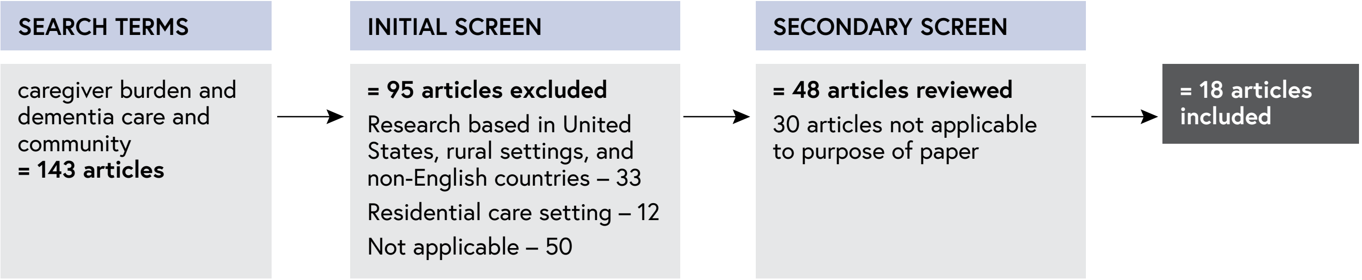

FIGURE 1: PRIMARY SEARCH STRATEGY

reviewed and sorted into two groups of caregiver burden and caregiver burden resources. Upon further review of the articles, an additional six articles were excluded as the content was found not to be suitable for this literature review. As a result, 26 scholarly articles were used for the purpose of this literature review.

DISCUSSION

CAREGIVER BURDEN AND DEMENTIA CARE IN THE COMMUNITY

Caregivers of people living with dementia experience many challenges as the disease progresses. As dementia develops, it leads to increased dependency and a consequent need for continual assistance by their caregivers.[13,14] People with dementia experience disruptive symptoms such as sleep disturbances, incontinence, decreased mobility, inability to recognise family and friends, changes in sexual behaviour, disorientation, paranoia, wandering, and agitation.[11,14,15] As a result of this increased dependency, caregivers can experience symptoms of burnout. Caregiver burden is a term used to describe the negative effects of caring on the person's physical, mental, social, and financial wellbeing.[10–12,15] Family members, such as a spouse or adult child, usually become the caregivers of PWD, which puts added stress on their relationship especially when their loved one no longer recognises them.[10] In Australia, most people living with dementia are cared for by a family member and 25% of family caregivers provide 40 hours of care or more per week.[16,17] The care they provide includes assistance with activities of daily living, such as bathing, dressing, and eating, as well as essential activities of daily living, such as money management or transportation.[11,18] More than two-thirds of caregivers maintain at least 40 hours of care a week for more than 12 months, with one-third caring at that level for five years or more.[17] This continuous and demanding role can have a negative effect on caregivers' mental and physical health.

CAREGIVER BURDEN: AN EMERGING HEALTH ISSUE

Ageing in-place movement

As the number of PWD rises, the number of family caregivers looking after PWD will also follow in increasing numbers. While dementia is not an inevitable part of ageing, almost 10% of Australians aged 65 or over have the condition, rising to 30% of those aged 85 and over.[19] Subsequently, there will be a significant number of older people living with dementia in the coming years who will require healthcare resources both in the community and residential care. This poses significant challenges for aged care policy and services to shift from institutional care (higher-cost) to community care (lower-cost) for older people living with dementia.[20] The shift in aged care policy to support community care is based on the principle of 'ageing-in-place' which enables older people to remain in their own homes longer rather than entering residential care prematurely.[21] Similar to Canada, this policy shift has been supported by older people and governments however, this has redistributed care work from paid institutional carers (formal services) to unpaid carers (informal caregivers) such as family caregivers [7,20,22,23]. The Australian Institute of Health and Welfare [19] found the shift to 'ageing-in-place' aged care policies over the last two decades has resulted in the number of residential care places per 1,000 persons aged 70 years and over dropping from

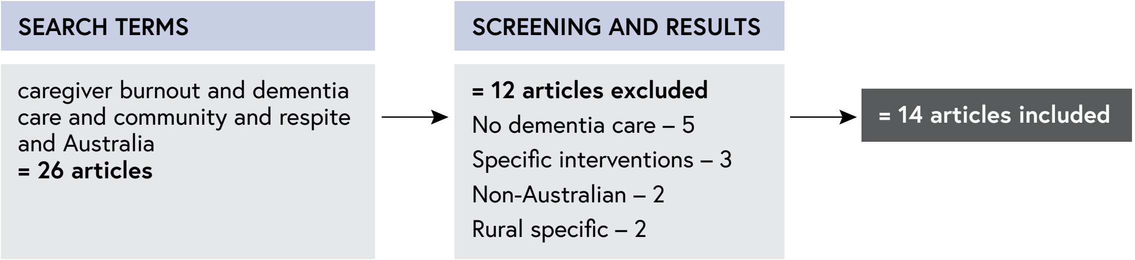

FIGURE 2: SECONDARY SEARCH STRATEGY

92.2 in 1995 to 86.8 in 2010 with the number of community-based aged care places increasing from 1.7 to 24.4 over the same period. Although this change in health policy was intended to allow older people to remain in their homes longer rather than entering institutions prematurely, there has been an inadvertent negative effect on family caregivers where they may feel pressured into taking on the role of informal caregivers.[7,22] The informal care provided by family caregivers assist in lowering the cost of care on health systems but it is at the cost of their own health and wellbeing if adequate support services are not in place. It is evident that community resources are needed to support family caregivers in maintaining their own health and wellbeing and to decrease the incidence of caregiver burden.

The effects of caregiver burden

Family members who care for PWD and live in the community experience high levels of stress and burden. It is well established that these caregivers often experience stress, depression, anxiety, physical illnesses, financial strain, social isolation, and poor quality of life as a result of their caregiving role.[5,7,13,14,18,23–28] The degree of functional impairment and behavioural disturbance of PWD has been shown to induce high levels of caregiver stress and lower levels of subjective wellbeing, which has been linked to higher rates of depression in caregivers.[14,28] It was found that one in four caregivers of PWD contemplated suicide more than once in a previous year which was a rate more than eight times than that of the general population.[25] O'Dwyer, Moyle and van Wyk found that nearly half of the participants in their study had experienced suicidal thoughts while caring and half of those made plans for a suicidal act.[29] Caregivers who considered suicide *'had poorer mental health, reacted more strongly to the behavioural symptoms of dementia, and were less satisfied with the social support they were receiving'*.[25(p.222)] Clearly, caregiver burden along with poor mental health and evidence of depression puts family caregivers of PWD at risk of suicide. It is important for HCPs to acknowledge the significance and the impact of caregiver burden for those caring for PWD.

People with dementia are commonly cared for informally by spouses or their adult children. The current demographic trend indicates that adult children are becoming primary caregivers to their ageing parents.[27] In Australia, 42% of main caregivers of PWD were their spouse/partner and 44% were their son or daughter,[19] while in Canada, 62% of adult children were primary caregivers to their ageing parents.[27] Adult children who become caregivers to their ageing parents experience different stressors to spousal caregivers. Bastawrous explains how the provision of care by adult children is unique as there is a role reversal within this established relationship.[27] The child who was once the receiver of support and nurturing must now provide the support and assistance to their parent. This role reversal not only disrupts the established relationship with the parent but combined with the other demands of caregiving can lead to hostility and resentment.[27] In addition, adult child caregivers often have to negotiate the caregiver role with other family members and this can cause significant family conflict and interpersonal stress.[24,27]

Adult children in a caregiver role have been termed the 'sandwich generation' where they provide care for ageing parents while still supporting their own children as well as their grandchildren in some cases.[20] Moreover, if these caregivers are still working, the burden of this multigenerational caregiving is compounded. They would have to prioritise their time and decide where and when the support is needed most, such as assisting their parents with their activities of daily living, while balancing their own work and family commitments. This can be difficult as adult children are typically at a stage in their lives where they have several roles and responsibilities such as being a spouse, parent and employee.[27] Subsequently, work responsibilities can be viewed as contributing to caregiver stress outcomes especially if the caregiver's employment involves long hours.[23] This sandwich generation of caregivers are also at the point in their lives where they have plans for advancing their career, travelling during their retirement, or pursuing their own interests.[20] The unexpected responsibility of caring for their ageing parent could affect their social and financial wellbeing.

Integrated care for caregivers model

Daniel's Integrated Care for Caregivers Model explains the factors that influence the health and wellbeing of a caregiver.[8] This model describes the nine domains of education, recreation, nutrition, sleep, exercise, support, spirituality, communication, and counselling, all of which provide the supporting base for four key elements of a caregiver's health and wellbeing; physical, emotional, mental, and spiritual.[8] As mentioned earlier in this paper, caregivers experience higher levels of stress and burden when these domains are negatively affected. These nine domains are fundamental in determining the health of the caregiver however education, sleep, emotional and psychological support, and counselling will be discussed further.

Daniel states family caregivers are often unprepared to provide care, have inadequate knowledge to deliver proper care,[8] and are unaware of community resources available to them. It is the responsibility of HCPs to provide support and education on the skills needed for caregivers of PWD to manage their care and to discuss the community resources available to them. Caregivers' sleep patterns may be affected over time, especially with the progression of the care receiver's disease, which may exacerbate depression and symptoms of chronic illnesses.[8] Healthcare professionals can ensure caregivers are taught strategies to manage the behaviours of PWD and to prevent the occurrence of these behaviours during the night (eg. taking them for daily walks during the day). Emotional and psychological support involves having positive interactions with a good social support network of family and friends especially under heightened stress.[8] Healthcare professionals should encourage caregivers to maintain their social support and social networks in order to minimise the incidence of caregiver burden and prevent depression. It is important for caregivers to understand the need for counselling as it helps caregivers improve communication and problem-solving techniques, learn various behavioural management strategies, maintain quality care and positive outlooks.[8] This model highlights the nine domains which HCPs should consider when assessing the health and wellbeing of caregivers.

Significance to healthcare professionals

It is important for HCPs to understand the caregiver experience when providing care to PWD. Caregivers often request information about dementia from prognosis to strategies on how to deal with disruptive behaviours.[5,8] Healthcare professionals have a responsibility to support family caregivers by providing education and counselling to promote their wellbeing. Educating caregivers is important as it empowers caregivers through knowledge and it is a way of supporting caregivers in their demanding role.[5,30] Moreover, HCPs are fundamental in providing ongoing emotional support to caregivers especially when they are faced with making difficult care decisions.[31] As mentioned earlier in this paper, it is essential for HCPs to recognise poor mental health in the presence of caregiver burden as it can lead to suicidal thoughts in caregivers. This can be a strong indicator of the caregiver's physical and emotional suffering warranting prompt intervention from HCPs.

Supporting caregivers in their challenging role has many benefits for caregivers, PWD, and healthcare systems. The significance of HCP involvement in decreasing the incidence of caregiver burden is that *'placement in residential care facilities has been associated with rapid deterioration in health, psychosocial challenges for patients and families, and increased mortality'*.[10(p.24)] Consequently, the ability for those living with dementia to remain in their homes longer with community support services delays institutionalisation and decreases mortality.[4,10]

COMMUNITY RESPITE SERVICES

People with dementia eventually decline physically and mentally affecting their ability to perform their activities of daily living. Vreugdenhil found that caregivers of PWD assisted with a wide range of activities which included self-care, meal preparation, transport, and communication.[20] Informal caregivers require formal services because caring for PWD can be complex, demanding, and at times assistance is needed around the clock. Formal services, which support caregivers in managing the people they care for, are referred to as respite services or respite care. Respite is defined as a pause, a temporary cessation, or an interval of rest.[32] Tretteteig found in their review that caregiver burden is significant and gives rise to a great need for support and help.[13] Respite care is a way of supporting caregivers and delaying institutionalisation.[6,13,14,30,31] It is also essential in the home management of PWD as it helps to decrease stress related to the demands of caring and also allows time for caregivers to rest and do things for themselves.[31] This temporary relief of their burden of care enables them to attend to basic everyday needs such as attending to their own healthcare, shopping, and social needs.[6] O'Connell and colleagues found that four out of five caregivers in their study stated that they had experienced lower stress levels since utilising respite services and more than half reported that their own health had improved since using the service.[6] Utilising respite services is crucial to the health and wellbeing of the caregiver and it could possibly lengthen their ability to care for PWD in their own home.

There are several types of respite services in the community which can be utilised in crisis situations or in part of a planned regular service to provide custodial care. The most common types of respite used are at a day centre, within the home, and at residential care.[6,14,30] In-home respite involves community health workers assisting PWD with their activities of daily living or simply watching over them in their home while their caregiver leaves for a much-needed break. Day centre respite involves PWD attending for a set period time to participate in planned activities whereas residential care respite involves a short stay, such as a week, within the facility.[6,14]

BARRIERS TO UTILISING RESPITE SERVICES

Clearly, there is a significant amount of research and systematic reviews on caregiver burden, dementia care and respite services in the community however there was limited research on why caregivers underutilise community respite services despite its benefits in reducing caregiver burden. Caregivers face many challenges when caring for PWD and HCPs may assume caregivers would regularly utilise the community resources available to them. Throughout the reviewed literature, it was evident that respite services were underutilised due to several key barriers. Caregivers were reluctant to utilise essential support services because of their negative emotions of grief, sadness, or frustration or they were unable to identify that their stress was directly linked to the care recipient.[11,12,18,32] Furthermore, caregivers lacked the knowledge of respite services available to them.[5,8,12,14,32,33] Eifert and Eddy also found some caregivers chose not to utilise respite services because they wanted to keep their loved one's diagnosis private and any acceptance of help from outside the family was seen as an invasion of privacy.[11]

In contrast, when caregivers utilised respite services, they discovered barriers themselves that prevented or limited further respite service use. Caregivers found respite services were inflexible or unreliable in their delivery times and it did not meet their needs.[6,12,14,18,22,32,33] Caregivers reported that there was a greater amount of work generated when preparing PWD for respite and this caused the caregiver more stress.[11,32] Caregivers also stated that managing the behaviour of PWD post-respite service use resulted in disruptive behaviours, such as resisting care or aggression, causing additional caregiver stress.[6,11,14] This interruption of the PWD's routine outweighed the benefits of utilising respite services as perceived by their caregivers. Lastly, caregivers expressed concerns of the cost of respite services and utilisation these services depended on caregiver affordability.[6,11,33]

STRATEGIES TO INCREASE RESPITE SERVICE UTILISATION

Current health policy dictates that one of its key goals is to delay the institutionalisation of PWD however there is overwhelming evidence that community resources should consider not only the care of PWD but also the health and wellbeing of their caregivers. The benefits of broadening the focus of care will help sustain caregivers to continue caring for PWD in their own home for years to come. HCPs have a significant role in performing thorough assessments on both PWD and their caregiver. These assessments will help identify any knowledge gaps in relation to physically and mentally caring for PWD and communicate vital information on the community respite services available to caregivers. The contact with caregivers and PWD during these assessments gives HCPs the opportunity to offer ongoing emotional support to both the caregiver and PWD. As the relationship between HCPs and caregivers develops over time, HCPs are in a position to identify when additional support is needed, such as counselling through a social worker or the initiation of respite services. This established and long-standing relationship between HCPs and caregivers facilitates continuous communication where caregivers are able to inform HCPs of any issues they might encounter in relation to respite services, such as inflexibility, unreliability, and unaffordability.[32] Healthcare professionals should work with the community multidisciplinary team to address the barriers of specific services with the goal of increasing respite service utilisation by caregivers. Furthermore, HCPs should help caregivers create a plan of care following respite service use to address disruptions and behaviours of PWD and minimise caregiver stress post-respite.

RECOMMENDATIONS FOR FUTURE RESEARCH

There is limited knowledge on which respite services have been beneficial to caregivers as the articles that were reviewed only described the respite services in relation to PWD and not their caregivers. Additional research is required to investigate the specific types of respite service caregivers need and which respite services have been most successful for caregivers. This knowledge can assist HCPs in improving utilisation rates of respite services and inform health systems on where to focus the funding of their community resources for PWD and their caregivers.

CONCLUSION

Caregiver burden is undoubtedly a prominent health issue which will persist as the population continues to age and the number of PWD increases. Caregivers of PWD partake in a demanding role which impacts their own health and wellbeing. Subsequently, health systems are responsible in providing support to these informal caregivers since they delay the use of formal services, such as residential care, and help PWD remain in their own homes longer. HCPs should perform thorough assessments of both the caregiver and PWD to maintain their health and wellbeing and to encourage the use of respite services. Furthermore, HCPs must identify the barriers to respite service utilisation by caregivers so that strategies are implemented and the incidence of caregiver burden is reduced.

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IN THIS ISSUE

EDITORIAL

RESEARCH ARTICLES

REVIEWS & DISCUSSION PAPERS

LETTER TO THE EDITORS

The *Australian Journal of Advanced Nursing* is the peer-reviewed scholarly journal of the Australian Nursing and Midwifery Federation (ANMF). The Mission of *AJAN* is to provide a forum to showcase and promote a wide variety of original research and scholarly work to inform and empower nurses, midwives, and other healthcare professionals to improve the health and wellbeing of all communities and to be prepared for the future.

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EDITORIAL

COVID-19 and residential aged care in Australia

The COVID-19 pandemic continues to have far reaching impacts on individuals, professionals, human services such as aged care and, society more broadly. In Australia we are proud of our success in limiting the direct impacts the virus has on mortality and morbidity. When reflecting on this pandemic we must recall that 'success' has many parents - everyone clamours to explain that their actions created a positive outcome. In contrast 'failure' is an orphan—no-one steps forward to acknowledge their responsibility for an adverse outcome. The reality is Australia's success with the emergency response and management of COVID-19 pandemic are in a large part due to inherent underlying geographic and population factors. We live on an island continent with an extraordinary ability to control our borders. We have an extremely low population density and our population is widely dispersed. Also instrumental was our coordinated and prompt public health responses and community cooperation.

As of June 24 2020, nationally the total number of COVID-19 infections was 7,521 with 103 deaths comprising 29 aged care residents.[1] Internationally, Australia rates extraordinarily well on these metrics.[2] What we must guard against are complacency and overconfidence.

This is evident in efforts to thank aged care staff for working extremely hard. We conflate our words of gratitude with unsubstantiated statements about how well the whole aged care sector is operating. The absence of catastrophic impacts of the COVID-19 pandemic in aged care homes in Australia that occurred around the world are not evident of a highly functioning system. The virus has not washed away the systemic failures highlighted in the interim report by the Royal Commission into Aged Care Quality and Safety.[3]

While the COVID-19 pandemic exacerbates and highlights the existing primary failures[4] in the provision of residential aged care in Australia. We are distracted by the profound shift in our usual way of life, the fear and angst with confronting a once in a century natural disaster.

We require a prudent approach if we are to guard against the high COVID-19 case fatality rate of residents in aged care homes. This article is intended as a sober reflection at the structural domains of the aged care sector and the COVID-19 pandemic. The domains are governance, workforce, models of care, evaluation including the use of data and finally, resources and infrastructure.

GOVERNANCE

Governance or the lack thereof is a recurring issue in aged care. Good governance comprises following the rule of law, transparency and accountability for service provision. The COVID-19 pandemic highlight major gaps in this domain for the sector. There was a slow recognition of the extremely serious risk COVID-19 posed for older people and the multiple authorities involved, creating confusion and lack of consistency to optimally manage the pandemic.

The initial Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19) did not reference the Royal Commission nor recognise aged care as a system that is failing in 'usual circumstances'.[5] At a federal level there are the regulators in Aged Care Quality and Safety Commission and two separate portfolios of government in health and aged care are involved. At a State level the Department of Health and Public Health Units as well as the providers for general practice and the acute hospitals.

This hampered development of a coherent policy and appropriate practice for a humane lockdown at each aged care facility. At a local level there was confusion for aged care providers and staff when an outbreak of COVID-19 occurred such as at Newmarch House.[6]

The lack of transparency in aged care was especially evident with the facility lockdown. Inability of families to visit their loved one was compounded by a pre-existing absence of a minimum standard of information about care delivery to residents. This type of public reporting that is user-friendly and easily accessible to consumers would have eased enormous worry for families and the community in general.

WORKFORCE

Much was made of the need to retain and upskill staff to manage the COVID-19 pandemic. Specifically, the need for residents to shelter in place and for facilities to be able to provide the additional clinical care. Recognition that the sector was understaffed and was not equipped to step-up service to that of an acute hospital was slow in being recognised and remains an issue. The federal government surge workforce initiative addressed aspects of these issues temporarily.

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What remains is a failure to address the long-term systemic issues highlighted again in a recent international comparison of aged care workforce. Eagar and colleagues report widespread and substantial gaps in the workforce which impacts on the quality of care for residents.[7]

The deskilling of the workforce by reducing the number of nurses employed in aged care homes continues to occur. The pandemic highlighted an unfair and unreasonable expectation that personal care attendants could and should 'step-up'. Asking personal care attendants to deliver highly technically care in an urgent and complex situation is bewildering given the entry requirements into this role is a very basic level of skill training.

This issue should have received a more robust public, aged and health care sector debate. As it goes to the essence of the standard of care for older people infected with COVID-19. The absence of a genuine resident voice is at the heart of this silence. A silence not overcome by boisterous peak bodies that represent providers, professionals or community dwelling older people.

MODELS OF CARE

The emergency response to the COVID-19 pandemic assumed that the existing model of care could readily adapt into an acute health model. The duality of purpose in residential aged care has not ever been satisfactorily resolved. Government, providers, health professionals, acute hospitals pivot around their preferred model of care to suit the immediacy of their argument. The workforce composition is predicated on a model of care that assumes aged care is a residence, a home to live in for well older people who occasionally need assistance with personal care. The reality is far different. A model of care must recognise that residents are frail older persons with cognitive impairment and multiple other comorbidities who are vulnerable to dramatic or life-threatening consequences from minor insults or injuries.

The older person in an aged care home has a diverse set of clinical, health maintenance and quality of life needs. The expertise for all aspects is unusual to find in one place.[8]

EVALUATION

The volume of data, statistics and tally counts during the first wave of COVID-19 were overwhelming. Sadly, there was little useful data to guide aged care. This was evident internationally in the United Kingdom and France with the incomprehensible failures to recognise or include the deaths of aged care residents in a nation's official case fatality count. In Australia, information about the number of aged care facilities with an outbreak, how these were managed and, the lessons to be learned were and remain difficult to access in the public domain. Detailed, relevant, standardised reports about the quality of care being delivered to residents were largely absent. Mostly because prior to the COVID-19 pandemic this information is either not collected or if gathered not released. Information indicative of whether the aged care sector was coping requires examining measures of system distress such as the use of restrictive practice, resident mental health and wellbeing and those exhibiting severe responsive behaviours.

The existing data indicated pre-existing deficits in infection control that could have informed specific strategies to improve our national approach in aged care.[9,10]

RESOURCES AND INFRASTRUCTURE

The limitations in our resources and infrastructure have been largely overlooked. Patched over with temporising measures with surge workforce or staff stepping in to fill the void because of the urgency of the situation.

The existing building designs and stock for aged care homes create conditions for rapid spread of infection. Small bedrooms, shared bathrooms, communal areas and a 'home-like' environment that precludes the space and equipment to maintain meticulous infection control.

CONCLUSION

The aged care sector requires transformation. The havoc wreaked by the COVID-19 pandemic globally and nationally may create an environment where the required changes are lost to other priorities. We should remember that it was good fortune that allowed Australia's aged care sector to survive so well. That the second and subsequent waves require good management. That requires understanding the existing gaps and bridging these in the short term for the pandemic. To achieve long term changes requires vigilance and advocacy.

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RESEARCH ARTICLES

The effects of a hospital-based perinatal breastfeeding program on exclusive breastfeeding in Taiwan: a quasi-experimental study

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ABSTRACT

Objective: To examine if a perinatal breastfeeding program would improve the exclusive breastfeeding rate at a baby-friendly hospital.

Background: The Ten Steps to Successful Breastfeeding and Baby-Friendly Hospital Initiative have been widely used to improve breastfeeding outcomes worldwide. A hospital-based multi-strategy intervention may provide an opportunity to increase breastfeeding in different countries.

Study design and methods: The study used a quasi-experimental design. Data was collected in a Baby Friendly hospital. A total of 60 mother-infant dyads were included. The experimental group took part in the multi-component perinatal breastfeeding program, while the control group received routine care. The multi-strategy program included prenatal breastfeeding education, birth kangaroo mother care (skin-to-skin contact and non-separation practices) at first breastfeed, continuous 24-hour rooming-in, ongoing kangaroo mother care with breastfeeding on cue, and hospital support visits. The exclusive breastfeeding rate was measured at hospital discharge, and one-month postpartum.

Results: The mothers who participated in the intervention had a greater exclusive breastfeeding rate at hospital discharge and one month postpartum than those in the control group. In the experimental group, 90% of the infants completed the first feeding within two hours after birth. At discharge, 93.3% of the mothers in the experimental group and 53.3% in the control group were exclusively breastfeeding. At one month postpartum, 83.3% of the mothers in the experimental group and 36.7% in the control group were still exclusively breastfeeding.

Discussion: The intervention program used in the current study is different to previous studies. The current intervention not only included prenatal education and postpartum support, but also included birth kangaroo mother care at first breastfeed and ongoing kangaroo mother care with breastfeeding on cue. Breastfeeding should be promoted through perinatal comprehensive clinical and social support starting in the prenatal period and continuing through intrapartal, postpartum, and follow-up periods.

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Conclusion: This study was the first study to use a hospital-based multi-strategy intervention including the non-separation of mother-infant dyads and other breastfeeding support for mothers in Taiwan. The program was associated with a significant improvement in the exclusive breastfeeding rate at one month postpartum.

Implication for practice: This study provided initial evidence to support the implementation of mother-infant non-separation practices in improving breastfeeding outcomes. Health professionals can be re-educated regarding birth kangaroo mother care at first breastfeed and ongoing kangaroo mother care with breastfeeding on cue without increasing nursing workloads while infants' fathers and other family members (eg. mothers-in-law/mothers' mothers) can be encouraged to participate in order to achieve family-centred maternity care.

What is already known about the topic?
- Early and exclusive breast feeding and ongoing breast feeding is the optimal form of nutrition for newborn babies and promotes positive infant and mother outcomes.
- Birth kangaroo mother care plays an important role in providing the optimal atmosphere for a baby's instinctive reflex ability to breastfeed effectively in order to help infant imprinting and suckling.

What this paper adds:
- The newly developed hospital-based perinatal breastfeeding program has demonstrated effectiveness in promoting exclusive breastfeeding rate at one month postpartum.
- Including birth kangaroo mother care at first breastfeed and ongoing kangaroo mother care with breastfeeding on cue in a perinatal breastfeeding program may lead to more positive breastfeeding experiences for new mothers.

Key Words: birth kangaroo mother care, breastfeeding on cue, exclusive breastfeeding, breastfeeding education.

INTRODUCTION

In order to be accredited as a baby-friendly hospital, a hospital must demonstrate compliance with the international criteria relating to the Ten Steps for Successful Breastfeeding and the international code of marketing for breast-milk substitutes.[1] Breastfeeding confers significant health benefits to mother-infant dyads and, consequently, is recommended for all infants worldwide. Exclusive breastfeeding is advocated as the optimal nutrition for infants in the first six months of life.[2] Breastfeeding is widely known to provide health, social, and economic benefits, and 96.29% of mother-infant dyads who participated in Taiwan's Baby-Friendly Hospitals Initiative have engaged in breastfeeding; however, only 44.8% of the infants were still exclusively breastfed at six months in Taiwan-based hospitals.[3] Overall, the global breastfeeding movement has had a significant impact on increasing initiation of breastfeeding worldwide. However, while breastfeeding initiation rates are high, the duration of exclusive breastfeeding is quite short. In Australia, 93% of women initiate breastfeeding, but only 66% still breastfeed at six months, and only 29% are exclusively breastfeeding at six months.[4]

Globally, the early termination of breastfeeding is commonly due to negative initial breastfeeding experiences and perceived insufficient milk supply,[5–7] and these factors are primarily related to breastfeeding experiences in the first days after birth. Negative initial breastfeeding experiences might stem in part from the current maternity healthcare practice paradigm of mother-infant separation. Two cross-sectional surveys in Poland illustrated the effects of separation versus non-separation of mother-infant dyads immediately after birth on breastfeeding outcomes.[8,9] Mazur, Mikiel-Kostyra, and their associates have identified various factors in maternity hospital care affecting exclusive breastfeeding.[8] The most significant factors in hospital care relating to decreased initiation, continuation, and exclusivity were breastfeeding initiation more than two hours post-birth, a lack of skin-to-skin contact, and mother-infant separation lasting longer than 24 hours.

Previous research has suggested the use of the following five interventions to facilitate the continuation of exclusive breastfeeding: prenatal breastfeeding education (PBE) for parents,[10–12] birth kangaroo mother care (BKMC) at first breastfeed,[1] continuous 24-hour rooming-in,[13–15] ongoing kangaroo mother care (KMC) with breastfeeding on cue,[16] and support from health professionals.[17] Therefore, it is important that non-separation practice (that is, skin-to-skin contact) is applied from birth to discharge to promote breastfeeding outcomes. It is also important for multi-strategy interventions to encourage parents to maintain exclusive breastfeeding for an extended duration. That said, as we found no previous studies utilising the intervention we used in the Taiwanese study, we consider this to be the first study in Taiwan to use an intervention combining "BKMC until the first breastfeed is completed" with other key strategies to promote an extended duration of exclusive breastfeeding.

BACKGROUND

Prenatal breastfeeding education (PBE) for parents is important as an effective single intervention for the promotion of breastfeeding. One of the psychosocial factors commonly affecting the early termination of breastfeeding is the lack of support from the father of the infant.[18] Consequently, infants' fathers need to participate in PBE in order to better support breastfeeding. A systematic review and meta-analysis provided evidence that PBE increases the initiation of breastfeeding and the short-term duration of breastfeeding, although it did not have a significant impact on the long-term duration of exclusive breastfeeding.[10,11,19] One early breastfeeding program reviewed in a previous study focused on the benefits of breastfeeding, traditional hands-on breastfeeding skills, and getting started.[20] However, the program did not provide any new information on the importance of the concept of mother-infant dyad non-separation or infant-led breastfeeding skills.[21] Rather, the program was designed to provide more general PBE and psychological preparation for parents.

The classifications of the stages of kangaroo mother care (KMC) are as follows: birth, very early, early, intermediate, and late stage.[22] Birth kangaroo mother care (BKMC) and very early kangaroo mother care (VEKMC) initially occur in the delivery room. BKMC begins immediately (within one minute) post-birth and before cutting of the umbilical cord. VEKMC begins after finishing initial infant care such as pharyngeal suction, Apgar score, drying of head and skin, and cord care - usually between 20 and 30 minutes post-birth. Early KMC occurs from the first hour to the first week post-birth and is done with infants who are easily stabilised and begins as soon as they are stable post-birth. Intermediate KMC usually begins after seven days post-birth when the infants have completed early intensive care, still require oxygen and may have apnea and bradycardia. Late KMC usually occurs many weeks post-birth when the infants have completed the intensive care phase, have stable respiration, and are breathing room air.[22]

The non-separation paradigm is defined as mother-infant dyads remaining together from the first minute after birth (called birth kangaroo mother care, or BKMC) until hospital discharge (called ongoing kangaroo mother care, or KMC). BKMC is defined as mothers holding their naked and full-term infants upright and prone, with skin-to-skin contact, on the mothers' abdomen or chest during the first minute after birth.[23] As a part of BKMC, infants are allowed to breast crawl[24–26] and have self-regulatory[27] access to breastfeeding. This is called "BKMC at first breastfeed." BKMC is the best practice for providing opportunities for the first feeding,[28] facilitating mother-infant bonding, facilitating mutual physiological adaptation, and encouraging longer durations of exclusive breastfeeding.[29–31] BKMC plays an important role in providing the optimal atmosphere for the instinctive reflex ability to breastfeed effectively in order to improve breastfeeding outcomes.

The definition of ongoing KMC is that full-term infants have skin-to-skin contact (SSC) with their mothers beginning within the first minute after birth and continuing as much as possible throughout the postpartum period. SSC involves the infant, wearing only a diaper, being placed between the mother's breasts and then covered by a blanket. Ongoing KMC is initiated in a hospital and can be continued at home. Evidence for ongoing KMC includes its effect on three major aspects of mother-infant dyads: (a) bonding;[32, 33] (b) physiology, such as thermoregulation[34] and analgesia;[35] (c) increasing parental sensitivity to infant cues;[33] and (d) breastfeeding initiation, duration, and exclusivity.[31] Ongoing KMC is the best practice for providing an opportunity for mothers to learn pre-feeding behaviour. BKMC at first breastfeed and ongoing KMC with breastfeeding on cue are critical for effective latch-on and suckling.[28] An ideal time for first latch-on occurs during BKMC, when infants use their sense of smell to locate the breast and nipple. Mothers learn the signs of prefeeding behaviour from engaging in KMC. Ongoing KMC helps infants to stay calm and quiet and facilitates the initiation, continuation, and exclusivity of breastfeeding. When mothers are encouraged to breastfeed on cue, they need support from health professionals and family members.

Health professional support[36] and support from the infant's father[37] are beneficial and valuable to the initiation and continuation of breastfeeding. Mother-infant dyads need breastfeeding support from the infants' fathers and health professionals prior to hospital discharge so that the mothers can go home confident of adequately nourishing their infants, establish and maintain a rich milk supply, and avoid psychophysiological breastfeeding problems (such as the delayed onset of lactation and perceived insufficient milk supply). Interventions combining PBE with health professional support were the most common interventions for improving breastfeeding intentions and outcomes.[38,39] However, no combined interventions were found in the previous studies conducted in Taiwan. Our study thus incorporated the various international recommendations on PBE for parents, BKMC at first breastfeed, continuous 24-hour rooming-in, ongoing KMC with breastfeeding on cue, and health professionals' support into a single program, which we called a perinatal breastfeeding program (PBP), for healthy primiparous mothers who gave birth vaginally to healthy full-term infants at a baby-friendly hospital in southern Taiwan. The purpose of the study was to examine the effectiveness of this PBP in terms of improving exclusive breastfeeding rates at hospital discharge, and one-month postpartum.

METHODS

The study used a quasi-experimental design. In order to minimise contamination across groups, the study first investigated a control group that received routine care before then investigating the experimental group that took part in the PBP. The study included healthy and pregnant women in the third trimester of their first pregnancy who were receiving regular prenatal care. The participants were recruited before giving birth using several criteria: (a) primigravida status, (b) vaginal delivery, and (c) willingness to breastfeed. However, they were excluded if they had (a) pre-existing medical problems or (b) complications with their pregnancy such as preeclampsia or eclampsia. After birth, a second check of eligibility for the study was conducted in the delivery room. The mothers and infants were included in this check. The infant inclusion criteria were: (a) singleton status, (b) a 1-min Apgar score of 7 or greater, and (c) 37–42 weeks of gestation at birth. The criteria of (b) and (c) define a healthy full-term infant, which was a prerequisite for doing BKMC. Potential participants were excluded based on the conditions of separation of infant-mother dyads that interfered with the initiation of breastfeeding such as: (a) mother had postpartum complications or (b) infant had a congenital disease or an acute illness.

This study was conducted at a baby-friendly medical centre in southern Taiwan. Primigravida women who met the inclusion criteria were contacted by the researcher at 34–37 weeks' gestation for a face-to-face interview at a regularly scheduled prenatal clinic appointment. The study used a nonprobability, convenience sample of third trimester primigravida women. For sample size calculation, a medium effect size was set at 0.3. The alpha was set at 0.05, power at 0.80, and number of repetition at 2. We used G-Power version 3.1, applying the F-test approach with a 20% drop-out rate.[40] At least 56 mother–infant dyads were needed.

The maternal prenatal demographic questionnaire (MPDQ) included the mother's age, education level, occupation, parenting leave, whether the mother attended group breastfeeding classes, and the father's support for breastfeeding. The BKMC log included the timing of SSC, duration of KMC, timing of first feeding, and duration of the first breastfeeding session. A KMC log was provided to the mothers to record the frequency and duration of KMC. The researcher obtained the total hours of rooming-in from nursing records. The Index of Breastfeeding Status (IBS) was used to measure the exclusive breastfeeding rate. The IBS is a self-report instrument used to measure the pattern and incidence of breastfeeding status. The IBS has the following categories: exclusive breastfeeding, almost exclusive breastfeeding, high breastfeeding, partial breastfeeding, token breastfeeding, and formula feeding.[41] Exclusive breastfeeding is defined as 100% human milk and no other liquid or solids given to the infant. Almost exclusive breastfeeding is defined as human milk plus vitamins, minerals, water, or juice given infrequently. High breastfeeding is defined as above 80% human milk with one or less than one formula feeding per day. Partial breastfeeding is defined as more than one formula feeding per day. Token breastfeeding refers to breastfeeding for comforting the infant and not for nutritional reasons. Formula feeding refers to no breastfeeding. If the mothers chose to mix feeding or stop breastfeeding their infants, they were asked when they started mixing or stopped breastfeeding, and what the reasons for the decision were.[41]

The BKMC log and KMC log recorded the implementation of the intervention. The IBS recorded the classification of the infant feeding and collected the qualitative data, such as a reason for formula feeding. Therefore, the reliability of the instruments for variables are not applicable. The MPDQ was completed during the aforementioned prenatal visit. MPDQ (prenatal clinics), BKMC log (after birth immediately), and IBS (before hospital discharge and one month postpartum) data were collected from both groups, while KMC log data were only collected from the postpartum experimental group.

THE PBP AS INTERVENTION

The PBP is a theoretically based intervention used to provide PBE and postpartum breastfeeding support for the parents. The control group was studied first and received routine care. When data collection for the control group was completed, 26 nursing and medical staff were instructed about the intervention in a one hour session. The training course included information on the PBP, particularly focused on BKMC at first breastfeed and ongoing KMC with breastfeeding on cue. Appendix A (see Supplementary Data File) details how the PBP used the Prenatal-Intrapartum-Postpartum-Follow-up model to guide the study. Appendix B (see Supplementary Data File) shows the differences between routine care (control group) and the PBP (experimental group).

Each of the couples in the experimental group participated in a 90-min one-on-one PBE session before birth. They also received a booklet with an audio-video CD-ROM titled "New Idea of Successful Breastfeeding" (Image 1, Supplementary Data File) that was developed by the researcher. The contents of the booklet and the supporting audio-video CD-ROM were validated by three health professionals and three mothers who had breastfeeding experience. All of the couples were asked to read the booklet and watch the video before the PBE class. The PBE was implemented during the third trimester of pregnancy.

The researchers provided a kangaroo sling to each of the experimental mother-infant dyads for safety during ongoing KMC, as well as a booklet to guide the mother on how to engage in ongoing KMC and how to monitor the safety of the ongoing KMC (Image 2, Supplementary Data File).

DATA ANALYSIS

The research hypothesis was that mothers who participate in the PBP will have a greater incidence of exclusive breastfeeding when compared to those in the control group at the time of hospital discharge and one month postpartum. Data were coded and analysed by using SPSS version 20.0 for Windows. The MPDQ, BKMC log and KMC log data were analysed using the independent t test, Chi-square test and Fisher's exact test. The IBS data were analysed using the Chi-square test and Fisher's exact test. Descriptive statistics, including frequencies, means, and standard deviations, were used to examine the demographic characteristics. The independent t test, Chi-square test, and Fisher's exact test were used to analyse differences between the two groups.

ETHICAL CONSIDERATIONS

With respect to ethical considerations, the study was approved by the Institutional Review Board in the study hospital (IRB number: KMUH-IRB-980062). All of the participants agreed to participate and signed an informed consent form.

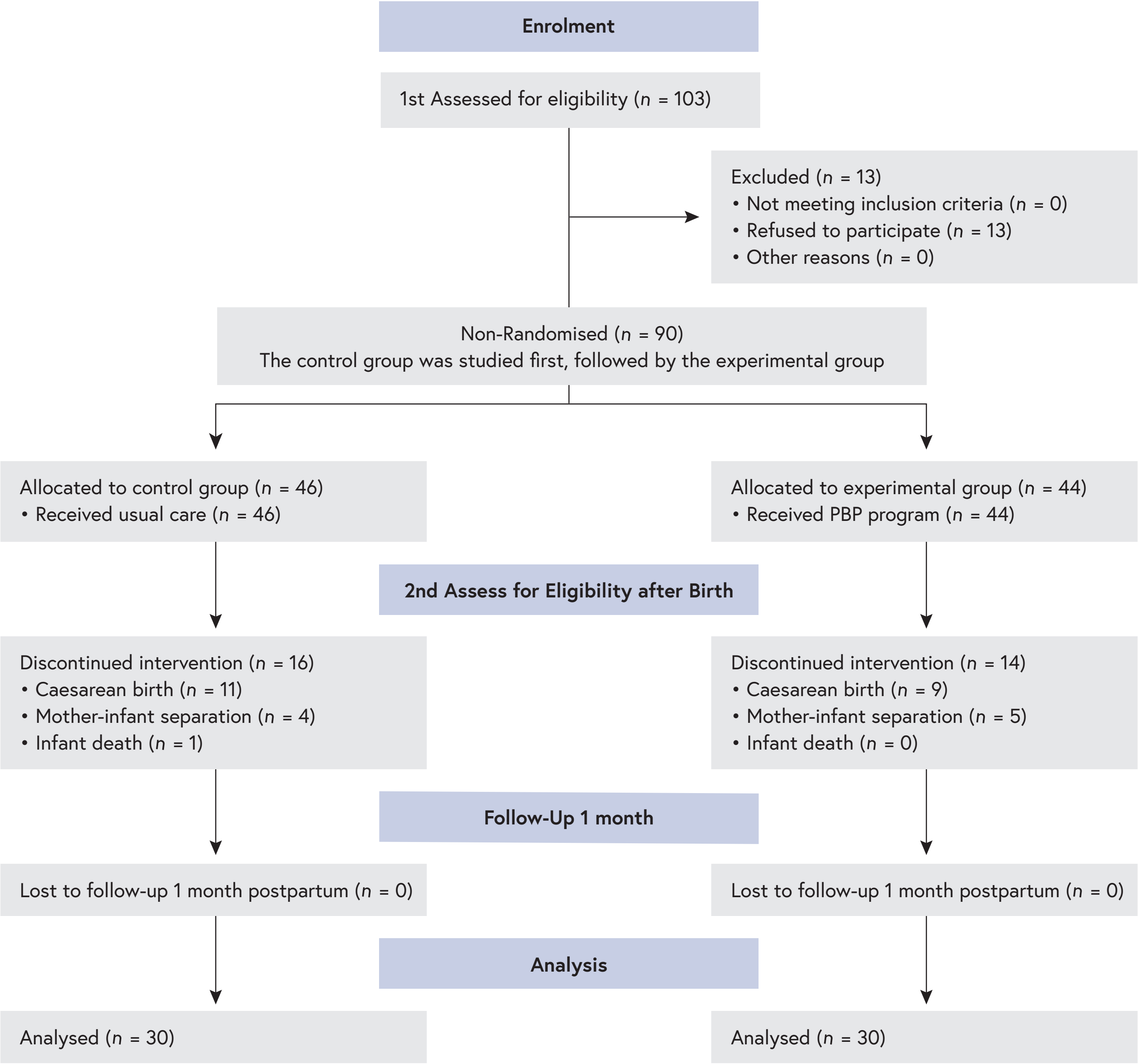

FIGURE 1: FLOWCHART OF PARTICIPANTS' RECRUITMENT

RESULTS

A total sample of 103 pregnant mothers was recruited. Thirteen of these potential participants declined participation and the remaining potential participants were assigned into the control group (CG, *n* = 46) or the experimental group (EG, *n* = 44). Then, at the second assessment of eligibility after birth, 30 potential participants were excluded due to having cesarean birth (*n* = 20), infant death (*n* = 1) or mother-infant separation (*n* = 9), leaving a final total of 60 participants (CG, *n* = 30; EG, *n* = 30) who were included in the study (Figure 1).

Ninety percent of the infants' fathers were very supportive or supportive of breastfeeding in the MPDQ (Table 1). With the exception of taking prenatal group breastfeeding classes (*p* = .029), there were no significant differences between the experimental group and the control group with regard to the demographic variables. This difference reflected the fact that a greater number of mothers in the control group (43.3% vs. 16.7%) had taken a prenatal group breastfeeding class (Table 1).

TABLE 1: PRENATAL DEMOGRAPHIC CHARACTERISTICS

Measure	Total Group	PBP Group	Control Group	Statistics		
	N = 60; *M* (*SD*)	*n* = 30; *M* (*SD*)	*n* = 30; *M* (*SD*)	x^2	t	*p*
Maternal age (years)	31.25 (3.28)	31.33 (3.68)	31.17 (2.89)		–.20	.85
	n (%)	*n* (%)	*n* (%)	x^2	t	*p*
Maternal education level						
≤ 12 years	10 (16.7)	03 (10.0)	07 (23.3)	1.97 [a]		.30
> 12 years	50 (83.3)	27 (90.0)	23 (76.7)			
Maternal occupation						
Non-medical	32 (53.3)	14 (46.7)	18 (60.0)	1.07		.30
Medical	28 (46.7)	16 (53.3)	12 (40.0)			
Parenting leave						
Yes	11 (18.3)	05 (17.2)	05 (20.0)	.07		.80
Group breastfeeding classes						
Yes	18 (30.0)	05 (16.7)	13 (43.3)	5.08		.029*
Paternal breastfeeding support						
Neutral	06 (10.0)	03 (10.0)	03 (10.0)	.44[a]		.93
Supportive	18 (30.0)	10 (33.3)	08 (26.7)			
Very supportive	36 (60.0)	17 (56.7)	19 (63.3)			

Note. PBP = perinatal breastfeeding program; [a]Fisher's exact tests were used for cell sizes < 5; * *p* < .05.

TABLE 2: OUTCOMES OF INTRAPARTUM-POSTPARTUM INTERVENTION

Measure	PBP Group	Control Group	Statistics		
	n = 30; *M* (*SD*)	*n* = 30; *M* (*SD*)	x^2	t	*p*
Timing of SSC (hr:min) at birth	00:02 (0:03)	00:14 (0:04)		13.09	.00***
Duration of SSC (hr:min) [b] at birth	01:19 (0:21)	01:06 (0:25)		–2.23	.02*
Timing of first feeding (hr:min) [b]	01:33 (1:40)	07:09 (8:43)		3.34	.00**
Rooming-in hours (hr:min)	19:55 (7:19)	20:10 (5:45)		.15	.88
Duration of KMC (hr:min)	06:52 (4:26)	00:00 (0:00)		–8.45	.00***
	n (%)	*n* (%)	x^2	t	*p*
First feeding ≤ 2 hrs. after birth					
Yes	27 (90.0)	04 (13.3)	40.05 [a]		.00***
KMC (Day 2)					
Yes	24 (80.0)	00 (.0)	50.74		.00***

Note. PBP = perinatal breastfeeding program; SSC = skin-to-skin contact; KMC = kangaroo mother care.
[a]Fisher's exact tests were used for cell sizes < 5. [b]Missing data; * *p* < .05. ***p* < .01. ****p* < .001.

With the exception of the duration of rooming-in hours, there were statistically significant differences in the implementation of the interventions included in the PBP, reflecting the fact that the control group did not receive the PBP intervention (Table 2).

In the experimental group, 90% of the infants completed the first feeding within two hours after birth. There was a statistically significant difference between the two groups in the timing of the first breastfeeding ($t = 3.34$, $p < .01$; $x^2 = 40.05$, $p < .001$).

The numbers of mothers continuing to breastfeed in the total study cohort, the control group, and the experimental group are presented in Table 3.

TABLE 3: INDEX OF BREASTFEEDING STATUS (IBS)

Measure	PBP Group	Control Group	Statistics	
	n = 30; *n* (%)	*n* = 30; *n* (%)	x^2	*P*
IBS (T_1)				
Exclusive	28 (93.3)	16 (53.3)	13.32^a	.00**
High	01 (3.3)	02 (6.7)		
Partial	01 (3.3)	11 (36.7)		
Token	00 (.0)	01 (3.3)		
IBS (T_2)				
Exclusive	25 (83.3)	11 (36.7)	15.95 ^{a}	.00***
High	03 (10.0)	04 (13.3)		
Partial	02 (6.7)	14 (46.7)		
Formula	00 (.0)	01 (3.3)		

Note. PBP = perinatal breastfeeding program; T_1 = discharge data collection; ***p* < .01. ****p* < .001.

T_2 = one-month postpartum data collection; ^{a}Fisher's exact tests were used for cell sizes < 5.

At discharge, 93.3% of the mothers in the experimental group and 53.3% in the control group were exclusively breastfeeding. At one month postpartum, 83.3% of the mothers in the experimental group and 36.7% in the control group were still exclusively breastfeeding. These differences were statistically significant ($x^2 = 13.32$, $p < .01$ at T_1; $x^2 = 15.95$, $p < .001$ at T_2).

DISCUSSION

This study provides initial evidence to support the implementation of mother-infant non-separation practices (that is, SSC) in improving breastfeeding outcomes in Taiwan. In Taiwan, all baby-friendly hospitals provide very early KMC, with the first mother-infant dyad contact following the completion of initial infant care, and most infants have their first breastfeeding within four hours of birth. Early maternal-newborn contact not only improves the birth experience[42] but also enhances breastfeeding outcomes.[13] The approach used in this study was different from the routine care, in that in BKMC, the mother-infant SSC began in the first minutes after birth and lasted until the first breastfeed. It was also different from the approaches used in other studies as it emphasised innate mutual self-regulation between the mother and infant via non-separation while the dyad remained hospitalised. This st udy encouraged the mothers to practice not only continuous 24-hour rooming-in, but also ongoing KMC with breastfeeding on cue. While as a single intervention prenatal breastfeeding education may be an effective approach,.[43] the PBP is a hospital-based multi-strategy intervention to promote ongoing breastfeeding outcomes post-partum. The experimental group of mothers in this study had a greater incidence of exclusive breastfeeding compared to the control group, which is consistent with the prior research.[28, 39] In this study, 83.3% of the experimental group and 36.7% of the control group mothers were exclusively breastfeeding at one month post-birth. In comparison, in Kupratakul et al.'s RCT study, 77.5% of the experimental group of mothers (n = 40) and 52.6% of control group of mothers (n = 40) were exclusively breastfeeding at one month post-birth.[39] Kupratakul's study was conducted in Bangkok, Thailand, using the knowledge-sharing practices with empowerment strategies (KSPES) program for prenatal education and postpartum support strategies to improve the rates of exclusive breastfeeding. The PBP used in the current study is different from the KSPES program, as the PBP not only included prenatal education and postpartum support, but also BKMC at first breastfeed and ongoing KMC with breastfeeding on cue.

These findings suggest that the additional prenatal education and postpartum support strategies used in the present study may help improve the rates of exclusive breastfeeding at one month postpartum. Most of the infants in this study were assisted in latching on to the breast correctly by the researcher. Only two of the infants were able to crawl up to the breast, self-latch, and suckle. As such, BKMC until the first breastfeeding was completed had a significant impact on the breastfeeding outcomes. This study on BKMC with first feeding was similar to that of Widstrom's with regard to early optimal self-regulation, and this phenomenon impacts the exclusive breastfeeding rate.[28]

The most influential factors are maternal breastfeeding intention and knowledge, as well as social support from family members or health professionals.[19] Breastfeeding should be promoted through perinatal comprehensive clinical and social support starting in the prenatal period and continuing through the intrapartum, postpartum, and follow-up periods. This suggests that efforts should be made in PBPs to help women obtain positive initial breastfeeding experiences to increase the rate of exclusive breastfeeding.

LIMITATIONS

This study had some limitations. The telephone follow-ups were similar between the two groups because the researcher found it difficult to refuse to answer breastfeeding questions from those in the control group. Therefore, the control group were, at least partially, supported for breastfeeding after going home. This could have affected research outcomes. Many participants were not familiar with KMC and so refused to participate. As such, generalisation of the results of this study to the general population should be done with caution, as KMC may have varying acceptability among different populations. Ongoing KMC was hindered by the family members, especially mothers-in-law. The mothers-in-law were worried that the mother or infant would catch a cold while doing KMC. Traditional Taiwanese practices after birth (for the first month) include the mother staying at home, being taken care of by others, eating a special diet, and obeying traditional rituals. The introduction of KMC, with which mothers-in-law are generally not familiar, could have been facilitated in the study by including them in prenatal education, as will be done in future studies. Multicentre studies should be performed to ensure increased sample sizes and, potentially, more representative samples of the target population, as this could increase the generalisability of future studies. Further research is needed to measure duration of exclusive breastfeeding up to six months post-birth among different populations, to determine if duration is consistent with WHO recommendations. Moreover, other outcomes such as the mother's satisfaction with the experience could be measured in future studies.

CONCLUSION

The findings provide early evidence to support the implementation of a PBP in improving the exclusive breastfeeding rate. The results of this study supported the BFHI launched by the WHO and UNICEF to Step 4: "Place babies in skin-to-skin contact with their mothers immediately following birth for at least an hour. Encourage mothers to recognise when their babies are ready to breastfeed and offer help if needed"[1(P34)] The results also supported the Academy of Breastfeeding Medicine Committee guidelines that "the healthy infant can be given directly to the mother for skin-to-skin contact until the first feeding is accomplished," and that "the initial physical assessment [should be] performed as the infant is placed with the mother". Future studies may conduct group PBE classes, which are more feasible and would decrease the nursing workload. In summary, the promotion of successful exclusive breastfeeding requires multi-strategy nursing interventions to overcome individual differences. The findings from this study provide preliminary evidence to support the implementation of mother-infant non-separation practices in improving breastfeeding outcomes.

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REVIEWS & DISCUSSION PAPERS

Prehospital interventions to prevent hypothermia in trauma patients: a scoping review

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ABSTRACT

Objective: The aim of this review is to map the prehospital rewarming measures used to prevent hypothermia among trauma victims.

Background: Hypothermia is responsible for an increase of the mortality and morbidity in trauma victims and its recognition and early treatment are crucial for the victim's haemodynamic stabilisation. Prehospital interventions are particularly important, especially those that target bleeding control, haemodynamic stability, and safe body temperature. Registered nurses may be pivotal to prevention and minimisation of the dangerous effects of hypothermia.

Study design and methods: A scoping review was used to identify articles from several online databases from 2010 to 2018. Studies in English, Spanish, and Portuguese were included. Two reviewers performed data extractions independently.

Results: Seven studies were considered eligible for this review: two quantitative research studies, one qualitative research study, and four literature reviews. Rewarming measures can be divided into two main groups: passive rewarming, which includes the use of blankets, positioning the response unit to act as a windbreak, removing the patients' wet clothes, drying the patient's body, and increasing the ambient temperature; and active rewarming which includes the use of heating pads, heated oxygen,

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warmed intravenous fluids, peritoneal irrigation, arteriovenous rewarming, and haemodialysis.

Discussion: Active measures reported by the included studies were always used as a complement to the passive measures. Active rewarming produced an increase in core temperature, and passive rewarming was responsible for intrinsic heat-generating mechanisms that will counteract heat loss.

Patients receiving passive warming in addition to active warming measures presented a statistically significant increase in body core temperature as well as an improvement in the discomfort caused by cold.

Conclusion: Rewarming measures seem to be essential for the prevention of hypothermia and to minimise the discomfort felt by the patient. In many countries registered nurses can play important roles in the prehospital context of trauma victim's assistance. Greater understanding of these roles is necessary to the development of better practices.

Implications for research, policy, and practice: The findings of this study highlight that passive and active rewarming measures must be implemented as soon as possible for trauma victims. Many measures are incorporated in trauma relief protocols; however, the lack of consensus on their inclusion results in an undervaluation of this issue, which inevitably compromises the safety and wellbeing of trauma victims. In practice, supportive frameworks and an intervention plan (based on heat loss reduction and heat supply) are required to ensure that first responders including registered nurses are able to prevent and treat hypothermia.

What is already known about the topic?

- Hypothermia is a serious threat to trauma victims in the prehospital context and can induce a "vicious cycle" of hypothermia, acidosis, and coagulopathy.
- To prevent or control the decline of a trauma patient with hypothermia, treatment of hypothermia should ideally begin in the prehospital context.
- Prehospital nurses must be able to develop advanced practice competence to function effectively in their role.

What this paper adds:

- This paper mapped out what measures can be used by prehospital healthcare workers including nurses.
- This study identified all the rewarming measures that may improve the health and wellbeing of patients with hypothermia.
- The combined use of active and passive measures seems to provide better outcomes in the prevention and treatment of hypothermia in trauma victims.

Key words: Multiple trauma; emergency care; nursing; body temperature regulation; warming.

BACKGROUND

The metabolic imbalance that results from trauma, and the subsequent decrease in oxygen perfusion, is responsible for physiological exhaustion that will take the patient into a “vicious cycle” called Lethal Triad: metabolic acidosis, hypothermia, and coagulopathy.[1] Hypothermia in trauma victims is clinically important when the body temperature drops below 35°C for more than four hours. Hypothermia can be classified as being mild (35–32°C), moderate (32–28°C) and severe (<28°C). It results from blood loss, patient exposure to the surrounding environment, cold fluids administration and loss of thermoregulatory capacity, common in intoxicated or neurologically damaged victims, and is responsible for ventricular arrhythmias, afterload decrease, increased peripheral vascular resistance, and deviation of the oxygen dissociation curve to the left.[2,3]

Hypothermia affects more than 60% of severe trauma victims and is an independent mortality risk factor. In addition to its implications for the cardiovascular, renal and neurological systems, hypothermia also plays a major role aggravating coagulopathy, hence increasing mortality and morbidity.[4] The risk factors for hypothermia are low Glasgow Coma Scale, low air temperature, and a wet patient.[5] Recognition and early treatment of hypothermia are crucial for the victim’s haemodynamic stabilisation.

Prehospital interventions are particularly important, especially the ones promoting bleeding control, haemodynamic stability and the patient’s rewarming.[6] Rewarming measures should be implemented in prehospital care and involve the use of passive measures – intrinsic heat-generating mechanisms to counteract heat loss – and active rewarming measures.[4] Since in many countries such as Sweden, Portugal, Finland, Belgium, England, Wales, Spain, and The Netherlands, emergency medical services include nurses in prehospital care, the knowledge and the ability to implement these measures are essential for nurses. These nurses have proven to be important for victims’ illness and injury assessment, treatment, and in steering the patient to an optimal level of care.[7]

Literature provides little and unclear knowledge about the type of rewarming measures that must be implemented in prehospital settings in order to prevent hypothermia in trauma victims. There is limited evidence on how to implement rewarming interventions, and, in this context, there is a need to perceive not only the kind of interventions that ought to be used, but also if we should use active rewarming measures rather than passive ones, and the situations in which they should be applied. Hypothermia treatment should ideally begin in the prehospital context, with hypothermia wraps, battery-powered inline fluid warmers,[6] duvets, plastic "bubble wrap", and cotton blankets.[8] However, there is no consensus about the best way to prevent and treat hypothermia in a prehospital setting.[8]

A scoping review was conducted to systematically map the research carried out on prehospital rewarming measures crucial to prevent hypothermia among trauma victims and to identify the existing knowledge gaps. The following research questions were formulated: Which are the prehospital rewarming measures used to prevent hypothermia in adult trauma victims? What are the characteristics of these rewarming measures? In what contexts/types of trauma have these measures been implemented? In addition, the purpose of this scoping review is to summarise the research findings and identify the existing gaps in the research.

METHOD

The review was conducted according to the methodology for Joanna Briggs Institute scoping reviews,[9] and prepared using the PRISMA Extension for Scoping Reviews (PRISMA-ScR) (see Appendix A, Supplementary Data).[10] The review protocol was established, followed and was previously published.[11]

The search strategy aimed at finding both published and unpublished papers with a three-step search strategy. An initial search, limited to PubMed and CINAHL, identified the articles written on this topic. It was followed by the analysis of the words contained in the titles and abstracts, and of the index terms used to describe those articles. A second search using all previously identified keywords and index terms was carried out in the selected databases: CINAHL Plus with Full Text, PubMed, Cochrane Central Register of Controlled Trials, Scopus, PsycINFO, The JBI Connect+ and Cochrane Database of Systematic Reviews. The search for unpublished studies included: RCAAP – Repositório Científico de Acesso Aberto de Portugal; OpenGrey – System for Information on Grey Literature in Europe. Finally, the reference lists of all the articles identified were analysed. The search strategy for PubMed is presented in Table 1.

TABLE 1: SEARCH STRATEGY FOR PUBMED

#1	((((((fracture[Title/Abstract]) OR Dislocation[Title/Abstract]) OR Dislocation[MeSH Terms]) OR Trauma[MeSH Terms]) OR (Wounds and Injuries[MeSH Terms])) OR Hypothermia[MeSH Terms]) OR Shivering[MeSH Terms]
#2	(((((((Thermal comfort[Title/Abstract]) OR Resistive Heating[Title/Abstract]) OR Management[Title/Abstract]) OR rewarm*[Title/Abstract]) OR passive warming OR[Title/Abstract]) OR active warming[Title/Abstract]) OR Rewarming [MeSH Terms]) OR Body temperature regulation[MeSH Terms]
#3	(((((((((((pre-hospital[Title/Abstract]) OR prehospital[Title/Abstract]) OR pre hospital[Title/Abstract]) OR Emergicenters [Title/Abstract]) OR emergency care[Title/Abstract]) OR Emergenc*[Title/Abstract]) OR Emergency Health Services[Title/Abstract]) OR Emergency Service, Hospital[MeSH Terms]) OR Critical Care (MeSH 2018)[MeSH Terms]) OR Emergency Treatment[MeSH Terms]) OR first aid[MeSH Terms]) OR emergency responders[MeSH Terms]) OR Accident[MeSH Terms]
#4	#1 AND #2 AND #3
#5	#4 NOT child*

Published and unpublished studies in English, Portuguese and Spanish language, from 01/01/2008 to 31/12/2018 that described all passive and active prehospital rewarming interventions used to prevent hypothermia among trauma patients were considered for inclusion.

Following the search, all identified citations were uploaded into Endnote V7.7.1 (Clarivate Analytics, PA, USA) and the duplicates removed. In order to assess their eligibility, titles and abstracts were screened by two independent reviewers (MM and FM). The full papers were then examined based on the following inclusion criteria:

PARTICIPANTS

This scoping review considered all studies that focus on adult patients (aged 18 and over) who were victims of trauma. Trauma patients are defined as patients with (suspected) injuries from mechanisms of blunt or penetrating forces, falls, explosions, heat, cold or chemical toxicants.[12]

CONCEPT

This scoping review considered all rewarming measures implemented and evaluated by health professionals (nurses, physicians and paramedics) in victims of trauma aiming to prevent or treat hypothermia. For this review, rewarming measures included all kinds of treatment performed as emergency care, with the following characteristics: mechanism of action, duration, dose and frequency.

CONTEXT

Emergency care provided in prehospital settings was considered for inclusion. Care within non-emergency and hospital settings was not eligible for inclusion.

TYPE OF STUDIES

This scoping review considered all types of studies, namely systematic reviews, quantitative, qualitative and mixed-method studies in order to consider different aspects of the rewarming interventions.

Data were extracted by two independent reviewers (MM and TA) from the selected studies using a form that was developed specifically for this review to collect relevant data from each paper and include specific details about the populations, concept, context and the study methods. This form was previously tested by the reviewers before its use (Appendix B, Supplementary Data).

Any disagreement between the reviewers that may have come up during any of the previous steps was resolved with the inclusion of a third reviewer.

The findings were tabulated and accompanied by a narrative synthesis to address the review objective.

RESULTS

Once duplicates were removed, a total of 1,195 citations were identified from searches in databases. Based on their titles and abstracts, 1,135 were excluded. Sixty full-text articles were retrieved and assessed for eligibility. Of these, 53 were excluded for the following reasons: 27 did not study the main topic, 17 due to intervention, two included children or adolescents and four due to language. Three studies were excluded, as the full text references were unable to be retrieved. The remaining seven studies were considered eligible and included two quantitative research studies, one qualitative research study and four literature reviews. Of the quantitative research studies, one was a randomised control trial and the other a case report. All studies using a qualitative approach were conducted using interviews. Included studies were conducted across six different countries: two were conducted in Sweden,[13, 14] and the remaining undertaken in UK,[15] South Africa,[16] Norway,[17] USA[18] and Canada[4].

The study selection is presented in Figure 1.

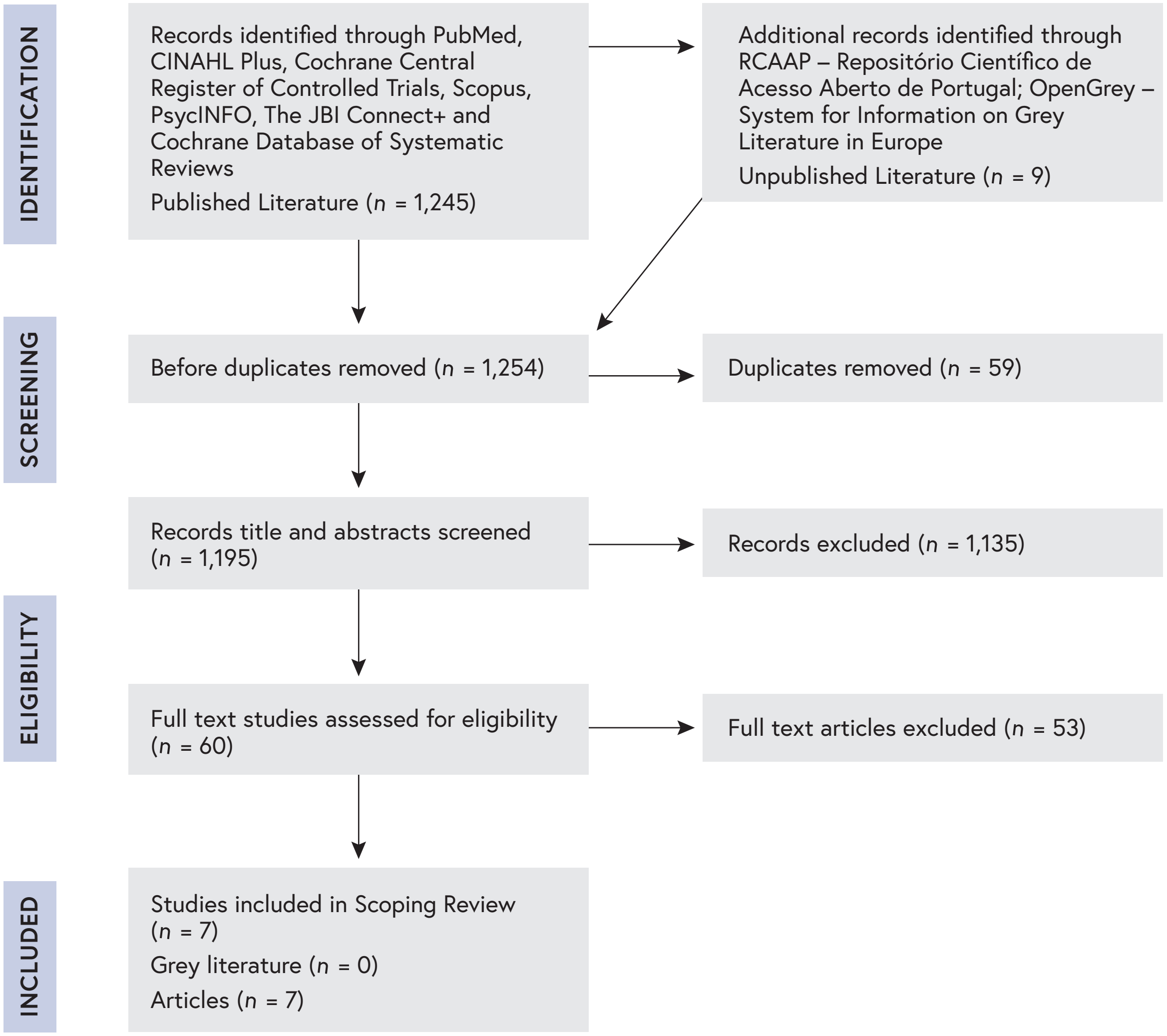

FIGURE 1: FLOWCHART OF THE PROCESS OF STUDY SELECTION

The details and specificities of the included studies are presented in Table 2.

TABLE 2: DETAILS OF INCLUDED STUDIES

Authors	Methods	Participants characteristics	Rewarming measures	Conclusions
Alex and colleagues (2013)[13]	Interview.	20 adults injured in the mountains with several fractures. Initial body core temperatures: 32.6°C to 37.7°C. Outside temperature: 4°C to 14°C. Wind: windless to 10m/s.	Seven victims (mean age of 39) were treated with passive warming (blankets). 13 victims (mean age of 55) were treated with passive warming and active heating pads (42 · 28 cm).	Passive heat applied from beneath led to a higher heat loss reduction compared to that applied over the patients' chest. The heating pads were described as warm, comfortable and stopped shivering. Active heat needed to be applied both from underneath and on the victim's chest. Turning up the ambient temperature inside the ambulance unit is not effective.
Owen and Castle (2008)[16]	Case reports.	Two patients. An elderly man had been involved in a car accident with an abdominal gunshot wound and a male pedestrian involved in a hit-and-run accident with several fractures.	Minimised further exposure by positioning the response unit to act as a windbreak; Blankets with applied heating pads and warmed intravenous (IV) fluids.	Measures have been effectively increased tympanic temperature (34.0°C to 35.3°C) after 30 min.
Perlman and colleagues (2016)[4]	Review.	n/a	Remove wet clothing; Avoid cold surfaces; Heating blankets (electric or hot air); Heated intravenous fluids; Extracorporeal heating measures (dialysis, peritoneal lavage, continuous arteriovenous heating - CAVR); Humidified oxygen.	The early use of warming blankets and the removal of wet clothing are recommended, followed by aggressive rewarming on arrival at the hospital if the patient's injuries require damage control therapy.
Gill and Cox (2008)[18]	Review.	n/a	Airway rewarming; Blankets (aluminium, connective and fluid circulation); Radiant warmer; Body Cavity Lavage; IV fluids, CAVR.	Central (core) rewarming is by far the most efficient way to rewarm a patient. Normothermia is obtained more quickly through CAVR. Airway rewarming and aluminium blanket seem to be the most ineffective warming methods.
Giannoudi and Harwood (2016)[15]	Review.	n/a	Passive external rewarming: warm blankets or increasing ambient temperature. Active external rewarming: forced air-warming devices and other heaters. Active internal core rewarming: warming fluids and heated oxygen. Warmed bladder and peritoneal irrigation, arteriovenous rewarming and even haemodialysis.	Extracorporeal rewarming techniques are the most efficient, increasing body temperature at a rate of 4–5 °C per hour (compared to only 2 °C by the other aforementioned techniques).
Lundgren and colleagues (2011)[14]	RCT.	48 blunt trauma patients with a mean coded Revised Trauma Score of 7.83.	22 patients receive passive warming (blankets) and 26 patients receive passive warming (blankets + active warming: chemical heating pad reaching about 50°C within two minutes, applied across the anterior upper torso).	Additional active warming significantly improves thermal comfort even further and might also reduce the cold-induced stress response.
Kornhall and Martens-Nielsen (2016)[17]	Review.	n/a	Chemical or electrical heating pads and blankets, applied on the axillae, chest and back. Bolus administration of fluids warmed to 40–42°C. Insulating materials, such as sleeping bags, blankets or bubble wrap. Airtight vapour barrier immediately outside the wet clothing. Extracorporeal circulatory support.	Bolus administration of fluids warmed to 40–42°C prevents further core body temperature. Use of ECC rewarming in hypothermic avalanche victims in cardiac arrest or in pure hypothermic cardiac arrest is associated with extremely poor outcomes.

Alex and colleagues sought to verify if active heating measures were more effective than the application of passive measures alone.[13] The two groups were offered the same model of passive rewarming measures (blankets), and, in one of them, as a supplement, active rewarming with heat pads was also offered. Regarding the passive measures, the two groups reported that their application protected them against the cold; however, the need for a greater supply of heat was also evident. The group that received active rewarming in addition to blankets claimed they felt more comfortable and warmer. In addition, passive measures applied to the back and chest of the victim offered greater comfort and better results in reducing heat loss compared to when they were applied only on the victim's upper torso.

Shivering must be avoided since it increases oxygen demand by up to about 400–500% of the basal requirement and,[19] in some studies, it was possible to verify that it only stopped after the heating pad was applied.[13] Space blankets only led to a limited rise in temperature, on the other hand, heating pads resulted in a body temperature rise by a mean of 0.74°C over a 30-minute period.[16]

Despite the increase in body temperature, decrease in cold discomfort, improvement of vital signs and blood pressure, and stabilisation of the patient's heart and respiratory rates; Lundgren and colleagues found that passive heating with blankets is less effective when used alone than when used in addition to active measures.[14] The use of passive measures combined with active measures showed better results in heating and providing comfort when applied to the victim's back and upper chest. Shivering was corrected only after the application of the heating pads. In patients that were group assigned only to passive warming, initial ear canal mean temperature was 35.1°C, and at the second measurement, it had increased to 36.0°C. In the group assigned to active warming, the initial temperature recording was 35.6°C and the second was 36.4°C. In the group assigned to passive and active warming, all 26 patients showed a decrease in the cold discomfort index, whereas in the group assigned for passive warming, only 15 out of the 22 patients presented a decrease in the cold discomfort scale.

In Owen and Castle's opinion,[16] the first rewarming passive measure is the positioning of a response unit to minimise further exposure. According to these authors, the unit will act as a windbreak.

Preventing further heat loss should be the first concern when approaching the victims, so the removal of wet clothes and the protection of areas such as the victim's head and neck,[4,17] so often neglected, should receive rescuers' special attention. It should be noted that wet clothing removal in a very cold and wet environment will further expose the victim to heat loss by evaporation, a situation that may be minimised by adding an airtight vapour barrier immediately outside the wet clothing.[17]

Increasing ambient temperature does not provide a relevant consensus.[13–15] For Alex and colleagues rising temperature inside the ambulance did not seem to be as efficient as the heating pads,[13] however, increasing ambient temperature may be used as a complement to the initial rewarming procedures.[14,15]

Heated intravenous fluids administration continues to raise many questions regarding its effectiveness even though it is integrated within current protocols.[16] In order to reach acceptable body temperature in people with hypothermia, heated fluids total volume would have to exceed 10 litres, a value that will compromise haemodynamic stability.[18,20] It should be noted that these fluids do not contribute themselves to the victim's rewarming,[18] and they should be previously heated to avoid hypothermia worsening.[15]

Heated oxygen, peritoneal irrigation, arteriovenous rewarming and even haemodialysis are potential active internal rewarming measures,[15] however, there is no evidence of their applicability and efficacy in prehospital settings.

The results also found that rewarming measures are offered regardless of the type of trauma, the type of injuries found and the victims' prognosis; and since hypothermia is responsible for increased pain, anxiety and fear of dying,[13] it seems that the prompt implementation of rewarming measures is a priority not only to achieve haemodynamic stabilisation[14,16,17] but also to increase the victims' comfort.[13,14]

DISCUSSION

Implementing effective rewarming measures for trauma victims in order to prevent and/or treat hypothermia has been an increasing concern for prehospital teams. Thus, it is important to study the measures that should be implemented in prehospital settings and the contexts in which they should be applied. This review aimed to map the existing evidence and to define new lines of research that will support prehospital care providers in assessing the effectiveness of existing passive and active measures.

For the purpose of rewarming, several measures are available. However, there is few or poor evidence related to their applicability, the context of their applicability and which measures should be implemented: passive, active or both.[5] This work describes existing knowledge covering the different prehospital passive and active rewarming measures used in trauma victims. The results focused mainly on the increase in the core temperature and/or the decrease in cold discomfort.[21]

It is already known that rewarming measures are determinant not only for hypothermia prevention, but also to minimise the discomfort felt by the patient. This discomfort is mainly felt due to the cold being greater than the pain that resulted from the traumatic event.[13] The thermal sensation that results from the cold was reported by many trauma victims as being more uncomfortable than the pain itself.[22] Furthermore, hypothermia is responsible for a large percentage of mortality among trauma patients when temperature is below 32°C and remains poorly handled.[4]

Different mechanisms of heat transfer are responsible for hypothermia: radiation, conduction, convection and evaporation. It is possible to find suitable measures to counteract each of them. To fight radiation one should use a warming blanket, increase ambient temperature, use radiant heaters and avoid unnecessary anaesthesia; to fight conduction, the removal of wet clothing is recommended and nurses should prevent the victim from being in contact with cold surfaces; for convection, nurses should use warming blankets; and for evaporation, one should use humidified gases.[4,23]

Overall, the rewarming measures can be divided into two main groups: passive rewarming that includes the use of blankets, positioning the response unit to act as a windbreak, removing wet clothes and drying the victim's body, and increasing ambient temperature; and active rewarming that uses heating pads, heated oxygen, warmed intravenous fluids, peritoneal irrigation, arteriovenous rewarming and haemodialysis as a last resort.[19,27]

All these measures are relevant and have advantages/disadvantages, as well as specific conditions to be applied. For example, removing the victim's wet clothing is an important passive rewarming measure,[4] however, and due to existing environmental conditions, it should be understood that the removal of wet clothing can increase heat loss. In wet and very cold environments, it is suggested not to remove clothing but to place an airtight vapor barrier immediately outside the wet clothing.[17]

Regarding the active warming measures, all included studies used them as complementary measures to the passive ones. Active rewarming produced an increase in core temperature,[24] and passive rewarming was responsible for intrinsic heat-generating mechanisms that will counteract heat loss.[4] These measures, when combined, induce a statistically significant increase of the body core temperature as well as an improvement in cold discomfort.[14]

LIMITATIONS

Our results should be interpreted while taking into account some limitations. First, although we used a rigorous and robust method, the results of this review were intended only to map measures and not to evaluate their effectiveness. On the other hand, this review allows future effectiveness studies to be developed from all the evidence gathered. Second, we are aware that prehospital practices are not always performed by nurses. However, in this case, other clinicians can also obtain relevant information that they can integrate into their practice. At last, the studies included in this review were all developed in extremely cold environments, and in that sense we wondered whether the effectiveness or perception that prehospital teams had of the problem would be the same in "milder" environments; in other words, it remains unanswered whether or not the temperature control is a real concern in prehospital activity during the treatment of trauma victims. Naturally this seems to be a minor problem in certain environments. Hypothermia does not arise exclusively from cold environments, it is a consequence of the pathophysiology of the traumatic event, so hypothermia investigation is necessary for every trauma victim regardless of the ambient temperature.

Based on these findings and analysing the role of nursing in this specific area, it is essential that prehospital care providers develop an intervention plan/operation protocol for hypothermia prevention. This protocol should be based on two fundamental premises: heat loss reduction and heat supply. The first is possible through the implementation of passive rewarming measures and the second through the implementation of active rewarming ones. Even so, these actions should be methodical and not delay the administering of other equally important procedures to the trauma victim, this may include, airway maintenance with cervical spine protection, breathing and ventilation management, circulation assessment and management with haemorrhage control, brief neurological examination and exposure/environmental control.[25]

CONCLUSION

Hypothermia, in addition of being an important mortality risk factor among trauma victims, is an element that plays an extraordinarily relevant role in these patients' complaints and discomfort.

This review's findings highlight a set of rewarming measures (active and passive) that can be integrated into the practice of prehospital RNs. The combined use of active and passive measures seems to provide better outcomes.

An intervention plan/operation protocol for hypothermia prevention should be developed by prehospital care providers and should integrate two main premises: heat loss reduction and heat supply. Implementation of such a protocol is important in supporting the safety and improvement of trauma patient outcomes.

Future studies should aim at obtaining these different effectiveness measures and understanding which ones are best suited for prehospital settings. In addition, they must be able to respond to two different circumstances: hypothermia prevention in trauma victims and hypothermia treatment in those whose central temperature value is already lower than recommended.

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IN THIS ISSUE

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The *Australian Journal of Advanced Nursing* is the peer-reviewed scholarly journal of the Australian Nursing and Midwifery Federation (ANMF). The Mission of *AJAN* is to provide a forum to showcase and promote a wide variety of original research and scholarly work to inform and empower nurses, midwives, and other healthcare professionals to improve the health and wellbeing of all communities and to be prepared for the future.

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The mental health impact of COVID-19

As we come into the later part of 2020, COVID-19 continues to take lives and threaten health, aged care, and maternity systems around the world.[1] With the focus of attention on the direct impacts of the SARS-CoV-2 virus, it is the combined weight of the real and potential impairment of the capacity and resources of, especially, health and aged care sectors, – as well as the broader economic fallouts impelled by government-imposed restrictions that is fomenting a growing crisis for the less conspicuous issue of poor mental health and wellbeing.

Mental ill health is a serious and growing issue in many countries. Prior to the pandemic, understanding of the size and severity of the burden of mental ill health on individuals, communities, and workforces was beginning to take form. Now, more than ever, we must turn our attention not away from COVID-19, but toward how the conglomerate of challenges the pandemic has emphasised can be addressed with targeted policy, practice, and research. COVID-19 is unlikely to disappear any time soon, but even more durable than the virus itself will be the ongoing impacts on, and because of, the mental health and wellbeing of those most affected by the pandemic. This means that there is also the opportunity to make meaningful and sustainable changes to the way things like mental ill health are addressed.

Our nurse, midwife, and care worker colleagues as well as those from other professions and disciplines are still striving to care for their patients, mothers, babies, and older residents and clients in some of the most demanding contexts while also trying to keep themselves and their own loved ones safe at home. In many cases, workers have not been able to go home – either by choice or necessity – due to fears that they may infect vulnerable family members. Some nurses caring for people with COVID-19 have faced stigma, abuse, and aggression from anxious and frightened members of the public – even their own families – likely fanned by the media's sensationalist and morbid coverage of cases where workers at the frontlines have been exposed to infection, sometimes due to inadequate organisational policies and practices, and lack of access to sufficient personal protective equipment (PPE) and resources.[2] Emerging reports tell us of the serious emotional and psychological impact that working in health, maternity, and aged care is having on our workforces.[2] Not only is going to work dangerous and terrifying, but for those who are removed from the workforce due to potential exposure or infection, insecure work and lack of organisational and government support means that not going to work might be just as stressful due to a reduced income and low future job prospects. Indeed, in some places almost entire workforces have been sent home to self-isolate due to possible exposure. Many workers may also leave their jobs permanently due to stress and burnout caused or augmented by COVID-19 – which would be disastrous especially in contexts with already insufficient nursing workforces such as aged care. It is clear that the emotional and psychological burdens of working during the COVID-19 pandemic are incredibly taxing on our health, maternity, and aged care systems and workforces and that there is a current and ongoing need for effective mental health supports and services to ensure the safety, wellbeing, and sustainability of these essential groups.[3,4]

For staff working in mental health and dementia care fields, COVID-19 has brought with it new and challenging issues. A recent World Health Organization survey has highlighted that treatment for mental health disorders has been disrupted in 61 percent of 105 countries.[1]

Working safely and appropriately with patients with dementia and serious mental health presentations such as schizophrenia while wearing PPE such as a mask or face covering can be extremely challenging as it can cause great distress and fear.[5] Further, for people experiencing chronic, persistent, and severe mental ill health physical and social distancing measures, disinfection and decontamination practices, and engaging in safe interventions in response to violent and aggressive behaviours are all complicated.[6] Severe mental ill health and dementia and the need to adequately care for those who experience them have typically been pushed to the side of policy agendas for many years, and the damage the pandemic could do in this sector has likely not been well quantified or prepared for. People with severe or ongoing mental ill health and dementia are often some of the most vulnerable members of society, come from marginalised groups, and are disproportionately impacted by additional and associated challenges in terms of physical health, housing, social inclusion, and employment.[7] People with dementia and those who experienced pre-existing mental ill health and those that work closely with them are clearly a special needs group that requires considerable attention during and following the pandemic to ensure that the gaps between their health and wellbeing status and outcomes and the broader community do not widen further.[8,9]

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Beyond the health, aged care, and maternity workforce itself and those with pre-existing dementia or mental ill health, the wider community is also facing an almost unprecedented trial in terms of maintaining mental health and wellbeing.[10] While many parts of Australia and the world have moved well along with the relaxation of the government restrictions put in place in an effort to reduce community transmission and the burden on already stretched health systems, some localities such as Victoria Australia remain under heavy lockdown with strict laws governing leaving the house, socialising with people from other households, and what businesses can be open. When these restrictions drag from weeks to months, many people even those who would have felt mentally and emotionally resilient at the outset can begin to struggle with isolation and disconnection from both family and friends as well as their communities.[11] While some people have been able to transition relatively easily to working from home, many others have simply lost their jobs completely and face the stress of potentially not having one to return to. The stress and damage COVID-19 has done include skyrocketing depression and anxiety,[12] domestic violence,[13] substance use,[14] and suicide.[15] There will be a need for drastic and sustained action to ensure that the mental health impact on the community is addressed now and in the future. This is going to take actions not only within health and aged care but across government portfolios from housing, employment, social services, industry, and the environment – because let us not forget about the mental health impact of climate change and the environmental disasters that it has led to most recently. Indeed, it could be argued that COVID-19 mental health and emotional difficulties are happening within the context of continuing climate change and environmental disasters resulting in cumulative negative impacts. In this way, COVID-19 is taxing peoples' resilience and coping within a pre-existing context of cascading disasters and is becoming a tipping point that manifests in mental ill health.

This year, 2020, has brought with it many unprecedented tests and sadly claimed many lives. Many sectors and communities have been stretched to their limits responding to a virus without a cure. Some have been led by governments that provide little in the way of useful leadership or sometimes even factual information or accountability, and many face significant collective and personal challenges on top of already less than adequate access to equitable care and support. Mental health is and will be a pressing issue for a vast number of people across many segments of society and addressing it will take action and cooperation across many contexts and between diverse groups. Now more than ever we need to work collaboratively to help one another – especially our most vulnerable community members who often lack the voice, resources, and platforms to help themselves.

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EDITORIALS

Recency of practice and emergency registration: preparing for surge capacity in the time of COVID-19

The COVID-19 pandemic has placed a huge strain on the health and aged care workforces globally, with nurses being at the forefront of patient testing, tracking, and care. The World Health Organization (WHO) estimates that 10% of all COVID-19 infections are among healthcare workers (HCWs). With over 20 million infections worldwide, this would equate to two million HCWs infected.[1] The number also varies greatly, ranging from 1% through to 40% of infections.[2] While not fully quantified, the number of nurses who have died as a result of COVID-19 is known to be high. The International Council of Nurses' (ICN) CEO, Howard Catton, has called for accurate reporting of data about nurse deaths, particularly as it appears that nurses may comprise the majority of healthcare workers (HCWs) who have died due to COVID-19 infection. Catton made the observation in a June press release that:

> "[n]*ursing is looking like one of the most dangerous jobs in the world at the moment. We need to get these data for every country and work out exactly what is going on that explains the variations that are evident with even a cursory glance at the figures. Only then will we be able to learn how best to keep our nurses safe and prevent any repeat of these terrible statistics in the future.*"[3(para 12)]

Back in June, ICN's analysis, based on data from the National Nursing Associations (NNAs), official figures, and media reports from a limited number of countries indicated that more than 230,000 HCWs had contracted the disease, and more than 600 nurses had died.[3] Those figures can only have increased since then. In addition, the workforce is depleted, not only through death, but also through illness and the requirement for isolation following potential exposure or infection. As a result, many countries have called for either retired nurses, or nurses who had been out of the workforce, to return and be upskilled to take on clinical work so that currently practising nurses could step up to the COVID-19 front line.[4]

The recently released *State of the World's Nursing Report 2020* showed that, across the world, there is an estimated shortage of six million nurses.[5] The pandemic has put further pressure on an already overstretched health system. Healthcare systems across the world are operating near or above capacity. This will continue for many months, if not years, and the health workforce cannot be readily 'turned on and off' – it takes long periods to educate, train, and equip new staff.

In addition to the risks of sickness and death from COVID-19, there are other physical and psychological tolls that COVID-19 will take on nurses and other HCWs for many, many years to come. Depression is seen in 50% of the workforce in some countries, in addition to high anxiety rates, and moral injury.[6] Those nurses who are stepping up to address surge capacity also need to be prepared for these eventualities.

NURSING WORKFORCE SURGE CAPACITY AND EMERGENCY RE-REGISTRATION TO PRACTISE

As part of the ICN's work in the early stages of the pandemic, and during discussions in a series of webinars and other forms of communication with NNAs, a common theme emerged regarding the need to develop strategies to increase surge capacity within the nursing workforce. Given that different member countries had differing regulatory structures and policies, NNAs requested an informal paper with advice and a potential framework that could be adapted to the varying requirements of different countries.

International evidence suggests that factors such as the degree/level of professional experience, age, and time away from practice appear to impact on the maintenance and decline of competence.[8] Evidence also suggests that clinical practice experience guided by a nurse preceptor within a refresher program can be experienced as beneficial for nurses returning to practice following time away.[9] There is also limited evidence suggesting that it is important to gain consistent practical clinical experience within the year following study completion to support ongoing competence.[10]

Based on this and other evidence, we developed a matrix of interrelated factors that could be taken into account when determining who might be eligible to return to practice, what level of work they might be able to undertake, and what further education or preparation they might require. It was envisaged that suitable practitioners would be granted temporary "emergency registration". This matrix, together with informal advice and a scoring system, was provided to member countries on request as a draft framework that might assist their workforce planning (see Table 1). Many countries, including Australia, had already developed emergency registration provisions, so it was felt there was no requirement for formal advice from ICN.

In order to use the framework, firstly, a series of questions should be considered when setting criteria for emergency registration:

1. **Recency of practice**: How long is it since the applicant last practised any form of nursing?
2. **Former scope of practice**: Where did the applicant last work and what level of seniority did they hold in that role?
3. **Level and extent of expertise**: For how long had the applicant practised since registration and how skilled were they considered to be?
4. **Level and extent of education**: What qualifications does the applicant hold and how current are they?

Based on these criteria, a scoring system was developed to support the assessment of appropriate applicants to a suitable role.

TABLE 1: CRITERIA AND SCORING FRAMEWORK FOR COVID-19 EMERGENCY TEMPORARY RETURN TO PRACTICE

	Criteria	Scoring		
1	Recency of practice	<5 years	5–10 years	>10 years
		3 points	2 points	1 point
2	Scope of practice	Clinical front line	Clinical education	Administrative/ non-clinical work
		3 points	2 points	1 point
		Highly skilled clinical nurse	Some clinical nurse expertise	Junior clinical nurse
		3 points	2 points	1 point
3	Level and extent of expertise	+10 years clinical experience	5–10 years clinical experience	<5 years
		3 points	2 points	1 point
4	Level and extent of education	Clinical Masters degree or higher	Post graduate degree less than a Masters degree	Graduate clinical certificate
		3 points	2 points	1 point

Based on the scoring system and documentation to support the scores, it was suggested that differing emergency registration levels could be applied. Applicants would need to demonstrate they had had no previous restrictions on their registration and also that they concurred with the level of registration to which they were allocated. Four levels were proposed and the roles each level might be expected to perform are discussed below.

- Full emergency registration (>12 points) could be granted to applicants who were considered competent to take up registration as frontline clinicians immediately.
- Level 2 emergency registration (9-11 points) might be granted to those applicants who required online education in essential refresher topics such as infection control, resuscitation, manual handling, medications management. These programs could be fast tracked through university and/or employer websites.
- Level 3 emergency registration (7-8 points) might be awarded to applicants who were not considered suitable to work on the front line, either due to recency or physical constraints, but might be able to provide guidance and support to the public under protocol in telehealth and other online services.
- Level 4 emergency (5-7 points) might be awarded to applicants who were not considered suitable to work on the front line, either due to recency or physical constraints, but might be able to provide guidance and support to the public under protocol in telehealth and other online services. However, in order to be able to take up these positions, they would also require online education to be able to update essential clinical knowledge.

We envisaged that the emergency registration would apply for 12 months and, at that stage, and depending on the national requirements for an emergency workforce, all applicants would be given the opportunity to apply for permanent registration with the understanding that conditions might continue to apply until full registration requirements were met. Ideally, these former emergency registrants would be given special consideration and support to meet the requirements.

Additional necessary issues to be addressed as part of the emergency registration process were also considered to include; whether the applicant adequately understands the level of commitment required to serve in this capacity; that there needed only be one system through which emergency registrations are granted; that practising without a licence even during an emergency would still carry legal ramifications such as civil or criminal charges, and that employers would need to address the registration level of applicants and their requirement for professional liability insurance.

The information, whilst informal, has been shared as guidance with nurse leaders in many countries and all WHO regions across the world. Countries have been rapidly re-registering and recruiting nurses who have retired or left the profession. In an effort to protect the public, the nursing profession, and trust in the profession, it is essential that the elements discussed above be considered in developing a framework for emergency registration. The decisions made now will have an immediate impact and one that will be sustained for many years to come.

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RESEARCH ARTICLES

Continuity of care for people with multimorbidity: the development of a model for a nurse-led care coordination service

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ABSTRACT

Objective: To collaboratively develop a model of nurse-led care, within a multidisciplinary team and support continuity of care at the primary–secondary interface for people with multimorbidity.

Background: Existing models of care are frequently based on a medical model, designed to manage a single disease condition, and thus pose a significant challenge to provide healthcare for people with multimorbidity. Particular design elements for models of care affecting the primary–secondary interface have been previously demonstrated, however, these have not been applied to the development of a nurse-led model of care for people with multimorbidity.

Study design and methods: This paper, the first in a series of two, is part of a broader action research study and reports on the development of a model which will subsequently be assessed in terms of feasibility to provide a nurse-led care coordination service for people with multi-morbidity. This paper reports on the first action research cycle and methodology including a literature search, stakeholder engagement forums, validation workshop, team meetings, and professional engagement and validation.

Results: Data from two stakeholder forums were sorted into 257 'structure, process and outcome' statements and 86 goal related statements. These were cross referenced with design elements on models of care from the literature and finally aggregated into themes. The aggregated themes

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were then integrated into a model of care for a nurse–led care coordination service. The model consists of an overarching component, 4 domains and 6 operational areas with underpinning criteria.

Conclusion: Through stakeholder consultation, consideration of the strengths of previous models and building blocks, a new nurse-led model of care that provides a pathway for transitional healthcare management at the primary–secondary interface has been developed. Inclusion of governance and culture within the model's domains enables the approach to be pragmatic and adaptable, contributing to the potential for successful change management and model implementation in the clinical workplace. Further evaluation and refinement of the model is planned and will be reported on, in part 2 of this two-part series.

Implications for research, policy, and practice: These findings provide direction for model implementation and further research required regarding nurse-led models of care. The supporting documents, systems, and processes reported, positions the model to support change and guide clinical practitioners and nursing management working at the primary–secondary healthcare interface. The future success of model implementation could provide evidence for health workforce policy and coordinated healthcare management.

What is already known about this topic:
- Particular design elements for models of care affecting the primary–secondary interface have been previously demonstrated.
- Interventions delivered at the primary–secondary care interface, particularly stepped care and models of shared care are effective for the management of depression.
- Established model design elements and interventions to improve continuity of care at the primary–secondary interface have not been applied to nurse-led models of care for chronic conditions and still require development within research settings.

What this paper adds:
- A new person-centred nurse-led model of care coordination, with healthcare management activities intended to support and enable development of the person's agency in their healthcare optimisation.
- A model with specific domains and criteria with the potential for application to nurse-led services across primary and secondary settings, for a range of patients.
- Inclusion of governance and culture as domains within the model, to enable the best possibility for change, model implementation and continuity of care between the primary–secondary healthcare interface.

Key words: nurses, 'model of care', 'continuity of patient care', 'chronic disease management', 'transition and care'

INTRODUCTION

This article, the first in a series of two, is part of a broader action research study to evaluate the feasibility of a nurse-led care coordination service to improve continuity of care for people with multimorbidity.[1] This paper reports on the development of a model for nurse-led care coordination using stakeholder consultation and validation processes as part of the first action research cycle within a broader study. The second paper in the series reports on an implementation study and evaluates the model as part of subsequent action research cycles. Multiple design elements have previously been identified for models of care both within Australasia and internationally to support care at the primary–secondary interface.[2,3] These elements provide direction for services to aim for continuity of care; however, a medical approach underpins the focus within the elements, and it is therefore timely to explore nurse-led healthcare models at the primary–secondary interface (primary health care–community/general practice and secondary care–acute/tertiary care, outpatient setting).

Continuity of care is recognised as essential to high quality healthcare and relates to an individual's experience of connection, coherence and consistency of care delivered over time.[4,5,6] Continuity of care is relevant across a range of clinical settings, and has different components: informational, management, and relational, which can all be measured by particular criteria within continuity of care measurement indices.[7] The emphasis on each component of continuity differs depending on the type and setting of care.[6] Despite an understanding of continuity of care,[6] it is evident that providing and promoting continuity of care for people with multimorbidity is challenging within current healthcare systems and models of care.[8]

Multimorbidity is commonly defined as the co-existence of two or more chronic health conditions in an individual.[9] Increasing prevalence and complexity of multimorbidity within general populations is a global phenomenon and more coordinated models of healthcare delivery, ones that facilitate continuity of care for people with multimorbidity, are required.[8,10–24] A person-centred, nurse-led approach, rather than a single-disease management program could provide more effective, high-quality care.[25]

BACKGROUND

A healthcare delivery model is underpinned by a theoretical framework that guides the practices and interventions of patient assignment and care which support the underlying philosophy of care.[26] Existing models of care are frequently based on a medical model, designed to manage a single disease condition, and thus pose a significant challenge when considering people with multimorbidity.[24] Due to the complexity of care requirements generated from chronic and multiple disease situations, these people require continuity of care *across* the health sector. When achieved, this is correlated with both improved patient outcomes and satisfaction.[5] A single disease-focused model of care is unsuitable for managing, measuring and improving the health of people with multimorbidity.[24] The literature calls for a move to a patient/person-centred model of care, one that is holistic and able to facilitate coordination and effective management of the multiple complex health and psychosocial needs of the individual person.[27–29]

The chronic care model (CCM) set a precedent to systematically and holistically manage care for people living with chronic health conditions,[27] and provided a foundation for the development of subsequent models that were more consumer focused than traditional medical models. Consumer focused models included: chronic disease integrated care,[28] guided care,[29] partnership,[26] case management,[30,31] transitional care,[32] person-centred care and patient-centred care models.[33,34]

The term 'patient-centred care' refers to a model of care that is "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions".[35] The literature tracks the evolution of the patient-centred care model and notes the transition to the term *person*-centred.[33,34,36–42]

This move in terminology from patient-centred to *person*-centred care delivery aims to acknowledge the *entirety of a person's* needs and preferences, beyond only the clinical or medical.[33] The concept of a *person* driving their own healthcare decisions is now recognised and considered the gold standard in health care.[33] Two key elements of person-centred care include identification of a lead care coordinator and integrated communication. The former enables one person to be the primary contact for the person, their healthcare team and all service providers to facilitate communication and transitions across settings.[33] The latter requires establishing a system that supports simultaneous access to care plans across settings. Person-centred care has been shown to "advance concordance between care provider and patient on treatment plans, improve health outcomes and increase patient satisfaction".[36]

The transitional care model (TCM) provides and facilitates time-limited services during episodes of acute illness across settings, and has the potential to be adapted to a range of services.[32] This evidence-based model of care includes a focus on person-centredness, the use of advanced practice registered nurses, care coordination, continuity of care and the use of evidence-based tools and interventions. However, the model does not overtly address organisational culture or governance – two key areas that can pose significant challenges to implementing new services.

A model of care inclusive of positive organisational culture strategies to promote good outcomes between primary and secondary healthcare sector transitions is required. Organisational culture embodies our collective ways of thinking, feeling and behaving in healthcare organisations and is acknowledged as a complex construct with many layers across health sectors.[43] Braithwaite's systematic review on organisational and workplace cultures and patient outcomes found there was a "consistently positive association held between culture and outcomes across multiple studies, settings and countries",[44] supporting consideration of this concept within a new model of care.

Effective governance at the primary–secondary interface is also critical for continuity of care. Successful governance mechanisms are characterised by clear leadership, built trust, articulation of organizational goals and consideration of the workforce through planning, implementation, and evaluation of change.[45] Nicholson's systematic review of governance models for primary and secondary care provides detail on the necessary elements for effective governance,[46] thus providing sound direction for the application of governance elements to primary–secondary health services. Yet the elements are not positioned within an overall recommended healthcare or nurse-led model. A disruptive innovation is required,[47] a nurse-led care coordination service, specifically designed to influence outcomes at the primary–secondary interface.

The advent of the COVID-19 virus pandemic necessitates the examination of nurse-led models of care with a new sense of urgency.[48] The drastic resource implications of COVID-19 on our existing health system mean there has never been a more suitable time to enact a new way of thinking. Keeping those at greatest risk out of hospital, yet with access to specialist services, whilst still engaged with primary care is imperative. The capacity to manage a traditional approach at the primary–secondary interface is evaporating and change is required. A nurse-led care coordination service could be a disruptive innovation in healthcare delivery that facilitates keeping people safe in the community.[47,49] Nam's blog on disruptors in healthcare notes 'disruptive innovations cost less, and over time, do more'.[47] An innovative and adaptive model of care which includes evidence-based design elements applicable across healthcare sectors is required.[46] The critical element to this disruptive innovation in the current climate is to progress proactively, rather than ad-hoc, particularly when evidence–informed strategy is currently limited.

There is a paucity in nurse-led services providing continuity of care and a person-centred approach for people with multimorbidity. Furthermore, there is no guiding model of care that addresses the significant issues of healthcare culture and governance between the primary and secondary healthcare sectors. Regarding patient needs within a healthcare system, the literature notes that patients' four most pressing requirements are:

1. convenient access to providers (via telephone, internet or in person),
2. clear communication of individualised care plans,
3. support from a single coordinator of care who can help prioritise competing demands and continuity of relationships,
4. providers who listen to and acknowledge patients' needs, appreciate that these needs are unique and fluctuating, and have a caring attitude.[49]

These requirements, clearly articulated by healthcare consumers, can be addressed when contextualised within appropriate organisational cultures, and governed effectively. The development of a nurse-led model of care applied within a multidisciplinary framework, underpinned by a person-centred approach, that addresses continuity of care issues, will seek to address the current problems of care fragmentation for people with multimorbidity, and respond to their most pressing needs.

STUDY DESIGN AND METHODS

AIM

The aim of the study was to collaboratively develop a model of care for a nurse-led care coordination service. A range of stakeholders were engaged, with a view to subsequently implement a pragmatic nurse-led model of care within a multidisciplinary team in an outpatient setting that could support continuity of care at the primary–secondary interface, for people with multimorbidity.

DESIGN

This paper is part of a broader action research study and reports on the development of a model which will subsequently be assessed in terms of feasibility to provide a nurse-led care coordination service for people with multi-morbidity. As part of the broader study, Kemmis and McTaggart's action research approach was used including: planning, action, reflection, observation, and revision planning.[50]

The broader study has 2 phases,[1] the first phase and first action research cycle focused on model development and included a systematic review (PROSPERO registration number: CRD42018095780, submitted), stakeholder engagement forums, validation workshop and clinical team meetings. Reporting on the stakeholder engagement process aimed to capture stakeholder knowledge and experience by combining pragmatism and idealism into a workable model that addressed patient care delivered across the secondary and primary health care sectors.[1] Phase 2 (to be reported in a subsequent paper) included further action research cycles, with a mixed methods approach and multiple data collection points with validated data collection tools.[1] Phase 2 focused firstly on operationalising the model with implementation of service protocols, procedures, clinical guidelines, and the lead nurse care coordinator role, and secondly on evaluation of the nurses', multidisciplinary staff and patients' experiences of the nurse-led care coordination service and model.

SETTING AND PARTICIPANTS

Participants for this study included 44 stakeholders who attended one of two forums. Stakeholders included nurses, medical staff, an occupational therapist and pharmacists from within the outpatient clinic – multidisciplinary ambulatory consulting service (MACS); consumer advocates; 2 Aboriginal women who expressed representation for both the Aboriginal and the Torres Strait Island peoples' voices; healthcare executives from the primary and secondary healthcare sectors; general practitioners; practice nurses; nurse managers; academics and registered nurses. Eight stakeholders attended a follow up validation workshop.

ETHICAL APPROVAL

Ethics approval was obtained by the Human Research Ethics Committee (HREC) (reference number: HREC/17/RAH/552) at the University of South Australia (application ID: 200958) and the Central Adelaide Local Health Network (CALHN) (reference number: R20171204).

DATA COLLECTION

Data were primarily collected through a consultative process in two stakeholder forums and a validation workshop. Consultation data were further refined through meetings and professional discussions with the MACS team who were to implement the model. Data were also validated through a literature search.

Stakeholder forum

Two stakeholder forums were facilitated by consumers, academics and healthcare professionals, each of 3 hours duration. On commencement of each forum a presentation was delivered to provide the context and aims of the forum. Four tables each with 5 to 6 participants worked through 5 activities related to the strategy, structure, process and roles required to implement a nurse-led service for people with multimorbidity. A final activity required participants to identify their top 3 goals for a nurse-led service to achieve success. A scribe for each table collected participant responses. The stakeholder forums resulted in a draft nurse-led model of care with an overarching component, 4 domains, 6 operational areas and underpinning criteria.

Validation workshop

The validation workshop was of three hours duration and facilitated by an academic and a health professional. The draft model along with background context and aims for the validation workshop were presented. Participants reviewed the domains and model criteria in table groups, with activities guided by facilitators. Two tables of approximately 4 people each reviewed the model, cognisant of its operational application in a pragmatic outpatient setting. The draft model data were then compared with 'Models of care' literature and a further iteration resulted. To ensure continuity of care for patients transitioning between the secondary and primary healthcare settings, the consequential model domains were then mapped to the Australian Primary Healthcare Nurses Association (APNA) 'building blocks for nurse-led clinics'.[51]

DATA ANALYSIS

The broader study used recognised and validated instruments to collect data in relation to continuity of care, patient-centredness, workplace culture and the nurses' practice role.[1] A concurrent approach to data collection using quantitative and qualitative methods within cycles allowed both sets of data to be interpreted together, providing a richer and more comprehensive response to research questions.[1,52] This study, (Phase 1) focusing on stakeholder consultation and validation, adapted Braun and Clarke's methodology of thematic analysis,[53] to categorise and synthesise data into a workable model that could later guide the implementation of the nurse-led service. Finally, the consultation data and model domains were aligned with literature evidence and preliminary results of the systematic review (PROSPERO registration number: CRD42018095780, submitted). Synthesis of the outcomes from the stakeholder consultation process with the literature search and systematic review were key elements of the analytic process.

RESULTS

STAKEHOLDER WORKSHOPS AND VALIDATION FORUM

Data from the two stakeholder forums were sorted into 257 'structure, process and outcome' statements and 86 goal related statements,[54] and finally aggregated into themes (see Tables 1 and 2). The aggregated themes were again presented in a draft model with an overarching component, 4 domains, 6 operational areas and underpinning criteria. Subsequently, information from the participant validation workshop was integrated into the draft model.

TABLE 1: DEVELOPING THE MODEL FROM PARTICIPANT 'STRUCTURE, PROCESS AND OUTCOME' ACTIVITY:[54] STATEMENTS (INCLUDING NUMBER OF RELEVANT STATEMENTS)

Theme and number of table activity statements	Synthesised Statements	Model: Overarching component, domains and areas
Multi-disciplinary communication and work (12)	A patient-centred approach to care provision within a multidisciplinary team, across the healthcare sector are essential components of a nurse-led model of care	Multidisciplinary, inter-health sector collaboration (overarching component of the model)
Patient-centred individualised care (13)	The processes need to be streamlined into one place/point of contact for the patient, addressing a range of patient conditions with patient-centred care, sensitive to both the Aboriginal and the Torrens Strait Islander peoples' and interpreter needs	The person
Enable patient agency (13)	Patients need to be supported to develop health literacy and agency through provision of information, involvement in care planning, and having a voice within the healthcare system	The person
Care Coordination within a multidisciplinary best practice care model (29)	Provide integrated coordinated care within a multidisciplinary best practice care model to support communication processes from referral to discharge.	Coordination
Model of care supported across the health sector (13)	An integrated patient-centred health system, characterised by engaged partnerships at all levels across the health sector, with contemporary structures, processes and roles	Governance

TABLE 1: DEVELOPING THE MODEL FROM PARTICIPANT 'STRUCTURE, PROCESS AND OUTCOME' ACTIVITY:[54] STATEMENTS (INCLUDING NUMBER OF RELEVANT STATEMENTS) (continued)

Theme and number of table activity statements	Synthesised Statements	Model: Overarching component, domains and areas
Disparate funding mechanisms (6)	Separate state and commonwealth funding models do not support continuity of care	Governance
Essential components of a valuable model of care (9)	A model of care and systems that involve a multi-disciplinary team, develops quality care plans and is integrated across the acute & primary care sectors	Governance
Communication at all levels within the health system (18)	Effective communication and coordination of care require appropriate transition management, good workforce relationships and streamlined health records	Communication
A culture that enables power balance and good relationships across the health sector (10)	The healthcare culture requires balance between nursing and medical leadership with sharing of expertise and an understanding of scope of practice to empower nurses in nurse-led clinic roles	Culture
Skilled systematic health assessment (7)	Nursing assessment and consultations need to be characterised by systematic assessment, conducted by educated and skilled nurses and supported by resources, tools, and software.	Health assessment
Patient-centred care processes within a multidisciplinary team (26)	Appropriate referral, assessment, communication, goal setting, health coaching, self-monitoring, and care optimisation are required as part of the health management process. Care planning and interventions need to be supported by resources, tools, and software. The care process is linked with multi-disciplinary engagement, effective monitoring, and evaluation of care and key performance indicators.	Care processes
Patient and carer relationships (7)	Relationships and support are central to enable patients' agency in their healthcare management	Patient, significant others and carer relationships
Key performance Indicators and best practice (18)	Measurement of key performance indicators within the multidisciplinary team is a valued part of best practice and processes	Clinical best practice
Evaluation and improvement are multi-faceted (12)	Evaluation and improvement processes within the multidisciplinary team are an integral part of best practice	Evaluation and improvement
Streamlined and congruent systems between the primary and secondary healthcare sectors (32)	Systems, processes, and resources that support multimorbidity best practice guidelines, are patient-centred, enable patient flow, and support timely service accessibility are required	Systems, processes and resources
Information technology (22)	Disparate information technology and data management systems do not support effective communication or workflow	Systems, processes and resources
Workforce development (10)	Skilled staff supported by systems that provide access to continuing professional development and education pathways	Systems, processes and resources
Statements subtotal = 257		

TABLE 2: INTEGRATION OF PARTICIPANT GOAL STATEMENTS INTO THE MODEL

Theme and number of goal statements	Synthesised Statements	Model domain/area
Communication and collaboration (13)	Communication and collaboration with all providers and services across the healthcare sector and with the patient	Communication
Patient/person-centred care (27)	Partnership with the patient in quality care that empowers and enables decision-making and involvement	The person
Care coordination for people with multimorbidity (22)	Coordinated model of care that optimises health for people and ensures patient-centred, planned, managed and effective care	Coordination
Systematic process (7)	A systematic person-centred process of care	Systems, processes and resources
Cultural awareness (7)	Culturally competent, skilled (advance practice) nurse-led services	The person
Role (4)	Workplace and nursing role satisfaction along with advocacy and equity are underpinning values	Systems, processes and resources
Service characteristics (6)	The service needs to be sustainable, nimble and value learning	Systems, processes and resources
Sub-total: goal statements	**86**	
Total Statements	**343**	

MODEL FOR A NURSE-LED CARE COORDINATION SERVICE WITHIN A MULTI-DISCIPLINARY CLINIC

Model Aims

The key aim of the model (see Figure 1) developed by the authors is to provide a 'map' or guide for implementing and working in a nurse-led care coordination service within a multidisciplinary team. The model is intended to be implemented from the outpatient setting and enable continuity of healthcare for people with multimorbidity. Additionally, the model aims to facilitate well-co-ordinated transitional care between the secondary and primary healthcare settings; monitoring and keeping patients managed well in the community and reducing avoidable hospital admissions.

FIGURE 1: MODEL OF CARE: NURSE-LED CARE COORDINATION SERVICE

The Model: Overarching component, domains and operational areas

The model contains an overarching component, 4 domains, 6 operational areas and the person at the centre of the model. The overarching component of *Multidisciplinary inter-health sector collaboration* guides and provides cohesion for the domains and operational areas. A multidisciplinary approach to care for people with multimorbidity is supported in the literature and was promoted and validated as an essential component at the stakeholder forums.[56,57] Similarly, inter-health sector collaboration supports health teams to communicate consistently and effectively between the secondary and primary healthcare sectors, to achieve continuity of care.[55]

Inner circle, the person

This represents the person/patient at the centre of the nurse-led care coordination service. All healthcare management is intended to enable support and development of the person's agency in their healthcare optimisation.

Blue outer circle and inner coloured triangles

The outer circle contains four domains with the aim to support patient transitions between outpatient and community/general practice settings. Other models of healthcare delivery do not overtly include culture or governance, domains necessary to enable effective communication, care coordination and overall high-quality service delivery.[44,56] The inner circle is composed of 6 operational areas (represented by coloured triangles). Each domain and operational area include criteria to provide guidance for the development of documents, systems and processes required within a nurse–led service. The domains, operational areas, criteria and supporting documents, systems and processes are further detailed in Table 3.

Operation of the model

The patient is at the centre of the model and the key approach is for the nursing care coordinator to lead care coordination strategies that enable continuity of care for the patient between the outpatient setting and community/general practice.

Continuity of care is important in healthcare delivery and good clinical outcomes.[4,5] Coordination and continuity of care between hospital outpatient services and the community/general practice setting is part of the outpatient nurse's role and work. The nurse within this model will be the central point of contact for the patient and health team. The nurse's role is to facilitate optimisation of the patient's health status, liaise with medical and allied health professionals regarding complex health management, coordinate additional services, provide education or counselling, and support the patient's journey between the secondary and primary healthcare sectors.

TABLE 3: DOMAINS, OPERATIONAL AREAS, CRITERIA AND SUPPORTING DOCUMENTS, SYSTEMS AND PROCESSES

Domain	Criteria	Supporting documents, systems and processes
1. Coordination	Care Coordinator role: • participates in consumer recruitment, referral and triage into service (e.g. patient acuity triage document) • coordinates patient flow, optimisation and discharge from service (e.g. patient flow/journey document) • ensures continuity of care through coordination of inter-health sector transition (e.g. handover or communication protocol with primary health care)	• Care coordinator role and task description • Performance review, measurement and development tools • A range of clinical and management tools to support the care coordinator role
2. Governance	Governance that enables**:** • clear workplace leadership, structure, management, lines of responsibility, roles, expectations and outcomes (e.g. care coordinator role addresses activities and responsibilities between line managers and health team members) • governance facilitates communication and shared processes between nursing outpatients and community/GP rooms (e.g. documents outline communication and other processes between leadership roles in and accountable for the care coordination service and primary health care)	• Organisation structure • Workplace structure • Reporting lines • Role specifications • Communication plan • Clarity of service role and intersection with the community/general practice
3. Communication	Communication plan that supports: • the care coordinator role and care coordination service, relationship building and health optimisation of the patient	The communication plan identifies key points of patient transition or milestones to trigger systematic communication. Specific communication points and modes are identified: • within the organisation • within the workplace and healthcare team (e.g. procedures and frequency of communication required are documented in nurse-led service communication plan) • with consumers, patients/significant others and carers • with the primary healthcare sector (phone calls, email, letter, fax etc.)
4. Culture	• Processes and systems that support learning, safety, respect, consumer and professional engagement	• Organisation respectful behaviours policy • Governance, leadership and policies supportive of safety and learning culture • Bi-annual workplace culture assessment
5. Health assessment	• The person's story, holistic health situation assessment, including focussed assessments where required e.g. risk of hospital readmission, risk of depression and anxiety, activation level, health literacy	• Evidence-based holistic health assessment and focussed assessment tools
6. Care processes	• The processes required to provide care and support the patient's health optimisation and journey between the secondary and primary healthcare sectors	• Patient waiting room menu • Patient flow and journey chart • Patient categorisation and prioritisation (complexity and acuity) guideline • Referral processes • Multidisciplinary care planning – health optimisation processes – discharge preparation and ongoing care/management – Transition management • Care mapping • Care coordination • Inter-health sector communication
7. Patient and carer relationships	• Consumer/carer/significant other engagement in the care processes – building trust, ensuring time for interactions	• Care conferences • Care planning • Activation level • Self-management – goal setting – health optimisation – health coaching and education • Transition planning, preparation and engagement
8. Clinical best practice	• Provide person-centred care, self-management where possible, and evidence-based clinical procedures and pathways	• Evidence-based nursing clinical policies, procedures and pathways for people with multimorbidity • Audit or other tools to assess effectiveness of clinical practice

TABLE 3: DOMAINS, OPERATIONAL AREAS, CRITERIA AND SUPPORTING DOCUMENTS, SYSTEMS AND PROCESSES (continued)

Domain	Criteria	Supporting documents, systems and processes
9. Evaluation and improvement	• MACS team and person/consumer engaged with evaluation and improvement, embedded quality improvement in the service	• Lead and contribute to quality improvement initiatives, cycle and processes • Lead and contribute to person/consumer engagement with quality improvement cycle and processes • Contribute to and implement nursing research within MACS • Contribute to continuing professional development education and up-skilling • Fulfil nursing key performance indicators • Support medical and allied health key performance indicators
10. Systems, processes and resources	• Support safe skill mix, multidisciplinary work and interactions/flexibility between nursing outpatients and community/GP rooms	• Support effective ongoing systems • Lead, support and design new systems and processes: apply 10 principles of 'good work design' (e.g. patient flow and transition)

DISCUSSION

This nurse-led care coordination service model is evidence-based and relevant to the nursing best practice for management of people with multimorbidity. It incorporates key findings from the literature regarding best outcomes for people with multimorbidity,[8,24,32,57,58] and advances previous significant models of care (see Table 4). The Chronic Care Model and Transitional Care Model are two models that provide best practice management of people with chronic health conditions.[27,32,59] Wagner's model takes a health systems approach, while Hirschman focuses on nurse-led multidisciplinary interventions that target chronically ill and complex adults or patients at risk for poor outcomes after discharge.[27,32] Additionally, the Australian Primary Healthcare Nurses Association has developed a series of building blocks to assist nurses in the primary healthcare sector to successfully initiate nurse-led services.[51] This model is designed to be implemented from the secondary healthcare sector, and through cross referencing with the above models, demonstrates the capacity to effectively intersect with the primary healthcare sector and advance care for people with multimorbidity.

The model places the patient at the centre of care, with the key approach of a nursing care coordinator to lead care coordination strategies that enable continuity of care for the patient between the outpatient setting (secondary care) and community/general practice (primary health care). Continuity of care is important in healthcare delivery and good clinical outcomes.[4,5] Coordination and continuity of care between hospital outpatient services and the community/general practice setting is part of the outpatient nurse's role and work. The nurse within this model will be the central point of contact and 'go to' person for the patient and health team. The nurse's role is to facilitate optimisation of the patient's health status, coordinate additional services, provide education or counselling, and support the patient's journey between the secondary and primary healthcare sectors.

Each domain/component within the model is like the blood circulating from artery to arteriole and eventually cell. The intent being to provide a flow of information and guide the development and provision of more specific resources or systems for implementing the care coordination service (see Table 3); ensuring the right information is available at the right place. For example, within the *coordination* domain, a job and person specification document would be required to guide the effectiveness and outcomes of the care coordinator role. Similarly, as part of the *care processes* area, a waiting room menu was developed for patients to identify the top 3 issues they needed to address with the healthcare team during an appointment.[60] Protocols were also developed for patient triage, acuity, and flow through the service, as well as nursing risk assessment and multidisciplinary care plans and other documents. A key goal of the nurse-led care coordination service is to return the patient to the primary healthcare sector for continued monitoring and management, reducing future avoidable hospitalisations. This new model of care is required because although it overlaps with other evidence-based models, the additional domains of governance and culture have not been overtly included in previous models. The additional domains could enable the best possibility for continuity of care between the secondary and primary healthcare sectors. Table 4 includes a comparison of the proposed model of care with previous models. It is acknowledged that not all aspects of each model are represented in the table below.

Collaborative development of the model with stakeholders such as healthcare consumers, secondary and primary health sector clinical practitioners, healthcare executives, academics and Aboriginal and the Torres Strait Island peoples, has resulted in a model that is both clinically applicable and evidence based. Pragmatism and adaptability were significant considerations when the model was developed, as these concepts prepare the model for use in the 'real world' clinical setting. Similarly, the domains of governance and culture enable the model to be pragmatic and adaptable,

TABLE 4: MODELS OF CARE: CROSS-REFERENCING

Current model (nurse-led care coordination service)	**Model characteristics/domains**			
	Wagner[27]	**Mitchell[2]**	**Hirschman[32]**	**APNA building blocks[51]**
Multidisciplinary inter health sector collaboration	Productive interactions, prepared proactive practice team	Interdisciplinary teamwork	Fostering coordination	Build the team
1. The person	Informed activated patient			Patient engagement
2. Coordination	Community • Resources and policies • Self-management support		Fostering coordination, promoting continuity	Staffing and HR
3. Governance				Staffing and HR
4. Communication	Productive interactions, prepared proactive practice team	Communication and information exchange	Maintaining relationships, collaborating	
5. Culture				
6. Health assessment			Assessing/managing risks and symptoms Screening	Patient pathways, systems and processes
7. Care processes		Access and acceptability	Educating/promoting self-management	Systems and processes
8. Patient and carer relationships			Engaging patients and caregivers	Patient engagement
9. Clinical best practice		Use of shared care guidelines or pathways		Best practice
10. Evaluation and improvement				Evaluation and improvement
11. Systems, processes and resources	Health Systems: • Organisation of health care • Delivery system • Decision support • Clinical information	A viable funding model, training and education	Staffing	A clear plan, systems and processes, location, facilities and funding Staffing and HR

contributing to the potential for successful change management and model implementation in the clinical workplace. Developing a new model of care is significant – but the challenge is to develop a model with valued potential to benefit patient care. In these times of disruption, it is acknowledged that consideration of change is required for successful introduction of a new model of care.[61]

The model developed from a pragmatic consultation process and literature review. It is anticipated that this pragmatic process will continue as implementation of care processes, documentation, systems, procedure development and nursing interventions associated with the domains and operational areas evolve. However, to ensure maximum uptake of the model, planning and preparation for its translation into practice is vital.[62] Implementation will be challenging,[63] and a collaborative process with stakeholders will be required. Identification of the culture within MACS and consultation with the MACS nurses and healthcare team, organisational leadership, primary healthcare nurses and practices and patients all associated with the MACS Unit will be necessary. The feasibility and effectiveness of the model will be assessed in subsequent action research cycles of the broader study. It is anticipated the model will evolve during the implementation of the nurse-led care coordination service. This will take place within the MACS clinic in the outpatient setting.

LIMITATIONS

This study was phase 1 in a pragmatic action research design, intended to engage a broad cross-section of stakeholders and provide clinicians with opportunities to participate and guide model development. However, there are limitations of the study that should be considered. The limitations included lack of a control or comparator group/model within the process, although previous models developed were considered and used as a standard to mitigate this. The setting in which team meetings and professional engagement and some validation took place was geographically limited – being present at one outpatient site only. This study employed a qualitative approach prohibiting validation and reliability testing of the stakeholder forum and validation workshop. This could be a consideration for future studies; incorporating a validated survey tool at workshops could augment data analysis and further validate the model.

IMPLICATIONS

These findings provide a template and model for implementation of nurse-led services to guide clinical practitioners and nursing management from the secondary healthcare setting. The model's focus on person-centredness, coordination and communication augment the possibility of work between the secondary and primary healthcare sectors, providing a future pathway to enable effective health sector patient transition. Patient categorisation, pathways, and resource distribution, nursing roles and care guidelines have also been developed to support implementation of the model. Future systems, processes, education and work are required, but a foundation for change has been established. The collaborative and pragmatic approach to model development and supporting implementation resources, positions the model ideally for positive disruption and implementation rather than the risk of unplanned and unscheduled care delivery.[47]

Although an underlying barrier to effective transitions results from different funding sources for the secondary and primary healthcare sectors, this can be overcome by starting with small steps from local health networks, outpatient departments and primary healthcare practices. Nursing professional and industrial associations, as well as governments all recognise the need for new models of care and new nursing roles to address not only the complex care needs of people with multimorbidity, but also, increasing healthcare funding expenses.[64,65] Changes in professional and structural boundaries are required to address the increasing complex needs of people with multimorbidity; this model provides direction for how this can be achieved.

CONCLUSION

A pragmatic approach drawing upon stakeholder consultation and evidence derived from relevant literature has been incorporated into the methodology of developing this nurse-led model of care. The model is person-centred, with all healthcare management activities intended to support and enable development of the person's agency in their healthcare optimisation. The model also focuses on nursing care coordination within a multidisciplinary approach and inter-health sector collaboration, to enable continuity of care between the secondary and primary healthcare sectors for people with multimorbidity. The model domains and criteria provide the potential for it to be adapted to nurse-led services providing care for a range of patients. Through stakeholder consultation across the health sector, consideration of the strengths of previous models and building blocks within the primary health sector, the model recognises patients' most pressing needs and provides a new pathway for transitional healthcare management. It includes an overarching component (multidisciplinary inter-health sector collaboration), four domains (co-ordination, governance, communication and culture) and six operational areas (health assessment, care processes, patient and carer relationships, clinical best practice, evaluation and improvement, and systems, processes and resources).

Part two in this series will report on the model feasibility and identify barriers and enablers to implementing a nurse-led care coordination service. The paper will report on patients', nurses' and healthcare staff experiences and identify the structures, processes and outcomes required to implement a nurse-led care coordination service. The feasibility of the nurse-led model to support continuity of care across the secondary and primary healthcare sectors for people with multimorbidity will be determined. The successful implementation of this model may provide a future pathway for implementation of nurse-led services both nationally and internationally.

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RESEARCH ARTICLES

"A protracted struggle" – A qualitative blog study of endometriosis healthcare experiences in Sweden

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ABSTRACT

Objective: The aim of this study was to identify and describe endometriosis healthcare experiences based on affected individuals' blog posts.

Background: Endometriosis is a chronic gynaecological disease that often has a negative effect on mental, physical, sexual and social health, resulting in lower quality of life. Endometriosis healthcare experiences have typically been described in terms of normalisation, trivialisation and a lack of knowledge from healthcare professionals. These experiences are often reported via individual interviews or focus group interviews. Studying internet blogs may contribute additional information that might not be disclosed during interviews. Therefore, observing and analysing content from blog posts may present an opportunity to gain additional understanding of how healthcare encounters can be experienced by individuals with endometriosis.

Study design and methods: This is an inductive qualitative study based on blog posts. The blog posts were written in Swedish and posted online without passwords. Sixteen blogs written between 2008 and 2019 by people aged 22-34 were included. The bloggers had been diagnosed with endometriosis one to seven years prior to writing the blogs and lived all over Sweden. Data collection was performed in March 2019 using an online search engine. A combination of different research terms was used to find the blogs. After considering the blogs on the basis of inclusion and exclusion criteria, 12 blogs remained, and another four blogs were included via links from one of the blogs. The analysis was conducted using thematic analysis according to Braun and Clarke.

Results: The results are presented under one main theme, "A protracted struggle", and two subthemes, "The response plays a significant role" and "The value of competence". The bloggers described their healthcare experiences as a long struggle including contact with a large number of different healthcare professionals (HCPs), where the response was significant for their physical and mental health. They emphasised the advantages of person-centredness, competence and continuity in the HCP contact.

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Conclusions and implications for practice:
The results demonstrate that the journey through healthcare was experienced as a prolonged struggle, including normalisation, trivialisation and distrust. The results imply that more improvement work remains to be done within endometriosis healthcare. Taking patients' complaints seriously and providing prompt and effective investigations and treatment may lead to more positive healthcare experiences.

What is already known about the topic?

- Endometriosis healthcare experiences have typically been described in terms of normalisation, trivialisation and a lack of knowledge from healthcare professionals.
- Previous qualitative studies on the subject are interview studies, which may be influenced by the presence of researchers.

What this paper adds:

- The care-seeking behaviours involved a wide range of strategies. The descriptions varied from extensive care-seeking from different doctors and clinics, to refraining from seeking care due to a fear of being treated badly.
- The wording used in the blogs was tougher and more unforgiving, and included mostly negative aspects compared to what has been presented in interview studies. This may be explained by the "diary-like" characteristics of blogs and the free way of presenting narratives in a blog.

Keywords: Endometriosis, blogs, qualitative analysis, healthcare encounter, thematic analysis

BACKGROUND

Endometriosis is a chronic, inflammatory and oestrogen-dependent disease occurring in around one in every ten individuals of fertile age born with a uterus. It is characterised by the implantation and growth of endometrial-like cells outside the uterine area. The ectopic cells cause inflammation, bleeding and pain, and may result in the formation of lesions, adhesions and cysts. The most common symptoms are pain during menstruation, persistent pelvic pain, dyspareunia, fatigue/weariness, urinary and intestinal complaints and a reduced level of fertility. The symptoms often appear as early as menarche.[1]

Within the field of endometriosis, the literature on healthcare experiences is growing, well cited and presented in meta-analyses and reviews.[2,3] Many individuals with endometriosis report negative experiences when seeking care for endometriosis-related symptoms. They often report experiences of normalisation, trivialisation and a lack of knowledge from healthcare professionals (HCPs).[2–4] The normalisation and trivialisation of one's own menstruation pain, together with normalisation and trivialisation by family members, society and HCPs, is often considered the main reason for delays in diagnosing the disease.[2,5] This delay may cause considerable physical, mental and social damage and often has a negative impact on wellbeing and quality of life.[6–9]

The majority of research on experiences of endometriosis healthcare encounters consists of qualitative interview studies with either individual interviews or focus group interviews. Studying blogs in which patients provide detailed descriptions of experiences without the presence of probing researchers may provide additional information that might not be disclosed during interviews.[10] The blogs give unique access to the blogger's experiences and feelings without the influence of pre-defined research purposes.[11–13] Therefore, observing and analysing content from blog posts presents an opportunity to gain additional understanding of the experiences of healthcare encounters among those affected by endometriosis.

To our knowledge, only a few previous studies have used material from peer-written public domain websites to explore experiences related to endometriosis.[5,14] Krebs and Schoenbauer analysed online narrative postings and revealed two dominant discourses related to the diagnostic delay in endometriosis: the discourse of biological normality that normalises the suffering as "just part of being female", and the discourse of psycho-abnormality, which trivialises the suffering as imagined and "all in the patients' heads".[5] Neal and McKenzie focused on how bloggers presented and valued information sources about endometriosis on their blogs.[14] We have found no studies analysing blog post about endometriosis healthcare experiences.

The aim of this study was to identify and describe endometriosis healthcare experiences based on affected individuals' blog posts.

METHOD

DESIGN

This qualitative inductive study was conducted using blogs as the data source. When reporting on the study and writing this article, we were guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.[15]

SETTING

This study was based on data from Swedish blogs. In some parts of Sweden, like other Western countries where research on endometriosis healthcare experiences has been conducted, patients have to be referred to a gynaecologist by a general practitioner, while in other parts, they can make appointments directly with the gynaecologist.

SAMPLING AND DATA COLLECTION

A purposive sampling was used, which involved blogs containing posts that responded to the aim.[16] Inclusion criteria were blog posts written in Swedish, by individuals diagnosed with endometriosis, and which included descriptions of healthcare experiences related to endometriosis. Exclusion criteria were blogs protected by passwords, blogs written by individuals with other chronic diseases and blog posts regarding infertility treatment.

Data collection was performed in March 2019. An online search engine was used to find the blogs, using a combination of different research terms. The search generated 98 usable links, of which 26 were blogs. After considering the blogs based on inclusion and exclusion criteria, 12 blogs remained. One blog contained links to other blogs, and four blogs were included via these links. In total, 16 blogs were included in the study. The included blogs were written between 2008 and 2019 by people aged 22-34 (mean age 28). In two blogs, the bloggers' ages were not disclosed. The bloggers had been diagnosed with endometriosis one to seven years prior to writing the blogs (mean four years). They lived in both small villages and big cities all over Sweden. They all identified as female, but their ethnicity was not disclosed.

DATA ANALYSIS

Thematic analysis according to Braun and Clarke was chosen for the analysis of the blogs.[17] To become familiar with the text and to get a sense of the content, the blogs were read through, and thoughts, ideas and patterns were identified. In the next phase, relevant extracts from the 16 blogs were copied into a Word document. Data that did not correspond to the aim was excluded during the process. This resulted in 155 pages (Times New Roman, font size 12) which included 431 data extracts. The document was printed and the data extracts were cut out and then grouped manually. All text writing was performed in Word.

The data extracts were labelled with preliminary codes and organised into 17 subthemes. Once each subtheme had been examined, certain subthemes were grouped together and nine new subthemes were generated. In the next phase, the subthemes were grouped and combined into one main theme and two subthemes. Again, they were labelled as described. Example of the analysis and the relationships between data extracts, codes and subthemes are presented in Appendix A.

Two of the authors (HD and EH) were responsible for the analysis process. To ensure the quality of the analysis process, a pilot analysis of one blog was conducted and discussed with all authors. This analysis was included in the study. The final themes and subthemes were discussed and agreed on within the research team.

ETHICAL CONSIDERATIONS

The study was conducted in accordance with the declaration of Helsinki.[18] As this work was based on existing blogs and the work was conducted within the frame of university education, no ethics committee approval was necessary according to Swedish law.[19] The advisory board for studies conducted within the frame of university education granted oral approval for the study according to standard procedure (date of approval: 21 December 2018). Due to blog-hosting websites declaring that text available on their websites is public and voluntarily published, consent was assumed.[20] To ensure confidentiality and to reduce the traceability of quotations via search engines, the research terms, names of blogs and names of blog writers were omitted. Only short segments from blog posts were used as quotations, and certain words in the quotations were replaced with other words with a similar meaning.[21]

RESULTS

The analysis resulted in one main theme, "A protracted struggle", and two subthemes, "The response plays a great role" and "The value of competence".

As the main theme suggests, having to make repeated visits to healthcare in order to get the proper care and treatment was experienced as a long struggle that often involved contact with a large number of different HCPs and healthcare institutions. The response from HCPs during these encounters was essential to the bloggers' physical and mental health. During the encounters, a person-centred and individually adapted approach, without normalisation, trivialisation and objectification, was warranted. When their symptoms were taken seriously, the bloggers described feeling seen and confirmed. To achieve this, the HCPs had to be competent, they had to have knowledge of endometriosis and they needed to be able to transfer their knowledge. The bloggers stated that gaining knowledge made them feel confident in accepting, understanding and managing the disease. Furthermore, they preferred to meet the same person, as continuity in HCP contact was valuable and made them feel secure. In the following, the main theme and the subthemes are described in detail, and are exemplified using quotations from the blogs. The names attributed to the quotations are aliases.

A PROTRACTED STRUGGLE

The bloggers described their encounters with healthcare as a long struggle for which there was no end in sight. In order to get proper help, they had to seek care repeatedly and they encountered both organisational and personal obstacles. They expressed their frustration at having to wait for "their turn" in a state of acute or chronic pain. The waiting time to see a physician or a nurse who took their problems seriously, and the long journey towards a diagnosis, were described as persistent suffering. The bloggers described having to fight and badger to get the telephone calls, referrals and examinations they had been promised.

> *I wait for telephone calls from the Gynaecology Department and the doctor, and it can be a long week's wait without any contact at all. When that happens I feel betrayed, because you feel alone in the fight. It is not okay that this happens.* – Anna

The struggle was described as being particularly hard during times of acute pain. The bloggers were disappointed and angry at having to beg for painkillers and care. Encountering the phrases "in a moment" or "soon" was unacceptable, and made them feel forgotten or left behind.

Another aspect of the struggle was the lack of continuity in their contact with HCPs. Many bloggers wrote that meeting new HCPs repeatedly made them feel exposed and vulnerable. They had to undergo many pelvic examinations. They also had to tell new people their life stories and provide them with detailed and sensitive information about areas of their lives that they considered private, such as sexual problems or concerns about fertility. It also somehow took them back to earlier periods of their lives and the struggles they had to endure in the past to get to where they were today. Returning to square one made some bloggers feel despair, while others just felt hopelessness. However, when there was continuity in their contact with the HCPs, the bloggers often felt secure and safe, and seeking care became less of a struggle.

> *How much fun is it to undergo gynaecological examination after gynaecological examination? Gynaecological examinations are something I will never get used to. It is always exposure. The doctor often asks difficult questions, when I lie there in that terrible chair.* – Helene

Several bloggers pointed out that they felt it was time for the HCPs to take responsibility for the care they provide, and to work towards adapting the care to the individuals' unique needs. They were tired of having to fight for care when the HCPs did not take enough responsibility in trying to help them. In some cases, the bloggers were so dissatisfied that they brought charges against the HCPs based on inhuman treatment and not having their rights to proper care respected.

During their struggles for satisfactory care, some bloggers also felt the need to visit other hospitals or clinics. While the action itself was described as unacceptable, some bloggers also felt relieved and calmed as they could now replace arrogant HCPs with hopefully better ones.

For some, the struggle for satisfactory care had led to burnout, anxiety and depression. They felt that they had lost several years to this battle. Some bloggers even said that they would rather be dead than to continue with this struggle. As Josephine put it: *This struggle is so hard… You kind of have to be healthy to have the strength to fight for proper care.*

THE RESPONSE PLAYS A SIGNIFICANT ROLE

As patients, the bloggers felt dependent on the HCPs and the response they received when disclosing their symptoms to the HCPs. They attached a great deal of value to being seen and confirmed during their healthcare encounters. However, there were many stories of HCPs not wanting to prescribe painkillers, or where the bloggers felt that they had to beg to get proper pain relief. Several bloggers had been told that they were imagining or overstating their pain. Some HCPs had even called them drug addicts, which they found offensive and degrading.

> *I know all too well what it is like to be distrusted by the system, to be called a hypochondriac, an addict, to hear that I am too young to be sick. I am only 27 years old, but I have the body of a 70-year-old. The psyche died a long time ago.* – Sophie

Several bloggers described encounters with HCPs who considered pain to be physically harmless, as pain during menstruation is something "normal". They also described how stressful it was repeatedly having to hear that their problems were psychosomatic and that they should seek psychiatric care instead. Some bloggers had also been misdiagnosed with a number of different disorders, such as anxiety, irritable bowel syndrome, premenstrual syndrome or sexually transmitted diseases.

The bloggers described situations where HCPs had recommended pregnancy as the best cure for endometriosis. This made them feel hopelessness and fear, as some bloggers did not feel ready to have children, and some of them feared subfertility or infertility.

> *Also, I am starting to get tired of this rant that I should have children as soon as possible. I would love to do so if I was in a good financial situation, but I'm not! My husband is studying and I only work 75%… and some days I can barely take care of myself, so how does a child fit in there too.* – Therese

Taken together, the blogs painted a picture of a healthcare that continually misinterpreted, normalised and trivialised endometriosis symptoms. When the bloggers received a negative response from HCPs, they described feelings of loneliness, violation and disbelief. This appeared to result in low self-esteem, low self-confidence and feelings of anxiety, resignation and despair. Some bloggers described how they stayed at home trying to endure extreme pain instead of seeking care, due to the fear of risking an encounter with a cold-hearted HCP. For Maria, the lack of trust and belief in HCPs had led to a phobia of hospitals:

> *After all my visits to idiot doctors, I now have a phobia about doctor's visits. Even when I go in with sinusitis, I think they will say I am making it up and should seek mental help.* – Maria

While this dark picture of the responses received during their healthcare encounters dominated the blogs, some bloggers also described HCPs who gave them a positive response. Being seen as an individual and not as a body or an object was a key factor for a positive healthcare experience. Bloggers who felt confirmed often described gratitude towards the HCPs. They were filled with joy when they felt that the HCP listened to them, asked the "right" questions, was on their side, and confirmed their pain and symptoms. Furthermore, the bloggers appreciated engaged and interested HCPs who tried to adopt a person-centred approach, i.e. involving them in planning their treatment and care.

> *They have brought food, dried my tears, talked to me in a separate room and encouraged me a lot. Exactly what you need when you have a disease like this. Someone who shows understanding and doesn't judge you. Someone who comes back with a smile even though you have just vomited!* – Linda

> *He started by saying: "Now I've read through your medical journal (!). I understand you've had a tough time. How can I help you?" NO doctor has ever said that to me.* – Linnéa

THE VALUE OF COMPETENCE

In the bloggers' experience, HCPs' knowledge about endometriosis varied. Their expectations of encountering HCPs with competence in detecting, suspecting and treating endometriosis were often dashed. Instead, many bloggers found that HCPs lacked knowledge of the disease, were irresolute when it came to treatments, and spread old myths about endometriosis. This lack of competence led to what the bloggers considered incorrect treatments, and not having their care needs fulfilled. Several bloggers felt violated and frustrated when HCPs claimed to be experts but showed their lack of competence by asking inadequate questions or conveying inaccurate information. Many bloggers expressed their anger and distrust, sometimes with harsh words and profanities.

> *Healthcare in Sweden, damn it, is not as good as it should be, as it could be! We pay very high taxes to ensure good medical care, but instead we get unskilled staff who ignore your needs and do not believe you! Instead, they shrug their shoulders and think "You'll be fine".* – Molly

> *I think it is so terribly awful that many doctors do not even know what endometriosis is and how it works. I have been told incorrect facts about endometriosis by several doctors. However, one of the worst things is that so few people really know about the disease.* – Sarah

There were also instances where bloggers met HCPs whom they considered competent. This often generated feelings of hope, joy and thankfulness. Receiving an explanation for their pain and symptoms made them feel calm and secure. Accurate information was experienced as being important in order to understand what the endometriosis was doing to their bodies and how they could best manage the situation. Sometimes the bloggers were referred to an endometriosis specialist for a second opinion, to a physiotherapist in order to help with non-pharmacological pain relief, for example, or to counsellors who could support them with the emotional consequences of the disease. Being referred to specialists and additional professionals was described in positive words, and the bloggers did not see this as a sign of weakness or incompetence in the HCP. Instead, they considered HCPs' ability to admit their own limits and turn to other professions for help as a sign of competence.

> *"Lisa, does it hurt when you have intercourse?" I nodded. "Okay. Are you in pain when you menstruate? Do you bleed? Do you have any vaginal discharge, and what is it like?" Well. Right. It was as if he was reading me like an open book. I just needed to nod. How strange it felt, suddenly someone understood me. Who knew. Who believed in me. I started to relax. He knew what he was talking about.* – Lisa

DISCUSSION

This study examined the experiences of endometriosis healthcare encounters as described by affected individuals on their own blogs. By examining these blogs, we gained an exclusive insight into the accounts of their life stories. The encounters were thematised under one main theme, "A protracted struggle", and two subthemes, "The response plays a significant role" and "The value of competence". The bloggers described their healthcare experiences as a long struggle including normalisation, trivialisation and distrust in their contact with a large number of different HCPs. There were also positive encounters, which were often characterised by continuity, a person-centred approach and the HCP's high degree of competence.

The experience of healthcare encounters in Swedish settings as both positive and negative has been reported previously,[4,22] and is validated by this study. Hence, the positive encounters seem to be real, and not just something that the interviewees may feel obliged to say when participating in a research project.

However, there were far more blog posts about the negative aspects of healthcare experiences. The struggle of having an “invisible” disease that can have fatal consequences in terms of physical and mental health was an underlying theme in all the blogs. Although this struggle has been described in a number of earlier qualitative studies,[2,3] the findings in this study are unique, since people may be more likely to speak from their hearts in their blogs. Sometimes very harsh language was used in the description of incompetent HCPs, and swearing and calling them names was common. This provides a new dimension of understanding for the bloggers’ situation, as unfiltered information was analysed. It could also be explained by the fact that bloggers often seemed to write their blog posts immediately after the experience, compared to retrospective accounts in many interview studies.

One should bear in mind that the distinctly negative or positive experiences could also be related to the diary-like function of blogs. The findings could be interpreted as results of an “online diary”, where it is possible that people tend to blog when they feel that they are being treated very badly, or very well.[12] Hence, the blog posts may be representative of only the worst or the best periods in life.

Diary-like or not, there is a growing body of research where information is received from social media, such as blogs, discussion forums or Twitter posts. This is part of what is called the Big Data revolution, [23] and although it may come with limitations as mentioned above, and potential ethical difficulties, there are advantages to hearing the voice of the patient with clarity and immediacy. This type of data can be used to evaluate and improve the quality of healthcare and healthcare encounters.[10] Sharing experiences on social media and blogs may also provide affective support and epistemic experience to others in the same situation.[14]

The bloggers described that they appreciated when their HCP consulted other professions for additional treatment, for example counsellors or physiotherapists. The organisation of endometriosis care into multi-professional teams around the most complex cases is recommended in international guidelines for endometriosis care.[11] The number of professionals involved in the team may depend on resources and organisational or economic conditions, but ideally, the team should involve diverse professions with specialisations in different fields: a gynaecological surgeon, a urologist, a colorectal surgeon, a specialist nurse, a specialist gynaecology radiologist, a pain specialist, and a counsellor or a psychologist. Sometimes, representatives from patient support organisations are included in these teams. The benefits of these teams are multi-layered and lead to higher quality decision-making, standardised person-centred care and improved outcomes.

One possible disadvantage may be that the shared decision-making and patient involvement can be limited, as patients typically do not attend the team meetings.[24] The bloggers in this study who had experiences from multi-disciplinary teams wrote only positive things about them. They appreciated when the gynaecologist involved other HCPs to support them with the emotional consequences of the disease (ie. contact with counsellors), or to provide self-care (ie. contact with physiotherapists). The wish for a biopsychosocial approach was a common theme in the bloggers’ thoughts about what was lacking in their current care situation. This corresponds with a recent study, in which we highlighted the gap between physicians’ ambitions to take a biopsychosocial approach and the experiences of such an approach among their patients.[25]

Furthermore, the need for person-centred care was expressed in the blog posts. The bloggers wrote that having the HCP decide on medical and surgical treatment without asking for their input was outdated and old-fashioned. They demanded to participate in the planning of their care. The advantages of person-centred care have been described in both endometriosis literature and healthcare literature in general.[26–29] Incorporating patients’ needs and perspectives into care delivery is part of a paradigm shift, where the patient’s engagement with their care is now considered a key to high quality healthcare and successful outcomes.[27,28]

Rozenblum and Bates argue that patients today are more engaged with their care in general,[30] which may be a reason behind the increase in using the internet to share and rate their healthcare experiences with others. Using online discussion forums and groups is a common way to connect with others in the same situation, to share experiences of treatment and care, and to warn against or recommend treatments, hospitals or even HCPs, to others. Before the internet revolution, patients made choices about where to receive healthcare based largely on factors such as proximity or the recommendations of a friend. Easy access to patients’ feedback online may be a way for healthcare organisations and researchers to incorporate patients’ perspectives into the organisational quality improvement process.[30] This idea is highly relevant to endometriosis healthcare, where the implementation of person-centredness is an important part of international guidelines.[1,31]

The present study has several strengths, including the methodology whereby bloggers wrote freely and voluntarily about what was important to them during their healthcare experiences. The recall bias that may occur with more traditional methods of data collection, such as focus groups or interviews, can be assumed to be decreased since blogs are often written in real time.[32] The anonymity of the internet may also provide a more spontaneous, unfiltered way of sharing perceptions, thoughts and feelings.[32,33] This anonymity comes with limitations, as we were not able to ask follow-up questions or get a deeper understanding of the stories; we simply had to rely on the text.

Furthermore, as in other studies analysing blogs,[34] due to the bloggers' anonymity, we cannot ensure that they are who they claim to be online and that they had really experienced the situations they described. However, this limitation accounts for many data collection strategies. For example, there is no guarantee that participants are entirely truthful when answering posted questionnaires.

The blogs analysed in this study were all written by people who identified as women. There is a selection bias, as using blogs as a data source can only capture the experience of those who are willing to share their experiences openly in the public domain. The voices of those who do not blog, or who do not want to share their blogs, together with those who do not identify as female, are thus not included in this sample. The bloggers did not write about their ethnicity but the blog posts contained no information about being treated in a different way because of their skin colour.

The results might be transferrable to other contexts where individuals affected by endometriosis live in countries and regions with similar healthcare organisations.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE AND RESEARCH

The journey through endometriosis healthcare was described as a protracted struggle, where normalisation, trivialisation and distrust still seem to characterise a large part of the bloggers' healthcare experiences. However, there were also positive encounters and important aspects including continuity in HCP contacts, a person-centred approach and the competence of the HCP. This implies that a great deal of improvement work remains to be done within endometriosis healthcare, and that taking pain and symptoms seriously should be one of the main points to develop. Future research could focus on examining and improving the management of dysmenorrhea and other early endometriosis symptoms, especially among HCPs who meet these people at a young age, such as school nurses and HCPs at youth centres. If awareness of endometriosis and its symptoms were to be a common theme at every healthcare setting providing care for uterus carriers of fertile age, including young people and teenagers, the protracted struggle could perhaps be shortened.

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RESEARCH ARTICLES

Nursing student evaluations on the quality of mentoring support in individual, dual, and group approaches during clinical training: a prospective cohort study

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ABSTRACT

Objective: To examine how Bachelor of Science nursing students evaluate the quality of mentoring support during clinical training using three different types of mentoring approaches.

Background: The mentoring approach and the mentor–student relationship are important factors that determine nursing students' satisfaction with their clinical experience. However, there are significant differences in the approaches to mentoring in nursing, and there is no global consensus around a universal form of mentorship.

Study design and methods: The participants were first-year Bachelor of Science students (*n* = 86) divided into three groups exposed to three different mentoring approaches: Group 1 = dual (two mentors/group of students); Group 2 = individual (one mentor/one student); Group 3 = group (one mentor/group of students). The validated Mentor Support Evaluation Questionnaire (MSEQ) was used to assess the quality of mentoring support.

Results: Students from Group 2 reported a significantly higher level of mentoring support quality ($P < 0.01$; $M = 4.8$; $SD = 0.32$) in comparison to students from Group 1 ($M = 4.1$; $SD = 0.66$) and students from Group 3 ($M = 3.32$; $SD = 1.71$).

Discussion: Nursing students exposed to different mentoring approaches vary in their reported quality of mentoring support. The highest quality of mentoring support was reported by students in the individual approach, and the lowest quality of mentoring support was reported by students mentored in a group of four to six students by

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a single mentor. In the individual approach, the students highlighted the continuous availability of the mentor, recognition of personal study needs, respect, safety, appreciation, and patience.

Conclusion: The approach to mentoring is an important factor that affects students' satisfaction with their clinical experience, and in return it influences achievement of final learning outcomes and professional development of students.

Implications for research, policy, and practice: The results of this study emphasize the importance individualizing the mentorship process in order to increase students' satisfaction and lead to more successful acquisition of knowledge, skills, and attitudes. These results also indicate the need to continuously monitor student evaluations of the quality of mentoring support and their overall satisfaction with the mentoring approach during clinical training. A future qualitative, longitudinal, mixed-methods study is recommended in order to investigate and describe the specific and (in)direct causes of student (dis)satisfaction in the mentor–student relationship.

What is already known about the topic? There are different types of mentor approaches in nursing education. Comparisons of students' perceptions of mentor–student relationships in different mentoring approaches, such as individual, dual, or group mentoring, represent an under-researched area.

What this paper adds: Findings from this study provide evidence to better understanding the specific advantages and disadvantages of mentor–student relationships in individual, dual, and group approaches from the students' point of view.

Keywords: mentor, mentorship, nursing students, satisfaction, training support

INTRODUCTION

Clinical experience is an essential component of all undergraduate nursing student degrees.[1] The design and duration of clinical training (CT) received during Bachelor of Nursing programs vary throughout the world,[2] and they sometimes even vary within the same country.[3]

Croatia, like most member countries of the European Union (EU), has implemented Directive 2005/36/EC into its education system. This directive defines that during the course of a three-year study and a minimum of 4,600 hours, Bachelor of Science (BSc) nursing students in Croatia should spend at least 2,300 hours in a clinical environment under the supervision of a clinical mentor with a BSc and who is a qualified Registered Nurse (RN).[4,5]

Despite implementation of the EU directive, the mentoring system in the Republic of Croatia has not experienced significant changes. CT is mainly organized as a group mentoring approach, in which an individual approach to each students' needs is not possible. Usually five or six students have one common mentor who has a qualified BSc and is a registered nurse (RN). However, the group mentoring approach is still common throughout the world,[13,25] and many studies have described a number of difficulties reported by students and mentors during this form of mentoring.[1,3,17,42]

In Croatia, the dual mentoring approach, when a student has two mentors for support and assistance, is rarely used except in situations of certain specific clinical exercises, and the individual approach is hardly used at all.[6] A relevant indicator for the importance of the topic being researched is the fact that students spend a large number of hours with their mentor, during which they develop a relationship that is a key element in their satisfaction.[5,7] The literature shows that the satisfaction of nursing students with their mentors is a frequently investigated topic around the world.[1,7–10] However, there is a lack of research and insufficient comparisons of students' perceptions of the mentor–student relationship in relation to different mentoring approaches such as individual, dual, or group mentoring in CT. The purpose of this study is to bridge this global gap and provide data to better understand the specific advantages and disadvantages of the mentor–student relationships in individual, dual, and group approaches from the student's point of view.

BACKGROUND

CT is a vital component of a nursing student's study program.[1] It gives the student an opportunity to achieve competence in nursing practice. Despite recent definitions,[11] Nowell et al. state there is global confusion in defining mentorship and the role of a mentor in nursing.[12] There are different types of nursing CT programs around the world,[3,12,13] but there is no single universal form and no agreement on how nursing students should be mentored. A similar situation is also present in the supervision of nurses. There is insufficient evidence to directly inform the selection of a specific model or way of supervising clinical training.[14] Many differences in mentoring approaches exist.[14–16] Numerous authors state that the level of satisfaction of nursing students depends on the quality of CT as well the mentor–student relationship and the quality of their interaction.[1,17–21] Students list their mentor's support and encouragement among the most important of their mentor's activities.[22] This is especially important for nursing students during their first year of study who are at the initial stages of acquiring competency and need significant mentor assistance in most activities during CT.[23]

According to the literature review conducted on different mentoring approaches, to date, the highest level of satisfaction is expressed by students who have a one-on-one mentor–student relationship.[18,24] Research conducted by Warne et al. shows that the most important element in CT experience is the supervisory one-on-one relationship.[18] Furthermore, in relevant research conducted on a sample of 418 nurses students, with the aim of assessing the level of nursing students' satisfaction with different mentoring approaches, researchers found that the mentoring approach significantly influenced the students' level of satisfaction, while variables such as age, gender, year of study, and duration of CT did not significantly influence their level of satisfaction.[25]

Nursing students' satisfaction in the present CT system is, an important factor to achieve expected learning outcomes and excellence in clinical education,[5] as well as retention in the profession.[1] A mixed-methods study from Australia also found differences in students' satisfaction depending on demographic characteristics,[1] which imposes the need to adjust mentoring practices. Research conducted in Malaysia in 2017 listed student satisfaction among six important factors of CT.[26] It is important to emphasize that nursing student participants in a previous mixed-methods study conducted in Croatia stated unfulfilled expectations from their mentor and the feeling of dissatisfaction during CT had a significantly negative effect on their behavior and demotivated them in terms of effectively performing CT tasks.[5]

Continuous examination of students' expectations and experiences during CT can improve the socio-educational environment and assist in creating, sustaining, and attaining the educational goals of students,[27] in turn, this has a significant, positive impact on patient safety during CT.[23] The need to improve upon mentoring systems is apparent.[18] Despite numerous studies conducted around the world in the field of nursing education and mentoring, it is necessary to apply new studies and teaching strategies based on the new evidence.[28,29] This study will investigate factors which ensure the best-valued elements in student–mentor relationships are potentially applied to other forms of mentoring work, which can be transferable in nature and have implications in the broader concept of mentoring in nursing education. This article intends to better understand student perceptions of the quality of mentoring support depending on the mentoring approach, and it will identify the factors and mentor behaviors that contribute to student satisfaction during CT.

Therefore, the main aim of this study was to examine how BSc students evaluate the quality of mentoring support during CT with respect to individual, dual, and group mentoring approaches.

METHODS

PARTICIPANTS

The participants in the study were first-year undergraduate nursing students (n=86) in the 2018/2019 summer semester from a Higher Nursing Education Institution in Croatia, EU. First-year BSc nursing students were selected because they were in the initial phase of acquiring specific knowledge, skills, and attitudes, had high expectations of their mentors, had a lower level of independence than students in later years of study, required thorough mentoring guidelines and demonstrations of clinical procedures and techniques, and they had significant and complete mentoring support and assistance in some activities during CT.[23] Out of the total of 86 participants in this study, 8 (9.3%) were male and 78 (90.7%) were female. Participants were 18 to 24 years old, and the average participant age (mean) was 20.3 years (SD=1.2).

STUDY DESIGN

This prospective cohort study was conducted during 60 hours of regular CT in hospital teaching departments. The selection criteria for departments to be included in the study stated they should not be an intensive care unit, and they had to be a clinical educational department where regular CT was performed.

Purposive sampling, based on research objectives, was performed according to the defined criteria. Hence, during the study, three groups of nursing students were examined (further referred to as Group 1, Group 2, and Group 3). Formation of groups and subgroups (SG), as well as their schedules in the clinical departments, was done based on regular training groups of first-year BSc students (Fig 1). Thus, given this was a homogenized sample of students, and given the effort to make the results of this study as close to reality as possible, students were divided into groups and subgroups according to an alphabetical list of surnames. This method is a common procedure for dividing students into exercise groups. Regular rotation of groups ensures that all students have the opportunity to clinically train in all departments during a particular course, semester, and academic year. Students from all three groups were exposed to different mentoring approaches. Group 1 had dual mentoring support (two mentors) during clinical training, Group 2 had individual, one-on-one mentors, and Group 3 had one mentor for the group of students.

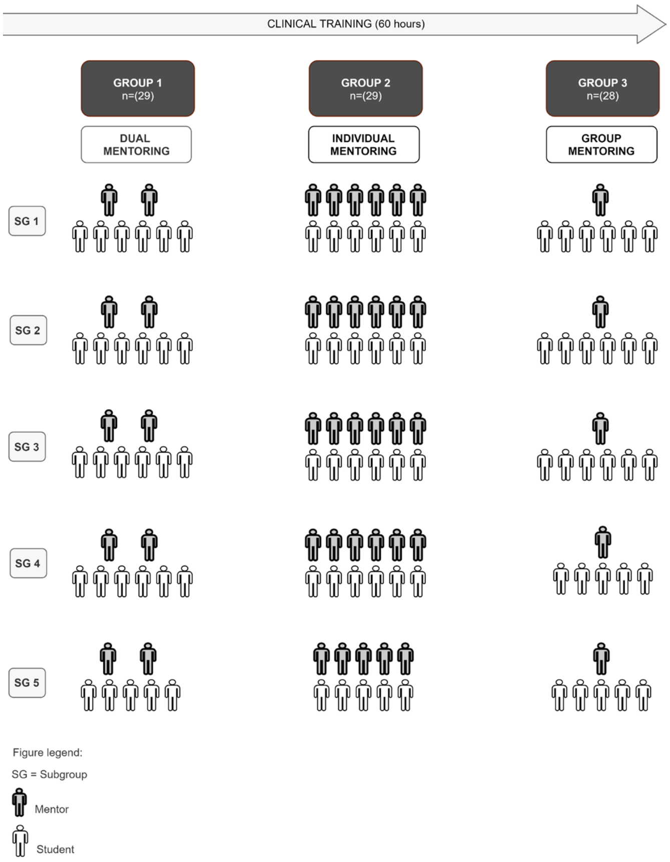

FIGURE 1: DESIGN OF STUDY – DISTRIBUTION OF GROUPS AND SUBGROUPS OF STUDENTS AND THEIR MENTORS DURING CT

The mentors in the study (*n*=44) were BSc nursing graduates who were qualified RNs employed in the faculty base as head nurses and were also employees at the University. The mentors performed their regular work assignments in clinical departments (work organization and patient care) in the presence of students. Mentors assigned a patient to each student for continuous monitoring, planning, performing, and evaluating health care, as well as keeping clinical records. During execution of their work assignments, mentors simultaneously demonstrated the procedures to assigned students and provided them with explanations.

Participants in Group 1 (*n*=29) performed their CT in a group of five to six students. They were mentored by two official mentors (dual mentoring approach) (Fig 1). Both mentors were involved in all phases of CT and worked according to a written CT operating plan. Mentors simultaneously participated in the preparation of students for CT, assessment of the condition and needs of patients, health care planning, demonstration of clinical skills, implementation of immediate patient care, evaluation of care, preparation of health care documentation, providing feedback to the student, and evaluation of cognitive, psychomotor, and effective student achievement according to defined elements and evaluation criteria.

The second group (Group 2) of participants (*n*=29) was composed of students who performed their CT one-on-one with a faculty mentor (individual mentoring approach) (Fig 1). According to the aforementioned steps of the CT Operational Plan, mentors used an individualized and holistic approach of working with their students, beginning with individual preparation of the student for CT as well as working with and continuously monitoring their student to prepare them for the final evaluation of the student's knowledge, skills, and attitude. This kind of individualized supervision model has proven to be a crucial factor determining students' total satisfaction during their clinical training periods.[25,30]

Participants from Group 3 (*n*=28) performed CT in a group of five to six students under the guidance of a single official mentor (group mentoring approach) (Fig 1). The mentor, while performing regular department assignments, conducted occasional joint meetings with the students. Thus, the mentor worked independently with all students in the group regarding the CT operating plan, from the preparation phase to the final evaluation phase, for all students. This mentoring approach is consistent with current regular CT curricula and is implemented at most Croatian nursing facilities.[17]

DATA COLLECTION PROCEDURES

Questionnaires with thorough explanations of all study details were forwarded through joint student e-mails (Group 1, Group 2, and Group 3) in the form of an online survey. Study participants filled their assessments/questionnaires immediately after 60 hours of CT, and they sent their filled Google Forms questionnaires to the researchers anonymously via their student e-mail. All 86 (100%) students completed the questionnaires voluntarily and completely.

INSTRUMENT

Following written consent from the original author of the questionnaire, the statements from the standardized Mentor Support Evaluation Questionnaire (MSEQ) were used to validate the mentoring support, as observed in another study.[31] The instrument was originally designed by the *Croatian Institute for Social Research* primarily to support all participants in the mentoring process and to prevent the risk of poor-quality mentoring. Poor mentoring is very often a consequence of insufficient competency to perform mentoring duties.[31,32] MSEQ is based on the Croatian Qualifications Framework document, which regulates the entire system of qualifications and occupational standards at all education levels in the Republic of Croatia.[33] The questionnaire explicitly focuses on the mentor's competencies and relationship with the students, and it is primarily intended to measure the level of student satisfaction with mentoring support and their general relationship with mentors.

The original MSEQ consists of 39 statements in total, 25 of which are related to students' satisfaction with mentoring support and the mentor–student relationship during CT, while the 14 remaining statements relate to students' satisfaction with the delivery of academic courses/theoretical classes. Regarding the aim and focus of this study (mentor–student relationship in the clinical environment), the 14 statements related to academic courses/theoretical class were removed from the questionnaire.

Principal component analysis with varimax rotation was performed with the remaining 25 statements from the original questionnaire in order to check the factoring structure. Using this procedure, one factor was extracted which explained 18.23% of the variance. The average intercorrelation among items was 0.73, and Cronbach's alpha, measuring the internal consistency of the questionnaire, equaled 0.98.

For the purposes of this study, a team of three nursing experts (two associate professors in nursing and one senior lecturer) was formed to verify the validity of the MSEQ. Responses to the questionnaire were evaluated on a rating scale (from 1=I completely don't agree to 5=I completely agree), in which a higher number represents a higher level of agreement with the statement in question as well as higher student satisfaction with the provided support and the mentor–student relationship. Along with the aforementioned 25 items taken from the original questionnaire, the participants responded to questions related to general demographic information (e.g., gender and age).

STATISTICAL ANALYSIS

Statistical analyses of the acquired results were performed using Statistica 13 (TIBCO Software Inc., 2017). In the first phase of processing, the latent structure of the questionnaire was checked using principal component analysis with varimax rotation and with the Gottman–Kaiser criterion of factor extraction with a characteristic value greater than 1. The reliability of the questionnaire was verified by Cronbach's alpha coefficient. In further analyses, descriptive data (arithmetic mean, standard deviation, and percentages) were calculated. Due to significant deviations in the distribution of total satisfaction of mentoring support and relationships with the mentor (as well as individual elements) among the three different groups, and with respect to a normal distribution, Kruskal–Wallis tests were used with post-hoc Rank tests.

ETHICAL APPROVAL

The ethical committee of the University approved the study at their regular meeting (IRB approval number: 2198-1-79-37/19-02). All participants were informed of the aim of the study and other study details, and all voluntarily agreed to participate. Participants were able to stop participating at any time without any consequences. Anonymity of the participants during and after the study was guaranteed.

RESULTS

STUDENT EVALUATIONS ON THE QUALITY OF MENTORING SUPPORT WITH RESPECT TO THE MENTORING APPROACH

Since the psychometric characteristics of the applied MSEQ questionnaire were confirmed to have a single-factor structure and a very high level of reliability, the difference between the mean values of the total levels of satisfaction among the three examined groups of students was initially tested.

After analyzing student evaluations, the results indicated that students belonging to Group 2, mentored on the one-on-one approach (one mentor per student), ranked the quality of mentoring support as very high (mean=4.8; SD=0.32), and they were significantly more satisfied with their mentor support ($H_{(2)}$=33.69, P<0.01; the Kruskal–Wallis test) when compared to students in Group 1 (mean=4.1; SD=0.66) and Group 3 (mean=3.3; SD=1.17) (Figure 2).

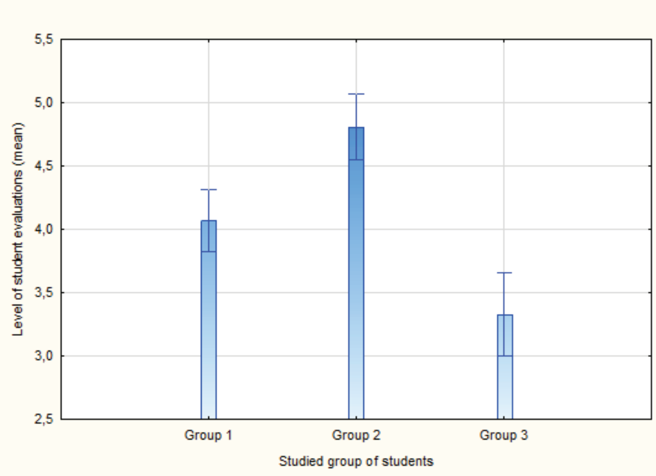

FIGURE 2: OVERALL LEVEL OF STUDENT EVALUATIONS OF MENTORING SUPPORT AMONG THREE GROUPS OF STUDENTS CONSIDERING THE MENTORING APPROACH (N = 86)

SPECIFIC DIFFERENCES IN NURSING STUDENT EVALUATIONS ON THE QUALITY OF MENTORING SUPPORT WITH RESPECT TO THE MENTORING APPROACH

Specific aspects of the evaluations and detailed differences among the three examined groups of students with regard to all 25 elements of the questionnaire are presented in Appendix A.

Quality of mentoring support among students in the first, second, and third groups was analyzed, and statistically important differences (P<0.05, Kruskal–Wallis) were found for all 25 questionnaire items (Appendix A).

Further pairwise examinations between the mean values of student evaluations for the examined groups showed significantly higher satisfaction among Group 2 students when compared to Group 3 students for all 25 questionnaire items ($P<0.05$, post-hoc rank test) (Appendix A).

The post-hoc rank test indicated a significantly higher satisfaction level among Group 2 students when compared to Group 1 students for 22 out of 25 questionnaire items ($P<0.05$); exceptions were for item number 6, "I arranged deadlines for certain tasks with my mentor" ($P=0.244$), item number 14 "The mentor followed my work and gave me feedback" ($P=0.117$), and item number 24 "I did not feel that my mentor was neglecting me due to other activities" ($P=0.130$) (Appendix A).

In contrast to the previous results, post-hoc analyses of Group 1 and Group 3 student satisfaction levels indicated that Group 1 students were significantly more satisfied in only 4 out of 25 questionnaire items. These items included number 2, "The mentor allows me to follow his/her work and explains his/her professional procedures and decisions" ($P=0.014$), item number 6, "I arranged deadlines for certain tasks with my mentor" ($P=0.039$), item number 14 "The mentor followed my work and gave me feedback" ($P=0.047$), and item number 24 "I did not feel that my mentor was neglecting me due to other activities" ($P=0.024$) (Appendix A).

DISCUSSION

The results of this study clearly indicate that the three groups of nursing students exposed to different mentoring approaches significantly differed in the reported quality of mentoring support, which is in accordance with other research.[8,13,25,34]

The highest-quality level of mentoring support (average = 4.8) was found in Group 2 students, who were mentored by a single official mentor. The lowest grade in Group 2 (4.5) was higher than the highest grade in Group 1 (4.4), and especially in Group 3 (3.9). Students were very satisfied with the one-on-one mentoring approach (4.8). In the individual approach, students experienced continuous availability of their mentor, recognition of personal study needs, respect, safety, appreciation, and patience. These results were also confirmed in recent international studies, in which only 25% of the sample had an individualized supervisory relationship and stated that these students were most satisfied with the individual mentor–student relationship.[25] The highest student satisfaction in the individual mentoring approach has also been confirmed by other studies around the world.[8,10,34,]

Previous studies have emphasized that the one-on-one mentoring approach is the most effective in clinical practice.[25,30] In the Crawford qualitative study, results showed that students perceived their relationship with their mentor as pivotal to their development as a nurse.[8] They developed supportive and caring relationships, which resulted in students expressing deep respect for their mentors and vice versa. Saarikoski states that the individual mentor–student relationship is a key element in satisfaction and professional socialisation, and they describe positive effects of individual mentoring such as continual feedback, respect, and confidence regarding student satisfaction and the learning outcomes.[24,35]

The next group of students according to the quality of mentoring support (mean=4.1) was Group 1, where students were mentored by two employees of the faculty base. Students from Group 1 gave the lowest scores for guided learning and critical thinking. In addition, they did not perceive their mentor as a role model. On the other hand, Group 1 participants emphasized the possibility of following their mentor's work, common agreement and adherence to the agreement, feedback information, and the feeling that they were not being neglected. Dual mentoring may be an appropriate solution to meet the needs of the students, including additional academic and psychosocial support and promoting a positive attitude.[36,37] The importance of these student statements were described in the Crawford study, in which students reported common agreement and appreciation in their relationships with mentors. The importance of feedback was also emphasized by a student's statement "no news is bad news".[8] The same results in the literature review state that feedback has a purpose to improve nursing students in their practice.[38] The results in our study can be explained by the fact that two mentors had regular work commitments and, therefore, did not have enough time to provide individual support to students, but they were able to pay enough attention to procedures and student behavior, which is extremely important according to students' expectations.[5]

The lowest quality of mentoring support (mean=3.3) was found in Group 3, where students were mentored in a group of four to six students by a single official mentor. Group 3 students indicated very low levels of satisfaction with mentoring support and that students did not acquire the necessary skills, were unable to think critically, and did not perceive their mentor as a role model. Clinical training in real environments needs to provide students the possibility to integrate theory and practice and to help them acquire necessary clinical competencies and skills in decision making, critical thinking, ethical reasoning, and professional communication.[39,40] Salamonson et al. conducted their studies in four universities in Australia and also confirmed students showed some negative experiences during CT such as lack of time to teach, excessive nursing workload, and lack of engagement, and they expressed dissatisfaction with the mentors' focus on learning rather than their needs.[1] Therefore, mentors as clinical and pedagogical professionals should encourage critical thinking and be a role model to their students.[5] Finally, students in this study were not satisfied with this form of mentoring. Similar results were shown in another study where group supervision was dominant in the sample.[25] Antohe et al. stated that it is necessary to shift the group supervision model towards individual supervision. Group mentorship models in nursing pose a significant challenge worldwide since mentors simultaneously have to perform dual roles.[23] The assumption is that, in group mentorship, the mentors do not have the capacity to develop satisfactory interpersonal relationships with their students, which has proven to be, in many studies conducted so far, the most important characteristic as well as the most demanding category in mentorship.[41] In a systematic review, Jokelainen et al. also reported students want to be treated as individuals during placement learning.[15]

From the aforementioned results, it is clear that the main detractors of a more effective mentorship were the mentor's regular workload, lack of time, and the number of students assigned to a single mentor.[1,3,42]

Post-hoc rank tests of the differences among participants from all three groups also recognized significantly higher-quality mentoring support for all 25 questionnaire items in Group 2 participants, when compared to Group 3 participants, and for 22 questionnaire items when compared to Group 1 participants. The absence of a significant difference in the three mentioned items can be interpreted by the notion that the mentor from Group 2, despite their individual approach, did not have enough time for the students because of their regular work assignments at the department. Moreover, both mentors in Group 1 had more time dedicated to students, but the results from other questionnaire items suggest that it was still insufficient. Group 1 participants gave significantly higher ratings than the participants from Group 3 in only four items, which can be interpreted by the overload of a single mentor from Group 3 with his own work assignments and group of students. It is evident that the pairwise test between Group 2 and Group 1 identified a single mentor in a group of students as a key deterrent for a more effective mentorship, i.e., in this case, a form of mentorship which would provide a higher level of student satisfaction.

The results clearly indicate that students cannot be seen as a group, but rather as individuals.[43] Mentor duties, when incorporated with the regular duties of a nurse, receive insufficient dedication during regular working hours, especially when it comes to a group of students.[23,44] Previously quoted research confirms that the level of student satisfaction depends on their perception of dedication and monitoring of their mentor. Students with mentors that continuously monitor them have a higher level of satisfaction in comparison to the students without continuous monitoring.[25] The results give clear recommendations to tailor education according to students' needs.[7] D'Souza et al.psychomotor, and affective skills in the Middle East. Objective: The aim of the paper is to assess the satisfaction with and effectiveness of the clinical learning environment among nursing students in Oman. Design: A cross-sectional descriptive design was used. Setting and Participants: A convenience sample consisting of 310 undergraduate nursing students was selected in a public school of nursing in Oman. Methods: Ethical approval was obtained from the Research and Ethics Committee, College of Nursing in 2011. A standardized, structured, validated and reliable Clinical Learning Environment Supervision Teacher Evaluation instrument was used. Informed consent was obtained from all the students. Data was analyzed with ANOVA and structural equation modeling. Results: Satisfaction with the clinical learning environment (CLE stated that mentors need to change their educational strategies and reorganize CT for nurses in order to provide better mentoring support and learning opportunities, thus increasing the level of student satisfaction.[34] In circumstances where it is not possible to provide individual mentoring approaches to meet the needs of students, it is necessary to pay special attention to ensure efficient use of mentors' time. In addition, mentors should take into account the fact that good teaching preparation is important, but it is more important to recognize their students' needs.

STUDY LIMITATIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

This study included only a sample of nursing students at the University in the Republic of Croatia in order to facilitate implementation and ensure more effective control of the study.

In Group 2, only one mentor was included in the mentoring process, and this might be considered negative given the students dependence on the knowledge and competencies of only one person.

Future work should identify occasions where the individual approach is not possible, and should identify how the most valued elements from the individual mentoring approach might be applied to other mentoring approaches.

A qualitative, longitudinal, mixed-methods study monitoring the same participants is being planned, which will provide student interviews that will describe the specific and (in) direct causes of student (dis)satisfaction in the mentor–student relationship and mentor support in more detail.

IMPLICATIONS FOR RESEARCH, EDUCATION AND CLINICAL TRAINING

Results of this study offer new insights, which can help clinical facilities and educational institutions understand student expectations during clinical training and identify and moderate the factors that impact their satisfaction during CT. Continuous examination of the expectations and experiences of students during CT can improve the socio-educational environment and assist in creating, sustaining, and attaining the educational goals of students, which, in turn, has a significant, positive impact on patient safety during CT. This study investigated factors that can ensure the best-valued elements in student–mentor relationships are potentially transferred to other forms of mentoring work, which can be transferable by nature and provide implications in the broader concept of mentoring in nursing training. This article provides a better understanding of students' perceptions of the quality of mentoring support depending on the mentoring approach, and it identified the factors and mentor behaviors that contribute to student satisfaction during CT.

CONCLUSIONS

This study found that students who experienced a one-on-one mentoring approach were most satisfied with their mentoring support. According to evaluations on the quality of mentoring support, the next group of students ranked were those mentored as a group by two mentors. The least satisfied with their mentoring approach and support were the students mentored as a group by a single official mentor. The results of this study indicate that having to perform regular department duties along with mentoring a group consisting of more students detracted from the quality of mentorship, and what surfaced as a key problem was mentor overload caused by multiple simultaneous duties. Therefore, the results of this study emphasize the importance of individualizing the mentorship process in order to increase student satisfaction and promote successful acquisition of knowledge, skills, and attitudes. These results indicate the need to continuously monitor student evaluations regarding the quality of mentoring support and their overall satisfaction with the mentoring approach during CT.

The results indicate very low satisfaction in the quality of mentoring support in the dual and group mentoring approaches. The students were not satisfied, they did not acquire the necessary skills, they were unable to think critically, and they did not perceive their mentor as a role model. All of the above can have a negative impact on the achievement of learning outcomes, student competencies, and the quality of patient care.

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RESEARCH ARTICLES

Happy, Healthy, Ready – working with early childhood non-government organisations for developmental surveillance for vulnerable children

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ABSTRACT

Objective: This study sought to improve: (1) knowledge of child development among non-health child and family workers; and (2) identification and referral of children from culturally and linguistically diverse (CALD) backgrounds at developmental risk, by partnering child health services with non-government early childhood education and family support services in two suburbs with high numbers of families from CALD backgrounds.

Background: Children from CALD backgrounds have increased risk of developmental problems going undetected prior to school entry, thereby missing early intervention.

Study design and methods: This was a quality improvement project. The model comprised: (1) co-locating a child and family health nurse CAFHN in a non-health setting or visits by early

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childhood health staff to undertake developmental surveillance and (2) training non-health staff on child development and New South Wales (NSW) developmental surveillance tools. Evaluation used a mixed methods design analysing qualitative data from parents, early childhood workers, CAFHNs, and paediatricians and de-identified activity data from CAFHNs, and other early childhood health services.

Results: Non-health workers increased their referrals of children at developmental risk to CAFHN or other child health providers. In Rockdale, 44% (n=62) and Botany 41% (n=98) of children screened had one or more significant developmental vulnerabilities. CAFHN reported developmental surveillance for families who were not accessing traditional clinic-based services.

Discussion: This study tested a model of developmental surveillance and entry into the child and family health system in a non-health setting, thus providing a 'soft' entry for parents who might not otherwise engage with these services.

Conclusion: The project demonstrated a new way of working for CAFHNs and facilitated identification of developmental risk in children from CALD backgrounds, who would otherwise have been missed.

Implications for research, policy, and practice: This relatively small-scale model of practice change has resulted in improved access for a marginalised population, but further research is needed to refine the model and test it for scalability and replicability.

What is already known about this topic?
Our team undertook a systematic review of outreach developmental surveillance occurring in non-health settings. Eight studies across high, middle and low income countries have been identified with a total of 150,047 children aged 18 months to five years, the majority from low socioeconomic backgrounds. Only one study has been based in Australia[10] in a regional area in Victoria which showed increased detection of children who were developmentally vulnerable. No studies have had a specific focus on CALD populations in Australia or have been based in the context of the NSW health and developmental surveillance system.

What this paper adds:
This paper describes the outcomes of a quality improvement project implemented in Rockdale and Botany – two disadvantaged areas of South Eastern Sydney – to increase access to developmental surveillance and early intervention for children from culturally and linguistically diverse (CALD) backgrounds attending supported playgroups and early childhood education services.

Key words: Developmental screening, detection, child development, Child and Family Health Nurse (CAFHN), culturally and linguistically diverse (CALD), migrant, refugee, interagency, multi-agency

INTRODUCTION

One in five Australian children starting school are developmentally vulnerable, which means that they do not have the skills (learning, socio-emotional, physical) to flourish at school.[1] Developmentally vulnerable children are at increased risk of poor long term adverse academic, health and vocational outcomes.[2–5]

Children from non-English speaking homes, who are not proficient in English at school entry and/or socioeconomically disadvantaged, are 1.5 times more likely to be developmentally vulnerable compared to their English speaking and/or more affluent peers.[3,6] Given the potentially adverse long-term consequences of developmental vulnerability, children who are developmentally vulnerable need to be identified as early as possible so that they can be referred for early intervention and receive support prior to school commencement.[5,7,8]

Unfortunately, only 18% of children who are developmentally vulnerable receive early intervention in the preschool years.[1] This is despite the fact that in New South Wales (NSW) there is a program of universal early childhood developmental surveillance throughout the early years, starting at birth (the zero to four weeks check) and continuing to age four, prior to enrolment in school. Traditionally the model of early childhood developmental surveillance through NSW public health services is through a single universally offered home visit in the first few weeks after a baby's birth (the 0 – four week check) by a child and family health nurse (CAFHN), with parents then invited to visit local child and family health centres for the remaining checks, also undertaken by a CAFHN. Child and family health nurses provide a universal 'soft' entry point into the health system supporting access to early intervention. Generally speaking, CAFHNs work in child and family health centres in a centre-based setting, other than when undertaking the universal home visit.

Centre-based CAFHN services are universally available but may be harder to access for vulnerable families. Research in disadvantaged areas of Sydney found that socioeconomically disadvantaged families from CALD backgrounds were not attending child and family health centres and were therefore missing developmental checks.[4]

Services should consider how they invest their resources to specifically target those families whose cultural, locational or economic context create social determinants that adversely affect their long-term health outcomes.

There has been increasing interest in models of early childhood developmental surveillance that address poor access to mainstream services and subsequent long-term disadvantage for vulnerable families, including those from CALD backgrounds.[9]

These sites were chosen due to documented disparities in the performance of children from Rockdale and Botany on the Australian Early Development Census (AEDC) compared to the NSW average. For Rockdale and Botany, the proportions of children identified in the AEDC as developmentally vulnerable on one or more domains were 22.2% and 23.1% respectively, compared to 20.2% NSW average. In addition, child and family healthcare providers, including CAFHNs, and staff in non-government organisation (NGO) early childhood services were noting under-representation of CALD families in early childhood developmental surveillance. Children might be referred to a supported playgroup because of familial vulnerabilities but this does not automatically equate to a referral to a CAFHN or other providers of early childhood developmental surveillance. As a response, a model of practice for CAFHNs in a non-health setting was designed and tested, the elements of which, if successful, might be replicated or adapted in other locations.

Our objectives were to:

(1) Investigate the effect of a training program on the knowledge levels relating to child development among non-health child and family workers.

(2) Identify if there had been an improvement in identification and referral of children at developmental risk from CALD background when the model was implemented.

(3) Ascertain the views of service providers, parents or grandparent caregivers on the suitability of the model for the participating families.

In Rockdale, CAFHNs were fundamental to the study and testing of the non-health setting model of practice.

METHODS

MODEL

The model comprised: (1) co-locating a CAFHN or regular visits by early childhood health staff (community child health doctor, paediatrician, speech pathologist) to undertake early childhood developmental surveillance in NGO providing early childhood services, supported playgroups or family support services; and (2) training NGO early childhood staff on child development and use of the Parents' Evaluation of Developmental Status (PEDS), which was the NSW Health developmental surveillance tool at the time. This tool has now been replaced by the "Learn the Signs – Act Early" parental self-assessment tool.

The PEDS is an evidence-based screening tool in the form of a 10-item questionnaire that elicits and addresses parental concerns about children's development, health and wellbeing. It is completed by the parent individually or in consultation with their healthcare provider, usually a CAFHN. This tool was used by NGO early childhood staff in discussion with parents. Early childhood health providers score the PEDS form to identify concerns that predict issues if identified at particular points in a child's development (predictive or non-predictive concerns). The PEDS Interpretation Form assists early childhood healthcare providers, such as CAFHNs, to make the decision to refer, further screen, keep a watch, advise parents or reassure.

Parents identified by NGO early childhood service staff as having concerns (via PEDS) or identified as having not attended scheduled early childhood health checks were referred for a developmental screen with a CAFHN or community child health doctor. Staff in the participating supported play group and family worker program described 'warm transfers' where they walked a parent in to the CAFHN for an appointment.

If required, children were referred by the CAFHN for further specialist assessment to a Developmental Assessment Service. The team from the Developmental Assessment Service visited the site as well and this was identified as an enabler for some families to take the step to additional assessment and support.

The Botany project entailed visits to supported playgroups from Community Child Health Doctor and Speech Pathologist, with some assessments conducted in local and familiar locations (e.g. shopping centre). A CAFHN became part of the team during the study and visited playgroups to meet parents and discuss child development.

EVALUATION DESIGN

A mixed-methods design was used to evaluate this quality improvement project. The qualitative study included focus groups, interviews with service providers, parents, and grandparent caregivers to understand the suitability of the model components for participating families. The quantitative study entailed a retrospective review of the Community Health and Outpatient Care (CHOC) activity database for the Rockdale and Botany areas and descriptive analysis of the data.

DATA COLLECTION

In Rockdale, 45% of children lived in a home where English was not the language spoken at home. After English, Nepali was the most frequently spoken language at home, followed by Mandarin and Cantonese.

The table below describes the data sources and data collection methods:

TABLE 1: DATA SOURCE AND COLLECTION METHOD

Data source	n	Data collection method
2 x English-speaking parent/ grandparent focus groups with mixed participants from different ethnic backgrounds. 1 x Nepali speaking parent/ grandparent focus group 1 x Bengali speaking parent/ grandparent focus group	n = 30 (approx.)*	Collected during NGO supported playgroups in Botany and Rockdale attended by parents and/or grandparents with their children/ grandchildren
Interviews with NGO and health providers in Botany and Rockdale.	n = 13	Collected in the participant's workplace or by telephone
Results from pre and post training survey of NGO attendees to assess changes in knowledge as a result of the training.	n = 16	Provided by survey author
Results from previously administered parent survey in Rockdale (English speaking only)	n = <50	Provided by survey author
Activity data collected by Sydney Children's Hospital (SCH) and South Eastern Sydney Local Health District (SESLHD)	n = 149	Provided by SCH and SESLHD
* Parents joined/left the group in response to child needs so exact numbers are not available.		

QUANTITATIVE DATA COLLECTION

Knowledge: Pre and post-training surveys were administered to attendees to assess changes in knowledge as a result of the training. A total of 22 staff attended the training, with 21 (95%) completing the pre-training survey and 16 (76%) completing the post-training survey. The survey was completed by attendees prior to completion of the training and re-administered two months post-training by the project officer (LS) and project lead (SW).

Retrospective audit: The de-identified data collected by the project officer (LS) or project leads (VS; DP; JS; SW) covered the period from commencement of the model in 2014 up to June 2018 and included age of child, country of birth, language spoken at home, and country of birth of parents (if collected) as well as developmental vulnerabilities identified and service contacts with CAFHN.

QUALITATIVE DATA COLLECTION METHODS

Focus groups: Parents and grandparents were invited by participating NGO services to take part in focus groups to gather their views of the model and their perception of how it has affected them and their families. English speaking focus groups were moderated by the English-speaking research assistant (KE). Two language groups were planned to be homogenous to enable culturally specific discussion. One of these groups was moderated by a Nepali-speaking facilitator, and the other by a Bengali-speaking facilitator using the interview guide in Figure 1. Both facilitators were trained in group facilitation, were briefed by the research assistant (KE) prior to the focus groups and debriefed afterwards by KE. English-speaking focus groups were audio recorded and transcribed verbatim using a transcription service.

Parent/Grandparent Focus Group Guide

1. What does child development mean to you?
2. How has your understanding of child development changed since you first started coming to (playgroup, childcare, family support, CAFHN clinic)?
3. What do you think helps or hinders a child's ability to develop? Why do you say this?
4. How do you get information if you have questions about your child's development?
5. What did you think of the (playgroup, childcare, family support) worker talking to you about your child's development?
6. Was it appropriate to discuss your child's development during (playgroup, childcare, family support)? Why do you say this?
7. What do you think CAFHN do?
8. What was it like seeing the CAFHN or the paediatric doctor at the (Centre name)?
9. What was it like seeing the paediatric doctor from the DAS (if appropriate)?
10. How do you think things would have gone if you had not seen the CAFHN and/or the paediatric doctor? Why do you say this?
11. What would you do now if you were worried about your child's development?
12. What would you like to see done differently? Why do you say this?

FIGURE 1: PARENT /GRANDPARENT FOCUS GROUP GUIDE

Telephone/face to face interviews: Participants were nominated by their organisations and invited to take part in an interview. Interviews were conducted by phone or face to face with NGO and health providers to understand the impact of the model on their work practices and the perceived impact on participating families using the interview guide in Figure 2. Interviews were recorded and transcribed. Interviews were conducted by KE.

Provider interview guide

1. Can you please describe "Getting in Early – Getting it Right" to me?
2. Why do you think your service is part of "Getting in Early – Getting it Right"?
3. How has taking part in "Getting in Early – Getting it Right" changed your relationship with the other services? Why do you say this?
4. How has "Getting in Early – Getting it Right" changed how you work?
5. What did you think of the training you received for "Getting in Early – Getting it Right"?
6. What sort of feedback do you get from referrals you make as a result of "Getting in Early – Getting it Right"?
7. What do you think has worked well so far in "Getting in Early – Getting it Right"?
8. What do you think could work better in "Getting in Early – Getting it Right"? Why do you say this?
9. What have families told you about what they think of "Getting in Early – Getting it Right"?
10. Would you remain engaged with the program if it continued? Why do you say this?

FIGURE 2: PROVIDER INTERVIEW GUIDE

Additional reports: Reports from a previous survey of parents in the Botany area, regarding barriers and enablers to accessing early childhood developmental surveillance were reviewed.

DATA ANALYSIS

Qualitative data was analysed by the research assistant (KE) using NVivo^{TM} 10, against the expected outcomes of the projects and applying emergent themes approach within grounded theory. Analysis identified emerging themes related to processes and unintended consequences. Analysis continued until all major themes were identified.

Descriptive analyses of the quantitative data was undertaken by the project officer (LS) and project leads (TR; SW) in conjunction with the Centre for Research in Nursing and Health, University of Wollongong (RF), using the Statistical Package for the Social Sciences (SPSS^{TM} version 24.0). Frequencies, means and their standard deviations were calculated for quantitative data. All quantitative activity data was de-identified. Pre and post training survey results used simple descriptive statistics to measure increase in knowledge, undertaken by the project officer (LS) and project leads (TR; SW).

ETHICS

Ethics approval was gained from the SESLHD Human Research Ethics Committee (HREC)[1], with Site Specific Approval from Sydney Children's Hospital Network HREC[2]. Information and consent forms for Nepali and Bengali-speaking participants were provided in English and in Nepali or Bengali. Translation was provided through the NAATI accredited SBS Translation Service.

RESULTS

QUANTITATIVE DATA

Identification and referral

Data for 149 children were analysed (Rockdale n=90*; Botany n=59**) (Table 2)

TABLE 2: SAMPLE SIZE OF CHILDREN RECORDED (ROCKDALE AND BOTANY)

	Rockdale	Botany
Male	42	41
Female	48	18
Age Range	Two months – 62 months	12 months – 64 months

* Total families offered PEDS.
** Children for whom PEDS referral was sent to SCHN (out of total of 98 screened) by SECC and The Deli Women & Children's Centre. Data not available Botany Family & Children Centre.

Of the 55 clients who saw the CAFHN, 43 were existing clients and 12 were new clients. Of the clients recorded as known to CAFHNs (n=41), 63.4% (n=26) were not up to date with their scheduled child development checks. These checks are the means by which developmental issues can be identified early within a universal child health system, reducing the risk that delays in parental perception of developmental concern may delay identification and early intervention. The diagram below (Figure 3) describes the number of families offered PEDS, and those who accepted in the Rockdale project.

In Rockdale, 45% of children lived in a home where English was not the language spoken at home. After English, Nepali was the most frequently spoken language at home, followed by Mandarin and Cantonese. A record was kept of the number and proportion of parents requiring an interpreter for their initial and ongoing contact with Child and Family Health Services. Of the 88 parents recorded for this characteristic, 5.7% (n=5) required an interpreter.

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[1] 17/264 (HREC/17/POWH/542)

[2] SSA/18/SCHN/3

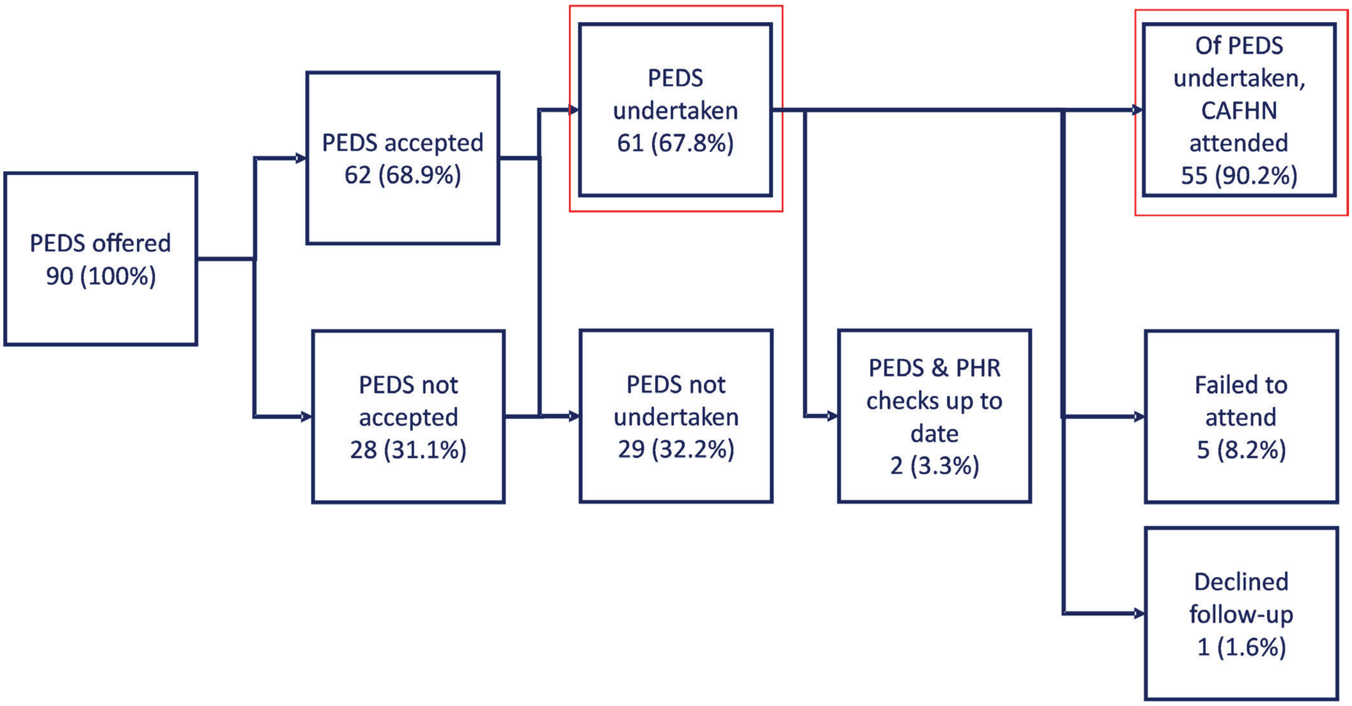


FIGURE 3: ROCKDALE NUMBERS UNDERTAKING PEDS AND REFERRED TO CAFHN

Note: This data was available for Rockdale only and not for the Botany arm.

TABLE 3: CHILDREN IDENTIFIED WITH ONE OR MORE PREDICTIVE CONCERN BY LANGUAGE (ENGLISH/NON-ENGLISH) SPOKEN AT HOME (ROCKDALE)

PEDS Outcome Pathways	English		Other than English		Total
	n	%	n	%	
A – two or more predictive concerns	7	58%	5	42%	12
B – one predictive concern	5	46%	6	54%	11
	12	**52.2%**	**11**	**8.7%**	**23**

TABLE 4: NUMBERS OF CHILDREN PREVIOUSLY KNOWN TO THE CAFHN, WHO RECONNECTED AND WERE IDENTIFIED AS HAVING ONE OR MORE PREDICTIVE CONCERNS (ROCKDALE)

PEDS Outcome Pathways	PHR child development check NOT up to date	PHR child development check up to date
A – two or more predictive concerns	9	1
B – one predictive concern	2	3

PREDICTIVE CONCERNS (ROCKDALE AND BOTANY)

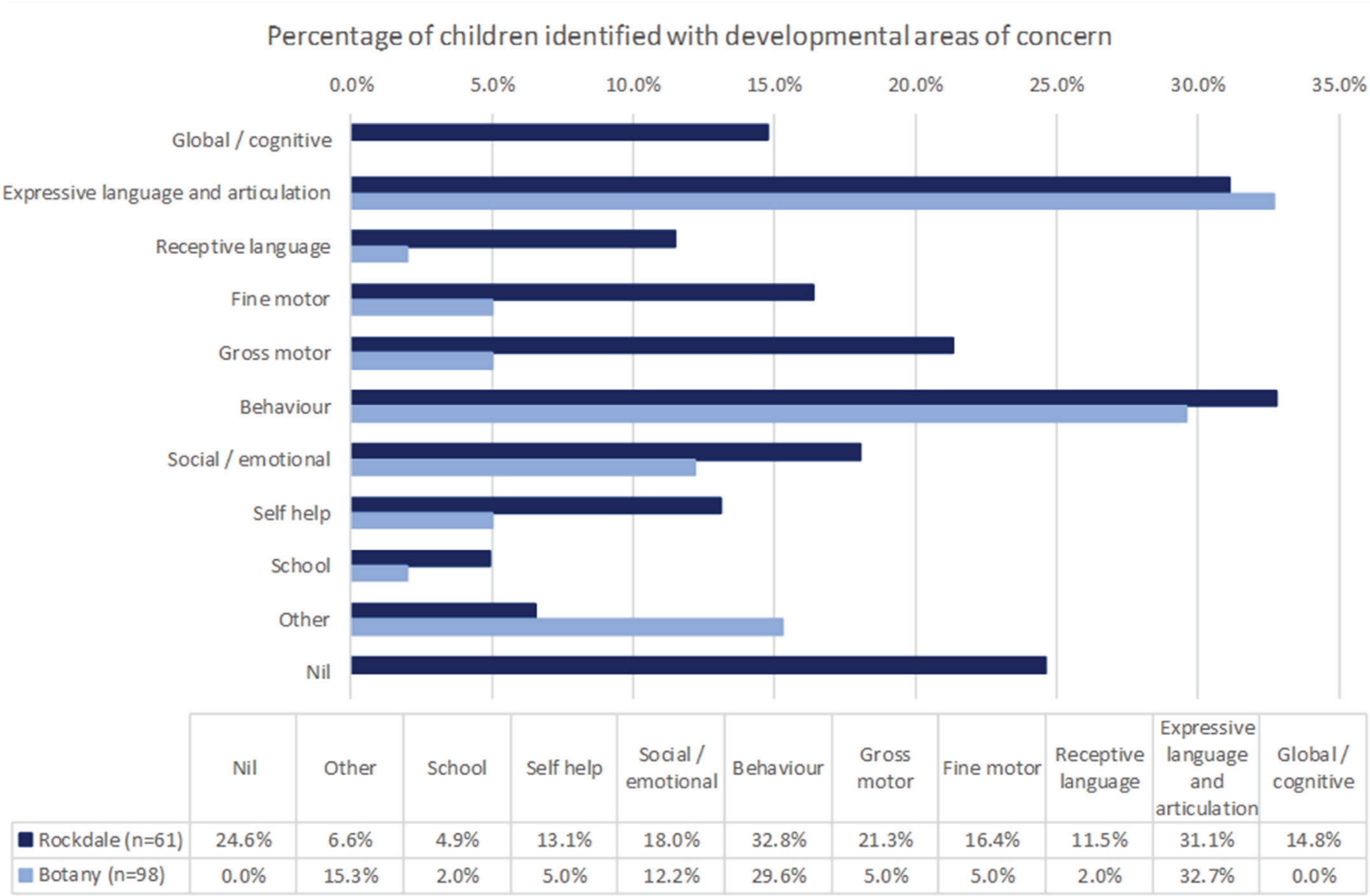
Of the 61 Rockdale families and 98 Botany families who undertook the PEDS, 37.7% and 40.6% were recorded with one or more predictive concerns on the PEDS, indicating developmental vulnerability and requiring further assessment and referral.

The Rockdale project recorded the number of children with predictive concerns identified by the CAFHN, by home language, and the results are shown below for the top language groups.

Children identified as having two or more predictive concerns were more likely to be not up to date with their PHR child development check. Of 10 children identified as having two or more predictive concerns, who were previously known to the CAFHN and had reconnected with the service, nine were not up to date with the PHR child development checks (see below).

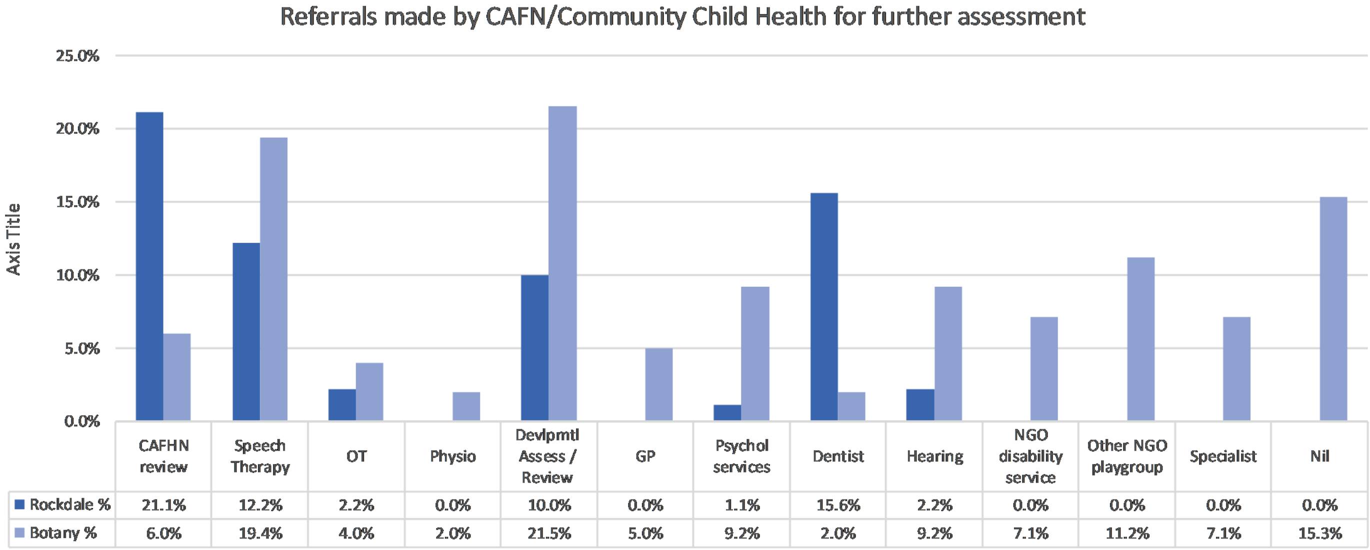
DEVELOPMENTAL AREAS OF CONCERN (ROCKDALE AND BOTANY)

Figure 4 describes the developmental areas of concern identified in assessments. The highest proportion of identified concerns was in expressive language and articulation and in behaviour.



	Nil	Other	School	Self help	Social / emotional	Behaviour	Gross motor	Fine motor	Receptive language	Expressive language and articulation	Global / cognitive
■ Rockdale (n=61)	24.6%	6.6%	4.9%	13.1%	18.0%	32.8%	21.3%	16.4%	11.5%	31.1%	14.8%
■ Botany (n=98)	0.0%	15.3%	2.0%	5.0%	12.2%	29.6%	5.0%	5.0%	2.0%	32.7%	0.0%

FIGURE 4: IDENTIFIED DEVELOPMENTAL AREA OF CONCERN (ROCKDALE AND BOTANY)



	CAFHN review	Speech Therapy	OT	Physio	Devlpmtl Assess / Review	GP	Psychol services	Dentist	Hearing	NGO disability service	Other NGO playgroup	Specialist	Nil
■ Rockdale %	21.1%	12.2%	2.2%	0.0%	10.0%	0.0%	1.1%	15.6%	2.2%	0.0%	0.0%	0.0%	0.0%
■ Botany %	6.0%	19.4%	4.0%	2.0%	21.5%	5.0%	9.2%	2.0%	9.2%	7.1%	11.2%	7.1%	15.3%

FIGURE 5: REFERRALS MADE BY CAFHN/COMMUNITY CHILD HEALTH FOR FURTHER ASSESSMENT (ROCKDALE AND BOTANY)

REFERRALS FOR FURTHER ASSESSMENT (ROCKDALE AND BOTANY)

Referrals were made to a range of child and family services as a result of initial assessment. Figure 5 (below) shows the variation in referrals across the two projects. Both projects had similar rates of referral to Developmental Assessment Services.

More families were referred to speech pathology services from Botany, where a speech pathologist was a member of the project team. A higher proportion of children in Botany were referred for developmental assessment/review, which may reflect the team being led by community paediatricians and community child health doctor in the early stages.

A higher proportion of Rockdale families were referred to dental services, driven by CAFHNs including "Lift the Lip" (oral health check) in their child development check and the health service dental service providing an on-site screening visit.

QUALITATIVE DATA

IMPROVED KNOWLEDGE AND REFERRALS BY NGO PROVIDERS

In questionnaires administered pre and post-training, non-health staff who attended the training reported a gain in knowledge and/or confidence relating to early childhood development and surveillance from 68.4% to 71.4%.

In interview, Developmental Assessment Services (DAS) reported a change in the level of need in referrals they were receiving, as well as a perceived increase in the range of families from CALD backgrounds being referred for further assessment.

INCREASED FAMILY COMFORT WITH AND ACCESS TO CAFHN

Focus groups with families in Rockdale and Botany revealed that few of the participants distinguished between the services provided by the on-site CAFHN and accessed through the supported playgroup, and the activities provided in the supported playgroup itself. This was particularly noticeable in the English-speaking focus group where questions regarding CAFHNs were answered in terms of the parents' overall experience with the supported playgroup that they attended.

> *"…all of us different cultures, different kind of things here, so we don't know what to do. So at least if we have professional help, it will make – leave us in peace."*
> Parent from English-speaking group

Where parents in focus groups differentiated between services provided by the playgroup and those provided by the CAFHN, they described the support they received from CAFHNs as including advice about eating and sleeping, establishing routines, dental care and tips for playing with children.

> *"It was good. It was good. She's the one who told me that just, like, she said, she's the one who told me that I need to brush his teeth, because I thought, we should have started brushing his teeth at around two or something, because I just usually use my hand, but then, now we starting to brush his teeth…"*
> Parent from English-speaking group

> *"Child and Family Health Nurses give tips during consultations; give us helpful tips and guide us in case we are ignorant about certain things and so on. Therefore, it is good to discuss with Child and Family Health Nurses as we get guidance from them to teach our children as they are experienced and have qualifications."*
> Parent/Grandparent from Nepali-speaking group

The regular contact with early childhood health professionals was viewed by health service early childhood health professionals, participating CAFHNs, and NGO services as a strong enabler in encouraging parents to follow up referrals and remain engaged.

> *"…it has been really good to be able to say this is a person you might need for your process of assessment. So… really having that soft entry point has been most helpful."*
> Botany Early Childhood Service Provider

A TEAM-BASED APPROACH

Several participants from NGO services emphasised the importance of supporting families to follow through on referrals and attend assessments. They saw the projects as a team effort, with each agency involved providing a specific element of the overall project. In both Botany and Rockdale, interviewees commented on the value they gained from the ongoing relationship with child and family health services and CAFHNs. They reported increased confidence that their opinions were respected and families seen in a timely manner. Similarly, health professionals, including CAFHNs, commented on the importance of engaging with NGO early childhood/family support services and building good relationships.

> *"I think it's the personal contact, I think it's knowing the people. Them knowing us and us knowing them, I really think that makes a big difference that people know who you are."*
> SESLHD Health Professional

DISCUSSION

This is the first study to examine models of care which specifically address access for culturally diverse and socioeconomically disadvantaged communities to early childhood developmental surveillance and CAFHNs by partnering with community organisations. Consistent with the emerging evidence on these models we found that these outreach models are more effective in engaging families of low socioeconomic background in participating in developmental screening, with earlier detection of neurodevelopmental vulnerabilities.[10,11]

A key component contributing to the model's success is training of non-government organisation staff in early childhood development. Understanding developmental risk and the steps that can be taken to address this has helped staff in the participating NGO services to identify children who will benefit from further screening, and to more effectively use the existing universal developmental surveillance provided through early childhood health services. Although NGO staff generally reported a good baseline knowledge of child development prior to training, their reported confidence in being able to apply this knowledge when talking with families about early childhood development and concerns improved following the training.

A similar result was found in Victoria, Australia, where The Wodonga Early Years' Service Coordination Framework tested the PEDS with childcare workers, pre-school teachers and primary school teachers, as well as child and maternal health services. The PEDS was reportedly easy to use across these different service providers and was also well-received by parents. There was increased capacity for early childhood service/education providers and child and maternal health services to appropriately refer.[10]

In terms of the significance for nursing, this study has demonstrated the utility of a model of developmental surveillance and entry into the child and family health system in a non-health setting.

Co-location of a CAFHN on-site at the Rockdale NGO service was recognised as an enabling factor in parents attending initial assessments and further developmental assessments if required. CAFHNs noted the ability to observe children and families in the supported playgroup as of added value in the assessment process.

In this study, by having regular contact with a CAFHN in a safe, supportive and familiar environment, families who might otherwise not attend child and family health clinics were introduced to CAFHNs, developmental surveillance activities and provided with ongoing support if developmental vulnerabilities were identified.

Consistent with previous literature we demonstrated that those children who are most likely to be developmentally vulnerable were the least likely to have had developmental surveillance done in their health checks.[5,12] In our study, we also found that children identified with one or more predictive concerns were less likely to be up to date with their child health checks. In other words, our new model of care has found children who might not have been identified as having a developmental concern until they were attending primary school, and ensured that they are linked into essential early intervention.

CONCLUSION

The Botany and Rockdale models of care have demonstrated the potential for improving access to CAFHNs and other early childhood developmental health services, developmental surveillance, detection of developmental concerns and early intervention for children from culturally and linguistically diverse backgrounds. We have shown that child health services and CAFHN services can change their practice, can successfully provide developmental surveillance in locations apart from child and family health centres, and can work in collaboration with the NGO sector. Our next steps are to scale up these models across multiple sites and with different priority populations.

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Conflict of interest
K Edwards was contracted to undertake the independent evaluation of the project, on which this article is based.

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Author contributions
SW TR DP RS and LS contributed to the design of the study. RF, KE, TR and SW undertook the analysis. All authors contributed to the writing of this article. Primary author was KE and senior author SW.

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REVIEWS & DISCUSSION PAPERS

Implications for bachelor of nursing programs when using student experience survey findings as an indicator of course quality

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ABSTRACT

Objective: To discuss the implications of using student experience surveys to improve the quality of teaching and learning within bachelor of nursing programs in Australia.

Background: Australia's recent independent review of nursing education suggests that not all graduates are sufficiently prepared for their registered nurse role, indicating problems with program quality. Student experience surveys are widely used in course development processes.

Discussion: A reliance on student experience survey findings for course development may contribute to course changes based on student satisfaction that place overall graduate capability at risk. Because student experience surveys have design limitations, satisfaction only partially aligns with learning and learning outcomes, and students' subjective beliefs about self, nursing and learning potentially influence their survey responses, the exclusive use of student experience surveys in course development and teacher evaluations is contested.

Conclusion: Using student experience survey findings as an indicator of course quality has unacknowledged implications for bachelor of nursing programs. Findings from student experience surveys should be situated within a context of other elements or factors when making curriculum decisions. Teacher and course evaluations based primarily on student satisfaction can have unintended consequences for course content, course delivery, student learning and learning outcomes and ultimately impact on the reputation of the university.

What is already known about the topic?

- Student experience surveys are used widely in higher education in Australia.
- Universities monitor student satisfaction as an indicator of course quality through student experience surveys.

What this paper adds:

- The relationship between the characteristics of course quality and student satisfaction require further exploration in practice-focused programs such as nursing.

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- The governance of course quality using student experience as a primary indicator may unintentionally limit course development, catering to student preferences rather than focusing on learning experiences that are required for graduate capability.

Keywords: student experience, satisfaction, nursing, course evaluation

INTRODUCTION

Graduates of bachelor of nursing programs must be able to meet the complex healthcare needs of a diverse and ageing population. A recent review into nurse education in Australia suggested that there was a belief amongst stakeholders that not all graduates are adequately prepared for a registered nurse role, recommending the development of external mechanisms to manage this issue.[1] However, issues relating to the quality of nursing graduates can, and should, be addressed within bachelor of nursing programs.

While focused on quality graduates, Australian universities are interested in high student enrolments and associated revenue. As such, satisfied students, including nursing students, are important. In a competitive higher education environment, universities rely on students reporting positively on their educational experiences to enhance the reputation of each institution and to attract both local and international students.[2,3] Further, with government funding linked to student enrolments, attracting future students is critical for university survival.[4] Understanding students' satisfaction with their teachers and courses is important to enhance university business.

In writing this article, the authors intend to provoke debate around the dominant use of student satisfaction as the indicator of quality in bachelor of nursing programs. A post-structural approach was adopted to explore the unintended effects of student satisfaction as a primary indicator of bachelor of nursing program teaching and learning quality.[5] A post-structural perspective challenges knowledge as absolute and focuses on re-thinking dominant discourses.[6] In this case, the privileging of student satisfaction within the discourse of program quality.

STUDENT EXPERIENCE SURVEYS IN AUSTRALIAN HIGHER EDUCATION

Student experience surveys enable universities to acquire information on student satisfaction. 'Student satisfaction refers to the favourability of a student's subjective evaluation' [7(p.3545)] in relation to their higher education experience overall or to components of the degree. While the terms 'course' and 'program' and 'course' and 'subject' or 'unit' may be used interchangeably,[8] for the purpose of this paper the Australian Nursing and Midwifery Accreditation Council (ANMAC)[9] approved terminology will be used. A 'program' refers to the degree in its entirety and 'courses' refer to components of a program.[9] Courses are embedded within programs.

Three main student experience surveys are used in Australian universities: Student Experience Survey, the Course Experience Questionnaire (part of the Graduate Outcomes Survey) and internally administered student experience surveys.[10] Each of these surveys will be discussed next.

STUDENT EXPERIENCE SURVEY

The Student Experience Survey is a national survey of all university undergraduate programs and is conducted annually. It assesses students' satisfaction with the overall quality of the educational experience, teaching quality, learner engagement, learning resources, student support and skills development, using Likert scales. All students in all programs in all universities respond to identical survey items. The percentage of students providing positive feedback is reported on the national Quality Indicators of Learning and Teaching website.The results, in the form of a star system, are also used to rank universities in the Good Universities Guide. A high star ranking is considered desirable for attracting future students and as a quality education indicator.[11]

COURSE EXPERIENCE QUESTIONNAIRE

The Australian government also promote the Course Experience Questionnaire, which is a measure of student satisfaction with the overall program. It is circulated to all recent university graduates, noting that not all graduates complete the survey. The Course Experience Questionnaire includes one question on overall satisfaction with their program, six questions on teaching, and five questions on generic skills.[11]

INTERNALLY ADMINISTERED STUDENT EXPERIENCE SURVEYS

Australian universities commonly use internal survey tools to measure the students experiences of teaching and courses although how this is done varies across institutions.[10] Instruments consist of mandatory fixed questions, which are the same across the institution; and open-ended questions to identify what works well and what could be improved. Some institutions enable academics to select optional additional items from a database.

Internal student experience surveys are commonly administered centrally, with data provided to academic staff following the assessment period in each semester. These instruments are invariably used for routine evaluation to assure the University and Program Director that the course is contributing to learning in the program as intended, to encourage academic staff to engage in scholarship of teaching through reflection on feedback, to link student feedback to academic staff promotion, and provide a mechanism for students to provide input into quality of teaching and learning.

DISCUSSION

In addition to established concerns about adequate sample size to reduce response bias,[12] student experience surveys have other limitations. Three limitations are identified: student experience surveys may not be fit for purpose; alignment between student satisfaction and learning is partial; and student satisfaction is influenced by personal beliefs and values. Due to the limitations of student experience surveys, when academic staff make changes to their courses based on survey results, there may be unintended consequences for student learning.

STUDENT EXPERIENCE SURVEYS MAY NOT BE FIT FOR PURPOSE

Student experience surveys were designed to gauge student perspectives of the educational environment at the program level.[2] However, core questions from national surveys are used for internal surveys.[10] While in some universities academics may be able to add additional questions, the core questions may not be relevant to unique disciplinary course requirements.

Generic measures tend not to capture student experiences achieved in non-university, ie. workplace, settings. The assumption inherent in student experience surveys is that students learn predominantly in the university environment.[13] Bachelor of nursing programs require students to learn in both the university and the nursing workplace with students spending at least 800 hours in a variety of healthcare settings.[14] Health settings are varied and include, but are not limited to, hospitals, rural and remote clinics and community settings.[14] Different measures for nursing student experience on work-based placement exist,[15] but are not automatically included in centrally managed surveys. How nursing students' placement experiences impact on their responses to internal university and national surveys is unknown, suggesting an area for future research.

In summary, nursing is a practice-based program, with placement experiences constituting a large part of the program. The usefulness of the findings of student experience surveys for nursing courses is dependent on nursing students' perceiving the survey as relevant to their learning. The standard surveys are not fit for purpose. Even if the lecturer is able to selects additional questions on workplace experiences from a databank, the survey findings may not accurately indicate the alignment between the course and program expectations and outcomes. It is timely for nurse academic leaders to partner with education leaders to develop student experience surveys that are more sophisticated and able to capture students' placement as well as classroom experiences.

ALIGNMENT BETWEEN STUDENT SATISFACTION AND LEARNING IS PARTIAL

There is partial alignment between student satisfaction and learning, with potential implications for nursing student graduate outcomes. Learning requires student engagement, often through emotions such as excitement and high interest or frustration and difficulty, with 'disorienting dilemmas' considered important to facilitate learning.[16] Negative feelings of frustration may facilitate learning but translate to students' feeling unsatisfied in surveys. If effective learning requires a degree of psychological discomfort, then some degree of dissatisfaction may be necessary for learning to be effective.[17]

In the example of bioscience, a systematic review of interventions to improve learning found that the focus on student satisfaction with supportive learning interventions was inadequate and recommend refocusing evaluation on acquisition of bioscience knowledge and understanding at graduation.[18] In an in-depth study of nursing students' learning experiences, students indicated that course content, which is perceived as complex, such as bioscience, may result in dissatisfaction with their learning.[17] Dissatisfaction on surveys may indicate that students find the content complex, rather than accurately reflect their learning.

Satisfaction may also be low when nursing students perceive content to be less relevant. A systematic review of pedagogical strategies to teach nursing students evidence-based practice found that those students who had difficulty understanding the relationship between research findings and nursing practice may indicate dissatisfaction with research courses.[19] Students may fail to understand how certain knowledge will assist them in their future role as a registered nurse and become dissatisfied with their learning.[17] Students must gain knowledge of both research and other areas fundamental to nursing if they are to be prepared for their future role as a registered nurse,[14] but may not realise the value of learning complex knowledge and skills until later in the program or after they graduate.

Personal perceptions of satisfaction with learning may not align with external assessments of performance. In an evaluation of a nursing communication skills training course, researchers found that self-rated ability and satisfaction were linked, but that neither was linked to objective assessment by an educator.[20] Nursing students who were most satisfied tended to rate their communication skills more highly, but on objective assessment were found to perform no better than students who rated their communication skills lower.[20] Therefore, the alignment between student satisfaction and learning is partial at best.

In summary student satisfaction with their experiences may only be partially aligned with student learning. Where evidence-based teaching and learning strategies lead to students learning complex content or material that is not perceived as relevant, this learning may reflect negatively in teaching or course experience scores.

As indicated earlier, one purpose of conducting internal university experience surveys for teaching and courses is to engage staff in the scholarship of teaching, providing material for reflection and course development. When student satisfaction does not align fully with learning, the risk of making changes to teaching strategies and course content based on survey results only may lead to unintended consequences for the curriculum and graduate outcomes. Generic academic skills courses for new nurse academics should address the social and political practice, as well as pedagogical, elements of curriculum design in higher education. While a scholarship of teaching exists in universities, the unique elements in nursing programs require academic nurses to be critical of the alignment of student experience surveys and learning. There is no national community of nurse academics, where new academic nurses can enter into scholarly debate about the merits of student experience surveys and other higher education policies.

STUDENT SATISFACTION IS AFFECTED BY PERSONAL BELIEFS AND VALUES

Satisfaction is a highly subjective concept, and therefore influenced by factors unique to each individual. As student diversity increases,[21] their personal backgrounds and expectations about nursing and nursing knowledge will impact how they experience satisfaction with the program.

In a grounded theory study of nursing students' satisfaction with learning, learning was conceptualised as a journey, where student satisfaction was not stable or directly related to a teaching strategy or course.[17] Rather, satisfaction ebbed and flowed, with intense emotional experiences of joy, irritation, fear and hope.[17] Through each student's unique nursing journey, their experiences of satisfaction, dissatisfaction or ambivalence with learning were also unique.[17] Factors that may influence student satisfaction include available time to study, in the context of work-life balance and personal beliefs about historical models of nursing education.[17]

Nursing students who need to work while studying may be less satisfied with their learning experience. For example, in a study of student learning in the workplace, researchers found that nursing students who worked more than 16 hours per week were less satisfied with their placement than students who worked less.[22] While satisfaction with placement may be negatively affected by working, it is not clear whether students learned valued knowledge, understanding and skills while on these placements. Further research into the relationship between personal characteristics, such as the need to work, satisfaction, and learning are required.

Student satisfaction may be influenced by personal beliefs about the kind of nurse they want to be.[17] In Australia, nursing continues to be conceptualised in the traditional way, as a practical profession, where nursing education privileges 'the pragmatic over the esoteric, the practical over the theoretical and character over intellect'.[23[p115]] However, in today's climate of continuous change and development, graduates are expected to be flexible, responsive and innovative in response to changing community need.[14] Students who expect pragmatic, may be dissatisfied with esoteric, and this may be reflected negatively in experience surveys.

In summary, students' personal situation, life experience, beliefs and expectations influence their satisfaction with learning. With an increasingly diverse student population, nursing academics seeking career promotion are expected to design multiple teaching strategies to support students' diverse situations and learning preferences, while at the same time trying to pursue their own research. For academic staff, the challenge of balancing the triumvirate of teaching, research, and service in order to progress their careers, can be overwhelming.[24]

IMPLICATIONS FOR TEACHING AND LEARNING IN BACHELOR OF NURSING PROGRAMS

While nationally administered surveys for student and course experience are recognised as important for benchmarking the higher education sector, internally administered student experience surveys have implications for teaching and learning in bachelor of nursing programs. Providing students an opportunity to provide input into the quality of teaching and learning is laudable but carries inherent, and implicit risks. Surveys not being fit for purpose, partial alignment between student satisfaction and learning, and the impact of personal beliefs and values on satisfaction raise implications for teaching and learning.

Generic survey questions in internal surveys are not fit for purpose when used within courses. Rather, the inclusion of these questions is to align teacher practice with the university goal of higher student satisfaction scores. When using questions based on the Course Experience Questionnaire as the fixed questions in the internal surveys, alignment is achieved. When student satisfaction at course level is low, academic staff and their managers become focused on how to address the low scores. The implication for curriculum design is that academic staff may undertake course re-design to enhance appeal of the courses for future students. However, making the course appealing and improving learning may not be the same. Further investigation into how academic staff use internal survey findings in curriculum design is required.

While it is widely accepted that student satisfaction can indicate learning, the alignment is partial rather than complete. Focusing on evidence-based teaching when students may be more satisfied with less challenging approaches to learning can pose dilemmas for staff aiming to improve student satisfaction. Higher education experts suggest that satisfaction surveys have placed pressure on academics to gain high ratings but without necessarily focusing on doing so by increasing teaching standards, assessment and learning outcomes.[10] Avoiding these negative consequences of student satisfaction surveys can result in nurse academics continuing with traditional teaching approaches and avoiding innovative ones.[25]

In addition to the partial alignment between student satisfaction and learning, there is widespread evidence of low response rates to surveys, with associated bias.[12] Given these examples, and their implications for learning, we suggest that nurse academics and university management should ensure that student satisfaction data is used in combination with other evidentiary sources such as student grades, engagement in course related learning activities, and performance in work-based experiences.

Students are diverse in their backgrounds, experiences, beliefs, values and expectations, and as such will have unique experiences of satisfaction. However, nurse academics are held to account for student satisfaction. Evidence of positive student attitudes and satisfaction are often required for staff promotions, awards, performance review and contract renewal.[10,25] Therefore, in order to remain employed, or progress their careers, staff are highly motivated to ensure students are satisfied with their educational experience.

Retaining courses, or course content, in the curriculum where students have indicated low satisfaction can pose a dilemma to staff interested in enhancing student satisfaction. It might enhance student satisfaction, and therefore more positive responses to surveys, if course content that students perceived as less important was reduced or removed from the curriculum. For example, how to manage low satisfaction scores on more problematic courses, such as complex courses in bioscience and or esoteric nursing research/evidence-based practice theory. In this situation, there is conflict between an action that may enhance student satisfaction, i.e. remove courses with low satisfaction, and one that might enhance learning, and ultimately nursing practice following graduation, i.e. keep the course despite low satisfaction scores. Rather than removing the course, nurse academics may benefit from collaborative reflection with more experienced academic mentors,[24] in order to identify changes that can leave the overall curriculum intact.

Enabling students with complex lives and multiple personal commitments to acquire sufficient learning to provide effective nursing care on graduation while also ensuring they respond positively to student satisfaction surveys has implications for teaching and learning. Any expressed dissatisfaction is potentially problematic for nurse academics when it impacts on their career opportunities and progression. Balancing the need for students to be satisfied with their education and learn what is required for nursing practice provides nurse academics with serious challenges in the current higher education environment.

CONCLUSION

In preparing this argument for collegial consideration, we have aimed to be provocative, providing an alternative discourse for the use of student experience questionnaires in course development. The quality of nursing graduates is dependent on the quality of the course and how that quality is determined requires continual review. This argument is inductive in nature, reflecting the purpose of providing an alternative discourse. As an inductive argument, it can be considered an educated opinion piece, which adds to the rich discourse of course development in nursing education.

Using examples from nursing literature, we argue that using student experience surveys in undergraduate nursing programs may result in unintended outcomes for learning with unanticipated consequences for employers of nursing graduates and consumers of care. Graduates of bachelor of nursing programs are not simply consuming a program of education, they are preparing themselves for practice as a registered nurse. The current use of student satisfaction as an indicator of course quality is not producing graduates that are meeting industry requirements.[1] While the transfer of nursing education into the higher education sector was widely supported by nursing's professional bodies, it is timely for the profession's leaders to review the use of student satisfaction in course quality and find innovative ways to support nurses who are also academics – a specialty of its own.

RECOMMENDATIONS

In light of the discussion above, we recommend the following actions be implemented to address the use of generic internally administered student experience surveys for courses within a bachelor of nursing:

1. Australian Nursing and Midwifery Federation could explore a partnership with the National Tertiary Education Union so that the implications of university policy on nurse and midwifery curricula can be more specifically addressed.

2 Deans of Nursing and Midwifery could consider how to manage student satisfaction related tensions between studying in an academic context while maintaining a program that requires placement in healthcare services to enhance learning and graduate outcomes.

3 Generic academic skills courses provided for nurses who are new to the academy must address the socio-political, as well as pedagogical, elements of curriculum design and development in order to critically evaluate higher education policy.

4 Australian College of Nursing could develop an academic nurse interest group, where nurse academics can develop collegial relationships, undertake collaborative research into educational practices and policies, and enter into scholarly debate about the merits of higher education policies, such as student experience surveys.

5 Further research into the value of generic student surveys within the broader context of a capable nursing graduate is required.

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REVIEWS & DISCUSSION PAPERS

The importance and value of reporting guidance for scoping reviews: A rehabilitation science example

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ABSTRACT

Objective: Scoping reviews use a systematic approach to synthesize a body of knowledge. The use of scoping review methodology is increasingly common. Despite recommendations to guide the conduct of scoping reviews, inconsistencies exist with regards to their methodology and reporting. In this case-study, we reflect on our experience using the PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation to improve reporting for a scoping review we initially conducted prior to the release of the PRISMA-ScR reporting guidelines.

Study Design and Methods: We evaluated the scoping review against 22 criteria included in the PRISMA-ScR. For each criterion, we provided a rating representing the degree to which we felt the scoping review met the individual criterion in the PRISMA-ScR. We also provided comments to substantiate our ratings, along with recommended revisions for the scoping review and considerations for future scoping reviews.

Results: We identified a number of strengths in the initial reporting of our scoping review , as well as opportunities for improvement. The most substantial areas for improvement included the protocol registration, data items and data charting process. Based on our evaluation, we made revisions to the scoping review manuscript to improve our reporting.

Conclusion: Our evaluation helps to highlight the value of using reporting guidelines to improve reporting of scoping reviews, while also exposing several challenges. In future, we recommend consulting the guidelines during the initial preparation of the scoping review manuscript rather than retrospectively.

What is already known about the topic?
- The use of scoping review methodology is becoming increasingly common.
- While recommendations to guide the conduct of scoping reviews have been published, inconsistencies exist in both scoping review methodology and reporting.

What this paper adds:
- Despite some challenges, we found the PRISMA-ScR to be an effective tool to guide a structured reflection on our scoping review reporting.
- We encourage authors completing scoping reviews to make use of the PRISMA-ScR to guide their own scoping review reporting.

Keywords: Rehabilitation Research; Interdisciplinary Research; Research Design

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OBJECTIVE

In this case study we reflect on our experience using scoping review guidelines – at the time recently published – to improve reporting for a completed but unpublished scoping review we had conducted. Specifically, we outline the process used to objectively evaluate our scoping review reporting using the PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation, share improvements that resulted from this process, and comment on our PRISMA-ScR user experience. In doing so, we highlight the value of using these reporting guidelines to improve reporting consistency for scoping reviews, while also exposing several potential challenges.

BACKGROUND

Scoping reviews use a systematic approach to synthesise a body of knowledge. Scoping review methodology lends itself to exploring the extent and nature of research in a given area, establishing the need for a systematic review, providing a means of summarizing and disseminating a range of research findings, and identifying gaps in knowledge.[1] Within the past decade, there has been a rapid increase in the number of scoping reviews being conducted.[2]

Our scoping review, focusing on competence assessment for airway suctioning, was initially guided by Arksey and O'Malley's seminal framework for the conduct of scoping reviews, and incorporated additional recommendations proposed by Levac et al.[1,3] Airway suctioning is one technique used by nurses and other health care professionals to remove retained pulmonary secretions. While it can be a necessary element of patient care, caution must be used when performing this technique to avoid causing harm.[4] In our scoping review, we examined the nature and extent of research on the assessment of clinical competence for health care professionals who perform airway suctioning in adults.[5] We specifically selected a scoping review methodology given the broad nature of the review, the lack of previous reviews in this area, and the expected methodological variability across relevant studies.[6]

Despite published recommendations to guide the conduct of scoping reviews,[1,3,6] inconsistencies have been reported with regards to both scoping review methodology and reporting.[2,7] The 2009 PRISMA statement provides a detailed checklist of items to include for the reporting of systematic reviews and meta-analyses.[8] When we first conducted our scoping review in early 2018, similar guidelines for scoping reviews were not yet available. However, shortly after preparing a copy of our scoping review manuscript, but prior to its submission to a journal, the PRISMA-ScR was published.[9] Included in the 27-item PRISMA-ScR are 20 essential items for reporting on scoping reviews and two optional items; the remaining five items are from the original PRISMA checklist and are not applicable to scoping reviews. In the interest of striving to improve reporting in our own scoping review, we took the opportunity to use the newly published reporting guidelines as a tool to guide a structured reflection on our work, and have documented this process.

METHOD

An objective evaluation of our scoping review was conducted against the 22 relevant criteria included in the PRISMA-ScR. For the evaluation, we used a version of the manuscript we had prepared for submission to a peer-reviewed journal. For each item, we provided a rating representing the degree to which we felt our scoping review met that individual criterion. To do this, the lead scoping review author (EM) considered each of the criteria in the reporting guidance against the reporting in our review. The assigned score for each item ranged from 1 to 5, with 1 representing poor alignment with an individual criterion and 5 representing excellent alignment. In addition, author EM provided comments to substantiate each rating, along with recommended revisions to improve the consistency of our reporting. The draft ratings, comments and recommendations were presented to an interdisciplinary group of health care professionals as part of the oral defense for a doctoral level comprehensive exam. This interdisciplinary group included two physical therapists, one nurse and one occupational therapist, all of who hold university level faculty appointments and had experience in the conduct of scoping reviews. Two members of the group had been involved in conducting the original scoping review, while two had not. All group members had the opportunity to review the proposed ratings, comments and recommendations in detail, pose questions, provide feedback and voice concerns or disagreements. After making minor modifications to the recommendations, the group achieved general agreement. Based on our findings from this evaluation, we revised our scoping review manuscript prior to submitting it for publication in a peer-reviewed journal.

RESULTS OF OUR EVALUATION

We identified ten items with opportunity for improvement (i.e. that were assigned a rating less than 5/5). Of these items, five were assigned a rating of 4/5, two were assigned a rating of 3/5, two were assigned a rating of 2/5 and one was assigned a rating of 1/5. Eleven out of the 12 remaining items were found to be in excellent alignment with criteria detailed in the PRISMA-ScR and were assigned a rating of 5/5. The exception was item #19: *Critical appraisal of sources of evidence (results)*; this is an optional item that was not applicable to our scoping review. Based on our evaluation, we identified nine recommended revisions to our scoping review, as well as several considerations for future scoping reviews. Our evaluation is summarized in Table 1.

TABLE 1: ALIGNMENT OF OUR SCOPING REVIEW WITH ITEMS FROM THE PRISMA-SCR

	Item	Rating	Comments
TITLE			
1	Title	3/5	We identified the report as a scoping review in the title and described the concept but the population and context of interest were missing. **Recommended revision:** Revise the title to reflect the population (health care professionals who perform airway suctioning) and context (suctioning performed with adults). Revised title: *Assessing the clinical competence of health care professionals who perform airway suctioning with adults: A scoping review.** *Note: The final manuscript title was further revised at the request of the publishing journal and differs slightly from the title included here.
ABSTRACT			
2	Structured summary	4/5	We provided a comprehensive abstract but the date of the literature search was missing from the abstract. **Recommend revision:** Add the date of the literature search (March, 2018) to the abstract.
INTRODUCTION			
3	Rationale	5/5	We provided a thorough rationale for the review, as well as the reason the research objectives lent themselves to a scoping review approach (i.e. lack of previous comprehensive reviews conducted in this area and anticipated heterogeneous nature of the evidence).
4	Objectives	5/5	We included an explicit statement about the objectives and questions being addressed, with reference to key elements (population, concept and context).
METHODS			
5	Protocol and registration	2/5	We developed a protocol a priori, but the protocol was not registered and we did not provide details about how to access it. **Recommended revision:** Add a statement indicating the protocol is available upon request from the corresponding author. Consider options for registering future protocols.
6	Eligibility criteria	5/5	We clearly stated the eligibility criteria and provided a rationale for these criteria.
7	Information sources	4/5	We described sources of information in detail. We provided a search date for the scientific database search but not for the gray literature search. **Recommended revision:** Add the date for the gray literature search.
8	Search	4/5	We presented the full electronic search strategy for at least 1 database (presented in sufficient detail to be reproducible) and provided a detailed account of our gray literature search. We explicitly stated the role of the librarian in developing and refining the search strategy; however, we did not explicitly state who performed the search. **Recommended revision:** Explicitly state that the lead author (EM) performed the search.
9	Selection of sources of evidence	4/5	We explained the process for selecting sources of evidence but did not specify the software used for screening. **Recommended revision:** Add a statement indicating that the online software Covidence was used for screening.
10	Data charting process	2/5	We stated that a data extraction form created by the authors was used and that it was piloted/calibrated. We lacked detail in our description of the process and did not specify what software was used or who completed the final data extraction. **Recommended revision:** Add that Excel was used for data extraction. Two authors (EM and LB) independently extracted data from the first 5 included studies and compared the results for accuracy. The primary author (EM) then completed the final data extraction.
11	Data items	1/5	We did not list the variables for which data were sought. **Recommended revision**: List and define the variables for which data were sought.
12	Critical appraisal of individual sources of evidence (optional)	5/5	We included a rationale for why this was not done in our scoping review.
13	Summary measures	N/A	---
14	Synthesis of results	4/5	We clearly explained the method of handling and summarizing the charted data; however, it would be beneficial to provide additional detail regarding the process used for qualitative content analysis. **Recommended revision:** Provide a more detailed description regarding the process used for qualitative content analysis.
15	Risk of bias across studies	N/A	---
16	Additional analyses	N/A	---

TABLE 1: ALIGNMENT OF OUR SCOPING REVIEW WITH ITEMS FROM THE PRISMA-SCR (continued)

	Item	Rating	Comments
RESULTS			
17	Selection of sources of evidence	5/5	We stated the number of sources of evidence screened, assessed for eligibility and included in the review with reasons for exclusions at each state presented using a flow diagram.
18	Characteristics of sources of evidence	5/5	We provided a descriptive summary (table format) and citations for all included studies.
19	Critical appraisal of sources of evidence (optional)	N/A	---
20	Results of individual sources of evidence	5/5	We summarized the results of the individual sources of evidence using a table, as well as in the written results section of the scoping review under the heading *Descriptive summary.*
21	Synthesis of results	5/5	We included the figure *A Map of Elements Commonly Included in the Assessment of Knowledge, Skills and Judgement Related to Suctioning,* as well as presenting a written summary of results related to each of the three themes that emerged.
22	Risk of bias across studies	N/A	---
23	Additional analysis	N/A	---
DISCUSSION			
24	Summary of evidence	5/5	We summarized the main results and discussed the implications, linking back to the main objective and questions.
25	Limitations	5/5	We discussed the limitations of our scoping review in detail.
26	Conclusions	5/5	We provided a general interpretation of results with respect to objective and questions. We also discussed potential implications and next steps.
FUNDING			
27	Funding	3/5	We listed the sources of funding for our scoping review. We did not extract data or report on the sources of funding for the included studies. **Recommended revision:** No revision to the current scoping review. Consider capturing this data for future scoping reviews.

DISCUSSION

Using a retrospective reflective approach guided by the PRISMA-ScR, we identified a number of strengths in our scoping review reporting, as well as multiple opportunities for improvement. In our discussion, we elaborate on these opportunities for improvement and reflect on our PRISMA-ScR user experience.

OPPORTUNITIES FOR IMPROVEMENT

We initially titled our scoping review manuscript *Assessing competence for airway suctioning: A scoping review.* This title identified our manuscript as a scoping review and included the concept of interest (i.e. the assessment of competence for airway suctioning), but the population (i.e. health care professionals who perform airway suctioning) and context of interest (i.e. airway suctioning performed in adult populations) were not clearly articulated. The concept, population and context of interest serve as the basis for developing the inclusion and exclusion criteria in a scoping review and should be stated concisely in the title.[6] Following our guided reflection, we revised the scoping review manuscript title to include these important descriptive elements. The final manuscript title was then further revised at the request of the publishing journal. The published title *Assessing the clinical competence of health care professionals who perform airway suctioning in adults* does not identify the article as a scoping review. This negatively impacts the quality of our scoping review reporting and in retrospect was a missed opportunity for us to engage in further dialogue with the publishing journal advocating for the consistent application of scoping review reporting guidelines.

Our evaluation also identified several other essential details that were missing from the scoping review. For example, while we provided a comprehensive abstract for our scoping review, we failed to include the date of the literature search within the abstract. We also neglected to include the date of our gray literature search in the body of the manuscript. These methodological details were subsequently added in order to facilitate the reader's ability to assess the extent to which the scoping review is up-to-date.[9]

One of the most substantial areas for improvement that we identified concerned our scoping review protocol and registration. Publishing a systematic review protocol can improve methodological transparency and reduce the unintended duplication of a review.[10] In planning our scoping review, we developed a detailed protocol a priori.

We initially intended to register this protocol, but struggled to find an appropriate platform to do so. In the end, we proceeded having neither published nor made the protocol publicly available. In our manuscript we made reference to our protocol but did not provide direction on how to access it. To better align with the PRISMA-ScR, we revised our manuscript to include an explicit statement that the protocol would be provided upon request from the corresponding author. This strategy was able to partially mitigate the issues we identified concerning our protocol. However, in the interest of promoting greater transparency and rigor in the conduct of scoping reviews, in future we would endorse a more proactive approach to register or disseminate the protocol in advance of conducting a scoping review. One possibility for this, provided as an example within the PRISMA-ScR, would be to register the protocol with Open Science Framework, a free publicly accessible on-line platform.[11]

Another key area where we identified our scoping review reporting as lacking was with regards to the data items and the data charting process. Levac et al. recommend that two authors independently perform data extraction for the first five to ten records, then convene to ensure their approach is consistent with the aims of the scoping review.[3] Similarly, Peters et al. propose the potential need to trial the data extraction form across several studies.[6] In our own review, two authors independently extracted data from the first five included records, then met to discuss the findings and make minor modifications to the data extraction form. However, we did not list and define all of the variables for which we sought data and failed to describe the full data charting process. Upon reflection, it was clear that neglecting to include this information obscured important methodological details in our review and would impede the reproducibility of our results. Following our guided reflection, we subsequently included these details within our scoping review.

PRISMA-SCR USER EXPERIENCE

In our situation, the majority items included in the PRISMA-ScR were found to be clear, concise and easy to apply. One area where we felt that further explanation would have been helpful was with the 'funding' item. Under that item, only minimal explanation and elaboration is provided to support the recommendation to describe funding for the included sources of evidence. The Joanna Briggs Institute (JBI) reviewer's manual takes a less definitive approach, stating that sources of funding for the included studies may be included.[12] We acknowledge that capturing this data and reporting it could be valuable; for example, if the funding sources for the included studies would conceivably bias their results. For our own scoping review, we did not extract this data or report it as we did not feel that it would impact the interpretation of our findings or add substantial value to our results.

Despite the existence of a wide variety of reporting guidelines [e.g. the CONsolidated Standards of Reporting Trials (CONSORT),[13] the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement,[14] etc.], adherence to reporting guidelines remains suboptimal.[15,16] Widespread adoption of the PRISMA-ScR guidelines by authors should help improve reporting in scoping reviews, but does not fully address the issue. Adoption of the PRISMA-ScR guidelines by research funders, journals, journal editors and peer-reviewers is also important.[17] Without this, scoping review authors may continue to experience tensions between reporting guidelines and feedback received during the publication process (e.g. as we did with regards to the title of our scoping review). Finally, because the PRISMA-ScR had not yet been published when we initially conducted our scoping review, we made use of it only after a copy of our manuscript had been completed. A more efficient and practical approach would be to consult the guidelines during initial preparation of the scoping review manuscript.[18]

Given that we evaluated our own scoping review, we acknowledge the lack of author independence. Despite this potential limitation, our evaluation and user commentary help to highlight the value of using reporting guidance to improve the reporting of scoping reviews.

CONCLUSION

Overall, we found the PRISMA-ScR to be an effective tool to guide a structured reflection on our scoping review reporting. Through this process, we uncovered both areas of strength and opportunities for improvement within our scoping review, strategies to consider for future scoping reviews, and several potential challenges. We would encourage other authors completing scoping reviews to make use of the PRISMA-ScR reporting guidelines.

Implications for research, policy and practice
Improving consistency and transparency in the reporting of scoping reviews is an important step in promoting scientific rigor across this growing methodology. In discussing our experience using the PRISMA-ScR, we hope to encourage others completing scoping reviews to make use of these reporting guidelines.

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REVIEWS & DISCUSSION PAPERS

The non-medical surgical assistant and inequity in the Australian healthcare system

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ABSTRACT

Objectives: The objective of this discussion paper is two-fold. The first is to quantify if the non-medical surgical assistant increases access to surgery by investigating what percentages of cases these clinicians undertake in the private sector surgical units where they work. The second is to examine procedural and distributive justice and how they impact on private sector surgical care.

Aim: The aim of this paper is to investigate if the non-medical surgical assistant increases equity via access, for the patient, to private sector surgical care; and if government policy has an impact on equity in the form of access.

Background: The private healthcare sector completes approximately two-thirds of all elective surgery in Australia; without this contribution, there would be more pressure on the public healthcare sector. In the private sector, recognition and federal funding of the surgical assistant differs depending on whether this clinician has a medical or non-medical, eg. nursing, qualification. The role of the non-medical surgical assistant is well established internationally and this role has been practiced in Australia for more than 20 years.

Discussion: Inequity; as a result of the procedural injustice of government funding policy, impacts the private sector surgical patient causing distributive injustice. This distributive injustice results in an out-of-pocket expense to the patient. Rising out-of-pocket expenses has started a trend of patients moving away from private health insurance and into the public sector. The registered nurse and nurse practitioner are qualified to practise as a non-medical surgical assistant and provide increased access to care, and effective care compared to the medical surgical assistant. The nurse practitioner is an eligible provider of Medical Benefits Schedule services but restricted from accessing the intraoperative assisting item numbers.

Conclusion: The non-medical surgical assistant; or at least the nurse practitioner as non-medical surgical assistant; require access to the Medical Benefits Schedule intraoperative item numbers. Access would alleviate the out-of-pocket expense incurred by Australian patients when a non-medical surgical assistant assists with their surgery. Lack of access to these item numbers means patients may have their surgery delayed until an appropriately skilled medical surgical assistant is available, or the public healthcare sector can accommodate them.

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Implications for research, policy and practice:
This paper illustrates a need for change in Australian government policy to reflect contemporary, evidence-based practice.

What is already known about the topic?

- The international literature reports that advanced practice nursing roles increase access to healthcare.
- The nurse practitioner role in Australia is now well established, and the Australian literature illustrates increased access to care.
- The Medical Benefits Schedule Review Taskforce was formed to investigate a system that is not consistent with contemporary, evidence-based healthcare.

What this paper adds:

- The nurse practitioner and registered nurse, in the role of non-medical surgical assistant, increase access to private sector surgical care.
- Australian government policy limits access to private sector surgical care through its inequitable policies that contravene the spirit of fair trade.
- According to peak professional bodies' policy and position statements, the nurse practitioner and registered nurse are legitimate providers of surgical assisting services.

Key Words: Australian private healthcare sector, nurse practitioner, Australian government health policy, procedural justice, health insurance, distributive justice

INTRODUCTION

Whether due to political policy, social differences, geographical location or the ability to economically fund care; inequity in healthcare is an unfortunate, but persistent, division in the promotion of social justice.[1] This paper investigates inequity, in Australia for both patients and clinicians considering the principles of justice and access.[2] The two types of justice of interest are distributive justice (sometimes called economic justice) which addresses fairness regarding decision outcomes and advocates that equal work should equate to equal pay.[3] The second is procedural justice which refers to fairness about how decisions or policies are made and suggests that decisions should be fair and based on fact.[4,5]

The objective of this paper is two-fold. The first is to quantify if the non-medical surgical assistant (NMSA) increases access to surgery by investigating what percentages of cases these clinicians undertake in the private sector surgical units where they work. The second is to examine procedural and distributive justice and how they impact on private sector surgical care. Figure 2 illustrates the salient points of this argument.

The aim of this paper is to investigate if the NMSA increases equity via access, for the patient, to private sector surgical care; and if government policy has an impact on equity in the form of access. This topic of equity and the NMSA sits within a larger body of research investigating the NMSA in Australia from the perspective of effectiveness, legitimacy, and equity. These three descriptors form part of the conceptual framework of the pillars of quality, as outlined by the father of quality in healthcare, Avedis Donabedian.[6–8] The relevance of Donabedian's pillars of quality was illustrated in the United States of America (USA) in 1990 when the Institute of Medicine released two reports known as the Quality Chasm Series. The individual reports were, *"To Err is Human: Building a Safer Health System" and "Crossing the Chasm of Quality"*.[9,10] These reports were pivotal in moving the conversation regarding quality in healthcare into the mainstream media, the corporate forum and, most importantly, into public healthcare policy. Donabedian's conceptual framework of the pillars of quality was the source material for these reports which investigate the provision of care that is safe, effective, appropriate, equitable and optimises the healthcare dollar.[10,11]

Donabedian's pillars of quality are relevant to the Australian healthcare system as they align with the Australian government's commitment to delivering healthcare that is *consumer centred, driven by information, and organised for safety*[12]; informed by the objectives of the Australian Government's strategic framework of *achieving a safe, equitable, effective and sustainable health system.*[13]

Previous research has quantified that the NMSA is a safe and effective provider of surgical assisting care using the comparator of the medical surgical assistant (MSA).[14] Similarly, it has been established, through surveys of key stakeholders, the examination of peak professional bodies' position statements and a review of the law that the nurse practitioner (NP) and registered nurse (RN) are legitimate clinicians to perform the role of NMSA in Australia.[15–17]

Due to inequity in the delivery of healthcare many first-world countries currently report differing access to healthcare.[18,19] In the United States of America (USA) the National Advisory Council on Nursing Education and Practice said that a diverse nursing workforce is essential for the development of equity in healthcare. The need for diversity in the nursing workforce is supported by the notion that advanced practice nurses (APNs) improve the quality and accessibility of care which increases patient satisfaction.[20]

The Australian literature informs that the APN and NP enhance access to healthcare.[21–28] Nurse Practitioners were first endorsed in Australia in 2001. To date some 1,839 NPs practice in Australia, however, despite being eligible providers with access to the Medical Benefits Schedule (MBS), NPs in the private sector of the Australian healthcare system are only able to access four consultation, six telehealth, and no procedural MBS item numbers.[29,30] This significantly curtails NP private practice.[22,30]

As many patients have multi-morbidities, medical care is increasingly complex, and even routine surgical procedures can involve significant risks. The optimal surgical team should be assembled for all surgical procedures. Surgical assistants work closely with the principal surgeon to maximise safety and efficiency. Surgical assistants are an essential part of the surgical team and make a vital contribution to the high standards of surgery available to Australian patients.[31]

Historically surgical assisting in Australia has been undertaken by medical practitioners called medical surgical assistants (MSA). These clinicians are readily available in the public healthcare sector in the form of doctors-in-training. Medical surgical assistants in the private sector are either doctors whose only role is a surgical assistant or general practitioners (GP) who work a dual role.[32] General practitioners that work a dual role may be unavailable for urgent or emergency procedures; similarly, as specialty-specific, surgical techniques evolve a specialist assistant may be required.

The NMSA is a clinician who is not a medical practitioner, who provides care to the perioperative patient. In Australia, the role of the NMSA is predominately undertaken by an RN or the NP.[33] This role has been practised in Australia for more than 20 years, and RNs and NPs who practice as NMSA fulfil the requirements of peak professional bodies to act as a surgical assistant.[34] Brennan suggested in 2001 that the advanced practice of perioperative nurses as surgical assistants could provide cost-effective patient care in the Australian healthcare system.[35] Supporting this; a 2011 Parliamentary research paper investigating "*What are we doing to ensure the sustainability of the health system?*" suggested investigating role substitution from the medical practitioner to the NP could be a potential cost-saving strategy.[36]

All MSAs within the private sector of the Australian healthcare system have access to surgical assistant MBS item numbers.[37] The MBS is for the payment of services for the patient. Access for the MSA means the patient is entitled to a rebate for the MSAs' intraoperative services. Currently, only MSAs can access a surgical assistant MBS rebate. Lack of access to the MBS for the NMSA is not an issue of the NMSA not being paid enough due to lack of an MBS rebate; it is an issue of the NMSA (in some cases) not being paid at all. The broader point is the distributive injustice of MBS funding not being available to all clinicians who are qualified to perform a role. Distributive injustice is not restricted to the NMSA but affects many NPs in other specialities of private practice in Australia.[30]

Regarding the NMSA, the process of allowing access to the MBS is a cost-neutral exercise for the government and private health insurers; as an MSA or an NMSA is used, not both. The NMSA would cost the same as the MSA if given access to the current MBS surgical assistant item numbers. Initially, the role of the NMSA evolved because it was sometimes difficult for a surgeon to obtain an MSA for procedures in the private sector.[16] However, some surgeons choose to use an NMSA due to the specialised nature of particular surgery. Examples of this are cardiac surgery or robotic surgery, which requires specialised skills.[32]

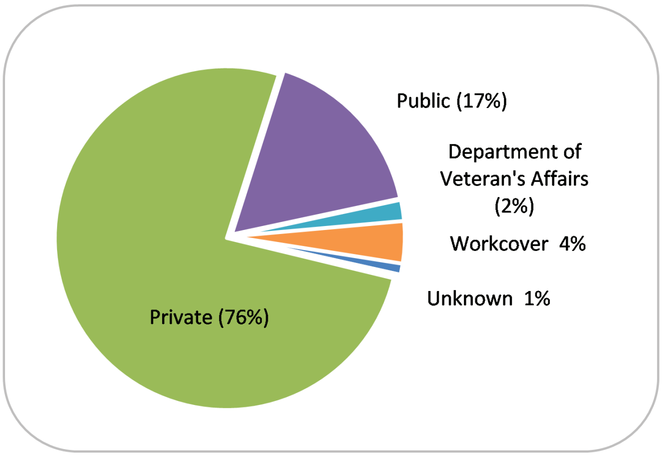

FIGURE 1A: NON-MEDICAL SURGICAL ASSISTANT PROCEDURES BY PATIENT TYPE IN 2016.

Source: Constructed with data from, and permission of, the Australian Association of Nurse Surgical Assistants.[38]

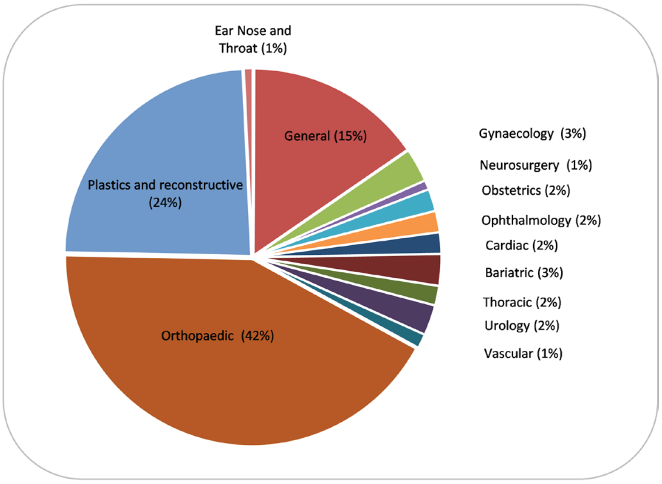

FIGURE 1B: NON-MEDICAL SURGICAL ASSISTANT PROCEDURES BY SURGICAL SPECIALTY IN 2016.

Source: Constructed with data from, and permission of, the Australian Association of Nurse Surgical Assistants.[38]

Due to doctors in training in the public sector, the role of the NMSA is predominately within the private sector.[15,16,33] In 2016, 76% of operations supported by NMSAs took place within the private sector across a range of surgical specialties.[32]See Figure 1a and 1b

THE FOUR TIERS OF INEQUITY

Figure 2 uses a hierarchical pyramid model to illustrate how the relationships between inequitable access, remuneration and costs, can ultimately interact to affect the attainment of equity for NMSAs and their patients in the Australian healthcare system.

INEQUITABLE ACCESS

Access is a term used in academic literature and government policy to describe the receipt of treatment. This concept is underpinned by an individual's medical condition and not their ability to pay.[1] For this reason, the Australian healthcare system has a public and private sector. The public healthcare sector services patients who are unable to pay for care. The median waiting time for a surgical procedure in the public sector in 2016-17 was 38 days; however, if the surgery was non-life threatening (elective), e.g. total hip replacement the median waiting time was 250 days. Due to private health insurance, 67% of all elective surgery in Australia is performed in the private sector.[39,40] By Australians investing in private health insurance, there are shorter waiting times in the public sector and less demand on public sector beds.[40]

Due to the nature of the system, waiting times are not readily available for the private sector; however, they are reported to be shorter than in the public sector.[41] Securing an MSA for procedures in the private healthcare sector can be difficult. In a survey of Australian surgeons in 2015-2016, 27.5% revealed they had postponed or cancelled cases as an appropriate surgical assistant was not available. Further, 22.7% of surgeons said it was difficult or very difficult to secure a surgical assistant, irrespective of their geographical location, for urgent or emergency private sector procedures.[16]

In this situation, the NMSA can increase access to surgery; however, the current lack of government remuneration can restrict this access. An example of this is the Department of Veteran's Affairs (DVA) patient. Access to surgery is limited as the DVA patient does not pay out-of-pocket expenses in the private sector. This means if an MSA is unavailable, the DVA patient may have their procedure postponed until an appropriately skilled MSA is available instead of using an NMSA and paying an out-of-pocket expense.

A situation which illustrates increased access occurred when a group of NMSAs fulfilled the role of surgical assistant for a contract of 110 public beds in a private sector hospital.[42] Cost and availability rendered the MSA, not a feasible option. The six operating theatre unit was regional, and the NMSA also fulfilled the role of surgical assistant for many private, surgical patients.[43]

Inequitable access to surgery exists in many regional centres. Similar to Canada, Australia struggles with doctor shortages outside of metropolitan areas.[44] While the government has a migration program to procure overseas trained doctors (some of whom may act as an MSA) to regional areas, this program has failed due to cultural difficulties; and lack of training for overseas doctors to function in regional and remote areas without significant support.[45] To demonstrate how the NMSA increases access to surgery in private sector regional Australia, data from four regional hospitals, defined by postcodes,[46] was collected over three months from 1 April 2018 – 30 June 2018 (see Table 1).

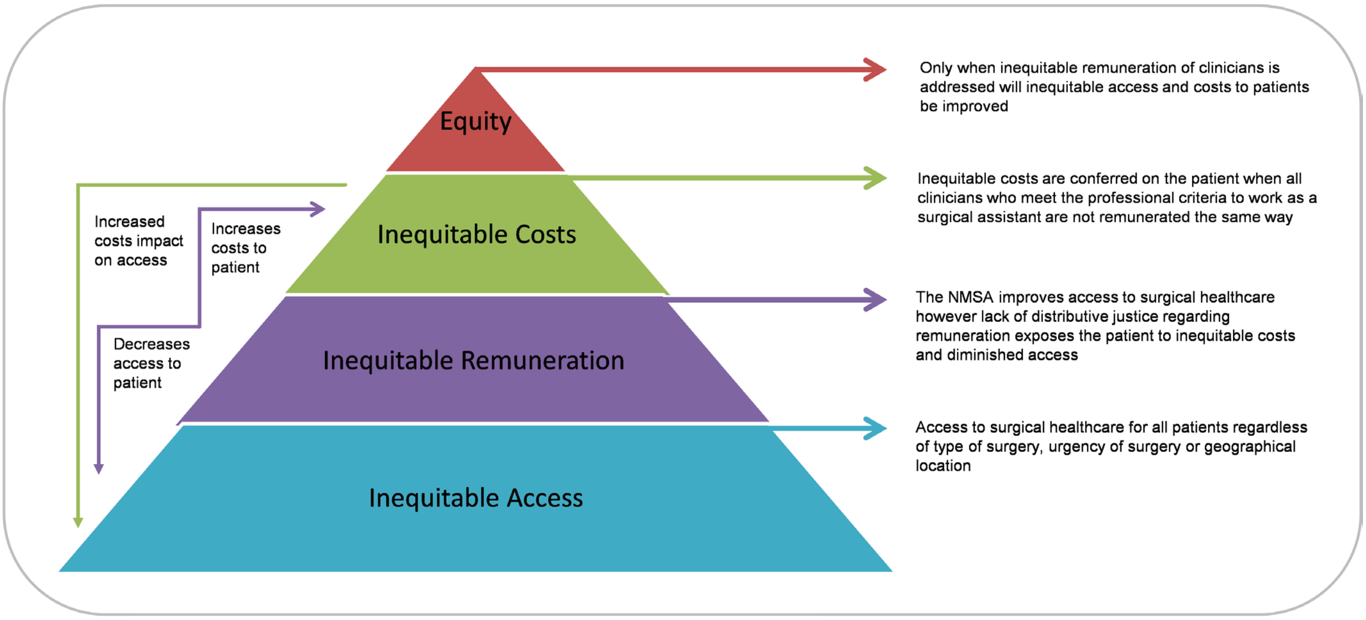

FIGURE 2: PYRAMID OF INEQUITY: AUSTRALIAN NON-MEDICAL SURGICAL ASSISTANTS AND PATIENTS.

TABLE 1: REGIONAL HOSPITALS SURGICAL ASSISTANT BREAKDOWN (THREE MONTH PERIOD 1 APRIL 2018 – 30 JUNE 2018).

Surgery Type*	**Hospital 1 – 190 bed facility**	**Hospital 2 – 137 bed facility**	**Hospital 3 – 200 bed facility**	**Hospital 4 – 16 bed facility**
General	Total Cases – 186 MSA – 120 (64.5%) NMSA – 66 (35.5%)	Total Cases – 273 MSA – 173 (63.37%) NMSA – 20 (7.33%) Nil – 80 (29.30%)	Total Cases – 811 MSA – 407 (50.19%) NMSA – 330 (40.96%) Nil – 74 (9.12%)	Breakdown of specialties not available
Orthopaedic	Total Cases – 247 MSA – 83 (33.6%) NMSA – 164 (66.4%)	Total Cases – 218 MSA – 131 (60.09%) NMSA – 67 (30.74%) Nil – 20 (9.17%)	Total Cases – 913 MSA – 349 (38.22%) NMSA – 535 (58.6%) Nil – 29 (3.18%)	
Gynaecology/Obstetric	Total Cases – 93 MSA – 52 (55.9%) (Caesars 37%) NMSA – 41 (44.1%) (Caesars 63%)	Total Cases – 87 MSA – 27 (31.04%) NMSA – 21 (24.14%) Nil – 39 (44.82%)	Total Cases – 22 MSA – 7 (31.82%) NMSA – 0 (0%) Nil – 15 (68.18%)	
Urology	Total Cases – 4 MSA – 2 (50%) NMSA – 2 (50%)	Total Cases – 302 MSA – 4 (1.33%) NMSA – 6 (1.99%) Nil – 292 (96.68%)	Total Cases – 307 MSA – 28 (9.12%) NMSA – 0 (0%) Nil – 279 (90.88%)	
Plastic/Reconstructive	N/A	Total Cases – 118 MSA – 11 (9.32%) NMSA – 1 (0.85%) Nil – 106 (89.83%)	N/A	
Ear, Nose and Throat	Total Cases – 11 MSA – 0 (0%) NMSA – 0 (0%) Nil – 11 (100%)	Total Cases – 127 MSA – 32 (25.20%) NMSA – 0 (0%) Nil – 95 (74.80%)	Total Cases – 360 MSA – 0 (0%) NMSA – 0 (0%) Nil – 360 (100%)	
Robotic	N/A	Total Cases – 16 MSA – 0 (0%) NMSA – 16 (100%)	Total Cases – 12 MSA – 12 (100%) NMSA – 0 (0%)	
Cardiothoracic/Vascular	N/A	Total Cases – 55 MSA – 8 (14.55%) NMSA – 0 (0%) Nil – 47 (85.45%)	Total Cases – 59 MSA – 56 (94.92%) NMSA 3 (5.08%)	
Total procedures	**1,198**	**2,179**	**2,484**	**530**
Procedures requiring an assistant	**530**	**517**	**1727**	**113**
NMSA assistant %	**51.50%**	**25.33%**	**50.26%**	**56.63%**

Permission to access data was received from each hospital and data was retrieved from the electronic hospital records

* Surgical procedures performed in theatre but not requiring an assistant at these hospitals ie. Endoscopy, Dental, Electroconvulsive therapy (ECT), Cardioversion and Pain procedures etc. are not listed.*Surgical procedures performed in theatre but not requiring an assistant at these hospitals

Of note here is that some of the private surgical procedures in this data are unavailable in the public hospitals in these regions. This means patients without private health insurance or unable to pay out-of-pocket expenses for the NMSA, would need to travel to a metropolitan hospital to receive their surgery. This is costly for the patient, may cause delays for their procedure and potentially compounds public-sector pressure.

In Hospital 1, the NMSA assisted for 51.5% of cases, in Hospital 2, the NMSA assisted for 25.3% of cases. Hospital 1 and 2 represent all private surgery undertaken in a regional town with a population of approximately 115,000. The NMSA assisted for 38.5% of all private surgery in this town, carried out during the data collection period. Surgeons, in this region, are also training the NMSAs to assist for Robotic surgery as this will provide a consistent service. The NMSA assisted with more Caesarean Sections; often an urgent procedure conducted out-of-hours. The NMSA assisted for 63% compared to the MSA who assisted for 37%.

Hospital 2 has records of perioperative staff, i.e. scrub and scout staff, acting as a surgical assistant for some of the procedures. It is anticipated that this practice occurs in many hospitals. This practice is contrary to the Clinical Guidelines of the Australian College of Operating Room Nurses and exposes these non-designated staff to medico-legal consequences should patients experience intraoperative or postoperative complications.[15] In a recent survey of perioperative staff, 17% said they performed the impromptu role of surgical assistant daily, and 18.7% performed the position once a week.[15] The practice of improvised use of perioperative staff as surgical assistants, coupled with the fact that an NMSA assisted for a quarter of the surgery conducted at this hospital reinforces the notion that a need exists in Australian for the NMSA.

In Hospital 3, the NMSAs assisted for more than 50% of the orthopaedic procedures. For this hospital, orthopaedic procedures represented over a third of all surgical procedures for the data collection period.

Hospital 4 is located in a regional town with a population of 42,000 and is the only private hospital in the area. Mainly operating on day procedures, the hospital has a 16-bed capacity. Over 50% of procedures needing a surgical assistant, were undertaken by the same single NMSA.

As was evident at the inception of the role of the NP in Australia, advanced practice nurses are one strategy to improve access to medical services in regional or rural Australia yet they lack the private sector remuneration to sustain this.[28,47–50]

INEQUITABLE REMUNERATION VIA AN MBS PATIENT REBATE

According to peak professional healthcare organisations (Royal Australasian College of Surgeons, The Australian College of Operating Room Nurses, The Australian College of Nurse Practitioners, and The Australian Association Nurse Surgeon's Assistants) the NP and RN are legitimate clinicians to undertake the role of NMSA.[34,51–53] Similarly, the Australian Health Professional Regulation Agency (AHPRA) does not specify any requirements or place any limitations on which clinicians can undertake the role of a surgical assistant. However, in the private sector, Medicare via the MBS will only remunerate the medical practitioner as a surgical assistant.[54] Medicare is not the law but the government's interpretation of the law.[55] Given this, the government can alter the MBS rules as they see necessary. The rules that exclude the NMSA to funding is not a discrete issue of private sector funding but a broader issue of distributive justice which advocates equal work should equate to equal pay.[3] The concept of distributive justice also leads to the notion of anti-competitive restriction of activity that some professionals have benefited from since the creation of the MBS in 1975.[56]

According to the Australian Government's website on the topic, "Fair Trading" is Australian commonwealth and state/territory laws that protect the worker, their business and their customers from unfair trading practices.[57] The role of the Australian Competition and Consumer Commission (ACCC) is to uphold fair trading, encourage competition and regulate national infrastructure.[58] Paragraph six of the ACCC website elaborates that, *Competitive, informed and (when necessary) well-regulated markets lead to lower prices, better quality products and services, and more choice. This increases the prosperity and welfare of all Australians*. The ACCC takes action to improve consumer safety, protect competition or stop conduct that is anti-competitive or detrimental to consumers.[58]

As the NMSA cannot access the MBS for an assisting rebate for patients, a lack of distributive justice for both the NMSA and their patient is demonstrated. This would appear not to protect the worker who may not be paid if the patient reneges on the out-of-pocket. The out-of-pocket expense causes financial harm to the consumer of the surgical service, a form of procedural injustice due to government policy. Additionally, physical harm may come to the patient who cannot pay the out-of-pocket and therefore may have to wait for their surgery. Delayed surgery increases hospital length of stay and complication rate.[59] Anti-competitive MBS rules supported by the government allows the MSA a monopoly on access to the MBS for surgical assisting services.

Similar to the MSA, the NMSA must satisfy credentialing requirements at each clinical site where they practice and; specific to NP, have a collaborative agreement with a surgeon which includes a surgical assistant scope of practice. The NP also has an MBS Provider Number yet is denied access to the surgical assistant Item Numbers. However, there are international and Australian data that demonstrates the NMSA has equivalent patient outcomes to the MSA.[14,58–63] Patient outcomes investigated in the Australian data considered six dependent variables; time in the operating theatre, intraoperative time, admission to Intensive Care, length of stay, discharge destination and readmission within 28 days. The results showed no statistically significant difference and no clinically relevant difference between the MSA and NMSA.[14]

While the RN working as an NMSA satisfies hospital credentialing and peak professional bodies' criteria; the NP offers those in government an uncomplicated opportunity to regulate the role of the NMSA. The NP model of care has a principal goal of improving access to high-quality care, yet provisions under the MBS for this eligible provider have not been reviewed regarding relevance to the patient and functionality of the role for a decade.[22] As Bryant outlined, combining the NMSA and NP roles achieves:

1. Standardised education – with a Master's Degree approved by the Nursing Midwifery Board of Australia;
2. National competencies, ie. Standards for Practice;
3. Identification on the AHPRA register separate to Registered Nurses; and
4. Title protection[60]

Nurse Practitioners working in the private sector of the Australian healthcare system are an underused resource and remain curtailed by the small number of MBS Items for which the patient receives a rebate. While patients support healthcare delivered by the NP, limited access to the MBS for NPs increases costs borne by the patient and reduces accessibility to private NP care.[25,61–63] A practice audit of clinicians in the role of NMSA in Australia, revealed that all NPs in the NMSA role but one possessed a NMSA qualification in addition to their Nursing and Midwifery Board of Australia recognised Master's Degree.[33]

INEQUITABLE COSTS

The Australian Government was predicted to spend $87.9 billion on health in 2017-18.[64] Approximately 47% of the Australian population chooses to also pay for private health insurance in addition to the assurance offered by Medicare.[65] In 2014-15, 4.5 million of the 10.6 million admissions to public (14% of admissions to public hospitals) and private hospitals (83% of admissions to private hospitals) were funded by private health insurance.[39] It is essential to the functioning of the public healthcare sector that Australians maintain their private health insurance and utilise the private healthcare sector for surgical procedures, however; due to rising costs of health insurance premiums and an additional overall 3.3% rise in out-of-pocket expenses, the number of Australians with private health insurance dropped by 0.9% from June 2017 – June 2018.[39]

Patients in the private sector of the Australian healthcare system pay taxes to Medicare and private health insurance premiums to cover the costs of their care while undergoing surgical procedures in the private sector. These costs include the payment of a rebate to the patient for the surgical assistant. Topical in Australia at the moment is the significant out-of-pocket expenses that the patient incurs from private clinicians such as surgical assistants who charge the patient a gap above the rebate they receive for services related to surgery.[32,66] While the MSA may choose to charge the patient an out-of-pocket expense in addition to the rebate they receive; the NMSA charges an out-of-pocket fee as their only form of payment.

The surgeon will use an MSA or an NMSA; the NMSA is not a duplication of services for the healthcare sector but is a duplication of payment for the patient who has already paid their taxes and health insurance premiums and must also pay an out-of-pocket expense for the NMSA's clinical services. In these circumstances, the patient is being exposed to procedural injustice by the Commonwealth Government who sets the rules for the MBS.[37] The definition of procedural justice states that decisions should be fair and based on fact.[4] Limiting access to the MBS assisting Item Numbers is not fair, and as the NMSA has equal patient outcomes to the MSA, this limitation is not based on fact.

The MBS Review Taskforce is currently evaluating "*Proposed changes to remuneration arrangements for surgical assistants*" and released a document on 4 September 2018 for stakeholder consultation. The proposal is to change the process for the remuneration of those with access ("medically qualified") to the Assistance at Operations Item Numbers TN9.1. 51300-51318. While this document does not outline the NMSA as an alternative to the MSA, it has created an opportunity for peak professional bodies to suggest the NMSA as an eligible provider of this service.

The MBS Review Taskforce has also released a document, "*Report from the Nurse Practitioner Reference Group 2018*" for stakeholder consultation on 6 February 2019. This report outlines 14 recommendations. Eight of the recommendations focus on increased access to the MBS for patients treated by the NP. Recommendation 10 says, "*Enable patients to access MBS rebates for procedures performed by an NP.*"[22] Neither of these processes was finalised at the time of publication of this paper in 2020.

CONCLUSION

Government policies negatively impact on the private sector surgical patient, when the NMSA does not have access to the MBS surgical assisting item numbers. This lack of procedural justice afforded to patients to achieve improved health through private sector surgery limits the access or causes an extra financial burden.

There has been a consistent move away from patients investing in private health insurance, due partly to the cost of insurance premiums and secondly to large out-of-pocket expenses. A move away from private health insurance increases the waiting times in the public healthcare sector.[67] Those patients who make the financial sacrifice to invest in private health insurance are penalised by government policy restricting a rebate for some clinician's clinical services.

In the context presented here, access to surgery for the patient in the private sector is most limited when the operation is highly specialised needing an experienced surgical assistant; when the procedure is urgent or an emergency; or when the procedure is in a regional location. Access is limited when no MSA is available, and the patient cannot pay the out-of-pocket expense for the NMSA.

As outlined in the MBS Review Taskforce – Report from the Nurse Practitioner Reference Group, "*Inequity in funding mechanisms should not prevent people from receiving comprehensive, evidence-based care*".[22] The lack of distributive justice imposed on the NMSA and particularly the NP as an eligible MBS provider does not reflect contemporary NP practice. The question here is not "should NPs be undertaking this role?" but "why are NPs not funded when undertaking a role for which they meet the professional criteria?" Until the NMSA; or a least the NP as an NMSA; is given access to the MBS assisting item numbers patients will continue to have restricted access, be economically penalised or have their surgery delayed until an appropriately skilled MSA is available or the public healthcare sector can accommodate them.

RECOMMENDATIONS

The Australian government is committed to achieving a safe, equitable, effective and sustainable health system, but this is not happening.[13] Likewise, it was the MBS Review Taskforce's mission to align the MBS to contemporary healthcare practice. This has not occurred in relation to the NMSA.

To allow patients equitable access to private sector surgical care, the MBS must align with contemporary perioperative practice. While access to all RNs and NPs in the role of NMSA would enhance patient access to surgery; as a minimum, the Australian government via the MBS must enable the NP to access the Category 3 TN.9.1 51300-51318 surgical assistant item numbers.

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