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Editorial Open Access

End-stage Dementia: A Challenge to Palliative Care?

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Fulfilling the needs of people with dementia is one of the biggest challenges to health and social care services in western societies. At the time of writing in 2012, the number of people with dementia in the UK is estimated to be 800,000 and this figure is set to rise [1]. The UK National Institute for Health Research prioritised research and development in improving outcomes for people with dementia with announcements of successful commissions in the autumn of 2012 [2]. Further, good quality end-of-life care and the entitlement to palliative care by all adults who need it is a clear priority for the National Health Service and enshrined in many care pathway documents [3]. In other words, the problem is not being ignored and the recognition of the need for people with dementia to receive good quality end-of-life care is part of the government's rhetorical response. However, demographic change, resource constraints and the public spending cuts in the UK might make the rhetoric of providing palliative care to all who need it impossible to achieve. In what follows I explore why provision is not the only challenge.

Defining Dying

Within the extension of palliative care to all the provision of palliative care for those people with dementia who are dying raises specific challenges and two of these are the foci of this brief editorial. First, the distinction between 'living with dementia', where independent living can be sustained and 'dying with dementia', in which people are entitled to palliative care, is difficult to make. This is because the trajectory of dementia is far from straightforward. Dementia is contested as a terminal illness and classified as life-limiting, even though the median survival rate is 18 months from admission to care home [4]. While two thirds of people with dementia live at home, one third are cared for in nursing/care homes and hospital settings especially at the end of life [1]. In a review of the literature on palliative care for people with dementia Sampson [5] highlights how medical and nursing staff overestimate prognosis in advanced dementia. The reality is that in these settings it is most likely that the period of dying will be narrowly defined as the last few weeks or even days [6].

Cox and Cook [7] warn against taking a simplistic approach to dying with or from dementia by locating the problem of dementia within the affected individual. They argue that training in a social model of disability alongside a palliative and person-centred approach, one can help care home staff to deliver good quality end-of-life care. Further, this new culture of care would allow for a better involvement of people with dementia and their carers at the end of life.

Despite the promotion of such models of care, evidence suggests that the quality of care for older people with dementia leaves much room for improvement [8]. Kellehear [9] reminds us that dementia is not solely a medical problem and argues that 'people without money, influence or well-functioning memories are less likely to have good quality care at the end of life'.

Facilitating Choice

A second area of concern lies in the area of choice. Autonomy and choice is central to the UK's NHS National Service Framework for Older People [2]. Palliative care as the gold standard of end-of-life care also has person-centred care as its central ethos. Compromised autonomy from the cognitive impairment that is so often part of dementia increases the challenge to palliative care practitioners in facilitating choice.

The tension between autonomy and acting in someone's best interests is not new. In relation to end-of-life care, along with others, Meisel [10] argues that autonomy might wield a kind of tyranny over end-of-life decision making. Fundamentally, Meisel argues, individuals do not exist in isolation; rather they live in a complex set of relationships. In dementia care, this tension is brought into sharp focus and Nolan et al. [11] argue for 'relationship-centred care' as a viable alternative. Such arguments highlight the reality that when autonomy is so seriously compromised other forms of establishing need have to be found. However, the way that the need for care is interpreted could be part of the problem. For example, by defining dementia predominantly by its physical symptoms and locating it at the level of the individual. Certainly, the case that end-of-life care has been increasingly medicalised [12] has resulted in pleas for recognising and strengthening the social elements of care.

Of great concern is that the inadequacies of end-of-life care for people with dementia fuels the strong lobby, often led by celebrities with early-stage dementia, who argue for the right to die before the illness becomes too distressing. For many who fear loss of respect for autonomy as one of the worst possible symptoms at the end of life, the freedom to choose when to die (often by assisted suicide) is presented as the only viable option.

Assessment and Conclusion

The purpose of this editorial is to stimulate debate about some of the challenges to the 'greying' societies of the 21st Century. One alternative could be to look at models of palliative care that do not start from here but rather from resources within the community. For example, in Kerala in Southern India, faced with an ageing population and despite limited resources, a model of palliative care has been developed which relies on community support and trained volunteers and which successfully reaches a high percentage of the population [13]. This model uses the best that palliative care has to offer within a social model of care. Here dying is less of a sequestered event to be feared and handled only by professionals – death is part of life and good quality end-of-life care part of the skill of the community.

Such a public health model of care could be the solution as Kellehear advocates [14]. However, the real challenge of converting the institutionally rooted medical model to one that can respond the exponentially growing model of need to avoid shameful deaths and opting for assisted suicide as the preferred solution remains.

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