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'Early planning makes for a good death': residential aged care nurses' views on caring for those in the last months of life

Priyanka Vandersman^{1*} and Jennifer Tieman¹

Abstract

Background The residential aged care (RAC) sector provides care to a significant number of older people across frail and vulnerable years, all the way through to death. As such, palliative care, and considerations for end-of-life caring, need to be considered as core in aged care practice in Australia.

Aim To explore how RAC nurses understand, describe, and provide care to people who are in the last months of life.

Methods A qualitative descriptive research study design based on the secondary analysis of data collected as part of a larger study. Focus groups and semi-structured interviews were conducted with RAC nurses working in Australia using video conferencing software and telephone. Data collected was managed using the NVivo software and analysed using reflexive thematic analysis.

Results Sixty-four participants from 14 RAC services across three Australian States took part in study. Four themes emerged from the analysis of the data, namely: (1) The last months of life have unique caring needs; (2) Identifying the last months of life is complex (3), Care provision is driven by task orientation, and (4) Good end-of-life care is acknowledged yet limited. Participants highlighted differences in the needs of older people experiencing gradual decline versus those in the terminal stage. Early discussions about death with families and residents were deemed valuable, but resource constraints limited the opportunities of quality one-on-one care.

Conclusion Nurses see value in recognising early health decline and identifying residents nearing end-of-life, but workflow and resource limitations hinder their ability to engage effectively. Developing and implementing resources and processes to enable nurses to identify early decline and deliver timely, quality end-of-life care is imperative.

Keywords Residential aged care, Nurses, End-of-life care, Early deterioration, Palliative care

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Background

The global population is ageing with estimates that 16% of people will be over the age of 65 [referred to as older people hereafter] by year 2050 [1]. As the ageing population grows, the burden of noncommunicable diseases is increasing, leading to a rising demand for palliative care among older people. According to the World Health Organisation [2] an estimated 25.7 million people require palliative care during the final year of their life. Despite growing global demand, access to palliative care remains limited, with at least half of those in need unable to receive adequate services. It is estimated that only 14% of individuals in need of palliative care actually receive it, with the majority of these services concentrated in European countries [2, 3]. Australia is experiencing similar trends, with a steadily growing ageing population, with estimates suggesting that by year 2050, 18.7% of Australians will be over the age of 65. This demographic shift is driving increased demand for aged care services, including the need for residential aged care.

National aged care utilisation data highlight a growing demand for residential aged care services among older Australians who require support in their later years [4]. In the 2020 to 2021 period alone, nearly 200,000 older people received care within residential aged care facilities. For many, these facilities become their final place of residence. In Australia, approximately 36% per cent of deaths among people aged 65 and over occur in residential aged care, and the majority of resident exits [83%] are due to death [5, 6]. The residential aged care sector provides care to a significant number of older people throughout their frail and vulnerable years, all the way through to the point of death. As such, palliative care, and considerations for end-of-life caring can be seen to be a core aspect of aged care practice in Australia.

Palliative care is defined as a critical approach that provides relief of suffering for a person living with a life-limiting illness and their family by supporting quality of life [7]. This is done by early detection, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual [2]. The demand for palliative care in Australia and other parts of the world has been rapidly increasing due to the ageing population, higher prevalence of chronic diseases, the recent emergence of coronavirus 2019 (COVID-19) [8], and is expected to double by 2060 [9]. With advocacy from the aged care sector and peak palliative care bodies, there is now an increasing shifting towards a model where palliative care is considered core business for aged care, and high quality palliative care is expected wherever older people chose to live [10]. Non-specialist palliative care providers across all settings, including residential aged care have a significant role in enabling palliative care provision. Given many older Australians spend their last

years living in a residential care setting, there is a need to ensure that quality end-of-life and palliative care be provided to these older people in this care setting.

In the Australian aged care setting, nurses have a key clinical role in caring for older people who are in the last year of life. Registered staff who are regulated by a governing body, including Registered Nurses (RNs) and Enrolled Nurses (En) provide direct clinical and general care to older people [11]. Additionally, RNs perform clinical assessments, make care decisions, coordinator services, collaborate with other health professional, and delegate and supervise care provided by ENs and other staff [12]. Unregistered staff, or Care Workers (CWs) such as Personal Care Assistants, Health Services Assistants and Assistants in Nursing, who make up a large portion of the aged care workforce, support nursing care by assisting with personal care and activities of daily living [13]. Given these two groups interact with older people most closely, they are ideally placed to identify early change in health and decline in status. However, identifying decline is known to be somewhat challenging, as recognition and diagnosis of irreversible health decline in older people comes with a degree of uncertainty [14]. A conceptual model of good end-of-life care in residential aged care homes is thought to include the adoption of a palliative approach starting from the recognition of physical or social triggers [15]. Yet it is not clear from the literature how residential aged care nurses identify and cater for residents with gradual health decline.

There has been research into clinician recognition of end-of-life, EOL planning and care in dementia [16–20] and other life limiting illnesses such as lung disease [21, 22] and heart failure [14, 23, 24], and often focussing on medical physicians. Similarly, there is a growing body of research in acute deterioration detection in older people in residential aged care facilities [25, 26]. However, there has been little research into how nurses, including care workers, recognise, describe, and address the slow and irreversible health decline that many of their residents' experience in the last months of their life.

Aim This study seeks to investigate how nurses in residential aged care facilities identify, articulate, and address the gradual irreversible decline in the health of their residents.

Methods

Design

A qualitative descriptive study based on the secondary analysis of data collected as part of a larger study using semi-structured one-on-one interviews and focus groups.

Setting

The ELDAC Digital Dashboard Implementation (EDDI) - qualitative study formed part of a larger multi-method implementation study conducted as part of the ELDAC (End-of-life Directions for Aged Care) project funded by the Australian Government to support palliative care practice in aged care. The aim of the main ELDAC Digital Dashboard Implementation (EDDI) study was to explore the feasibility and merit of implementing a Dashboard to support end-of-life and palliative care in the Australian aged care setting [To be published separately]. The Dashboard is an integrated data visualisation model designed to track as well as visually present key end-of-life processes and indicators for reporting and clinical decision-making at the client, managerial, and organisational levels. It helps clinical staff prompt and prioritise care; assists managers to track performance; and support organisations to report service level end-of-life care activities.

Data from the EDDI study was collected through focus groups and one-on-one interviews that were conducted with aged care staff at the beginning and end of the study period. This paper reports on the findings from first set of focus groups and one-on-one interviews before the implementation study began and explores nurses' perspectives on caring for people who are in the last year of life.

Study participants

The participants of this qualitative study were nurses, care-managers, and care workers working in Australian residential aged care setting. Care workers, also known as Assistants in Nursing in Australia [27], provide direct care and are often the first to detect changes in residents' health, reporting these to nurses with clinical responsibilities. Their inclusion ensured comprehensive insights into early recognition and management of resident decline.

Sampling and recruitment

As part of the larger study, aged care services with access to the palliative care dashboard were approached with an invitation to participate in the main multi-method implementation study [EDDI Study]. The invitation clearly noted that involvement was completely voluntary. Interested parties were provided with relevant information to share with their respective Boards/Executives before participation decision was made.

After confirming site-level participation, the site contact—typically the manager or site champion—received the qualitative study invitation poster along with participant information and consent forms, with a request to distribute them among clinical and care staff. The recruitment materials noted that invitation was to take part in a

focus group [or an interview] and the participation was voluntary. Potential participants were encouraged to get in touch with the study team directly and ask any questions before deciding to take part in the study. Informed consents were obtained from 83 participants (aged care staff) across 15 residential aged care sites (with a combined total of 998 client beds available at the sites) from three different states (Queensland, Western Australia, and Tasmania).

Research team

The research team was composed of an experienced health academic researcher with a background in palliative and end-of-life care, and information technology in aged care (JT); and a research fellow with a nursing degree and experience in digital health, chronic and palliative care research (PV).

Data collection

Data were collected virtually via video conferencing software and telephone as face-to-face interviews were not feasible amidst the COVID-19 related restrictions imposed across aged care services at the time. Six one-on-one interviews and 11 focus groups, with up to 8 participants per unique aged care site were conducted. The data collection approach was directed by the research question and considered to meet the analytical requirement of data saturation [28]. Focus groups and interviews were conducted between September and November 2020. A question guide was used to facilitate data collection. All interviews were audio and/or video recorded and transcribed verbatim by an external professional transcription service. The interviewer kept field notes as well as a journal for critical self-reflection and minimisation of researcher bias.

Documentation of data, methods, decisions, and end-product have been thought to demonstrate dependability, and self-reflection of the research process for reflexivity [29, 30]. The standards for reporting qualitative research (SRQR) checklist was used to enhance the quality and transparency of this study [31].

Data analysis

Qualitative data was managed using the NVivo version 12 software. Reflexive thematic analysis [32, 33] was used to organise data to generate themes using an inductive approach (Braun and Clarke 2006), so the analysis was data-driven and not guided by a theoretical approach. Familiarisation of the data was achieved by researchers reading and re-reading transcripts and listening to audio and video recordings of interviews, with ongoing reflexive consideration of researcher assumptions and potential biases, to enhance credibility and confirmability. Initial codes were then generated by capturing segments

of raw data and organising them into meaningful groups. Codes were then reconsidered and further coded to create notable trends and patterns [34]. Child and parent codes were used for a hierarchical approach, creating multiple child codes under each parent code. Data was coded by a second researcher and codes then compared and discussed until consensus was reached for intercoder dependability, to ensure an accurate reflection of the data [35]. Themes and sub-themes were reviewed and refined collaboratively within the research team. Credibility was further enhanced by use of participant quotations to ground interpretations in the data.

Ethical considerations

Ethical approval was received via Flinders University Social and Behavioural Research Ethics Committee (8594). All interview participants were informed that participation was voluntary, and that consent could be withdrawn at any time. A small monetary reimbursement (\$25 gift card) was offered to participants as an acknowledgement of their time and contribution. Data collected was deidentified and stored securely on password protected computers at Flinders University.

Results

Site and participant characteristics

Data was collected across 14 residential aged care facilities as one facility withdrew participation before the digital dashboard was implemented. Six one-on-one interviews, and 11 focus groups were conducted lasting on average 40–60 min. There were 64 participants in total and the majority of participants were female (86%), employed as RNs (56%) providing direct care to residents predominantly working in metro services. This was followed by nurses in clinical or managerial leadership roles (23.5%), enrolled/endorsed enrolled nurses (EN/EEN) (14%), and care workers/admin-support (6.5%).

In the following section, participants are reported using the key conventions as below: (Role: RN=Registered Nurse, EN=Enrolled Nurse, EEN=Endorsed Enrolled Nurse, CNC=Clinical Nurse Consultant).

Four themes emerged from the analysis of the data, namely: (1) The last months of life has unique caring needs; (2) Identifying the last months of life is complex (3), Care provision is driven by task orientation, and (4) Good end-of-life care provision: acknowledged yet limited.

Theme 1: The last months of life has unique caring needs

Participants noted that there is a noticeable stage of irreversible health decline that their older residents experience before they reach the very end-of-life where they are actively dying.

There was a consensus that this stage is marked with a noticeable health decline over months [typically 6–12 months] and a recognition that needs may change. Participants noted that the care needs of the older person during these months are different to the care they would need at the terminal/actively dying stage:

.... like we have started [the resident] on 'palliative' stage, so she is kind of in the middle. She's not on the end-of-life [actively dying] stage yet but she's going there slowly... every person deserves to be on palliative care before going on end-of-life care. (CNC_Metro).

They [the family] understand that palliation is not just about end-of-life medications and syringe drivers, but it is trying to address those symptoms that come into play as and when they do. It's improving the quality of life that they [the resident] have got (Manager_Metro).

Participants described the dynamic nature of care needs of their residents who are in the last months of their life and outlined how the focus of care can shift from resident to the family depending on the context:

...as they travel through the trajectory, their needs are different... We are not necessarily giving emotional care to the resident whose death is imminent. And at the end of their life, we are giving that emotional care to families... (CNC_Metro).

The dynamic nature of the care needs at the end of life also meant there was a level of unpredictability. Participants noted instances where an older residents' decline and deterioration can be followed by recovery leading to a state of bidirectional movement in and out of the actively dying state:

if you do think that they have got three months or six months, you assess them, and then sometimes they seem to bounce back... they're eating and drinking again, they're more alert. So, then you take them off the palliative form and you'd put them back just on their normal care plan (EN_Metro).

Theme 2: Identifying the last months of life is complex

Identification of a residents' slow health decline was carried out based on physical and behavioural assessments and recognition of subtle changes in participation and behaviours. Nurses gathered cues to that served as indicators of deterioration:

...we find that they are not participating in activities... they are not eating, drinking well ... we had

a resident with dementia [he used to] walk all day but [now] we find that he's not sitting good, now he's not swallowing, and he cannot walk- something is changing within his health. (RN_Metro).

Diagnosis of a life limiting or chronic illness, or emergence of frequent health incidents were also a guiding factor in identifying decline or prompting consideration of end-of-life care:

...we track how many admissions the resident had to hospital. We had a resident who wasn't palliative but had gone to hospital two or three times in a month because he had pneumonia. So, this is some sign which we think that yes, the resident is going down... (Manager_Metro).

While there were processes to identify a resident's decline, some participants noted reliance on non-measurable cues to express a perception of decline in residents:

... there's just that feeling of you look at someone and the things they do, and the way they react. You just think: they're not taking part in their everyday activities, they're not showing interest in their appearance. They don't have that general greeting that they give you when they come in ... It's just something like that, I can't explain it medically (EEN_Rural).

Further complicating factor was the lack of clarity around use of various terminologies to indicate the stages of a resident's health decline:

*But for the palliative care, I think some other places has something called comfort care? (RN_Metro).
... "Okay, a person can be palliative." You've said three phases, so one is not end-of-life. The middle bit where you said end-of-life recognised, we call that phase palliative. Then the third phase is end-of-life, which is going end-of-life dying, like that's the dying phase (Manager_Metro).*

Theme 3: Care provision is driven by task orientation

The context in which nurses identify decline, and care for residents was partially illustrated by being highly assessment and task driven:

If there is an increasing event of reduced appetite, I try to assess what's the root cause, and refer to the doctor. ...I can put her [resident] on a food chart to monitor the food and fluid intake. Then...the physi-

cal appearance like the skin turgor, hydration of the skin... (RN_Metro).

Participants were very focused on completing tasks and making sure the associated paperwork was updated:

In the care plan, we assess: Waterlow, the swallowing ability, pain, the FRAT, incontinence... If the resident has three or four falls, the FRAT needs to be updated after every fall... Whenever the resident's mobility needs change, that will reflect exactly at the same time on our care plan (Manager_Rural).

These assessment and documentation processes were incorporated by some as prompts for care and action:

We have one form ... we can say if the resident got more than three symptoms, and then we can start an end-of-life pathway. Then after that we will get doctors, family to [be] involved, and then we will document... There's two assessment we have to do: end-of-life pathway profile and the end-of-life assessment (CNC_Metro).

Often these subtle cues of deterioration were assessed and observed by one set of staff, and then passed on to others for further assessment or diagnosis:

Yes staff [care workers] definitely do [pick up gradual decline] and the nurses do assessments and stuff when there are any changes... And that is usually referred onto then the doctor, and usually we would have a terminal diagnosis, usually the GP (general practitioner) will generally give them an estimation. (Admin and Support_Remote).

Theme 4: Good end-of-life care provision: acknowledged yet limited

Participants demonstrated that good end-of-life care was important, and they shared their perceptions of what good care, or a good death looks like. Engaging with the resident in conversations about death to promote acceptance, and offer reassurance was noted as a desirable outcome:

...and by then, the good result is that they [Residents] are openly talking about their own imminent death. And they want to know what will happen- "Will I stay here? Will you send me to hospital, will you move me?..." And they're comfortable talking about that... That's a really good result ... That reduces the fear... and restlessness at the end (Site Manager_Metro).

Making preparations and confirming end-of-life wishes early for a smoother end-of-life journey was thought to support good death outcomes for the resident and their family:

...if we feel like a resident is not in the dying stage but they're going to be there soon, we have a meeting with the family: "this is what we've got on file for you, is this what you would still prefer for your mum or dad ...?" We have that conversation there so when that person does eventually pass away, they can focus on grieving, not organising and having to run around and do everything (Clinical Lead_Remote).

While there was focus on what constitutes good end-of-life care, challenges in achieving this were also recognised. One of the factors perceived to be problematic was the unpredictability of the course of recovery or progression into death:

...you send them to hospital because you think they just might recover... Most times we are successful in them talking with the hospital if they have been deemed comfort [terminal stage] ... But sometimes the hospital is sort of to-ing and fro-ing and then they [resident] are just simply too frail to come back to us and that's the bad result. (Site Manager_Metro).

Issues with time and staffing obstructing nursing staff from being able to give one-on-one time and care uninterrupted without distraction was regarded as important but difficult:

...I could sit there and do what I would really love to do: hold that person's hand, and just be with them in that moment. And not have to worry about giving pain relief to someone or the carer saying so and so is not showering for me (CNC_Metro).

Lack of resources and training of staff impeding the urgent care of residents – resulting in increased hospitalisations, was seen as serious concern:

If we have a resident here who's in excruciating pain we don't have the equipment, we don't have the training and we don't have the guidelines to follow for some of that. That's why they go to the hospital because they're in health [setting] and they've got more [resources] (Clinical Lead_Remote).

Discussion

This study adds to the growing body of literature on nurses' understanding and practices in relation to end-of-life deterioration. While existing evidence suggests that nurses in the aged care settings recognise the unique care need of their dying residents [36, 37], our findings add to this by exploring how nurses in Australian residential aged care identify and respond to early signs of decline. This focus offers additional perspective on how end-of-life care gradually unfolds within a non-specialist care context, often well before a resident is formally recognised as nearing the end of life. The study also highlights the organisational and relational challenges faced by nurses in managing this phase of care, particularly in settings marked by complex comorbidities, prolonged relationships with residents, and limited access to specialist support.

The nurses involved in this study recognised that the care requirements of residents undergoing slow, gradual health decline are distinct from those who are actively dying. Identifying the pre-terminal stage where an older person is approaching the last months of life is essential to carry out appropriate conversations and end-of-life care planning interventions [38]. However, nurses alluded to several challenges in making this distinction, including inconsistencies in how terms such as "palliative" and "end-of-life" care are understood and applied. Consistent with previous findings, nurses in this study noted that palliative care is often perceived as applicable only in the final days or weeks of life [39, 40]. This interpretation may limit the adoption of a broader palliative approach earlier in the care trajectory. As a result, the opportunities to provide holistic, coordinated care during the final months of life may be missed [41].

The gradual and prolonged nature of health decline observed among older RAC residents, is known to pose challenges in identifying and predicting when an older person is approaching end-of-life [42, 43]. Nurses in this study similarly reported complexities around early identification of slow health decline in their residents including the challenge of unpredictability posed by the dynamic bi-directional movement between deterioration and recovery in some residents. However, nurses undertook various objective and intuition-based assessment activities to identify cues of slow decline in health of their residents. There is existing evidence to indicate that nursing and care staff in the aged care setting rely on clinical signs and indicators to identify when their resident experience acute deterioration or when they approach the stage of active dying [26, 36, 40, 44]. The findings of this study expand our understanding in this field by highlighting that a similar approach of objective and intuition-based assessment is carried out by nurses to identify the early cues of slow and gradual health decline that many

RAC residents experience. These cues can be complex and quite ambiguous and may not be sufficiently valued to attach actions to them that would support end-of-life care planning. Similar findings have been reported in studies conducted within RAC [or equivalent] settings both in Sweden [45] and the United States [44] where staff encountered challenges in recognizing early decline. Many triggers identified were vague, offering limited clarity, particularly in acknowledging a foreseeable but not yet imminent death. As the comorbidity profile of RAC residents becomes increasingly complex, the dying process extends over time [46]. In institutionalised settings like RAC, this underscores the necessity for service processes and appropriately skilled staff to conduct thorough assessments, identifying early signs of early health decline. Such an approach can enable care planning that adapts to the evolving needs of older individuals as they progressively deteriorate all the way through to the point of their death.

Contextual factors and the culture of the care setting influences how care is operationalised [47]. In the context of aged care setting, nurses in this study reported medicalised and objective assessment driven approach to identifying and meeting the end-of-life care needs of their residents. Similar patterns have been noted among palliative home care nurses and hospice managers where nursing care at the end-of-life is expressed predominantly within a medical or treatment framework [48, 49]. Likewise, a study focussing on prioritisation of care in RAC found that activities considered important by nursing and care staff in aged care were predominantly task-focused than person-centred [50].

While appropriate assessment and treatment approaches are essential elements of quality end-of-life care [51], there is value weighting nursing expertise in 'being' and 'understanding' alongside the more objective clinical aspects of 'doing' and 'assessing' [52]. This concern is echoed by several empirical studies which have highlighted the challenge of delivering holistic care aligned with the philosophy of palliative care [53–55]. A recent systematic review observed that palliative care is increasingly influenced by biomedical approaches to disease management with holistic approaches acknowledged yet seldom integrated into care practices [56]. Similarly, the study conducted by Frey, Powell and Gott [57] found that clinicians viewing palliative care through a biomedical lens tend to perceive care as primarily focused on clinically directed symptom management. This approach presents a challenge, particularly in light of findings from a recent study by Kenny, Street [58] which identified that the most important aspects of end-of-life care for middle-aged and older Australians are cost, symptoms experience, and family caregiver stress. This finding underscores the necessity of adopting an

approach to care that prioritises holistic well-being of the older people and their families, extending beyond clinical tasks. Such an approach may facilitate the provision of end-of-life care that is compassionate, comprehensive and patient-centered [59].

Despite their task-oriented approach, nurses in this study were dedicated to providing quality end-of-life care to their residents. Consistent with existing literature on good quality end-of-life care from both the perspective of nurses and family caregivers [15, 60], the nurses expressed willingness to engage in discussions about death and dying, initiate early care planning in collaboration with residents and their families, and consider the grief and bereavement needs of family caregivers. These aspirations align with the findings of a recent review of systematic reviews on good death published in the *Lancet* [61]. This review outlines 11 conditions for a good death, with eight of them emphasizing psychological, relational, communicational, spiritual and practical aspect of care [61]. Initiating conversations early with family caregivers, and the older person, with the aim of fostering an understanding that death is likely to occur in the foreseeable future can help nurses plan and provide good quality end-of-life care [60], while helping them form the foundations of good death highlighted by Zaman, Espinal-Arango [61].

It was abundantly clear that nurses' intention to provide good quality end-of-life care to their residents was limited by resource constraints. In some instances, this limitation led to undesired outcome such inability to offer comfort and presence to the older person, or hospitalisation. Two recent Australian studies have reported similar findings, indicating that nurses in residential aged care settings encounter difficulties in delivering optimal care at the end of life, particularly in environments with limited resources [62, 63]. The difficulty was evident in the remote service catering to Australian Aboriginal and Torres Strait Islander communities, where limitations in resources and skills resulted in suboptimal care outcomes, including hospitalization. Another study involving rural Australian nurses echoed these findings, highlighting inadequate resources and nursing skills as barriers to providing quality end-of-life care [64]. Given over 7 million Australians live across the vast non-metropolitan geography of Australia [65], including majority (65%) of the Australian Aboriginal and Torres Strait Islander population [66], there is a need to provide adequate resources and training to RAC services and nursing staff in these areas. This ensures they can effectively address the end-of-life care needs of the population they serve.

Strengths and limitations

A major strength of this study is that it gathers information and insights from a range of sites including metro, rural and remote locations. It also further offers diversity in terms of sizes of sites/number of beds (ranging from 20 to 147) and includes services specialising in Australian Indigenous populations. There are, however, some limitations that should be considered when interpreting the findings of this study. Firstly, because of the high level of participation from an organization based in Queensland, the majority of the study's sites were located in Queensland. Therefore, it's important to exercise caution when attempting to apply these results more broadly. Secondly, participants were self-selected, meaning that the findings may not accurately reflect the perspectives of those who chose not to take part in the study. Thirdly, there was limited involvement and input from care workers, so the findings may not be fully representative of their views on integrating technology into direct care practices. Fourthly, as secondary analysis was conducted, there may have been opportunities for nuances or specificities of the research question that may have been missed. Finally, due to COVID-19-related visit restrictions in Australian aged care services during 2020, face-to-face data collection was not feasible, and data were collected virtually. This mode of data collection may have limited participant engagement and the depth of responses. Although data were gathered during the pandemic, the study did not specifically investigate its impact on end-of-life care. Broader disruptions to staffing, visitation, and care delivery may have shaped participants' experiences and should be considered when interpreting the findings.

Conclusion

Caring at the end of life is an essential component of service delivery in residential aged care facilities, where a significant number of older people live and die. Nurses working in this setting have a responsibility to recognise and address the unique care needs of those in their last year of life. Identifying signs of declining health early on is a complex task, especially given the resource limitations of these settings, as well as the complex health conditions often present in the aging population. It is imperative to establish supportive systems to aid nurses in identifying deterioration, delivering palliative care, and fulfilling their roles effectively, so that they could provide high-quality care for residents from the onset of decline all the way through to their death. Additionally, there's a pressing need to foster a cultural shift across health and care environments concerning end-of-life care. Rather than waiting until death is certain and imminent, a proactive approach to care from an earlier stage should be adopted, even when death is not imminent. This shift

aims to ensure that appropriate planning for end-of-life is in place for older individuals and their families to receive optimal care.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12912-025-03411-3>.

Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

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Author contributions

PV and J.T wrote the main manuscript text and PV prepared the supplementary materials. All authors reviewed the manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

This study has adhered to the World Medical Association Declaration of Helsinki and ethical approval for this study has been received from Flinders University Social and Behavioural Research Ethics Committee (8594). All interview participants were informed that participation was voluntary and could be withdrawn at any time. Informed consent to participate was obtained from all the participants in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

1. United Nations. World Population Prospects 2022: Summary of Results. Department of Economic and Social Affairs PD. 2022. Contract No.: UN DESA/POP/2022/TR/NO. 3.
2. World Health Organisation. Palliative care 2020 [Available from: <https://www.who.int/news-room/fact-sheets/detail/palliative-care>]
3. Clark D, Baur N, Clelland D, Garralda E, López-Fidalgo J, Connor S, Centeno C. Mapping levels of palliative care development in 198 countries: the situation in 2017. *J Pain Symptom Manage*. 2020;59(4):794–807.
4. Australian Institute of Health and Welfare. People using aged care 2022 [Available from: <https://www.gen-agedcaredata.gov.au/topics/people-using-aged-care>]
5. Australian Institute of Health and Welfare. People leaving aged care 2022 [Available from: <https://www.gen-agedcaredata.gov.au/topics/people-leaving-aged-care>]
6. Australian Institute of Health and Welfare. Interfaces between the aged care and health systems in Australia—where do older Australians die? 2021. Available from: <https://www.gen-agedcaredata.gov.au/getmedia/269ddea5-fa8d-4b78-9e1b-c8f41c999c2b/Interfaces-between-the-aged-care-and-health-s>

- systems-in-Australia-where-do-older-Australians-die.pdf#:~:text=Hospital%20is%20the%20most%20common%20place%20of,care%20(36%).%20This%20changes%20as%20age%20increases:&text=Among%20those%20who%20die%20aged%2065%20and,(44%20of%20women%20and%2028%20of%20men).
7. Kircher CE, Hanna TP, Tranmer J, Goldie GE, Ross-White A, Moulton E, et al. Defining early palliative care for adults diagnosed with a life-limiting illness: a scoping review. *BMC Palliat Care*. 2025;24(93). <https://doi.org/10.1186/s12904-025-01712-7>.
 8. World Health Organisation. Global atlas of palliative care. 2nd ed. London, UK: WHO; 2020.
 9. Sleeman KE, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson IJ, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Global Health*. 2019;7(7):e883–92.
 10. Palliative Care Australia. Palliative Care in Aged Care 2022 [Available from: <https://palliativecare.org.au/resource/palliative-care-in-aged-care/>]
 11. Mitchell I, Lacey J, Anstey M, Corbett C, Douglas C, Drummond C, et al. Understanding end-of-life care in Australian hospitals. *J Australian Healthc Hosp Association*. 2021;45(5):540–7. <https://doi.org/10.1071/AH20223>.
 12. Australian College of Nursing. The role of registered nurses in residential aged care facilities - Position Statement. 2016.
 13. Australian College of Nursing. Unregulated health care workers - Position Statement. 2019.
 14. Glogowska M, Simmonds R, McLachlan S, Cramer H, Sanders T, Johnson R, et al. Sometimes we can't fix things: a qualitative study of health care professionals' perceptions of end of life care for patients with heart failure. *BMC Palliat Care*. 2016;15(3):3.
 15. Gonella S, Basso I, De Marinis MG, Campagna S, Di Giulio P. Good end-of-life care in nursing home according to the family carers' perspective: A systematic review of qualitative findings. *Palliat Med*. 2019;33(6):589–606.
 16. Bloomer C, Thorn M. Benefits of increasing skills in the care workforce in recognising end of life in dementia patients. *BMJ Supportive Palliat Care*. 2012;2(2):184–5.
 17. Davies K, Reid CM. 34 Recognising the patient with frailty or dementia approaching the end of life – focus group reports. *BMJ Supportive Palliat Care*. 2018;8(Suppl 1):A23.
 18. Lee RP, Bamford C, Poole M, McLellan E, Exley C, Robinson L. 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*. 2017;12(6):e0179355–e.
 19. Browne B, Kupeli N, Moore KJ, Sampson EL, Davies N. Defining end of life in dementia: A systematic review. *Palliat Med*. 2021;35(10):1733–46.
 20. Moon F, Kissane DW, McDermott F. Discordance between the perceptions of clinicians and families about end-of-life trajectories in hospitalized dementia patients. *Palliat Support Care*. 2021;19(3):304–11.
 21. Rona D. Recognising end of life in patients with COPD: the value of collaborative care. *J Community Nurs*. 2020;34(2):46–51.
 22. Lim RBL. End-of-life care in patients with advanced lung cancer. *Ther Adv Respir Dis*. 2016;10(5):455–67.
 23. Higginbotham K, Jones I, Johnson M. A grounded theory study: exploring health care professionals decision making when managing end stage heart failure care. *J Adv Nurs*. 2021;77(7):3142–55.
 24. Dickman K, Carey M, Rao A, Worthington A, Hilton L, Kavanagh R, et al. 47 Knowsley trigger tool - A tool to aid identification of heart failure patients nearing end of life and promote communication between heart failure specialist nurses and primary care. *Heart*. 2014;100(Suppl 3):A26–7.
 25. Daltrey JF, Boyd ML, Burholt V, Robinson JA. Detecting acute deterioration in older adults living in residential aged care: a scoping review. *J Am Med Dir Assoc*. 2022;23(9):1517–40.
 26. Chambers S, Spooner A, Parker C, Jack L, Schnitker L, Beattie E, et al. Clinical indicators of acute deterioration in persons who reside in residential aged care facilities: A rapid review. *J Nurs Scholarsh*. 2023;55(1):365–77.
 27. Nursing ACo. Assistants in Nursing (however titled) - Position Statement 2016.
 28. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. *BMJ*. 2000;320(7227):114–6.
 29. Tobin GA, Begley CM. Methodological rigour within a qualitative framework. *J Adv Nurs*. 2004;48(4):388–96.
 30. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods*. 2006;18(1):59–82.
 31. O'Brien BC, Harris IB, Beckman T, Reed D, Cook D. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014;89(9).
 32. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Res Psychol*. 2006;3(2):77–101.
 33. Byrne D. A worked example of Braun and Clarke's approach to reflexive thematic analysis. *Qual Quant*. 2022;56(3):1391–412.
 34. Tuckett AG. Applying thematic analysis theory to practice: A researcher's experience. *Contemp Nurse*. 2005;19(1–2):75–87.
 35. Olsen NS, Williamson AM. Development of safety incident coding systems through improving coding reliability. *Appl Ergon*. 2015;51:152–62.
 36. Goddard C, Stewart F, Thompson G, Hall S. Providing end-of-life care in care homes for older people: a qualitative study of the views of care home staff and community nurses. *J Appl Gerontol*. 2013;32(1):76–95.
 37. Marshall B, Clark J, Sheward K, Allan S. Staff perceptions of end-of-life care in aged residential care: a new Zealand perspective. *J Palliat Med*. 2011;14(6):688–95.
 38. Kennedy C, Brooks-Young P, Brunton Gray C, Larkin P, Connolly M, Wilde-Larsson B, et al. Diagnosing dying: an integrative literature review. *BMJ Supportive Palliat Care*. 2014;4(3):263–70.
 39. Wallerstedt B, Benzein E, Schildmeijer K, Sandgren A. What is palliative care? Perceptions of healthcare professionals. *Scand J Caring Sci*. 2019;33(1):77–84.
 40. McInerney F, Ford R, Simpson A, Willison M. Residential aged-care workers and the palliative approach: tensions in the field. *J Hospice Palliat Nurs*. 2009;11(6):344–52.
 41. Ryan S, Wong JL, Chow R, Zimmermann C. Evolving definitions of palliative care: upstream migration or confusion? *Curr Treat Options Oncol*. 2020;21(3):20.
 42. Szilcz M, Wastesson JW, Johnell K, Morin L. Unplanned hospitalisations in older people: illness trajectories in the last year of life. *BMJ Supportive & Palliative Care*; 2021.
 43. Guo P, Pinto C, Edwards B, Pask S, Firth A, O'Brien S, Murtagh F, E M. Experiences of transitioning between settings of care from the perspectives of patients with advanced illness receiving specialist palliative care and their family caregivers: A qualitative interview study. *Palliat Med*. 2022;36(1):124–34.
 44. Porock D, Oliver DP. Recognizing dying by staff in long-term care. *J Hospice Palliat Nurs*. 2007;9(5):270–8.
 45. Åvik Persson H, Sandgren A, Fürst C-J, Ahlström G, Behm L. Early and late signs that precede dying among older persons in nursing homes: the multi-disciplinary team's perspective. *BMC Geriatr*. 2018;18:1–11.
 46. Frey R, Barham S, Balmer D, Boyd M, Robinson J, Gott M. Palliative care delivery in residential aged care: bereaved family member experiences of the supportive hospice aged residential exchange (SHARE) intervention. *BMC Palliat Care*. 2020;19(127).
 47. Lynch B, Ryan AA, O'Neill M, Penney S. The factors that influence care home residents' and families' engagement with decisionmaking about their care and support: an integrative review of the literature. *BMC Geriatr*. 2022;22(873).
 48. Glasdam S, Ekstrand F, Rosberg M, van der Schaaf A-M. A gap between the philosophy and the practice of palliative healthcare: sociological perspectives on the practice of nurses in specialised palliative homecare. *Med Health Care Philos*. 2020;23(1):141–52.
 49. Graven V, Petersen A, Timm H. Hospice care: between existential and medical hope. *Mortality*. 2021;26(3):326–42.
 50. Ludlow K, Churrua K, Mumford V, Ellis LA, Braithwaite J. Staff members' prioritisation of care in residential aged care facilities: a Q methodology study. *BMC Health Serv Res*. 2020;20(1):423.
 51. Mitchell I, Lacey J, Anstey M, Corbett C, Douglas C, Hensley M, et al. Understanding end-of-life care in Australian hospitals. *Aust Health Rev*. 2021;45(5):540–7.
 52. Sjoberg M, Edberg AK, Rasmussen BH, Beck I. Documentation of older people's end-of-life care in the context of specialised palliative care: a retrospective review of patient records. *BMC Palliat Care*. 2021;20(91).
 53. Klarare A, Hagelin CL, Fürst CJ, Fossum B. Team interactions in specialised palliative care teams: a qualitative study. *J Palliat Med*. 2013;16(9):1062–9.
 54. Dalgaard KM, Delmar C. The relevance of time in palliative care nursing practice. *Int J Palliat Nurs*. 2008;14(10):472–6.
 55. Bastone E, Bailey C. Spiritual care provision to end-of-life patients: A systematic literature review. *J Clin Nurs*. 2020;29:3609–24.
 56. Bryk A, Roberts G, Hudson P, Harms L, Gerdtz M. The concept of holism applied in recent palliative care practice: A scoping review. *Palliat Med*. 2023;37(1):26–39.
 57. Frey R, Powell L, Gott M. Care vs. care: 'Biomedical' and 'holistic' worldviews of palliative care. *Eur J Integr Med*. 2013;5(4):352–64.

58. Kenny P, Street DJ, Hall J, Agar MR, Phillips J. Community Preferences for the Care of Older People at the End of Life: How Important is the Disease Context? *The Patient-Patient-Centered Outcomes Research*. 2024:1–13.
59. Alruwali AN, Alruwali M, Ramadan OME, Elsharkawy NB, Abdelaziz EM, Ali SI, Shaban M. Compassion fatigue in palliative care: exploring its comprehensive impact on geriatric nursing well-being and care quality in end-of-life. *Geriatr Nurs*. 2024;58:274–81. <https://doi.org/10.1016/j.gerinurse.2024.05.024>. July-August 2024.
60. Skorpen Tarberg A, Landstad BJ, Hole T, Thronæs M, Kvangarsnes M. Nurses' experiences of compassionate care in the palliative pathway. *J Clin Nurs*. 2020;29(23–24):4818–26.
61. Zaman M, Espinal-Arango S, Mohapatra A, Jadad AR. What would it take to die well? A systematic review of systematic reviews on the conditions for a good death. *Lancet Healthy Longev*. 2021;2(9):e593–600.
62. Mitchell G, Melaku M, Moss G, Makoni B, Lewis L, Mutch A. Evaluation of a commissioned end-of-life care service in Australian aged care facilities. *Progress Palliat Care*. 2022;30(4):229–37.
63. Nagarajan SV, Poulos C. Australian residential aged care home staff experiences of implementing an intervention to improve palliative and end-of-life care for residents: A qualitative study. *Health Soc Care Community*. 2022;30(6):e5588–601.
64. Wood M, Forsyth S, Dawson H. Remote area nurses' perceptions of the enablers and barriers for delivering end-of-life care in remote Australia to aboriginal people who choose to pass away on their traditional lands. *Rural Remote Health*. 2021;21(3):1–8.
65. Australian Institute of Health and Welfare. Rural and remote health 2023 08 April 2024. Available from: <https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health>
66. Australian Bureau of Statistics. Estimates of Aboriginal and Torres Strait Islander Australians. 2021 08 April 2024. Available from: <https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/estimates-aboriginal-and-torres-strait-islander-australians/30-june-2021>

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