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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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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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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.

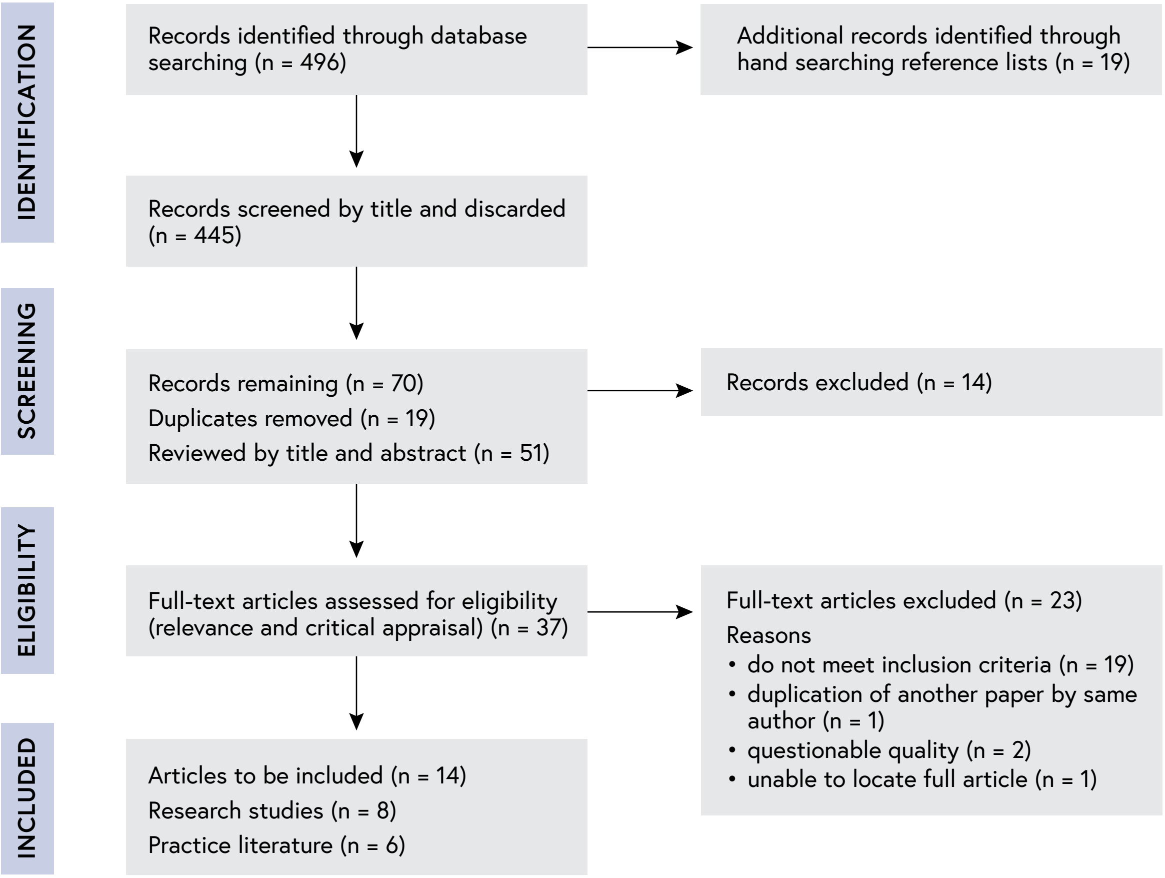

FIGURE 1: PRISMA FLOW DIAGRAM

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.

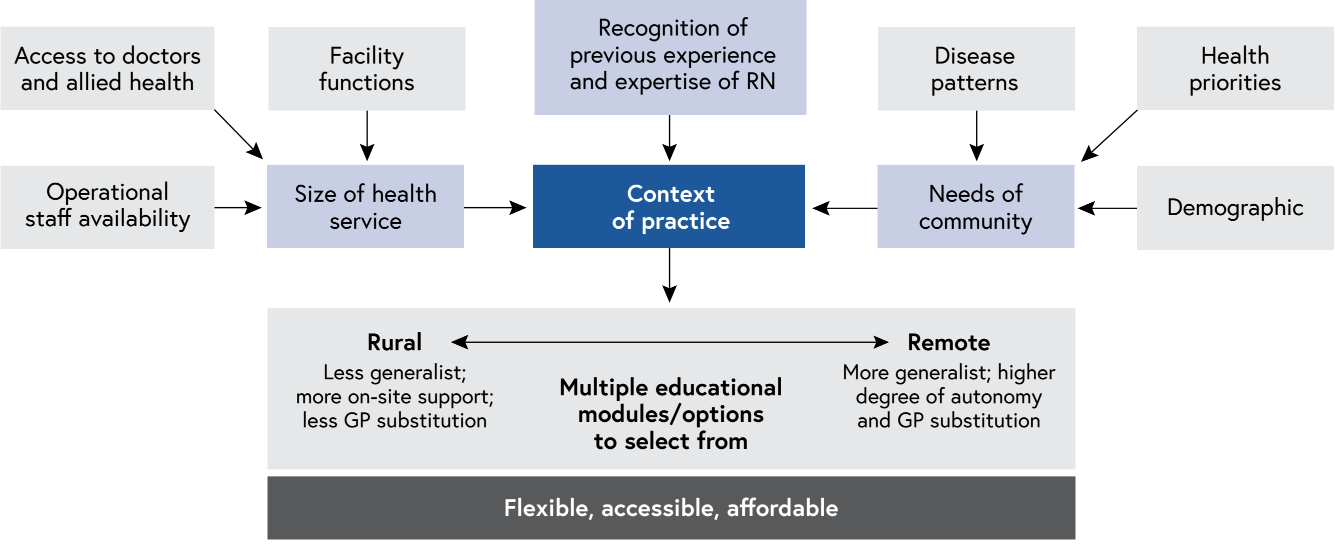

FIGURE 2: CONSIDERATIONS FOR EDUCATIONAL PLANNING

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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