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Enhancing palliative care at home: a generalist community nursing case study

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ABSTRACT

Objective: This quality improvement project aimed to explore the experience of home care nurse managers implementing a general palliative approach to care. Implementation comprised several interlinking activities encompassing stakeholder engagement and an education program in the outer eastern region of a home care and nursing organisation in Melbourne, Australia, between September 2019 and December 2020.

Background: High quality provision of community-based palliative and end-of-life care means people are much more likely to die at home, supported by family, friends and services. To achieve this, care staff must be adequately trained and supported, alongside a collaborative approach with other generalist and specialist providers.

Study design and methods: This Case Study reports on the participant perspectives of the stakeholder engagement and education program. Focus groups and an interview were used to elucidate the experience of nursing and allied health professionals providing a general palliative approach in the community. The 2006 National Institute of Clinical Studies framework to identify barriers to best

practice healthcare guided the development of focus group questions and the deductive analysis of data.

Results: Seven Nursing Care Managers and one Social Worker participated in two online focus groups and one interview. Three overarching themes highlighted the value of tailored education in increasing staff knowledge and confidence, the factors for a successful generalist-specialist partnership, and the unique nature of the home care setting which requires accessible systems and processes.

Discussion: This project supports assertions that generalist services can play a valuable role when a palliative approach to care is incorporated. It also underscores the importance of collaborative working partnerships between generalist and specialist services in providing quality community-based palliative care. Future research should examine the needs and perspective of clients, carers and families receiving a general palliative care approach in the community.

Implications for research, policy and practice: Investment in developing the capacity and capability of generalist service staff to deliver palliative care

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is vital, particularly when caring for people in their homes. Although small, this study demonstrates that consideration should be given to embedding staff with specialist palliative care training within generalist organisations to drive and champion evidence-based palliative care provision, training, policies and procedures that meet the unique needs of mobile workforces. Future research should examine the effectiveness of different models and methods for education and generalist-specialist partnerships that meet the needs of mobile home nurses, particularly regarding long-term impact and sustainability.

What is already known about the topic?

- Most Australians prefer to be cared for and die in their own home.
- Home care nurses are key generalist health professionals who support community-based palliative and end-of-life care, organising and providing care, coordinating the input of other health and social care professionals.

- Home care nurses face challenges in meeting their clients' palliative care needs (such as symptom management and communication) and have deficits in their knowledge and confidence of caring for palliative clients.

What this paper adds:

- This case study demonstrated that facilitating ongoing education opportunities that draw on the expertise of local palliative care champions or internal specialists can enhance care provision.
- Nurse care managers believe the value of generalist services, particularly home care services, in the generalist-specialist palliative care partnership, needs to be understood and respected.
- Tailored investment in home care to provide a general palliative approach would be beneficial given the unique challenges of this mobile workforce.

Keywords: Palliative care; home care services; Education, Nursing; qualitative research; Nurse Practitioner

BACKGROUND

Palliative care focuses on improving the quality of life of people affected by life-threatening illnesses, including the prevention and relief of suffering through identification, assessment and treatment.¹ This care extends to family members, and encompasses physical, psychological, social and spiritual support. At least 120,000 Australians each year may benefit from access to palliative care.² As many Australians desire to be cared for and die at home,^{3,4} the provision of quality community-based palliative care is vital. Home nursing and care organisations are key providers of community-based palliative care, with staff often the linchpin, in supporting palliative clients, organising and providing care, coordinating the input of other professionals and of specialist equipment.⁵ Previous research has identified the difficulties faced by home care nurses in meeting their clients' palliative care needs, such as symptom management and communication, as well as requirements for further training to enhance their knowledge and confidence of caring for palliative clients.⁵⁻⁷

In this context, generalist palliative care is delivered by health and care professionals with broad clinical responsibilities who provide primary, ongoing care; and have established relationships with the person and their care community.² This is distinct from specialist palliative care services which support complex needs through multidisciplinary teams with specialised palliative care training.

This case study presents the qualitative evaluation findings from a quality improvement (QI) project that aimed to promote a general palliative approach as part of standard practice in a home nursing and care organisation. The purpose of the qualitative evaluation was to explore the experiences of participating care managers, and barriers and enablers to providing a general palliative approach.

METHOD

SETTING

This project focused on home care provided in the Outer East of Melbourne, Australia, by a national not-for-profit home care, retirement living and residential aged care provider. In this catchment area (Local Government Areas of Maroondah, Knox and Yarra Ranges), the organisation provides care to approximately 2,600 clients yearly, 70% of whom have multimorbidity. The rationale for this project was multi-factorial with de-skilling of the existing workforce over time associated with cessation of region-based funding to provide community-based specialist palliative care, to being a generalist palliative care provider. Of note, only 1% of clients in the catchment area were recorded as having specialist palliative care involvement despite multimorbidity and predicted need.

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QUALITY IMPROVEMENT ACTIVITIES

To incorporate a general palliative approach, several interlinking QI activities encompassing stakeholder engagement, education, and evaluation were conducted between September 2019 to December 2020 (Table 1). The QI activities were managed and supported by a palliative care specialist (Nurse Practitioner) embedded within the organisation, whose remit is to drive evidence-based generalist palliative care provision, policy and guidelines; build capacity from within the organisation, provide expert support, consultation and escalation as needed. Identified as having a pivotal role in guiding and supporting staff, Care Managers, comprising Grade 3 Registered Nurses who provide clinical support, advice, and supervision to Local Area Teams, were the focus of the project activities and outcomes. COVID-19 restrictions meant that some activities did not occur.

QUALITATIVE EVALUATION

Two focus groups, each of two hours duration were conducted at the end of the project in November 2020 by GJ and LD, with seven Care Managers via Microsoft Teams videoconferencing platform; and a one-hour interview was conducted with a Social Worker. Consent was provided for recording, transcription, and analysis.

Focus group and interview questions were developed to explore and understand:

- Experience participating in the project
- Perceived barriers and enablers to taking a generalist palliative approach with clients
- Resources, training and processes needed to successfully support clients
- Experience in partnering with external services to deliver palliative care

Verbatim transcripts were imported into NVivo for coding. The coding framework was based on the National Institute of Clinical Studies framework to identify barriers to best practice healthcare.⁸

The primary researcher (GJ) conducted line by line coding against the framework, then deductive thematic analysis was used to identify and categorise three key overarching themes. These overarching themes were developed through discussions with the research team.

ETHICS

This study was approved by the Bolton Clarke Human Research Ethics Committee, Approval Number 170035.

TABLE 1: QUALITY IMPROVEMENT (QI) ACTIVITIES

QI Activity	Aim	Activities conducted	Activities planned but unable to occur due to COVID-19 pandemic
Stakeholder engagement	To strengthen relationships with key stakeholders and providers	Meetings with operational and care managers, project steering committee (7 x 1.5 hour), primary health network, and specialist palliative care provider. The major specialist community based palliative care service for the region comprises nursing, medical, allied health and bereavement support 24/7.	
Educational program	To facilitate and provide innovative ways to improve staff knowledge and confidence in providing a general palliative approach	Tailored education based on pre-project survey to identify learning needs, comprising <ul style="list-style-type: none"> • In-person education day with specialist palliative care provider, covering: Defining Palliative Care, Communication in the Palliative Care Setting, Advance Care Planning, Symptom Assessment and Management, The Dying Process and End of Life, Grief and Loss, Self-Care • Tailored e-newsletters x 5, and final quick reference guide, emailed at regular intervals, including information, links to resources, related organisational policies and procedures and evidence-based tools to be considered for applicability and implementation. Topics covered included Advance Care Planning; Recognising Deterioration; Responding to Deterioration; Symptom Monitoring; Grief, Loss, Bereavement and Looking After Yourself. • In-house support from a Nurse Practitioner – Palliative Care and Advance Care Planning Champion (Social Worker). 	Planned face-to-face learning and mentoring opportunities, including joint visits with Nurse Practitioner, shadowing, and monthly meetings
Mixed methods evaluation	To evaluate the impact of the QI activities on key palliative care indicators, and understand the experience of, and barriers and enablers to providing general palliative care in home care	Analysis of quarterly operational data from electronic care records Focus groups and interviews with Nursing Care Managers and Social Worker	Feedback was unable to be sought from client, carer, and General Practitioners (GPs)

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FINDINGS AND DISCUSSION

Thematic analysis identified the following overarching themes: 1) targeted education increased staff knowledge and confidence, but more is needed; 2) collaborative teamwork with effective communication and information sharing underpins a successful generalist-specialist partnership; 3) the home care setting is unique and requires accessible systems and processes. Quotes illustrating each theme are outlined in Table 2.

TARGETED EDUCATION INCREASED STAFF KNOWLEDGE AND CONFIDENCE, BUT MORE IS NEEDED

The project was positively received and valued by participants. Participants identified the benefit of tailored education appropriate to the context, with clear and consistent definitions, and how knowledge translated into systems and day-to-day practice. Participants reported that they felt more confident with delivering a palliative approach. The Advance Care Planning (ACP) education

content was described as addressing a real need, with recommendations made to extend this to the broader workforce and community of care. Of note, participants articulated that a lack of client and family understanding hampered their ability to put this knowledge and skills into practice, in their role of “planting the seed” and starting a conversation around ACP. This is in accordance with previous research that identified deficits in ACP knowledge,^{9,10} and reflects the continued stigma and negative connotations around palliative care and death.¹¹

Challenges were reported in striking the balance between providing care and ongoing education in a geographically diverse and mobile workforce, with scheduling and resourcing challenges identified. ‘On-the-road’ peer-mentoring or buddying could not optimally occur during the project due to COVID-19 restrictions; however, participants supported this as a valued solution. Mentorship from clinical leaders and observation of experienced nurses is integral to imparting knowledge, influencing care practices, and facilitating integration of theory into practice,¹² and could

TABLE 2: QUALITATIVE THEMES AND REPRESENTATIVE QUOTES

Overarching Theme	
Targeted education increased staff knowledge and confidence, but more is needed	<p><i>"It's added to the arsenal of things that we have in our, you know, in our pocket that we can use on a day-to-day basis with our clients."</i> [P1, G2]</p> <p><i>"It's lovely knowing that the [Nurse Practitioner] is there as a resource and as a second opinion if we need her"</i> [P1, G2]</p> <p><i>"I think a lot of RNs [Registered Nurses] still fear admitting palliative clients. They just, you know, the fear of being asked questions they're not gonna know answers for and things like that"</i> [P3, G2]</p> <p><i>"And that's a big scary word or words for people - advance care planning is - for some people."</i> [P2, G2]</p>
Factors in a successful generalist-specialist partnership: collaborative teamwork with effective communication and information sharing	<p><i>"I put it in regards to the clients. I say look, you know you don't want us asking the clients all the same questions that you've asked... Do you mind sending through all your health information and your care plans and things. So that just then, that indicates to me like what the family support worker's doing, what the massage person is doing. What everybody else is doing"</i> [P3, G2]</p> <p><i>"It's like it's always been that we get the dirty work... and not that we think it's dirty work...but we do the hands-on care, and they just go in and change the syringe drivers. It just it, it seems to me that we need more support ... from them to do the things that need to be done while they're at the visit."</i> [P4, G1]</p> <p><i>P1, G1: "I feel like there should be a bit more cooperation on their part, on [Specialist Provider]'s part to support us too. 'cause that's what we're here for."</i></p> <p><i>P4, G1: Absolutely. Sharing the care."</i></p> <p><i>P1, G1: And sharing the communication too."</i></p>
The unique home care setting requires accessible systems and processes	<p><i>"You're nursing the person on the journey to the end, and you're also nursing the people who are there with them."</i> [P3, G1]</p> <p><i>"Yep, 'cause they're the conversations we have while we're doing the bed bath, or, you know, whatever we're doing. While we're doing the care, we're sort of having these conversations. It's not separate to - It's sort of all happens there."</i> [P4, G1]</p> <p><i>"They've already established that trust with you as the Care Manager, or as the primary nurse in that area... then it makes it easier for the family and the client to transition to their next stage of life if that relationship is already formed."</i> [P1, G1]</p> <p><i>"The families haven't been really, the whole thing of having someone die at home hasn't been explained to them, how, what it actually entails. You don't want to say how difficult it is, because you want to support them for as long as you can, but there does come a time where it's just not practical or safe for that person to remain at home and we have to be the bad guys that say "Look, sorry, you just can't do this anymore."</i> [P4, G1]</p> <p><i>"Occasionally we have a lot of distance between our clients, whereas when you're closer into the city and the suburbs are more compact, there's less space between client A, client B. Just getting two people to be in the same place, you gotta work out where they're coming from in the first place. They're quite physically large. And to get from one end to the other, and then have two people meet up at a given place at a given time..."</i> [P3, G1]</p> <p><i>"It would be nice to have maybe one that's more generalised, so one that incorporates pressure area care, mouth care, ...restlessness. It might be a bigger care plan, but it kind of covers everything"</i> [P2, G1]</p>

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prove more cost-effective than more formal, in-person education sessions. Identifying trusted local leaders who can act as a conduit for information dissemination would complement this approach. One such supportive avenue within the project with which participants had increased awareness and utilisation was the Palliative Care Nurse Practitioner, with access to this subject matter expert instilling confidence in staff and provision of timely evidence-based information that could then be cascaded outwards.

FACTORS IN A SUCCESSFUL GENERALIST-SPECIALIST PARTNERSHIP

A team approach was perceived as crucial to providing quality palliative care. Findings supported the view that a successful collaborative partnership between generalist and specialist palliative care providers is a key enabler to provide quality care.¹³ The peer-reviewed literature identifies key factors for such partnerships including good communication between providers; clear definition of roles and responsibilities; opportunities for shared learning and education; appropriate and timely access to specialist palliative care services; and coordinated care.¹⁴ Care Managers articulated that the partnership could be compromised by a lack of a clearer delineation between each service's role, service provision, scope, and expectations; with participants feeling their contribution and strengths were not understood or valued. This experience of generalist providers feeling undervalued by specialist colleagues is not uncommon, nor are tensions between generalist and specialist care cultures.^{13,15} Participants spoke of experiences of poor communication and information sharing between partners leading to duplication and often disjointed care provision. This may be compounded by an increasing task-focused and time-limited service provision which can hinder multidimensional, holistic symptoms management and care.¹⁵ However, shared learning opportunities, such as the project's education day led by the specialist service, were viewed as beneficial for strengthening the partnership.

THE UNIQUE HOME CARE SETTING REQUIRES ACCESSIBLE SYSTEMS AND PROCESSES

Participants explained that the context of providing at-home general palliative care is unlike other community or acute healthcare services. For participants, flexibility and adaptability to change was important in delivering a general palliative approach, given the unpredictability and different complexity of individual client's situations. Integral to managing this was fostering the trusted, often long-term relationships with clients and carers, complementing care provision with informal discussions. This complex nature of home care, with relationships being the basis of care, is in line with previous research.⁵

However, despite caring for people at home being less costly than residential aged care,^{16,17} participants reported that resources required to provide quality general palliative care are not insubstantial. Resource management for the level and amount of care required for a client to remain and die at home was particularly challenging given the competing priorities in a generalist service, as not only a provider of specialist palliative care services. This was compounded by managing client and family expectations with the realities of palliative care at home. Participants discussed the tension between being supportive and practical, which required facilitating difficult conversations.

It was acknowledged and evidenced that each Care Manager works differently, given their experience, staff and locale, which needs to be considered and accounted for in any new initiatives. Having a standardised approach is integral to embedding the palliative approach, yet it needs to be responsive to the unique nature and demands of home care, including workforce and service availability, which can vary with client age and location.

Central to the role of Care Managers was planning and coordinating care, however they noted that existing symptom management care plans were under or incorrectly utilised and did not meet the complex needs of palliative care clients. Although participants were supportive of having a single simplified general palliative care plan, they were acutely aware of the barriers of this being implemented with a need to strike the balance between documentation and spending time supporting the client and family.

CONCLUSION

This case study explored the experiences of nurse care managers, alongside perceived barriers and enablers to implementing a general palliative approach as part of standard practice in a home nursing and care organisation. This case study illustrates that home care services can provide community, home-based, generalist palliative care to clients, their family and carers, as they have fostered trusted, often long-term relationships, alongside having the requisite clinical skills. It is recommended that palliative care as a standard practice of care delivery, is embedded and driven from within organisations, for all members of the workforce, appropriate to scope, and recognised as a natural and inevitable part of the care journey. Inclusion of specialist practitioners within generalist services can support the tailoring and translation of best practice into the unique home care context. Greater efforts should be made to ensure support from collaborative partnerships with specialists and other generalists, through a team-based approach that recognises each parties' strengths. Further investment and resourcing would greatly benefit a generalist palliative care approach in home nursing to support community members to be more likely to remain at home, prevent avoidable hospitalisations, and allow them to die in their place of choice.

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