

# **More research is needed to understand how to provide optimal palliative dementia care to people living at home**

**Commentary on:** Miranda R, Bunn F, Lynch J, Van den Block L, Goodman C. Palliative care for people with dementia living at home: A systematic review of interventions. *Palliat Med* 2019;33(7):726-742

## **Implications for research and practice**

- The EAPC domains provide a useful framework for guiding palliative dementia care for those living and dying at home
- Research is required to better understand how to design and implement palliative dementia care interventions for people living at home

## **Context**

Dementia is a leading cause of death[1] and keeping people with dementia at home for longer is a key governmental goal. There is growing recognition that dementia is a terminal illness and a palliative care approach may be appropriate. The European Association of Palliative Care (EAPC) provides a comprehensive definition of palliative dementia care and a framework for outcomes of good end-of-life care[2]. Palliative dementia care should be continuous, proactive person-centred care with timely recognition of the dying phase whilst providing comfort, psychosocial and spiritual support and avoiding unnecessary burdensome treatments. Despite this recommendation, people living with dementia do not routinely receive good end-of-life care.

## **Methods**

This study reviewed the evidence on palliative care interventions provided for people with dementia living at home. The EAPC framework was used to guide analyses and to identify gaps in the evidence. Four electronic databases were searched for papers reporting on specialist and non-specialist palliative care interventions for people with dementia living at home. Specialist palliative care interventions were included if they addressed physical and psychosocial needs of people with dementia and delivered by palliative care specialists. Non-specialist palliative care interventions were selected if they aimed at improving end-of-life care outcomes such as managing pain and behavioural symptoms for people with advanced dementia. A quality rating checklist was used to assess quality of studies and presented as either strong, moderate or weak.

## **Findings**

Eight studies conducted in the USA (four), UK (one), Italy (two) and Japan (one) were included. Three studies evaluated specialist palliative dementia care interventions whilst five evaluated non-specialist palliative care interventions. Three studies were of moderate quality whilst the remaining five were graded weak. Using the EAPC framework, the authors found that studies focused on continuity of care, symptom management, and psychosocial support. Due to poor methodological quality of studies, the authors were unable to provide conclusive remarks on intervention efficacy and barriers and facilitators to implementation.

## **Commentary**

This timely review of palliative dementia care interventions delivered at home comes at a point when more people are dying with dementia and increasing pressure on health and social care funding and resources means keeping people at home is a global priority.

This review highlights striking gaps in the evidence. Only one study explored the effect of a palliative care intervention on reducing burdensome and potentially unnecessary treatments at the end-of-life. People with dementia experience burdensome transitions near the end-of-life with on average of two admissions in the last year of life[3]. Research is needed to determine how a palliative care approach may address unmet needs of people living with dementia and their carers whilst reducing potentially avoidable treatments and hospitalisation.

With majority of research conducted in care homes this paper emphasises how little we know about how to provide optimal palliative dementia care to people living at home. Limited evidence suggests that palliative care interventions have potential to improve symptom management and address psychosocial needs of people with dementia but these findings come with a caveat of poor methodological quality and inconsistency in the assessment of appropriate outcomes. Using place of death as an indicator of good death may not always be appropriate or the place of the person's choice.

Complexity of dementia and difficulty in recognising the dying phase[4] pose challenges to developing appropriate models of care. Specialist interventions using an integrated, multidisciplinary approach to palliative dementia care with timely input from specialist palliative care services is required to address the complexity of dementia and to reduce fragmented care[5].

Future studies should adopt a mixed methods approach to explore contexts in which palliative dementia care interventions are delivered and potential mechanisms that function as barriers and facilitators to implementation. Better understanding of contexts and mechanisms and how they impact on end-of-life care outcomes will aid implementation and sustainability of interventions in clinical practice.

## References

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