

Journal Watch – Dementia & Non-cancer Illness – March 2018

Article:

End-of-life care: A qualitative study comparing the views of people with dementia and family carers

Poole M, Bamford C, McLellan E, Lee RP, Exley C, Hughes JC, Harrison-Dening K, Robinson L.

Palliative Medicine. Vol. 32(3) 631–642 (October 12, 2017)

Article link: DOI: [10.1177/0269216317736033](https://doi.org/10.1177/0269216317736033)

Review:

Strengths: Addresses a critical research gap. By recruiting current and bereaved carers provided a more balanced perspective between expectation and experience. Produced interesting results that have the potential to inform policy and practice.

Weaknesses: Defined early dementia as having received a diagnosis within the past 3 years, and/or an MMSE score cut off of >20. However, there are several types of dementia and even within the same category they can progress at varying frequencies. Onset of symptoms and time to diagnosis are also variable. Finally, an MMSE of >20 is broad, they did not specify domains of deficiency, nor range of scores among participants. Difficult to know how “affected” patients were at time of study. Topics discussed during the initial Q-sort exercise may have influenced responses in the follow-up interview. We cannot assume that the views of patients in early stage dementia accurately represent those in the more advanced stages of the condition. Small study size. Patients are all from one area in England. The impact of gender was not examined.

Relevance to Palliative care: This study begins to address the disconnect between neurology and palliative care. It is step in identifying areas where additional resources and supports/training may be required to improve the delivery of better quality care. For example, better education around dementia, its prognosis, and common end of life issues. Potential need for a specialist dementia nurse or care coordinator.