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‘Caregivers for dying older people: an investment for the future’

Paper to be presented by

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Caregivers for dying older people: an investment for the future'

'Mirror, mirror on the wall, who's the fairest of them all?' (Snow White: The Brothers Grimm)

This well known children's rhyme reminds us of the perils of vanity. It was said by the wicked older queen, when the lovely young Snow White was in the room and the mirror did not lie. I take this as my theme in this talk about caregivers of people dying in late old age as I will argue that current idealisations, policies and services have a romantic and arguably unrealistic notion of what it means to die in late old age. So in this talk I will focus on three elements of dying when older in which current policies and practices fail to fully understand issues for caregivers of frail older people:

- Models of the 'good death'
- Place of care and place of death,
- The availability and role of family carers

In the United Kingdom, 83.5% of all deaths occur in those over 65 years and evidence suggests that older people are 'the disadvantaged dying' having less access to health and social care services than younger people (Seymour, Witherspoon, Gott, Ross and Payne 2005). Current data on ageing of the population in Western European countries indicate between 14-18% of the population are over 65 years, and 3.3-5.2% are over 80 years (Hoeftler 2010). There is a predicted to be a major increase in those over 80 years in the future.

Models of the 'good death'

It is our common fate to die but the manner and timing of our deaths vary (Nuland 1994) and the meanings accorded to these deaths are culturally and historically determined (Field et al 1994). For example, Young and Cullen (1996) provide a rich and vivid account of dying and death in the East End of London, areas of the city that are now unrecognisably changed from the narrow rows of terrace houses where families and neighbours all knew each other, to very expensive but anonymous, high-rise apartments where wealthy city workers live. Arguably what has emerged in the last few decades are a number of narratives that construct 'death and dying' within particular ways (Clark, 2002). For example, 'medicalised deaths' that are presented as 'emotionally and spiritually empty, clinical, hospitalised, alone and dehumanised' have been compared with those taking place in the home, hospices or specialist palliative care units.

Hospice movement have created a 'narrative' about the good death which comprises of the following features:

- Aware and cognitively intact
- Surrounded by family members and friends
- Pain and symptoms controlled, emotionally controlled and 'hygienic'
- Dying from a clearly identifiable and 'named' disease – normally in the UK and many parts of Europe is this cancer, with a relatively predictable dying trajectory
- Acceptance of one's fate
- Autonomy and individual choice

- Cared for in the ‘safe’ surroundings of a ‘nice’ and ‘homely’ hospice

What is the reality of dying for frail older people?

- High levels of dementia, confusion which may be longstanding or transient
- Spouse may have already died, family geographically dispersed or out-of-touch, peers and siblings may also have died.
- Pain may be under-recognised, other symptoms may be over or under treated (Seymour et al 2005)
- Co-morbidities – living with many conditions and dying from (or with) a number of chronic conditions – may be hard to determine exactly what the person will die from.
- Lack of awareness of diagnosis eg COPD and heart failure (Gott et al 2007). Prognostication difficult.
- Therefore general awareness that death is possible and may even be desired (some people may feel that they have been living too long).
- Little perceived choice and often no real choice
- Autonomy may not be valued to the same extent as by younger people
- Cared for in care homes (nursing homes) which may vary in quality. The Netherland has specific medical specialisation in this area but many other countries do not. In UK, care homes are generally not regarded as high status or desirable places to die, and there may be concerns about the quality of end of life care (Froggatt and Payne 2006).

As Gott et al (2008) have argued, palliative care services in the UK have largely developed services for middle aged and younger patients with cancer, which are based on a specific type of dying trajectory and a model which prioritises awareness and acceptance, autonomy and individual choice, in the context of family engagement with the dying person. What is argued here, is that this fails to acknowledge the different experiences and preferences of older people dying in late old age.

Place of care and place of death

In the UK, there is a divergence in reported preferences for dying at home (approximately 50-60%), compared to under 20% who do so, although there are marked regional variations (Higginson and Sen-Gupta 2000). In England and Wales, the End of Life Care Strategy (Department of Health 2008) has prioritised enabling patients to make choices about place of care and aims to increase home death rates. However, there is a growing critique that these policies fail to acknowledge the needs and preferences of older people (Gott 2008) and that home deaths may not be regarded as feasible or appropriate by them (Gott et al 2004; Thomas et al 2002).

The availability and role of family carers

Within Europe there are estimated to be 100 million family, friends and neighbours providing care, whose contribution to care often exceeds the financial expenditures of their countries on formal nursing services although it is difficult to estimate exactly how many are engaged in caring for a person near the end of life (Eurocarers: European Association for Working

Carers, 2008). In the UK, Help the Hospices estimates that at any one time approximately half a million family members are providing care to a dying person (Heatley 2006). Despite the important work that carers contribute there is increasing evidence that they are often unprepared for the many demands they might face and they experience considerable physical, psychological, social and financial challenges (Hudson and Payne 2008). In this paper, family carers will refer to all people with a close social and emotional bond, not just those related by kinship or marriage (NICE 2004). In late old age, family carers may themselves be older people, such as a spouse, and with differential longevity, older women often survive their spouses and have no immediately available care providers. Increasingly older people have to rely on intergenerational care which may be impacted upon by changing roles for women, with more of them in paid employment, combined with economic mobility in many parts of Europe (Payne et al in press).

The availability of family carers able and willing to provide care at home is a major determinant in achieving a home death for cancer patients and a major reason for admission to hospital is breakdown in family care (Thomas, Morris, and Harman 2002; Gomes and Higginson, 2006). While this central role for carers is increasingly acknowledged there remain major knowledge gaps in how to provide appropriate support to them during the dying phase (Grande et al 2009). When the home becomes the site of care for dying older people, the relocation of care work from institutional to domestic settings can create tensions between home and new types of work-site that can fundamentally challenge the meaning of home. Formal care workers entering the home need workspaces that are clean, hygienic and efficient for the purpose of delivering care (McKeever 2001). This frequently requires the reorganisation of domestic space to accommodate the ‘paraphernalia of care’ (for example, a hospital bed, commode, etc). Whilst such artefacts are routinely available in institutional settings, these spaces can be organised to conceal some of the more disconcerting features in ways that cannot be easily achieved in domestic settings (Roberts and Mort 2009). There has been only limited investigation of the ways in which the importation of artefacts associated with institutional care can affect the meaning attached to the domestic home (Milligan 2000; Gott et al 2004). Yet older people and their carers are unlikely to welcome the reordering of the home as a clinical work space, instead placing value on the home as a private, comfortable and aesthetically pleasing space that is imbued with personal memories and a sense of history and belonging.

The differing requirements of home and work for older people, informal and formal caregivers mean that the physical and symbolic meaning of the home must constantly be negotiated as both a site of care and of social and personal life. The significance of home as a social space, for example, points to why healthcare providers may encounter resistance from older people and their families in their attempts to reorganise domestic settings to accommodate the end of life care needs of the care-recipient, for example the provision of Hospice at Home services (Phillipson 2007). Hence the desire to improvise or subvert the logics of care aids in order to retain a sense of home produces an ambiguity of place for both carer and care-recipient – one that brings home and care into tension as the aesthetics of health care systems jostle against the aesthetics of home.

So while professional care workers and equipment related to care provision within the home may be beneficial to the carer and care-recipient, they also transgress the social space and ‘normal’ domestic functioning of the home, creating a change in the meaning and sense of home. Work around end of life care and ‘place of death’ suggests that whilst older people may initially prefer to be cared for by family carers within the home, contrary to

expectations, as levels of care needs intensify, the nature of home changes such that many would prefer to be cared for elsewhere (Brown 2003; Gott et al 2004). Any attempt to understand the implications and experiences of policies designed to support the home death for older people and their family care-givers thus brings into focus the complexity of the home both as a site of social interaction and personal meaning – and as a site of care that brings both the public and the private into tension (Milligan 2009). These ‘felt’ changes in the home environment may have important embodied health effects for family carers both during the process of providing care and in the lasting memories of that experiences in bereavement.

Conclusion

This paper has identified that current models of end of life care may espouse values and preferences that are not shared by older people and their caregivers. Moreover, models of the ‘good death’ that have emerged from the modern hospice movement fail to acknowledge the particular challenges facing older people and their caregivers. Contemporary policy directives likewise may not adequately address the preferences of older people approaching the end of life and their caregivers. Family members may find themselves in an unfamiliar situation about which they lack knowledge and experience. The home therefore becomes transformed as both a site of care work and emotional safety. These tensions are little recognised within the palliative care literature and may account for the failure to understand and design interventions best suited to support family carers of older people.

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Basic statements

1. Family carers are central to the provision of palliative care for older people.
2. Contemporary models of palliative care have largely been developed to meet the needs of middle aged and younger people with cancer.
3. This paper highlights the tensions in providing care at home for older people.

Questions

1. In what ways to preferences and experiences of dying vary in older versus younger people?
2. What happens to notions of 'home' during the process of providing end of life care for an older person?
3. What are the challenges facing family carers of older people?