

Guest editorial

End-of-life care issues in advanced dementia

CT Sudhir Kumar

Honorary Consultant Psychiatrist, Comprehensive Dementia Care Project, Alzheimer's and Related Disorders Society of India, Cochin, Kerala, India

Jacob Roy Kuriakose

Chairman, Alzheimer's Disease International, London, UK

ABSTRACT

Appropriate management of advanced dementia requires it to be recognised as a terminal condition that needs palliative care. Interventions during this stage should be carefully chosen to ensure the improvement or maintenance of the quality of life of the person with dementia. Advanced care planning is an important aspect of dementia care. Carers and relatives should be

educated and encouraged to actively participate in discussions related to artificial nutrition, cardiopulmonary resuscitation (CPR) and other medical interventions.

Keywords: advanced dementia, end-of-life care, palliative

Caring for someone near the end of their life is an integral aspect of dementia care. The advanced stage of dementia is recognised as a terminal illness; however, many relatives and health professionals find it difficult to acknowledge this. Creating awareness about advanced dementia is therefore essential. It is important to focus on dementia as a disease that starts affecting the brain, but then, as it progresses, affects the whole body. This will result in the shift from aggressive medical treatment to palliative care in advanced dementia. There are differences in end-of-life care for patients with dementia and those who are still cognitively aware.¹ Issues associated with end-of-life care share certain aspects with those suffering from various other degenerative diseases, but there are some unique challenges as well.

In a condition like advanced dementia, it is beyond the skill of doctors to give an accurate estimation of how long the patient is going to live. Researchers have been working on tools to estimate the lifespan of people with dementia in the advanced stages of the disease. The terminal stage is often defined by a set of symptoms that include rapid irreversible deterioration on a day-to-day basis, the inability to eat orally, changes in breathing patterns,

weight loss, lack of mobility and semiconsciousness. Towards the end of their life, a person with dementia (PwD) is usually unable to communicate and also becomes completely dependent on others for day-to-day living. They are usually doubly incontinent, frequently have infections like pneumonia and are troubled by bed sores.

Ways should be found to provide quality person-centred care for advanced dementia. Ethically appropriate care in advanced dementia consists of several principles. Good person-centred care responds to the needs of the individual patient successfully. There has been a steady increase in the number of dementia patients receiving palliative care in hospices in the developed world,² but this has not received considerable attention in the developing world. Many also question the transference of a patient in the end stages of life to an unfamiliar setting. Slowly but steadily, end-of-life care in dementia is moving towards a palliative care approach. Access to specialist palliative care should be based on need.³ Even towards the end of life it is possible to help the person have a good quality of life and a dignified death. Families need to be educated about nutrition, cardiopulmonary resuscitation (CPR) and

pain management to help them actively take part in decision making. During the decision-making process, religious and cultural aspects of care should also be considered.

Advanced care planning (ACP) is also essential in dementia. It refers to a process of discussing an individual's preferences for care they would like to receive at a time when they may no longer be able to make such decisions or be able to make their wishes known. It is quite difficult to know the best time to carry out ACP in dementia as the patient loses the capacity to make decisions as the disease progresses. Many consider it unacceptable and inappropriate to discuss end-of-life issues and death with patients who have dementia and their relatives as it might be a traumatic experience. However, a recent qualitative study has shown that ACP done for people with memory problems and dementia soon after diagnosis can be acceptable and perceived as a positive and useful intervention. Carers found it helpful to know the patient's wishes in case they had to make a decision on behalf of the patient in the future.⁴ Advance directives, in which a person with dementia can indicate his or her wish to refuse medical treatment, have been associated with reduced family stress.⁵

Even though dementia is an illness that affects one's cognitive abilities, it is often not an all-or-nothing phenomenon, even in an advanced stage of the disease. Carers should be sensitive about the body language, reactions, gestures and facial expressions of the PwD since they are valid guides to their feelings and preferences. There definitely will be times when the PwD is able to express him/herself very clearly and the people around them should stay alert to these instances so that they can understand their preferences and wishes. Every effort should be taken to explain things to the PwD. Even in places where there is no equivalent of a legally valid advanced directive, efforts should be taken to document in detail the PwD's expressed wishes, especially regarding artificial nutrition, CPR, ventilating and medical treatments, and they should be honoured as far as possible. People close to the patient would be good advocates to let the medical team know about their values and possible choices.

Artificial nutrition is a sensitive issue and a difficult decision to make for professionals and relatives alike. At some stage of the disease, many patients stop eating. Patients in an advanced stage of dementia do not eat for several possible reasons, including impaired swallowing, fear of choking, aspiration, lack of taste and aversion to food. Progressive loss of learned behaviour is a core feature of dementia. As commonly believed, tube feeding may not increase survival rates in severe dementia.⁶⁻⁹ There is also some evidence to suggest that tube feeding is not

associated with improved nutritional status, prevention of pressure ulcers or reduced infections.¹⁰ Lack of eating may not be associated with pain or discomfort.¹¹ It should be a carefully considered decision whether to tube feed someone who cannot consent or understand what is happening as it is a procedure that has discomfort and several complications. In most cultures, providing food for survival is a basic aspect of love and care and withholding it equates to starvation and suffering, which would evoke severe feelings of guilt. Transcultural aspects of care beliefs should be taken into account in all decision making.¹² Feeding patients small amounts of food by spoon, giving small sips of fluids, keeping the mouth and lips moistened and good oral care are more important than tube feeding in most patients.

What constitutes appropriate medical care and how invasive can the interventions be for someone with advanced dementia? A helpful guide to medical decision making would be whether the procedure provides any long term benefit and the amount of discomfort associated with it. When in doubt, it would also be helpful to consider whether the PwD would have wanted it if he/she was able to make the decision, judged by his/her decision making and actions from the past. Carers should be actively involved in all decision making processes. The discussion should be geared towards withholding aggressive interventions without tangible benefits. The treating team should identify a surrogate decision maker for the patient based on the patient's previous wishes or the closeness of the relationship. They should explain in detail the possible prognosis and the medical treatments available. It should be the responsibility of medical personnel to educate the family about the benefits and burdens of each treatment option. This should be explained in detail and information leaflets should be provided if possible. After this discussion there should be some clarity in the relative's mind as to what the appropriate treatment is and what would be burdensome and invasive to the patient, impairing their quality of life. Diagnostic tests and procedures should be carefully chosen to ensure that they have some bearing on improving quality of life. Stressed relatives who want the best for their loved ones can sometimes forget that the most invasive and aggressive tests and treatment may not necessarily contribute to a better quality of life. It is often the responsibility of the professional to focus the attention on quality of life. Aggressive interventions should be replaced by good quality palliative care resulting from effective care co-ordination. The focus should be on symptom management and developing specialist palliative care services.

There are several other decisions that the treatment team must make and care components they have to be aware of. These include the management of pain, the use of CPR, ethnic differences and spirituality. The impact of pain on the behaviour of a PwD is becoming more recognised. Adequate pain management is an important aspect of good quality care and carers should be educated on how to recognise, identify and monitor pain.¹³ There have been ethical concerns about applying the traditional default of using CPR in end-stage dementia patients, which can have untoward effects. Using this default is flawed in end-stage dementia patients as a large majority of patients would not have wanted it. There have been proposals of using no CPR in end-stage dementia as the default unless specifically chosen by the patients in an advance directive or by a surrogate decision maker.¹⁴ Behavioural and psychological symptoms associated with dementia will remain a challenging issue, even in advanced stage. Aggression and resistance to care may be indicators of unmet needs such as under-detected or undertreated pain, delirium or infection.¹⁵

Families go through varying degrees of feelings of loss, depression, anxiety, guilt, frustration and hopelessness, and often they do not get an opportunity to express their feelings as they are too busy with caring for the patient and fear being judged. It is important to provide family carers with space and time to talk about their own feelings. They should be equipped to deal with anticipatory grief. The multidisciplinary care providers should be mindful of this as studies have shown that ethnic group differences exist in end-of-life care experiences among carers, even though carer pressures are similar. Disparities in end-of-life care for people with dementia from ethnic minority groups appear to exist, possibly because of the double disadvantage of dementia and ethnic minority status.¹⁶

The training of nursing and auxiliary staff in hospitals and care homes in the palliative care approach is essential to improve their knowledge and skills in this area. Even if there are ethical and practical difficulties in conducting good-quality research in advanced dementia, there should be no reason not to use a palliative care approach in dementia management. Palliative care specialists emphasise that identifying and responding to the physical care needs of the PwD must form the cornerstone of any approach.¹⁷ There are several care models, such as the Gold Standard Framework (GSF), that focus on care in the last year or months of life, or, like the Liverpool Care Pathway (LCP), focus on the last days and hours of life. GSF is a systematic approach for professionals to provide good quality care at the end of life.¹⁸ GSF emphasises good com-

munication, coordination, control of symptoms, continuity, continued learning, carer support and care of the dying. There should be regular communication and information-sharing between the family and the professionals involved in care to ensure improved quality of care and avoid confusion, mistrust and misunderstanding so that everyone involved is aware of what is happening.

REFERENCES

- 1 Sampson EL, Gould V, Lee D *et al.* (2006) Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age and Ageing* 2006; 35:187–9.
- 2 Miller SC, Lima JC and Mitchell SL. Hospice care for persons with dementia: the growth of access in US nursing homes. *American Journal of Alzheimer's Disease and Other Dementias* 2010;25:666–73.
- 3 Harris D. Forget me not: palliative care for people with dementia. *Postgraduate Medical Journal* 2007; 83:362–6.
- 4 Poppe M, Burleigh S and Banerjee S. Qualitative evaluation of advanced care planning in early dementia (ACP-ED). *PLoS ONE* 2013;8(4):e60412. doi:10.1371/journal.pone.0060412.
- 5 Engel SE, Kiely DK and Mitchell SL. Satisfaction with end-of-life care for nursing home residents with advanced dementia. *Journal of the American Geriatrics Society* 2006;54:1567–72.
- 6 Mitchell SL, Kiely DK and Lipsitz LA. The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. *Archives of Internal Medicine* 1997;157: 327–32.
- 7 Fisman DN, Levy AR, Gifford DR *et al.* Survival after percutaneous endoscopic gastrostomy among older residents of Quebec. *Journal of American Geriatric Society* 1999;47:349–53.
- 8 Sanders DS, Carter MJ and D'Silva J. Survival analysis in percutaneous endoscopic gastrostomy feeding: a worse outcome in patients with dementia. *American Journal of Gastroenterology* 2000;95:1472–5.
- 9 Meier DE, Ahronheim JC, Morris J, *et al.* High short-term mortality in hospitalized patients with advanced dementia: lack of benefit of tube feeding. *Archives of Internal Medicine* 2001;161:594–9.
- 10 Sampson EL, Candy B and Jones L. Enteral tube feeding for older people with advanced dementia. *Cochrane Database Systematic Review* 2009;15(2): CD007209.
- 11 Pinderhughes ST and Morrison RS. Evidence-based approach to management of fever in patients with end-stage dementia. *Journal of Palliative Medicine* 2003;6:351–4.
- 12 Van der Steen JT, Hertogh CM, de Graas T *et al.* Translation and cross-cultural adaptation of a family booklet on comfort care in dementia: sensitive

- topics revised before implementation. *Journal of Medical Ethics* 2013;39:104–9.
- 13 Scherder E, Herr K, Pickering G, *et al.* Pain in dementia. *Pain* 2009;145:276–8.
- 14 Volandes AE and Abbo ED. Flipping the default: a novel approach to cardiopulmonary resuscitation in end-stage dementia. *Journal of Clinical Ethics* 2007;18:122–39.
- 15 Sampson EL. Palliative care for people with dementia. *British Medical Bulletin* 2010;96:159–74.
- 16 Connolly A, Sampson EL and Purandare N. End-of-life care for people with dementia from ethnic minority groups: a systematic review. *Journal of American Geriatrics Society* 2012;60:351–60.
- 17 Lawrence V, Samsi K, Murray J, *et al.* Dying well with dementia: qualitative examination of end-of-life care. *British Journal of Psychiatry* 2011;199:417–22.
- 18 SCIE. *End of life care for people with dementia*. Social Care Institute of Excellence, 2013. www.scie.org.uk/publications/dementia/endoflife/index.asp (accessed 31/07/2013).

ADDRESS FOR CORRESPONDENCE

Jacob Roy Kuriakose, Alzheimer's Disease International, 64 Great Suffolk Street, London SE1 0BL, UK. Tel: +91 (0) 488 522 3801; email: kjacobroy@gmail.com