

RESEARCH BRIEF

Staff perceptions and experiences of palliative care in aged residential care facilities

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Introduction

Nations with an ageing population, including New Zealand, have growing end-of-life and/or palliative care needs for their people. Historically, aged residential care (ARC) facilities have not been acknowledged as locations where palliative and end-of-life care is provided (Phillips et al., 2015). However, there are challenges to incorporating specialised palliative care services into aged-care facilities and residents' end-of-life care (Lockett et al., 2014). This integrative review explores the perceptions and experiences of staff working in, or associated with, ARC facilities about the provision of palliative care in these settings. The terms "patient" and "resident" are deliberately used in this research brief. "Patient" describes a person who has been admitted to the facility for palliative, end-of-life care. A "resident" is someone who was admitted to the place of residential care and, as their health deteriorates, may need palliative care.

Background

The higher levels of multi-morbidity, dementia, frailty and other life-limiting conditions among those in ARC facilities can be very challenging, and complex palliative care may be required for months or possibly years prior to death. Therefore, providing care at this level requires more resources, including an appropriate level of staffing (Hawley, 2017). Staff working in these facilities must possess expertise in delivering care to enhance the quality of life for individuals with complicated co-morbidities and complex needs for advanced palliative and end-of-life care (Frey et al., 2019). Furthermore, the model of palliative care delivered in ARC is different to that provided to cancer patients (Boyd et al., 2019), warranting an integrative review of literature that focuses on the provision of palliative care in ARC.

Methodological approach

This study followed the six-step integrative review framework based on Whittemore and Knaf's original work, subsequently elaborated by Toronto and Remington (2020). An integrative review brings together diverse perspectives to foster a deeper understanding of a specific phenomenon (Whittemore & Knaf, 2005).

A PCC (Population – any health professional working in the aged-care sector; Concept – palliative care or end-of-life care; Context – long-term residential care) framework was used to construct the review question, stated as: "*Staff perceptions and experiences of palliative care in aged residential care facilities*". Primary qualitative research studies were searched using key search terms "palliative



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care", "end-of-life", "terminal care", "aged care", "long-term care" and "geriatric care". Search phrases included the key terms and variations of "experiences", "perspectives", "perceptions", "thoughts", "attitudes" or "feelings".

The databases searched included CINAHL, PubMed, and Journals@Ovid.

Table 1. Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Staff working in aged-care facilities above 18 years of age and providing palliative care	Staff providing palliative care in the community, hospice and private/public hospitals
Staff experiences and perceptions about palliative care in aged-care facilities	Staff experiences regarding other levels of care, including dementia and behaviour management
Review of primary research published between 2011 and 2024	Abstract only articles
Published research articles	Non-English primary research
All types of primary research based on the topic	Palliative care study based on hospital and community settings
	Palliative care studies on children

Findings

Of the 348 records identified, 53 were screened, and 38 studies were excluded due to wrong setting, outcome, study design, population, time frame and language. Fifteen met the inclusion criteria for the review. Publications were from eight countries: New Zealand (n=2), Australia (n=4), Canada (n=1), Belgium (n=1), the United Kingdom (n=2), the United States (n=1), Italy (n=1) and Ireland (n=3). For the purposes of developing this research brief, two articles (one from the UK and one from Ireland) were excluded as they both focused on additional constraints of providing end-of-life care during the COVID-19 pandemic. The studies included in this review were published between 2011 and 2024.

Three key themes emerged from the analysis: Understanding palliation in ARC; transitioning through palliative/end-of-life care; and resourcing palliative care in ARC.

Understanding palliation in ARC

Findings from this review revealed a palliative approach is multi-faceted, requiring a balance between physical, emotional and “quality” care (McVey et al., 2014). Cable-Williams and Wilson (2017) found that despite a great deal of palliative care being provided in nursing homes, and one in three residents dying yearly, some staff objected to calling this work palliative care. Therefore, a shared understanding of the philosophy of palliative care is of upmost importance to facilitate the delivery of appropriate care, especially if the patient has been discharged to the ARC facility for end-of-life care (Hill et al., 2018; McKinlay et al., 2019; Omori et al., 2022).

...everybody just thinks it's just death straight up and you're only here to look after them for two weeks and they'll die. I think it's not. It's ensuring that their life is lived to the fullest and as independently as they can and for as long as possible. (Personal care assistant, McVey et al., 2014, p.204).

In addition, the concept of palliative care should be raised with the patient and family on admission to the long-term care facility (Hill et al., 2018; McKinlay et al., 2019). This means that families need to be informed that the patient has been admitted for comfort care, rather than active care to cure the condition that has resulted in them being transferred to residential care.

“...they [the family] don't really understand what it [palliative care in ARC] means...the family hasn't been explained what that means” (Geriatrician, Omori et al., 2022, p.690).

[We have] ... a discharge summary from the hospital saying this person is palliative, but then when we go to start the conversations, both the patient and the family have got a totally [different] idea. (ARC RN clinical manager, McKinlay et al., 2019, p.23).

Timely, comforting, caring and meaningful communication is pivotal in providing palliative care (Albers et al., 2014; Borbasi et al., 2021; Gonella et al., 2020; McVey et al., 2014), with Omori et al. (2022) reporting staff believed it was important to use “caring” words, rather than blunt terms such as “terminal”, to prepare the family for the fact that their loved one is dying.

...you say, 'We're not going to make your mum, or your

dad, or your husband any better, but we can make sure that they're very comfortable, that you're with them when you want to be.' (Interview, senior manager/director, residential/nursing home, Lee et al., 2017, p.7/19)

Transitioning through the stages of palliative end-of-life care

The second theme that emerged from this review is the transition from active care, through palliative care and end-of-life care. Care that is consistent with the resident's documented preferences is one of the top-ranked quality indicators for palliative-oriented care (Gonella et al., 2020). This is more successful where advance care planning has already been established (McKinlay et al., 2019). Providing care aligned with the patient's wishes, negotiating the relationship between staff, family and patient, and being attentive to the patient's care needs is challenging in the absence of such documentation (Albers et al. 2014; Gonella et al., 2020; McKinlay et al., 2019; Muldrew et al., 2019).

Poor communication between staff and families can lead to the family having unrealistic expectations that the resident will receive active care when they need palliative care (Omori et al., 2022). Staff note subtle changes that indicate a resident's condition is deteriorating, but families, who have not been fully informed, may be struggling to understand the significance of the declining health (Muldrew et al., 2019; Omori et al., 2022). The use of futile or aggressive treatment in the absence of advance care planning creates ethical tension for staff, as they experience conflict between what they feel is right and their duty of care (Muldrew et al., 2019). For example,

[A person with dementia] had three hospital admissions, he'd had five lots of different antibiotics but all different doctors and when I actually sat down and spoke to the family and said 'I think he's dying', nobody had actually just sat them down and made that decision. (Interview, nurse, primary care, Lee, et al., 2017, p.9/19).

Staff want to provide the best possible care to the patient. However, the significant change in the patient's care needs during end-of-life care, and the lack of space in their rooms, puts pressure on staff to meet those needs, testing staff capabilities and staffing levels (McVey et al., 2014).

Resourcing palliative care in ARC

Clinical staff in aged-care facilities need to develop skills in identifying and managing symptoms such as pain, breathing difficulties or terminal secretions, thus avoiding unnecessary hospitalisation (Lamppu & Pitkala, 2021). Added to the complexities of multi-morbidities, findings from this review also reveal that limited resources and low staffing levels in ARC facilities compromise their ability to meet residents' palliative care needs (Cable-Williams & Wilson, 2017; Frey et al., 2020; Gonella et al., 2020; Hill et al., 2018; McKinlay et al., 2019; McVey et al., 2014; Muldrew et al., 2019). Resources include staffing levels, access to specialist medical services and other medical equipment, and availability of on-site GP services. Compared to public hospitals or hospices, the staff at ARC admitted that they did not possess the same comprehensive range of specialised equipment or specialised roles such as palliative clinical nurse specialist, or counsellor (Gonella et al., 2020; McKinlay et al., 2019).

It's the resource thing... families [think] ... hospice and hospital are free ... I ... say to them ... the hospital gets \$2000 a day for a bed ... [but] ARC gets \$130 and they are supposed to provide the same level of care." (GP, McKinlay et al., 2019, p.20).

Providing high-quality palliative care is fundamentally more time-consuming since challenges in communication make it harder to assess the resident's needs effectively. Additional time is required to comfort the resident and create a peaceful atmosphere (Cable-Williams & Wilson, 2017; Hill et al., 2018).

In the afternoon it's very difficult, sometimes you get three palliative cases, they all have syringe drivers; three syringe drivers to be monitored by one nurse. And sometimes one syringe driver plays up and sometimes the other syringe driver needs to be recalibrated. That's already three patients and how about my 30 patients who need their regular medications? And family members visit in the afternoon waiting for you. And you want to sit with this patient who is actually dying... (RN, McKinlay et al., 2019, p.20).

In addition, staff in ARC, undertaking these new and more challenging responsibilities, are directed to comply with financial limitations (Midtbust et al., 2018). Consequently, they are torn between their obligation to provide effective palliative care for residents and their growing workload (Musto et al., 2015).

Conclusions and recommendations

The findings of this review indicate that the provision of palliative and end-of-life care is expected as part of the services delivered in ARC. However, barriers have been identified for providing effective care for residents and their families. Staff and families need to understand the philosophy of palliative care — it involves providing quality care to a patient through the complex stages of frailty and end-of-life. The concept of palliative care needs to be raised with the patient and their family on admission to the ARC facility, and the patient, family and staff must all be involved in advance care planning. Finally, policy-makers need to make a substantial effort to recognise the increasing demand for palliative and end-of-life care in aged-care facilities and provide adequate resourcing to meet those needs.

References

- Albers, G., Van den Block, L., & Vander Stichele, R. (2014). The burden of caring for people with dementia at the end of life in nursing homes: A post death study among nursing staff. *International Journal of Older People Nursing*, 9(2), 106–117. <https://doi.org/10.1111/ijn.12050>
- Borbasi, J. A. L., Tong, A., Ritchie, A., Poulos, C. J., & Clayton, J. M. (2021). "A good death but there was all this tension around" — perspectives of residential managers on the experience of delivering end of life care for people living with dementia. *BMC Geriatrics*, 21(1), 306-314. <https://doi.org/10.1186/s12877-021-02241-7>
- Boyd, M., Frey, R., Balmer, D., Robinson, J., McLeod, H., Foster, S., Slark, J., & Gott, M. (2019). End of life care for long-term care residents with dementia, chronic illness and cancer: Prospective staff survey. *BMC Geriatrics*, 19, 137. <https://doi.org/10.1186/s12877-019-1159-2>
- Cable-Williams, B., & Wilson, D. M. (2017). Dying and death within the culture of long-term care facilities in Canada. *International Journal of Older People Nursing*, 12(1), e12125. <https://doi.org/10.1111/ijn.12125>
- Frey, R., Balmer, D., Boyd, M., Robinson, J., & Gott, M. (2019). Palliative care nurse specialists' reflections on a palliative care educational intervention in long-term care: An inductive content analysis. *BMC Palliative Care*, 18(1). <https://doi.org/10.1186/s12904-019-0488-4>
- Frey, R., Balmer, D., Robinson, J., Boyd, M., & Gott, M. (2020). What factors predict the confidence of palliative care delivery in long-term care staff? A mixed-methods study. *International Journal of Older People Nursing*, 15(2), e12295. <https://doi.org/10.1111/ijn.12295>
- Gonella, S., Basso, I., Clari, M., Dimonte, V., & Di Giulio, P. (2020). A qualitative study of nurses' perspective about the impact of end-of-life communication on the goal of end-of-life care in nursing home. *Scandinavian Journal of Caring Sciences*, 35(2), 502-511. <https://doi.org/10.1111/scs.12862>
- Hawley P. (2017). Barriers to access to palliative care. *Palliative Care*, 10. <https://doi.org/10.1177/1178224216688887>
- Hill, E., Savundranayagam, M. Y., Zecevic, A., & Kloseck, M. (2018). Staff perspectives of barriers to access and delivery of palliative care for persons with dementia in long-term care. *American Journal of Alzheimer's Disease & Other Dementias*, 33(5), 284–291. <https://doi.org/10.1177/1533317518765124>
- Lampuu, P. J., & Pitkala, K. H. (2021). Staff training interventions to improve end-of-life care of nursing home residents: A systematic review. *Journal of the American Medical Directors Association*, 22(2), 268–278. <https://doi.org/10.1016/j.jamda.2020.09.011>
- Lee, R., Bamford, C., Poole, M., McLellan, E., Exley, C, & Robinson, L. (2017). End of life care for people with dementia: The views of health professionals, social care service managers and frontline staff on key requirements for good practice. *PLoS ONE*, 12(6). <https://doi.org/10.1371/journal.pone.0179355>.
- Luckett, T., Phillips, J., Agar, M., Viridun, C., Green, A., & Davidson, P. M. (2014). Elements of effective palliative care models: A rapid review. *BMC Health Services Research*, 14(1). <https://doi.org/10.1186/1472-6963-14-136>
- McKinlay, E. M., Moran, S. V., Morgan, S. J., Sari, P., Kerridge, J. M., & Pullon, S. R. (2019). What does palliative care look like in a New Zealand aged residential care facility when patients are admitted to die? *New Zealand Medical Journal*, 132(1505), 14-28.
- McVey, P., McKenzie, H., & White, K. (2014). A community-of-care: The integration of a palliative approach within residential aged care facilities in Australia. *Health & Social Care in the Community*, 22(2), 197-209. <https://doi.org/10.1111/hsc.12077>
- Miller, S. C., Dahal, R., Lima, J. C., Intrator, O., Martin, E., Bull, J., & Hanson, L. C. (2016). Palliative care consultations in nursing homes and end-of-life hospitalizations. *Journal of Pain and Symptom Management*, 52(6), 878-883. <https://doi.org/10.1016/j.jpainsymman.2016.05.017>
- Midtbust, M. H., Alnes, R. E., Gjengedal, E., & Lykkeslet, E. (2018). Perceived barriers and facilitators in providing palliative care for people with severe dementia: The healthcare professionals' experiences. *BMC Health Services Research*, 18(1). <https://doi.org/10.1186/s12913-018-3515-x>
- Muldrew (née Preshaw), D. H., McLaughlin, D., & Brazil, K. (2019). Ethical issues experienced during palliative care provision in nursing homes. *Nursing Ethics*, 26(6), 1848–1860. <https://doi.org/10.1177/0969733018779218>
- Musto, L. C., Rodney, P. A., & Vanderheide, R. (2015). Toward interventions to address moral distress: Navigating structure and agency. *Nursing Ethics*, 22(1), 91-102. <https://doi.org/10.1177/0969733014534879>
- Omori, M., Jayasuriya, J., Scherer, S., Dow, B., Vaughan, M., & Savvas, S. (2022). The language of dying: Communication about end-of-life in

residential aged care. *Death Studies*, 46(3), 1-11. <https://doi.org/10.1080/07481187.2020.1762263>

Phillips, J., Hosie, A., & Davidson, P. (2015). Palliative care in the nursing home. In N. Cherny, M. Fallon, S. Kaasa, R. K. Portenoy, & D. C. Currow (Eds.), *Oxford textbook of palliative medicine* (5th ed., p.125-136), Oxford University Press. <https://doi.org/10.1093/med/9780199656097.003.0014>.

Toronto, C. (2020). Overview of the integrative review. In C. E Toronto & R. Remington (Eds.), *Step-by-step guide to conducting an integrative review*. Springer Nature Switzerland.

Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing*, 52(5), 546–553.