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Pushing forward the cause of palliative care in dementia

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Conflicts of interest statement:

There are no conflicts of interest in writing this piece, although I am committed to the cause of improving the quality of care for people with advanced dementia. In pursuing this commitment I have become aware of the pioneering work of Professor Volicer, one of the authors of the paper being commented on, whom I am now honoured to count as a personal friend.

Pushing forward the cause of palliative care in dementia

It is, perhaps, amazing that a paper published in 2009 on symptoms in advanced dementia should warrant much comment. After all, dementia has been around for a very long time. And yet, a recent paper by Mitchell and colleagues is timely and very important.¹ Why?

It is a timely step in terms of pushing forward the cause of palliative care in dementia. In 323 nursing home residents with dementia in the Boston region, over the course of 18 months, 54.8% died.¹ Hence, a main implication of the paper is that advanced dementia is a terminal condition; in which case, palliative care becomes an appropriate response. Furthermore, the paper demonstrates prospectively the significant morbidity associated with advanced dementia in US nursing homes. The study found that the probability of pneumonia was 41.1% and the six-month mortality rate from pneumonia was 46.7%. There was a slightly higher probability of developing a fever (52.6%), but a similar mortality rate (44.5%). The probability of eating problems was 85.8%, but the mortality rate was lower at 38.6%. Roughly 40% experienced distress caused by either dyspnoea or pain. Given that palliative physicians already deal with these sorts of end-of-life issues, their expertise is pertinent. It may be that this expertise should be reserved for complex cases, but the implication is clear: a palliative care approach with appropriate interventions (without investigations or treatments that would be ineffective or burdensome) is required.

Much is already known about advanced dementia. Mitchell and colleagues¹ cite an important study, which showed (albeit retrospectively) that people dying with dementia had symptoms and health care needs comparable with cancer patients.²

They do not acknowledge significant data that has emerged from the Netherlands in recent years concerning advanced dementia in nursing homes.³ Of course, the differences between practice in the USA and Europe have to be kept in mind. In this American study, 7.3% of people with advanced dementia received some form of tube feeding.¹ This figure would be lower in the UK, but we should also keep in mind that practice and attitudes are not uniform across Europe. For instance, the important role of nursing home physicians in the Netherlands undoubtedly influences the culture of care and the quality of research in Dutch nursing homes.³ The Boston study was not based on detailed, day-to-day observations of patients in the advanced stages of dementia, but on quarterly reviews of the notes and interviews with the nurses. So episodes of distress might have been missed and the study did not comment on the quality of care.¹ Nonetheless, this paper provides an informative, rigorous, prospective view of morbidity in advanced dementia.

In what other ways is the paper important? It shows there are things to be done and, in my view, not only in nursing homes. There will be many people with advanced dementia living in their own homes who will also benefit from skilled medical, nursing and social interventions to ease their suffering. People admitted to hospital with dementia – in this study 12.4% were hospitalized in the last three months of life¹ – need to be treated appropriately too. In a recent UK hospital study, 24% of those with severe cognitive impairment died during their admission, with an adjusted mortality risk of just over four; and in those admitted from nursing homes the prevalence of dementia was 91.9%.⁴

Wherever they are, people with advanced dementia require expert care, which must be holistic in at least two senses. First, distress in severe dementia does not always have a physical basis and various psychosocial approaches may be the most suitable means to alleviate suffering. Secondly, dementia usually involves other people, who have to (amongst other things) make decisions for the person for whom they care. The evidence in the recent study suggests healthcare proxies who have an understanding of prognosis in dementia are more likely to accommodate less aggressive end-of-life care.¹ It may be that advance care planning would help.³ There is some evidence that incorporating such an approach can be effective.⁵

This paper¹ is also important in terms of the conceptual issues it raises. Clinical decisions are, at one and the same time, ethical decisions. End-of-life care in dementia emphasizes this point. What will often be at issue is the need to withhold investigations or treatments. Clinicians need to be clear about the professional, ethical and legal frameworks that govern such decisions.

Research is also necessary, but the issues are complex and need sophisticated methodology. For example, there are no accepted gold standards (despite numerous instruments) to measure distress, suffering or pain in severe dementia when the person cannot communicate. Deciding on what constitutes a good outcome if, for instance, antibiotics are withheld is, therefore, problematic and necessitates clear thinking and good clinical judgements.

Such issues focus attention on the apparent dichotomy between care and cure. A huge emphasis is placed on the importance of early diagnosis in dementia. To some extent

this is encouraged by talk of a cure. Part of the importance of the paper¹ is that it highlights the enormity of the task of caring for people with dementia. It may, in any case, be that the dichotomy is illusory: palliative care is not solely about caring at the expense of curing. Perhaps we need the notion of supportive care, which emphasizes a broad approach to people with dementia from the time of diagnosis until death, with attention being paid to the complexities of bereavement.

Finally, this paper¹ should amaze us in that it implies, because of the high morbidity and mortality coupled with the increasing prevalence as society ages, that dementia should be mainstream. This should not be a peripheral concern for medicine, requiring merely ‘Cinderella’ services. What is required is a new attitude and a new imperative. In society at large, as recently suggested in the UK by the Nuffield Council on Bioethics, there should be an attitude of ‘solidarity’: people with advanced dementia remain our ‘fellow travellers’.⁶ It is amazing that the medical implications of this still have to be pointed out, but good that they have been.

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