

Hospices and care homes—similarities and differences in relation to palliative care

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Built in 1967, St Christopher's Hospice in the UK heralded the beginning of the modern hospice movement with the first teaching/research-based hospice (1). It wasn't that there were no hospices in the UK at the time, but it was Dame Cicely Saunders who saw the need for specialty training and research in "terminal care", as an important addition to both health and social care.

I had the privilege of working at St Christopher's Hospice as a ward sister from 1979 to 1982. I left in order to take the hospice vision into the hospital setting (2,3)—and then on still further into the care home setting (4). It was when I was visiting Dame Cicely in the early 2000s that I noticed a book on her bookshelf that I recognised, "*The Care of the Aged, the Dying and the Dead*", first published in 1935 by Professor Worcester (5). It was as though things were coming full circle. Dame Cicely had been inspired by a professor of medicine from the USA while starting the hospice movement in the UK. I had been inspired by Dame Cicely to take what I had learnt from the hospice movement back into UK care homes.

As early as 1989, Balfour Mount highlighted the similarities between palliative care and geriatric practice:

"Both make the whole person and his or her family the focus of care, while seeking to enhance quality of life and maintain the dignity and autonomy of the individual. Judicious use of investigations is advocated and both eschew unwarranted treatment while providing symptom control and relief of suffering. Both are necessarily multi-disciplinary and both are areas which prompt phobic reactions from society at large. Finally both Geriatrics and Palliative Care are new medical technologies which challenge the restorative, often aggressive and increasingly technological practices in technological areas of medicine (6).

Building a model of palliative care for frail older people in care homes

However, I would like to suggest that despite similarities addressed by Balfour Mount in the above paragraph there are also differences (see *Table 1*) (7).

Over the last 15 years, I have worked with care home staff on a number of research and quality improvement initiatives. I believe there are more subtle differences between palliative care and geriatrics that we need to be alert to if we are not going to impose a model of palliative care developed for cancer onto the care of frail older people at the end-of-life.

A vivid memory stands out, some years ago now, when I was asked by a matron of a nursing care home to assess the level of pain of a resident who had advanced dementia. I confidently went to do the assessment—an assessment that I had done many times before in various roles as a nurse specialist in palliative care—not realising then how different it is undertaking an assessment with someone who cannot tell you the intensity of their pain, its frequency and location etc. I shamefully took the resident at their word, without paying attention to their mobility, and reported to matron that her pain was not a problem. The importance of a totally different way of assessing pain in people with advanced dementia and those with cancer began to dawn on me. My skill as a specialist palliative care nurse was not as transferable as I had thought! I realised for the first time that I could not directly impose what I had learnt from specialists in palliative care onto frail older people in care homes, and that there were sophisticated symptom assessment tools for people with advanced dementia that needed to be used such as PAINAD, DOLOPLUS-2,

Table 1 Differences between cancer palliative care and end-of-life care in the elderly dying (Hockley 2002) (reproduced with kind permission from Open University Press, Buckingham MK18 1XW)

| Cancer palliative care | End-of-life care in the elderly dying |
|--|--|
| Focus in one disease process | Multiple disease processes |
| Emphasis on dying in mid-age or younger when life is generally seen as being 'cut short' | Natural ending of life often understood by both the resident and those caring within the context of care homes |
| Clearer concept of "prognosis" so terminal care can be planned | Often quicker dying trajectory following a more dependent, lengthier disease process |
| Professional holistic relationship between patient and staff | Often a much closer/emotional relationship between resident and care home staff as resident becomes "part of the family" and may have lived in the care home over a year |
| More support from family/friends | Less support from family/friends—often care home staff and other residents seen as family |
| Both patient and family often want life extended | Elderly, frail people in nursing homes frequently speak about dying and that it would be nice "to go to bed one night and not wake up" |
| Morphine and other medication frequently used to control symptoms | Pain requiring strong opioids less common |
| Multidisciplinary model of care | Nurses and care workers having the greatest input of care |
| Patients more often cognitively intact | Greater percentage of residents in nursing homes are cognitively impaired |

(8,9), Pain assessment tools that are not done at the patient bedside with the patient like in specialist palliative care but undertaken instead with those (formal carers and family) who know the person with advanced dementia and who are caring regularly for them. It is the formal and informal carers who can report levels of facial grimacing, crying out, resisting care, adopting defensive positions, not eating etc. It is these aspects that combine to form the assessment.

There are also differences in the actual dying phase. In frail older people "distress" might not necessarily be pain; often anxiolytics are more important than opiates (10). I saw specialist palliative care nurses prescribing opioids in syringe drivers with little awareness of the accumulation of the opioids, and the sudden distress caused from hallucinations, because of the reduced renal function in older people. Older people naturally have a tendency to become dehydrated if not encouraged to drink because of reduced thirst perception as part of the ageing process. I began to see the importance of developing a model specific to the needs of frail older people in care homes.

Furthermore, the terminology used in the different professional backgrounds is not easily transferable. "Palliative care" is widely used within hospices, and within the acute oncological setting. However, within geriatrics/medicine for the elderly where rehabilitation has underpinned much of the care, "palliative care" can be

misinterpreted as care during the last days of life and so seen as "giving up". Just as it was right to create different pain assessment tools for people with advanced dementia, and to reconsider the different medications at the very end of life, so it is important to be mindful of different terminology.

In a recent submission to *Age and Ageing* (11), we were challenged as authors by the use of the term "palliative care". Under the reviewers' guidance, we felt it right instead to substitute our use of palliative care with the word "frailty" in order to embrace the language of geriatrics/medicine for the elderly. Although the principals of palliative care are relevant to older people as well as cancer, there is a need to respect the vocabulary and mind-set of each specialty one works alongside to enable them to practise holistic care and future care planning.

Just as Dame Cicely saw the need for a specialty training as part of the new hospice movement, so we have a vision for a teaching/research-based care home (<http://www.ed.ac.uk/usher/primary-palliative-care/themes/all-settings/establishing-a-care-home-centre-of-excellence-inno>). This is not new for the USA (12). However, for us in the UK it is. There are now 3 times the number of care home beds compared to all the hospital beds in the UK. Care homes are an industry that has been created relying on health and social care support from within the community. However, with reduced community support and increasing frailty of

residents within care homes, there is a need for specialty training in care homes in order to create proper pathways for career development especially for formal carers and nurses. It is a vision that takes aspects from what we have learnt from the hospice movement and what we have learnt from our work with frail older people in care homes, increasingly those with advanced dementia. The use of volunteers (both young and those who are retired from full time work), student placements, a nursery/crèche for care staff are just a few of the innovative aspects.

Conclusions

From my experience of having worked over twenty years within specialist palliative care and then developing high quality palliative care for frail older people in care homes for the last fifteen years, I believe unless one is very careful there can be a danger of imposing skills developed within the cancer population onto other specialties. It is important that in the case of frail older people in care homes both the language used and care given are developed alongside rather than imposed.

Aspirations for a teaching/research-based care home centre of excellence could revolutionise care in care homes in the same way that Dame Cicely challenged the care for people with terminal cancer.

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None.

Footnote

Conflicts of Interest: The author has no conflicts of interest to declare.

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