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Palliative care for dementia—time to think again?

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Summary

It is estimated that there are 35.6 million people with dementia worldwide and this is projected to increase to over 115 million by the year 2050. Dementia is a progressive neurodegenerative disease that significantly reduces survival. End-of-life care received by this group is often poor and does not equate to that offered in other life limiting illnesses.

This review highlights results from a large UK study of informal carers of people with dementia to

explore what are determinants of care for people with dementia and their family carers. New perspectives as to models of care for end-of-life care for patients with dementia are discussed together with how these may be implemented and delivered within wider community settings and contexts, where many people with dementia may be cared for in the future.

Introduction

It is estimated that there are 35.6 million people worldwide with dementia with a projected increase to over 115 million by 2050.¹ Within the UK, the prevalence of dementia is estimated at around 820 000.² Dementia affects one in five of the population older than 85 years³ and an ageing population means more people are living and dying with dementia and by 2051 it is estimated that there will be approximately 1.7 million people with dementia in the UK. Research suggests that end-of-life care received by this group is often poor^{4,5} and does not equate to that offered in other life-limiting illnesses. Results of a recent UK qualitative study exploring end-of-life care experiences of informal carers of people with dementia indicate that little has changed in the past 10–20 years (J. Crowther, unpublished results). A geographically focused

service evaluation is underway to address these problems at a local community level in an attempt to establish which services are required and whether a more specialized approach for end-of-life care for dementia can and should be developed.

Dementia is a progressive neurodegenerative disease that significantly reduces survival⁶ and is predominantly a disease of older age. The symptoms, consequences and trajectory can be unpredictable affecting not only the person with dementia but also their families and those closest to them.

What happens during end-of-life care?

A national, qualitative study was undertaken in the UK (2008–11) exploring experiences of informal carers of people with dementia. This was in an

Table 1 Characteristics of participating bereaved carers

Bereaved carers ($n=40$)	
Place of death	
District general hospital	22 (55)
Care homes	14 (35)
Family homes	4 (10)
Gender	
Male	10 (25)
Female	30 (75)
Relationship to person with dementia	
Husband	7 (17.5)
Wife	17 (42.5)
Son	3 (7.5)
Daughter	10 (25)
Other family	2 (5)
Friend/neighbour	1 (2.5)
Age range: 18–86 years	
Range of time spent caring: 18 months to 20 years; average time: 5.1 years	
Range of time since death: 3 months to 5 years; average time: 1 year 9 months	

Values are given as n (%).

attempt to determine underlying needs for end-of-life care for people with dementia and their family carers. Sample characteristics can be found in Table 1.

The research consisted of in-depth interviews with bereaved family carers of people with dementia which were digitally recorded and transcribed. Field notes were also used to supplement interpretation and analysis.

Death occurred in many different environments, e.g. district general hospitals, nursing and residential care homes and four occurred within a family home. Five themes emerged: carers as experts; kindness, humanity and compassion in care; the hard work of caring; living and dying with dementia in the face of uncertainty and communicating in a world of chaos and unpredictability. There were only four referrals to specialist palliative and end-of-life care services amongst the sample and these referrals were all made as the person with dementia also had a known and confirmed diagnosis of cancer. It is of interest that patients with a dual cancer and dementia diagnosis were more likely to be referred to palliative care services; however, a dual diagnosis of dementia and another life-limiting chronic illness did not appear to trigger specialist palliative care services referral. Results indicated communication and compassion were fundamental to the successful delivery of palliative and end-of-life care.

This study identified issues separating dementia from other life-limiting illnesses. It also identified and highlighted the importance of a humane and compassionate approach. Importantly, it added to

the dearth of literature regarding personal experiences of dying with dementia and issues contributing to difficulties with the provision of standard models of palliative and end-of-life care for this patient population. Issues which included the often prolonged 'dying trajectory' and issues regarding inappropriate admission of patients from care homes to hospital at the end of life. Half a million people die each year in the UK. A third of these are frail, elderly and suffering from dementia.⁷ This vulnerable group of patients tend to die in hospital where recognition of care of the dying is not a core role.⁸ Mitchell *et al.*⁹ argue that dementia patients at the end of life require access to high-quality specialized care. However, despite the growing prevalence and huge morbidity associated with dementia, these patients are still receiving suboptimal palliative care.

Results from the UK study informed further studies focusing on a local level within Cheshire in North West England. The views and practices of all carers (informal family and formal paid carers) of people with dementia who may be in their last year of life and approaching death are being determined from within a range of care provision and caring environments, i.e. family care, 24-h care, district general hospitals, primary care, mental health services, domiciliary care, third sector and voluntary organizations. Information is being collected via qualitative interviews and survey-based questionnaires. Early results from the current study indicate that there is much work and investment required on a local level. This is across care environments and contexts in order to support the desired reduction of inappropriate hospital admissions and subsequent deaths in this environment for people with dementia nearing end of life. Although not yet analysed, we believe much of the findings will be applicable to other areas within the UK.

Gott and Ingleton¹⁰ suggest older people are less likely than younger people to have access to specialist palliative care and more likely to die in settings where concerns have been raised about the quality of end-of-life care provided, notably hospitals and care homes. Many professionals and voluntary agencies are involved in the provision of dementia care during the last year of life and time surrounding death. Diverse interventions may be required and different groups may become involved at different times dependent on levels of need. The person with dementia may require the involvement of specialist dementia services, speech and language therapists, physiotherapists, social workers and primary care colleagues. Specialist palliative and end-of-life care services may also be engaged to support with symptom assessment and

management. The coordination and timely referral to all these services is also a challenge.

Frequently more intervention may be required by family carers who may experience high levels of stress and distress as the illness progresses. In the UK, social care via day centres, respite care and input from the third sector and voluntary organizations such as Age UK or the Alzheimer's Society may be involved and also the Admiral Nursing service, a service to support carers funded by a charity Dementia UK, can be of huge support to patients and their families but this service is not available within every geographical area. One of the first models of dementia care was that of Scott and Pace¹¹ in the South of England which demonstrated that while there was a need for a specialist dementia service, the service which was developed did not experience the very large number of referrals to the service or onto hospice care that had been predicted suggesting that generalists do have the ability and skills to appropriately refer people with dementia to more specialist end-of-life and palliative care services.

Due to the predicted increase in incidence and prevalence of dementia, we need to consider the role of both generalists and specialists. Generalists are those who have not received accredited levels of palliative care training but who routinely provide care for people including those with dementia at end of life. Specialists are those who have received accredited training within palliative care and who focus on more complex cases and provision of support to generalist colleagues through partnership working.¹²

A community approach

Palliative and end-of-life care should not be viewed solely in the context of generalists and specialists within health care. It needs to be considered in the wider community context and include those who provide a number of support services, i.e day care, respite care, befriending, hospice, domiciliary and 24-h care. Kellehear¹³ and Heath¹⁴ argue that the community has a responsibility to support and care for their own in relation to death and dying. They suggest that death needed bringing back into the arena of life. End-of-life care has been medicalized and taken over by the professionals. Heath¹⁴ argues that this needs to be relinquished back to local communities. This is synonymous with both Kellehear's vision for compassionate cities and communities and the UK government focus on developing 'dementia friendly communities'.¹⁵ Discussions regarding the most suitable environments in which to

provide end-of-life care for people with dementia will continue. Reducing the number of inappropriate hospital admissions for people with dementia as they approach their death is a priority in the UK. Increasing the number of deaths within family homes where this is desired requires investment within local communities, support for families and an increase in services, both generalist and specialist, if this is to become a realistic option for end-of-life care. The demands of an ageing population suggests that need will increase—the social imperatives of a community approach and encouraging local communities to be involved with the care of people at the end of life, including those dying with dementia, will be vital to providing support for a greater number of deaths within the family home. People dying with cancer in the UK are offered a 'preferred place of end-of-life care'—in terms of equality should a preferred place of care also be offered to people with dementia and their families?

Conclusion

Has end-of-life care for older people with comorbidities improved for our generation? Kellehear¹⁶ argues an overly romanticized historical picture bears little relation to realities of abandonment and mercy killing of older people practised by our hunter-gatherer ancestors.¹⁰ As in modern day, frail older people were viewed at times as a problem for society, although Kellehear¹⁶ argues that dying was historically viewed as an inevitable part of living. Kellehear concludes that recognizing the inevitability of dying and discussing within families and communities, as well as at a service and policy level, is fundamental to ensuring a humane response to the growing demand for end-of-life care for our increasing ageing populations whatever illness they may experience.

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