



Jones, K., Birchley, G., Huxtable, R., Clare, L., Walter, T., & Dixon, J. (2019). End of life care: A scoping review of experiences of Advance Care Planning for people with dementia. *Dementia*, 18(3), 825-845. <https://doi.org/10.1177/1471301216676121>

Peer reviewed version

Link to published version (if available):
[10.1177/1471301216676121](https://doi.org/10.1177/1471301216676121)

[Link to publication record in Explore Bristol Research](#)
PDF-document

This is the accepted author manuscript (AAM). The final published version (version of record) is available online via SAGE Publications at <http://doi.org/10.1177/1471301216676121>. Please refer to any applicable terms of use of the publisher.

University of Bristol - Explore Bristol Research

General rights

This document is made available in accordance with publisher policies. Please cite only the published version using the reference above. Full terms of use are available: <http://www.bristol.ac.uk/red/research-policy/pure/user-guides/ebr-terms/>

Dementia: the international journal of social research and practice

End of life care: A scoping review of experiences of Advance Care Planning for people with dementia.

Kerry Jones

Department of Health and Social Care, The Open University, Milton Keynes, United Kingdom

Giles Birchley

Centre for Ethics in Medicine, School of Community Medicine, University of Bristol, Bristol, United Kingdom

Richard Huxtable

Centre for Ethics in Medicine, School of Community Medicine, University of Bristol, Bristol, United Kingdom

Linda Clare

The Centre for Research in Ageing and Cognitive Health, School of Psychology, College of Life and Environmental Sciences & PenCLAHRC, Institute of Health Research, University of Exeter Medical School, University of Exeter, Exeter, United Kingdom.

Tony Walter

Centre for Death and Society, Department of Social and Policy Sciences, University of Bath, Bath, United Kingdom

Jeremy Dixon

Centre for Death and Society, Department of Social and Policy Sciences, University of Bath, Bath, United Kingdom

Abstract

Despite increasing attention given to dementia by international governments and policy makers the focus of end of life care has been on the dying trajectory of malignant disease. People with severe dementia have complex physical and psychological needs, yet, the disease is not always recognised as terminal. Advance care planning involving people with dementia and their families can provide opportunities to discuss and later, initiate timely palliative care.

We conducted a scoping review of studies exploring decisions associated with the EoLC of people with dementia. Eligible studies had to report on decision making at the end of life and by whom (the dying person, clinician/health professional or relative/family member).

Twenty five eligible studies reported on advance care planning and end of life care decisions for individuals with dementia. The papers highlight several challenges that need to be addressed in order to provide adequate and effective care for people with dementia as they near the end of their life.

Corresponding author:

Kerry Jones. Department of Health and Social Care, The Open University, Milton Keynes, MK7 6AA, United Kingdom.

Email: Kerry.jones@open.ac.uk

Key words

dementia, end-of-life care, advance care planning, decision-making, death, dying

Introduction

Globally, it is estimated that there are 36 million people living with dementia, rising to 66 million by 2030 (Alzheimer's Disease International, (ADI), 2012). The World Health Organisation, (WHO, 2012) describes dementia as a public health priority which urgently needs attention. The WHO also recognises that despite more recent national and international government initiatives such as the UK's Department of Health End of Life Care Strategy (DoH, 2008), people with dementia continue to receive inadequate support and care towards the end of their lives (WHO, 2012).

Dementia is a progressive neurodegenerative disease characterised by impairments in memory, language, and sensory awareness and changes in personality (International Association of Gerontology and Geriatrics, (IAGG), 2011). Dementia is an illness of progressive deterioration leading to eventual death. However, the trajectory of dementia is unpredictable with average life expectancy ranging from 3 to 10 years (Evans & Goodman, 2008; Shega, Levin & Hougham, 2003; van der Steen, 2010). Adding to this complexity is the frequent presence of co-morbidities such as cancer or cardiovascular disease (Xie, Brayne & Mathews, 2008).

Although people with severe dementia have complex physical and psychological need, the disease is not always recognised as terminal by health and social care practitioner's (Evans & Goodman, 2008).

As a consequence, some people with dementia can receive undignified treatment and be in considerable, often unrecognised pain (Anquetin et al., 2013; Suarez & Farrington-Douglas, 2010). Sampson, Burns & Richards (2011) also indicate that people with advanced dementia, have been found to suffer substantially from a range of symptoms including restlessness, difficulty swallowing, agitation and anxiety towards the end of life, and are also more susceptible to pneumonia, urinary tract and other infections leading to futile and distressing admissions to acute hospitals.

While the importance of palliative care for people with dementia is recognised globally, a coordinated palliative care philosophy is lacking (Gott, Ibrahim, & Binstock, 2011; Houttekier, et al, 2010; van der Steen et al, 2013). Several studies (Ashton, Roe, Jack and McClelland, 2014; Gott et al, 2011; Di Giulio et al., 2008) have highlighted the failure to adopt a palliative and supportive approach to people with dementia and the use of inappropriate interventions. Poor quality end of life care for people with dementia was similarly identified as a concern in The National Health Service England Actions for End of Life Care (2014-16).

The WHO (2011) describes Advance Care Planning (ACP) as a discussion about preferences for future care between an individual and a care provider in anticipation of deterioration in the person's condition. The National Council for Palliative Care (NCPC) suggests that the benefits of having this discussion are that it provides an opportunity to discuss and later, initiate timely palliative care (NCPC, 2007, NCPC, 2012). Translated to dementia, it is suggested that these discussions should take place in the early stages of the disease (van der Steen et al, 2013). However, the topic can be distressing for some people, especially when health and social care professionals do not have the interpersonal skills or training to facilitate such a sensitive discussion or are reluctant to assume responsibility for discussing ACP (Sampson et al., 2011).

While the international literature suggests that ACP can reduce the burden of decision making for future care and withdrawal of treatments in the event that a person loses capacity, the legal standing of these plans and the complexity and range of the various forms (Advance Statements, Advance Directives,) can contribute to the lack of implementing ACP in a range of settings (Lacy, 2006; Jeong, Higging, & McMillan, 2011).

Advance Care Planning

Advance Directives (AD) are legally binding documents that record decisions made while a person has capacity to make a decision regarding the treatment and care that he/she should be given in the event of becoming incapacitated. AD's are meant to express precedent and prospective autonomy in the future and a way of protecting the interests of their creators by enabling them to avoid futile and burdensome treatment (Clarke, Galbraith, Woodward, Holland & Barclay 2015). This compares to Advance Statements in which verbal or written preferences about care are stated but which are not legally binding as is the case in the UK (Alzheimer's Society, 2014).

While the international terminology surrounding decisions about EoLC is agreed, the legal framework surrounding EoLC differs between countries (Sampson, Raven, Ritchie & Blanchard, 2005). For example, the Patient Self-Determination Act of 1991 in the U.S., and the Belgian Right's Act 2002 in Belgium, has given patients the right to reject medical treatment and to select a legal representative to speak for them in the event that they lose capacity (De Gendt, Bilsen, Stichele & Deliens, 2013). In outlining the patient's preferences, ACP's can either be patient driven through AD or by physicians through 'physician's orders.' Written by a physician, the 'order' is meant to be developed with input either from the patient or their representative.

In the event of incapacity, The Mental Capacity Act 2005 (MCA) in England and Wales provides a statutory framework for how to proceed when people are judged to be incapacitated in making decisions about their EoLC (DoH, 2007; NCPC, 2007). This legislation enshrines a particular type of advance directive, described as the 'advance decision to refuse treatment.' Where the statutory formalities are satisfied, such advance refusals of treatment are binding. If a patient lacks such an 'advance decision', the MCA 2005 requires that any decision made for that individual is in accordance with his/her 'best interest (Huxtable, 2015).

However, the benefits of this approach have not been fully realised or evaluated (Brinkman-Stoppelenberg, Rietjens, & van der Hiede 2014).

In contrast to the advanced stages of other conditions such as cancer, most people with severe dementia lack the capacity to make decisions about their care and treatment, significantly impacting on the quality and person centredness of care at the end of life (Brayne, Gao, Dewey & Mathews, 2006; De Bosek, 2003; Evans & Goodman, 2008; Moy et al, 2010; Rabins, 2006). Even if preferences for withdrawing treatment and goals of care are discussed and documented at the early stages of dementia, several authors (Ashton et al, 2014; Evans and Goodman, 2008) have raised concerns that people with early-stage dementia may come to adapt and shift their views of what constitutes a good quality of life as the disease progresses. In these circumstances health and social care practitioners may turn to family members as 'proxies' or surrogate decision-makers as a way of ascertaining what a person's preferences for end of life care might be (Elwyn et al., 2010).

Proxy decision making

Proxy decision-making is also legally permitted in many jurisdictions. The precise terms again vary: in England and Wales, for example, the MCA 2005 allows the conferment of a 'lasting power of attorney' (or 'welfare attorney') to make decisions on behalf of the person who no longer has capacity.

A lasting power of attorney can make decisions about a person's health and personal welfare (Robinson et al., 2012). Yet, proxy decision-making at the end of life is a subject of much debate (DoH, 2008; Beauchamp, and Childress, 2008). The English provisions require that the proxy be bound to serve the patient's best interests. However, the assessment includes reference to the patient's present or past wishes.

Indeed, in many bioethical discussions, it is suggested that proxies derive their authority from the patient's autonomy. Proxy decision-making is therefore intended to respect the autonomy of the individual concerned by utilising those decisions or preferences discussed previously (Huxtable, 2015).

However, this is based on the assumption that proxy decision-makers are sufficiently well informed to infer preferences about treatment in hypothetical future situations (DoH 2009; Hawkins, Ditto, Danks & Smucker 2005). Moreover, some older people may choose to avoid discussing their potential care needs or their preferences for treatment and how these should be adhered to (Hawkins et al., 2005; High and Turner, 1987; Kaufman, 2005). This raises the suspicion that proxies might not always be well-placed to put themselves in the position of patients.

Another assumption concerns proxy decision-makers' attitudes and abilities to ascertain the person's needs, and to understand his/her preferences for care and treatment. While there may be congruency in particular circumstances, a number of studies that have explored proxy decision-making and ACP have found that the preferences of the carer, doctor and person with dementia are not always concordant (Caresse, Faden & Finucane, 2002; Hines, 2001; Hopp, 2000). A related area of empirical research has examined the accuracy with which proxies were able to predict treatment preferences for individuals and found that this was lowest in relation to people with stroke or dementia (Shalowitz, Garret-Mayer & Wendler 2006).

While decisions regarding capacity and preferences for future care attempt to ameliorate the deleterious consequences of dying with severe dementia, for some families this is highly problematic as they attempt to justify decisions in the face of a person's deteriorating ability to communicate about their health (Black et al., 2009; Gessert & Peden- McAlpine, 2009). Moreover, carers, and family members of people with dementia are frequently expected to act as proxy decision-makers and to make difficult and emotionally demanding choices at a time when they are experiencing distress and 'anticipatory grief' (Clarke et al, 2015). However, in the absence of family members, health professionals treating a patient for the first time can face constraints in providing appropriate EoLC due to a lack of available knowledge about a person's health history, and as a consequence may intensively treat an individual near the end of life (Seymour, 2009).

Moreover, several studies have found that health professionals involved in dementia specific care lack the skills to implement ACP, due to the vast array of documentation available for formally recording an ACP and also due to the timing of initiating discussion with people with dementia (Ashton et al.,2014;Robinson et al., 2012; Sampson et al., 2011). Indeed, the recording of documentation can cause considerable confusion and raise questions about their legal transferability between care settings, for example from home to hospital. A further limitation is posed by the extent to which it is possible to capture all scenarios (Robinson et al., 2012).

Several studies in this review highlight the complex challenges that we as a society face in providing a supportive approach to people with dementia nearing the end of their lives. In contrast to other chronic conditions, people with dementia lack the capacity needed to make decisions about their care and treatment.

ACP then as the WHO (2011) point out, is a way of improving choice and autonomy for people with dementia and to ensure the provision of good quality EoLC. Further, that professionals working with people with dementia who have reduced capacity should initiate and encourage advance planning (Royal College of Physicians (RCP), 2016). In the UK, However, there is a paucity of evidence about whether ACP impacts upon outcomes towards the end of life or has any influence on the 'quality of death.' Further, it is unclear who is making decisions about end of life care and whether it involves the person with dementia, their carer or any number of individuals involved in their care (care home manager, doctors, nurses).

Globally, the number of people with dementia is rising, and these issues represent real challenges. We need more clarity on how decisions are made and how to best prepare for future care decisions in order for people with dementia to experience a 'quality of dying.'

The dying well with reduced agency (DWRA) project seeks to explore how decisions are made by bringing together researchers from four UK universities with an interest in end-of-life decision-making for those who lack capacity to make decisions about their care. This review is part of a larger study which also explores frailty and severe traumatic brain injury. This paper is a synthesis of the literature on dementia specific issues concerning EoLC.

The scoping Review

A review of the evidence on decision-making about goals of end of life care is invaluable to inform future thinking on recommendations and priorities for new research. In this review of the evidence concerning EoLC for people with dementia and the decisions which influence care at the end of life the following research questions guided the review process:

- a. **Who is involved in the decision-making process?**
- b. **How are decisions made concerning EoLC and what is the outcome in facilitating a good death?**
- c. **In what way do systemic factors impact upon EoLC**

Methods

In this review we set out to map the existing literature that constitutes the primary research evidence base in what is a complex and heterogeneous field of EoLC research, and to determine the potential for conducting primary research (Levac, Colquhoun & O' Brien, 2010) specific to individuals with dementia. This comprised a rapid assessment of the medical, ethical, gerontology and social scientific literature due to DWRA project timescales.

This scoping review aimed to synthesise the research evidence on decision-making concerning EoLC for people with dementia. In undertaking the review, we apply our experiences using the Levac et al., (2010) methodological framework, an approach which Levac et al (2010) further developed following a review of scoping studies conducted by Arksey and O'Malley (2005).

Throughout this process we followed a six-stage methodological framework: identifying the research question; searching for relevant studies; selecting studies; charting the data; collating, summarizing, and reporting the results; and consulting with stakeholders to inform or validate study findings.

The scoping process requires analytical reinterpretation of the literature in a field where there is a paucity of randomised control trials. A scoping review thus, represents a way to examine the extent, range and nature of research activity, identify gaps in the literature and clarify a complex concept such as advance care planning and dementia. We used transparent methods throughout and the review process was guided by a protocol developed by the lead author with advice from experts in knowledge synthesis and systematic reviews.

Adopting scoping review methods meant that we could incorporate a range of study designs, cross sectional as well as complex intervention (Levac et al., 2010).

Data Sources

To identify relevant studies in the medical and psychosocial literature we searched the following databases: Medline; PsychINFO; CINAHL; Cochrane database of systematic reviews; Assia; Ageinfo (1945 – 2015). We identified all relevant articles on a) decision-making at the end of life pertaining to all dementia's (i.e. Alzheimer's, vascular, Lewy Body), b) the location in which EoLC discussions took place, and c) where ACP's and AD's took place; we used primary search terms "- " death, dying or end life" and " decision making ", " palliative care" coupled with secondary descriptors of "hospital, care/nursing home, community."

Inclusion and exclusion criteria

Our inclusion criteria specified that studies: 1) address the decision making process about end of life care for people with dementia . 2) identify where EoLC took place [hospital, home, community] and whether location impacted upon decision making processes 3) specify who was consulted or made decisions concerning EoLC. We considered articles written in English. We screened the titles and abstracts of all articles retrieved through the initial database search, and obtained the full texts of all studies that could potentially met the inclusion criteria. Full text articles were then examined in detail by two reviewers [KJ GB] working independently to determine whether or not the study met criteria for inclusion in the review. Any disagreements were referred to a third reviewer (LC). We also checked the reference sections of all included studies for potentially relevant papers. We excluded studies which reported multiple chronic conditions and where less than 75% of the population study included people with dementia.

We also excluded studies which focused only on staff training or which referred to a paediatric population. Other studies excluded were those which referred to older frail individuals showing signs of disorientation without a specific diagnosis of dementia.

For the purposes of this scoping review, the population, intervention, comparators and outcomes (PICO) framework to inform the review objectives are presented below.

Table 1. Picos

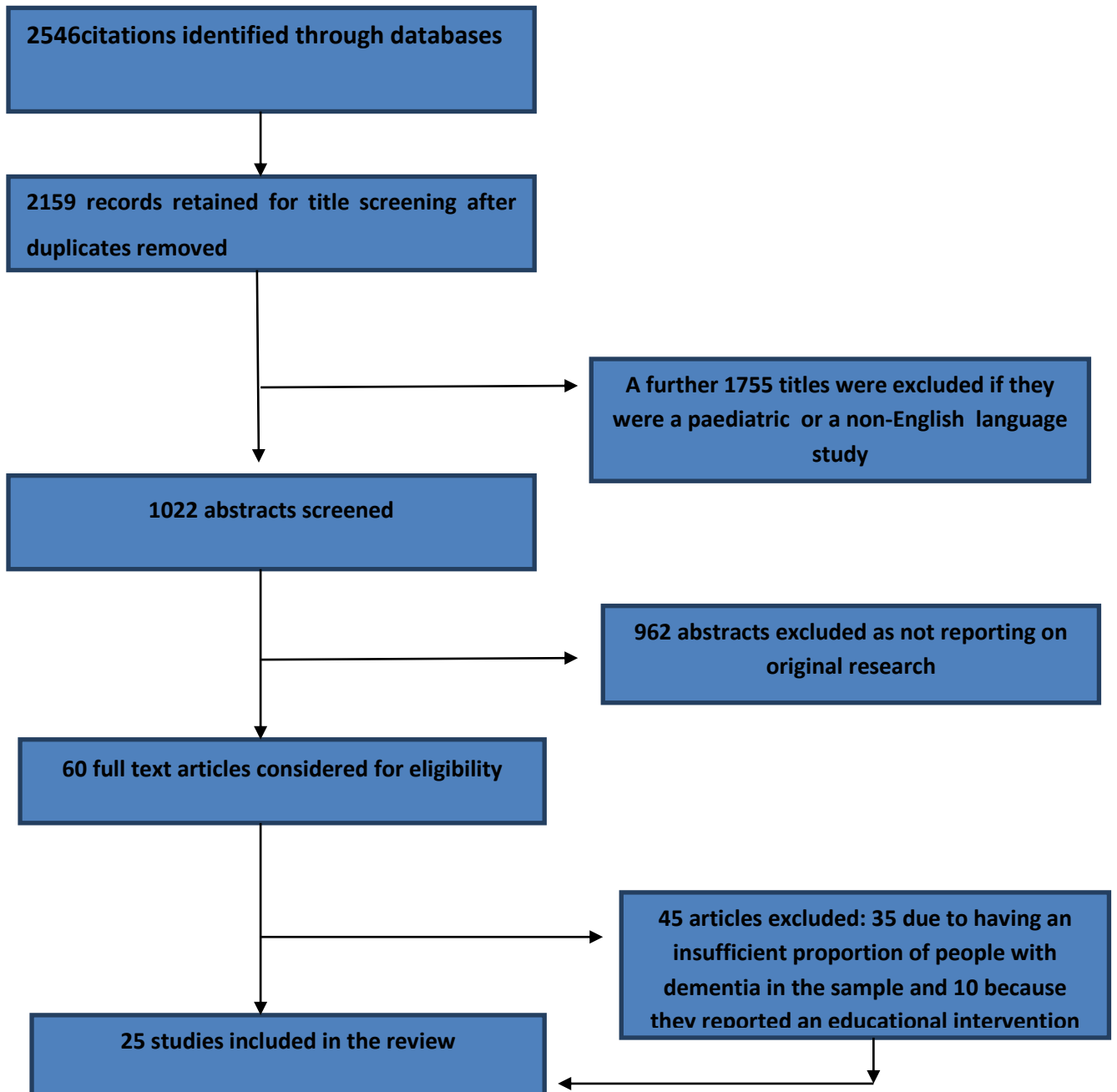
Population	Intervention	Comparison	Outcome	Setting
People with dementia Spouse Relative Carer Health professional Doctor/nurse Social care professional	Discussion about ACP Discussion about AD by people with dementia by relatives by health professionals by social care staff	Preferences and wishes Decisions by people with dementia by relatives by health professionals by social care staff	How EoL happens Who decides	Hospital Community Care home Integrated care

Data Extraction

The full text articles identified as suitable for inclusion were examined independently by two of the authors [KJ, GB]. A third reviewer [LC] made the final decision in cases where consensus could not be reached. The papers were not assessed for quality as this does not form a part of the review method. The full papers of studies that met inclusion and exclusion criteria were retrieved and examined independently by the first two authors of this paper (KJ, GB). Papers were reviewed and data including measured outcomes, patient and descendent characteristics, intervention characteristics, sample size, type of study (intervention, RCT, demographic, retrospective and qualitative), the agent of decision making (the person, relative and or clinician) and location of study was reviewed. Data were extracted using a proforma developed by the first reviewer (KJ).

A flow chart describing the screening process is shown in figure 1.

Figure 1 Flow chart of review process



Characteristics of reviewed studies

Of the 25 studies that meet the inclusion criteria, the main focus is upon the experiences of EoLC and the role of health professionals (doctors, nurses and home care managers) and families in decision-making. We found 10 papers which describe the involvement of family members in proxy decision-making. Of these, 2 studies focus on the outcome of a consultation involving both family members and the person experiencing dementia. Studies which focus upon health care practitioner (doctors, nurses, care assistants, care home manager) and familial decision-making feature in 6 papers; while a further 5 papers identify decision-making by health care practitioner's only. Only 3 focused on the person who was the subject of decision making. Of these, two reported on concordance on EoLC preferences between the person diagnosed in the early stage of dementia and their spouse who was identified as their carer.

Health care practitioner's perspectives on achieving a good death is the focus of 17 studies (both prospective and retrospective) while the views of family carer's of the quality and satisfaction with EoLC can be found in 3 studies.

The settings in which the studies took place varied: 16 were conducted in care homes, one of which focused upon the EoLC trajectory between care and hospital; 7 studies were conducted on hospital sites (including a memory service and psychogeriatric clinic); 3 were surveys conducted, 1 with families, 1 with family physicians, nurses in nursing homes and families, and 1 through physicians based either in hospital or in private practice in the US.

Due to the restriction to reviewing English language articles only, several studies were conducted in English speaking societies: 7 in the USA; 7 in the UK; 2 in Belgium; 2 in the Netherlands; 1 in Japan, 1 in Ireland, 1 in Israel and 1 in Italy.

Study methods also varied. 10 were qualitative employing interviews or with a combination of observations and focus groups; 3 were surveys eliciting views on EoLC and how to respond to certain scenarios; 4 used interventions 3 were retrospective in design involving documentary analysis and case reviews; while 2 were epidemiological. Only 1 study reported a randomised control trial, while 1 was described as cross sectional and 1 as a cohort study.

Heterogeneity among the types of studies included and the measures used to assess outcomes precluded an effort to summarise quantitative data across studies in the form of any generic effect size measures and caution against quantitative statements. A summary of data extrapolated is in the additional papers section of this article.

Results

In this review, the majority of data gathered by studies was largely retrospective involving surveys, documentary analysis of patient records and interviews with families, clinicians or those directly involved in a patient's end of life care. No attempt was made to summarise quantitative data across the studies since this was unlikely to inform the research questions.

Our synthesis generated 3 main themes with a focus on decision making and who is involved, systemic factors within and between various care agencies and the 'quality of death' including the withdrawal of treatment or invasive procedures. The papers identified the role of families and health care professionals in decision making, although to a much less extent, the role of the person with dementia. These discussions often took place in dyad's (between carers and professionals or between professionals and families) and exposed the challenges in initiating discussion about ACP and needs for EoLC in the future.

Systemic factors reveal the facilitators and barriers in providing EoLC within and between various locations of care including residential care home and hospitals, particularly during out of hours. A lack of knowledge about dementia and providing care, together with a reluctance to engage in a discussion about ACP pose a significant barrier.

Ultimately, health professionals identify the need for training. This in part explains why with input from dementia specialist services such as Admiral nurses and Community Matron's, care staff may feel more equipped to provide EoLC for people with dementia. However, this support is not universal and as a consequence family carer's have to make complex decisions and often in distressing situations when a person is admitted to hospital. Even prior to this, carer's face difficulties in making decisions about EoLC with their relative who has dementia when in the process of developing ACP's.

Family involvement in Advance Care Planning

Family members of people with advanced dementia are often asked to make complex treatment decisions and at times with little support (Livingston, 2013; Reinhardt et al, 2014). Such treatment decisions can relate to the use of resuscitation, hospitalization, artificial nutrition and hydration, antibiotics, analgesics and diagnostic tests.

Several studies (Ayalon, Bachner, Dowlatsky, & Heinik, 2012; Allen et al., 2003; Black et al., 2009; Reinhardt, Chichin, Posner & Kssabiann, 2014; Sampson et al., 2010) provided data on the involvement of family in decision-making. Family members were described as spouses or friends whose role as primary carers also led to their involvement in discussion about ACP. In Allen et al's., study (2003) of ACP in nursing homes, residents were more likely to have an ACP for EoLC, if an AD had already been made and was in the possession of the proxy decision-maker (family member).

These residents were described in the study as lacking the capacity to understand the treatment choices made or the consequences of their treatment preferences and were instead reliant upon their families to raise awareness of the AD (Allen et al, 2003). However, several studies (Ayalon et al., 2012; Livingston et al., 2013; Reinhardt et al., 2014) consistently describe the difficulties carer's experience in making decisions on EoLC.

In the US, Reinhardt et al, (2014) conducted a prospective randomised controlled trial for family members who were asked to make complex treatment decisions about individuals with dementia. Family members of nursing home residents with dementia received either structured face-to-face conversation (at baseline, 3 months, and 6 months) about EoLC options and goals or telephone contact at baseline and at 6 months. The group receiving a face-to-face discussion with the palliative care team, reported higher levels of satisfaction with EoLC and were more likely to have made proxy treatment decisions when compared with the group being contacted by telephone only. Reinhardt's study demonstrates that support and planned discussion for some family carers who are consulted about EoLC can be supported in making treatment decisions on behalf of the person with dementia.

Reinhardt's study compares with Sampson et al's (2010) UK randomised controlled trial involving people with severe dementia, comprising 33 carer/patient dyads following emergency hospital admission. The intervention consisted of a palliative care assessment which facilitated an ACP discussion with the carer who was invited to write an ACP for the person with dementia.

Of the 33 carer/patient dyad's recruited 22, were assigned to receive the intervention while 11 were assigned to receive usual care following emergency hospital admission. Only 7 carer's (intervention group) wrote an ACP despite the presence of intensive support from an experienced nurse specialist. Sampson and colleagues noted the considerable difficulty in recruiting carer's to the study. This in part could be explained by the potential distress and preoccupation of accompanying a person in the later stages of dementia to emergency admissions.

The timing then of discussion is a contentious issue. While decisions about EoLC would be beneficial in order that a person is able to receive the most appropriate person centred care, ACP discussions at the point of emergency admission is considered for some, too challenging despite the support of highly experienced health professionals. Notwithstanding these challenges, Sampson et al argue that the reluctance of carer's to write plans needs to be explored further.

The role of health care professionals in ACP

Decision making at the end of life in dementia raises clinical issues as well as challenging ethical considerations for health care professionals (Parsons et al, 2013; van der Steen, 2005). This complexity is reflected by several studies that sought to elicit practices and views related to decision making by doctors, nurses and care assistants or other professionals, including the views of care home managers who had either planned or delivered EoLC for individuals (Nakanishi & Honda, 2009; Parsons et al., 2013; Robinson et al., 2012; Sloane, Zimmerman, William & Hanson, 2008; van der Steen et al., 2005).

Robinson et al's (2012) qualitative study in the UK examined the views and experiences of ACP of a wide range of professionals (n=96) occupying either clinical or non-clinical roles in dementia or palliative care. Their findings demonstrate the challenges professionals experienced in discussing and developing ACP. Professionals identified three areas of uncertainty: the legal status of ACP, the usefulness of ACP's and how to implement ACP's.

Palliative care specialists and community nurses were the most confident in initiating ACP's since they had the most experience of this form of care, while General Practitioner's (GP's) and ambulance staff expressed more uncertainty. Robinson et al's findings about GP's follow those of Cavalieri's et al., (2002) earlier study in the US and which found that doctors working in the community needed more training about ACP to initiate discussion.

While professionals in Robinson et al's study agreed on the whole that ACP was good in theory, they found it problematic to implement. Not only were some professionals reluctant to broach the subject of ACP, there was also uncertainty about who was responsible for drafting the ACP and confusion about the definition and legal status of AD's compared to ACP's since varying bespoke forms were used. Even where patient preferences were documented, professionals felt unable to deliver optimal care due to an inadequate lack of integrated care between services and dementia specialist support.

While some professionals are fairly confident in initiating discussion about EoLC, notably palliative care specialists, there are also health care staff who exhibit considerable reticence about the value of ACP, despite national and international policy initiatives promoting ACP (DoH, 2008; WHO, 2011). For example, some professionals in Robinson et al's study have expressed concern that ACP forms are just a 'tick box' approach for use as a care quality audit.

Clearly ACP is a challenging and complex area to enact, especially in time pressured and one in which staff have identified a need for training in other studies (Dening et al, 2012 a. 2012 b, Forbes, Bern-Klug & Gessert, 2000; Livingston et al., 2013, Reinhardt, et al., 2014). There is also a need to simplify and standardise ACP documents and provide greater clarity about individual responsibilities. Whether this is hierarchal or involves specialist medical input requires an assessment of capacity to be incorporated in to the process.

Joint decision making: Families and health care professionals

For many people in the later stages of dementia and near the end of life, a decision to start or forego treatment is taken by both families and health care practitioner's (Sloane et al, 2008). One Dutch study of a nursing home (Rurup et al., 2006) focused upon the attitude of physicians, nurses and relatives towards medical end-of-life decisions concerning patients with dementia.

Fifteen statements about artificial nutrition and hydration (ANH), advance directives, hastening death, self-determination and euthanasia, and nursing home policy were presented to physicians, nurses and relatives of nursing home patients experiencing from dementia. Nurses (35%) and relatives (47%) were more likely than doctors (15%) to fully agree that refusal of food and drink should be respected. Spouses also agreed more often to refusal of ANH if they felt that the person with dementia had more pain and a lower degree of comfort.

Nurses agreed more often with this if they had more experience in nursing home care, as did nurses who stated that their religious beliefs did not influence ANH decision making (Rurup et al, 2006).

A notable difference between families and nurses compared to doctor's views concerned euthanasia which is lawful under certain circumstances in the Netherlands. Sixty three percent of nurses and 63% of relatives were of the opinion that euthanasia was permissible for incapacitated patients if they had signed an AD, and 34% of doctors' felt this was permissible. From Rurup's study we can see that shared decision making is not without conflict, with the opinion of families family's more in keeping with those of nurses than the views of doctor's. This suggests that varying levels of responsibility in decision making of EoLC can lead to different attitudes towards end of life decisions.

Including the person with dementia in ACP

As a progressive disease dementia can be experienced as a condition in which cognitive decline deteriorates gradually and with it decision making capacity about future goals and needs of EoLC.

To understand the process of decision making by people with dementia, this review was able to locate only two studies by Denning et al (2012 a, 2012, b) conducted in the UK and by Triplett & Black(2008) in the US.

Triplett & Black (2008)conducted their study in Maryland, US, a state in which the Maryland Health Care Decisions Act contains AD templates to enable a person with dementia to list treatment decisions related to their condition and to name a health care agent to act as a proxy decision maker.

Analysing the AD of eighty–one individuals with advanced dementia, Triplett and Black’s study found that half were unwilling to document decisions about comfort care , pain relief or invasive treatment (feeding tube). Of those people that had raised pain treatment, the majority (85%) wished to receive the treatment even if this might shorten their life.

Yet despite the invasiveness of a feeding tube, only twenty individuals had documented refusal for the procedure, while none conveyed any wishes about hospitalization for acute issues. This suggests that the consequences of various treatment options is either not fully explained or realised.

Triplett & Black’s (2008) study also revealed that some AD’s were either incomplete (filled out incorrectly, or were missing signatures) or were unwilling had conflicting accounts of comfort care and treatment wishes (allowing pain treatment, but not if it would shorten life) there by contradicting the preferences documented.

This suggests that some capacitated participants in Triplett Black's study, were unwilling to hypothesise preferences in relation to future scenarios of deterioration such as emergency admission or artificial nutrition. Instead, some participants are deferring decisions about future EoLC to a Health Care Agents. Moreover, both participants and their families may be unfamiliar with legislation and how this differs from state to state and the effect of this on the decisions that are made. Triplett & Black (2008), also noted the variance in the content and language of documents, an issue that has been identified elsewhere (Dening et al., 2012 a; Livingston et al., 2012; Reinhardt et al., 2014).

In the UK, Dening et al's (2012 b) study examined how people with dementia together with their spouse or nearest carer defined their wishes and preferences for EoLC when attending an assessment in a memory clinic. The results suggested that people with dementia and their carer's find discussion of their preferences challenging. Carer preferences not only predominated those of the person with dementia, carer choices were framed in the context of their current experiences of providing care, rather than future possible events such as emergency admissions. Similarly, people with dementia found defining what their preferences might be in response to hypothetical scenarios difficult since they found it hard to imagine their future selves.

While evidence suggests that ACP can contribute to enhancing quality of life and a 'good death', thereby reducing the carer's burden of making the 'right' decision it may be limited in helping people with dementia themselves address future issues (Forbes et al., 2000; Lamberg, Person, Kiely & Mitchell, 2005; Stewart, Goddard, Schiff & Hall, 2011). Moreover, some people with dementia while capacitated defer decisions to relatives who have the task of making the 'right decision.' Yet, decisions formed upon the principles of 'best interest' can be subverted by the very systems that are influential in EoLC.

Systemic barriers to EoLC

Are there any systemic factors such as integrated working that can affect the care provided? Since most of the studies reviewed focused on nursing and care homes (n=16) followed by hospital sites (n=7), systemic barriers to and facilitators of enacting EoLC could be pertinent.

Dening et al's (2012 a) UK study identified several barriers implementing EoLC through a whole systems approach involving a wide variety of fifty health and social care staff (from residential care, out of hours hospital admission, doctor's support for carer's, ambulance staff, care home and hospice staff, care managers, Admiral Nurses (who support people with dementia and their family carer's)and acute hospital nurses. Several barriers to implementing good EoLC were identified: pathways of care; the impact of hospitalisation; care pathways; ACP; impact on carers, and staff skills and training.

A lack of co-ordinated care was observed by Dening and colleagues in addressing the complex health and social care needs of people with dementia towards the end of their life particularly when support services were unavailable outside of the hours (OOH) of 9-5, Monday – Friday. As a consequence, this presented ambulance staff who were the first to arrive, with little alternative but to admit the person to hospital. In the event, hospital staff are unable to locate GP records which might alert them to any co-morbidities and severity of a patient's dementia.

Similarly, residential and care staff in Dening et al's study had variable awareness of ACP and dementia and were therefore uncertain about any alternative support available other than to admit a person with dementia to hospital. Residential care staff also feared censure from regulatory authorities if they did not call emergency services. This may explain why staff felt they lacked confidence to provide care and as a result requested more training (Dening et al., 2012 a).

The decision to call on emergency services was associated with reactive care in response to a deterioration in a person's condition and also uncertainty around when and if a person was dying.

In Denning et al's study, there was little to suggest if at any stage people with dementia had been consulted about their wishes and needs for EoLC. As a consequence, carers had to make complex decisions on behalf of their relative with very little support or information. Carers reported on the emotional and physical demands of caring for a relative with dementia and of having to push for services which were described as 'unpredictable and fragmented.'

While these experiences created significant demands on carers, both families and professionals to a lesser extent, were able to identify areas of good practice. Admiral Nurses and services which provided a Community Matron to provide 'in reach' support to nursing homes were regarded favourably.

This study was unique in that it took a whole systems qualitative approach to identify barriers to providing end of life care for people with dementia and which involved family carers and also health and social care professionals. The study highlighted the concerns of staff in being able to provide quality care and to coordinate such critical care towards the end of life. The involvement of a wide variety of professionals at this critical juncture included ambulance staff who did not view themselves as part of a 'dementia work force.' This demonstrates the dissonance between perceived responsibilities within systems of care surrounding people with dementia and the consequences which prevail as a result.

Facilitating a good death

The concept of a good death has been used interchangeably in the literature. The general consensus is that a good death is typified as one free from distress and suffering for patients, families and caregivers in accordance with a person's wishes and ethical standards (Di Giulio et al., 2008; Montelioni & Clark, 2004; Sloane, Williams, Zimmerman & Hanson, 2008; Stewart et al., 2011).

Several studies in this review provided insights into the quality of the deaths experienced by those with dementia with reference to the intensity of treatment interventions at the end of life, including resuscitation, and ANH (Ayalon et al., 2012; Monteleoni and Clarke, 2004; Nakanishi and Honda, 2009 ; Potkins et al., 2000; Rurup et al., 2006). Other studies focus on the use of drug treatments such as antibiotics, statins and sedation (An Vandervoot, Houtekker, Van der Block, van der Steen, 2014 et al; Di Giulio et al., 2008; Parsos et al., 2013; Potkins et al., 2000), and hospital admission (De Gendt et al., 2013; Sampson et al., 2010).

In Parson et al's (2013) study in Northern Ireland (NI) and the Republic of Ireland (ROI) there is considerable variation in decision making among health professionals (n=622) about continuing or discontinuing certain treatments at the end of life for people with dementia. In response to a vignette case study developed by Parson and colleagues, approximately half of the professionals in NI and ROI recommended prescribing antibiotics in which a patient displayed symptoms of pneumonia. When the person was resident in hospital they were less likely to be prescribed antibiotics compared with residents in their own home or in a nursing home and under the care of a GP. In addition, antibiotics were more likely to be prescribed in the absence of a patient's advance directive or if a relative had expressed a wish for more active treatment.

While infections repeatedly occur in the later stages of dementia, the benefits of antibiotics to aggressively treat symptoms at the end of life is unclear (van der Steen, 2005). This suggests a level of uncertainty in prescribing antibiotics owing partly due to the lack of evidence base guidance for health professionals (Parsons et al., 2013).

Parson et al's findings compare with those of studies undertaken in the Netherlands by van der Steen et al., (2005). When people with dementia developed pneumonia in Dutch nursing homes, physicians withheld treatment in up to 23 percent of cases. Instead opiates were frequently used to manage symptom control.

Similarly, other studies (Anquinet et al., 2013; An Vandervoot et al., 2014) describe sedation as an important way of managing distressing symptoms (breathlessness, pain, choking, restlessness), and thus, facilitating comfort care.

The withholding of certain treatments such as antibiotics and opting instead for opiates, may reflect a way of easing pain in dying patients for whom a prolonged life equals prolonged suffering. However, Anquinet et al., (2013) and An Vandervoot et al., (2014) also demonstrate that when sedation is insufficient in alleviating symptoms or suffering (breathlessness, bedsores, anxiety) quality of death as perceived by family caregivers is lacking.

Deciding then when to withdraw active treatment and opt for comfort care is challenging not least since there is limited evidence to guide health professionals on the discontinuation of treatment. This suggests that ACP needs to be flexible enough to include comfort care in discussion as well as planning the withdrawal of treatment.

Discussion

Due to Western society's commitment to patient autonomy, the use of ACP and AD to guide decisions about EoLC in the event that a person loses capacity has been promoted internationally (WHO, 2011). The studies reviewed here however, demonstrate that ACP and EoLC decision making processes are a complex one involving multiple factors.

Decision making is not a one off-choice, but involves different individuals at different points of time of care both before and at the end of life, and in various sites of care (hospital, care home). There have been few examples of what it means to facilitate a good EoLC and a good death other than limiting treatment intensity. Yet suffering is reported here also. In spite of clinicians' decision to limit treatment, people with dementia reportedly experience distressing symptoms including breathlessness, anxiety and pain.

To a lesser extent, studies have collected data on both family and the person with dementia and more on clinicians' perspectives on decision-making and facilitating a good death. While there have been reports of congruency between the preferences and wishes of carers and people with dementia, there have been cases where EoLC preferences cited by people with dementia do not concord with those of carer's or between carer's and those of doctor's.

This has implications for the model of proxy decision making in both the UK and the US, where decisions are prevaricated on the assumption that autonomy of the patient is honoured by adhering to patient's previously held preferences. Where in some instances decisions are supported, ACP studies examining proxy decision making also reveal differing complex realities (Caresse, et al., 2002). Indeed, people with dementia and their spouse's may consider their perspectives on EoLC challenging to review, and when they do it is often in the context of their current experiences (Denning et al, 2012 b).

While the support for carer's is highlighted in varying strategies for example in the RCP (2016) NHS End of Life Strategy 2014-2016, there remains little in the way of research on experiences on carers' at the end-of-life (Sampson et al., 2011). Yet, carers are frequently requested both by the person experiencing dementia and the health professional to act as a proxy for often complex treatment decisions at the end-of-life and at a time when they may be experiencing anticipatory grief.

Key concerns have also been raised in this review due to the consequences of a lack of integrated working as demonstrated by Sampson and colleagues including the reluctance of health professionals to assume responsibility to initiate and discuss goals and treatment for EoLC. While there is an identified need to support staff including interagency communication and working, future initiatives which promote good quality EoLC will need to involve all those affected including the range of care setting in which dying takes place.

Education and training as identified in this review can be an integral component of ACP and which a range of core competencies including good communication skills, legal and ethical awareness, and recognition of when ACP may be appropriate. Such training should be worked based and the quality of training and care reviewed annually. This is an approach which is supported by the RCP (2009).

In this paper we refer to good death as that which minimises suffering and being free from pain at the end-of-life (Sampson et al., 2011). To this we should add being surrounded by those who are important to the dying. This does not necessitate a highly technical environment, but vigilant, well supported professionals, working with relatives, communicating and coordinating care. Future research could focus on palliative care interventions that include all members of a clinical care team and which promotes a wider discussion of care goals, treatment decisions and management and to a much greater extent involving the family.

Ideally, this would take place in a supportive environment and conducted in a sensitive and considered way. However, we have noted that decision making about EoLC is not a one-off event, but which may necessitate adjustment along with that of a dementia pathway which is at times unpredictable.

This review has documented on studies that are largely retrospective in design and focusing on clinicians' decision making in both real and hypothetical situations and upon families' accounts of the quality of death and dying. As the numbers dying with dementia increase worldwide more high quality research evidence is needed to inform approaches to EoLC for people with dementia.

Declaration of Conflicting Interests

None declared

Funding

The review was funded by the author's work based GW 4 accelerator fund from the Universities of Exeter, Bristol, Bath and Cardiff. The lead author conducted this review whilst employed at the University of Exeter.

References

Allen, R.S., DeLaine, S.R., Chaplin, W.F., Marson, DC, Bourgeois, M.S, Dijkstra, K, Burgio, L.D. (2003) Advance Care Planning in nursing homes and possession of advance directives. *The Gerontologist*, 43,(3), 309-317.

Alzheimer's Disease International *World Alzheimer's Report 2012. Overcoming the stigma of dementia*. Alzheimer's Disease International.

Alzheimer's Society. Dementia UK update 2014.

http://alzheimers.org.uk/site/scripts/download_info.php?fileID=2323. Accessed 3 November 2015

Anquinet, L., Rietjens, J.A.C., An Vandervoort, M.A., van der Steen, J.T., Stichele, R.V., Deliens, L., & Van den Block, L. (2013) Continuous deep sedation until death in nursing home residents with dementia: A case series. *JAGS*, 61, 1768-1776

Arksey H, O' Malley L. (2005) Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, 8, 19-32.

Ashton, S., Roe, B., Jack, B., & McClelland, B. (2014) End of life care: The experiences of advance care planning amongst family caregivers of people with advanced dementia- A qualitative study. *Dementia International Journal of Social Research and Practice*. [Doi: 10.1177/1471301214548521](https://doi.org/10.1177/1471301214548521). Accessed September 3, 2015.

Ayalon, L., Bachner, Y.G., Dwolatzky, T., & Heinik, . (2012) Preferences for end-of-life treatment: concordance between older adults with dementia or mild cognitive impairment and their spouses. *International Psychogeriatrics*, 24 (11), 1798 – 1804.

Beauchamp, T.L., Childress, J.F.,(2008) *Principles of biomedical ethics* (6th ed). New York: Oxford University Press.

Black, B.S., Fogarty, L.A., Phillips, H., Finucane, T., Lorek, D.J., Baker, A., Rabins, P.V.,(2009) Surrogate Decision Makers' Understanding of Dementia Patients' Prior Wishes for End-of-Life-Care. *Journal of Ageing and Health*, 21, (4), 627-649

Brayne, C., Gao, L., Dewey, M., & Mathews, F.E. (2006) Dementia before Death in Ageing Societies – The Promise of Prevention and the Reality. *PLoS Med*,3, E397

Brinkman-Stoppelenberg, A., Rietjens, J.A.C., & van der Heide, A. (2014) The effects of advance care planning on end-of-life-care: A systematic review. *Pall Med*.28:1000-25.

Carrese, J.A., Faden, R.R, & Finucane, T.,E. (2002) Planning for death but not serious future illness:Qualitative study of housebound elderly patients. *British Medical Journal*, 325, 7356: 125

Cavaliere ,T.A., Latif, W., Ciesleski, J., Ciervo, C.A., & Forman, L.J. (2002) How physicians approach advance care planning in patients with mild to moderate Alzheimer's disease. *JAOA* 102,(10) 541-544.

Clarke, G., Galbraith, S., Woodward, J., Holland, A., & Barclay, S. (2015) Eating and drinking interventions for people at risk of lacking decision-making capacity: who decides and how? *BMC Medical Ethics*, 16-41.[Doi: 10.1186/s12910-015-0034-8](https://doi.org/10.1186/s12910-015-0034-8). Accessed 3 November, 2015

De Bosek, M.S., Lowry, E., Lindeman, D.A., Burck, J.R., & Gwyther, L.P. (2003) Promoting a good death for persons with dementia in nursing facilities. Family caregivers' perspectives. *JONA'S Healthcare, Law, Ethics and Regulation*, 5 (2), 34-41.

De Gendt, C., Bilsen, J., Stichele, R.V., & Deliens, L. (2013) Advance care planning and dying in nursing homes in Flanders, Belgium: a nationwide survey *Journal of Pain Symptom and Management*, 45 (2), 223-234.

Dening, K.H, Greenish, W., Jones, L., Mandal, U., & Sampson, E.L. (2012 a) Barriers to providing end of life care for people with dementia: a whole-system qualitative study. *BMJ Supportive and Palliative Care*. [doi:10.1126/bmjspcare-2011-000178](https://doi.org/10.1126/bmjspcare-2011-000178). Accessed 3 November 2015

Dening, K.H., Jones, L., & Sampson E.L. (2012 b) Preferences for end of life care: A nominal group study of people with dementia and their family carers. *Palliative Medicine*, 27 (5), 409-417.

Department of Health. (2007) *Mental Capacity Act 2005: Code of Practice*. London: HMSO.

Department of Health. (2008) *End of life care strategy: Promoting high quality care for all adults at the end of life*. London, DoH.

Department of Health *Living Well with Dementia: a national dementia strategy* 2009.

www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy(2009, accessed 3 November 2015)

Dempsey D (2013) Advance care planning for people with dementia: Benefits and challenges. *International Journal of Palliative Nursing*, 15 (5), 227-234.

Di Giulio, T., Toscani, F., Villani, D., Brunelli, C., Gentile, S., & Spadin, P. (2008) Dying with advanced dementia in long-term care Geriatric Institutions: A retrospective study. *Journal of Palliative Medicine*, 11 (7), 195-202.

- Elliott, B.A., Gessert, C.E., & Peden-McAlpine, C. (2009) Family decision making in advanced dementia: Narrative and ethics. *Scandinavian Journal of Caring Sciences*;23:251-258.
- Elwyn, G., Laitner, S., Coulter, A., Walker, E., Watson, P., Thomson, R. (2010) Implementing shared decision –making in the NHS. *BMJ*, 341, c5146
- Evans, C. & Goodman, C. (2008) End of Life Care for Older People with Dementia Living in a Care Home. *Journal of Integrated Care*, 16 (6), 15-26.
- Forbes, S., Bern-Klug, M., & Gessert, C. (2000) End-of-life decision making for nursing home residents with dementia. *Journal of nursing Scholarship*, 32 (3), 251-258.
- Gott, M., Ibrahim, A.M., Binstock, R.H., (2011) The disadvantaged dying : Ageing, ageism, and palliative care provision for older people in the UK. In M. Gott, & C. Ingleton (Eds.), *Living with ageing and dying (Chapter 5)* Oxford, UK: Oxford University Press.
- Hawkins, N.A., Ditto, P.H., Danks, J.H., & Smucker, W.D. (2005) Micromanaging death: Process preferences, values and goals in end-of-life medical decision making. *The Gerontologist*, 45, 107-117.
- High, D.M., & Turner, H.B. (1987) Surrogate decision-making: The elderly's familial expectations. *Theoretical Medicine*, 8, 303-320.
- Hines, S.C., Glover, J.J., Barbow, A.S., Holley, J.L., Badzek, L.A., & Moss, A.H. (2001) Improving advance care planning by accommodating family preferences. *Journal of Palliative Medicine*, 4, 481-489.
- Hopp, F.P (2000) Preferences for surrogate decision makers, informal communication, and advance directives among community-dwelling elders: Results from a national study. *The Gerontologist*, 40, 449-457.

- Houttekier, D., Cohen, J., Bilsen, J., Addington-Hall, J., Onwuteaka-Philipsen, B.D., & Deliens, L. (2010) Place of death of older persons with dementia. A study in five European countries. *Journal of the American Geriatrics Society*, 58, 751-756.
- Huxtable, R. (2015) "Advance decisions: Worth the Paper They Are (Not) Written On? *BMJ End of Life*; 5 eoljnl-2015-000002
- International Association of Gerontology and Geriatrics (IAGG)(2011) *The Global Burden of Dementia Worldwide*.
- Kaufman, S.R. (2005) *How American Hospitals Shape the End of Life*. Scribner: London.
- Lamberg, J.L., Person, C.J., Kiely, D.K., Mitchell, S.L. (2005) Decision to hospitalize nursing home residents dying with advanced dementia. *JAGS*,53, 1396-1401.
- Lacy, D.(2006) End of life decision making for nursing home residents with dementia: A survey of nursing home social service staff. *Health and Social Work*, 31, (3), 189-199.
- Levac, D., Colquhoun, H., &O'Brien, K. (2010) Scoping studies: advancing the methodology. *Implementation Science*,5, (69) 1-9.
- Livingston, G., Lewis-Holmes, E., Pitfield, C., Manela, M., chan, D., Constant, E., Jacobs, H., Carson, N. & Morris, J. (2013) Improving the end-of-life for people with dementia living in a care home: an intervention study. *International Psychogeriatrics*, 25 (11),1849-1858.
- Meier, D.E., Aronheim, J.C., Morris, J., Baskin-Lyons, S., & Morrison. R. S. (2001) High short-term mortality in hospitalized patients with advanced dementia: lack of benefit of tube feeding. *Archives of Internal Medicine*, 161 (4), 594-599.
- Morita,T., Chinone, Y., & Ikenaga,M. (2005) Efficacy and safety of palliative sedation therapy: A multi center, prospective, observational study conducted on specialised palliative care units in Japan. *Journal of pain symptom management*, 30,320-328.

Monteleoni ,C., & Clark, E. (2004) Using rapid-cycle quality improvement methodology to reduce feeding tubes in patients with advanced dementia: before and after study. *BMJ*, Aug 28, 329 (7464), 491-494. [Doi:10.1136/bmj.329.7464.491](https://doi.org/10.1136/bmj.329.7464.491) Accessed September 10, 2015.

Moy, J., Marson, D., Edlestein, B., Wood, S., &Saldivar, A. (2010) Decision making capacity. In: K. Warner-Schaie &S. Willis (Eds.) *Handbook of thepsychology of aging*. 7th edn.London: Academic Press.

Nakanishi, M., &Honda, T. (2009) Processes of decision making and end-of-life care for patients with dementia in group homes in Japan. *Archives of Gerontology and Geriatrics*, 48, 296-299.

National Council for Palliative Care (2012)*Response to All Parliamentary Group on Dementia 2012 Inquiry: Improving dementia diagnosis rates in the UK*. NCPC 1st.

National Council for Palliative Care. Advance Care Planning: A Guide for Health and Social Care Staffhttp://www.ncpc.org.uk/sites/default/files/AdvanceCare_Planing.pdf (2007 accessed 8 November, 2015)

NHS England (2011) *Actions for End of Life Care: 2014-16*. Leeds: NHS England

Parsons, C., McCorry, N., Murphy, K., Byrne, S., O'Sullivan, D., O' Mahoney, D., Passmore, P., Patterson, S., & Hughes, C. (2013) Assessment of factors that influence physician decision making regarding medication use in patients with dementia at the end of life. *International Journal of Geriatric Psychiatry*, 29, 281-290.

Potkins, D., Bradley, S., Shrimanker,J., O'Brien, J., Swann, A.,& Ballard, C. (2000) End of life treatment decisions in people with dementia: Carer's views and the factors which influence them. *International Journal of Geriatric psychiatry*,15, 1005-1108.

Rabins, P. V., Lyketsos, C..G.,&Steele, C.D. (2006) *Practical Dementia Care*[2nd edition] New York: Oxford University Press.

- Reinhardt, J.P., Chichin, E., Posner, L., Kassabiann, S. (2014) Vital Conversations with family in the nursing home: Preparation for end-stage dementia care. *Journal of social in end-of-life & palliative care*, 10 (2) 112-116.
- Robinson, L., Dickinson, C., Bamford, C., Clark, A., Hughes, J., & Exley, C. (2012) A qualitative study: Professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but...'. *Palliative medicine*, 17 (5), 401-408.
- Royal College of Physicians (2016) End of Life Care Audit – Dying in Hospital. London: RCP
- Rurup, M.L., Onwuteaka –jilipsen. B.D., Pasman, H.R., Ribbe, M.W., van der Wal, G. (2006) Attitudes of physicians, nurses and relatives towards end of life decisions concerning nursing home patients with dementia. *Patient Education Counselling*, 61, 372-3809
- Sampson, E., Burns, A., & Richards, M. (2011) Improving end-of-life care for people with dementia *The British Journal of Psychiatry* 199, 357-359.
- Sampson, E., Ritchie, C., Lai, R., Raven, P.W., & Blanchard, M.R. (2005) A systematic review of the scientific evidence for the efficacy of a palliative care approach in advance dementia. *International psychogeriatrics*, 17 (1), 31-40.
- Sampson, E.L., Jones, L., Thune-Boyle, I.C.V., Kukkastenvemas, R., King, M., Leurent, B., Tookman, A., & Blanchard, M.R. (2011) Palliative assessment and advance care planning in severe dementia. An exploratory randomized controlled trial of a complex intervention. *Palliative Medicine*, 25 (3), 197-209.
- Seymour, J. (2009) Critical Moments: Death and Dying in Intensive Care. In S. Earle, C. Komaromy., & C. Bartholomew (Eds.) *Death and Dying*. (pp. 130-135) Buckingham: The Open University.
- Shega, J., Levin, A., Hougham, G. (2003) Palliative Excellence in Alzheimer's Care Efforts (PEACE): A Program Description. *Palliative Medicine*, 6 (3), 15-20.

Shalowitz, D.I., Garrett-Mayer, E., & Wendler, D. (2006) The accuracy of surrogate decision makers: A systematic review. *Archives of Internal Medicine*, 166, 493-494.

Sloane, P.D., Zimmerman, S., Williams, C.S., & Hanson, L.C. (2008) Dying with dementia in long term care. *The Gerontologist*, 48, (6), 741-751.

Stewart, F., Goddard, C., Schiff, R., & Hall, S. (2011) Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families. *Age and Ageing*, 40, 330-335.

Suarez, P., & Farrington-Douglas, J. (2010) *Acute awareness: improving hospital care for people with dementia*. London: The NHS Confederation.

Triplett, P., Black, B.S. (2008) Content of advance directives for individuals with advanced dementia. *Journal of ageing and mental health*, 20 (5), 583-506.

Vandervoot, M.A., Houttekier, D.H., Van de Block, L., van der Steen, J.T., & Van der Stichele, R. (2014) Advance care planning and physician orders in nursing home residents with dementia: A nationwide retrospective study among professional care givers and relatives. *Journal of pain and symptom management*, 42, (2)245-256.

van der Steen, J.T. (2010) Dying with Dementia: What we Know after More than a Decade of Research. *Journal of Alzheimer's Disease*, 22, 35-55.

van der Steen, J.T., Radbruch, L., Hertogh, C.M., de Boer, M.J., Hughes, J.C., & Larkin P (2013) White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendation from the European Association for Palliative Care. *Palliative Medicine*, 28, 197-209

van der Steen, J.T., van der Wal, G., Mehr, D.R., Ooms, M.E., & Ribbe, M.W. (2005) End of life decision making in nursing home residents with dementia and pneumonia: Dutch physicians intentions regarding hastening death. *Alzheimer's Disease Associative Disorders*, 19 (3), 148-155.

World Health Organisation. *Palliative care for older people: Better practices*. (2011) Rome, Italy: WHO, Regional Office Europe.

World Health Organisation. *Dementia a public health priority* (2012) Geneva, Switzerland: WHO.

Xie, J., Brayne, C., Mathews, F.E. (2008) The Medical Research Council Cognitive Function and Ageing Study Collaborators. Survival times in people with dementia: analysis from population based cohort study with 14 year follow up. *British Medical Journal*, 336 (7638) 258-62.

Yeun-Sim Jeong, S., Higging, I., & McMillan, M. (2011) Experience with advance care planning: nurses' perspective. *International Journal of Older People Nursing*, 6, 165-171

Authors

Kerry Jones PhD, MA, FHEA, MBCAP is a Lecturer in End-of-Life Care at the Open University where her research interests include death and dying, communication at the end-of-life, living with terminal conditions and the experiences of clinical and non-clinical staff in providing end-of-life care. Kerry is currently the OU academic, co-producing a programme on 'Dying Well' with the BBC. As well as teaching on a BMBS at the University of Exeter Medical School and to clinicians and therapists working in EoLC, more recent projects with the Open University have included dementia, older people and frailty, end of life care over the life course (perinatal - older), clinician experience of ACP and suicide.

Giles Birchley PhD, BSc, RN is a Senior Research Associate in Healthcare Ethics at the Centre for Ethics in Medicine in the School of Social and Community Medicine at the University of Bristol. His research focuses on clinical ethics and end of life decision-making, especially for those who are unable to formally consent to such decisions.

Richard Huxtable PhD, MA, LLB is Professor of Medical Ethics and Law, and Director of the Centre for Ethics in Medicine in the School of Social and Community Medicine at the University of Bristol. His research focuses on health care ethics and law in relation to end-of-life care, clinical ethics support services, and surgery. He is a Trustee of the UK Clinical Ethics Network and the National Council for Palliative Care.

Linda Clare PhD ScD CPsychol FBPsS FacSS is a Professor of Clinical Psychology of Ageing and Dementia and leads the Centre for Research in Ageing and Cognitive Health (REACH) at the University of Exeter. Her research focuses on maintaining cognitive health in later life and living well with cognitive impairment and dementia. She currently chairs the British Psychological Society's Dementia Advisory Group.

Tony Walter PhD is Honorary Professor of Death Studies at the University of Bath, UK. He has published on a wide range of topics around the end of life.

Jeremy Dixon is a Lecturer in Social Work at the Department of Social and Policy Sciences at The University of Bath, UK. His research interests focus around the sociology of mental health and illness and the sociology of risk and uncertainty. He is a board member of the International Sociological Association's Research Committee on the Sociology of Mental Health and Illness. He remains a qualified social worker and continues to practice as an Approved Mental Health Professional.

Characteristics of included studies

Author	Year	Study location	Study Type	Participant Group	Site	Aims of the study	Overview of methods	Outcome measures	Results
Allen, R.S, et al	2003	USA	Epidemiological cross sectional study.	Nursing home residents and proxies n= 78	Care Home	To Identify nursing home residents who can participate in ACP for EoLC	Participants recruited from intervention study designed to improve communication between nursing staff and residents.	Health chart review; proxy interviews; resident assessment and observation of residents, survey of nursing staff. Analysis of DNR's, Religiosity assessed through 5 item measure (Reach, by Coon et al, 1999), Items: (Functional Independence measure, Coon et al, 1999), Philadelphia measure scale; Pain Measure Scale (Parmalee, et al, 1991); Charlson Morbidity Index (Charlson et al 1987), Computer Assisted Behavioural Observation (CABOS) (Burgio et al, 1994)	Residents more likely to have advance directives when proxies are aware of patient wishes. Patients and their proxy decision makers were more likely to have and AD if they were deemed less religious and patients socially engaged.

Anquinet, L. et al	2013	Belgium	Retrospective cross sectional	Proxies involved in care of people with dementia who had died n= 177	Sixty-nine care homes recruited	To describe the characteristics of continuing deep sedation until death and prior decision making process of nursing home residents and evaluate the practice against that of sedation guideline recommendations.	Nursing home administrator identified resident and a proxy decision maker (relative/carer) most involved in care. Nurse, GP, relative were sent questionnaire 3 months post death.	GP, nurse and relative questionnaires containing validated instruments: Quality of life in Late-Stage Dementia (Weiner et al, 2000) to assess quality of dying in the last week of life and the Comfort Assessment in Dying End of life in Dementia (CAD-EOLD)(Volicer, et al, 2001), Cognitive Performance Scale (Morris et al, 1994), Global Deterioration Scale (Reisberg et al, 1982) to assess severity of dementia 1 month prior to death.	Continuous and deep sedation until death for these nursing home residents at the end of life did not guarantee a process free of symptoms (fear, swallowing difficulty).
Ayalon, L. et al.	2012	Israel	Cross sectional	n= 53 people with dementia and their carer dyads. Total n= 106.	Psychogeriatric clinic	To evaluate concordance in end of life preferences between patients and their carers	Conducted in two psychogeriatric clinics, interviews.	Through interviews, case vignettes describing severe dementia cases. Demographic data [age, gender, education, co-morbidities, MMSE]. Statistical analysis performed of three types of preferences - patient, spouse with regard to patient, spouse about own treatment options.	Patients more likely to opt for treatment decisions than spouses. While some mild agreement limited evidence for projection of spouses' preferences on patients.

Black, S. et al	2009	USA	Qualitative descriptive time series design. Data collected at baseline, every 3-5 months, following death.	Carer's as proxy decision makers n=34	Nursing home	How surrogate decision makers for people with dementia develop understanding of patient preferences for EoLC and wishes.	Qualitative. Recruitment as part of a larger CareAD study of nursing home residents in 3 Maryland nursing homes. Purposive sub sample of surrogates enrolled in CareAD study.	Interviews - surrogates to describe course of illness, process of formal/informal ACP, knowledge of AD documents, their patients understanding of patient's prior wishes, patient most recent health problem, and treatment decisions made for those problems.	PWD had previously recorded an ACP [59%], discussed preferences for EoL [56%]. Main wish not to be kept alive by machines or by extraordinary measures.
.Cavalieri, T.A. et al	2002	USA	Survey	Of 271 approached, 63 physicians responded to survey	Physicians in private practice and in hospital.	To assess if ACP was provided, specific topics discussed and actions taken if ACP not offered for mild and moderate dementia, questions asked about the care given.	Fifteen item survey	Survey	Of those physicians who responded, 81% counselled patients on ACP, 19% did not. Among 51 physicians (88%) living will discussed, power of attorney by (53%), future plans (45%), living arrangements (57%), end of life care (47%). Authors argue physicians need to have more knowledge about dementia.

De Gendt, C., et al	2013	Belgium	Survey	N= 318, nursing homes in which a mix of nurses responded to 1240 deaths and nursing home administrators responded to 1303 deaths.	Nursing homes	To investigate the prevalence and characteristics of AD's , physician's orders for end of life care in nursing homes and the authorisation of a legal authorisation in relation to clinical characteristics	Survey	Survey	Having an AD or physician's orders was associated with receiving palliative care. Residents with a physician's order more often died in the NH. Nine percent had an authorized legal representative.
Dening , K.H et al	2012a	UK	Qualitative	Recruited n = 50 carers recently bereaved by dementia	Hospital	To identify perceived and real barriers that prevent people with dementia receiving EoLC .	Whole system (as part of rapid participatory appraisal)	Semi structured interviews and focus groups	Five areas identified as barriers i. Impact of hospitalisation ii. Care pathways, iii. ACP, iv. Impact on carers, v. Staff training and skills. Lack of integrated care.

Dening, K.H. et al	2012b	UK	Nominal group technique	Recruited n= 6 people with dementia; n= 5 carers; n= 6 dyads	Memory service on 3 sites [Mental Health Facilities]	To explore whether people with dementia and their carers were able to generate and prioritise preferences for EoLC and to examine if carers influence choice.	Three nominal groups (NGI) were conducted in 5 stages: i. slide generation of ideas, ii. discussion iii. Further generation of ideas, iv. Discussion and theme and v. ranking.	NGT groups and thematic analysis	NG I : carers of people with dementia in order or priority i. To be in control, ii. have a good QOL, iii.to have good QOL care, iv. Comfortable death. V. treated with respect and dignity, vii. Have carer support. NG II: people with dementia in order i. maintain family links, ii. Independence, iii. feel safe, iv. not be a burden, v. treated with respect and dignity, vi. Have choice in place of care, vii. Pleasurable activities, viii. respect and dignity..
--------------------	-------	----	-------------------------	--	---	---	--	----------------------------------	--

Di Guilio, P. et al	2008	Italy	Retrospective exploratory study	Study recruited n= 141 people will all type dementias .	Italian care homes n=7	To describe the last month of life in cases of severe dementia and the clinical decisions in the undertaken to manage EoLC	Review of clinical and nursing records of patients who had died in previous 12 months.	MMSE, cause of death, data from clinical and nursing records of the last 30 days of life. Symptoms, signs, intensity, treatments (antibiotics, analgesics, anxiolytic, artificial nutrition, hydration, restraints, and CPR attempts and life sustaining drugs in last 48 hours.	Half of patients had pressure sores. During last 48 hours interventions inappropriate: tube feeding (20.5%), intravenous hydration (66.6%), antibiotics (71.6%), self sustaining drugs (34.0%).
Forbes, S. et a	2000	USA	Qualitative	Study recruited n= 28 family members of people with dementia	Care homes	Describe familial decision making process for EoL treatments	Four focus groups in selected nursing homes [n=4] Naturalistic inquiry provided framework for descriptive study	Content analysis of focus groups containing 5-8 family members.	Five themes describe decision-making I. emotional effect, II. Insult to the life story III. Two faces of death, IV. Values and goals regarding end-of-life-treatments and V.Unrecognised dying trajectory.

Lamberg et al.	2005	USA	Cohort	Decedents=240	Care homes	What inform decisions to/ not to hospitalise care home residents	Demographics informed by Minimum Data Set (USA medicare) from last 6 months of life; cognitive performance score; planned DNAR, DNH or Palliation	Factors associated with hospitalisation	Do not hospitalise was associated with: Proxy not being a child of patient, eating problem, aged >92, length of stay >2 years; 40% of DNH orders written in last month of life; 34% had DNH 180 days .
.Livingston et al	2013	UK	Qualitative intervention	Carers n=53; Residents of care home n=98	Care home	Evaluation satisfaction of care	Intervention = end of life training for staff; method= one to one interview with staff; review for advance wishes, interviews with families of decedents	QOL of resident; Family stress; Family satisfaction with care; place of death	Increased deaths in care home rather than hospital following intervention; intervention increases family satisfaction; documented advance wishes and DNAR.
Meier, D.E., et al	2001	USA	Follow up of hospital index of feeding tubes	People with dementia = 99 recruited	Hospital	To assess long-term survival in an inception cohort, incident tube feeding placement during the index hospitalization, and the influence of tube feeding on survival in this group of patients.	Ninety-nine hospitalized patients with advanced dementia and an available surrogate decision maker were followed up	Other variables measured included advance directive status, presence of a long-term primary care physician, level of involvement of the surrogate decision maker, admitting diagnosis, prior hospitalizations.	Median survival of the 99 patients was 175 days. Eighty-five (85%) survived the index hospital. Tube feeding was not associated with survival (P =.90).

Monteleoni, C. & Clarke, E.	2004	USA	Intervention	Patients where ANH discussed n =40	Hospital	To reduce feeding tube placement in advanced dementia	Retrospective chart review followed by educational intervention (EoL and feeding education for staff) followed by further review	Presence of dementia, advance directive, ability to eat	Educational intervention reduced numbers of feeding tubes.
Nakanishi, M. & Honda, T.	2009	Japan	Survey (Retrospective cross sectional survey)	Decedent's=33	Care home	Content of EOL decision-making in dementia	Self-administered questionnaire to care home manager about circumstances of last week of life;	Review of cases	Family want place of death to be in a care home, but 50% of residents want to die at home; 1/3 of patients able to feed orally; 50% of those unable to feed orally were drip fed; no PEG feeding.
Parsons et al	2014	Ireland / N Ireland	Epidemiology	Clinicians=1079	Care home	Which medications do physicians withhold at EOL	Factorial survey with vignettes; names five medications where literature recommends withdrawal at EOL	Effect of patient related factors and country of practice on EOL prescribing	Widespread uncertainty in prescribing practice at EOL. Jurisdiction affects prescribing. Place of patient residence affects prescribing (hospitals less likely to prescribe antipsychotics and antibiotics.

Potkins et al.	2000	UK	Survey	Carers=50	Hospital and care home	What do families withhold at EOL, what affects the decision	Questionnaire with vignettes; case note review	Decisions about CPR, IV fluids, IV/Oral antibiotics ; Effect of age, dementia severity, psychiatric comorbidity, physical illness, family relationship	Carers responded to vignettes as proxy decision makers: 46% wanted CPR; 60% IV fluids; 52% IV antibiotics; 60% oral antibiotics. There was no effect in relation to other treatments; psychiatric comorbidity, physical illness and QOL did not influence decisions.
Reinhardt et al.	2014	USA	Intervention (Randomised)	Family=110	Care home	Effect of structured conversation about EOL care vs social contact	interview, group discuss CPR, hospitalisation, ANH, Pain and symptom management	family satisfaction; family well being	Single in depth meeting with family increased family satisfaction with care; increased writing of advance directives; increased limitations of treatment at EoL.

Robinson et al.	2012	UK	Qualitative	Clinicians=95	Hospital, care home and the community	Dementia professional experiences of advance care planning at EoL	Focus group interviews (14) face to face semi-structured interviews (18) with professionals from palliative care (doctors and nurses) dementia care, social services, law, voluntary sector	Themes	Multiple reservations about ACP among professionals. Uncertainty about usefulness of ACP (good in theory, problem in practice).
-----------------	------	----	-------------	---------------	---------------------------------------	---	--	--------	---

Rurup et al.	2006	Netherlands	Survey	Physicians=107, Nurses=178, Family=136	Nursing homes	Level of agreement of end of life decisions between physicians, nurses and families	Survey after decision about ANH; 15 statements and 5 item Likert-type response	survey items regarding ANH, advanced directives, euthanasia, self determination, institutional policy for foregoing treatment	Validity of Advance directives agreed by all parties; highlights differences between physicians and patients. Physicians disagree with euthanasia in incapacitated patient even if AD requests. Nurses disagree that death from ANH is peaceful.
Sampson et al.	2011	UK	Randomized control trial of complex intervention	Carer/patient dyads=33	Hospital	Improve EOLC, encourage carers to write ACP	Phase 1 Qualitative interviews, 20 patients, 21 HCP; thematic analysis; Phase 2 Intervention study: patient dementia severity and clinical factors, carer wellbeing, education about dementia.	Patient: Physical health / Carer: Distress scale; - Decision satisfaction; -Quality of life; - Satisfaction with end of life care in dementia; measured after bereavement.	ACP may not be feasible when only proxies involved; Phase 1: Lack of awareness of terminal nature of dementia among HCP and carers; Phase 2: Reluctance of carers to write ACP, even with intensive support.

Sloane et al	2008	USA	Qualitative	Collected data from n= 677 staff; n=451 carers n= 451	Care Homes	To understand unmet needs of people who die in long term care. Comparison of with without dementia	Qualitative	Staff interviews characterised: illness course, physical symptoms, behavioural symptoms, treatment, psychosocial status, care provision. Family interviews described: family involvement in communication, decision making, and satisfaction with care.	No difference between with and without dementia for pain, psychosocial status and family involvement, ACP, interventions and hospice use. PWD died less often in hospital, experienced less shortness of breath, yet received more restraint, and sedatives.
. Stewart et al.	2011	UK	Qualitative interviews	Care home staff	Care home	To examine views of ACP in care homes for older people in two London Boroughs.	Interviews	Interviews	Facilitators: Staff felt it provided choice for residents and encouraged better planning. Barriers: staff and families perceived residents as reluctant to discuss advance care planning. Some care assistants were reluctant to be involved.

Triplet, et al	2008	USA	Documentary analysis; retrospective design	n=123 residents documents	Care home	To examine how people with dementia at EOL conveyed wishes for care in AD.	Documentary analysis from 3 nursing homes	Demographics: including dementia diagnosis, wills, power of attorney, documents for treatment preferences.	More years of education and white race significantly associated with AD. With exception of comfort care and pain treatment AD were used to restrict not request many forms of care.
.Vandervoot et al	2014	Belgium	Survey	Clinicians and relatives n= 205 decedents	Nursing home	Examine awareness of end of life planning and congruence between dementia patients' end of life decisions expressed to family and those documented by clinicians.	Survey	Survey	Communication regarding care is rarely patient driven and more professional or family driven. The level of congruence between professional care givers and relatives is low.
Van der Steen et al	2005	Belgium	Survey	Physicians who responded to review n=143 patients	Nursing home	Examine the decision making process to hasten the death of people with dementia who had pneumonia.	Survey	Survey	Fifty-three percent of physicians reported an explicit intention to hasten death; 41% withheld antibiotics or other palliative treatments to hasten death; 43% used opiates for symptom control.

