

The Rural Research Capacity Building Program Final Report

Do Rural Primary Health Care Nurses Feel Equipped for Palliative Care?

The professional and personal impact on rural and remote primary health care nurses who are required to provide palliative care as part of their generalist role.

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Principal Researcher

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Abstract

Community Primary Health Care nurses in rural and remote settings are required to provide palliative care as part of their generalist role. They have limited access to specialist medical and nursing support and sometimes there are no resident GPs. A study consisting of a mailed survey and follow up interviews was conducted to explore the experiences of these nurses, and to determine how personally and professionally equipped they felt for palliative care service provision.

Most respondents were registered nurses experienced in nursing and in rural and remote settings. They had only occasional palliative care patients, and more than half had provided palliative care for a friend or family member. The nurses either found palliative care rewarding, or preferred not to have to do it. However, even those who did not enjoy working with palliative care patients often went beyond the 'call of duty' to support a home death if that was what the patient wanted.

These nurses juggled multiple work roles as part of their generalist role, with some wearing 11 or more different 'hats'. Competing work demands were particularly challenging when a patient approached the terminal phase and required more care.

Three-quarters had attended palliative care education in the last two years but 88% required more education. Barriers to education included competing work roles, work load, geographical isolation, and lack of backfill. The nurses were prepared to access education using a range of mediums including online education, videoconference and face to face education.

Implications for health services involve ensuring systems and networks are in place to ensure timely and relevant clinical advice, support and debriefing particularly when a nurse has a negative experience, and access to relevant education using modes of delivery that are not constrained by geographical isolation.

Keywords

Clinical support

Education

Support

Remote

Emotional impact

Executive Summary

The important role that Primary Health Care (PHC) nurses play in the provision of palliative care was highlighted in Palliative Care Australia's 'A Guide to Palliative Care Service Development: A Population Based Approach' (Palliative Care Australia 2005). This model outlines the relationships between specialist palliative care services and primary care services, and assumes that most palliative care patients will have non-complex needs that can be met by a PHC provider. A smaller number of patients with complex needs will require specialist palliative care.

The role of the PHC provider and their relationship with specialist services was further reinforced with the release of the NSW Health Palliative Care Role Delineation Framework (NSW Health 2006a) which is based on the work by Palliative Care Australia. This population and needs-based approach is also endorsed in the National Palliative Care Strategy (Department of Health and Ageing 2010) which states that not all people approaching the end of life need specialist palliative care and acknowledges that PHC providers give high quality care for people at end of life through a palliative approach. The framework goes on to describe the role of PHC providers as "to provide supportive care, including pain and symptom management, social, spiritual and emotional support, education and bereavement risk assessment for patients, care givers and family members" (NSW Health 2006a).

In rural and remote communities, community PHC nurses are the primary carers for palliative care patients with both complex and non-complex needs. They face a number of professional and personal challenges without the specialist training and support networks that their specialist counterparts are able to access.

The aim of this mixed method study was to examine the experiences of the community PHC nurses in rural and remote communities of Far West of NSW who are required to provide palliative care as part of their generalist role, and explore how equipped they feel to be able to provide this role. The sites in the study sample were the 14 geographically isolated rural and remote communities located in the former Far West Area Health Service of NSW.

The study found that the 34 respondents were nurses who were experienced in working in rural and remote settings. They had only intermittent palliative care cases which caused concern for some nurses who felt inadequate in some aspects of palliative care. However, most knew where to access specialist advice when required, thus highlighting the importance of accessible clinical networks that are known to staff. The nurses stressed the importance of clinical support that is timely and relevant to the case at hand. These nurses juggled multiple roles as generalists, with almost half wearing 11 or more 'hats'. They found it difficult at times combining their other roles with palliative care, particularly in the end stages due to the time required by palliative care patients and other workload demands.

The majority of nurses enjoyed working with palliative care patients and felt that the nature of the work, the strong connections made with patients and family, the sense of privilege in being involved in their care, and a strong commitment to their community were factors that sustained these nurses. A smaller number of nurses did not enjoy working with palliative care patients, and would only do so because it was part of their generalist role. However, even those nurses who did not enjoy palliative care went beyond the call of duty to support a home death if that is what the patient wanted. Some had experienced situations that had a negative impact on them personally and professionally, which raises the question about how to support these generalist nurses who are dealing with complex cases in geographical and professional isolation. Most nurses felt that the role definition of PHC providers in

palliative care was an accurate reflection of the work they do, while a few who would prefer not to provide palliative care believed it was more closely aligned with the role of a specialist palliative care nurse.

Almost all nurses had accessed palliative care education within the past two years, but it competed with other training and for some was not a priority due to the infrequency of palliative care cases, again highlighting the need for timely, clinically relevant case review. Almost nine out of ten nurses said they required additional education but also indicated there were significant barriers to education, with isolation, lack of backfill and workload constraints noted most frequently. The nurses accessed education using a range of delivery modes including on-line, videoconference and face to face education. Nurses who did not enjoy palliative care chose not to access palliative care education, preferring topics more aligned with their interests.

The study reinforces the need for timely, relevant clinical support and education from palliative care medical and nursing specialists. These support and education networks need to be easily accessible and not constrained by geographical isolation. Promotion of extended clinical placements at specialist palliative care services, the availability of a range of on-site and on-line resources, along with management support for 'time-out', flexible models of care, debriefing and clinical supervision may assist the PHC nurses feel more competent and confident in their work with palliative care patients and families. Retaining this experienced workforce in remote areas requires the provision of appropriate education and clinical and emotional support despite the infrequency of palliative care cases in some communities.

Introduction

Palliative care in rural and remote communities is provided across a range of settings by various Primary Health Care professionals. The role description for these providers has been outlined in documents from peak agencies such as Palliative Care Australia and NSW Health and encompasses supportive care, including pain and symptom management, social, spiritual and emotional support, education and bereavement risk assessment for patients and their families.

Generalist community nurses are pivotal in providing palliative care in rural and remote communities and face a number of professional and personal challenges. This study examines the experiences of these nurses who are required to provide palliative care as part of their generalist role. It explores how equipped they feel to provide palliative care, and looks at the professional and personal impacts of providing palliative care in small communities. The study identifies some of the challenges these nurses face in order to better understand their experience.

Recommendations for education, clinical and emotional support for these nurses are based on their identified needs, which will be of interest for local health services and peak palliative care agencies.

Background

Primary health care (PHC) or community nurses play a crucial role in providing palliative care services for rural and remote communities (Troller 1995; Evans *et al.* 2003; Dunne *et al.* 2004; McCarthy and Hegney 2001; Palliative Care Australia 2005). For the purpose of this study, palliative care patients are defined as those people with a life limiting illness from which they will eventually die. They have physical, psychological, practical and social needs that must be addressed within cultural and spiritual considerations (Nadimi and Currow 2011).

The importance of the role of PHC providers was highlighted in Palliative Care Australia's (2005) model which describes the relationships between specialist palliative care services and primary care services, and assumes that most palliative care patients will have non-complex needs that can be met by a PHC provider. A smaller number of patients with complex needs will require specialist palliative care.

The role of the PHC provider and their relationship with specialist services was reinforced with the release of the NSW Health Palliative Care Role Delineation Framework (NSW Health 2006a), based on the work by Palliative Care Australia. This population and needs-based approach is also endorsed in the National Palliative Care Strategy which states that not all people approaching the end of life need specialist palliative care and acknowledges that PHC providers give high quality care for people at end of life through a palliative approach (Department of Health and Ageing 2010).

This population and needs based model proposes that all people with a life limiting illness be conceptualised as falling into three sub-groups based on the complexity of their needs: Sub-group C = Complex Needs, B = Intermediate and A = Primary Care. (Figure 1)

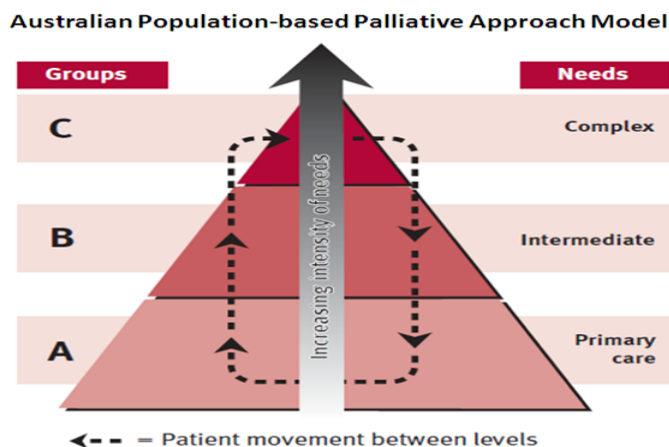


Figure 1: Conceptual model of population based palliative care needs

Source: Palliative Care Australia

Sub-group A is the largest group and comprises those palliative care patients who do not require access to specialist palliative care. Needs of this group are met by primary care, generalist service providers.

Sub-group B comprises palliative care patients who have intermittent exacerbations of pain and symptoms or emotional distress, and may have a temporary increase in their level of

need for specialist palliative care consultation and advice. Their ongoing care remains with the PHC provider.

The smaller sub-group C will have complex and intense needs requiring direct care from specialist services. Palliative care patients in rural and remote communities may have either a malignant or non-malignant palliative care condition, and can range from patients with needs comparable to Group A, B or C.

The framework describes the role of PHC providers as "to provide supportive care, including pain and symptom management, social, spiritual and emotional support, education and bereavement risk assessment for patients, care givers and family members" (NSW Health 2006a).

Specialist palliative care nurses have similar elements to their role description in working with patients with complex needs. Additionally, they have chosen to work in palliative care, have acquired specialist skills and have discipline specific support networks. In rural and remote communities, community PHC nurses are the primary carers for palliative care patients with both complex and non-complex needs within their generalist role, their access to support from specialist palliative care providers is constrained by geographical isolation or lack of specialist resources, raising the question of how equipped generalist rural and remote community PHC nurses feel about providing palliative care.

Rationale

Peak palliative care and health agencies are promoting the role of the PHC nurse in the care of palliative care patients with non-complex needs. In rural and remote communities, these nurses are caring for patients with both complex and non-complex needs, in addition to facing a number of challenges around isolation, multiple work roles, education and clinical support.

This study was conducted to explore the experiences of PHC nurses in rural and remote NSW who provide palliative care as part of their generalist role, how they feel about caring for palliative care patients, how well equipped they feel they are for their role in palliative care service provision, and what their education and support needs are to facilitate this level of care.

Study context

The 14 rural and remote sites in this study were part of the former Far West Area Health Service (FWAHS), which covered 270,000 square kilometres or 34% of NSW (Figure 2). With a total population of 48,600 almost half live in Broken Hill and 13% of the population is Aboriginal. The sites included Broken Hill, Balranald, Dareton / Wentworth, Menindee, Wilcannia, White Cliffs, Tibooburra, Ivanhoe, Bourke, Brewarrina, Walgett, Collarenebri, Lightning Ridge and Goodooga. The populations of these communities ranged from 119 to the largest centre with 20,223 people (Australian Bureau of Statistics 2007). One community had an Accessibility / Remoteness Index of Australia Rating (ARIA +) of 'accessible to moderately accessible', which indicates significant restrictions in accessibility to some goods, services and opportunities for social interaction. All other communities were classified as either 'remote' indicating very restricted access, or 'very remote' indicating very little accessibility (NSW Health 2006b).



Figure 2. Former Far West Area Health Service, NSW

The facilities where the community PHC nurses were based varied in the services and resources available on site. Some were small Multi Purpose Services (MPS) with a nursing clinic and no in-patient beds with once weekly Royal Flying Doctor Service (RFDS) visiting GP clinics. Others were slightly larger MPSs with some in-patient beds and a resident GP, through to a larger regional hospital in Broken Hill with resident GP services and a general physician. There are no resident or visiting palliative care medical specialists. In communities without in-patient beds, if a patient cannot be nursed at home, they must be relocated to a community which may be several hundred kilometres away.

In the smaller communities, a registered nurse and an enrolled nurse may be the only resident staff. Others worked as part of a smaller PHC team comprising a few PHC nurses. Nurses in the small MPS provide general emergency after-hours services, whilst the larger MPSs with in-patient facilities have no formal after-hours nursing services.

Study population

The study population comprised an estimated 40 community PHC nurses (Registered Nurses, Enrolled Nurses and Assistants in Nursing) who provide palliative care services as part of their role, and were located in the 14 rural and remote health services in the former Far West Area Health Service of NSW (Figure 2).

The Far West NSW Palliative Care Service Model

There is no resident palliative care medical specialist in the Far West of NSW but there is some provision for remote consultations using video conference or phone, and some patients travel long distances to visit specialists. A palliative care Clinical Nurse Consultant (CNC) and a small specialist palliative care nursing team are based in Broken Hill. There are three part-time specialist palliative care nurses located in remote communities outside of Broken Hill. The PHC nurses in the study sites work within a Primary Health Care model. The CNC and specialist palliative care nurses support the community PHC nurses who provide care in remote communities through supervision and mentoring, provision of an educational program, and real time clinical support by phone or joint consultative home visits. The community PHC nurses provide a wide range of generalist services and may also have managerial responsibilities. Palliative care education competes with mandatory training and other education for their time and attention.

Literature Review

Search Strategy

Assistance was sought from the Librarian at the Broken Hill University Department of Rural Health (UDRH). A literature search was conducted in relevant data bases from 2009 dating back to 1990, with a smaller search completed in 2011 to review more recent literature. Searches were performed on CINAHL, Medline, INFORMIT databases, PSYCINFO and ERIC.

A snowballing technique was used to source related relevant articles and literature / texts.

Search strategy (Medline)

Search Strategy 1 (SS1): primary health care

SS2: rural (keyword) rural health / rural health services, community health

SS3: nurses or nursing / attitude of health personnel

SS4: death / palliative care / terminal care / attitude to death

SS5: 1 or 2

SS6: 3 and 4 and 5

A more general search employing SS4 and SS3 and using education or training headings did not prove useful.

Results of Literature Review

The experiences of GPs, medical students and specialist palliative care nurses are well covered in the research (Sach 1997; Dunne *et al.* 2004; Wilkes and White 2005) with a gradually evolving evidence base dealing with the rural PHC nurse working with palliative care patients and families.

The literature acknowledges PHC or community nurses as pivotal in the provision of palliative care services in rural communities (Dunne *et al.* 2004; Evans *et al.* 2003; Palliative Care Australia 2005; Troller 1993) and the numerous challenges in the role. These nurses have only occasional palliative care patients (Rosenberg and Canning 2003) and often find managing pain and physical symptoms difficult (Dunne *et al.* 2004) with unrelieved symptoms such as intractable pain a major stressor (Troller 1993). They often feel ill-equipped to deal with the emotional and psychological demands of palliative care service provision (Crawford 2000; Dunne *et al.* 2004; Robinson *et al.* 2009). Nurses in small rural and remote communities face the additional stress of caring for neighbours or life-long friends, often having relationships with palliative care clients and their families beyond the professional context (Evans *et al.* 2003; Robinson *et al.* 2009).

As generalist nurses, they juggle multiple and diverse roles (Rosenberg and Canning 2003, Lenthal *et al.* 2009) and are usually the same providers of care both before and after palliative care referral (Woods 2001). They often feel unable to escape as they are approached after hours in small communities (McConigley *et al.* 2000) with geographical isolation presenting personal and professional challenges (McCarthy and Hegney 2001, Lenthal *et al.* 2009). The very nature of caring for terminally ill patients in rural and remote communities is very different to the scope of practice of nurses in metropolitan areas (Hegney *et al.* 1997). Advances in treatments of malignant and non-malignant conditions means that the palliative phase of care is often extended, with patients cared for in the community setting over a longer trajectory (Phillips *et al.* 2006).

A literature review of the state of knowledge about Canadian and Australian rural palliative care (of which there are many similarities) by Robinson et al (2009) showed consistent findings about the emotionally challenging nature of rural palliative care but an acknowledgement by nurses of its importance. The geographical isolation, blurred social and work boundaries, infrequent palliative care cases, and difficult psycho-social aspects of care were also noted consistently. The review found that despite these challenges, there was some evidence that willingness to provide palliative care is influenced by palliative care knowledge. Penz et al (2007) found that if perceived barriers to education such as isolation, time and financial constraints were also addressed, there is increased job satisfaction and participation in continuing education for rural and remote nurses. There is a lack of knowledge about palliative care for Aboriginal people in rural and remote areas, yet once education was provided to health professionals there was an understanding of the specific care needs of these patients and families (McGrath 2010). Another rural Canadian study by Goodridge and Duggleby (2010) found that nurses considered that inadequate knowledge and skills, lack of interest of some health providers, inadequate physical resources and staff shortages influenced the provision of effective and safe palliative care.

When this study commenced, there was no research on rural and remote community PHC nurses providing Palliative Care under the NSW Role Delineation Framework model (NSW Health 2006a). Rosenberg and Canning (2003) investigated professional development and support needs of nurses providing palliative care in rural and remote Queensland prior to the release of the of Palliative Care Australia population based approach model (Palliative Care Australia 2005).

Research Questions:

1. Describe the generalist PHC nursing workforce providing palliative care services within the former Far West Area Health Service (FWAHS) of NSW.
2. What is the experience like for these PHC nurses who provide palliative care in rural and remote communities?
3. How well equipped do these nurses feel to provide palliative care?
4. How do these nurses feel about providing palliative care as a part of their generalist PHC role?
5. What are the clinical, educational and supportive needs of these PHC to facilitate their role in Palliative Care as outlined by the Role Delineation Framework?

About the Principal Researcher

MC is a novice researcher who has had 25 years experience as a specialist palliative care nurse, with twenty three of those years spent working in rural and remote NSW. A pre-existing professional relationship exists between MC and the participants, with MC viewed both as a peer but also a senior person in the health organisation. As a Palliative Care Clinical Nurse Consultant, MC provides clinical advice, resources, information, education and service development initiatives to the area.

Method

This mixed method study involving questionnaires and in-depth interviews was conducted from August 2007 to December 2009.

Data collection

Eligible nurses were invited by letter to participate in the research project between August 2007 and December 2009. Invitation packs (letter, participant information sheet, consent form and anonymous questionnaire) were either distributed by Health Service Managers or mailed to all community PHC nurses who provide palliative care. Questionnaires were coded so it was possible to determine response sites. Participants completed a questionnaire outlining demographic information, and then described their experiences with palliative care service provision, years of experience, training, usual number of palliative care patients seen each year, educational needs, access and barriers to education. The questionnaire which consisted of Likert scales and closed and open ended questions, was pilot tested on seven rural PHC nurses from other regions.

Ten participants from eight of the 14 participating communities were invited to take part in a telephone interview to further explore their experiences of, and attitudes to providing palliative care. Interview participants were selected to maximise the degree of diversity among interviewees regarding geographical isolation, nursing role, time worked in rural and remote communities, and attitudes about palliative care (Table 2). Interviews were in-depth and semi-structured, lasting approximately 60 minutes. Interview participants were advised both in writing and at time of interview that additional support or counselling would be provided if required. Both the survey (Appendix 5) and interview questions (Appendix 6) were based on the research aims and research questions

Responses

From the estimated 40 eligible staff at the time of the study, 34 questionnaires were returned after reminders which included responses from all 14 rural and remote health services included in the study, giving an eventual response rate of 85%. Thirty Registered Nurses and four Enrolled Nurses participated, and all but one survey participant was female (Table 1). Demographic information from this cohort is consistent with a National Survey of Registered Nurses in very remote Australia (Lenthal et al 2011) where most were experienced, female nurses. The study did not ask for information on Aboriginality to protect confidentiality. Twenty-eight nurses consented to an interview and 10 were selected based on maximal sampling variation (Table 2).

Statistical analysis

Quantitative data analysis was undertaken with Excel 2000 (Microsoft). Descriptive statistics were calculated to summarise demographics, experience, number of roles, number of palliative care patients, education, access to specialist support, experience in palliative care, skills, and whether participants had cared for family or friends.

Qualitative analysis

Transcribed interviews were analysed for themes using inductive thematic analysis as described by Braun and Clarke (2006). Interviewing ceased when thematic saturation occurred. Three interviews were read independently at least twice by two researchers (MC and FB) who noted major themes. These were then discussed and combined into a number

of common themes. Further interviews were read independently (MC and FB) at least twice and themes noted. Any differences in classification of themes were resolved by discussion.

The results of quantitative and qualitative analysis are presented together in the results section of this report in order to best understand the meaning and significance of findings.

Ethical Review

The project was approved by the Greater Western Area Health Service Human Research Ethics Committee.

Results

Most questionnaire respondents had considerable experience in both nursing and rural and remote settings. Almost 90% were registered nurses, three-quarters had spent more than 20 years in the role and 40% had worked in rural and remote settings for more than 20 years. This is surprising given recent research on rural recruitment and retention benchmarks which suggest much shorter retention times (Chisholm *et al.* 2011). Two of the 34 nurses had a qualification in palliative care (Graduate Certificate), and 88% juggled six or more PHC work roles (Table 1). All but one of the respondents was required to provide palliative care as part of their role.

Table 1. Questionnaire Participant demographics: Rural and remote primary health care nurses in the former Far West Area Health Service of New South Wales

Characteristic	Number (n=34)*
Female	33 (97%)
Male	1 (3%)
Role	
Registered Nurse	30 (88%)
Enrolled Nurse	4 (12%)
Years in Role	
5 or less	1 (3%)
6-20	8 (24%)
>20	25 (74%)
Years in Rural and Remote	
5 or less	12 (36%)
6-20	8 (24%)
>20	14 (41%)
Number of PHC activities**	
1-5	4 (12%)
6-10	14 (42%)
11-15	8 (42%)
>15	7 (3%)

Qualifications in Palliative Care	
Yes	2 (6%)
No	32 (94%)
Required to Provide Palliative Care	
Yes	33 (97%)
No	1 (3%)
No. Palliative Care patients seen in past 12 months	
5 or less	23 (68%)
6-10	4 (12%)
11 or more	7 (21%)
Hours per week providing Palliative Care	
5 or less	16 (50%)
6-10	6 (19%)
11 or more	9 (28%)
Unsure	1 (3%)

* Respondents who did not answer were excluded when calculating percentage

** Respondents were asked to tick all that applied from a list of PHC activities.

Table 2. Interview Participant demographics: Rural and remote primary health care nurses in the former Far West Area Health Service of New South Wales

Characteristic	Number (n=10)
Female	10
Role	
Registered Nurse	9
Enrolled Nurse	1
Years in Rural and Remote	
5 or less	2
6-19	5
>19	3
Community ARIA Rating	
Very Remote	1
Remote	5
Moderately Accessible	4
Preference for Palliative Care	
Likes to do Palliative Care work	6
Would prefer not to do Palliative Care work	4

The major themes emerging from the interviews were the nature of their palliative care role, attitudes to palliative care, the emotional impact of providing palliative care, perceptions of competence, and support systems when working with palliative care patients (Appendix 1).

Palliative care role

The intermittent nature of palliative care cases concerned many nurses, with most having seen between one and five palliative care patients in the previous twelve months and spending five hours or less a week providing palliative care (Table 1), with increasingly more time spent with patients in the terminal phase.

“When a palliative care patient comes along and I haven’t had one for six months, things worry me. I’ve forgotten how to use a syringe driver or I’ve forgotten this or that. That’s the thing that really frightens me because I want to do the best for that patient.” (Interview 9)

Most staff agreed the definition of the PHC role under the Role Delineation Framework accurately reflected their work. However, at interview, some nurses thought this definition was more appropriate to a specialist rather than a generalist palliative care role.

“Sounds like a big lot of stuff [laughing]. It sounds like heaps but when you think about it that’s what you do every day anyway while you’re there. You do all those things without even thinking about them.” (Interview 4)

“Sounds like a job description of a palliative care nurse. Doesn’t sound like my job description.” (Interview 1)

“These things need to be covered by a specialist.” (Interview 5)

The range of palliative care duties performed included pain and symptom management, liaison with GPs, medication management, infusions, bowel and bladder care, delivery of equipment, personal care, dressings, wound and pressure care, stomal therapy, tube feeding, surveillance visits, social and welfare work, bereavement support and counselling.

All nurses juggled a variety of ‘professional hats’ within their PHC role, with 45% of the questionnaire respondents having between 11 or more different roles (Table 1). Whilst some nurses said during interview that they enjoyed this variety, there was community pressure to know a lot about everything.

“You’re a jack of all trades but master of none.” (Interview 6)

“You are expected to know everything because that’s what the general community expect.” (Interview 9)

The nurses also acknowledged that when a palliative care patient is dying, it puts additional pressure on their time and energy, and that the other work roles suffer unless a colleague is prepared to take on some of the work.

Attitudes towards Palliative Care role

There was a variety of attitudes towards palliative care (Appendix 1). Slightly more than half of the questionnaire respondents liked working with palliative care patients, and many actively sought out referrals made to their PHC service. Others were either neutral or did not like it however, most nurses acknowledged at interview that it is part of the role in small communities.

"I certainly choose to work with palliative care patients. I know of other Primary Health Care nurses who prefer not to." (Interview 10)

"No I don't particularly enjoy it. I often think I am not able to say the right thing or pick up on a matter that the family are seeking emotionally." (Interview 5)

"If you want to work here, then you have to be prepared to deal with palliative care patients." (Interview 2)

Nurses who enjoyed palliative care reported during interview a strong sense of satisfaction and found the role personally rewarding which helped sustain them in their role. Those who did not like palliative care spoke of a clinical job well done, which did not overcome their dislike.

"...satisfaction of seeing someone comfortable, home in their bed, in their own surroundings with their loved ones around them." (Interview 4)

"I don't like doing palliative care, but if someone is comfortable and they have a pleasant death with all their family around them ...that is very rewarding. But it doesn't make me want to do it." (Interview 5)

Providing palliative care was much more than just 'doing a job'. Even those who preferred not to provide palliative care went out of their way to allow patients to die at home. However, many of these services were provided informally and out of 'good-will', with lack of formal after-hours service models in the short, terminal phase of care a source of frustration for some nurses. One nurse who would prefer not to do palliative care nursing said:

"I put myself out so this can happen because I feel it's really important to die with dignity with your family around that love you. Just something you do, isn't it? I... ended up sleeping in a sleeping bag in the patient's home for a couple of nights until we could get some care in." (Interview 6)

Nurses who enjoyed providing palliative care valued the rapport and sense of connection with patients and families, whereas nurses who did not like palliative care focussed more on the clinical aspects.

"What I love is going in there and building that rapport with the family. You feel quite included in a really special sort of way. It's nice to feel you are making a difference." (Interview 10)

"Well, personally I probably back off ..." "I still treat them probably like a 'case', like any patient. The level I see in palliative care is like being part of a family and access to your personal life and stuff ...which I don't do." (Interview 1)

Emotional impact of Palliative Care

The death of palliative care patients had strong emotional impact on nurses irrespective of whether they found providing the care rewarding. The impact was magnified if they were unable to alleviate the patient's suffering.

“It is enjoyable to see the person being comfortable as they approach the end, but it is very emotional for me as well which I don’t really enjoy. If I’m seeing them in a lot of pain and all that I’m trying isn’t working, I get upset that it’s not working and feel that it’s my fault. I know its not but it just feels that way.” (Interview 8)

“Worst thing I have ever been through. It was horrific. Nothing worked. If I knew I was going to have something like that again, I would take the day off sick. I couldn’t ever do it again.” (Interview 5)

From the questionnaire, two thirds (22 out of 34) of the nurses have provided palliative care for a friend or family member. Nine found this difficult and very emotional, 12 said it did not present difficulties and one was unsure. Most of the nurses interviewed said that knowing the person made it easier to care for them, as they already know them and their family, and often their history. There was an overwhelming acceptance that in small communities you will nurse people you know well.

Self reported competence for palliative care

Again, there was a mix of how professionally and personally equipped the nurses felt to work with palliative care patients (Table 3).

Table 3: Proportion of questionnaire respondents who felt equipped to deal with various aspects of palliative care

Issue	Number (N = 34)
Feel professionally equipped to work with PC patients	15 (44%)
Feel personally equipped to work with PC patients	23 (67%)
Feel they have the skills to assist with spiritual needs	19 (55%)
Discussing spirituality	
avoid discussing	3 (9%)
haven't thought about it	4 (11%)
Encourage patients to explore feelings	22 (64%)
Feel comfortable offering bereavement support / risk assessment (informal and intuitive)	20 (58%)
Felt they had effective communication skills in PC	20 (58%)
Believed their knowledge about pain management facilitated effective pain management - access resources / advice when beyond skill base	18 (52%)

Although most nurses felt reasonably equipped in a variety of aspects of providing palliative care, some felt better equipped to provide physical care than spiritual care, and would refer to clergy or mental health services if they were available. Others felt inadequate when dealing with the management of physical pain.

“Generally feel equipped with pain management ...Not as confident with emotional or spiritual support.” (Interview 3)

“I still feel very much out of my depth with complicated things. Pain relief plays on my mind the most ...whether I am getting it right ...I don’t feel my knowledge is adequate.” (Interview 5)

Nurses reported a strong need for education to better equip them to provide palliative care, though recent attendance at palliative care education and training were positive given the competing demands for training and the barriers to accessing education. Although almost all questionnaire respondents had attended some form of palliative care education in the last two years, almost nine out of 10 said they required additional education. Pain and symptom management, grief and loss, and palliative care for malignant and non-malignant conditions were key educational needs. Nine out of 10 nurses indicated there were significant barriers to education, with isolation, lack of backfill and workload constraints noted most frequently (Table 4).

Table 4. Questionnaire respondents: Education requirements, type of education accessed and barriers to further education.*

Characteristic	Number (n=34)
Has attended Palliative Care Education	32 (94%)
Time Last Accessed Education*	
< 1 month ago	6 (18%)
1-6 months ago	9 (27%)
7-12 months ago	5 (15%)
>12 months <2 years ago	5 (15%)
>2 years ago	8 (24%)
Types of Education (multiple answers)	
In-Service	27 (79%)
Self reading	25 (74%)
Videoconference	16 (47%)
1-2 Day Seminar	14 (41%)
On-line education /Internet	9 (26%)
Palliative Care Conference	8 (24%)
Post-Grad Studies	4 (12%)
Requires additional education?	29 (88%)
On what topics do you require education? (multiple)	
Pain Management	22 (65%)
Symptom Management	22 (65%)
Grief and Loss	19 (56%)
Pall Care and Non-Cancer	18 (53%)
Pall Care and Cancer	17 (50%)
Communication	13 (38%)
Considers there are barriers to accessing education	27 (87%)
Barriers to accessing education (multiple)	

Isolation	26 (76%)
No backfill available	19 (56%)
Workload constraints	19 (56%)
Budget constraints	15 (44%)
Not a priority	8 (24%)
Lack of Pall Care cases	7 (21%)
Catch up burden	7 (21%)
Home/family commitments	6 (18%)
No management support	4 (12%)
No education at workplace	3 (9%)
Lack of Transport	3 (9%)
No technology	2 (6%)
Don't know where to access	2 (6%)

* Respondents who did not answer were excluded when calculating percentage

These nurses were willing to use a number of approaches to address skills development and support needs including online and more traditional approaches, but training often implied long distance car travel. Five of the ten nurses interviewed had undertaken a Program of Experience in the Palliative Approach (PEPA) involving a 3-5 day supervised placement at a specialist palliative care service to increase their awareness about palliative care principles and practices, which all reported was beneficial. Some nurses indicated that longer placements such as this were better than travelling long distances for one-day education sessions.

“...it’s too far to get to a two day workshop from here so you’re probably better off doing a week in one hit...” (Interview 4)

Online learning and face to face teaching were considered the most feasible methods of accessing further education (Table 5). Whilst many nurses commented at interview that the education via videoconference that is offered in their area on a monthly basis was useful, they were often prevented from attending by workload pressures. An interesting observation from the interviews was that many of the nurses who did not like working with palliative care patients routinely chose not to attend palliative care education. These nurses prioritised education topics more closely aligned to their interests or to the perceived needs of their community e.g. emergency nursing, diabetes, women’s health.

“I’m into childbirth and emergency stuff and women’s health. Palliative care just comes along with the job here. No, I would do a placement in something else” (laughing) (Interview 6)

Table 5. Questionnaire respondents: Participant rating of feasibility of various education modes

Mode	Number answered	Rated 1 or 2 (most feasible)	Rated 6 or 7 (least feasible)
On-line learning	25	13 (52%)	5 (20%)
Face to face	28	14 (50%)	8 (29%)
Videoconference	25	11 (44%)	5 (20%)
Distance Education	29	11 (38%)	2 (7%)
Phone Tutorial	26	6 (23%)	11 (42%)
Travel to education	28	8 (18%)	7 (25%)
Attend conferences	27	4 (15%)	13 (48%)

Access to clinical advice through contact with specialist palliative care staff was considered important in providing good palliative care. From both the questionnaires and interviews, most nurses acknowledged that they knew where to access clinical advice when confronted by challenging management cases, thus highlighting the importance of clinical support networks that were known to staff and easily accessible. The questionnaire showed that all but two nurses accessed clinical advice from specialist palliative care nurses when needed. Of these nurses, most had their needs met in this way, while interview respondents indicated that access to clinical advice needed to be timely and relevant to the case at hand.

“Case review at the time as things come up, that’s how you learn and remember.”
(Interview 4)

“...I didn’t have the skills and I was liaising with the CNS on the phone on how to administer this, how to administer that...” (Interview 9)

Some of the smaller communities involved in the study had very high Aboriginal populations, but only a few nurses at interview mentioned palliative care for Aboriginal people. The main issues mentioned were awareness of culturally appropriate communication such as use of language and the importance of identifying a spokesperson for the patient when there was a cancer diagnosis, managing large amounts of visitors in the in-patient setting, and acknowledging that most Aboriginal patients want to be returned to ‘their country’ to die, but some might not wish to die in their home for spiritual reasons.

“It was a huge learning curve for me about how Indigenous people deal with cancer.”
(Interview 9)

Support Systems

Peer support from team members particularly managers, the ability to take time out, and access to clinical support and advice were dominant responses from the interview participants when identifying sources of support. Interestingly, no nurse could easily take ‘time-out’ from their work day when the emotional burden was high. Of those interviewed, particularly from the smaller and more remote communities, there was a community expectation that they would attend all funerals of patients. For some, this helped their sense of ‘closure’, but they also felt their absence would be noted if they did not attend.

Nurses were asked at interview what sustains them in their work with palliative care patients and families. Some identified serving the community as both a nurse and community member, and ensuring good quality care for people in remote areas.

“This is my community, my home. I want to be part of that. I would like to see people at the end of their life, whether through Palliative Care or general nursing, peaceful and comfortable. I want to be part of that as a nurse and as part of the community as well” (Interview 3)

“People out here are entitled to the same quality of care as what they are anywhere else in an urban area, and there’s only one nurse here so I try to do that”. (Interview 6)

Nurses who enjoyed palliative care found the sense of job satisfaction, privilege and rapport with patients and families aspects of their role that sustains them. A strong level of commitment to their patients is an important aspect that also sustains the nurses in their role, even for those nurses who don’t like working in palliative care.

“Well it’s something that I would prefer not to do but I do it. I don’t find it enjoyable at all. ...but I think it’s wonderful that people can die at home. It’s much better for the families and it’s better for them, so I don’t mind doing the extra work” (Interview 6)

Other nurses identified a range of personal coping mechanisms that they considered helpful in sustaining their work with palliative care patients such as taking regular leave, hobbies, and living out of the main town to protect private time, while one admitted jokingly to another;

“Probably the alcohol and the cigarettes.” (laughing) (Interview 4)

Discussion

This study found that these rural and remote community PHC nurses saw palliative care as an important if small part of their role. Participants ranged from those who actively sought out palliative care referrals to their facility to those who preferred not to provide palliative care. It showed a range of levels of competence and confidence in providing particular elements of palliative care.

This was a small study but the response rate of 85% was good and the combination of survey and interviews allowed a deeper understanding of the issues and their meaning in remote communities than has been possible in other studies (Rosenberg and Canning 2004). Much research on working in palliative care concerns GPs (Sach 1997), medical students (Dunne et al 2004), or specialist Palliative Care Nurses (Wilkes and White 2005) who have chosen this discipline as their career choice and received appropriate education, training and exposure to palliative care practice. Additionally, these specialist staff can access more formalised support including discipline-specific peer support and specialist medical advice.

We found no studies which examined rural and remote PHC nurses providing palliative care under the NSW Health Palliative Care Role Delineation Framework (NSW Health 2006a). A

study of nurses who provide palliative care in rural and remote Queensland (Rosenberg and Canning 2003) focused on professional development and support needs of the nurses. Whilst our study explored support needs of the nurses, it also explored in greater depth how they felt about palliative care, how equipped they feel to provide palliative care and what the experience is like for them. The findings of the professional development and support needs of both studies were congruent and identified similar barriers to palliative care provision with similar recommendations around context-specific education, using accessible modes of education delivery, clinical placements, and the need for peer support networks.

This study highlights important issues for rural health services that must equip and support rural and remote “generalist” PHC nurses to provide high quality palliative care which is essentially provided by specialist nurses elsewhere. Maintaining evidence based practice is a continuing challenge for PHC nurses as they provide a wide range of services besides palliative care. The range of skills required is challenging without reference to the difficulties in accessing education which are exacerbated by distance, shortages of staff to provide backfill and poor access to specialist services and resources.

Rural health services need to provide a combination of educational opportunities including online, face to face and extended training opportunities such as those offered by the Program of Experience in the Palliative Approach (PEPA). Topics such as pain and symptom management, spiritual and emotional care, and non-malignant palliative care are priorities for further education. This training is however, unlikely to be sufficient alone and the availability of responsive and timely clinical advice is necessary from Clinical Nurse Consultants, Clinical Nurse Specialists, and from palliative care medical specialists at regional or metropolitan centres through the formalisation of clinical networks that follow patient treatment pathways. The increasing use of telemedicine in rural and remote areas will also provide nurses with case-relevant clinical advice and an opportunity for the patient to receive a specialist medical palliative care review, albeit ‘a virtual consultation’. These models are currently being trialled in various parts of the study area. The availability of clinical advice “in real time” either by phone, telemedicine or joint face to face patient consultation is vitally important.

The nurses made use of clinical advice from specialist palliative care providers and educational opportunities, though methods to target or encourage those nurses who would prefer not to provide palliative care and choose not to attend relevant education should be considered. The review findings by Robinson et al (2009) consider palliative care knowledge an influential factor in the willingness to provide palliative care, yet this study found some nurses who preferred not to provide palliative care did not attend education opportunities, posing a challenge for health services in maintaining a skilled and competent workforce. Whilst some nurses acknowledged that there were certain clinical aspects of care for which they felt less equipped (e.g. pain management or spiritual care) along with varying preferences for palliative care, their commitment to provide the best level of care possible for their patients was very strong.

An area for further research within the general PHC workforce (not specifically rural and remote) is how nurse preferences for palliative care relate to competency and the potential impact of these preferences on patient care. In remote communities with few alternative carers, it is likely to have implications for both nurse and patient. While questions of clinical competence and performance may be amenable to educational and training solutions, the questions of social and emotional impacts may need more imaginative approaches to supervision and support. Particularly important challenges include: how to support nurses who have had a particularly bad experience in providing palliative care, how to help them

deal with issues of grief and loss recognising that some may be providing care for family members or close friends, and how to provide appropriate relief to prevent burnout whilst simultaneously working within flexible models of care that facilitate short-term after hours support for patients who are dying. This group of nurses had long years of rural health experience, which raises questions about whether the area health services will be able to retain such nurses with high levels of experience.

Whilst the study did not ask specifically, only a few nurses commented about the provision of palliative care to Indigenous people, which may have implications since these communities have high Indigenous populations. Whilst many of the nurses may be familiar with local cultural norms, ongoing training and education are required to help address the specific needs of Indigenous patients in the palliative care setting. Aboriginal Health Worker Palliative Care Forums run by PEPA and provided in rural and remote sites can supplement in-house cultural awareness training. Whilst all sites involved in the study have access to Aboriginal Health Workers to assist with effective and respectful communication and grief support, psycho-social, spiritual and practical issues as recommended by McGrath (2010), it is not known if their involvement is routine when caring for an Indigenous palliative care patient and their family. Further research may be required on PHC and Indigenous palliative care in this area.

In order for rural health services and peak Palliative Care agencies to facilitate the level of service required, further research into the professional and personal impact and associated needs of rural and remote PHC nurses should be undertaken. If our study proves typical, development and enhancement of clinical, education and support systems for this cohort will be required for palliative care and also for other elements of their varied and important role.

Strengths and Limitations

The population for this study was small but the response rate (85%) after reminders was good. One potential limitation is that the interviewer (MC) is very familiar with rural and remote palliative care service provision, and an outsider may have elicited different responses. This familiarity also serves as a strength due to an understanding of the nurse's role within the context of the study. Whilst a pre-existing professional relationship exists between the lead researcher and the participants, MC believes that the nurses were honest and frank in their responses.

Conclusions and Recommendations

Rural and remote community PHC nurses working in Far West NSW are experienced in rural and remote nursing and juggle multiple roles as part of their generalist work. They regard palliative care as an important part of their role, although infrequent palliative care cases affect feelings of clinical competence. They report a variety of attitudes and preferences to palliative care. Some nurses have a strong preference for palliative care nursing, while others only look after palliative care patients because it is a requirement of their PHC role.

Most nurses considered the PHC role description outlined in the Role Delineation Framework as a reasonable reflection of the work they do, yet their feelings of being equipped to provide palliative care is demonstrated in different levels of competence and confidence for particular elements of care. They face challenges associated with geographical and professional isolation, lack of resources and barriers to education and support, while the emotional nature of working with people from small communities who are dying can be very difficult.

Local health services need to ensure that rural and remote “generalist” PHC nurses feel clinically and personally equipped to provide the level of palliative care required under the Role Delineation Framework. Maintaining evidence based practice for nurses who provide a wide range of services besides palliative care is challenging. Addressing the clinical, education and supportive needs requires a multi-pronged approach.

Clinical Nurse Specialists and Clinical Nurse Consultants need to ensure that the clinical support they provide is timely and case relevant. Clinical support for complex patients through joint consultations with the PHC nurse where possible is important, although geographical isolation can limit face to face support. Joint consultations can be used as a clinical mentoring and education tool, in addition to providing the specialist palliative care nurse with base-line knowledge of the patient for future telephone advice if required. Where specialist palliative care nurses work part time, access to clinical support should not be hindered. Formalised pathways and clinical networks need to be available for the PHC nurse so they can contact a specialist palliative care nurse from a neighbouring health service, or access a palliative care medical specialist at a regional or metropolitan centre, either directly or via the patient’s GP.

All PHC nurses should have hard-copy access to the most current version of Palliative Care Therapeutic Guidelines that can provide them with immediate reference to assessment guidelines and evidence-based interventions. This resource will inform management options when liaising with GPs or other PHC professionals who may also have limited palliative care experience. Local promotion of on-line resources such as CareSearch, an Australian-based ‘Palliative Care Knowledge Network’ can also provide current, best practice information for staff and consumers.

Creative options such as accessing education, specialist advice, consultations and support through the increased use of communications technology in a clinically timely fashion should be explored further. All but one site involved in the study has access to videoconference facilities, but apart from monthly palliative care education sessions, this medium is underutilised. Recent Medicare reimbursement for specialist telehealth consultations will enable greater availability of support for both patient and PHC nurse via telemedicine .

To ensure PHC nurses feel equipped to provide palliative care and to meet their expressed need for more education, Health Service Managers in consultation with Clinical Nurse Consultants need to ensure that nurses attend some form of annual palliative care education that includes at a minimum, basic principles and practices of palliative care and annual competencies for syringe driver management. Regardless of individual preference, there should be an expectation that nurses will attend annual education updates. Additional case-specific education should be provided in a timely manner. Local management support is required by providing time for staff to attend monthly palliative care education sessions via videoconference.

Extended, supervised clinical placements for PHC nurses at specialist palliative care services, such as those organised by PEPA should be encouraged. The placements are fully funded, including backfill costs for the participant's workplace. Selection of placement sites can be strategic, as selecting the specialist palliative care service networked to a rural or remote community helps connect PHC and specialist services within health districts.

Much of the work of PHC nurses provided for patients in the terminal phase is done out of good-will and often outside of formal processes, while competing work demands make it difficult to get everything done well. Implementation of flexible models of care (in work hours and after-hours) during the terminal phase would enable a patient to die at home, reduce some of the nurse's frustration at not being able to provide formalised services after hours, and may improve job satisfaction.

Management support for processes that facilitate 'time-out' when required, debriefing (formal and informal), acknowledgement of the difficulties inherent in caring for friends and family, and clinical supervision may improve the nurse's feelings of competence, confidence and may help sustain them in an area of work that at times can be clinically and emotionally overwhelming.

A high level of commitment to their patients and to their community was a strong motivator for these nurses when providing palliative care under difficult conditions. How local health services equip and support them is critical in ensuring the sustainability of palliative care service provision in rural and remote communities.

Conflicts of Interest

MC is a CNC Palliative Care.

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Appendix 1: Coding Tree: interviews with rural and remote primary health care nurses in the former Far West Area Health Service of New South Wales

Themes	Number of respondents
1 Role	
1.1 Intermittent nature of role and the implications	5
1.2 Appropriateness of definition of PC role	10
1.3 Juggling multiple roles	10
2 Attitudes	
2.1 Whether or not likes and chooses Palliative Care	10
2.2 Satisfaction	3
2.2a Rapport/connection/personal satisfaction	10
2.2b Clinical satisfaction	5
2.3 More than just a job	7
3 Emotional impact	
3.1 Impact of suffering and unrelieved suffering	9
3.2 Caring for friends and family	10
3.3 No time out	4
3.4 Community expectations	6
4 Support	
4.1 Team/workplace support	8
4.2 Access to clinical advice	9
5 Self reported competence	
5.1 Feeling equipped or not	10
5.2 Education/barriers to education	9
5.3 Indigenous client needs	2



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GREATER WESTERN
AREA HEALTH SERVICE
NSW HEALTH

XXXX Primary Health Care Centre
PO BOX XX
XXXX

/ /

Dear Community Primary Health Care Nurse

You are invited to participate in a research project being led by Melissa Cumming, Area CNC Cancer and Palliative Care Services Greater Western Area Health Service (GWAHS) as part of a research Development Placement at the Broken Hill Centre for remote Health Research, Broken Hill Department of Rural Health, University of Sydney.

This study aims to investigate the professional and personal impact on Community Primary Health Care Nurses working in the rural and remote communities within the former Far West Area Health service (now part of Greater Western AHS) who are required to provide palliative care services as a component of their Primary Health Care role. The study will also investigate how equipped Community Primary Health Care Nurses feel to provide palliative care.

Participation in this study is completely voluntary. If you decide to participate, you can withdraw your participation at any time.

I have enclosed the following documents for your consideration:

- 1) Participant Information Sheet: outlines the research plan and your involvement should you agree to participate
- 2) Consent Form: enables you to consent to varying components of the study
- 3) Questionnaire
- 4) Reply Paid Envelope

If you agree to participate in the study, please complete the consent form and questionnaire and return in the reply paid envelope within 2 weeks or receipt of this letter. If I have not received the questionnaire after 2 weeks, I will give a follow up phone call to check that questionnaires have been received.

It is very important that all questions are answered honestly, and provide a true account of your role, particularly related to how competent you feel in providing certain aspects of palliative care. As the study is looking at nurses as a group, there is no reflection on individual nurses or their abilities. Any comments you make will be confidential, and all individuals will be de-identified.

If you have any concerns or questions, please do not hesitate to contact me on 08 80801452 or mcumming@gwahs.health.nsw.gov.au

Many thanks for your consideration of this invitation.

Yours sincerely

Melissa Cumming
Area CNC Cancer and Palliative Care Services
Greater Western Area Health Service
Research development Placement, Broken Hill UDRH

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GREATER WESTERN
AREA HEALTH SERVICE
NSW HEALTH

Title: Primary Health Nurses and their Role in Palliative Care

PARTICIPANT INFORMATION SHEET

1) What is the study about?

You are invited to take part in a research study to investigate the personal and professional impact on Community Primary Health Care Nurses working in rural and remoter communities, who are required to provide palliative care services as a component of their generalist role.

NSW Health's release of the Role Delineation Framework for Palliative Care is based on Palliative Care Australia's "A Guide to Palliative Care Service Development: a Population Based Approach" (2005). This framework considers Primary Care providers to be pivotal to any palliative care service provision. The study aims to look at how you feel about your role in caring for people with a life-limiting illness in rural and remote settings, how equipped you feel to provide this care, and what your professional, clinical, education and support needs are in order to facilitate this level of care.

2) Who is carrying out the study?

The study is being carried out by Melissa Cumming, Area Clinical Nurse Consultant Palliative Care and Cancer Services, Greater Western Area health Service as a component of her Research development Placement, Broken Hill Centre for Remote Health Research, University Department of Rural health, University of Sydney.

3) What does the study involve?

If you agree to participate in the study:

- You will be asked to complete a questionnaire as part of the study
- You will also be invited to participate in a on-on-one interview, which will possibly be conducted by phone. If you complete the questionnaire, you are not obliged to progress to an interview if you choose not to.

4) How much time will it take?

- If you answer all the questions, the questionnaire will take about 30-40 minutes
- 45-60 minutes will be allocated for the interview. The interview will be conducted in work hours, and at a place and time that is most convenient for you.

5) Can I withdraw from the study?

Participating in this study is completely voluntary. You are not under any obligation to consent and your decision whether or not to participate will not affect your future relations with Greater Western Area Health Service or University of Sydney.

If you decide to participate, you can withdraw your consent and discontinue participation at any time. The study is looking at nurses as a group and not individuals. Any information you offer either in the questionnaire or at interview will have no ramifications in terms of your employment or relationships with GWAHS staff.

6) Will anyone else know the results?

Only the researchers involved in the study will have access to information, and all information will be de-identified. If you request, you will be provided with a transcript of your interview for verification and a summary of the report. You can also request a copy of the final report. A report of the study will be presented to GWAHS and peak palliative care agencies with recommendations based on the outcomes of the study. A report of the study will be submitted for publication or presentation at conferences, but individual participants will not be identifiable in such a report or presentation. Copies of the final report can be obtained by contacting Melissa Cumming on 08 80801452 or mcumming@gwahs.health.nsw.gov.au

7) Will the study benefit me?

One of the desired outcomes of the study is to have greater awareness of the needs of Community Primary Health Care Nurses providing palliative care services in rural and remote communities, with potential for recommendations about how to assist you in your role.

8) Can I tell other people about the study?

Yes, you can tell others about the study.

9) What if I require further information?

If you would like to know more at any stage, please feel free to contact Melissa Cumming on 08 80801452 or mcumming@gwahs.health.nsw.gov.au

The ethical aspects of this project have been approved by the Human Research Ethics Committee (HREC) of the Greater Western Area Health Service. If you have any concerns or complaints please contact: The Executive Officer, PO BOX 143 Bathurst NSW 2795 or telephone 02 63395601

Thank you for considering this invitation. This information sheet is for you to keep.



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GREATER WESTERN
AREA HEALTH SERVICE
NSW HEALTH

Research Participant Consent Form

I,, give consent to my participation in the research project

which aims to investigate the professional and personal impact on Primary Health Care Nurses in rural and remote communities, who are required to provide palliative care services as a component of their generalist role.

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have read the Participant Information Sheet and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s
3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher/s now or in the future, and without having to give a reason.
4. I understand my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.
5. I understand that any information I offer in the questionnaire or at interview will have no ramifications for me or my relationships within GWAHS.
6. I understand that if I become distressed during an interview, I will be supported by the interviewer and offered referral to a counsellor or my GP.
7. I understand that a typed summary of my interview will be available for comment, and that I will be provided with a copy of the Executive Summary of the research project. I understand that I can request a copy of the final report of the study findings.
8. I understand the findings of this research will be offered for publishing / presentation, but that all personal information will be de-identified.

I consent to:

- Completing the attached questionnaire YES / NO
- Participation in the individual interview YES / NO
- The audio recording of my interview by the researcher/s YES / NO
- A follow-up telephone call to check or to invite me to a second interview if required YES / NO

Signed:

Name:

Date:

Postal Address: (w)

Phone: (w)

The ethical aspects of this project have been approved by the Human Research Ethics Committee (HREC) of the Greater Western Area Health Service.
If you have any concerns or complaints please contact:
The Executive Officer, PO Box 143 Bathurst NSW 2795 or telephone (02) 63395601



THE UNIVERSITY OF
SYDNEY



GREATER WESTERN
AREA HEALTH SERVICE
NSW HEALTH

Research Questionnaire

'Primary Health Care Nurses and their Role in Palliative Care'

*Thank you for your time in completing this questionnaire.
All details are de-identified and confidential.
Please return in the pre-paid envelope within 2 weeks.*

SECTION A: Information about yourself and your role

Please Circle or Tick the Appropriate Response

Q 1. Gender: M / F

Q2. Current Role Classification: RN EN AIN

Other _____

Q3. Years of Nursing Experience Post-Training:

< 2 yrs 2-5 yrs 6-10 yrs 11- 20 yrs >20 yrs

Q4. Time Spent Working in Rural and Remote Communities:

< 2 yrs 2-5 yrs 6-10 yrs 11- 20 yrs >20 yrs

Q5. Within your role as a Primary Health Care (PHC) Nurse, what type of nursing services are you required to provide? (tick all that apply)

Aged Care	<input type="checkbox"/>	Child & Family	<input type="checkbox"/>	Wound care	<input type="checkbox"/>
Palliative Care	<input type="checkbox"/>	Immunisation	<input type="checkbox"/>	ACAT	<input type="checkbox"/>
Diabetes	<input type="checkbox"/>	Women's Health	<input type="checkbox"/>	Health Promotion	<input type="checkbox"/>
Health Checks	<input type="checkbox"/>	School Screening	<input type="checkbox"/>	School Education	<input type="checkbox"/>
Asthma Education	<input type="checkbox"/>	Post-Acute Care	<input type="checkbox"/>	Community Development	<input type="checkbox"/>
Sexual Health	<input type="checkbox"/>	Emergency Care	<input type="checkbox"/>		

Other: _____

Q6. How many palliative care patients do you estimate that you have provided care for during the past 12 months?

Q7. Reflecting on your last one or two palliative care patients, or on your current case load if you have one, how many hours per week do you estimate that you would have spent providing palliative care?

Q8. Do you provide palliative care after hours? YES / NO

SECTION B: Education

Q9. a) Do you have any specific palliative care qualifications / s? YES / NO

b) If YES, name of qualification:

Q10. Have you previously attended / accessed any of the following palliative care educational opportunities? (tick all that apply)

Short in-service at workplace	<input type="checkbox"/>	1-2 day palliative care education day	<input type="checkbox"/>
Videoconference education	<input type="checkbox"/>	Palliative care conference	<input type="checkbox"/>
Post-Graduate course	<input type="checkbox"/>	Self-initiated reading	<input type="checkbox"/>
Internet	<input type="checkbox"/>	Other _____	

Q11. How long ago was your most recent palliative care educational opportunity? (tick one)

< 1 month	<input type="checkbox"/>	1-6 months	<input type="checkbox"/>	7-12 months	<input type="checkbox"/>
> 12 months but < 2 years	<input type="checkbox"/>	> 2 years	<input type="checkbox"/>		

Q12. a) Do you need additional education in order to assist you in your care of palliative care patients?

YES / NO /Unsure

If YES go to b). If NO go to Q13.

b) On what palliative care topics do you need additional education?

Pain Management	<input type="checkbox"/>	Symptom Management	<input type="checkbox"/>
Grief and Loss	<input type="checkbox"/>	Communication	<input type="checkbox"/>
Palliative care & cancer	<input type="checkbox"/>	Palliative care for non-cancer	<input type="checkbox"/>

Other: _____

c) Are there barriers to you accessing this education? YES / NO / Unsure

d) If YES, what are the barriers (tick all that apply)

Geographical Isolation	<input type="checkbox"/>	Not supported by management	<input type="checkbox"/>
Lack of staff replacement	<input type="checkbox"/>	Lack of access to transport	<input type="checkbox"/>
Workplace budget constraints	<input type="checkbox"/>	Workload constraints	<input type="checkbox"/>
Lack of access to technology (computer / internet / videoconferencing)			<input type="checkbox"/>
Other education takes priority over palliative care			<input type="checkbox"/>
Infrequent palliative care cases don't warrant extensive education			<input type="checkbox"/>
Lack of education provided at workplace			<input type="checkbox"/>
Home commitments limit ability to travel			<input type="checkbox"/>
Burden of catch up / workload on return to workplace			<input type="checkbox"/>
Do not know where to access education			<input type="checkbox"/>

Other barriers: _____

e) Given the barriers you have identified, what would be the best way for you to access the education you require?

Rank in order of preference: 1 = most feasible 7= least feasible

Videoconference	_____
Face to face education	_____
Attend conference	_____
On-line learning	_____
Telephone tutorials	_____
Distance education	_____
Travel to in-service / workshops	_____

If you have any other suggested methods of accessing palliative care related education, please comment:

SECTION C: Clinical Support

Q13. Are you able to access advice about pain management? YES / NO / Unsure

Q14. Are you able to access advice about symptom management? YES / NO / Unsure

Q15. From what source/s are you able to access advice about pain or symptom management? (tick all that apply)

Specialist Palliative Care Nurse	<input type="checkbox"/>	GP	<input type="checkbox"/>
Palliative Care Medical Specialist	<input type="checkbox"/>	Nursing Colleagues	<input type="checkbox"/>

Other:

Q16. a) Does the support you are able to access from specialist palliative care providers meet your needs? YES / NO / Unsure

b) If NO, what could be improved?

SECTION D: Primary Health Care and Palliative Care

Q17. a) Reflecting on your last one or two palliative care patients, or on your current palliative care case load if you have one, were / are you combining a number of different nursing roles? YES / NO

b) If YES, did you / do you find this difficult? YES / NO / Unsure
If NO go to Part d)

c) If YES, what things make it difficult? (tick all that apply)

Lack of time needed to spend with palliative care patients.....	<input type="checkbox"/>
Lack of time needed to spend with family / carer of palliative care patient.....	<input type="checkbox"/>
Time demands from other nursing roles.....	<input type="checkbox"/>
Emotional demands of going from one role to another.....	<input type="checkbox"/>
Changing mindset between disciplines (eg pall care to post-acute care).....	<input type="checkbox"/>

- Difficulty planning workday when responding to crisis situations.....
- Lack of palliative care knowledge or skills.....
- Inability to take time out
- Lack of staff to share the patient load
- Time demands when travelling between sites to see patients.....

Other:

d) If you answered NO, what assist you in combining multiple roles with palliative care service provision?

Q18. In rural and remote communities, many PHC nurses feel that they cannot get away from the demands or expectations of palliative care patients and their families.

a) Does this statement describe how you feel at times? YES / NO / Unsure

Comments:

b) If YES, how did you manage this situation?

Q19. In rural and remote communities, PHC nurses are often providing care for palliative care patients who are friends or even family.

a) Has this situation ever arisen for you? YES / NO

b) Did this present difficulties for you? YES / NO

Comments:

c) Did the situation impact on you professionally? YES / NO / Unsure

d) If YES what was the impact for you professionally?

e) Did the situation impact on you personally? YES / NO / Unsure

f) If YES what was the impact personally?

Q20. a) Have you cared for a palliative care patient who has died in less than ideal circumstances (eg severe physical or emotional suffering)?

YES / NO / Unsure

b) Can you please briefly describe what the circumstances were?

c) Did this impact on you professionally? YES / NO / Unsure

d) If YES, what was the impact for you professionally?

e) Did it impact on you personally? YES / NO / Unsure

f) If YES, what was the impact for you personally?

g) If you answered YES to either part c) or e), do you think this experience has influenced (positively or negatively) how you feel about providing palliative care?

YES / NO / Unsure

h) Comments:

Q21. Do you feel supported in your workplace when you have a palliative care patient load?

YES / NO

Comments:

Q22. Do you have access to debriefing or other support mechanisms that you feel comfortable using?

YES / NO / Unsure

SECTION E: General Questions

Please circle the most appropriate response to the following statements:

Q23. "I like working with palliative care patients"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q24. "I choose to work with palliative care patients"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q25. I only work with palliative care patients because it is a requirement of my role as a PHC nurse"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q26. I feel well equipped professionally to provide care to palliative patients"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q27. "I feel well equipped personally to provide care to palliative patients"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q28. "I am confident that I have the skills to assist palliative care patients with their spiritual needs"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q29. "I avoid discussing topics such as spirituality with palliative care patients"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q30. "I haven't thought about the spiritual needs of palliative care patients"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q31. "I encourage palliative care patients to explore their feelings about what is happening"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q32. "I do not feel comfortable when palliative care patients display their emotional pain"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q33. I feel comfortable when palliative care patients want to discuss issues about death"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q34. "I feel comfortable when offering bereavement support to the family or carer of a palliative care patient"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q35. "My communication skills when dealing with palliative care patients and their families are effective"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q36. "My level of knowledge about pain management enables me to facilitate effective pain management"

1	2	3	4	5
Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree

Q37. Do you have any other comments regarding palliative care?

Q38. Do you have any other general comments?



'Primary Health Care Nurses and their Role in Palliative Care'

Interview Questions

Introductions. Thanks for agreeing to participate. Request permission to record interview. Explain participants rights to stop recording at any time, or erase all/part of the interview on request. Reassure de-identification of information. Reassure re confidential information and no ramifications of any comments made. Review consent statement. Any questions?

Q1. "Could you tell me what experience you have had working with palliative care patients and their families in the rural and remote setting?"

(Probe: Amount of time? Number of patients? Frequency of patients? Role in their care?)

Q2. "How do you feel about working with palliative care patients and their families?"

(Probe: Enjoy / not enjoy? What factors make it enjoyable or not? Would you do this Type of work if you didn't have to? What are the good aspects? What are the most difficult aspects?)

Q3. "You have just described to me how you feel about working with palliative care patients? Can you tell me how those feelings influence your approach to providing palliative care?"

(Probe: In what ways doe sit influence the service you provide? Choose to work in palliative care? Avoid Palliative Care? Do the best you can though it isn't your discipline of choice?)

Q4. "Palliative Care Australia states that the role of the primary care providers is to:

"provide supportive care, including pain and symptom management, social, spiritual and emotional support, education and bereavement risk assessment for patients, caregivers and family members".

"How do you feel about this statement?"

(Probe: Do you think this statement is a reasonable reflection of what you do / should be able to do?)

Q5. "As a Primary Health Care Nurse, how equipped do you feel professionally and personally to provide the components of care outlined in this role definition?"

(Probe: What level of knowledge /skills / confidence / competence do you have? What gaps?)

Q6. “Tell me how confident you feel in delivering these components of care?”

(Probe: professional / personal aspects. What would you make you feel more / less confident? Education? Workplace support? Clinical support?)

Q7. “Are there aspects of providing palliative care that you find challenging / rewarding?”

(Probe: what causes most difficulties? Pain management, communication, families, emotional needs, spiritual needs, combining multiple roles, resources)

Q8. “How do you feel about the adequacy of palliative care education you receive / can access when you consider the clinical and supportive role you have in palliative care?”

(Probe: do you/can you access palliative care education? Are there gaps in your clinical knowledge that impact on your ability to provide care? What is needed to improve or maintain your knowledge base?)

Q9. “Are there factors that you can tell me about that make palliative care service provision by Primary Health Care Nurses in rural and remote settings even more challenging?”

(Probe: What makes the work more difficult in smaller communities? Isolation? Lack of specialist services? Lack of support? Caring for people you know? Unable to escape? Combining multiple roles?)

Q10. “Many Primary Health Care Nurses are combining a number of roles, including palliative care. Can you tell me how it is for you wearing multiple hats?”

(Probe: Is it difficult/ not difficult? Challenges? Dilemmas? How does this affect you? Is there anything that makes it easier?)

Q11. “Have you worked with a palliative care patient where you felt that you made a positive difference for that patient or family? Can you tell me about it?”

(Probe: What were the general circumstances of the case? What was it that made it is appositve experience for you?)

Q12. “How did that experience impact on you?”

(Probe: How did it make you feel?? Impact on future practice? Attitude to palliative care? Sustains your work?)

Q13. a) “Have you had a palliative care case where you felt that the outcome for the patient or family was less than ideal? Can you please tell me about the circumstances of that case?”

(Probe: What was it that made it less than ideal?)

b) “How did that experience impact on you?”

(Probe: How did it make you feel? Impact on future practice? Attitude to palliative care? Avoidance / commitment to palliative care? What support did you receive or access?)

Q14. What are your thoughts on support mechanisms for PHC nurses who may become distressed by palliative care? Have you / would you use them? Why?

(Probe: What formal / informal support mechanisms are you able to access? How do you cope when you perceive that a patient has suffered more than they possibly should have? What coping mechanisms have you developed? Who can you go to? Are there formal / informal debriefing processes? Can you take time out? Is accessing support from colleagues easier or harder in small communities? What support systems need to be in place but aren't?)

Q15. “Have you ever become upset or distressed when caring for a palliative care patient, and if so, how did you deal with that?”

(Probe: What circumstances? What level of distress did you experience? Was it a sense of helplessness? Accept that it is ok to cry? What support is available? Who can you go to? Does it impact on how you feel about palliative care? What self-care strategies do you use? Would you use same strategy in future?)

Q16. “What qualities do you see in yourself or others working with palliative care patients that assists in dealing with distress?”

(Probe: coping skills? Support systems? Attitude? Emotional distance? Values/ beliefs)

Q17. “What professional or personal skills or strategies are you able to draw on when a palliative care patient or family displays emotional or spiritual pain?”

(Probe: How do you manage those situations? Communication skills? How does it make you feel? What other resources or people are you able to draw on to assist you if needed?)

Q18. “What sustains you in providing palliative care to people in rural and remote communities?”

(Probe: What keeps you hanging in there? Do the positives out-way the negatives?)

Q19. “Is there anything I have not asked you about what it is like for you working with palliative care patients that you would like to tell me?”

(Probe: Are there any significant issues for you that I have missed in either the questionnaire or this interview? What message is there about the work that you do in palliative care that is important for this study?)

**Q20. “Do you have anything else you would like to add to our interview?
Thanks and wind up.**