

Clinical and Ethical Issues in Palliative Care and Dementia – An Overview

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Abstract

The prevalence of dementia across Europe and the world is increasing. People die with and from dementia and, as such, advanced dementia can be considered a terminal condition. This, alongside the realisation that care for people with dementia is deficient, has led to increasing interest in palliative care in dementia. Palliative care can be a rather broad term with different meanings, but nonetheless guidelines and expert opinions have been developed with the aim of improving overall care for people with dementia. Although at times the evidence on which these guidelines are based is somewhat sparse, they provide guidance in specific areas relevant to dementia. The main areas covered are pain, infection and fevers, artificial nutrition and hydration, resuscitation and psychological, social and spiritual needs. We shall consider the evidence on which guidance is based and then highlight a recent ethical framework developed to help thinking around the issues that arise in dementia care.

Keywords

Artificial nutrition and hydration, dementia, ethics, fever, infection, palliative care, pain, psychosocial approaches, resuscitation, spirituality

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Since the prevalence of dementia is increasing as the population ages, estimates of the number of people with dementia are constantly being adjusted; the current estimate is that 7–8 million people in Europe have got dementia.¹ In 2010, the number of people in the world affected by dementia is estimated to be 35.6 million.² People die with and from dementia, which is well known to be under-reported on death certificates.³ Dementia may well be the third leading cause of death.⁴

In a recent study in Boston involving 323 nursing home residents with dementia, 54.8% died over an 18-month period.⁵ There is a known association between poor cognitive function and increased mortality.⁶ Similarly, increasing cognitive impairment and severity of dementia was associated with higher mortality in a cohort of older people admitted acutely to a hospital in the UK.⁷ The implication of such findings is that advanced dementia is a terminal condition; if this is the case, palliative care seems to be an appropriate response.⁸

With the increasing interest in palliative care in dementia,^{9–17} it is perhaps surprising that a systematic review found little evidence to support its efficacy in advanced dementia.¹⁸ However, this may reflect terminology and underlying conceptual issues.

The terminological difficulty is that there is a whole host of components involved in palliative care – such as withdrawing or

withholding treatment, for instance – that may not show up in a search for ‘palliative care’ alone. This in turn reflects underlying conceptual difficulties, because ‘palliative care’ suggests everything from the palliative care approach, applicable to all chronic conditions from the time of diagnosis, to end-of-life care, where palliative care is understood to apply specifically to a person’s last few days.¹⁹ There are also practical difficulties: for example, it can be difficult to recognise when the person with dementia is actually entering the dying phase and prognostication remains tentative despite indicators such as general dependency, hip fractures and the need for artificial feeding proving useful.¹² Nevertheless, the holism of palliative care does seem relevant to dementia, whether at the time of diagnosis, when advance care planning may be appropriate,^{20,21} or at the time of death, especially if this approach to care is located within the broader framework of supportive care.^{22,23}

A greater awareness of the possibilities offered by palliative care for people with dementia has been driven by the accumulating evidence that their care is deficient. They are less likely to be referred to palliative care or to have attention paid to their spiritual needs and more likely to receive non-palliative interventions.²⁴ They have also been shown to be at higher risk of adverse events, iatrogenic harm and greater functional decline.²⁵ They receive less analgesia than non-cognitively impaired patients.²⁶ They experience similar morbidity in their last year of life to people with cancer,²⁷ and the morbidity is as severe.^{5,27}

The realisation that dementia care, especially at the end of life, is often inadequate and the recognition of the relevance of a palliative care approach has led to the development of guidelines or expert opinions concerning aspects of palliative care for people with dementia. This guidance tends to represent a synthesis of the latest evidence on particular aspects of care for people dying with or from dementia.²⁸ However, there is recognition that the evidence available is neither necessarily particularly high quality nor sufficient. What follows is a summary of the main aspects of available guidance and some of the evidence supporting the recommendations, but with the caveat that the evidence requires closer critical scrutiny.

A striking feature of the various guidelines and recommendations is that there is a high degree of uniformity. This probably reflects the limited nature of the evidence, but we would suggest it also reflects the shared values that underpin palliative care. Therefore, having considered some issues specifically relevant to palliative care in dementia, we shall (albeit briefly) proceed to highlight a recent ethical framework developed to help thinking around the issues that arise in dementia care. We shall conclude by reflecting on what has, perhaps to a degree, been under-emphasised in debates about palliative care in dementia.

Guidance and Guidelines

We are aware that many organisations have produced helpful local or regional guidelines and we have not attempted to produce a comprehensive overview, especially since many of the guidelines draw from the same sources of evidence. Authoritative documents can be found from, for example, Australia,²⁹ Europe,³⁰ North America^{31,32} and the UK.^{33,34} While this is not a systematic review, we would be surprised (and apologetic) if it transpires that some other set of guidelines might radically change the summary that we offer.

Pain

Pain management for people with dementia is often poor, with pain either not being detected or being inadequately treated.^{35,36} Indeed, it has been stated that “people with dementia often die with inadequate pain control.”¹² Detection of pain is obviously critical and a number of guidelines suggest observational scales should be used.^{29,30,33} Pain management is much the same as in other branches of medicine, where a mixture of non-pharmacological and pharmacological approaches, with the use of the World Health Organization’s (WHO’s) analgesic ladder, are commended.^{28–30,33,35} It is also recommended that analgesia needs to be given regularly, not just ‘as required’, and orally if possible. However, other means of giving medication (e.g. transdermal patches) can also be considered.^{29,30,35,37}

Although there is much agreement over the importance of pain and the need for it to be assessed carefully, it is not completely clear how best to achieve this for people who cannot communicate. There is no gold standard. Reviews have not been able to identify any one scale as best and, indeed, their psychometric properties can be criticised.^{38,39} Moreover, probably as a general rule, observational pain tools have a high false-positive rate for the detection of pain⁴⁰ because they also detect distress, of which pain is just one manifestation.^{33,35,41} Hence, a good deal of clinical acumen is still required to assess and treat distress adequately in people with dementia who might have pain. Research into pain management in this population is relatively sparse, and little is understood about

whether pain is experienced in the same way in people with dementia as in normal controls.^{35,42}

Infections and Fevers – The Use of Antibiotics

Pneumonia is a common cause of death.⁵ The question of when to treat with antibiotics and when not to is complicated, but the literature is thoroughly reviewed by Volicer.³¹ The National Institute for Health and Clinical Excellence–Social Care Institute for Excellence (NICE-SCIE) guidelines also present the controversies surrounding the use of antibiotics, particularly the use of parenteral antibiotics.^{31,33}

Antibiotics do not necessarily prolong life,⁴³ and at least in one study they worsened dementia.⁴⁴ The NICE-SCIE guidelines recommend that the use of antibiotics needs to be determined by the specific circumstances, but noted evidence that antibiotics can relieve distress.³³

Similarly, Alzheimer’s Australia²⁹ and Alzheimer Europe³⁰ recommend that decisions are made on an individual basis and that the benefits and burdens of therapy must be considered carefully. The Alzheimer Europe report in particular stresses the need for the prevention of infection.³⁰ Volicer, while presenting the evidence for the use of antibiotics, notes that they should be given orally.³¹ The parenteral route can produce more discomfort and it is well recognised that a patient who does not understand the intervention may try to remove cannulas.⁴⁵

Parenteral antibiotics have been shown not to improve survival or lessen functional decline.⁴⁶ However, there was a statistically significant increase in the diagnosis of respiratory tract illnesses as an indication for antimicrobial treatment as residents in one nursing home study approached death: in residents who died, 42.2% received antimicrobials during the last two weeks of life, often via the parenteral route, with implications in terms of the discomfort to the residents and antimicrobial resistance.⁴⁷

However, pneumonia is not the ‘old man’s friend’ and there may be considerable levels of distress: oral antibiotic use may reduce discomfort levels in patients with dementia who have pneumonia.⁴⁸ It can also be argued that ethical considerations may mandate the use of treatment for a potentially curable disease unless there is an advance directive to the contrary, i.e. an advance refusal of treatment.⁴⁹

A study in the Netherlands showed that antibiotic treatment was withheld in pneumonia only when the patient was frailer, with more severe pneumonia and more severe dementia (23% of cases). Therefore, it looks as if nuanced clinical judgements are being made concerning the likely benefits and harms associated with the use of antibiotics, in a context where they are mostly being used.⁵⁰

Artificial Nutrition and Hydration

Even in the early stages of dementia poor food intake is common. This may be due to failure to recognise food or dyspraxia, or it may be that the normal physiological drivers of appetite and satiety are lost owing to changes in limbic or hypothalamic function. As the disease progresses, swallowing itself may become compromised⁵¹ and hence the use of artificial nutrition and hydration (ANH) is often mooted. The prevalence of ANH differs according to location and patient characteristics, with up to 40% of patients being tube-fed in some

localities, mainly in the US.⁵²⁻⁵⁴ Thus, it may well be, as Volicer suggests, that the reasons for the use of ANH are not solely medical.⁵¹

Generally, guidelines are not in favour of artificial feeding in dementia.^{28,30,31,33,37,55} In large measure these recommendations are based on the review by Finucane and colleagues,⁵⁶ which was supported by an ethical commentary supplied by Gillick.⁵⁷ Abbey recognises the ethical difficulties that surround decisions not to feed someone and presents the case for providing information to families to help them to decide on the basis of the evidence.²⁹ The recommendations are generally to manage dysphagia conservatively, using food thickeners with appropriate posture and feeding techniques. Volicer,⁵¹ who does not in general support the use of feeding tubes, presents evidence suggesting that it is possible to change practice by engaging and educating staff to consider a variety of measures to reduce dysphagia as well as alternative feeding methods.^{56,58,59}

Similarly, the National Council for Palliative Care (NCPC) in the UK does not recommend percutaneous endoscopic gastrostomy (PEG) tube feeding in advanced dementia on the grounds that it cannot be justified given its high mortality rates.³⁶ Instead, the NCPC gives guidance on how to encourage good oral nutrition. For example, careful hand feeding, maintaining good oral hygiene to reduce infections following aspiration and the use of modified food can all be helpful. The NCPC emphasises that one of the key benefits of hand feeding is the continued human contact that it ensures.

A recent Cochrane review supports these recommendations. In the available studies, which included no randomised controlled trials, they found no evidence that enteral tube feeding provided any benefit in terms of either physical or mental health. However, it was noted that there was also little good-quality evidence about the harm from artificial feeding for people with dementia.⁵¹

There have been some dissenting voices. For instance, Regnard and colleagues raised questions about the quality of the evidence that is recognised in current reviews,^{51,56} and made the sensible point that nutrition should be considered as a priority sooner in dementia.⁶⁰ The same point was previously made by an expert group reviewing the evidence, since poor nutrition potentially contributes to poorer quality of life as the disease progresses, but the group still decided in favour of careful oral feeding for as long as possible and the use of artificial feeding only in unusual cases.⁶¹ As with antibiotic use and pain assessment, individuals should be judged according to their individual circumstances, which should be regarded holistically. In other words, in keeping with a palliative care approach, the person's unique biological, psychological, social and spiritual circumstances must be carefully weighed up.

Resuscitation

The probability of successful cardiopulmonary resuscitation (CPR) in an elderly person with dementia in an unwitnessed arrest in an institution is zero.⁶² In hospital, CPR is three times less likely to be successful in patients with dementia than in those who are cognitively intact.⁶³ Similarly, the NICE-SCIE guidance states that in severe dementia CPR is unlikely to be successful. The guidance suggests that there is a lack of proportion between the treatment and the likely outcome, and that therefore it should be regarded as an extraordinary treatment for which there is no moral imperative

to pursue.⁶³ Nonetheless, despite the futility of the treatment, the decision to withhold CPR must often be discussed with relatives, especially in situations where resuscitation is the default position.²⁸

Psychological, Social and Spiritual Needs

The need for more supportive care, and its current lack, is highlighted in several publications. For example, the Nuffield Council on Bioethics points out that people with dementia are unlikely to have attention paid to their spiritual needs,⁶⁴ and the NCPC notes that spiritual needs are often ignored.³⁶ NICE-SCIE recommends considering the psychological, social and spiritual needs of the person with a non-curable illness;³³ likewise, Alzheimer Europe notes the need to be aware of the global concerns of people with dementia and accordingly recommends that spiritual counsellors are included in their care.³⁰

Alzheimer's Australia is more directive and regards spiritual care as "essential to comprehensive palliative care."²⁹ It is suggested that a pastoral care worker with knowledge of these issues should be part of the multidisciplinary team.²⁹ Sapp notes that providing spiritual care to those who have lived within a religious tradition moves beyond the verbal to the symbolic, and those who cannot engage in conversation may still respond to music, familiar prayers, rituals and physical symbols.⁶⁵

Other psychosocial aspects of care are not considered in any detail by the guidance, although the NICE-SCIE guidance considers non-pharmacological treatments such as massage and aromatherapy in the management of pain.³³ The evidence for 'alternative therapies' is again somewhat sparse with, for example, only one study of aromatherapy considered to be of sufficient quality to be assessed in a Cochrane review.⁶⁶ Likewise, the quality of evidence for music therapy is poor.⁶⁷ However, anecdotal evidence lends support to these types of therapy,³⁶ and there is interest in developing supportive care programmes that incorporate them into institutional settings.⁶⁸

Consideration is also given in the literature to support for carers. For example, it is acknowledged that carers may be elderly and frail and that there may be greater levels of psychological morbidity among carers.³⁶ Therefore, a carer's assessment is recommended to help provide practical and psychological assistance to those supporting a person with dementia.^{33,36,55} An additional concern in connection with carers is that bereavement is not given the attention that it deserves in dementia. It is not straightforward, for it is recognised that many carers suffer 'anticipatory' and 'disenfranchised' grief as they see their loved ones fade away over the entire course of a prolonged illness.⁶⁹ Carers are often considered to suffer from 'carer burden'.

This moves us on to consider ethical issues, because much of this 'burden', which it should be said is sometimes experienced in a more positive light as providing a means for emotional or spiritual growth, reflects the day-to-day nature of the ethical issues that carers face. Thus, it has also been termed an 'ethical burden', suggesting that the right support will be that which acknowledges and assists with the moral nature of the difficulties faced by the family of the person with dementia and other close carers.⁷⁰

An Ethical Framework

Just over 10 years ago in both the US⁷¹ and Canada⁷² influential ethical guidelines were produced to help to shape the care given to people

Table 1: An Ethical Framework

Component	Description Relevant to Palliative Care
Component 1: A case-based approach to ethical decisions	Each case needs to be approached individually and the relevant ethical principles discerned, having established very clearly the pertinent facts, with attention being paid to the reasons for a particular decision differing from that made in some other similar case.
Component 2: The nature of dementia	Dementia results from a brain disorder that causes harm, so distress must be attended to and research must be pursued with as much vigour and support as are available for other conditions.
Component 3: Quality of life in dementia	It is possible to live well with dementia, especially if the psychosocial environment is optimal, but this requires the sort of impeccable assessment and skilled holistic treatment (biological, psychological, social and spiritual) that is available through palliative care services for other conditions.
Component 4: Promoting interests in autonomy and wellbeing	Autonomy and wellbeing are central principles in medical ethics, but in this context it is important to recognise the extent to which autonomy is relational, i.e. decisions about the person with dementia can have a profound effect on the lives of their carers, who must be considered too. It should also be recognised that wellbeing in dementia may be a matter of minute-to-minute experiences, which again emphasises the importance of the psychosocial surroundings.
Component 5: Solidarity	We are all in this together: as a matter of citizenship we need to attend to people with dementia with as much care as we can and to recognise the ways in which the person is situated in the context of family and friends, who will wish to contribute to the person's care and to decisions made about him or her.
Component 6: Recognising personhood	Although the person with dementia changes, the person remains a self who can value (affection, for instance) and be valued; the aim should be to maintain personhood, not to undermine it.

Derived from the Nuffield Council report: Dementia: Ethical Issues.⁶⁴

with dementia. Further texts have emerged reflecting the growth of interest in this area.^{73,74} More recently, in the UK the Nuffield Council on Bioethics produced a report looking at ethical issues generally in connection with dementia.⁶⁴ The report deals specifically with end-of-life palliative care in paragraphs 3.39–3.47, which can be accessed via the organisation's website.⁶⁴ However, in chapter 2 the report also sets out a framework to help people approach ethical issues. The framework has six components, which are summarised in *Table 1*. It is important to note that *Table 1* is based on the ethical framework in the report, but the descriptions of the components, while reflecting the spirit of the report, have been written for the purpose of this article.

Under component 1, we speak of discerning the relevant ethical principles. One such principle³³ (not explicitly discussed in the report, but see reference) that seems worthwhile to highlight in connection with palliative care might be that of 'ordinary and extraordinary means'.⁷⁵ According to this principle, we have a moral obligation to provide ordinary care but not to provide extraordinary care. In connection with palliative care for people with dementia, therefore, bearing in mind the discussion of this issue above, we might argue that we have a moral obligation to continue to feed the person (orally) while he or she is hungry, but no moral obligation to provide artificial nutrition via a PEG tube. How do we decide whether a treatment is 'ordinary' or 'extraordinary'? We ask how effective or burdensome the treatment (or investigation) is likely to be for the patient.

According to this principle, a treatment (e.g. ANH and PEG feeding, or CPR, or intravenous antibiotics, or transfer to an acute medical setting) that, under these particular concrete circumstances for this individual patient, is likely to be ineffective and burdensome is not one that we should feel morally obliged to pursue (even if we might pursue it under certain circumstances). The relevance of the individual circumstances is imperative and reflects the other requirement of component 1, which is that the actual facts must be ascertained in each case.

The Nuffield Council's framework and the doctrine of ordinary and extraordinary means go a long way towards helping with ethical decision-making in dementia. Each jurisdiction will be governed by its own laws to do with decision-making for people who lack capacity. Such laws will often encourage or support the use of proxy decisions or advance decisions.

Proxy decision-making involves someone close to the person making decisions for him or her. Advance decisions can be either very specific advance refusals of treatments or more general advance statements that capture the wishes, values and beliefs of the person. There are other ethical principles and approaches that could be considered (e.g. virtue ethics, the ethics of care, narrative ethics and so on) that are also relevant to palliative care in dementia. However, they are covered elsewhere^{74,76} and are beyond the remit of this article.

Conclusion

The WHO defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual".⁷⁷ The definition goes on to describe in more detail what this might mean. For instance, it entails intending neither to hasten nor to postpone death. However, it also states that it is "applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."⁷⁷ This statement demonstrates the extent to which our understanding of palliative care is linked to cancer treatment.

However, there is a greater realisation now that this should not be the case.^{34,36} Palliative care is relevant to all long-term conditions. In which case, how might we accommodate this statement from the WHO

concerning the applicability of palliative care throughout the course of the illness?

One answer is to point to the broader notion of supportive care.²³ Supportive care poses a challenge, which is the need to do away with the dichotomy of cure and care. It also means we require a much more positive and holistic attitude to the complex problems associated with (so-called) behaviours that challenge (i.e. shouting, aggression, agitation, sexual disinhibition, etc.). This will require something like the revolution that occurred when the hospice movement emerged and palliative care developed as a speciality. However, given the poor quality of care that many people with dementia are currently receiving towards the end of their lives, it is a revolution that we require as a matter of solidarity and of some urgency.⁷⁸ ■



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