THE LIVED EXPERIENCE OF REGISTERED NURSES PROVIDING PALLIATIVE CARE IN THE COMMUNITY:

A DESCRIPTIVE PHENOMENOLOGICAL STUDY

Emily Weston
PhD candidate, BN, BN Hons (1st class), B Soc. Sci, Dip Edit & Pub. Lecturer in Nursing,

School of Nursing, Midwifery and Paramedicine, Australian Catholic University

Supervised by
Assoc. Prof. Diana Jefferies,
Dr Antoinette Cotton, Senior Lecturer
Dr Paul Glew, Senior Lecturer
School of Nursing and Midwifery, Western Sydney University

INTRODUCTION

- In the Australian healthcare system, community nurses play a vital role in the arena of palliative care in the home through the promotion of individual choice that forms the foundation for person-centred care.
- However, the community setting is different to inpatient palliative care and yet, little is known about this area.

BACKGROUND

▶For many Australians, death occurs at the end of a long disease process. For people who have spent long periods of time in the hospital receiving treatment for their serious illness, dying at home is the ‘gold standard’ for a good death.

▶Much research is focussed on the provision of palliative care in Australia in the inpatient setting, yet little is known about the local community setting.

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A global exploration of palliative community care literature: An integrative review

Emily J. Weston RN, BN, BN (Hons), BSocSci, Lecturer in Nursing[1] | Diana Jefferies RN, PhD, Member of ACMHN, Senior Lecturer[2] | Virginia Stulz RN, RM, BHScN, MNH, PhD, Associate Professor of Midwifery[3] | Paul Glew RN, BN, MN, MAAppLing (TESOL), MBA (HSM), EdD, Senior Lecturer[2] | Fiona McDermid PhD, SFHEA, RN, RM, GradCert Emergency, GradDip Mid, Director Student Engagement/Senior Lecturer[4]

[1]School of Nursing, Midwifery and Paramedicine, Faculty of Health Sciences, Australian Catholic University, 22 Main Street, Blacktown, New South Wales 2148, Australia

[2]School of Nursing and Midwifery, Western Sydney University, Locked Bag 1797, Penrith, New South Wales 2751, Australia

[3]Centre for Nursing and Midwifery Research, Nepean Hospital, Level 1, South Wing, Court Building, Derby Street, Kingswood, New South Wales, Australia

[4]School of Nursing and Midwifery, Building 7, Office 6, Campbelltown Campus, Campbelltown, New South Wales, Australia

Correspondence
Emily J. Weston, School of Nursing, Midwifery and Paramedicine, Faculty of Health Sciences, Australian Catholic University, 22 Main Street, Blacktown, NSW 2148, Australia.
Email: emily.weston@acu.edu.au

Abstract

Aim: This review sought to discover how community nurses globally provide palliative care, with specific focus on how they manage the personal and professional stressors associated with caring for dying clients in the home.

Design: An integrative review methodology was used to gain insight into how community palliative care is delivered worldwide.

Background: The provision of home palliative care by community nurses gives clients the ability to spend their final days in familiar surroundings. Research has focussed on the provision of palliative care in the inpatient setting, with little known about the community setting.

Methods: Data were collected through a literature search, then a critical analysis approach was used to evaluate the strengths of palliative care literature by analysing recurrent themes to stimulate further research on the topic.

Data Sources: The following databases were used to conduct the literature search: CINAHL, Medline, Pubmed, Scopus, Ovid.

Results: The results highlighted the importance of building a skilled palliative community nursing workforce and the need to offer specialised palliative care training to nurses, particularly around difficult conversations and service coordination.

Conclusion: The literature identified the challenges implicit within the community nursing role in delivering palliative care, but it did not identify the factors that enhance the nurses' ability to manage the stressors associated with this role. The input of nurses must be sought to understand the development of resilience.

Implications for the profession: Community palliative care nursing requires time spent with clients and family members who are suffering, therefore predisposing nurses to stress. Effort must be made to provide palliative care nurses with support to enhance professional resilience.

KEYWORDS
community nursing, end of life, palliative care nursing, professional resilience

1 | INTRODUCTION

Palliative care is person-centred care provided for a person who is expected to die, and for whom the primary goal is to optimise their quality of life (World Health Organization [WHO], 2014) (Table 1). A person- and family-centred approach to palliative care is based on effective communication, shared decision-making and personal autonomy, therefore reinforcing the importance of the individual choosing the context for their care (Palliative Care Australia, 2018). Choice and preference are fundamental to person-centred care, therefore location at end-of-life is important (Palliative Care Australia, 2018).

The increased international demand for palliative care provision associated with ageing populations has led to an increased global focus on generalist palliative care provision, and its delivery occurs both in the community and in hospitals (Frey et al., 2018). By contrast, specialist palliative care is delivered in hospices and palliative care units by healthcare clinicians who have undergone specific training in palliative care. Consequently, the community nurse providing generalist palliative care at home might not have received the same level of training and support in their role as a mostly independent practitioner (Frey et al., 2018).

In Australia, community nurses and palliative physicians play a vital role in the arena of expected deaths at home (Palliative Care Australia, 2018). However, with reduced medical on-call assistance and increased responsibilities of nurses working independently, coupled with the practicalities of caring for clients at the end-of-life, the emotional burden can be onerous (Hasegawa et al., 2022). Current models of care use a mix of specialist inpatient palliative care providers and community services (NSW Health, 2019). However, individual preferences and monetary constraints point to an increasing demand for palliative care delivery in the community (Palliative Care Australia, 2018).

What does this paper contribute to the wider global community?

- This review aims to demystify the subject matter and highlight the roles played by the nurses who navigate this complex but life-affirming arena.

2 | BACKGROUND

For people who have spent long periods of time in the hospital receiving treatment for their serious illness; dying at home surrounded by family members is the 'gold standard' for a good death (Danielsen et al., 2018). For many individuals, death occurs at the end of a long disease process, with both patient and family aware of the prognosis (Griggs, 2010). Patients with palliative care needs elect to return home for the last days of life; however, this goal requires planning and support to be feasible. The generalist community nurse is a key healthcare clinician when a patient chooses to die at home (Adamson & Cruickshank, 2013). A 'good death' requires planning, symptom management and support; and this falls largely on the community nurse to facilitate. Community nurses play a central role in facilitating end-of-life care in the home and this involves assessing, practising and reflecting on ways to ensure that a good death occurs (Adamson & Cruickshank, 2013).

It is important to investigate how generalist community nurses navigate this area of care and maintain resilience in the face of loss when their primary responsibility is to care for clients at the end-of-life. Much research is focussed on the provision of palliative care in Australia in the inpatient setting (Cheluvappa & Selvendran, 2022; King & Yoong, 2023; Luckett et al., 2014), yet little is known about the community setting and looking at this problem globally will inform Australian practice. The aim of this review was to discover how community nurses globally provide palliative care, and how they manage the personal and professional stressors associated with caring for dying clients in the home.

3 | METHODS

The integrative literature review seeks to generate further research on a topic by critically analysing current research (Torraco, 2005). This approach was deemed most suitable for the research aims, as current literature were investigated to develop an understanding of

TABLE 1 Definition of terms.

Term	Definition
Community nurse	Nurses in community health provide an interpretative bridge between the acute sector and community services. A community nurse can provide services including: care after discharge, chronic disease management, 'hospital in the home' care, palliative care nursing and wound management (Australian Primary Healthcare Nurses Association, 2022).
End-of-life care	Typically, end-of-life care is provided when a person is likely to die in the next 12 months due to progressive, advanced or incurable conditions or old age (New South Wales [NSW] Health, 2019).
Palliative care	The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness (WHO, 2018).
Service provision	Service provision refers to the way inputs such as money, staff, equipment and drugs are combined to deliver health interventions.

STUDY AIM

The aim of this study was to explore the lived experience of nurses providing palliative care in the community.

Research Question

What is the experience of Registered Nurses who provide palliative care in the community?

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METHODS

Sixteen Australian Registered Nurses were interviewed for 30-60 mins each, and a descriptive phenomenological methodology was adopted to reveal the essence of their experiences.

Data was analysed using the Colliaizi method.

Participants were asked one question: what is your experience providing palliative care in the community?

Process of data analysis based on Colaizzi model
Step one is focussed on gaining a sense of the participants' overall experiences through reading the subject's descriptions.
Step two involves extracting significant phrases and statements (Colaizzi, 1978).
Step three is concerned with the formulation of meaning, and this implies that the researcher must bracket their own assumptions prior to formulating general restatements formed from the significant statements (Colaizzi, 1978).
Step four is concerned with organising the formulated meanings into clusters of themes (Colaizzi, 1978).
Step five involves exhaustively describing the investigated phenomenon (Colaizzi, 1978).
Step six involves describing the fundamental structure of the phenomenon.
Step seven involves returning the findings to the participants to validate the essential structure of the phenomenon.

FINDINGS

- The descriptive phenomenological interviewing approach enabled participants to reveal aspects of their experience they deemed worthy of discussion.

PARTICIPANT'S STATEMENTS

"… it's really heart-warming to see someone's final wish come true. … the thing about being a palliative care nurse is that often you don't even have to do that much to completely transform how things happen."

"I think that healthcare workers in general take on a lot. I think the expectation of the absorption of work for a healthcare workforce, generally, palliative care or not, is you just take it on. I think COVID really showed this, that you are just expected just to hold this space."

"But, you know, there's, there's not a finite amount of suffering in the world. I think we're all allowed to have our own problems as well. But sometimes we deny ourselves the space to deal with those after we've spent a whole day looking after people who arguably have had a worse day than us."

Palliative care is a specialty, and it's, and it's more than just something you learn. It's really a heart-centred practice. And it's not for everybody.

"I can't change the fact that these people are dying, but if I can contribute to the care and make one hour, one minute, one day, any better, what better job could you have? And I truly believe that."

"So many deaths and dying at home that I've witnessed that have just brought out this beauty in people because they have just provided this ultimate gift of love, which is to allow someone to have their final moments in the place that they want to."

Main Themes

Honouring the Good Death
The Role of the Community Nurse in Palliative Care
Acknowledging the Inherent Privilege of the Role
A Lack of Understanding about Palliative Care on a Personal and Societal Level
Barriers to Community Palliative Care Delivery
Facilitators of Palliative Care Delivery in the Community
Emotional Labour Experienced by the Community Nurse in Palliative Care

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Preliminary study results have revealed the nursing experience of providing palliative care in the community setting to be a holistic, relationship-based practice focused on carer education, communication and personal autonomy.

The creation of trust, family and carer support, and open conversations about end-of-life decision-making have also been revealed to be essential for the safe provision of palliative care in the home setting.

CONCLUSION

Through the lived experience of nurses who provide palliative care in the community has been revealed to be a deeply relational, culturally aware, and emotionally demanding practice, where nurses utilise a range of clinical and interpersonal skills to care for people at the end of life; all while navigating therapeutic connections, cultural beliefs, and the limits of care provision.

Thank you for your time.

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