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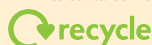


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Dying in the dark? Strengthening the contribution of palliative care to advanced dementia care

I have recently been involved in a project for the Older Person's Commissioner for Wales, exploring the views of health-care staff toward whistleblowing. This has included gathering data in a number of settings such as nursing homes and acute units for older people. We have also been asking final-year student nurses about their experiences of caring for older people and how they might raise concerns if they felt that care was not as good as they expected. This project is very different to my usual research interests, which have recently been focused on the needs of teenagers and young adults.

Exploring the care needs of older people at the end of life—especially those with dementia—has led me to question the applicability of much palliative care ideology to those who may not be able to respond to questions about pain or fears, and whose dying trajectory is a prolonged and often exhausting experience for family members who must first adjust to loss of the person, sometimes years before mourning the loss of the life.

What we have found so far is that those working with the most vulnerable want to provide kind, compassionate, and individually tailored care, but their ability to do so is shaped by their individual motivation and capacity, as well as the setting and culture in which they work and the resources available to them. Adversity in this context may arise owing to increasing demands, fewer staff, diminishing resources, and lack of reward, training or leadership (Maben et al, 2008). Low morale, burnout, and stress among staff are also known to have a negative impact on care (The Boorman Review, 2009). Alternatively, improvements in each of these areas could help to enhance resilience in staff and so improve care quality.

In a recent issue of IJPN, colleagues Barber and Murphy (2011) argue for more evidence to guide specialist palliative care nurses in relation to the care of older people with dementia. This is an important message given the official statistics suggesting that almost a quarter of a million people in the UK are now living with dementia—and some dementia charities argue that a more accurate estimate is probably double this figure owing to undiagnosed cases being supported by carers at home until they can no longer cope.

If this is the case then it is time to shine a light on end-of-life care provision in advanced dementia, and to develop new approaches to palliative care practice, research, and education. There are a number of unique challenges to be considered, not least of which are the many physical and emotional demands of caring for patients who may be unable to respond or provide positive feedback in a way that many palliative care professionals may be used to—and derive a sense of success and reward from. Researching whistleblowing has led me to question why care standards for older people can sometimes deteriorate so much, and why the excellence that has been developed in palliative care cannot be translated to meet the needs of more and more older people who are, it seems, currently dying in the dark.

Daniel Kelly

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