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Palliative care in residential care facilities: a brief review

Jeanne Samson Katz

The article by Kristjanson, Walton and Toye in this issue describes the Western Australian context of caring for older people dying in residential care. This response will very briefly draw on some of the work done in this area in the UK, Australia and the US. In the past few years several edited collections have provided extensive information about both the dearth of research as well as ongoing research in this area (e.g. Hockley and Clark, 2002; Katz and Peace, 2003; Morrision and Meier, 2003).

Twenty per cent of all deaths in the US occur in nursing homes (Buchanan et al, 2002) and 21% in the UK die in care homes (Froggatt, 2004). As Kristjanson et al point out, research in social gerontology has rather neglected the condition of older people as they approach death. This possibly reflects the lack of hard data, and some might suggest lack of interest in the plight of older people deteriorating and dying in all settings. Other than substantial work in South Australia by *Maddocks and Parker et al (2000, 2001)*, where not only was there recognition of these problems but also development of training for residential care workers in palliative care, till the mid 1990s there was relatively little research in the UK into aspects of living while dying of older people in different settings. Bearing in mind that the hospice movement was developing at a phenomenal pace, it is surprising that the palliative care needs of this sector were relatively neglected.

Studies have been undertaken into the quality of dying and management of death in care settings (Sidell et al, 1997; Katz et al, 2000; Froggatt, 2000, 2001a, 2001b; Keay and Schonwetter, 1998; Maddocks and Parker, 2001). A team from the Open University examined the way in which death and dying were managed routinely in the then different types of care homes (now all called care homes) in England (Sidell et al, 1997; Katz et al, 1999; Komaromy et al, 2000; *Katz et al, 2000b; Sidell et al, 2000; Katz et al, 2001; Katz and Peace, 2003*).

One disturbing finding was that substantial numbers of dying residents are transferred to hospital in their last days of life (Sidell and Komaromy, 2003). Decisions to transfer a resident were taken by the physician not always in consultation with the resident and the family. Home staff often agreed with these decisions because they recognized they might not be able to meet the needs of dying residents. Some of those residents who died in the home were observed to experience suffering and pain similar to those reported in the article in this issue by Kristjanson et al. The same team then undertook a second study that investigated staff training needs in caring for dying residents (*Katz et al, 2001a; Sidell, 2003*). These studies concluded, not dissimilar from Kristjanson et al, that caring for dying residents created stress for carers in these institutions and that delivery of high quality care to dying residents was hard to achieve.

Avis et al (1999) and Froggatt et al (2000) explored the potential input of community palliative care services in nursing homes in the mid 1990s, particularly exploring how advice and training could be provided by these 'experts' to residential settings. Where community palliative care exists in the UK, it provides opportunities for dying people, along with their informal carers, to participate in the decision making about whether and where to receive treatment and where it is practicable to die. Until recently (when Macmillan Cancer Relief deputed nurses particularly to cover this sector), an anomaly of community palliative care provision was that primary care teams rarely enlisted their support in relation to residents dying in care homes. One explanation for this might be that palliative care operates from a different paradigm from care home philosophy and some contend that the latter may have its own 'successful' ways of accommodating dying residents' needs (Froggatt 2001, 2004).

Key to addressing the fundamental needs identified by Kristjanson et al (addressing pain and symptom distress, how to respond to the less clear needs of residents with

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- Dementia
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dementia and meeting the needs of relatives) is improving the skills of carers through appropriate training. The national minimum standards for care homes for older people (Department of Health, 2001) specifies that in each care home 50% of carers need to have achieved National Vocational Qualifications in social care. Although these do not focus particularly on palliative care these, combined with the facilitated training developed by the Open University team (Macmillan Cancer Relief, 2004) and the Australian team (Maddocks et al, 2000) should help carers to build on their experience and acquire new skills in palliative care. Postgraduate training is also available on line from Australia (www.flinders.edu.au/courses/postgrad/palliative_aged) and should equip more potential researchers with academic skills to undertake studies into meeting older peoples' needs and understanding training needs of care workers in these settings. An area urgently demanding further research identified by Kristjanson as well as Morrison and Meier (2003) is how to establish and then address the palliative care needs of demented patients. This is clearly a major challenge to palliative care and gerontology researchers.



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