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## ORIGINAL RESEARCH

# Psychosocial care provision for terminally ill clients in rural Australian communities: the role of social work

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## ABSTRACT:

**Introduction:** Despite being one of the most avoided topics of all time, death is a guaranteed eventuality for us all. However, quality psychosocial care as death approaches is not a guarantee. Where people reside is likely to impact a person's accessibility to quality psychological, emotional, social, spiritual and cultural support. Structural forces such as funding and resourcing will also be a

contributing factor. Social workers have specific expertise in the psychosocial domain, yet enablers and inhibitors to social work referrals to support terminally ill clients in rural and remote communities have not been well explored. This study had two primary aims: to investigate the provision of psychosocial care for palliative clients in rural Australian communities and to identify

barriers and facilitators of social work referrals to address psychosocial concerns for palliative care clients.

**Methods:** Qualitative interviews were conducted with 38 rural participants across 24 rural and remote communities in the state of Queensland, Australia. The researcher travelled 7500 km to conduct these interviews over a 5-week period. The Rural, Remote, Metropolitan Areas classifications provided guidance on determining which communities would be considered regional, rural or remote communities. To explore the aims of the study, four participant groups were selected to participate in semi-structured qualitative interviews: group 1, social workers; group 2, community health nurses; group 3, community workers; and group 4, palliative clients/carers. For a comprehensive analysis, it was important to not only hear the views of those addressing psychosocial needs, but also include the voices of those receiving psychosocial care, resulting in all perspectives being captured. A thematic analysis was utilised, from which prominent, recurring themes were identified to form the basis for recommendations for future psychosocial care provision.

**Results:** Findings revealed that psychosocial needs for terminally ill clients were addressed in an ad-hoc, inconsistent manner across rural and remote Queensland. Eligibility and access for palliative care program funding impacted service delivery and what support could be provided. Furthermore, social workers were limited in what they could offer due to the vast geographical distances,

**Keywords:**

Australia, palliative care, psychosocial, social work, terminal illness.

which inhibited quality face-to-face interventions and the capacity to address urgent psychosocial concerns. This resulted in community nurses assuming the role that social workers would usually undertake in more urban settings. In communities where a generalist social worker was employed, referrals were often impacted by the perceptions of other professionals of social work competencies. Finally, the results highlighted that a disparity exists between the perspectives of palliative care clients and their caregivers and understanding of healthcare professionals of what were identified as important psychosocial concerns.

**Conclusions:** Palliative care funding in Queensland is insufficient to effectively address the existing demand. Resourcing for rural and remote palliative care in Queensland is inadequate to ensure holistic and quality approaches to psychosocial care in the end stages of life. Increased resourcing would result in better care, for longer time frames throughout a disease trajectory. Education and training for health practitioners to address skills and competencies in psychosocial care for terminally ill clients is a recommendation for professional development. Furthermore, there is a need for social work to develop national standards and competencies to enhance practitioner confidence to efficiently address psychosocial concerns for terminally ill clients. Whilst this study was undertaken in Queensland, Australia, the findings are echoed in other international rural communities.

## FULL ARTICLE:

### Introduction

The Australian Bureau of Statistics (ABS) reported that 160 909 Australians died in 2017<sup>1</sup>; with a significant percentage of these people dying following a period of chronic illness such as heart disease, dementia, cancer or respiratory illness<sup>2</sup>. Of interest, the 2016 ABS statistics report that approximately one-third of Australia's population reside outside major capital cities in areas classified as regional or remote<sup>3</sup>. Due to Australia's vast terrain this results in a ratio of three people per square kilometre of land, one of the lowest population densities in the world<sup>4</sup>. Furthermore, it is well documented that people living with cancer in regional and rural areas have poorer survival rates than those in capital cities, with the incidence of all cancers being higher in regional areas<sup>5</sup>. The likely need for psychosocial support for people and families during their journey with a life-limiting condition cannot be ignored or disregarded.

Amplified costs related to healthcare delivery, diminished numbers of rural health professionals and a growing trend towards centralisation of services have negatively impacted on access to quality healthcare services in rural and remote communities. This has limited the range of services available to the palliative client<sup>6</sup>. Challenges include distance, service accessibility and travel burden, minimal after-hours care, limited psychosocial and practical support, and economic factors that impact the provision of quality

palliative care services in rural and remote communities<sup>6,7</sup>. Studies relating to palliative care provisions in rural Canada and the USA echo similar issues as those reported in rural Australia<sup>8</sup>. Furthermore, in Australia, home deaths occur at half the rate of home deaths reported in Ireland, France, USA and New Zealand. This is despite the fact that 70% of people in Australia state they want to die at home<sup>8-10</sup>. However, in rural Australia, this choice is diminished due to a lack of services to assist and support home care and deaths at home.

In the last decade, healthcare reforms have impacted healthcare delivery throughout Australia. From 2008 onwards, specific health reform agreements have been formulated to guide funding allocation, spending and accountability. Within the reforms, palliative care falls under the 'sub-acute' category and is funded accordingly<sup>11,12</sup>. There is also palliative care program funding that can be accessed; however, in Queensland, a person would be required to be within the last 3 months of life to meet eligibility<sup>13</sup>. Furthermore, in Queensland particularly, a change in centralised health services and the implementation of local hospital and health boards has meant a sweeping shift of governance responsibility, resources and fiscal accountability to local and community healthcare services<sup>14</sup>.

Regarding the psychosocial domains, many definitions exist within the literature. Sheldon provides the most comprehensive

description, which includes psychological, emotional, social, spiritual, cultural and practical concerns<sup>15</sup>. In palliative care, each domain is carefully considered when a psychosocial assessment is undertaken to derive specific information that relates to wellbeing and inform care planning and meaningful interventions.

Social work perspectives, and the theoretical frameworks they draw upon, equip social workers to respond sensitively and effectively to the psychosocial needs of palliative clients<sup>16</sup>. A core component of the social work profession is its value based, person-in-environment perspective and the holistic approach to problem solving, including the individual, family and/or societal structures. A consistent bio-psychosocial-spiritual perspective combined with practical and clinical skills equip social workers to offer quality interventions<sup>17</sup>. Yet social work interventions with palliative care clients in rural and remote Australia remain scant despite social work's recognised capacity to provide effective interventions in the psychosocial sphere.

Evidence from the literature indicates that in many communities nurses respond to psychosocial needs despite this not being part of their original training<sup>18</sup>. Nurses in rural and remote settings often have limited access to other health professionals and therefore may assume expanded roles for which they have not been vocationally prepared, highlighting the psychosocial sphere as a shared and contested domain<sup>18,19</sup>.

The National Health and Medical Research Council provides comprehensive guidelines for psychosocial care for people with cancer, yet implementing the guidelines is problematic in the rural context<sup>20</sup>. Many rural generalist health workers encounter palliative clients only intermittently, meaning maintaining knowledge and skills is a challenge<sup>8</sup>. A lack of confidence as well as a gap in knowledge and skills have been identified as likely barriers to the delivery of psychosocial care in country contexts<sup>21</sup>. Social workers would not be excluded from this cohort as they too can respond prudently to referrals relating to psychosocial care for people near the end of life.

## **Methods**

A qualitative method was adopted where data were elicited through a series of semi-structured interviews. The study utilised Bronfenbrenner's ecological systems model as a conceptual theoretical framework to explore structural influences and how they interacted and ultimately impacted on the service delivery for both healthcare practitioners and the palliative care client within the micro-system<sup>22,23</sup>.

### ***Participants and sampling***

Participants were recruited using purposive sampling and then snowball sampling. Potential participants were identified by a local social worker and/or the community nursing service and provided with an information package. Target communities were those categorised as regional, rural or remote according to the Rural, Remote, Metropolitan Areas (RRMA) classification system, which categorises rural and remote areas of Australia in accordance with

population size and index of remoteness<sup>24</sup>. Participants consisted of either healthcare workers or palliative clients/family members. The healthcare workers were required to work in a rural community and have regular interactions with palliative clients and/or their families/carers. The palliative participants were required to be aged more than 18 years, reside in a rural or remote area and have the capacity to provide informed consent.

Social workers possess expert knowledge about navigating medical and social systems that are often barriers to palliative patients<sup>25</sup> and were therefore imperative to this study. Nurses from the local community nursing service were chosen as a second sample group because research highlights that nurses provide emotional support to families when access to other health professionals is limited<sup>18,19</sup>. Their perspectives based on regular face-to-face contact with families provided rich insights into the lived reality in rural communities.

After relevant sites and people were identified, snowball sampling assisted in locating a third participant group, identified as 'community workers'. This group was made up of individuals who were identified throughout the data collection phase that were not state health social workers or community nurses but were primarily addressing the psychosocial needs of palliative clients living in their area (eg home and community care workers).

The final group were palliative clients themselves and their spouses. These participants were identified by either a community nurse or community worker, who provided the information pack and consent forms. Three of these participants were living with late-stage cancer and were deemed to be within the last 3 months of life. Two of the interviewees were accompanied by their spouse, who also consented to be interviewed. Capturing the voices of the rural palliative client and their carer provided a critical dimension to the study not often attained in other research on rural palliative care.

The total participant group consisted of 38 individuals:

- state health social workers working in rural communities (mostly in small hospitals or state government community health centres) – male ( $n=1$ ) and female ( $n=10$ )
- community nurses – female ( $n=10$ )
- community workers – female ( $n=12$ )
- palliative clients/spouse – male ( $n=3$ ) and female ( $n=2$ ).

### ***Research questions***

The two aims of this research were to investigate psychosocial care provision for palliative clients in rural communities and to identify barriers and facilitators of social work referrals to address psychosocial concerns for palliative care clients. Four research questions were explored:

- How is psychosocial care provision being undertaken for palliative clients living in rural and remote areas of Queensland?
- How do contextual factors impact on the provision of psychosocial care?
- What are the perceived barriers and enablers to social work referrals?
- What have been the experiences for rural and remote palliative clients and their carers of psychosocial care?

### **Data collection and analysis**

Data were collected over a 5-week period via a rural research expedition to conduct the interviews in a successive time frame. A total of 24 towns were visited with 7500 km travelled. Thirty-eight participants were interviewed in total. Data were collected by means of semi-structured interviews to explore the 'lived experiences' of rural and remote people within the prevailing milieu of psychosocial care provision. The interview explored the experience of workers delivering services as well as the experience of terminally ill people (and/or their family member). An interview proforma was developed to guide the interview process.

The interviews were subsequently transcribed, uploaded in NVivo v10 qualitative analysis software (QSR International; <http://www.qsrinternational.com/nvivo>) to identify consistent themes. Thematic analysis was then undertaken by utilising King and Horrocks' 2010 three-stage model<sup>26</sup>. From the data, key themes could be interpreted in alignment with research questions and the aims of the study. Additionally, this process was undertaken and conceptualised within an ecological systems framework. To ensure trustworthiness and credibility, a second member of the research team reviewed approximately 10% of the transcript coding to ensure consistent interpretations. Discrepancies were resolved and consensus attained through in-depth discussions between the principal researcher and the two supervisors.

### **Ethics approval**

Ethical approval was obtained from three relevant institutional human research ethics Committees. As this study was centred on death and dying, it was acknowledged throughout the interview process that this was a sensitive topic and participants could terminate the interview at any stage. Strategies were put in place to manage any potential risks should they occur. For reporting purposes, the participants were attributed pseudonym names to protect their identity. The approval references from three ethics committees are:

- Darling Downs Human Research Ethical Committee – HREC/12/QTDD/7
- Griffith University Human Research Ethical Committee – HSV/07/12/HREC
- UnitingCare Queensland Human Research Ethical Committee – JOHNS12212.

### **Results**

The findings revealed a patchwork of psychosocial care that created an inconsistent situation throughout rural and remote Queensland. This was a result of either availability of staff members or their calibre of skills, competency, interest and experience. The interview questions were asked against the backdrop of existing literature that purports social workers claim expertise over the psychosocial domain for this clientele, possessing pertinent skills to undertake this role.

### **Ad hoc service delivery, which is unsustainable**

Palliative clients with limited life expectancy generally require urgent attention to their psychosocial concerns. They are not able to wait weeks for an outreach social worker to visit their rural community. Community nurses often recognise this gap and therefore assume this role themselves. However, this raises an issue regarding service quality and sustainability. Multiple participants stated that psychosocial care provision in their community was more 'about the person in the role, rather than the role itself'. One nurse stated:

*A psychosocial approach for the future is not really very good, because it is so dependent on the individuals. It's not through any wonderful government initiative or [named community nursing service] initiative, or anything like that, it's because you've got decent people. We do a very good job but if there's a change in staff, there's no structure in place to ensure that that's what happens, so we've fluked it here. (Yasmin, community nurse)*

### **Palliative care program funding**

Funding issues were a concern raised repeatedly by the majority of health practitioners interviewed. The transcripts of the 38 people interviewed revealed 70 references to funding and how the lack of funding impacted everyday service delivery. The limitation in Queensland of 3 months funding for care of people who are dying clearly was of great concern to the community nurses in these rural settings<sup>13</sup>.

*Funding under palliative care under the state government appears to be diagnosis related as opposed to palliation, which means you are no longer actively treating a disease and looking at end of life. If they don't die within three months, you risk losing the palliative care funding. They're not getting their definitions right 'cause they're using palliative as that last three months and that's not ... the true definition of palliation. (Erica, community nurse)*

### **Burden of travel and outreach work**

Social workers were limited in what they could offer due to the vast geographical distances. The burden of travel limited face-to-face time and comprehensive interventions. This was an issue for four social workers in particular, working as rural generalists. Social workers reported feeling pressured in trying to meet the psychosocial needs for palliative clients living hundreds of

kilometres away from their hospital or community base. One participant indicated that reduced face-to-face time with clients might compromise the quality of interventions:

*I outreach to two towns on one day, so it's basically three hours [of travel] on that Wednesday. ... So it's a huge amount of travel and not much in terms of actual face to face client time. (Ellen, social worker)*

### **Perceived competencies**

In some communities, the nurses perceived the psychosocial domain as pivotal to their role and some had undertaken additional study in this area. In other communities, the social worker was responsible for providing all psychosocial care for terminally ill clients. It was noteworthy that not all non-social work participants deemed social workers as possessing the required skills to effectively support palliative care clients in their community:

*Well it's not good enough for me to say, 'I'll just refer to a social worker'. For me, it has to be a social worker that is versed in palliative care. To me it makes no sense to refer someone to a social worker who has never dealt with palliative clients. And we [community nurses] get protective because we have done it all along; ... I will stand by the fact that social workers who work in palliative care should have special experience in palliative care. (Nellie, community nurse)*

Some nurses saw psychosocial care as integral to their role and a core nursing activity and therefore did not consider making a referral to a social worker for psychosocial support. Furthermore, the results revealed other nurses take on this sphere of care due to the difficulties of clients in accessing psychosocial support or unavailability of resources. This is congruent with existing research that highlights this gap in service delivery in rural and remote communities<sup>18,19</sup>.

### **Voices of palliative client/carers and their perceived psychosocial needs**

The data from palliative clients and their families were integrated into the analysis to provide a more comprehensive exploration of the issues previously discussed. All participants spoke of differing coping styles to deal with their illness. Interestingly, many of their responses centred on spiritual beliefs, closely linked to hope, resilience and coping. This was in contrast to the health workers, who focused on the importance of psycho-education and pragmatics such as wills and enduring powers of attorney. All palliative clients/carers highlighted how social interactions had become more difficult, yet familial relationships had deepened (particularly spousal) and held more meaning. However, the participants and spouses stated that they would like to have access to psychosocial support, if not for themselves, but for their spouse.

*If there were good counsellors and people available, they would be invaluable now. If someone was allocated to you, you know, like once a week or once a month, they could say ring you and say 'how ya going?' (Edward, palliative client)*

Edward's wife, Sherri, also added that when her husband spent 12 months in hospital, she needed to locate her own accommodation:

*For twelve months that Edward was in hospital, I had to find my own accommodation. It was not easy at all. We have never been offered counselling. (Sherri, spouse)*

Another participant who had received psychosocial support because she lived in an area serviced by a hospice stated she had a friend who lived 11 km away who could not access the support of the hospice because the friend lived outside the service's catchment area:

*I have a friend who has terminal lung cancer who lives in [named the community] and she doesn't have a lot of support. You know, recently diagnosed ... out of control pain wise. I told her to ring the hospice but she was told she was out of range. (Myra, carer)*

This highlights the inconsistencies and fragmentation of services in rural communities. Where a person resides geographically impacts on the services available when approaching end of life. The National Palliative Care Standards state, 'Palliative care should be available to all people living with an active, progressive, advanced disease, regardless of the diagnosis' (p. 5)<sup>27</sup>. Yet, arguably, high quality psychosocial care, an integral component of palliative care, is not readily accessible.

### **Discussion**

In keeping with Bronfenbrenner's ecological model<sup>22</sup>, macro influences filter down and influence service funding in rural communities. Skilled staff, adequately trained to assess psychological distress, existential and spiritual concerns and bereavement complexities, are limited in rural communities of Queensland. The data revealed there were no consistent systems when it came to psychosocial care in rural Queensland. Rather there was a 'luck of the draw' situation with a reliance on certain individuals having an interest in palliative care and who would therefore aim to meet the needs. The social worker is the healthcare professional who is usually responsible for provision of psychosocial care. However, in some cases community nurses or community workers assumed these roles, because of perceived lack of competency of social work staff or a lack of availability of appropriately trained staff. These findings are congruent with literature that report the psychosocial sphere is an ambiguous, shared and contested domain<sup>28</sup>.

Meaningful palliative care service planning cannot address such important issues as sustainability, consistency and ongoing care unless a comprehensive overview is conducted, taking into account Queensland's vast geographical areas and demographics<sup>29</sup>. To date Queensland does not have a statewide plan or equitable population-based funding arrangements to support the needs of terminally ill people across the state<sup>30</sup> despite persistent advocacy efforts from the state peak body, Palliative Care Queensland.

It is acknowledged that not all people who are terminally ill will require specialist palliative care services or, more specifically, psychosocial care. However, the researchers do purport all people should have access to it, if they choose, despite their geographical location. At present, this is not possible due to limited resourcing and staffing constraints. It is anticipated the 2018 state inquiry into aged care, end-of-life care and palliative care announced by the Queensland Government will examine how palliative care is undertaken in rural and remote communities. A media release by Palliative Care Queensland welcomed the inquiry, stating 'Queensland is significantly under-resourced; it has approximately 50% of the recommended number of specialist palliative workforce to meet the needs of the Queensland population. Additional resources, particularly in the regional and remote areas, are desperately needed.' (p. 1)<sup>30</sup>.

This study highlights the roles of social workers working with palliative clients in rural and remote Queensland. This has not previously been reported in the research literature. Barriers such as vast distances and workload pressures impact referrals and the quality of interventions. The data clearly show that upskilling in psychosocial care for palliative clients is an important factor to consider in rural and remote settings, particularly for existing generalist social workers whose skills were scrutinised and often discounted by referring practitioners. It is important that social workers demonstrate competence in the psychosocial domain, so that other healthcare professionals feel confident when making referrals. However, most rural social workers are employed in generalist roles with diverse caseloads (not palliative care specific). Few have specialist palliative care training and may lack confidence when dealing with the unfamiliarity of a dying client. In addition, the findings showed that extensive travel required by social workers in their outreach work compromised appropriateness and timeliness of sensitive psychosocial interventions. Situations such as this for rural and remote families living in Queensland are not uncommon and demonstrate the challenges in providing terminally ill clients with quality services.

#### ***Implications and recommendations for education and training for health practitioners***

The study revealed that palliative care and end-of-life issues are specialised areas of care that require specific training; however, the provision of such training is limited. It is important that training be centred on the holistic philosophy of palliative care, in alignment with the WHO definition incorporating psychological, emotional and spiritual aspects. Training and education need to incorporate:

- an understanding of the holistic nature of palliative care
- the principles of patient-centred care with terminally ill clients
- an understanding of how to address each psychosocial domain effectively (including spirituality/religiosity)
- an understanding of other health professionals' roles and scope of practice to facilitate appropriate referrals and multidisciplinary approaches to support terminally ill clients
- skills in undertaking 'difficult' conversations relating to end of life
- self-care strategies for 'emotionally charged' work<sup>31</sup>.

All healthcare workers who interact with palliative clients would benefit considerably from enhanced training in the areas listed. Such training could assist in addressing the disparity between what the palliative care client wants to focus on as opposed to what healthcare practitioners focus on from their own perception of what is needed. Training could comprise content similar to that offered by the Program of Experience in the Palliative Approach, an Australian national palliative care training program that provides training to health workers working with terminally ill people<sup>32</sup>.

As the results of this study have suggested, social workers are not utilised to their full potential because their roles may not be fully understood by other team members. Social workers need to adopt proactive roles in interdisciplinary teams to convey their expertise and roles in palliative care.

#### ***Implications and recommendations for social work and the profession***

Within Australia, a national standards and competencies framework for social workers in specialist palliative care teams, with accompanying guidelines specifically for rural generalist social workers, would prepare social workers to undertake high quality assessments and deliver quality interventions. An endorsed document by the Australian Association of Social Workers would provide generalist rural social workers with a framework articulating the scope of social work practice and guidelines when working with people approaching the end of their lives, and their families. A major task for the professional association would be to facilitate and endorse a framework that clearly articulates parameters of social work practice in palliative care.

In the USA and Canada, national competencies and standards are in place for social workers in palliative care; however, this is not the case in Australia. It is strongly recommended that competencies be developed as a matter of urgency for both the specialist and generalist rural social workers working with palliative clients. The Australian Association of Social Workers is currently considering and addressing this matter. However, it is anticipated the present study will provide further justification for its necessity and relevance.

#### **Conclusions**

This study explored questions relating to the nature of psychosocial care provision in rural and remote Queensland. It also

identified enablers and barriers to social work referrals for psychosocial care in the rural context. Social workers have psychosocial expertise, yet there is very little literature regarding their involvement with terminally ill clients. This study is one of the first to highlight the generalist social work role with palliative clients in rural regions and the substantial challenges social workers encounter when working across a geographically vast landscape. The study incorporated the perspectives of palliative care clients to explore their perspectives about how psychosocial needs were met.

Implications and recommendations for education and training for health practitioners and the social work profession highlight the need to address skills and competencies in psychosocial care for terminally ill clients. The aim is for future social workers to feel more confident in their capabilities to address psychological,

emotional, social, spiritual and cultural issues as they arise. However, support is required from a university curriculum level as well as an endorsed national standards and competencies document to serve as fundamental foundations.

Despite this study being undertaken in one Australian state (Queensland), the findings are consistent with those experienced in countries such as Canada and USA where geographical distances created barriers to timely interventions that influenced the effectiveness of the provision of psychosocial care in many rural communities<sup>8</sup>.

While death is an inevitable outcome for us all, measures need to be undertaken to ensure good psychosocial care is also an outcome, before and after the event. Advocating for those who are vulnerable is a must for health professionals. A lone voice is not enough.

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