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# The unmet palliative care needs of those dying with dementia

Laura Dempsey, Maura Dowling, Philip Larkin and Kathy Murphy

## Abstract

An estimated 33.9 million people are living with dementia worldwide. The overall estimated median survival time from onset of dementia to death is 4.1 years for men and 4.6 years for women, with longer survival times in those with early-onset dementia. Much has been discussed about the needs of this vulnerable group of people particularly in terms of their health-care and end-of-life care (EoLC) needs. However, the literature suggests that people with end-stage dementia are still not receiving adequate or appropriate EoLC. Difficulty diagnosing dementia, a stigma surrounding the disease, lack of education of the dementia disease process and the ability to identify complications encountered at end-stage dementia by health-care providers, families and carers are some of the factors preventing those with dementia receiving effective EoLC. Great strides have been made to improve dementia palliative care; however, this cohort of patients still receive fewer referrals to appropriate palliative care services than other terminally ill patients.

Key words: Dementia, Unmet needs, Palliative care, Good death

An estimated 33.9 million people are living with dementia worldwide (Barnes and Yaffe, 2011; World Health Organization, 2012) with this number expected to double every 20 years, reaching 81.1 million by 2040 (Ferri et al, 2005). Dementia is ranked as the sixth most common cause of death in high-income countries, accounting for 3.4% of the total deaths worldwide in 2004 (World Health Organization, 2008). Dementia prevalence rates for Ireland using EURODEM calculations suggest a present figure of 38 000 to over 100 000 by 2036 (O'Shea, 2007). People with end-stage dementia require specialist end-of-life care (EoLC) to improve comfort and quality of life (Nazarko, 2009). The World Health Organization (WHO, 2002) defined palliative care as:

*'an approach that improves the quality of life of patients and their families facing the problem 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'.*

WHO Europe (2004) further state that every person with a progressive illness has the right to palliative care. National Institute for Health and Care Excellence (NICE) guidelines (2013) recommend that people with dementia receive palliative care from the time of diagnosis to the point of death. The approach to treatment advocated by NICE aims to improve and enhance the individual's quality of life and allow the person to die with dignity in an appropriate environment. NICE recommends that palliative care is holistic, meeting the physical, psychological, social and spiritual needs of the person with dementia. There is an emphasis on adopting a person-centred approach to care, involving the individual with dementia, their views on treatment options and care provision while the person still has the ability to make decisions and communicate effectively (NICE, 2013). In Ireland, a report commissioned jointly by The Irish Hospice Foundation (IHF, 2008) entitled *Palliative Care for all – Integrating Palliative Care into Disease Management Frameworks* asserts that it is imperative that an integrated, co-ordinated and person-centred model of service provision is provided to those with dementia which is flexible to adapt and respond to the changing needs of the individual. Each person with dementia will have their own complex and unique experience of the

disease. This report also highlights the need for education and training for families who provide care and timely palliative care provision. Recognising the need for palliative care in dementia, the European Association for Palliative Care (EAPC) commissioned a research-based position paper producing the first evidence-based consensual definition of palliative care in dementia (van der Steen et al, 2013). International experts from palliative care, dementia and palliative care in dementia specifically participated in the Delphi study (van der Steen et al, 2013), aiming to describe core domains and defining optimal palliative care in dementia. Full consensus was achieved immediately in 8 out of 11 domains; after revision, full consensus was achieved on a 9th domain; and moderate consensus was achieved on the final 2 domains, those being nutrition and dehydration, and dementia staging in relation to care goals. In identifying research priority domains important to palliative care in dementia, this white paper (van der Steen et al, 2013) presents a framework to provide guidance for clinical practice, policy and research in the provision of palliative care in Europe and elsewhere.

### Obstacles to accessing palliative care for those with dementia

A plethora of literature exists advocating that people with dementia should have access to palliative care and hospice services (Mitchell et al, 2007; Birch and Draper 2008; Shega et al, 2008; Treloar et al, 2009; van der Steen, 2010; de Vries and Nowell, 2011). However, it is clear from the literature that people with end-stage dementia do not receive adequate or appropriate EoLC for a number of reasons; end-stage dementia is difficult to diagnose and dementia is often viewed as part of the natural ageing process (Phillips et al, 2011; Iliffe et al, 2013). Furthermore, there is a lack of education of the dementia disease process itself and the ability to identify complications which are encountered in end-stage dementia by healthcare providers, families and carers (Brodaty et al, 2003; Shega et al, 2003; Chang et al, 2005; Birch and Draper, 2008; Barber and Murphy, 2011; Iliffe et al, 2013).

As well as additional complications of bowel and bladder incontinence, pyrexia, infections and decubitus ulcers, terminally ill dementia sufferers have multiple complications with as high as 91% having a co-morbid condition (Moss et al, 2002; Mitchell et al, 2007). Co-morbidities complicate the clinical picture and may create a need for palliative care at any stage of the dementia process, since most people die with dementia rather than from it (Brunnström and Englund, 2009). The evidence base to guide practice with those dying with dementia is less well developed, although is now evolving (Boogaard et al, 2013; Iliffe et al, 2013; van der Steen et al, 2013). Gove et al (2010) in association with Alzheimer's Europe established practical and consensual recommendations for EoLC of people with dementia. The aim of their recommendations is to provide a basis for understanding and action with regard to EoLC not only for family caregivers but also for professionals, policy makers and anyone with an interest in palliative care.

Access to hospice and palliative care is also an issue for dementia sufferers. A retrospective case note audit of EoLC for people with dementia in an acute hospital setting conducted by Sampson et al (2006) found that dementia patients received significantly fewer referrals to specialist palliative care and less palliative medication than cancer patients, despite research indicating that symptom burden in those with advanced dementia and those with cancer was comparable (64% of dementia patients experienced pain and 57% loss of appetite) (McCarthy et al, 1997).

Similarly, Afzal et al (2010) examined 75 clinical case notes of people aged over 65 years who had died in an Irish hospital within a 6-month period, revealing that 18 patients were recorded as having dementia, 32 were documented as not having dementia while the remaining 25 patients notes did

not specify cognitive status. Findings revealed that dementia patients were less likely to be referred for palliative care, have carer involvement in decision making, or receive palliative medication and suggested that those with dementia may be receiving different EoLC to those who are cognitively intact (Afzal et al, 2010). A UK study by de Vries and Nowell (2011) audited internal case notes of patient admissions to one UK hospice. The hospice admission policy was inclusive of all terminally ill patients including those suffering from non-malignant disease; however of the 288 case notes audited, only 9% of hospice patients had a primary diagnosis of dementia or suffered from dementia as a co-morbidity to another terminal condition. Hospice referrals came from GPs (13), hospitals (12) and community matrons (2). The figure of 9% is much higher than found in earlier studies by McCarthy et al (1997) and Houttekier et al (2010) but is more consistent with the US data which is currently around 11% of hospice admissions (de Vries and Nowell, 2011).

The problem of variable quality of palliative care is particularly, although not exclusively, evident in community settings such as care homes (long-term care facilities) and primary care services (Lawrence et al, 2011). A pan-European study found a similar pattern across Europe (Piers et al, 2010). Access to palliative care services and social support are two factors (alongside environmental and material resources) that determine whether older people with dementia can remain living in their own homes at the end of life (Rolls et al, 2010) or necessitate hospital/ long-stay care admission.

### Difficulty diagnosing dementia and end-of-life dementia

Early diagnosis of dementia by physicians is imperative for contact with specialist services to be initiated so that timely decisions about treatment and preferences can be made. However, between 28% and 42% of GPs report difficulty disclosing a diagnosis of dementia (Downs et al, 2002; Cahill et al, 2012). As dementia progresses, the person's cognitive and communication abilities decline, making it more difficult for lay and professional carers to accurately ascertain the wishes and needs of the person with dementia. Koch and Iliffe (2010) identified that dementia is not diagnosed in time and there is a reluctance to diagnose dementia due to diagnostic uncertainty, fear of labelling or stigma within families or the community, lack of support, time and financial constraints. Identifying dementia as a progressive terminal illness allows those with dementia and their carers to consider palliative care approaches more readily and at an earlier stage (Mitchell et al, 2004; Aminoff and Adunsky, 2006; de Vries and Nowell, 2011).

The transition from living to actively dying for people with dementia can be protracted. This uncertainty affects how preferences and priorities are discussed, by whom and when, and whose opinions carry the most weight (Goodman et al, 2013). There can be an imbalance between the individual's perspective, the system of care they are in (for example a nursing home), and wider systems that provide EoLC (Froggatt et al, 2011). The difficulty of identifying those at high mortality risk underlines the need to consider the possibility of death with dementia, even in the earlier or mild stage of the disease (van der Steen et al, 2013).

In order to provide high-quality care to people with dementia, including the appropriate level of palliation, 'it is essential to identify and develop validated, reliable, sensitive, and accurate prognostic tools that can be used to identify end-stage dementia and that allow for advance preparation and planning' (Brown et al 2013: 390). Clinical prognostic indicators (CPIs) for EoLC are tools which help provide a guide to estimating when a person with advanced disease is in the last 6 months or year of life. When interpreted as part of the holistic assessment, it can assist to alert health and social care professionals when a patient may require EoLC. CPIs are advocated within the

Gold Standards Framework (Thomas, 2000) and are also included within generic standards for palliative care. In addition, they are useful in understanding disease trajectories and can help predict how needs may develop over time.

A US study by Mitchell et al (2004) revealed that only 1% of patients with advanced dementia admitted to a nursing home were perceived by staff being at end of life with a life expectancy of less than 6 months, yet 71% died within that 6-month period. Tools to improve mortality predictions have been developed for and validated in patients with advanced dementia (Mitchell et al, 2010; van der Steen et al, 2010). Potter et al (2013) conducted a systematic review of policy, guidelines, publications and position documents aimed to identify evidence-based signs and symptoms of end-stage dementia. From this review, 8 signs and symptoms associated with worsening function and increased mortality were identified and incorporated to develop the REACH toolkit to assist staff to identify people with dementia who were at end of life allowing for a palliative approach to care to be implemented. Specific prognostic markers for advanced dementia, focusing on a life expectancy of 6 months, have been developed and are based on scales which have attempted to classify the progression of dementia into stages such as the Global Deterioration Scale (Reisberg et al, 1982) or the Functional Assessment Staging Test (FAST) scale (Reisberg, 1988). A recent systematic review by Brown et al (2013) attempted to identify accurate prognosticators of mortality in elderly advanced dementia patients. In total, 7 studies met their inclusion criteria, 5 of which were set in the US and 2 in Israel. Methodology and prognostic outcomes varied greatly between the studies.

All but one study found that Reisberg's (1988) FAST scale, widely used to assess hospice admission eligibility in the US, was not a reliable predictor of 6-month mortality. The most common prognostic variables identified related to nutrition or eating habits, followed by increased risk on dementia severity scales and co-morbidities. Brown et al (2013) conclude that although the majority of reviewed studies agreed that the FAST scale criterion was not a reliable predictor of 6-month mortality, and a lack of prognosticator concordance across the literature exists.

### Care pathways for those with dementia

Palliative care for people with dementia is less well systematised (in the sense of having structured care pathways) than that for people with cancer and the evidence base to guide practice in palliative and EoLC for people with dementia is limited (Iliffe et al, 2013).

Integrated care pathways (ICPs) set out steps in the care of patients with specific conditions and describe expected progress of the patient as their condition advances. Care pathways aim to support the integration of clinical guidelines into clinical practice while also promoting better communication with the patient by giving them information about their care which is planned and progressed over time. ICPs have assisted in the management of chronic conditions but there is a need to recognise palliative care and EoLC as a unique and ultimate period within a person's pathway of care. Palliative care should be integrated within the patient's care pathway so that their care is planned and seamless.

Specific integrated care pathways and programmes were developed and implemented in the UK for patients who are approaching end of life such as the Gold Standards Framework (GSF) (Thomas, 2000) and the Liverpool Care Pathway for the Dying Patient (Marie Curie Palliative Care Institute, 2001). The GSF is a systematic evidencebased approach to optimising the care for patients nearing the end of life in the community and care homes, so that people are enabled to live and die where they choose. The Liverpool Care Pathway (LCP) was developed as a mechanism for dying patients, and their relatives and carers, to receive a high standard of care in the last hours and days of life. The LCP was originally developed by the Marie Curie Palliative Care Institute in Liverpool for cancer

patients in the acute environment, but was adapted for use in all generic care settings irrespective of diagnosis (Ellershaw and Wilkinson, 2011). It encouraged a multi-professional approach to the delivery of care that focused on the physical, psychological and spiritual comfort of patients and their relatives, and had been implemented by both non-specialist and specialist palliative care providers (Ellershaw, 2007). However, in 2012, the LCP received serious media criticism, highlighting reports of bad practice and professional concerns, mainly regarding hydration of dying patients, possible hastening of death, and consent and communication issues (Watts, 2013). An independent review into the use of the LCP in the UK recommended that the LCP be replaced by a personalised EoLC plan backed up by disease-specific good practice guidance (Neuberger et al, 2013).

According to Shipman et al (2008) there is a need to define good practice, and more needs to be known about the context of provision. A generic model for palliative care in dementia, suitable for use in different health and care systems as a guide to service quality is required, for appropriate outcomes to be identified, so that good care can be characterised in terms of quality indicators and benchmarks, and the effects of interventions can be measured (Iliffe et al, 2013). Iliffe et al (2013) devised one such generic model of palliative care for people with dementia which captures commonalities and differences across Europe (IMPACT project). The model includes features deemed important for the systematisation of palliative care for people with dementia, which are: the division of labour among practitioners of different disciplines; the structure and function of care planning; the management of rising risk and increasing complexity; boundaries between disease-modifying treatment and palliative care and between palliative and EoLC; and the process of bereavement. The model of palliative care for people with dementia has placed the person needing palliative care within a landscape of services and professional disciplines (Iliffe et al, 2013). NICE (2013) quality standard for supporting people to live well with dementia guideline outlines a palliative care pathway for people with advanced dementia and emphasises the need for the adoption of a palliative care approach from diagnosis until death to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing. Palliative and EoLC pathways are informed by the regional community facing model, which when implemented effectively, supports the delivery of quality palliative and EoLC.

### The concept of a 'good death' in dementia care

At the heart of palliative and terminal care lies the concept of a 'good death'. One of the primary outcomes of EoLC should be the experience of a good death by the patient and the family. Efforts have been made to conceptualise a good death; however, literature suggests that no one definite, clear, shared understanding of what constitutes a good death exists. It is based on the idea that a good death is not a single event, but a series of social events (Kendall et al, 2007). Closely related concepts such as quality of life at end of life, quality of care at the end of life, and quality of dying cause confusion (Kehl, 2006). The concept of a good death is highly individual and dynamic, and can be dictated by faith or culture. Some feel that death while sleeping is preferable, while others prefer to be awake and alert at the time of death (Pierson et al, 2002). This example of contrasting opinions of a good death echoes research findings that what one person considers a good death, may be in complete opposition to another. This suggests that clinicians and caregivers should consider the wishes and opinions of the patient and family as to what they consider a good death, and caution must be emphasised to clinicians and caregivers ensuring that their own perceptions of a good death does not bias or overpower the opinions of the patient and family. A dearth of qualitative research has been conducted in an effort to conceptualise a good death for terminally ill patients (Seale, 1991; Steinhäuser et al, 2002; Tong et al, 2003; Beckstrand et al, 2006; Kehl, 2006; Rietjens et al, 2006; Miyashita et al, 2008); however, due to the complexity and vulnerability of these participants, experiences of families and caregivers on this topic tend to appear more frequently in the literature (Morita et al, 2002; Bosek et al, 2003; Teno et al, 2004; Shiozaki et al, 2005; Papastavrou et al, 2007;

Sampson, 2011; Lee et al, 2013; van der Steen et al, 2013). Vig et al (2002) described good deaths as being pain free, dying in one's sleep, quickly, without suffering, and without knowledge of impending death. Bad deaths were characterised as being in pain, having a prolonged course of dying and being dependent on others. However, numerous studies suggest that a high proportion of patients at end of life die in pain (Steinhauser et al, 2002; Vig et al, 2002). Moreover, an abundance of literature exists to demonstrate that pain is undiagnosed and untreated in patients with dementia (Martin et al, 2005; Herr et al, 2006; Sampson et al, 2006; Horgas, 2010; Husebo et al, 2008; Barber and Murphy, 2011). An encouraging Dutch study by van der Steen et al (2013) analysed possible trends in families' evaluations of the quality of EoLC and the quality of dying in dementia. Individual patient data of 372 residents with dementia in 38 nursing homes and 13 residential homes over the period 2005–2010 was analysed. Outcome measures were the End of Life in Dementia-Satisfaction With Care scale (EOLD-SWC; range: 10–40) to assess quality of, or satisfaction with, EoLC, and the EOLD-Comfort Assessment in Dying scale (EOLD-CAD; range: 12–42) to assess quality of dying (comfort). Findings revealed a positive trend of increased satisfaction with EoLC. Families of those with dementia at end of life reported a possible increase in residents' end of life comfort and the emotional support provided for families, and families reported lower levels of emotional distress in residents. van der Steen et al (2013) suggest that ongoing surveillance of outcomes measuring end-of-life quality is important in view of the increasing health-care budget constraints, which is a universal issue, which has a knock on effect on care provision.

Several authors have linked a good death to the place of death (McNamara, 1994; Low and Payne, 1996; Payne et al, 1996; Semino et al, 2014). When addressing the needs of the terminally ill, it is important to identify where people die and where people choose to die. McNeil (1998: 6) presented a very balanced view of whether home deaths should always be held up as the gold standard for a good death, wisely stating that it 'matters less where we die, than how we die'. While the choice of where a person dies is an individual one, ultimately, there have to be resources available to allow that decision to be taken. This is echoed by Vig et al (2002), whose findings reported that the location of preferred death was irrelevant, however, it was clear that patients' preferences for EoLC need to be established from the patient themselves from an early stage in order for a good death for the individual to ensue. This is particularly pertinent in the case of people with dementia. Health professionals need to be more proactive in initiating early discussions around care planning and specifically advanced care planning to ensure that the needs of those with dementia are met (Burns, 2005). Advance care planning allows for improved communication and shared decision making, reducing unnecessary hospitalisation, the use of burdensome interventions such as tube feeding, and parenteral hydration in advanced dementia (Hertough 2006) and also facilitates discussion around place of death with the person with dementia.

The IHF (2011) recently launched their 'Think Ahead' programme which encourages people to think about important issues, talk to others about them (family, GP, etc) and tell key people in their lives about their decisions and preferences in relation to these matters. This method of advanced care planning is vital in the case of those with dementia so that their treatment and care preferences are adhered to at the end of life. It must be noted, however, that Ireland has no legislative provision for advanced care planning at this time. The increasing requests from patients and families to die at home has put considerable responsibility and pressure on primary care and palliative care teams, as the patient and their family depend on their support and management of the final stages of the patient's life. With national and international publications such as *Palliative Care For All* (IHF, 2008), End of Life Care Strategy and NICE quality standards for supporting people to live well with dementia and EoLC for adults (NICE, 2011; 2013) endorsing and supporting this initiative, more and more patients are being afforded the opportunity to die at home. Effective guidelines such as the GSF assists to optimise care provision and fulfil the wishes of patients nearing end of life through improved communication and advanced care planning (Tapsfield, 2006).



However, Shaw et al (2010) caution that its use is variable and the GSF's direct impact on patients and families, especially where dementia is present, is not yet known. Exley and Allen (2007) in a critique of 'home' as the preferred place for EoLC, observe that 'home' is not merely about physical space but the social and emotional relationships that are experienced there. The need for meaningful relationships, purpose and feeling safe for people with dementia in long-term care settings at the end of life are known (Birch and Draper, 2008; Hall et al, 2009; Ryan et al, 2009). Goodman et al (2013) concurs with this with residents in a care home in the UK identifying that relationships made them feel at 'home'.

Several studies have examined the experience of dying with dementia in a nursing home or residential care setting from the family member or health professional's perspective. Bosek et al (2003) interviewed 57 family member caregivers of a person with Alzheimer's disease whose loved one had died in a US nursing home. Despite the fact that all family members reported their loved one died with dignity, 28% believed that their family member had not experienced a good death. Family members cited a good death as one that conformed to the patient's preferences regarding when and where to die, if the death had occurred with the patient being comfortable, or if the experience by the family member of the dying process was a positive one. Bosek et al (2003) highlighted some proactive recommendations to improve the quality and process of the death. These include aggressive pain and symptom management, provision of information for family on the signs and symptoms of the anticipated death, maintaining familiar surroundings, providing accommodation for family presence, and an examination of family and caregiver's attitudes, beliefs, and expectations about death. More recently, Goodman et al (2013) explored the end-of-life preferences and priorities of people with dementia residing in a nursing home in the UK. Findings revealed that place of death was not a priority for these residents, but the relationships formed with the people around them made them feel at 'home'. Living and dying with dementia extends beyond any physical care needs and decisions about preferred place of care and according to Moriarty et al (2012), the challenge is how to develop practice and processes that reflect the fact. Goodman et al (2013) emphasise the necessity of documenting the end-of-life priorities of people with dementia at an early stage, as early as on admission, and for this discussion to be ongoing in order to facilitate the wishes and needs of the person with dementia at end of life.

## Conclusions and implications for practice

From the available literature highlighting the palliative care needs of people with dementia, it is clear that adequate or appropriate EoLC is not received by this vulnerable group. While great strides have been made to improve dementia palliative care, they still receive fewer referrals to appropriate palliative care services than cancer patients (Sampson et al, 2006). While excellent EoLC is attainable, greater efforts are required of health-care staff to firstly recognise dementia as a terminal illness, to initiate the dialogue on EoLC at an early stage of the illness, allowing the individual to take the lead on determining their own wishes and preferences of care. A good death with dementia according to Lawrence et al (2011) is being pain free and being surrounded by those closest to the person with dementia; these are not unachievable or particularly technical goals but necessitate effective communication, cooperation and coordination by health professionals. With reference to the increasing number of people who will require care as they die with dementia, service models to improve care must be adopted and implemented carefully, taking into account the variety of settings in which people with dementia die, as well as cultural, staff, organisation and budgetary factors, with due consideration to what may work best for whom and in what circumstances (Sampson et al, 2011). van der Steen (2013) purports that not all dementia sufferers require specialist palliative care, only if it is required for those with complex problems; however, a



palliative care approach is required as a baseline for those without complexities (van der Steen 2013). Furthermore, not all palliation occurs with palliative care. Health-care providers offer their own palliation in the treatment of difficult symptoms associated with dementia or as a result of other co-morbid factors.

As dementia is mainly as disease of older age, principles and practices of gerontological medicine and nursing should also apply. The aim of this paper is to highlight that there is still a need for health-care providers to recognise the eventual terminal nature of dementia, anticipate specific needs which will change over time, throughout the disease trajectory, and that a baseline palliative care approach for all is adopted, irrespective of the type or stage of dementia. Implementing a palliative approach to dementia care facilitates in the appropriate identification of any unmet needs of people with dementia while also promoting a continuum of care focusing on quality of life and values the uniqueness of the person (IHF, 2013).

### Declaration of interests

The authors have no conflicts of interest to declare.

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