Aged Care Research
& Industry Innovation
Australia

Evidence Theme

Palliative care

DEMENTIA CARE

This evidence theme on palliative care interventions for people living with dementia summarises one of the key topics identified by a scoping review of dementia research.

Key points

- Communication and cognitive difficulties can contribute to the person with dementia having a range of unmet needs at the end of life, including pain and uncontrolled symptoms. They may also be at risk of receiving burdensome and unnecessary treatments as they approach death instead of the more appropriate comfort care approach.
- Palliative care focuses on reducing symptoms and providing comfort, setting care goals, advance care planning, and involving the family in the circle of care. It can be provided by specialist doctors and nurses or non-specialist general practitioners, nurses, and aged care workers.
- Based on a small quantity of low-quality and contradictory evidence, there is insufficient evidence to know if palliative care interventions are effective in reducing pain and improving symptoms in people with advanced dementia. While there is abundant evidence that palliative care is effective in the aged care population in general, we need better quality studies on palliative care in this vulnerable population.

What is palliative care?

Dementia is a progressive disease that people will either die from or die with. [1] People living with advanced dementia are likely to experience pain and distressing symptoms as they near the end of life. [2] Because they often cannot communicate their needs, they may not receive the pain or symptom relief they require. [3] People may struggle with swallowing (dysphagia) and breathing (dyspnoea) difficulties, amongst others. They might also be given life-prolonging, but potentially burdensome treatments as they approach the end of life. This includes antibiotics for pneumonia, artificial nutrition and hydration for feeding difficulties, or trips to the emergency department. [2, 4] However, as people may live in the advanced stage of this condition for many years, it can be difficult to detect when someone is nearing the end of life. [5]

There is increasing worldwide awareness that palliative care services need to expand to include people with dementia. [6] Palliative care is a multidisciplinary approach to care for people and their families who are facing problems associated with any life-threatening illness. Palliative care focuses on improving quality of life by preventing and relieving suffering from pain or other problems which might be physical, psychosocial, or spiritual. [7] Palliative care can be provided by many types of healthcare providers. People with more straightforward and predictable needs are more likely to be managed in the community by general practitioners, nurses, or care workers with basic palliative care skills. [8] These skills should include the ability to evaluate and manage symptoms causing distress, initiate conversations around goals of care and advance care planning, and manage comorbidities. [1] However, people with complex and persistent needs at the end of life may qualify for specialist palliative care services provided by multidisciplinary teams with specialised skills and training. [8] Currently, only a very small proportion of people living with dementia (6.1 per cent) access specialist palliative care services in Australia. [9]

Are palliative care interventions effective?

Palliative care is routinely provided by healthcare providers as a component of care for people with dementia and is considered best practice, particularly for people with advanced dementia. However, the evidence demonstrating the benefits of approaches to palliative care in dementia remains limited. We found three reviews examining the effectiveness of palliative care interventions on outcomes for people with advanced dementia in the aged care setting. [10-12] Between them, these reviews examined a wide range of interventions, including:

- Staff education on symptom assessment and care [10]
- Family case conferences [11]
- Providing staff with family feedback on the quality of the care they provided to a (deceased) family member [11]
- Namaste Care [11]
- A multicomponent intervention involving staff training, clinical monitoring of pain, regular mouth care, and a structured approach to communication with families [11]
- Artifical nutrition [12]
- Late-stage use of antibiotics. [12]

While the outcomes assessed varied between reviews, patient comfort in dying and symptom alleviation at the end of life were high priorities. One review reported on improved outcomes after staff training to recognise resident needs. [10] These outcomes included:

- A significant increase in hospice referrals
- More staff assessments for pain
- An increased number of Do Not Resuscitate (DNR) orders
- Greater initiation of non-pharmacological treatments
- A significant increase in the number of deaths occurring in the residential facility, rather than a hospital. [10]

The second review found weak evidence of improved comfort in dying across a range of interventions, although the quality of this evidence was rated very low which makes this finding uncertain. [11] Interestingly, despite reporting an increase in pain assessments, studies within the reviews did not report on improvements in pain outcomes (e.g., symptom scores or the number of people receiving pain medication because of these assessments). As physical pain is central to suffering and distress, pain assessment and management should be made a priority for palliative care research in dementia care.

The third review provided evidence on the use of life-prolonging treatments for people with advanced dementia near the end of life. [12] It highlights that:

- Texture modification of food and fluids may be preferable to artificial nutrition and hydration (or tube feeding) for people with swallowing difficulties.
- Allowing the person in the final stages of dying to forego food and fluids does not necessarily cause suffering, provided mucus membranes are kept moist.
- There is some evidence to suggest that the use of IV antibiotics is of little benefit in end-stage dementia. [12]

Evidence limitations

All reviews highlighted concerns about the quality of the research on which they based their findings. This reduces the degree of certainty we might have about the benefits (or lack of benefits) of these palliative care interventions. For example:

- Most review findings were based on a very limited number of studies.
- There was very little similarity between the interventions used to determine the effectiveness of palliative care more broadly, making it difficult to come to strong conclusions.
- Studies assessed different outcomes, making a comparison of findings across studies difficult.

These problems are likely due to the challenges researchers face in trying to recruit this vulnerable population into their studies. [11] However, we clearly need more well-designed studies that can give us a better understanding of how to care for people with advanced dementia and their families at the end of life.

What can an individual do?

- Carers and families are not always aware that dementia is a condition with no cure which will inevitably lead to death. Take the time to know the signs that indicate dementia is progressing. Communicate your thoughts to the team and discuss informing the person's family so that they are prepared.
- Care workers can undertake professional learning about how dementia progresses over time using resources from CareSearch, palliAGED and the ARIIA website.

- People with advanced dementia will often have pain and symptoms they cannot communicate. Be watchful for signs and provide verbal and non-verbal reassurance that their needs have been understood and that you will work to meet them.
- Check the RACGP Silver Book sections on Dementia and Palliative and end-of-life care for practical guidance on care issues.

What can the organisation do?

- Raise the subject of dementia progression with the person living with dementia and their family early and gently return to it now and then. This approach can provide people with time to accept the life-limiting nature of the condition and prepare for the end of life.
- Support home and residential aged care staff to undertake training on palliative care for people with advanced dementia.
- Invite a specialist palliative care team to work with staff regularly to improve their ability to identify unmet palliative care needs. This might be in the form of a Palliative Care Needs Round. These are monthly staff triage meetings lasting an hour where staff discuss the needs of residents at greatest risk of dying or who have a high symptom burden. Download Palliative care needs rounds: The implementation guide for more information (University of Stirling and Calvary).
- Consider purchasing the Australian Pain Society eBook 'Pain in residential aged care facilities: Management strategies', 2nd edition and downloading its accompanying toolkit (free).

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