

Dying with dementia—how can we improve the care and support of patients and their families

Mari Lloyd-Williams¹, Karen Harrison Denning^{1,2}, Jacqueline Crowther¹

¹Academic Palliative and Supportive Care Studies Group, Institute of Psychology, Health and Society, University of Liverpool, Liverpool, UK; ²Head of Research, Dementia, UK

Correspondence to: Mari Lloyd-Williams. Professor and Director of Academic Palliative and Supportive Care Studies Group, Institute of Psychology Health and Society, University of Liverpool, L69 3GB, Liverpool, UK. Email: mlw@liverpool.ac.uk.

Submitted Mar 29, 2017. Accepted for publication Jun 01, 2017.

doi: 10.21037/apm.2017.06.23

View this article at: <http://dx.doi.org/10.21037/apm.2017.06.23>

Introduction

Palliative care for patients with dementia can be a challenge for clinicians where assessment of symptoms in patients who may not be able to express their needs is difficult and recognising that patients are entering the terminal phase complex. As academic clinicians we will discuss the current situation with a UK focus and review some of the recent research exploring palliative care for patients with dementia.

There are 683,597 people with dementia in the United Kingdom and the number of people with dementia in the United Kingdom is forecast to increase to 940,110 by 2021 and increase further to 1,735,087 by 2051, which is an increase of 38% over the next 15 years. Among those with dementia, at any one time approximately 55% have mild dementia, 32% have moderate dementia and 12% have severe dementia. Severe dementia increases with increasing age, from 6% for those aged 65 to 69 years to nearly 25% for those aged 95 years and over.

Dementia as a disease has gained a much greater profile over the last ten years with several high profile people speaking about the illness and how it affects them, however the media portrayal of dementia tends to be of someone in the latter stages of the disease, frequently living within a Nursing home environment and with a poor quality of life. It should be remembered however that the vast majority of people with dementia live at home in the community and only a third live within nursing home settings. It is also of interest that the proportion of those with dementia living in Nursing homes rises steadily with age, from around 25% of those aged 65–74, to over 60% of those aged 90 and above, where issues such as co-morbidity; general frailty and the

lack of family carers also contribute to Nursing home admission (1).

The World Health Organization's Global Burden of Disease report cited disability from dementia was accorded a higher weight than any other condition, with exception of spinal cord injury and terminal cancer (2). This may reflect the public perception of Dementia, and the fact it has a disproportionate impact on capacity for independent living (3–6). Dementia also has a huge impact on health and social care public funding.

Families carry the majority of the costs for dementia care. Informal care is estimated to involve 1.5 bn hours of unpaid care provided to dementia patients living in the community, valued at £12 bn. The estimated cost of this informal care is more than the combined cost of social care and healthcare for dementia. Each person with severe dementia living in the community requires an estimated 46 h of carer support per week (7,8). If we explore where people with dementia die in the UK, less than 1% die within a hospice setting, approximately 6% die in their own family home, around a third die in hospital and two thirds die within nursing home settings.

People with dementia may have very high needs for a long period of time before they die, and require large amounts of support and care (9). However, people with dementia and their relatives frequently state they wish to be cared for at home but this does not happen (10).

The trajectory of illness for people with severe dementia is difficult and unpredictable. For many families behavioural changes make care difficult as does the absence of any form of respite support at night. Respite is considered essential if

carers are to be enabled to care for a person with dementia within the family home at the end of life.

Day care was historically available for people with dementia to allow social interaction for the person with dementia and a break for their families but only around 2% of people with dementia in the United Kingdom now access day care services. Other forms of respite support involve a "sitting service", however, such support is often sporadic; time limited (usually 2 h/week) and dependent on where the patient resides, for example patients living in a more urban area are far more likely to be offered and to access such a service than someone living in a rural area where services are limited and the long distances involved in travelling to day care make access difficult (11).

The concept of "compassionate communities" has become established where communities are able to utilise their own strengths and resources, if allowed and encouraged to do so, in order to support people living in their communities with life limiting illness and at the end of life and several models of care have been established (12). Some are based on a good neighbour scheme where volunteers are matched with a carer and by mutual arrangement will be in weekly or fortnightly contact. Others have a specific remit to support patients who are nearing end of life and their families, e.g., Ashworth Time Bank in rural Cheshire matches volunteers specifically with families, and offer simple well-being interventions, e.g., hand massage, all with aim of supporting carer to continue to care at home for a person with dementia for as long as possible (13,14).

Multi-morbidity and dementia

Many people will also have other illnesses and disabilities in addition to their dementia. As with dementia, multi-morbidity correlates with age, representing the most common 'disease pattern' found among older people, and is characterised by complex interactions of coexisting diseases for which a medical approach focused on a single disease does not suffice. Common multi-morbid conditions include cancer, cardiovascular disease, diabetes and musculoskeletal disorders such as fractures.

Multi-morbid medical conditions are often positive predictors of mortality in dementia, although dementia itself can be the strongest predictor of mortality, with the risk being two to three times greater than those of other life-limiting illnesses. Multiple conditions not only have a cumulative effect but also interact to have a greater

impact than their sum total, and this is even more so in dementia. Moreover, people with dementia are more likely to experience under-assessment and under-treatment of any multi-morbid condition than people with other long-term conditions.

These illnesses and conditions, in addition to the dementia, often present generalist clinicians and family carers alike with practical problems in managing treatment regimens or in understanding the prognosis of this mix of diseases. It is often when a multi-morbid condition threatens the life of the person with dementia family carers find decision-making particularly difficult, especially in situations where the person with dementia is no longer able to make decisions for themselves. Such events can expose the fact that carers may not fully understand the life-limiting nature of dementia.

Frailty (the generalised physical and mental decline associated with advanced age) and dementia are becoming a focus of interest and study. People with dementia and frailty are at higher risk of acute hospital admission, falls and being placed in a care home. Despite the effect that dementia and frailty have on older people and their families, they have not traditionally been conceptualised as 'terminal' or 'life-limiting' conditions. There is also a perception that people with dementia live for many years into the advanced stages of the disease. A recent UK population study gave a median survival time from diagnosis of dementia to death of 4.1 years (15).

Recognising the end of life in dementia

Identifying when an older person with dementia is reaching the end of their life is not always easy. Some have attempted to identify prognostic indicators to guide practice and when to adopt a more palliative approach to care. However, these tools have been found more reliable at identifying people with dementia at low risk of dying than those at higher risk of death (16). Clinical judgement, discussion with families and carers, and taking the opportunity to reassess or shift the goals of care towards palliative care, especially at times of acute, inter-current illness or care transition, may be a more practical and reliable approach.

Being aware of the impact of acute illnesses in addition to dementia should alert clinicians to the possibility that a person with dementia may be nearing the end of life. For example, acute physical illness requiring emergency hospital admission, such as pneumonia or urinary tract infection, may be an indicator of imminent death in people

with advanced dementia, but it is difficult for clinicians to determine what may be treatable and whether treatment is in the best interests of the patient. There is very little evidence suggests that active interventions such as artificial hydration and nutrition or hospital admission prolong or improve the quality of life in people with dementia (17). However, there is a growing interest in how a palliative approach may be beneficial for frail older people with advanced dementia (18).

Palliative and end-of-life care in dementia

Historically, many older people and their carers have reported that palliative care services had not been available to them. This was doubtless due to the fact palliative care services had been concentrated on people with cancer and specialist needs. The eventual inclusion of dementia in palliative and end-of-life care and policy and guidance has resulted from several contributory factors: the increasing numbers of people with dementia, concerns about inappropriate interventions and treatments at the end of life, and discrimination that limits access to palliative and end-of-life care services (19).

Dementia affects the whole family, and people close to the person with dementia find themselves providing increasing amounts of care and support as the disease progresses. Hence those delivering care must be mindful of the whole family unit and the relationships therein. Often generalist services and resources that may be appropriate for people with dementia find it difficult to understand their role. Many express limitations in their knowledge and skills in caring for people with dementia (7).

Advance care planning (ACP) comprises discussions about and documentation of an individual's wishes and preferences for future care whilst they still have capacity to do so (20). ACP and such discussions are important and can be deemed critical for nursing home residents with dementia and should be revisited often, especially with each change in condition (21). Having these discussions and documenting wishes can help facilitate access to the most appropriate palliative and end of life care when the time arises. This will also support relatives who may have unresolved emotional needs arising from both witnessing the disease and institutionalisation of a family member and find making end of life care decisions on behalf of the person with dementia difficult and be reluctant to do so (22).

Planning for care at the end of life is beset with uncertainty, even when the carer and the person with

dementia perceive their care-giving/receiving relationship is good (23). Families affected by dementia may benefit from early and ongoing practical and emotional support to prepare for potential changes and aid decision making in the context of the realities of care towards the end of life.

Acknowledgements

None.

Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

References

1. Dementia Care prevalence Calculator. Available online: www.primarycare.nhs.uk
2. European Association of Palliative Care. Recommendations on palliative care and treatment of older people with Alzheimer's disease and other progressive dementias. Available online: <http://www.eapcnet.eu>
3. Denning KH, Jones L, Sampson EL. Preferences for end-of-life care: a nominal group study of people with dementia and their family carers. *Palliat Med* 2013;27:409-17.
4. Lloyd-Williams M, Abba K, Crowther J. Supportive and palliative care for patients with chronic mental illness including dementia. *Curr Opin Support Palliat Care* 2014;8:303-7.
5. Crowther J, Wilson KC, Horton S, et al. Compassion in healthcare - lessons from a qualitative study of the end of life care of people with dementia. *J R Soc Med* 2013;106:492-7.
6. Crowther J, Wilson KC, Horton S, et al. Palliative care for dementia--time to think again? *QJM* 2013;106:491-4.
7. Denning KH, Greenish W, Jones L, et al. Barriers to providing end-of-life care for people with dementia: a whole-system qualitative study. *BMJ Support Palliat Care* 2012;2:103-7.
8. Sampson E, Mandal U, Holman A, et al. Improving end of life care for people with dementia: a rapid participatory appraisal. *BMJ Support Palliat Care* 2012;2:108-14.
9. Lawrence V, Samsi K, Murray J, et al. Dying well with dementia: qualitative examination of end-of-life care. *Br J Psychiatry* 2011;199:417-22.
10. Davies N, Maio L, Rait G, et al. Quality end-of-life care for dementia: What have family carers told us so far? *A*

- narrative synthesis. *Palliat Med* 2014;28:919-30.
11. Scott S, Sampson EL, Jones L. The Compassion programme: looking at improving end-of-life care for people with advanced dementia. *Int J Palliat Nurs* 2012;18:212, 214, 216-7.
 12. Spotlight on Dementia Care: A Health Foundation improvement report. Available online: <http://www.health.org.uk>
 13. In Good Faith—Building Compassionate Communities. Health and Social Care Alliance, Scotland Alliance, 2013. Available online: <http://www.jitscotland.org.uk>
 14. Denning T, Denning KH. Palliative care in dementia: Does it work? *Maturitas* 2016;83:1-2.
 15. Xie J, Brayne C, Matthews FE, et al. Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. *BMJ* 2008;336:258-62.
 16. Sampson EL, Harrison Denning K. Palliative and End of life Care. In: Denning T, Thomas A. editors. *Oxford Textbook of Old Age Psychiatry*. Oxford: Oxford University Press, 2013:359-69.
 17. Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev* 2009;(2):CD007209.
 18. van der Steen JT, Radbruch L, Hertogh CM, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014;28:197-209.
 19. Miura Y, Asai A, Matsushima M, et al. Families' and physicians' predictions of dialysis patients' preferences regarding life-sustaining treatments in Japan. *Am J Kidney Dis* 2006;47:122-30.
 20. Robinson L, Dickinson C, Bamford C, et al. A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...'. *Palliat Med* 2013;27:401-8.
 21. Chang A, Walter LC. Recognizing dementia as a terminal illness in nursing home residents: Comment on "Survival and comfort after treatment of pneumonia in advanced dementia". *Arch Intern Med* 2010;170:1107-9.
 22. Sarabia-Cobo CM, Pérez V, de Lorena P, et al. Decisions at the end of life made by relatives of institutionalized patients with dementia. *Appl Nurs Res* 2016;31:e6-e10.
 23. Hospice UK. Hospice enabled dementia care: The First Steps: a guide to help hospices establish care for people with dementia, their families and carers. London: Hospice UK, 2015.

Cite this article as: Lloyd-Williams M, Denning KH, Crowther J. Dying with dementia—how can we improve the care and support of patients and their families. *Ann Palliat Med* 2017;6(4):306-309. doi: 10.21037/apm.2017.06.23