Citation for the published version:

Mataqi, M., & Aslanpour, Z. (2019). Factors influencing palliative care in advanced dementia: A systematic review. BMJ Supportive & Palliative Care. DOI: 10.1136/bjsports-2018-099450

Document Version: Accepted Version

This article has been accepted for publication in BMJ Supportive & Palliative Care (2019) following peer review, and the Version of Record can be accessed online at https://doi.org/10.1136/bmjspcare-2018-001692

Factors influencing provision of palliative care in advanced dementia: A systematic review

Mona Mataqi and Zoe Aslanpour

Department of Clinical and Pharmaceutical Sciences, School of Life and Medical Sciences, University of Hertfordshire, UK

Full name: Mona A. Mataqi
Address: Department of Clinical and Pharmaceutical Sciences, School of Life and Medical Sciences, University of Hertfordshire, Hatfield, AL10 9AB
Phone number: 01707284563
Email address: mamataqi@hotmail.com

Full name: Dr Zoe Aslanpour
Department of Clinical and Pharmaceutical Sciences institution, University of Hertfordshire
City and country of all co-authors: Hatfield, UK

Word count: 5112

Abstract

Background: Dementia is a progressive neurodegenerative life-limiting disease. The international literature indicates that patients with advanced dementia may benefit from palliative care provided during the end of life phase. However, evidence indicates that currently many fail to access such provision despite the increased recognition of their palliative needs. **Aim:** To investigate the factors influencing provision of palliative care services for people with advanced dementia. **Method**: A systematic review of mixed method studies written in English was undertaken. 11 electronic databases including Embase, Medline, PubMed, CINHAL and Scopus from 2008 to 2018 were searched. Narrative synthesis and content analysis were used to analyse and synthesise the data. **Key findings:** In total, 34 studies were included. 25 studies providing qualitative data, 6 providing quantitative data and 3 mixed methods studies. The findings identified organisational, healthcare professionals and patients related barriers and facilitators in provision of palliative care for people with advanced dementia from perspective of stakeholders across different care settings. The most commonly reported barriers are lack of skills and training opportunities of the staff specific to palliative care in dementia, lack of awareness that dementia is a terminal illness and a palliative condition, pain and symptoms assessment/management difficulties, discontinuity of care for patients with dementia and lack of co-ordination across care settings, difficulty communicating with the patient and the lack of advance care planning. **Conclusions:** Even though the provision of palliative care was empirically recognised as a care step in the management of dementia, there are barriers that hinder access of dementia patients to appropriate facilities. With dementia prevalence rising and no cure on the horizon, it is crucial that health and social care regulatory bodies integrate a palliative approach into their care using the identified facilitators to achieve optimal and effective palliative care in this population.

Key words: Advanced Dementia, Palliative Care, End of Life Care, Barriers, Facilitators.

Word Count: 296

1. Introduction

Dementia is a general term used to describe a group of progressive neurodegenerative syndromes in which there is cognitive deterioration leading to decline in memory, judgement, and learning as well as orientation impairment and behavioural changes interfering with the activities of daily living [1]. The clinical symptoms associated with dementia can be divided into three stages: early, middle and advanced stage [2]. The focus of this research is on the end stage dementia.

The prevalence of dementia is expanding rapidly and currently reaching around 50 million people worldwide [1]. The incidence of dementia is estimated to be over 9.9 million new cases per year worldwide, making dementia a global public health priority [1,3,4]. The number of people living with dementia varies from one region to another with the majority of cases i.e. 58% distributed around the low and middle-income countries (LMIC), which is projected to increase more rapidly in comparison to the high-income countries [4].

Advanced dementia is the stage of profound cognitive and physical impairment [2, 5]. It is characterised by dysphagia, incapability to communicate and severe memory decline [2]. The late stage of dementia is one of the main causes of disability and it account for 11.9% of the years lived with disability (YLD) and it is considered the primary reason of dependency and disability among the aging population [6]. A retrospective study concluded that people with advanced dementia experience similar symptoms and have equivalent healthcare needs similar to other terminal diseases such as cancer [7]. Thus, recognising advanced dementia as a terminal condition with the end of life care needs [8, 9].

The WHO has defined Palliative Care (PC) as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and treatment of pain and other problems, physical, psychosocial and spiritual” [10]. The same principles apply to end of life care (EoLC) in advanced dementia as defined by the European Association of Palliative Care (EAPC) [11].

The World Palliative Care Alliance (WPCA) and the WHO have recognised advanced dementia as a life-limiting condition and as a disease that requires PC at the end of life stage [12]. However, despite their efforts, the WHO does acknowledge that palliative needs of people with dementia are often unmet, under-assessed and under-treated in some regions [13]. Recent studies have suggested that a PC approach can be beneficial for patients with advanced dementia but the implementation process still presents unique challenges [14].

Several studies have explored the barriers associated with the provision of effective PC for dementia patients [15,16]. One of the main challenges is that despite the progressive nature of dementia, it is under-recognised as a terminal illness in some regions [17]. Additionally, even though there is a gradual decline in both cognitive and physical abilities, there are no abrupt health changes that can be used to clearly identify the terminal phase of dementia unlike cancer trajectory [18]. Furthermore, the communication difficulties experienced in the late stage of dementia, makes the delivery of care difficult and creates additional barriers to effective provision of PC [15]. Moreover, many studies indicated that healthcare providers have a vital role to play in transition of patients with dementia to PC services, but they are reluctant to do so [19, 20]. This could be due to ethical debates and differing views about extending the life of dementia patients [19, 20]. Finally, lack of care pathways and clinical guidelines on PC specific to dementia poses several dilemmas to the provision of optimal EoLC in this population [14]. Both of the Liverpool Care Pathway (LCP) and the Gold Standards Framework (GSF) are being used in the management of EoLC in dementia, which facilitates the delivery of PC in a range of care setting [21].

There has been an increased interest worldwide on extending PC services to include people with dementia [11]. Yet, the evidence suggests that many nations still have a long way to go in providing effective PC to people with advanced dementia. Therefore, the aim of this systematic literature review is to investigate the factors influencing the provision of PC services for people with advanced dementia through the following objectives:

- To investigate whether palliative care is empirically recognised as a care step in the management of patients with advanced dementia.

- To establish the barriers and enablers to provide end of life care for people with advanced dementia from the stakeholders’ perspective (i.e. patients, carers, healthcare professionals, healthcare commissioners/policy experts and manager/directors). A healthcare commissioner is defined as a member of the healthcare system that oversees the process of purchasing and monitoring healthcare services to improve health outcomes [22].

Word count: 775

Methods

A systematic review of mixed method studies of primary articles was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [23]. The search question was addressed using empirical evidence and the studies were included based on a predefined inclusion and exclusion criteria.

Search strategy:

11 electronic databases were used to search for primary articles that addressed PC for people with dementia. These were: Embase + Embase Classic; Ovid Medline; All The British Library subscribed journals; Health and Psychological Instrument; Health Management Information Consortium (HMIC); PsycEXTRA; PsycINFO; International Pharmaceutical Abstract; PubMed; CINHAL and Scopus. The reference lists of the included studies were scanned to identify additional relevant articles. A string for PubMed is outlined in Table 1. Using dementia as a MeSH term or searching specific alternatives terms of dementia, which included its different causes (e.g. vascular dementia, dementia with Lewy bodies and frontotemporal dementia, generated similar results. Therefore, dementia was used in all the subsequent searches. The search was limited to articles in English due to lack of resource for translation. Followings were excluded: grey literature, conference abstracts, literature reviews, editorials, correspondence, commentaries and protocol studies due to lack of time. The search was completed by the end of July 2018.

“Dementia” OR “Advanced Dementia” OR “End Stage Dementia” OR “Alzheimer’s”
AND
“Palliative Care”[Mesh] OR “Palliative Medicine”[Mesh] OR “Palliative Services” OR “Palliative Interventions” OR “Palliative” OR “Terminal Care”[Mesh] OR “Hospices”[Mesh] OR “End of Life Care” OR “Hospice Care”
AND
“Barriers” OR “Facilitators” OR “Factors” OR “Enablers” OR “Issues” OR “Challenges” OR “Contributors”

Table 1: Search Strategy of PubMed

Inclusion and exclusion criteria

All primary research articles including qualitative, quantitative and mixed method reporting barriers and/or facilitators in provision of PC in advanced dementia in all care settings worldwide were included. A 10-year timeframe from 2008 to 2018 was selected. The reason for choosing 2008 as the starting point was based on due to publication of the End of Life Care clinical practice guideline by the Department of Health [24], which for the first time promoted PC in dementia patients. This was followed by a flurry of studies focusing on dementia covering mild to moderate as well as advanced stages. This review only includes the advanced stage studies that are relevant for the end of life palliative services of dementia. This was done during title and abstract screening stage as well as full text screening process. Moreover, all the articles that did not discuss the barriers or the facilitators to the provision of PC in advanced dementia were excluded along with studies that evaluated the effectiveness of a specific facilitator approach/tool to the provision of PC in dementia.

Study selection

The process of the study selection is detailed in the PRISMA flow diagram [23] as can be seen in Figure.1. After merging results obtained through databases and manual searches, a total 1932 studies were noted, which went down to 1511 after duplicates were removed. The titles and abstracts of the remaining articles were then screened to identify potentially relevant studies using EndNote software [25]. 1428 articles were excluded based on the title and abstract screening. Afterwards, the full text article of the remaining 83 potential studies was obtained except for one (poster abstract). The full text articles were reviewed and assessed comprehensively against the inclusion and exclusion criteria, which resulted in the exclusion of 49 articles. Initially, one reviewer (MM) conducted the search and screened titles/abstracts. To check the validity a second researcher reviewed and assessed the papers against the same criteria. An academic clinician acted as a referee in case of any disagreement between the findings of the two-initial reviewer.

Data Extraction

The following information was extracted for each included study using Excel [26]: (1) aim of the study (2) the method used, method of analysis and study design (quantitative, qualitative, or mixed methods) (3) the country (4) the setting (care homes, hospitals, hospice care facilities, Specialists palliative care service, general practices, residential care homes, memory clinics, commissioning services, community setting, NHS continuing care units, adult services, specialist Elderly Mentally Infirm (EMI) homes, intellectual disability services, group living homes, adult day-care, nursing homes, mental health trust, assisted living residents, and patient’s home) (5) the sample size (6) whether or not PC was recognised as management step in advanced dementia and (7) The barriers and facilitators for provision of PC in this population. The results were extracted with a focus on the research question, aim and objectives. Data for the narrative synthesis and content analysis were only extracted from the result section of papers to maintain a degree of credibility.

Data synthesis and analysis

A narrative synthesis was conducted, drawing on the framework and techniques described in “Cochrane Consumers and Communication Review Group on Conducting Narrative Synthesis” [27]. The first step taken was developing a preliminary synthesis of the finding of the studies. Also, similar features of studies were summarised and grouped. The results were tabulated to identify patterns and emerging themes across the studies. All the data were then transformed into descriptive format. The data were coded and the frequencies of codes were identified. The theme appearing in more than one paper demonstrates a degree of validity. Therefore, the number of studies within a specific theme was reported in this review. Finally, content analysis was conducted to identify commonality as well as differences among included studies. One reviewer (MM) conducted the data synthesis and analysis. The final themes were achieved through discussion and agreement of both authors (MM and ZA). Through all the stages of the review 25% of the sample was checked by the second author to ensure reliability of the data.

Quality assessment

In this systematic review, as there’s a combination of quantitative, qualitative and mixed methods studies, the Mixed Methods Appraisal Tool (MMAT) was used as it allows assessing studies of various designs [28]. It is a validated tool developed at McGill University which comprises of a total of 19 methodological quality criteria for appraising quantitative (4 criteria for Randomised Controlled Trials (RCT), 4 criteria for Non-RCT and 4 criteria for descriptive quantitative), 4 criteria for qualitative and 3 criteria for mixed methods studies, which are scored on a nominal scale (Yes/No/Can't tell) [28]. Therefore, for both quantitative and qualitative studies the maximum score is 4 out 4, while for mixed methods studies the maximum score is 11 which is calculated through adding the score of the quantitative component with the score of qualitative component as well as the score for mixed methods studies [28].

Ethical issues

This is a secondary research, which means there are no participants involved and it was not subject to an ethical approval process.

Word count: 1051

Results

Description of included studies

A total of 34 studies [29-62] were included in the review (see Figure 1), with 25 studies providing qualitative data, 6 providing quantitative data and 3 mixed methods studies. Details related to the study characteristics are provided in the online supplementary file. The studies varied widely on a number of characteristics including country, setting and participants. Studies providing quantitative data tended to measure the barriers and facilitators of the provision of PC using questionnaires and cross sectional postal surveys. The qualitative studies measured the barriers and facilitators using semi-structured interviews, in-depth interviews, focus groups and participant observation. The 3 mixed methods studies used questionnaires/ semi-structured interviews, interviews and focus groups/ case note audit and economic data and telephone/online survey.

Country, setting and participants

The studies were conducted in several countries as can be seen in the supplementary file online including the United Kingdom, England, United States, Canada, Ireland, Netherlands, Belgium, Norway, Italy, Germany and Australia, all of which are high-income countries with the majority having taken place in the United Kingdom specifically England [4]. None of the studies were undertaken in a low and middle-income country. Data were mostly derived from care homes, hospitals, hospice care facilities, Specialists PC service, general practices and residential care homes (See supplementary file online). Out of all the studies, 29 derived data from healthcare professionals/providers [30-38, 40-53, 55- 57, 59, 60, 62], 11 from managers/directors of care facilities [34-36, 43, 44, 46, 47, 52, 57, 60, 61], nine studies from carers/caregivers [29, 38, 42, 45, 54, 56-59], one study from the patient's perspective [54] and seven focused on the commissioner's and policy expert's perspectives [35, 36, 39, 43, 44, 46, 56]. See also barriers to provision of PC from different stakeholders' perspectives in the online supplementary file for further details.

Barriers Affecting the Provision of Palliative Care in Advanced Dementia

Patient/carers Related Factors	Condition Related Factors	Policy Related Factors	Healthcare System Related Factors	Healthcare Team Related Factors	Therapy Related Factors	Attitude-awareness and beliefs Related Factors
Lack of ACP (11) [32, 38, 40, 42, 43, 45, 48-50, 54, 56]	Pain and symptoms assessment. (12) [34, 37, 42, 44, 45, 49-51, 55, 58, 59]	Medicare hospice eligibility criteria and requirement. (4) [35, 52, 60, 62]	Discontinuity of care and lack of co-ordination across care settings. (12) [32, 35, 36, 40, 43, 44, 46, 49, 51, 54, 55]	Lack of skills and training opportunities specific to PC in dementia. (17) [31, 32, 34-36, 38, 41-44, 49-51, 54-56, 61]	Lack of access to PC specialist support (5) [31, 32, 49, 55, 56]	Lack of awareness that dementia is a terminal/palliative condition. (12) [29, 31, 32, 40, 41, 44, 52-55, 59]
Communication difficulties between HCP and carers (7) [32, 35, 41, 42, 52, 55, 59]	Difficulty communicating with the patient. (11) [35, 40-42, 44, 45, 49, 51, 52, 55, 57]	Reimbursement Policies: Inadequate providers, difficult process. (3) [35, 60, 61]	Lack of funds and limited availability of resources. (9) [32, 35, 39, 41, 43, 46, 54, 55, 57]	Lack of knowledge and education of dementia. (8) [31, 32, 41, 42, 44, 45, 49, 51]	Lack of knowledge about PC in dementia. (4) [31, 34, 35 41]	Negotiation of risk; fear of legal consequences and blame. (4) [36, 38, 44, 48]
Lack of provision of the condition's necessary information (prognosis and future expectations) to carers/caregivers (5) [32, 38, 41, 42, 59]	Uncertainty identifying the terminal stage of dementia and difficulty initiation palliative therapy due to the unpredictable trajectory/prognosis. (9) [32, 33, 35, 38, 40, 41, 44, 47, 52]	Lack of commissioning guidance on dementia [39].	Lack of integration between services. (3) [35, 39, 49]	Lack of communication between services, HCPs and care settings. (8) [32, 35, 41, 43, 52, 57, 59]	Lack of standardised clinical guidelines/protocols and information. (4) [32, 36, 40, 41]	Lack of awareness and beliefs in ACP (4) [44, 45, 48, 56]
Family resistance and disagreement/conflicts over decision-making. (4) [32, 34, 41, 55]	Behavioural symptoms (BPSD). (8) [34, 42, 44, 52, 55, 56, 61]	Lack of key policy drivers in regard to advanced dementia care [43].	Lack of ACP discussions within primary and secondary care (3) [42, 43, 45]	Unnecessary hospitalisation: impact of hospitalisation. (8) [32, 38, 42, 46, 49, 51, 52, 56]		The use of PC is not considered meaningful in dementia. (3) [30, 35, 53]
Lack of respite services. (2) [32, 61]	Dysphagia (swallowing difficulties). (3) [34, 45, 50]	The presence of regulations and government's policy promoting fragmented care [43].	Services are driven via business model of care; driven by profit rather than optimal care. (2) [43, 44]	Low staff levels (8) [38, 39, 41, 43, 44, 46, 50, 57]		Lack of awareness of hospice availability/ PC to Advanced dementia (2) [52, 61]
Financial burden (2) [52, 56].	Difficulty maintaining adequate nutrition and hydration. (3) [49-51].	The use of Medicare skilled nursing facility benefit [60]	Lack of clear integrated dementia care pathways: Specifically in acute hospitals [56].	Poor interdisciplinary approach; between different HCPs, services and settings. (5) [32, 43, 55, 59, 61]		Societal attitudes towards older people (undervalued) [43].
			Difficulty accessing healthcare funds [54].	High levels of staff turnover. (5) [38, 41, 43, 44, 46]		Unfamiliarity with hospice admission criteria [62].
				Time Constraints. (4) [32, 35, 41, 57]		Dementia is not considered worthy of PC [55].
				Lack of consistency at workplace [43].		

Table 2: Barriers of the provision of palliative care in advanced dementia

Facilitators enabling the Provision of Palliative Care in Advanced Dementia						
Patient Related Factors	**Condition Related Factors**	**Policy Related Factors**	**Healthcare System Related Factors**	**Healthcare Team Related Factors**	**Therapy Related Factors**	**Attitude-awareness and beliefs**
Advance directives and care planning (12) [33, 34, 40-42, 44, 45, 47-49, 51, 60]	Provision of accurate prognosis algorithms: FAST terminality criteria. (2) [32, 52]	Medicare benefits for advanced dementia [52].	Ensure continuity of care through integration of services. (3) [44, 46, 47]	Multidisciplinary approach; between HCPs, services and settings: Collaboration with PC teams/hospice and access to PC specialists support. (11) [32, 33, 36, 41, 45-47, 49, 51, 55, 61]	Incorporation and implementation of the GSF and LCP into practice. (6) [36, 38, 45-47, 56]	Increase awareness of the public and family specifically about the dying process, the nature of dementia and services provided. (3) [40, 41, 47]
Educating family members and carers on the prognosis of dementia and future expectations. (3) [40, 41, 47]	Guidelines/ protocols and Care pathways. (3) [32, 33, 40]	UK Mental Capacity Act and the best interest approach [55]	Allocate funds and resources. (2) [32, 41]	Additional training specific to PC in dementia (End-of-Life dementia care) (10) [32, 33, 41, 45, 47, 51, 54, 55, 56]	Community Matrons Services [38].	Increase awareness about ACP [42].
Effective communication skills when dealing with family members (3) [42, 47, 57]	Pain assessment tools and scales [60].		The development of multi agency dementia care pathway [56].	Enhanced Education (3) [32, 40, 41].		
Emergency healthcare plans (DNACPR) [47].	Non-pharmacological interventions to manage BPSD or antipsychotics [60].		Cost effective PC interventions in the community [56].	Avoiding any unnecessary hospitalization (2) [44, 47]		
			Publicising of carer support services like Admiral Nurse Service and Memory Clinic [56].	Effective communication between HCPs [57].		
				Spending more time with dementia patients [41].		
				Advance directives tools such as “Five wishes”/ Advance directives forms [60].		
				Building relationships with the patients and their families [57].		

Table 3: Facilitators of the provision of palliative care in advanced dementia

Quality ratings

As mentioned above, the Mixed Methods Appraisal Tool (MMAT) was used to carry out the quality assessments of the studies. Quality ratings of qualitative and quantitative studies ranged from 2 to 4 and corresponding ratings from mixed methods studies ranged from 8 to 9 (out of 11) (See supplementary file online). However, one study of the mixed methods design was rated out of 10 instead of 11 as the quantitative method used looked at case note audit and the criteria assessing the response rate wasn't applicable [56]. Research questions, study design, sample size and participant/setting selection were mostly well described for all the data; whereas methods of data collection, analysis and reporting of findings were areas of weakness across lower quality studies. However, none of the studies were excluded on the basis of its quality.

Data synthesis and analysis

Narrative synthesis and content analysis first answered whether or not PC is empirically recognised as a care step in the management of patients with advanced dementia. In identifying barriers and facilitators for provision of PC in advanced dementia seven main themes emerged (Table 2 and 3). Furthermore, all interconnected 46 subthemes for the barriers and 27 subthemes for the facilitators were extracted. The seven main themes were factors related to patient/carers, condition (dementia), policy, healthcare system, healthcare team, therapy (PC), and attitude-awareness and beliefs. Fewer facilitators than barriers were reported and there was variation in the relative contribution of each study to each theme. Additionally, two papers specifically discussed pain management as the main barrier for the provision of PC (Table 4). Moreover, the narrative synthesis and content analysis further generated eight descriptive themes of the barriers from the perspective of patients, carers/caregivers, healthcare professionals/providers; managers/directors of care facilities and commissioners/policy experts (See supplementary file online).

Recognition of palliative care as a step in the care of advanced dementia

Out of the 34 studies, 24 studies recognised PC as a management step in the care of advanced dementia [31,33,34,36-38,40-47,49-51,56,57,59-62], whereas 7 studies rejected

PC as a management step [29,30,32,35,52-55] and 3 of them did not discuss it in their research [39,48,58].

Barriers and facilitators for the provision of palliative care in advanced dementia

A. Patient/Carer

The most commonly reported barriers within this theme were the lack of advance care planning (ACP) [32, 38, 40, 42, 43, 45, 48-50, 54, 56], communication difficulties between healthcare professionals and patient's caregivers [32, 35, 41, 42, 52, 55, 59], the lack of provision of information about the condition such as its prognosis and future expectations of carers/caregivers [32, 38, 41, 42, 59]. The facilitators included: advance directives/ advance care planning [33, 34, 40-42, 44, 45, 47-49, 51, 60] and emergency healthcare plans such as Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) [47].

B. Condition

This theme relates to the end-stage of dementia and how symptoms as well as cognitive and functional impairments of the disease formed several barriers to the provision of PC. The most frequently cited barriers were pain and difficulties in symptom assessment/management and communication [34, 35, 37, 40-42, 44, 45, 49, 51, 52, 55, 57-59]. Also mentioned were identification of the terminal phase and initiation of palliative therapy due to the disease prognostication [32, 33, 35, 38, 40, 41, 44, 47, 52]. On the other hand, facilitators related to advanced dementia were reported in several studies and included the provision of accurate prognosis algorithms such as Functional Assessment Staging Test (FAST) criteria [32, 52], which could be used to determine the terminal stage of dementia and the initiation of EoLC, and the development of care pathways and guidelines specific to dementia EoLC [32, 33, 40].

C. Policy

Few studies reported on policy related barriers to the provision of PC in dementia and included: lack of commissioning guidance on dementia [39], absence of key policy drivers with regard to advanced dementia care [43], the presence of regulations and government’s policy promoting minimal and fragmented care [43], the use of Medicare skilled nursing facility benefit [60], Medicare hospice eligibility/admission criteria and requirements and reimbursement policies [35, 52, 60-62]. Two studies discussed facilitators in this theme [52, 55], one of which suggested Medicare benefits for advanced dementia and the other recommended the use of UK Mental Capacity Act [63] and the best interest approach to manage conflicts and disagreements over decision-making which were mentioned under the patients/carers theme.

D. Healthcare system

Healthcare system related factors reported many organisational barriers such as discontinuity of care for patients with dementia and lack of co-ordination across care settings, as the most cited barriers [32, 35, 36, 40, 43, 44, 46, 49, 51, 54, 55]. Moreover, lack of funds and limited availability of resources [32, 35, 39, 41, 43, 46, 54, 55, 57], lack of integration between the social and healthcare systems and lack of organised PC approach/system [35, 39, 49] as well as the lack of ACP discussions initiated within primary and secondary care [42, 43, 45] dominated most of the reported barriers in this theme. Facilitators included allocating funds and resources [32, 41], cost-effective PC interventions in the community [56], publicising of carer's support services like Admiral Nurse Service and Memory Clinic [56], ensuring continuity of care through integration of health and social care services [44, 46, 47].

E. Healthcare professionals

22 studies identified barriers related to health care professionals (HCPs), with the most common one being lack of skills and training opportunities specific to PC in dementia (End-of-Life dementia care) [31, 32, 34-36, 38, 41-44, 49-51, 54-56, 61]. Unnecessary hospitalisation [32, 38, 42, 46, 49, 51, 52, 56], low staff levels [38, 39, 41, 43, 44, 46, 50, 57], lack of communication between services, HCPs and care settings [32, 35, 41, 43, 52, 57, 59] and the lack of knowledge and education of dementia among healthcare professionals were also common [31, 32, 41, 42, 44, 45, 49, 51]. Contrasting with the previous theme, many studies in this theme reported facilitators such as: enhanced education of HCPs [32, 40, 41], effective communication between HCPs [57], advance directives tools such as “Five wishes” document/ Advance directives forms [60, 64] to promote discussions about EoLC options as well as avoiding and minimising any unnecessary hospitalisation [44, 47]. The most frequently cited facilitators were

multidisciplinary approach between HCPs, services and settings, collaboration with PC teams/hospice and access to specialists support [32, 33, 36, 41, 45-47, 49, 51, 55, 61], as well as Additional training specific to PC in dementia [32, 33, 41, 45, 47, 51, 54, 55, 56].

F. Therapy

This theme relates to palliative/ EoLC in advanced dementia and included three main barriers: lack of access to PC specialist support [31, 32, 49, 55, 56], lack of knowledge about PC [31, 34, 35 41] and absence of standardised clinical guidelines/protocols and information regarding PC initiation and provision in advanced dementia [32, 36, 40, 41]. Facilitators for this theme included: incorporation and implementation of the Liverpool Care Pathway (LCP) and the Gold Standards Framework (GSF) into practice [36, 38, 45-47, 56].

G. Attitude, awareness and beliefs

The last theme discussed in 22 studies is attitude, awareness and beliefs and it highlighted how lack of public/HCPs awareness, misperceptions and attitudes could obstruct the provision of care. The most cited barrier was the lack of awareness that dementia is a terminal/palliative condition [29, 31, 32, 40, 41, 44, 52-55, 59]. Other barriers included: lack of awareness of hospice availability to advanced dementia and unfamiliarity with hospice admission criteria [52, 61, 62] as well as the lack of awareness and beliefs in ACP and fear of legal consequences and blame [36, 38, 44, 45, 48, 56]. Facilitators for this theme included: increasing awareness of the public and family regarding the nature of dementia and available services [40, 41, 47].

Barriers and facilitators of pain managements in advanced dementia

Two studies specifically examined the barriers and the facilitators of pain assessment and management in advanced dementia.

Pain assessment and management [37, 58]	
Barriers	**Facilitators**
Inability to diagnose pain and uncertainty about the pain etiology due to difficulty communicating with patients. (2)	Collaboration between different HCPs.
Lack of guidance and support.	Using non-verbal cues
Complex prescribing and treatment approaches; overtreatment, poor treatment.	WHO analgesic ladder.
Side effects and Adverse Drug Events (ADE)	Seeking specialists input.
Route of Administration; refusal to take medication, swallowing difficulties, poor gut absorption, nausea and vomiting and impaired consciousness.	Further training in managing pain in patients with behavioral challenges.
Lack of training in specific areas like distinguishing between pain and non-pain BSPD and managing pain in complex patients.	

Table 4: Barriers and facilitators of pain assessment and management.

The most commonly reported challenges in these two studies are inability to diagnose pain and uncertainty about pain aetiology due to communication difficulties with the patients [37, 58]. Other barriers included: lack of guidance and support, complex prescribing approaches and Adverse Drug Events (ADEs) [37, 58]. Moreover, administration of medication in people with advance dementia posed several dilemmas, which are associated with refusal to take medication, dysphagia, poor gut absorption, nausea and vomiting and impaired consciousness [37, 58]. Additionally, one of the two studies mentioned the lack of training in specific areas like distinguishing between pain and non-pain BSPD and managing pain in complex patients [37]. Only one study covered the facilitators of pain assessment and management and they included: Using non-verbal cues to assess pain, WHO analgesic ladder to aid prescribing decisions, seeking specialists input, and further training in managing pain in patients with behavioural challenges [37].

Stakeholder’s perspective

The stakeholders included: patients, carers, healthcare commissioners and policy experts, healthcare professionals and manager/directors. Eight descriptive themes were generated to categorise the previously mentioned barriers under the perspective of stakeholders (See supplementary file online).

A. Attitude, awareness and beliefs

Apart from commissioners and policy experts, all other stakeholders didn’t recognise dementia as a terminal illness nor a palliative condition. Only HCPs feared the legal consequences and blame of looking after these patients.

B. Advance Care Planning (ACP)

Only patients, caregivers and HCPs discussed ACP and its implications on the provision of care. Family and caregivers lacked awareness of ACP and perceived the lack of initiation ACP discussions within the primary and secondary care as a barrier to the provision of PC to their relatives as many of them suffered the consequences of making these decisions later on.

C. Communication

Carers perceived the lack of communication between HCPs and other care settings as a barrier as well as the lack of provision of necessary information regarding their relative’s conditions. HCPs agreed with the carers on these two points stating that lack of the caregiver’s knowledge regarding the prognosis of the condition could hinder the process of ACP.

D. Skills, training and knowledge in care provision

All participants agreed that lack of skills and training opportunities specific to PC in dementia was a main barrier to the provision of PC care in this population. Both carers and HCPs identified pain assessment and management as a challenging issue while HCPs and manager/directors of PC services agreed that BPSD hindered the provision of care.

E. Pathway of care

Apart from dementia patients, all stakeholders indicated that discontinuity of care for patients with dementia and lack of co-ordination across care settings and lack of collaboration between different HCPs, services and settings as a barrier to the provision of PC in this population. Furthermore, both HCP and managers/directors of care facilities found that the lack of standardised clinical guidelines/protocols was a barrier in delivery of PC while commissioners/policy experts perceived that lack of commissioning guidance on dementia was adversely affecting to their role and responsibilities.

F. Policy and regulations

All three participants (HCPs, commissioners/policy experts as well as managers/directors of care facilities) perceived Medicare hospice eligibility criteria and requirements as main barrier to admission of people with advanced dementia to hospice care facilities.

G. Funds and resources

HCPs and commissioners/policy experts stated the need for funding and perceived lack of funds and limited availability of resources as well as difficulty obtaining financial reimbursement as barriers to the provision of PC in advanced dementia. Managers/directors of care facilities and several HCPs discussed the lack of respite care services available for caregivers while caregivers themselves identified the financial burden of PC and the difficulty accessing healthcare funds as a significant problem.

K. Organisational issues

HCPs, managers/directors and commissioners/policy experts perceived the high staff turnover due to high workload, low pay, and low job satisfaction as a barrier of the provision of care especially in this population. Moreover, managers/directors of care facilities and HCPs both agreed that the lack of consistency at work place and low staff levels hinders the dynamic of PC.

Word Count: 2055

Discussion

The findings from this review are consistent with the literature, which shows significant gaps and poor experiences during the end of life phase among this population. To best of our knowledge, this review is the first systematic review analysing the perspectives stakeholders on the contributory factors influencing the provision of PC in advanced dementia. This review has provided an insight into the patient's journey through the end of life stage in dementia drawing on a number of stakeholders from different countries and settings. Findings suggest that there are significant barriers preventing the transition of people with advanced dementia to a palliative care approach. These barriers exist on many levels and can be attributed to cultural, policy, disease and systematic aspects of the healthcare infrastructure.

The findings indicated that 7 studies rejected PC as a management step in advanced dementia. The lack of recognition that PC is a vital step in the care of dementia is itself a barrier to the provision of PC in this population. Another study confirmed that patients of non-cancer diagnosis tend to have lower referral rates to PC services and their experiences of care at end of life are poorer due to the lack of awareness and recognition of the terminal nature of their conditions [65]. The fact that all participants did not recognise dementia as a terminal illness nor a palliative condition, affected the patient's EoLC and prevented this population from accessing PC services. This highlights the level of awareness of a terminal illness not only improves the quality of life but also the quality of death as it gives the patient control over the future, allowing them to make choices and prepare for death [66]. This was emphasised in prospective nationwide survey of bereaved family members of advanced cancer patients that measured the impact of awareness of terminal illness on quality of death and care decision-making [67].

In addition, lack of access to PC services was identified as a key barrier to the delivery of EoLC in this population, which is in line with Alzheimer Society report 2015 citing poor access to PC services and hospice care in this population [68]. This can be attributed to Medicare skilled nursing facility benefit, Medicare hospice eligibility/admission criteria and requirements as well as the reimbursement policies. This reflects a policy deficit in the healthcare system structure that needs immediate modification.

The cognitive and functional impairments of advanced dementia are all deemed to be challenges that complicated the provision of EoLC in this population. However, it was evident from the perspective of all participants involved that healthcare providers and staff lacked the necessary level of skills and training specific to End-of-Life dementia care to provide PC for pain assessment and management. Pain assessment has been seen challenging in this population and has promoted a number of tools aimed at objective measurement. Lichtner et al identified in a systematic review of pain assessment 28 tools that could be used in clinical practice for people with advanced dementia [69]. Limited exposure to such methods of assessment is noted among the included studies. Furthermore, all healthcare participants perceived the absence of standardised clinical guidelines/protocols and information regarding PC initiation and provision in advanced dementia hindering provision of care. These issues were addressed recently in a systematic review assessing the PC content in dementia clinical practice guidelines and indicated that EoLC was minimal [70]. This highlights the need for evidence-based recommendations and clinical practice guidelines specific to end of life dementia care.

Moreover, the lack of integration between the social and health care systems was another key barrier that hindered the patients and carers journey through dementia. Governmental authorities must bring together the social and health care systems through integration of services and collaboration across different settings in order to ensure continuity of care, shared decision making and better healthcare outcomes. Unnecessary hospitalisation in this population hindered the provision of PC, which could be attributed to the negative impact of hospitalisation on people with advanced dementia. Advanced directives tools such as the “Five wishes” document, advanced directives forms and emergency healthcare plans (DNACPR) could help promote these discussions about end of life care options, facilitate ACP and minimise any unnecessary hospitalisation. A survey exploring the impact of the “Five wishes” document in planning ahead in life-limiting illnesses concluded that 90% of the participants found the document helpful [71]. Caregivers reported noticeable deterioration of the patient’s state whenever they’re admitted to the hospital. This was attributed to hospital-acquired infections, worsening of BPSD, and bedsores. A national audit measuring the quality of dementia care at acute hospitals established that the staff levels, level of training and support, specialist services and discharge planning is poor and regarded the overall quality of dementia care at acute hospitals as suboptimal [72].

Implications towards practices

Implications for health and social care regulators, policymakers and commissioner as well as senior managers/directors of care facilities:

- Raising awareness through public health campaigns that advance dementia is a terminal illness and publicising carers support services such as Admiral Nurse Service and Memory Clinic.
- Involving frontline staff in the development and implementation of training programs.
- Development of evidence-based recommendations and clinical practice guidelines specific to end of life dementia care.
- Where applicable, policy makers can help provide Medicare's benefits for advanced dementia and modify Medicare hospice eligibility criteria and requirements.
- Health and social care regulatory bodies can increase cost effective palliative care interventions in the community

Strengths and Limitations of the systematic review

To the best of our knowledge, it is the first systematic review conducted regarding the factors influencing the provision of PC from the perspectives of different stakeholders. The systematic review is a mixed studies systematic review, which presents a whole picture and will thus have unlimited applicability in many contexts.

The lack of studies that included the patient's perspective could be considered as a limitation of this systematic review. Another limitation could be that all of studies included were conducted in high-income countries, thus the generalizability of the findings of this review may be difficult. Moreover, the use of plurals in the search terms e.g. barriers, excluded articles that listed a singular barrier, which is a major limitation of the research.

Future research

All of studies included were conducted in high-income countries, which highlights the need for future research to be also conducted in Low and Middle Income Countries. Only one study included the patient's perspective after obtaining their consent in the early stages of dementia. This could be carried out in future research in order to obtain patients' perspective.

Conclusions

This is the first systematic review analysing the perspectives stakeholders on the contributory factors influencing the provision of PC in advanced dementia. Provision of PC was empirically recognised as a care step in the management of dementia, however, there are several barriers that hinders the access of dementia patients to the appropriate facilities. With the prevalence of dementia rising and no cure on the horizon, it is crucial that health and social care regulatory bodies integrate a palliative approach into their care. The stakeholders are challenged with the results of this review to implement and use the identified facilitators to achieve optimal and effective PC in this population improving the lives of patients with dementia and their families and ensure quality and equality in the provision of end-of-life care.

Word count: 1231

Acknowledgements

I would like to express my gratitude to the module lead Mr John Corkery who played a pivotal role in the research process, providing me with key academic tools and feedback in all research stages. Also, I would like to thank the Ministry of Higher Education for giving me a scholarship and supporting me financially.

Licence for Publication

Competing Interest

Competing Interest: None declared.

References

1 World Health Organisation. Dementia. World Health Organization. 2017.http://www.who.int/mediacentre/factsheets/fs362/en/ (accessed 15 Feb 2018).

2 Prince M, Jackson J. *World Alzheimer Report 2009: The Global Prevalence of Dementia*. London: : Alzheimer’s Disease International 2009. https://www.alz.co.uk/research/files/WorldAlzheimerReport.pdf (accessed 18 Feb 2018).

3 Alzheimer's Disease International. Dementia statistics. Alz.co.uk. 2015.https://www.alz.co.uk/research/statistics (accessed 18 Feb 2018).

4 Prince M, Wimo A, Guerchet M et al. *The World Alzheimer Report 2015, The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends.*. London.: : Alzheimer’s Disease International (ADI) 2015. https://www.alz.co.uk/research/WorldAlzheimerReport2015.pdf (accessed 18 Feb 2018).

5 World Health Organisation. *Neurological disorders: public health challenges*. Geneva: 2006.

6 Mathers C, Ma Fat D, Boerma J. *The global burden of disease*. Geneva: : World Health Organization 2008.

7 McCarthy M, Addington-Hall J, Altmann D. THE EXPERIENCE OF DYING WITH DEMENTIA: A RETROSPECTIVE STUDY. *International Journal of Geriatric Psychiatry* 1997;12:404-409.

8 Bayer A. Death with dementia—the need for better care. *Age and Ageing* 2006;35:101-102.

9 Hughes J, Robinson L, Volicer L. Specialist palliative care in dementia. *BMJ* 2005;330:57-58.

10 World Health Organisation. WHO Definition of Palliative Care. Who.int. 2018.http://www.who.int/cancer/palliative/definition/en/ (accessed 23 Feb 2018).

11 Van der Steen J, Radbruch L, Hertogh C et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine* 2014;28:197-209.

12 Connor S, Bermedo M. *Global Atlas of Palliative Care at the End of Life*. 1st ed. Lancaster, England: : The Worldwide Hospice Palliative Care Alliance 2014.

13 World Health Organisation. *Palliative care and dementia statement – Worldwide Hospice Palliative Care Alliance*. Geneva: : World Health Organisation 2015. http://www.who.int/mental_health/neurology/dementia/NSA_WHPCA.pdf (accessed 23 Feb 2018).

14 Sampson E. Palliative care for people with dementia. *British Medical Bulletin* 2010;96:159-174.

15 Birch D, Draper J. A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia. *Journal of Clinical Nursing* 2008;17:1144-1163.

16 Sachs G, Shega J, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine* 2004;19:1057-1063.

17 Addington-Hall J. *Positive Partnerships: Palliative Care for Adults with Severe Mental Health Problems*. London: : National Council for Hospice and Specialist Palliative Care Services 2000.

18 Murray S, Kendall M, Boyd K et al. Illness trajectories and palliative care. *BMJ* 2005;330:1007-1011.

19 Coetzee R, Leask S, Jones R. The attitudes of carers and old age psychiatrists towards the treatment of potentially fatal events in end-stage dementia. *International Journal of Geriatric Psychiatry* 2003;18:169-173.

20 Forbes S, Bern-Klug M, Gessert C. End-of-Life Decision Making for Nursing Home Residents with Dementia. *Journal of Nursing Scholarship* 2000;32:251-258.

21 Harris D. Forget me not: palliative care for people with dementia. *Postgraduate Medical Journal* 2007;83:362-366.

22 NHS. Causes of dementia. Nhs.uk. 2018. https://www.nhs.uk/conditions/dementia/causes/ (accessed 17 Feb 2018).

23 Liberati A, Altman D, Tetzlaff J et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *Journal of Clinical Epidemiology* 2009;62:e1-e34.
24 Department of Health. *End of Life Care Strategy: Promoting High Quality Care for all Adults at the End of Life.*. London: : Department of Health 2008. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf (accessed 9 Mar 2018).

25 Clarivate Analytics. *EndNote X8*. 2016.

26 Microsoft Corporation. *Microsoft Excel*. 2011.

27 Ryan R. *Cochrane Consumers and Communication Review Group: data synthesis and analysis*. Cochrane Consumers and Communication Review Group. 2013. http://cccrg.cochrane.org/sites/cccrg.cochrane.org/files/public/uploads/AnalysisRestyled.pdf (accessed 3 May 2018).

28 Pluye P, Robert E, Cargo M et al. *Proposal: A mixed methods appraisal tool for systematic mixed studies reviews.*. McGill University, Canada. 2011. http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/84371689/MMAT%202011%20criteria%20and%20tutorial%202011-06-29updated2014.08.21.pdf (accessed 4 Apr 2018).

29 Andrews S, McInerney F, Toye C et al. Knowledge of Dementia: Do family members understand dementia as a terminal condition?. *Dementia* 2017;16:556-575.

30 Beernaert K, Deliens L, Pardon K et al. What Are Physicians' Reasons for Not Referring People with Life-Limiting Illnesses to Specialist Palliative Care Services? A Nationwide Survey. *PLOS ONE* 2015;10:e0137251.

31 Brazil K, Galway K, Carter G et al. Providing Optimal Palliative Care for Persons Living with Dementia: A Comparison of Physician Perceptions in the Netherlands and the United Kingdom. *Journal of Palliative Medicine* 2017;20:473-477.

32 Carter G, van der Steen J, Galway K et al. General practitioners’ perceptions of the barriers and solutions to good-quality palliative care in dementia. *Dementia* 2015;16:79-95.

33 Champion E. What support do nurses need to provide palliative care for people with dementia?. *Nursing Older People* 2017;29:34-39.

34 Chang E, Daly J, Johnson A et al. Challenges for professional care of advanced dementia. *International Journal of Nursing Practice* 2009;15:41-47.

35 Davies N, Maio L, Paap J et al. Quality palliative care for cancer and dementia in five European countries: some common challenges. *Aging & Mental Health* 2014;18:400-410.

36 Davies N, Maio L, Vedavanam K et al. Barriers to the provision of high-quality palliative care for people with dementia in England: a qualitative study of professionals' experiences. *Health & Social Care in the Community* 2014;22:386-394.

37 De Witt Jansen B, Brazil K, Passmore P et al. ‘There’s a Catch-22’ – The complexities of pain management for people with advanced dementia nearing the end of life: A qualitative exploration of physicians’ perspectives. *Palliative Medicine* 2017;31:734-742.

38 Dening K, Greenish W, Jones L et al. Barriers to providing end-of-life care for people with dementia: a whole-system qualitative study. *BMJ Supportive & Palliative Care* 2012;2:103-107.

39 Gotts Z, Baur N, McLellan E et al. Commissioning care for people with dementia at the end of life: a mixed - methods study. *BMJ Open* 2016;6:e013554.

40 Grisaffi K, Robinson L. Timing of end-of-life care in dementia: Difficulties and dilemmas for GPs. *Journal of Dementia Care* 2010;18:36-39.

41 Hill E, Savundranayagam M, Zecevic A et al. Staff Perspectives of Barriers to Access and Delivery of Palliative Care for Persons With Dementia in Long-Term Care. *American Journal of Alzheimer's Disease & Other Dementias®* 2018;:153331751876512.

42 Johnson A, Chang E, Daly J et al. The communication challenges faced in adopting a palliative care approach in advanced dementia. *International Journal of Nursing Practice* 2009;15:467-474.

43 Kupeli N, Leavey G, Harrington J et al. What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the UK? Health care professional perspective. *Dementia* 2018;17:164-179.

44 Kupeli N, Leavey G, Moore K et al. Context, mechanisms and outcomes in end of life care for people with advanced dementia. *BMC Palliative Care* 2016;15.

45 Lawrence V, Samsi K, Murray J et al. Dying well with dementia: Qualitative examination of end-of-life care. *British Journal of Psychiatry* 2011;199:417-422.

46 Lee R, Bamford C, Exley C et al. Expert views on the factors enabling good end of life care for people with dementia: a qualitative study. *BMC Palliative Care* 2015;14.

47 Lee R, Bamford C, Poole M et al. End of life care for people with dementia: The views of health professionals, social care service managers and frontline staff on key requirements for good practice. *PLOS ONE* 2017;12:e0179355.

48 Livingston G, Pitfield C, Morris J et al. Care at the end of life for people with dementia living in a care home: a qualitative study of staff experience and attitudes. *International Journal of Geriatric Psychiatry* 2011;27:643-650.

49 McCarron M, McCallion P, Fahey-McCarthy E et al. The Role and Timing of Palliative Care in Supporting Persons with Intellectual Disability and Advanced Dementia. *Journal of Applied Research in Intellectual Disabilities* 2011;24:189-198.

50 McCarron M, McCallion P, Fahey-McCarthy E et al. Staff Perceptions of Essential Prerequisites Underpinning End-of-Life Care for Persons With Intellectual Disability and Advanced Dementia. *Journal of Policy and Practice in Intellectual Disabilities* 2010;7:143-152.

51 McCarron M, McCallion P, Fahey-McCarthy E et al. Supporting persons with Down syndrome and advanced dementia. *Dementia* 2010;9:285-298.

52 McCarty C, Volicer L. Hospice Access for Individuals With Dementia. *American Journal of Alzheimer's Disease & Other Dementiasr* 2009;24:476-485.

53 Ouchi K, Wu M, Medairos R et al. Initiating Palliative Care Consults for Advanced Dementia Patients in the Emergency Department. *Journal of Palliative Medicine* 2014;17:346-350.

54 Poole M, Bamford C, McLellan E et al. End-of-life care: A qualitative study comparing the views of people with dementia and family carers. *Palliative Medicine* 2018;32:631-642.

55 Ryan T, Gardiner C, Bellamy G et al. Barriers and facilitators to the receipt of palliative care for people with dementia: The views of medical and nursing staff. *Palliative Medicine* 2012;26:879-886.

56 Sampson E, Mandal U, Holman A et al. Improving end of life care for people with dementia: a rapid participatory appraisal. *BMJ Supportive & Palliative Care* 2012;2:108-114.

57 Sims-Gould J, Wiersma E, Arseneau L et al. Care provider perspectives on end-of-life care in long-term-care homes: implications for whole-person and palliative care. *Journal of Palliative Care* 2010;26:122-129.

58 Tarter R, Demiris G, Pike K et al. Pain in Hospice Patients With Dementia. *American Journal of Alzheimer's Disease & Other Dementiasr* 2016;31:524-529.

59 Thuné-Boyle I, Sampson E, Jones L et al. Challenges to improving end of life care of people with advanced dementia in the UK. *Dementia* 2010;9:259-284.

60 Tilly J, Fok A. Policy Barriers to Quality End- of- Life Care for Residents With Dementia in Assisted Living Residences and Nursing Homes. *Alzheimer's Care Today* 2008;9:103-112.

61 Torke A, Holtz L, Hui S et al. Palliative Care for Patients with Dementia: A National Survey. *Journal of the American Geriatrics Society* 2010;58:2114-2121.

62 Upchurch L, Thornton K. Hospice Referrals of Patients With Alzheimer Disease in Southeastern Georgia. *Journal of Hospice & Palliative Nursing* 2012;14:199-209.

63 Department for Constitutional Affairs. *The Mental Capacity Act.*. London: : The Stationery Office 2005.

64 Aging With Dignity Organisation. *Five wishes*. 2018. https://fivewishes.org/docs/default-source/default-document-library/product-samples/fwsample.pdf?sfvrsn=2 (accessed 25 Jul 2018).

65 Boland J, Johnson M. End-of-life care for non-cancer patients. *BMJ Supportive & Palliative Care* 2013;3:2-3.

66 Miyashita M, Morita T, Sato K et al. Good Death Inventory: A Measure for Evaluating Good Death from the Bereaved Family Member's Perspective. *Journal of Pain and Symptom Management* 2008;35:486-498.

67 Ahn E, Shin D, Choi J et al. The impact of awareness of terminal illness on quality of death and care decision making: a prospective nationwide survey of bereaved family members of advanced cancer patients. *Psycho-Oncology* 2013;22:2771-2778.

68 Collins J. *Living and dying with dementia in Scotland: Barriers to care.*. Marie Curie Cancer Care. 2015. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/february-2015/living-and-dying-with-dementia-in-scotland-report-2015.pdf (accessed 27 Dec 2018).

69 Lichtner V, Dowding D, Esterhuizen P et al. Pain assessment for people with dementia: a systematic review of systematic reviews of pain assessment tools. *BMC Geriatrics* 2014;14.

70 Durepos P, Wickson-Griffiths A, Hazzan A et al. Assessing Palliative Care Content in Dementia Care Guidelines: A Systematic Review. *Journal of Pain and Symptom Management* 2017;53:804-813.

71 Wiener L, Ballard E, Brennan T et al. How I Wish to be Remembered: The Use of an Advance Care Planning Document in Adolescent and Young Adult Populations. *Journal of Palliative Medicine* 2008;11:1309-1313.

72 Timmons S, O’Shea E, O’Neill D et al. Acute hospital dementia care: results from a national audit. *BMC Geriatrics* 2016;16.

Figure 1: PRISMA Flow Diagram