The extended palliative phase of dementia- an integrative literature review

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Abstract
This article presents an integrative literature review of the experience of dementia care associated with the extended palliative phase of dementia. The aim was to highlight how dementia is defined in the literature and describe what is known about the symptomatology and management of advanced dementia regarding the needs and preferences of the person with dementia and their family carer/s. There was no consistent definition of advanced dementia. The extended palliative phase was generally synonymous with end of life care. Advanced care planning is purported to enable professionals to work together with people with dementia and their families. A lack of understanding of palliative care among frontline practitioners related to a dearth of educational opportunities in advanced dementia care. There are few robust concepts and theories that embrace living the best life possible during the later stages of dementia. These findings informed our subsequent work around the concept, ‘Dementia Palliare’.

Key words: advanced dementia, integrative literature review, palliare, palliative care,
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Introduction

In response to the rising incidence of dementia across the globe there have been calls for governments to commit to providing good quality care for people with dementia (WHO, 2012), for countries to share and build solutions to deliver services across the continuum of care (DoH, 2013) and to prioritize and improve the training and development of the dementia workforce (WHO, 2012, European Parliament, 2010).

As the condition progresses, living well with dementia requires increasing levels of support and care. The progression of dementia is often separated into mild, moderate and severe corresponding to early, mid and late or advanced stages. The middle to late stages of the disease often signals a loss of autonomy, independence and reduction in physical and cognitive function. This stage has been described as the beginning of an extended, intensive palliative care phase (Reisberg et al., 2006). Reisberg et al., (2006) noted that this period may be more than twice as long as the early stages of the disease (up to ten years). To date, the literature has tended to focus on diagnosis and early dementia care to the relative exclusion of advanced dementia care.

In light of this gap, a project to provide educational solutions for the dementia workforce in Europe was funded by the Erasmus Plus programme, led by Tolson and colleagues at the University of the West of Scotland and involving partners in Sweden, Finland, Czech Republic, Slovenia, Portugal and Spain (http://www.uws.ac.uk/palliareproject/). The project aims to create a range of evidence based participatory and practice based learning resources to equip qualified practitioners from health and social care disciplines to champion improvements to advanced dementia care in their workplace. This paper highlights one aspect of the project, an integrative literature review of the experience of dementia care associated
with the extended palliative phase of the illness. The project team reached consensus that the extended palliative phase most closely corresponds to Barry Reisberg et al.’s (2006), stages 6 & 7 of the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS) (see Figure 1 below). The term ‘advanced dementia’ was used as a short operational definition of the extended palliative phase.

[Add Figure 1 about here]

Aims

This paper will present and discuss the findings of an integrative literature review which aimed at creating a shared understanding of dementia care and family caring associated with the extended palliative phase of dementia. In particular, it will attempt to reduce the current knowledge gap by highlighting how advanced dementia is defined and recognized in the literature and describe what is known about the symptomatology and management of advanced dementia in relation to the needs and preferences of the person with dementia and the family caring for that person. We conclude with highlighting how these findings have informed our subsequent project work.

Methods

Search strategy and inclusion criteria

The literature review was guided by the integrative review method described by Whittemore and Knafl, (2005). This involved a three-step strategy: i) an initial search of databases, followed by analysis of text words contained in the title and abstract, and of the index terms used to describe the article; ii) a second search using all identified keywords and index terms in the included databases; iii) finally, reference lists of all papers included in the review were searched for additional studies.
Our main focus of interest for the integrative literature review was the extended palliative phase of dementia as defined above. During October through to December 2014, test searches were made in various databases using the following search terms: dementia, experience, advanced dementia, palliative, end-of-life, care, need/s and family. The results were used to inform the search protocol. The CINAHL, PubMed, Social Science Citation Index, Cochrane, Zetoc and EthOS databases were searched during January 2015, using the search terms ‘dementia’ and ‘palliative’. An updated database search for the period from January 2015 through to February 2016 was subsequently conducted for the purposes of this article (the full search results are available on request from the first author).

Based on the test searches, the inclusion criteria were as follows:

- A focus on the advanced stages of dementia, stages 6 and 7 (Reisberg et al., 2006)
- Peer-reviewed publications
- Publications written in English during the period 2010- February 2016

**Selection criteria and search results**

The screening process is highlighted in Table 1 below. Those references that were deemed to be potentially relevant from a second screening of title and, where necessary, the abstract, were then reviewed in full-text by dividing them into the core variables of interest and allocated to the project review teams in Sweden, Portugal and Scotland respectively. Namely, i) definitions of the extended palliative phase; ii) symptomatology and iii) management in relation to the needs of the person with dementia and for family caring .
Methodological quality evaluation strategy

A total of 492 references were identified for the appraisal and quality grading process. Guidance from the Joanna Briggs Institute (JBI, 2014a, b, c) provided the overarching framework for our quality evaluation strategy. The intention was to summarise current best evidence and make tentative conclusions regarding the level of this evidence wherever possible. More specifically, the review teams followed the steps outlined by the Centre for Evidence Based Medicine to ensure transparency and validity throughout the entire reviewing process (CEBM, 2014). The teams first read the paper to check if it concerned the topic area and, if so, several validity questions were addressed (See Figure 2 for the list of questions and critical review process). The majority of papers were evaluated at JBI level 4, meaning they were predominantly observational or descriptive in nature.

Data analysis

An appraisal grid was adopted by the team to summarise the key data into a matrix or spreadsheet. Following the guidance of Whittemore and Knafl (2005), this process facilitated data comparison involving the identification of themes and assembling of the data around these identified themes and/or related subgroups. The final phase of conclusion drawing involved verifying the identified patterns, relationships and commonalities with the primary source data for accuracy.
Findings

The appraisal and quality grading process for each variable of interest led to a final sample of 109 papers (see Table 1 for further details). A summary of the key findings according to each of the three variables of interest will be presented in turn.

i) Definitions, descriptions and recognition of the extended palliative phase of advanced dementia

The terms ‘advanced dementia’ (Aminoff, 2014; Nourhashemi et al., 2012), ‘severe dementia’ (Nourhashemi et al., 2012; Sampson, 2010) and ‘end stage of dementia’ (Aminoff, 2014; Potter, Fernando & Humpel, 2013) were all used within the literature. However, they were used sparingly and mainly in the title and/or as a key word. There was no common, comprehensive description or recognition of the extended palliative phase in the papers. Thus, when the extended palliative phase starts is often not defined. However, where it is defined, stages 6 and 7 on the Global Deterioration Scale are cited (Reisberg et al., 2006). Van der Steen et al., (2016) found a lack of consensus among experts on the applicability of palliative care through all stages of dementia. Most experts agreed that the focus is on the advanced stages of the disease and the benefits of earlier onset of a palliative approach have little evidence. Nevertheless, many patients may die before reaching the advanced stages of dementia (van der Steen et al., 2016).

Relevant text about the extended palliative phase of dementia often included descriptions of symptoms, prognosis, and the difficulties in recognising the phase itself. Dementia was described as a progressive disease (Crowther et al., 2013a; Harrison et al., 2012; Nourhashemi et al., 2012), as a life-limiting and life-threatening disease (Kydd & Sharp, 2015; van der Steen, 2010) with an unpredictable course and with no curative treatment.
currently available (Nourhashemi et al., 2012; van der Steen, 2010), characterised by a trajectory of terminal decline or ‘steady prolonged dwindling’ which often included a prolonged ‘dying trajectory’ (Crowther et al., 2013a; Kydd & Sharp, 2015; Nourhashemi et al., 2012).

The extended palliative phase of dementia appeared to be related to the end of life and the active stages of dying. Definitions of end of life were often imprecise (Nourhashemi et al., 2012). The end stage of dementia was associated with high levels of suffering (Aminoff, 2014) and increased mortality and morbidity (Potter et al., 2013). There were descriptions related to moving into the dying phase and dying, which included the challenge of predicting survival time (Rexach, 2012). When a time period was mentioned for the palliative phase it varied considerably such as a few years to many years (Harrison et al., 2012; Sampson, 2010), the last year of life (Harrison et al., 2012; Rexach, 2012; van der Steen, 2010), six months (Potter et al., 2013) and the final month (van der Steen, 2010). Jayes, Arnold and Fromme (2012) acknowledged the significant challenges for clinicians to determine hospice eligibility in the US given the six-month prognosis eligibility requirement which often creates a barrier for those patients with advanced dementia who exhibit a slowly declining trajectory with periodic exacerbations. (Brown et al., 2013) argued for further studies to identify reliable, sensitive and specific prognosticators to allow increased availability of palliative care to dementia patients.

Thuné-Boyle et al.’ s (2010) study highlighted that among those people who have moderately severe dementia who are admitted to hospital; approximately half will have died within six months. This is further substantiated by the work of Potter et al., 2013 concerning the development of a toolkit to more easily recognise clinical symptoms concerning ‘end
stage dementia’. They highlighted a correlation between the number of symptoms being reported in those people with dementia and recurrent hospital admissions within the last 6-12 months. In other cases, they had recurrent requests to see their general practitioner (GP) or experienced recurrent interventions.

The ‘Gold Standards Framework’ (GSF) was put forward as a structured approach to help staff working in care homes, GPs and ‘out of hours’ staff to recognize when the last year of life may have begun and to help assess patients’ needs, symptoms and care preferences (Sampson, 2010). However, the GSF was not developed specifically for people with dementia. People with advanced chronic illness and without cancer were often identified for palliative care at a particularly advanced stage of their illness, often in the last weeks or days of life (Harrison et al., 2012).

Thuné-Boyle et al., (2010), Beck et al., (2015) and de Vries and Nowel (2011) highlighted that health care professionals have difficulty recognizing dementia as a terminal neurodegenerative illness. (Nourhashemi et al., 2012) noted that dementia is rarely mentioned as a cause of death and it is often not listed as a cause of death on death certificates.

Nevertheless, the probability of dying for people with dementia at a certain age is reported as 2 or 4 times greater than that of people of the same age without dementia and the risk of death is higher for people with dementia than for cancer patients in general (Rexach, 2012). Indeed, the life expectancy for people with advanced dementia is considered as being similar to patients with metastatic breast cancer (Rexach, 2012; Sampson, 2010).

**ii) Symptomatology in relation to the needs of the person with dementia and for family caring**
It was widely acknowledged in the literature that in the advanced stages of dementia, symptom management is often more important than the scientific diagnosis itself (Murray et al., 2012). It was recognised that understanding the symptomatology of dementia is complex compared with other syndromes and clinical conditions. The symptoms experienced by people with advanced dementia were predominantly described in bio-medical terms. For example, recurrent infections such as urinary tract infections, pneumonia and oral thrush, which untreated can cause/exacerbate the experience of pain (Potter et al., 2013; Thuné-Boyle et al., 2010). Symptoms were also often related to activities of daily living, such as the need for help with daily tasks for survival, difficulties with communication, mobility, eating and/or drinking. Early emergence of psychosis, persistent confusion, withdrawal, lethargy, apathy, depressed mood, agitation or aggression in the dementia trajectory was associated with greater cognitive decline and level of dependence (Zahodne et al., 2015).

In addition to memory loss and other cognitive changes, a frequently reported physical symptom affecting people with advanced dementia was pain (Murray et al., 2012). The persistence of the experience of pain among people with dementia was seen to vary over time and to be influenced by a range of factors, such as the type of dementia, environmental conditions, other co-morbidities and age. Moreover, pain was often seen to affect the behavioural, physical, psychological, emotional, and spiritual condition of people with advanced dementia (Davies et al., 2014). Hendriks et al., (2015) reported that pain was a persistent symptom that increased during the last week of life. It was argued that pain is commonly undertreated (Davies et al., 2014; Ryan et al., 2012; Thuné-Boyle et al., 2010) with central neuropathic pain in particular representing the most undertreated type of pain among people with dementia (Scherder & Plooij, 2012). Davies et al., (2014) highlighted that undertreated pain can lead to avoidable hospital admissions. Ryan et al.’s hospital surveys
(2013) revealed that among those patients identified with palliative care needs, dementia was a predictor of both physical and psychological discomfort.

Monroe et al., (2013) explained that as people with advanced dementia begin to demonstrate memory decline and poor oral skills, they experience a corresponding difficulty to communicate their pain. Klapwijk et al.’s (2014) study of the use of an observational tool to chart symptoms of discomfort and/or pain among residents with advanced dementia, highlighted the importance of observation skills to compensate for the lack of verbal communication. Further, Sampson et al.’s (2015a) review of European palliative care guidelines concluded that new guidelines should consider the use of observational pain tools for people with cognitive impairment.

Nevertheless, Dowding et al., (2015) highlighted the challenges in assessing pain among people with dementia using eligible pain assessment tools as nurses often relied on intuition and experiential knowledge when interpreting signs of pain. Using this approach, less experienced nurses failed to recognize pain through behavioural responses among persons with dementia (Burns and McIlfatrick, 2015). Sampson et al.’s (2015b) study revealed that on admission a quarter of patients with dementia admitted having pain using self-report by FACES, (a self-assessment tool with drawn faces showing increasing amounts of pain) while over half had pain during rest/movement, when assessed with the Pain Assessment in Advanced Dementia scale (PAINAD). Dowding et al., (2015) argued that tools which recognise behaviour related to pain among people with dementia and that include information from family carers can facilitate pain assessment and management. Cordner et al., (2010) purported that quality of life may be improved for people with advanced dementia using appropriate assessment and treatment of pain and effective management of behaviour.
problems. Jordan et al., (2012) highlighted the relevance of the PAINAD and Disability
Distress Assessment Tool (DisDAT) as being the ‘right tools for the job’ for professionals to
as certain individual manifestations of pain and distress among people with advanced
dementia, but only in the right hands as they acknowledged that assessment of pain is a
complex and skilled task.

Sampson et al.’s study (2014) of behavioural and psychiatric symptoms among hospitalised
people with dementia revealed that over a third of participants experienced symptoms of sleep
disturbance, depression, phobia or anxiety at some time during their stay. Depression was
reported to be common among people with advanced dementia and was seen to negatively
affect their cognition and self-concept. Burton et al., (2014) also noted that people with
dementia may experience psychiatric disorders, either as a result of their dementia illness or
due to a co-existing mental illness or co-morbidity. Delirium was identified as a common and
distressing complication that is often experienced by older people with dementia (Estabrooks
et al., 2015). Clegg et al., (2014) explained that older people living in long term care (LTC)
settings posed the greatest risk of developing delirium, which in turn led to a worsening of
dementia, enhanced the mortality risk and precipitated hospital admission. It was noted that
recognition of delirium is often complicated by other behavioural manifestations. Also, that
nurses generally use subjective measures to assess delirium, leading to under detection of
delirium. An objective assessment using the Confusion Assessment Method (CAM) was
argued to be more appropriate. Oligario, Buch and Piscotty (2015) compared subjective
assessments of experienced registered nurses and CAM in 50 paired cases with underlying
dementia cared for in a hospice. In nearly half of the cases there was a disagreement and
several of those with objective delirium were missed. Further, patients without objectively
assessed delirium received Haloperidol. Clegg et al., (2014) suggested a pharmacist led
medication review and monitoring plan supported by a software based intervention as a way of identifying medication that can contribute to delirium in older people in LTC settings. Krumm et al., (2014) reported on the relevance of the Minimal Documentation system for Palliative care (MIDOS) tool to enhance the quality of palliative care for residents with dementia in nursing homes.

From a more holistic perspective, the concept of suffering was seen to be a highly relevant and complex, multi-faceted concept which is often linked with feelings of anxiety and depression. Aminoff (2012) reported that end stage dementia patients with decubitus ulcers had a higher mini-suffering state examination score compared to those ESD patients without bedsores. Smith et al., (2014) suggested that understanding the dimensions of suffering could provide a deeper insight into the experiences of people with dementia. However, they argued that the dimensions of suffering are not well explored in the literature. Overall, there was a dearth of literature from our elicited searches that focused on the psychological, spiritual and existential needs and preferences of people with advanced dementia and their family carers. This is confirmed by Gijsberts et al.’s (2013) ethnographic study findings of the lack of due attention given to spiritual issues within the formal care process of Dutch residents with dementia and van der Steen et al.’s (2014a, b) studies concerning optimal palliative care among older people with dementia, including spiritual care provision.

The experiences of family or informal carers - commonly, family members (mainly spouses and adult children) but also friends and neighbours, who provide regular help, support and care to a relative or significant other with dementia, was raised in the literature. Their role was deemed to be increasingly important given global ageing demographic changes (Pot & Petrea, 2013). It was highlighted that carers of people with dementia who provide intensive amounts
of care over a prolonged period often experience chronic stress or burden which places them at increased risk for physical and mental ill-health compared to their none-caregiving counterparts (Brink, Stones & Smith, 2012). Carers of people with dementia are more likely to experience symptoms of depression, anxiety and anger/frustration together with impaired sleep leading to poorer self-rated health and well-being and an increased risk for cardiovascular disease, cancer and premature death (Irwin et al., 2013). This was often associated with their caring roles in relation to personal care, including incontinence care and managing behavioural problems of their relative with dementia together with prolonged sleep deprivation (Muders et al., 2015). Further, it was reported that carers of people with advanced dementia experience a greater negative impact on their physical and mental health and social life compared with other groups of carers (Chan et al., 2013; Irwin et al., 2013; Muders et al., 2015).

The concept of anticipatory grief was raised as a common response to the situation of caring for a family member/significant other with dementia (Slape, 2014). The complex range of responses to placing a spouse with dementia in a LTC facility was also addressed in the literature. Whilst some carers experienced improvements in physical symptoms and cardiovascular health compared to carers providing continuing care at home, over time carers showed an increase in mental health symptoms. This was often related to feelings of regret, guilt, loss, separation and surrendering the role of regular ‘hands on care’, in addition to the loss of control, changed roles and relationship with their spouse (Peacock et al., 2014; Peacock, 2013).

There were fewer studies that explored the positive aspects of caring for people with dementia. However, there are studies which recognised that carers of people with dementia
may also experience feelings of well-being and take comfort in the knowledge that they are carrying out an important caring role (Irwin et al., 2013; Muders et al., 2015). Further, psychological resilience and satisfaction with caregiving were identified as protective factors against negative outcomes, while unresolved grief was a risk factor (Shuter, Beattie & Edwards, 2014).

**iii) Management in relation to the needs of people with dementia and their family**

A common theme running through the literature is the palliative approach as an appropriate model of care for people with advanced dementia due to its emphasis on quality of life, maintaining functioning, maximizing comfort, a family approach and the relevance of a multidisciplinary team (Lee et al., 2015; Phillips et al., 2013; Raymond et al., 2014a; Rosenwax et al., 2015; Ryan et al., 2012; van der Maaden et al., 2014; van der Steen et al., 2014a; van Soest-Poortvliet et al., 2015a). Whilst the philosophy of palliative care was seen as wholly appropriate, the general lack of specialist palliative care or indeed an acceptable standard of general palliative care for people with advanced dementia was questioned (Crowther et al., 2013b; Toscani et al., 2013). This was often related to the lack of an overall coherent understanding and recognition of advanced dementia among professionals (Thuné-Boyle et al., 2010). Ryan et al. (2012) highlighted professionals’ reluctance to see people with dementia as suitable recipients of specialist palliative services, arguing that their difficulties tend to be different from those of cancer patients. This led to using a different approach to palliation in dementia, relying upon core nursing skills such as mouth care, pressure care and maintenance of dignity, which was argued, could be adequately provided by non-specialist teams.
However, it was acknowledged that general palliative care was not likely to be able to address complex needs among people with advanced dementia. Barber and Murphy (2011) argued the need to combine evidence-based knowledge from specialist nurses in both dementia care and palliative care in order to provide the best possible care for people with advanced dementia. Ryan et al. (2012) noted growing concerns about the resources available to provide palliative services to an ageing population and the general lack of critical debate about how these challenges might be overcome using different models of provision. Within the policy field, Nakanishi et al.’s review (2015a) of national dementia strategies revealed that palliative care was not explicitly referred to in eight of the 14 participant countries. Nevertheless, person-centred care, communication and shared decision making together with continuity of care and family care and involvement were well represented domains.

The concept of person-centred care is frequently raised in the literature as a suitable approach for the advanced stage of dementia as the needs and preferences of the people with dementia together with their family serve as the focal point for care planning and decision making (Phillips et al., 2013; van der Steen et al., 2014a). Sims-Gould et al., (2010) recommended ‘whole person care’ for older people living in LTC settings which focuses on meaningful, enhanced relationships between residents, families, staff and volunteers. Raymond et al., (2014a) argued that person-centred care is frequently cited in the more recent empirical literature, yet it is rarely well defined and/or articulated.

Van der Steen et al., (2014a) advocated a biopsychosocial approach to the management of pain, discomfort and behaviour, supported by a range of validated tools to measure, monitor and evaluate the effectiveness of care provided due to the complexity of experience and co-morbidity of the health needs among people with advanced dementia. The avoidance of
overly aggressive care, burdensome or futile treatment was generally recommended in the literature, including the careful balancing of risks and benefits when considering any transfers to hospital (van der Steen et al., 2014a). Araw et al.’s study (2013) highlighted the benefits of a palliative care team intervention in managing older hospitalised advanced dementia patients. However, some cultural differences still remain within the recent international empirical literature. Nakanishi & Miyamoto’s (2015b) cross-sectional survey of 275 nurses and other care workers from 74 LTC facilities in Japan about their knowledge and attitudes concerning palliative care for people with advanced dementia, revealed that higher levels of positive attitudes were observed among nurses that had established an end of life care manual and those in facilities with a physician’s written opinions on end of life care. Nevertheless, it was acknowledged that in Asian culture personal wishes are seldom discussed and life-sustaining treatment is often preferred to palliative care among individuals with advanced dementia and their families.

Van der Steen et al., (2010) noted that written information on comfort care was welcomed by practitioners of European countries with widely differing attitudes towards advanced dementia care and decision making. However, a further cross-cultural adaptation study involving Italy, Netherlands and Japan highlighted that providing artificial feeding and fluids and discussing euthanasia were deemed sensitive topics and guidance about them needed careful consideration of ethical aspects and adaptations to local standards and practice (van der Steen et al., 2013a). Nakanishi et al.’s (2015c) study of a culturally adapted comfort care guide and seminar for nursing home staff in Japan led to increased knowledge scores among participant staff.
Within the literature, artificial nutrition use was seen to vary across countries. Valentini et al. (2014) explained that there are cultural, emotional and psychological influences on decision-making in this area with a difficult balance to be found between responding to hunger and thirst and artificial feeding at the end of life. It has been shown that there is no evidence that the use of feeding tubes improves clinical outcomes or survival for people with advanced dementia (Brook & Ojo, 2015; Stephens et al., 2014; Thuné-Boyle et al., 2010). Raymond et al., (2014a) argued that the use of food and fluids in comfort care for people with advanced dementia is rarely considered and that there is a dearth of studies concerning hydration.

Parsons et al., (2014) revealed that there was considerable variation in decision-making among hospital and community doctors with regards to withholding, continuing or discontinuing medication such as antibiotics, cognitive enhancers and statins at the end of life and further research and guidelines in this area was called for. The use of antibiotics among people with dementia at the end of life was viewed as controversial because on the one hand they can help to reduce discomfort due to the alleviation of the symptoms of infection (Toscani et al., 2015; van der Steen et al., 2014a), whilst on the other hand they can potentially delay death and thus can be seen to prolong suffering (Raymond et al., 2014a). Tjia et al.’s study (2010) of nursing home residents (n= 323) with advanced dementia in the US revealed that questionably beneficial medications were common in advanced dementia even as death approaches.

There was widespread recognition in the literature of the need to increase training and education about providing palliative care for people with dementia, as a lack of understanding, confidence and knowledge among staff working in LTC and hospital settings is shown to have a negative impact on care provision (Carter et al., 2015; Manu et al., 2012;
Ouchi et al., 2014; Potter et al., 2013; Raymond et al., 2014b; Sampson, 2010; Sternberg, Bentur & Shuldiner, 2014). Albers, Van den Block and Vander Stichele (2014) reported high levels of emotional and physical burden among nursing staff caring for residents with dementia at the end of life in nursing homes. Van der Steen et al., (2014a) outlined core competencies and recommended a baseline level of knowledge of the palliative care approach for all staff across the multi-disciplinary team, with those working with people with advanced dementia being able to apply their knowledge of palliative care with their patient group, resulting in a combined, appropriate knowledge and skill level across the multi-disciplinary team. It was also recognized that training about palliative care regarding people with dementia and their families should be provided at undergraduate and postgraduate levels for medical and nursing professionals. Luzny et al., (2013) proposed the Pain relief, Autonomy, Nutrition support, Skin to protect bedsores, Spiritual and Social support (PANSS) as a suitable model of complex psychogeriatric palliative care in routine clinical practice within the Czech Republic. Kuhn and Forrest’s (2012) US based pilot training, consultation and coaching project to introduce palliative care in two nursing homes for residents with advanced dementia, highlighted the importance of consistent participation by a nursing home’s leadership for successful implementation.

The importance of staff working together with families and recognizing family carers as key partners in the provision of care was a common theme in the literature. Hennings, Froggatt and Payne (2013) recommended that communication skills be included in educational programmes for nursing home staff to help them acknowledge carers of people with dementia in their own right and listen to their stories. Penders et al.’s (2015) study revealed that only one fifth of family carers of residents with advanced dementia were aware that their relative had dementia, highlighting the need for staff to improve communication with carers. Lewis
(2014) explained that nurses need to educate family carers on the progression of dementia, on what to expect, especially at the end of life, and about treatment options.

It was argued that support should be offered according to the needs and preferences of the family and their individual caring situation and especially at key transitions in the dementia illness trajectory of their relative/significant other (Thuné-Boyle et al., 2010; van der Steen et al., 2014a). Hennings, Foggatt and Keady (2010) and Thompson and Roger (2014) explained that carers of people with advanced dementia require both instrumental and emotional forms of support, in addition to information and decision-making support with regards to the illness trajectory and their individual caring situation. Dawson et al., (2015) noted an association between family caregiver anxiety and depression and abusive behaviour towards people with dementia, which reinforces the need for targeted support interventions that reduce carer burden and facilitate the development of appropriate coping strategies.

Morgan et al., (2015) highlighted regional challenges in carer support, as carers of people with dementia in rural areas have limited access to support groups, counselling or respite (Morgan et al., 2015). Further Ehrlich et al., (2015) reported that rural carers experienced greater financial burden compared to their urban counterparts. Nevertheless, caring for a loved one with dementia was seen as a part of life in rural areas. Connolly, Sampson and Purandare (2012) explained that carer preparation for and reactions to the death of the people with dementia may vary between ethnic groups. Thompson and Roger (2014) noted the importance of individualized bereavement support for family carers.

Advanced care planning (ACP) was highlighted in the literature as an appropriate intervention to enable professionals to work together with people with dementia and their families and thus
enable the person-centredness of care (Dawson et al., 2015; Ryan et al., 2012) and the adoption of an early palliative care approach (Meeussen et al., 2012). Dening, Jones and Sampson (2013) noted that the wishes and preferences of people with dementia and their family carers may differ. Kaldjian et al., (2010) revealed that the surrogate decision makers they interviewed expressed diverse preferences regarding goals of care and diverse assessments about the impact of dementia on personhood. A common theme within the literature is that ACP should take place early in the disease trajectory whilst people with dementia have sufficient cognitive abilities to articulate goals and the desired direction of care in the advanced stage of the dementia illness, including end of life care preferences, in collaboration with family members/significant others and staff. In this way, the ACP process is seen as a valuable way of building trusting relationships between all three parties (Stewart-Archer et al., 2015; Stewart et al., 2011; Vandervoort et al., 2014). A Dutch study highlighted that advanced decisions were commonly made on admission to nursing home for people with dementia. The decisions covered cardiopulmonary resuscitation and future hospitalisations, while discussions about tube-feeding, treatment with antibiotics and rehydration were postponed. Usually the physician took the initiative to the ACP and the timing depended on the patient’s condition and family factors. This responsive and proactive approach by the physician was seen as affecting patient care and outcomes (van Soest-Poortvliet et al., 2015b). Van der Steen et al., (2013b) also found that a family’s awareness of dementia as a ‘disease you can die from’ predicted higher patient comfort at the end of life, highlighting that educating families on the nature of dementia is an important part of ACP. Indeed, education and support for families as well as training for staff around issues of end of life care decisions within advanced dementia is clearly reflected within the literature (Reinhardt et al., 2014; Stewart et al., 2011).
Nevertheless, overall across Europe the challenges identified in the literature of implementing ACP as a standard form of dementia care practice largely stemmed from a general reluctance among professionals to initiate ACP, often as a result of lack of time, poor communication skills and/or a fear of increasing anxiety among patients and their family together, in some cases, with the family’s reluctance to engage in the process and/or staff’s reluctance for the family to be involved (Ampe et al., 2015; Beck et al., 2015; Brazil et al., 2015; Dawson et al., 2015; Lawrence et al., 2011; Robinson et al., 2013; van der Steen et al., 2014a). As a result, further systematic practice development work and implementation research is recommended in the area. To this end, tools for facilitating shared decision-making were reviewed by Austin et al., (2015). They found that watching a 2 minute-video about advanced dementia and ACP led to more people with dementia choosing comfort as the primary goal for future care. Agreement about decisions between surrogates and patients was increased by watching the video. Further, a tool on feeding options in advanced dementia was found to decrease decisional conflicts and increase the use of dysphagia diets (Austin et al., 2015). An information booklet from a family perspective was shown to be suitable to inform Dutch and Canadian families on comfort care in dementia and could thus be integrated within ACP, particularly for families who wish to be informed early (van der Steen et al., 2012).

However, Sampsom et al.’s study (2011) of a palliative care and ACP intervention revealed that despite intensive support from an experienced nurse specialist few carers wrote an ACP indicating the need for further research in this area.

A common theme within the literature was the lack of research into palliative care for people with dementia, especially in the community (Goodman et al., 2010; Raymond et al., 2014a; Sternberg et al., 2014). Perrar et al.’s (2015) systematic review revealed a dearth of empirical findings on the needs of people with ‘severe dementia’. The main identified challenges were
the lack of awareness of the need for palliative care as highlighted earlier and methodological concerns relating to securing ethical permission to research the care of people with advanced dementia. Recommendations were made for further research to be carried out in LTC settings (Hall et al., 2011) and within community care to support people with dementia in their own homes and their family carers (Goodman et al., 2010; Phillips et al., 2013; Sternberg et al., 2014). Candy et al., (2015) concluded that high quality empirical work is needed to ensure that the recommendations in the UK quality statements on end of life care in dementia are indeed best practice.

**Discussion**

It can be seen that the team devised a transparent process by which to search, source, select and evaluate the papers. This is a strength of the process, as undertaking systematised searching, sourcing, reviewing and synthesising is a complex task (Booth, Papaioannou & Sutton (2016). Nevertheless, the team grappled with the challenge of there being no coherent and generally accepted definition of advanced dementia within the literature. Whilst an effort was made to delineate this using the Global Deterioration Scale (Reisberg et al., 2006), this was not reflected in the literature. The extent of the challenge of searching and sourcing for such an ill-defined concept is significant, although unsurprising. As the experience of dementia is unique, diverse, with variability of deterioration across a range of biopsychosocial domains, naming or identifying which is useful to professionals, people with dementia and their friends and family, remains elusive.

The concept of palliative care is also one that has only been relatively recently considered in the context of dementia, so there is a risk that by using the word ‘palliative’ as a search term
we may have missed some papers on the topic. Indeed, the tendency in the literature was to
focus mainly on what could be termed end-of-life dementia care, with a dearth of work on the
stages prior to this.

The majority of the relevant papers were reviewed at JBI level 4. This strength of evidence is
common in this area, firstly given the ethical challenges of conducting research directly with
people with advanced dementia (Mitchell et al., 2006). Second, as the majority of people with
advanced dementia are cared for in nursing homes and hospitals, it is seldom that they are
under the care of specialist teams who may have connections to research-focused
professionals, as well as access to support and expertise to carry out research. This may be
linked to the undervalued nature of the care of older people, of nursing home care and of the
staff who work within them (Kydd et al., 2014).

As previously outlined, a major finding from our integrative literature review is the lack of a
clear, consistent and generally accepted definition of advanced dementia and, in particular, the
extended palliative care phase of the illness. In this respect, the included literature does not
seem to have moved beyond the current diagnostic and classification systems that have a
predominantly medical focus, that is, the DSM classification system, Reisberg, Ferris, and
Crook’s (1982) Global Deterioration Rating Scale (GDR) (Stage 6-7) together with the WHO
classification (2012) of the late (advanced) stage of dementia. Reisberg et al.’s scale provides
a seven stage model for planning dementia services which extends across the pre-diagnosis
stage to the final two stages described as continuing care and end of life palliative care (ADI
& WHO, 2012). Whilst these standard screening measures are undoubtedly the cornerstone of
current dementia care practice, nevertheless it is clear from our review that in addition, a more
comprehensive understanding and recognition of advanced dementia and the extended palliative care phase, including clearer prognostication, is urgently needed. Such holistic, evidence based knowledge and awareness will help equip professionals to deliver best practice to individuals and to support family caring during the extended palliative care phase of dementia.

Our review revealed that the extended palliative phase of dementia was often synonymous with end of life care and the active stages of dying (Nourhashemi et al., 2012). Further, we recognise that the transition between the continuing care stage and end of life stage in the WHO (2012) schema is poorly described and our findings confirm this lack of clarity.

Our review highlights the lack of robust conceptual or theoretical underpinnings that embrace being a person with advanced dementia situated within family relationships, and a changing sense of home and safety. More generally, within the literature the concept of person centred care was recommended as a suitable approach for the later stages of dementia. However, this too was often seen to be ill defined (Raymond et al., 2014a). Writing at a much earlier time about care for older people with dementia, Kitwood and Bredin (1992) acknowledged that a care practice remains relatively ineffective without a coherent theory. They argued that a comprehensive theory provides, ‘an awareness, a sense of value and the basis for concerted action’ (Kitwood & Bredin, 1992, p. 270). We agree with these sentiments and contend that they are still as relevant today regarding the care of people with advanced dementia, as they were when they were first written.
More recently, building on Kitwood’s personhood model, Spector and Orrell (2010) also proposed moving beyond a narrow clinical gaze to encompass a biopsychosocial model of dementia which takes into account positive as well as negative factors. In essence, this model suggests that with regards to psychosocial and biological processes there are firstly fixed factors, namely, aspects relating to history or risk factors that are not amenable to change, such as age, education and IQ. Secondly, there are tractable factors, namely, aspects that may be amenable to change, which can be viewed as either risk or protective factors depending on the extent to which they exist in the individual and the relative impact they may have on the level of dementia, (such as coping strategies, physical activity, social environment and quality of interactions). In this way, the biopsychosocial model views dementia as being malleable such that change, adaptation and improvement is feasible. Further, it implies that whilst certain aspects of dementia are beyond the control of the individual and their environment, others can indeed be influenced and potentially improved (Spector & Orrell, 2010). Within the included literature, there was a dearth of empirical studies that builds upon this model. Clearly, further empirical testing of the biopsychosocial model is highly warranted.

Our review acknowledged that the under-recognition of the extended palliative phase of dementia is largely due to a lack of understanding and awareness among frontline practitioners. This was seen to be the result of a general dearth of specific education in the area of advanced dementia care (Potter et al., 2013; Sampson, 2010), together with lack of systematic opportunities for staff to participate in continuous, evidence-based education and training in this area (Raymond et al., 2014b; Sternberg et al., 2014; van der Steen et al., 2014b). However, we recognise that an understanding of the advanced stage of dementia and the extended palliative phase of dementia is not likely to feature strongly in education for
health and social care professionals while it is not recognised and clearly defined in the empirical and policy literature. We acknowledge that there is an urgent need to change the narrative about the advanced stages of dementia and differentiate from end of life and dying towards living the best life possible during the later stages of dementia. Moving beyond theory, we argue that there is a need to equip the dementia workforce with insights into how they can best support people with advanced dementia towards having a good day or good moments. For example, as expressed by Eggers, Norberg and Ekman (2005) to promote caring based on an ‘attentive interest in nonverbal forms of communication’ and to strive for ‘mutual interpretation of the shared situation’. Helleberg and Hauge (2014) used the metaphor of a dance to explain the essence of good care for people with advanced dementia living in nursing homes. Nurses and care workers sensitively choose when it is appropriate to ‘follow’ the people with dementia. For example, to choose the right time, tempo, and adapt to the person’s sensitivity and to identify when it is apt to lead by being in the forefront.

The challenges surrounding the implementation of palliative services for people with dementia were highlighted within our review. Clearly, there has been a significant debate over the last twenty years approximately concerning the appropriateness of palliative care for the management of advanced, longstanding chronic conditions within old age (see for example Seymour & Hanson, 2001). These arguments tend to mirror the earlier work of McNamara (2004) and Seymour, Clark and Philip (2001) who questioned the appropriateness of a ‘5 star deluxe hospice care’ for the ‘privileged few’, namely terminally-ill cancer patients, in favour of a ‘good enough’ palliative care extended to a much broader patient population. This reflects Ryan et al.’s (2012) arguments concerning the appropriateness of a palliative care philosophy or approach within dementia care that can be delivered by non-specialist teams and basically consists of core nursing skills. A Pan European project already
in 2005 called for more innovative and creative interpretations of palliative care within the home, in day centres and nursing homes across Europe (Mestheneous & Triantafilla, 2005).

As previously outlined, we recognise that the current ‘state of the art’ in the field of advanced dementia care research is largely constrained by the fact that it does not lie within the domain of one professional group. In addition, advanced dementia care, as with geriatric medicine and gerontological nursing, continues to have a low status compared to other areas of acute medicine and nursing (Capezuti et al., 2012; A Kydd et al., 2014; Raymond et al., 2014a). We clearly acknowledge the need to develop innovative and systematic support measures to stimulate inter-professional research capacity building and knowledge sharing.

Our review confirmed that family carers play a central role in the care, help and support of their relative/significant other living with dementia (Pot & Petrea, 2013). We note however that there remains a lack of sufficient emphasis on the satisfactions of caring and an exploration of ways to help empower those carers who wish to continue caring to be able to do so. In this way, the literature fails to advance beyond our current understanding of family caregiving and the seminal work of Nolan, Grant and Keady (1996) regarding the temporal model of family care. This model recognised that experienced carers, over time, often develop a unique, detailed personal knowledge and experiences about how best to care for their relative/significant other. In so doing, they become ‘co-experts’ with regards to their individual caring situation. The role of practitioners is to work in partnership with carers so that both parties share knowledge and experiences with each other to ensure as good a quality of life as possible for the people with dementia and their carers (Brown, Nolan & Davies, 2001; Nolan et al., 2003).
Seeing carers as core partners in care is clearly endorsed within a palliative care philosophy and is advocated in recent dementia care policy (Pot & Petrea, 2013; Sternberg et al., 2014; van der Steen et al., 2014a). By contrast, in the literature there is a lack of recognition of the experienced carer as ‘co-expert’. Thuné-Boyle et al.’s study (2010) highlighted that few relatives perceived their significant other with advanced dementia as being in pain, despite many suffering from urinary tract infections, arthritis and pressure sores. Likewise, Hennings et al (2010) argued that family carers often require specific knowledge and competences. Clearly, targeted education is appropriate for new carers and those carers with no prior caring experience to avoid ‘trial and error’ learning.

**Implications**

The findings of this integrative literature review have helped inform our subsequent project work around the concept of ‘Dementia Palliare’ which represents a new way of working to help support people with advanced dementia who are not yet requiring end of life care, but who have limited opportunities for self-realisation and are increasingly reliant on the support of family carers and/or professionals for their health and wellbeing. More specifically, the literature review findings acted as the foundation for the Dementia Palliare Best Practice Statement (Holmerova et al., 2016) intended to guide practice and promote a cohesive approach to advanced dementia care which centres on the following elements: protecting rights, promoting dignity and inclusion; future planning for advanced dementia; managing symptoms and keeping well; living the best life possible; support for family and friends and advancing Dementia Palliare practice (see [www.uws.ac.uk/palliareproject](http://www.uws.ac.uk/palliareproject) for more details). The ultimate aim being to stimulate learning and awareness among multidisciplinary and
inter-professional teams and to help develop and improve advanced dementia care in partnership with people with dementia, their family and friends.
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### Stage 6: Severe cognitive decline (Moderately Severe Dementia)

- May occasionally forget the name of the spouse upon whom they are entirely dependent for survival.
- Will be largely unaware of all recent events and experiences in their lives.
- Retain some knowledge of their past lives but this is very sketchy.
- Generally unaware of their surroundings, the year, the season, etc.
- May have difficulty counting from 10, both backward and, sometimes, forward.
- Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will be able to travel to familiar locations.
- Diurnal rhythm frequently disturbed.
- Almost always recall their own name.
- Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment.
- Personality and emotional changes occur. These are quite variable and include:
  - Delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror.
  - Obsessive symptoms, e.g., person may continually repeat simple cleaning activities.
  - Anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur.
  - Cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.

### Stage 7: Very severe cognitive decline (Severe Dementia)

- All verbal abilities are lost over the course of this stage. Frequently there is no speech at all - only unintelligible utterances and rare emergence of seemingly forgotten words and phrases.
- Incontinent of urine, requires assistance toileting and feeding.
- Basic psychomotor skills, e.g., ability to walk, are lost with the progression of this stage.
- The brain appears to no longer be able to tell the body what to do.
- Generalized rigidity and developmental neurologic reflexes are frequently present.

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http://mc.manuscriptcentral.com/dementia
1. Does this study address a clearly focused question?

2. Did the study use valid methods to address this question?

3. Are the valid results of this study important?

4. Are these valid, important results applicable to our patient/population?

Is the paper relevant for full review?

**YES**

Following steps were carried out:

- Read the paper so as to understand different parts of the study in relation to the whole
- Appraised the paper in terms of its scientific merit
- Where possible, reviewers assigned a level of evidence to the paper
- Noted key limitations, findings and conclusions

**NO**

The paper was excluded

Figure 2. Validity questions used in the appraisal of studies within the project
Table 1. Screening process for the literature searches.

<table>
<thead>
<tr>
<th>Search terms (all databases)</th>
<th>Palliative AND Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limitations (all databases)</td>
<td>Published 2010-2015 Peer-reviewed English</td>
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</table>

<table>
<thead>
<tr>
<th>Database</th>
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<th>PubMed</th>
<th>Social Science Citation Index</th>
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<th>Zetoc</th>
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<tbody>
<tr>
<td>Searches performed Jan. 2015 and Dec. 2015</td>
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<td>n=561</td>
<td>n=502</td>
<td>n=97</td>
<td>n=308</td>
<td>n=6</td>
<td>n=1843</td>
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<tr>
<td>Selected for further reading</td>
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<td>n=222</td>
<td>n=91</td>
<td>n=7</td>
<td>n=34</td>
<td>n=4</td>
<td>n=492</td>
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<tr>
<td>Included after appraisal</td>
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<tr>
<td>Definitions</td>
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</tbody>
</table>

1Reasons for exclusion were duplicates, not fitting the any of aims, low scientific quality or could not be retrieved.