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Navigating care at the end of life: Perspectives of Australian residential aged care nurses

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Acknowledgement of the country

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ELDAC acknowledges the Traditional Custodians of the many ancestral lands and waters throughout Australia. We recognise the knowledge, strength and resilience of Aboriginal and Torres Strait Islander Peoples, and their continuing spiritual and cultural connections to land, water and community. ELDAC pays respect to Elders past, present and emerging.

Palliative care in residential aged care

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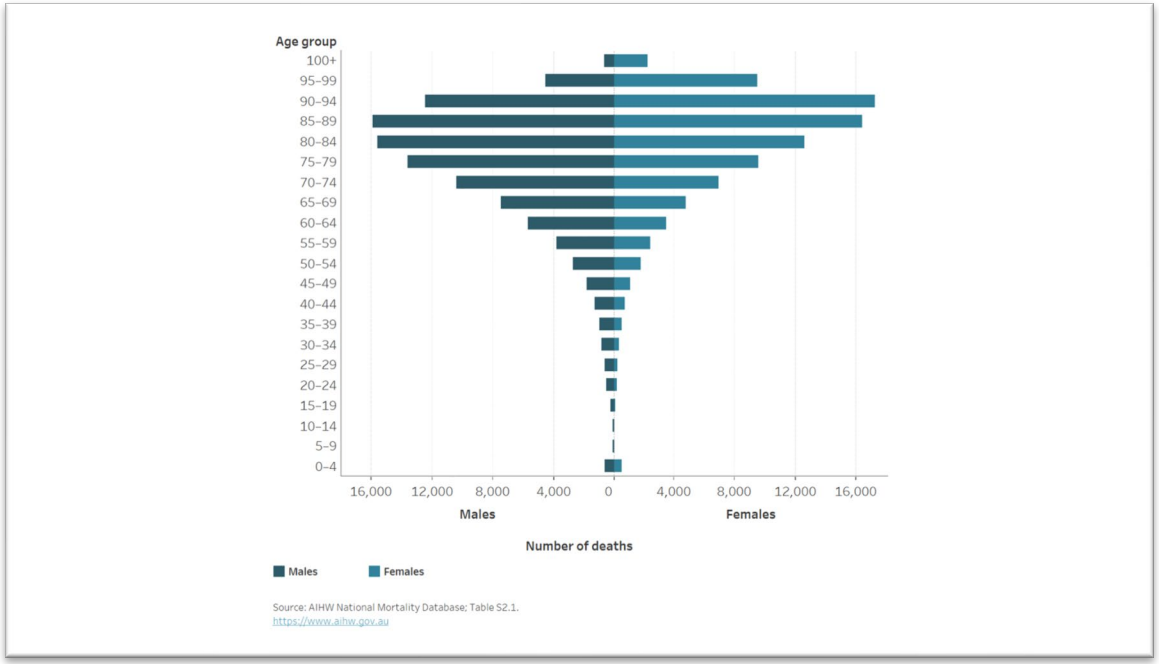
- Residential Aged Care (RAC) provides care and services to over 220,000 Australians. Most exits [83%] from the setting are via death.
- Many older Australians spend their last years living in RAC setting.
    - There is a need to ensure older people receive good quality palliative and end of life care as they experience health decline, deterioration and approach the eventual death.



Nursing role and challenges

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Nurses have a key clinical role in caring for older people in the last years of their life across all settings including RAC.

Growing awareness of the value of clinician recognition of end-of-life, need for EOL planning and care in dementia, lung disease, and heart failure, and identification of acute deterioration detection in older people in RAC.

Limited evidence on how nurses recognise, describe, and address the slow and irreversible health decline that many of their residents experience in the last months of their life

The challenge: Early identification of gradual health decline is essential to understanding and meeting the palliative care needs of the older person, yet somewhat challenging to identify and cater for.

Aim

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To understand how nurses in residential aged care facilities identify, articulate, and address the gradual irreversible decline in the health of their residents.

Methodological orientation

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This qualitative study was part of a larger multi-method implementation study [ELDAC Digital Dashboard Implementation Study] conducted to evaluate the feasibility and merit of implementing a palliative care dashboard into Australian aged care setting.

- Ethics approval was obtained from the Flinders University Human Research Ethics Committee.
- The data reported in this study was collected as part of the pre-focus groups and interviews conducted as part of the larger study.

Participation summary

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Setting

14 RAC sites – Two services included focusing on care for Aboriginal and Torres Strait Islander People

3 States: Queensland; Western Australia, Tasmania

Qualitative interview

6 One-on-One Interviews

11 Focus group discussions

Participants

Nurses; care-managers; clinicians; and admin support

Majority female [86%], employed as RN [56%]

Findings

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

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).

.... 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).

Findings

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Theme 2: Identifying the last months of life is complex

… "*…we find that they are not participating in activities… they are not eating, drinking well …* (RN_Metro).

We had a resident who wasn't palliative but had gone to hospital two or three times in a month …So, this is a sign that the resident is going down… (Manager_Metro).

… there's just that feeling …You just think: they're not taking part in their everyday activities, not showing interest in their appearance. They don't have that general greeting that they give you when they come in … I can't explain it medically (EEN_Rural).

But for the palliative care, I think some other places has something called comfort care? (RN_Metro).

Findings

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Theme 3: Care provision is driven by task orientation

If there is increase in reduced appetite, I assess what's the root cause, and refer to the doctor. ...I can put her [resident] *on a food chart. Then…the physical appearance like the skin turgor, hydration of the skin…* (RN_Metro).

...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).

Findings

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

… the good result is that they [Residents] *are openly talking about their own imminent death. … they want to know what will happen- That's a good result. It reduces fear* (Manager_Metro)

…if a resident is not in the dying stage but they will be there soon, we have a family meeting: "this is what we've got on file for you, is this what you would still prefer for your mum or dad?" (Clinical Lead_Remote).

…you send them to hospital because you think they just might recover… But sometimes the hospital is sort of to-ing and fro-ing and then they [resident] *are just too frail to come back to us. That's the bad result.* (Manager_Metro).

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

What does this mean?

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- Nurses recognise the care requirements of residents undergoing slow, gradual health decline are distinct from those who are actively dying.
- Challenges such as poor conceptual clarity around the identification of the pre-terminal stage and use of inconsistent terminologies make it difficult to identify the early health declines.
- Adding to the challenge was the task-focussed orientation of care delivery, which can limit ability to prioritise holistic wellbeing focused care aligned with the philosophy of palliative care.
- Nurses' intention to provide good quality end-of-life care is limited by resource constraints and task driven approach to care. In some instances, this limitation led to undesired outcome such inability to offer comfort and presence to the older person, or hospitalisation.

What does this mean?

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- Despite challenges nurses are dedicated to provide good quality end-of-life care to their residents, where the residents and their families were involved in early discussions about death and dying and collaborative care planning.
- Resource limitations, particularly in rural/remote areas have the potential to hinder quality care at the end of life, particularly around the need to provide comfort and presence, and can lead to undesired hospital admissions.

Conclusion

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- Identifying signs of declining health early on is a complex task, especially given resource limitations of these settings, as well as the complex health conditions often present in the aging population.
- There is a need to establish supportive systems to help nurses identify early deterioration in their residents and subsequently deliver timely and appropriate palliative care from the onset of decline all the way through to their death.
- Fostering a cultural shift across health and aged around end-of-life caring could support early and proactive identification of health decline among those in the last months of life.

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Any Questions or comments?

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