2018

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Recommended Citation

Martin, S. S. (2018). *Effects of Palliative Care on Quality of Life for People With Dementia and Their Informal Caregivers* [Master's thesis, Bethel University]. Spark Repository. https://spark.bethel.edu/etd/424

EFFECTS OF PALLIATIVE CARE ON QUALITY OF LIFE FOR PEOPLE WITH DEMENTIA AND THEIR INFORMAL CAREGIVERS

A MASTER'S CAPSTONE PROJECT

SUBMITTED TO THE GRADUATE FACULTY

OF THE GRADUATE SCHOOL

BETHEL UNIVERSITY

BY
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IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF
MASTER OF SCIENCE IN NURSING

NOVEMBER 2018

BETHEL UNIVERSITY

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November 2018

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Acknowledgements

I dedicate this project to my grandparents whose love for each other and their family outshines the challenges of dementia.

Abstract

Background: Dementia is a leading cause of debility and dependence and its incidence is increasing exponentially as the global population ages. Despite the terminal nature of dementia, the end-of-life process is often poorly recognized due to a prolonged decline and cognitive deficits. As a result, people with dementia may be subject to health care interventions that have questionable efficacy and may not align with their wishes. Palliative care, a plan of care that prioritizes comfort, is becoming more widely utilized for patients with chronic illnesses such as dementia.

Purpose: The purpose of this critical review of the literature is to determine if palliative care improves the quality of life for patients with dementia and their informal caregivers.

Results: Using Kolcaba's Comfort Theory as the theoretical framework, 18 investigations were reviewed and analyzed. Attributes of palliative care were aligned with Kolcaba's types of comfort and contexts of experience to determine how palliative care influences comfort and quality of life. Findings reveal palliative care positively impacts quality of life because it provides a framework that allows recognition of dementia as a life-limiting condition, promotes understanding of the barriers unique to dementia care, and identifies specific needs of caregivers.

Conclusion: The evidence from the literature shows that aspects of palliative care can positively impact the quality of life for people with dementia and their informal caregivers.

Implications for Research and Practice: Further research is needed to examine the role of palliative care in improving quality of life for people with dementia and their caregivers. Large investigations are needed in a variety of cultures to increase understanding of quality of life measures in dementia and how palliative care can support these goals.

Key Words: dementia, palliative care, dementia caregiving, quality of life

Table of Contents

List of Tables

Chapter One: Introduction

Humanity is aging. By 2050 it is estimated that 1.5 billion people, or 16% of the world's population, will be age 65 years or older (National Institute on Aging, 2011). Aging is happening simultaneously with shifting societal trends, including globalization of economies, rapid technological advancements, and changing family demographics. These changes will have a major impact on our health and our ability to care for the growing number of older citizens.

The potential for an active and healthy older adulthood is tempered by dementia, a chronic and progressive brain syndrome affecting 50 million people with nearly 10 million new cases diagnosed every year (World Health Organization, 2017). The National Institute on Aging broadly defines dementia as a neurodegenerative disorder that causes progressive and irreversible loss of neurons and brain functioning; there are three types: Alzheimer's Disease, frontotemporal disorders, and Lewy body dementia (2018).

Like other people with a terminal illness, people with dementia often experience restlessness, agitation, fatigue, pain, pressure injuries, dyspnea, constipation, and dysphagia as their syndrome progresses (van der Steen, 2010). However, unlike other terminally ill, the end-of-life process for patients with dementia may not be as well recognized due to their gradual decline and cognitive impairment. Therefore, people with dementia are subject to burdensome interventions and hospitalization with questionable efficacy and consistency with their wishes (van der Steen, 2010).

Extent of the Problem

Dementia is a leading cause of disability and dependence in older people, robbing them of their ability to function independently. Alzheimer's Disease is the sixth leading cause of death in the United States (Alzheimer's Association, 2018). The prevalence of dementia rises sharply with age; an estimated 30% of people age 85 years or older have dementia and most will eventually require constant care (World Health Organization, 2017). By 2050, the number of people with dementia is expected to grow to 131.5 million worldwide (Alzheimer's Disease International, 2017).

Dementia progression is often unpredictable and prolonged, and it is recognized as a progressive terminal illness despite variable survival (Birch & Draper, 2008). The disease follows a frailty pattern of decline during which patients suffer severe disability with substantial decline in function and increased dependence in activities of daily living in the last years of life (van der Steen, 2010). People with dementia experience cognitive decline and frequently a deterioration in their emotional control, social behavior, and motivation (World Health Organization, 2017b). This causes the impact of dementia to extend well beyond the affected person to their families, communities and greater society.

In 2004, Larson et al. found that patients generally live five to nine years following a diagnosis of dementia (van der Steen, 2010). However, prognostication is imprecise due to the multiple ways of defining the onset of dementia, the varying ages of populations under study, and concurrent illnesses, which may accelerate decline (van der Steen, 2010).

Dementia is "one of the most daunting and potentially costly consequences" of living longer (National Institute on Aging, 2011, p. 3). Though it is challenging to determine the costs of caring for patients with dementia due to coexisting chronic health problems and the frequency of informal caregiving in the population, Hurd and colleagues estimated in 2010 that the cost of dementia care in the United States falls between $157 billion and $215 billion, a financial burden similar to heart disease and cancer (2013).

Need for Critical Review

As the world’s population ages, and dementia grows as a leading cause of debility and death, there is an escalating need for greater understanding about how to deliver quality care for this population and their informal caregivers. The overwhelming majority of healthcare proxies for patients with advanced dementia in nursing homes identify comfort as the most important goal of care (Gallagher & Long, 2011). However, people with dementia are at risk for overtreatment with potentially burdensome interventions, such as antibiotics, tube feeding, and hospitalization shortly before death.

This literature review investigated if a palliative care (PC) approach can provide an effective framework to structure care that prioritizes comfort for people living with dementia. The goal of PC is to improve quality of life (QOL) for seriously ill people and their families by providing interdisciplinary support (Center to Advance Palliative Care, 2017). In 2018, the World Health Organization (WHO) defined PC as:

> an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (2018c, para. 1).

Mitchell et al. (2016) found PC is appropriate for all people who live with an incurable illness as it reflects the concept of people-centered care.

Research Question

The complexities of dementia complicate caregiving. Despite unprecedented advances in science and technology which have fueled longer life expectancy, much suffering remains unaddressed by modern health care (Saunders, 2001). The focus question in this review is this: does PC enhance QOL for patients with dementia and their informal caregivers?

Conceptual Framework

The theoretical framework for this critical review of the literature is Katharine Kolcaba's Comfort Theory. Gallagher and Long site several studies that found patients with dementia experience distressing symptoms and burdensome interventions that jeopardize comfort, and palliative teams are challenged to provide quality services for people with dementia and their families (2011).

Kolcaba's theory posits a philosophy of care whereby holistic comfort needs are identified and addressed. Enhanced comfort is related to desirable outcomes, such as higher patient function, fewer hospital admissions, and increased satisfaction with care for both patients and families. Comfort Theory is an important framework for interprofessional care, and a defining factor of PC, because the focus is on unifying a plan of care and the positive outcome of patient comfort (Kolcaba, 2013).

Kolcaba's theory is widely used as a framework to identify patient comfort needs. However, no studies using Comfort Theory in the context of PC and dementia were discovered in this course of this literature review. A few investigations were identified that explored the PC needs of specific populations of patients (e.g., cardiac patients or patients in nursing homes), however study participants in those investigations had chronic diseases other than dementia.

Significance to Nursing

Nurses—especially those in primary, long term, and home care—can play an important role in the early identification and management of dementia. Nurses can help lessen the stress for patients and informal caregivers by delivering quality care; however, nurses may not be adequately prepared to provide this care (Griffiths, Knight, Harwood, & Gladman, 2014). With the aging population, and subsequent greater incidence of dementia, it is important to understand the needs of dementia patients and their caregivers and devise appropriate training for nurses.

The Institute of Medicine states the aim of PC is to reduce the burden of disease, manage symptoms, optimize of QOL, guide advanced care planning, and administer social and psychological support to patients and families (National Academy of Sciences, the Institute of Medicine, 2014). As nurses frequently encounter dementia patients, it is important to consider the potential outcomes of a palliative plan of care and the roles that would be best fulfilled by nurses in such a plan.

Chapter Two: Methods

This chapter contains the literature review relating to the impact of PC on QOL for people with dementia and their informal caregivers. The search strategy included identifying relevant studies, distinguishing inclusion and exclusion criteria, and evaluating the studies.

Definitions

Common words and definitions used throughout this literature review include the following:

Dementia. A neurodegenerative disorder which causes progressive and irreversible loss of neurons and brain functioning, most frequently found in older adults (National Institute on Aging, 2018).

Informal caregiver. Spouses, adult children, daughters- and sons-in-law, grandchildren, friends or neighbors may serve as informal caregivers for people with dementia. Women are more likely than men to serve as caregivers (WHO, 2015). The responsibilities of caregivers vary according to needs and living arrangements. Some informal caregivers provide hands-on care, while others organize the care provided by others.

Palliative care (PC). A care approach for patients and their families faced with life-threatening illness. PC prevents and relieves suffering through the early identification, assessment, and treatment of pain and other problems, whether physical, psychosocial or spiritual (WHO, 2018). PC and end-of-life care are often used interchangeably in clinical practice, however there are differences. PC is associated with “the entire patient journey of people who are living with an incurable illness” (Mitchell et al., 2016, p. 55). End-of-life care is a continuation of PC and should commence when an illness has advanced sufficiently that death is near, typically within 12 months (Mitchell et al., 2016).

People-centered care. Organized around health needs and expectations, people-centered care incorporates the perspectives of individuals, families, and communities and requires that people have the education and support they need to make decisions and participate in their own care (WHO, 2018b).

Quality of life (QOL). In 2000, Revicki and colleagues defined QOL as the scope of human experiences related to a person's overall well-being (Bruckhardt & Anderson, 2003). A subjective measurement, QOL is unique to the individual. Scales have been developed to measure individual's perception of their QOL in a variety of contexts (e.g., chronic illness or employment).

Search Strategy

To identify the most applicable research studies for this project, a Bethel University reference librarian was consulted to discuss research strategies, database choices, and potential keywords. A literature search was conducted using CINAHL Plus with Fulltext, Cochrane Database of Systematic Reviews, and PubMed. Publication dates were limited to 2007 through 2018, with one exception for a seminal investigation by Ahronheim, Morrison, Morris, Baskin and Meier published in 2000. Search words included: dementia, palliative, nursing, comfort, comfort theory, and Kolcaba. Using these search terms, 903 articles were found in CINAHL and 1,709 articles in PubMed. Of these, 51 articles included the words nursing and comfort. No articles included Kolcaba. The 51 articles were evaluated to determine if they were related to the research question, with 17 articles found to be pertinent. In the Cochrane Database of Systematic Reviews, eight articles were found that related to these specific search words: dementia, palliative, comfort, and nursing.

Inclusion/Exclusion Criteria

The resulting 25 articles were examined to verify that they were published within the last 11 years and to determine the content's applicability to the research question, resulting in the inclusion of 18 articles in the matrix. Articles were accepted if they related to PC in patients with dementia in any setting where nursing care is delivered. The resulting 18 articles were reviewed and found applicable to the evidence-based practice question.

Criteria for Evaluating Research Studies

Each article was appraised using the tools from the *Johns Hopkins Nursing Evidence-Based Practice: Model and Guidelines* (Dang & Dearholt, 2018). Each article was systematically evaluated and rated to identify the strength and quality of evidence using the Johns Hopkins Research Evidence Appraisal Tool for research and non-research evidence. Both level of evidence and quality ratings were placed in the matrix (see Appendix).

Studies Selected for Review

Once the Research Evidence Appraisal Tool was completed, the collection included five Level I articles, two of high quality and three of good quality. One Level II article of good quality was included, along with ten Level III articles, five of high quality and five of good quality. One Level IV article of good quality, and one Level V article of high quality completed the list of sources for the critical review.

Chapter Three: Literature Review and Analysis

The goal of this critical literature review is to determine if a PC approach enhances the QOL for patients with dementia and their informal caregivers. A synthesis of the major findings is presented in this chapter and is organized by level of evidence. A critique of the strengths and weaknesses of salient studies is also provided.

Major Findings

People with dementia derive the greatest benefit from PC when their decline is recognized in a timely manner and is understood by the health care team and the informal caregiver to be terminal (Abernethy et al., 2013). Controversy exists around when to apply PC; there is a need to improve awareness of the terminal nature of dementia and the benefits of PC among both health care providers and the public (van der Steen et al., 2016; Chen, et al., 2018). Staff with additional training in dementia, roles often fulfilled by nurses or social workers, are beneficial for patient assessment and facilitation of PC discussions with informal caregivers (Sampson et al., 2011).

PC conferences were shown to reduce the likelihood and duration of hospitalization for patients with dementia (Abernethy et al., 2013). Care conferences are most effective in challenging cases when families need assistance to manage symptoms or plan care following hospital discharge; however, the additional focus on prognosis during a care conference can deepen distress for families and increase anxiety and depression symptoms (Carson et al., 2016). Decision aids, which provide information about available treatments along with associated risks and rewards, were shown to increase knowledge and reduce decisional conflicts for informal caregivers when considering invasive interventions such as feeding tubes and ventilators (Hanson, et al., 2011; Chen, et al., 2018).

It is difficult to initially implement PC when a patient with dementia is hospitalized. Health care providers should encourage patients and families to seek PC consultation before acute hospitalization is required, when goals can be established with less urgency (Ahronheim, Morrison, Morris, Baskin, & Meier, 2000). Ideally, people with early-stage dementia engage in their own proactive advanced care planning (ACP) while they still have the cognitive capacity to do so (Poole et al., 2018). See Table for a list of evidence-based interventions for dementia palliative care.

Level I evidence. A total of five Level I investigations are included in this review. Two of the investigations are of high quality, and three are of good quality.

A single PC care conference was found to reduce hospitalization for adults with life-limiting illness by 26% (Abernethy et al., 2013). After a randomized control trial of 365 family decision makers in four intensive care units, Carson et al. (2016) found that PC-lead discussions should not be routinely incorporated into the care of all patients with chronic critical illness, but rather greater benefit is derived in complex cases when specific needs are identified, for example, symptom management or disposition planning. Hanson et al. (2011) determined that when a decision aid was used in conjunction with face-to-face communication with medical providers, surrogate decision makers for people with dementia experienced reduced decisional conflict and increased knowledge. Sampson et al. (2011) found that a specific staff role may be necessary to address the PC needs of patients with advanced dementia. ACP is most beneficial before the person with dementia loses their mental capacity. It is not optimal to conduct ACP at the time of hospitalization, but rather incorporate ACP systematically into routine health care. The final Level I investigation, an older seminal investigation by Ahronheim, Morrison, Morris, Baskin, and Meier (2000), compared an intervention group, who received a PC consultation and daily discussions between the palliative team and patient surrogates, to a control group who received treatment by the primary care team. The randomized control trial found that the sense of urgency experienced during hospitalization hinders the effectiveness of the PC consult. Given the unique barriers for patients with dementia, it is difficult for PC teams to influence the treatment approach of people with advanced dementia while hospitalized.

Level II evidence. There is only one investigation identified as Level II evidence in this review. This 2018 article by Verreault et al. evaluated the effectiveness of a five-component intervention to improve quality of care and quality of death for patients with advanced dementia in long-term care. The results of the quasi-experimental, good-quality investigation found that multidimensional interventions including staff training, use of an observational pain scale, routine mouth care, an education booklet for families, and use of a nurse facilitator lead to improved scores on the Symptom Management for End-of-Life Care in Dementia Scale and the Comfort Assessment in Dying Scale. Scores for the Family Perception of Care Scale were also improved, although with less strength of evidence.

Level III evidence. There are 10 articles in this level, five of high quality and five of good quality. Nine articles were directly related to the dementia population. One high quality article reported nonclinical outcomes of a multidisciplinary PC program for Medicare beneficiaries with cancer, chronic obstructive pulmonary disease, heart failure, or dementia. This investigation found that programs designed to support transition of care from fully disease-focused to fully comfort care can reduce health care costs and help patients and families manage disease outside of a hospital. Proactive PC programs help avoid hospital use and costs commonly associated with the final months of life for patients with dementia with an average monthly savings of nearly $3,000 per patient (Cassel et al., 2016).

Four Level III articles reported investigations that examined the perspectives of professionals delivering PC to people with dementia. These investigations explored barriers, the relationship between care quality and the caregivers' perspective of PC, and PC literacy following online instruction. Two studies were qualitative, and data collection focused on professionals' who are caregivers for patients with dementia or who have a background in PC research or policy making. Results indicate barriers include professional uncertainty towards systematization of PC, a disconnection between the many professionals who work with patients with dementia, different assumptions about training needs, questions about negotiation of risk in the palliative setting, and incorrect correlation of PC to terminal care (Davies et al., 2014; Nakanishi, Hirooka, Morimoto, & Nishida, 2017; McInerney, Doherty, Bindoff, Robinson, & Vickers, 2018; Carter, van der Steen, Galway, & Brazil, 2017).

In 2014, Vandervoort et al. examined the relationship between ACP and quality of death for nursing home residents with dementia. The cross-sectional study surveyed the primary nurse, general practitioner (GP), the most closely involved family member, and the nursing home administrator of deceased residents with dementia. Researchers found that residents with DNR and "do not hospitalize" orders experienced less emotional stress in the last weeks of life. When nurses discussed the desired direction of care in advance with a family member, the study found people with dementia had lower ratings of discomfort and other common end-of-life symptoms including restlessness, gurgling and dysphagia. The study concluded that nursing home residents with dementia who have written their care wishes experience a higher quality of death.

Teno et al. (2011) sought to determine the effectiveness of hospice services for patients with end-stage dementia. In this high-quality investigation, telephone surveys were conducted to measure family members' perceptions of quality of care. Families of decedents who received hospice services were 50% less likely to report unmet needs than those who did not receive hospice services. The timing of hospice service initiation is important, as families who reported that hospice services were received at "the right time" (not too early or too late) had higher ratings of quality of care (Teno et al., 2011, p. 1534).

In 2018, Chen and colleagues published an analysis of the relationship between PC and the use of life-sustaining treatments in patients with dementia with and without cancer. This high-quality investigation was conducted in Taiwan with a sample size of 5,988 patients and found that less than 2% of patients with dementia received PC, and that hospice services were typically limited to those patients in the active dying stage. Dementia patients with a dual diagnosis of cancer experienced the fewest life-sustaining treatments. Comparatively, patients with dementia, but without cancer, had decreased use of invasive respiratory treatments and cardiopulmonary resuscitation. The study concluded that patients without cancer are not as well recognized in the traditional paradigm of PC.

Poole et al. (2018) is the only qualitative investigation included in this review whose sample included actual patients with dementia. The study included 11 patients with early stage dementia who scored greater than 20 on the Mini Mental State Exam, a 30-question test used to measure cognitive impairment. Researchers also interviewed 25 family caregivers to determine the end-of-life care factors most important to people with early dementia. The study identified seven core aspects important to end-of-life care and found patients and families have divergent views in their perception of dementia as a palliative condition. Opposition between patients and their families can complicate future decision-making and undermine the delivery of optimal PC. The study concluded that patients and families require both practical and emotional support from

PC professionals and family physicians lack dementia training in the context of treatment decision-making.

Harrop, Nelson, Rees, Harris, and Noble’s 2018 study examined the effectiveness of The Challenge Project, a service model that includes a community PC nurse specialist and dementia support worker in South Wales. Health care professionals, current caregivers, and bereaved caregivers were surveyed in this good quality investigation. The researchers found innovative service models, like The Challenge Project, improve access to PC and advance the knowledge, confidence, and skills of caregivers and professionals. The involvement of a nurse or social worker serving as a dementia specialist helped improve understanding of the dementia disease trajectory and benefits of early PC.

Level IV evidence. One interpretive synthesis is categorized as Level IV and is focused on the management of end-of-life care for patients with dementia. The article reported on the lack of specificity about research questions and priorities related to PC and dementia. This review included a rapid appraisal of research published in 2010 and 2011 and identified a lack of information about caregivers of people with advance dementia and little discussion in the literature of person-centered care. The authors concluded that health and social care initiatives are influenced by research evidence and political pressure, and researchers are challenged to conduct research that is relevant to society and policy makers (Raymond et al., 2014).

Level V evidence. A study by van der Steen et al. (2016) identifying GPs perceptions of the barriers and solutions of PC for patients with dementia is the only Level V investigation included in the review. This five-round Delphi investigation found that controversy exists for GPs around bringing up end-of-life issues prematurely and their uncertainty about when to apply PC. GPs surveyed were concerned about the relabeling of dementia care as PC due to the public's association of PC with dying or abandoning care. The authors also identified the importance of considering which expertise is responsible for dementia care.

Strengths and Weakness of the Research Studies

All studies included in the matrix are of high or good quality according to the Johns Hopkins Guidelines which provide benchmarks for translation of evidence to guide individual patient and system-wide improvements (Dang & Dearholt, 2018). There are numerous studies on the barriers that affect delivery of PC for people with dementia. Many studies used a range of outcome measurements and several had participation rates of 50% or greater. These studies can guide development of evidence-based best practices and inform future studies.

Of the 18 studies, 10 collected data from surviving family members rather than patients themselves. This could be construed as weakness in the evidence for the population with dementia, however, it is a strength in the context of this review. Although families are not the recipients of hands-on care, they are critically important consumers in the setting of dementia and PC as they frequently serve as informal caregivers and proxy decision-makers.

The weaknesses of the reviewed studies included small sample sizes, limited generalizability, and selection bias. Each Level I study included less than 500 sample participants. The largest sample size was found in Level III evidence in Chen et al. (2018), where nearly 6,000 patients with dementia who received PC in Taiwan were studied.

The generalizability of studies included in the review is limited. Western culture is heavily represented as most studies were conducted in the United States, England, South Wales, Ireland and Australia. These countries have unique health care systems and applicability of their findings may be limited to similar cultures. Several studies were conducted within a single state within the United States. In two studies, patients had a dual diagnosis of cancer that was demonstrated to predispose professional caregivers to propose, and informal caregivers to accept, a palliative plan of care.

Selection bias is an additional weakness of studies in this review. Possible bias exists due to clinician awareness of a patient’s enrollment in a study. Also, informal caregivers who elect to hospitalize a person with dementia may be less likely to accept a palliative plan of care as they expect care to be curative in the hospital. In addition, there is limited baseline knowledge to determine effectiveness of PC because, in at least one study, the exact date of PC initiation was unknown.

Summary

Overall, the evidence reviewed indicates that like those with other terminal conditions, people with dementia and their caregivers may benefit from a palliative plan of care due to the interdisciplinary focus on QOL measures such as comfort. Patients and caregivers benefit most from PC interventions when ACP occurs in advance of acute need and when decline in health is recognized in a timely manner. There are limited objective measures to substantiate qualitative findings; data was most often derived from caregivers due to the limited ability of patients with dementia to participate in research. The major strength of the literature underscored the common barriers to delivering PC to people with dementia. The major weaknesses were the lack of robust research methodology including small sample sizes, selection bias and limited generalizability.

Chapter Four: Discussion, Implications and Conclusions

This critical review of the literature found that multiple factors contribute to the efficacy of a palliative plan of care in enhancing the QOL for patients with dementia and their informal caregivers. This chapter includes a synthesis of the literature describing those factors. Gaps and trends in the literature are discussed, along with nursing practice implications and recommendations for future research. Finally, Kolcaba's Comfort Theory is applied to the practice question.

Answer to Practice Question

The research question that guided this appraisal is as follows: does PC enhance QOL for people with dementia and their informal caregivers? This appraisal was important because dementia is the leading cause of disability and dependence in older people (Alzheimer's Association, 2018). In addition, people with dementia are at risk for medical overtreatment, and caregivers of people with dementia identify comfort as the primary goal of care, the priority in a palliative plan of care (van der Steen, 2010; Gallagher & Long, 2011).

Measurement of QOL is subjective and is difficult to measure for patients with dementia due to their limited ability to communicate in advanced stages of the disease. Consequently, many researchers have investigated the impact of PC on the dementia population by studying their informal caregivers. Several investigations representing these important proxy points of view were included in this literature review.

Most investigations included in this review offer positive, albeit conditional, support for the consideration of a palliative plan of care for patients with dementia. For example, Verreault et al. (2018) found LTC patients with dementia who received PC interventions experienced improved quality of care and quality of death compared to patients who did not. In addition, families of decedents who received hospice services, a form of PC, rated their quality of care higher and identified fewer unmet needs than families of similar patients who did not receive hospice services (Teno et al., 2011). PC must be thoughtfully introduced and applied for patients with dementia. An investigation by Carson et al. (2016) found higher post-traumatic stress disorder symptoms in decision-makers of patients who received a PC consultation. Van der Steen et al. (2016) recommended sensitivity when using the words ‘palliative care’ due to association with dying or abandoning care.

Trends and Gaps in the Literature

Trends.

All investigations characterized dementia as a terminal disease and recommended consideration of a palliative plan of care. A major trend discovered in the literature is that dementia should be treated as a life-limiting illness and therefore PC should be considered because it prevents and relieves suffering, which influences a person’s overall wellbeing. This is a major strength as it was the purpose of the critical review of the literature. This critical review identified several PC interventions that increase perception of QOL and quality of care.

Timely recognition of decline is essential. Another trend of the critical review is that people with dementia benefit most from PC when there is timely recognition of decline. This is a positive outcome for the relationship of PC to QOL. When PC begins at the appropriate time, patients and families feel supported and better able to manage health and wellbeing outside of the hospital.

Conversations about care goals should happen early. Sampson et al. (2011) found it is not optimal to perform ACP at the time of hospitalization, instead ACP should take a systematic approach. And, it must be realized that many people do not wish to make ACP despite the recommendation to do so. It is most appropriate to consider PC before the need for acute hospitalization arises, when goals can be established with less urgency. People experience less emotional distress at end-of-life if they have written their care wishes in advance (Vandervoort et al., 2014). In addition, decision aids are effective tools for seriously ill individuals and their families (Hanson et al., 2011).

Care and education delivered by an expert dementia nurse is more effective. When families receive education from a caregiver with expertise in dementia, they experience greater satisfaction with the care received and they better understand the natural evolution of advanced dementia and the PC option (Verreault et al., 2018). Many facilities and agencies caring for patients with dementia are plagued with high turnover and poorly qualified staff; specialized programs are needed to improve training for these caregivers (Davies, 2014).

Gaps.

There is limited high-quality evidence defining how PC influences QOL for people with dementia and their caregivers. Individual studies found data supporting improved QOL with PC for people with dementia. Two of the five Level I studies were limited to the study of populations with advanced life-limiting illness and were not specific to the dementia population. This is a gap in the critical review because, although timely recognition of decline and early conversations about care goals were found to increase the effectiveness of a palliative plan of care, the sample sizes were small and have limited generalizability to populations with dementia.

Another gap in this research was the selection bias present in several studies. Had there been less bias, more of the research would have received a stronger appraisal on the Johns Hopkins Research Evidence Appraisal Tool (Dang and Dearholt, 2018). Caregivers that hospitalize a person with dementia may be predisposed to curative treatment, which may have influenced outcomes in investigations conducted in acute care settings. Blinding was also limited in several investigations as families and clinicians were often unable to be blinded to interventions due to their close involvement in the plan of care.

Implications for Nursing

The literature demonstrated that there are specific factors that enhance the efficacy of PC for people with dementia and their informal caregivers. Implications for nurses include the need to provide improved education about the terminal nature of dementia, to understand the unique barriers to caring for people with dementia and their caregivers, and to identify the specific needs of informal caregivers to better target PC interventions.

Provide education about dementia as a life-limiting condition. Nurses need to educate patients and caregivers about the natural evolution of dementia. Disease progression is prolonged, and often occurs over the course of several years. Nurses play an important role in communicating with patients and families about disease trajectory and the dying process (Vandervoort et al., 2014). Both formal and informal caregivers may lack the experience and education needed to anticipate care needs and understand options for care. When caring for patients with dementia, nurses should shift the paradigm of care away from prolonging life and instead focus on the maximization of comfort through the course of the disease.

Nurses should be knowledgeable about the application of a palliative plan of care to patients with dementia and work in cooperation with GPs to systematically include ACP in conversations about dementia care. Nurses can support physicians in the discussion of end-of-life choices in advance of imminent death and establish a PC culture where ACP is encouraged.

Understand the unique barriers to dementia care. It is important for nurses to be knowledgeable about declines commonly experienced by patients with dementia as these limitations affect a person's ability to make decisions and direct their own care. In addition to cognitive declines, people with dementia often experience deterioration of their emotional control, social behavior, and motivation (World Health Organization, 2017). Patients and caregivers often vary in their perceptions of dementia as a palliative condition which complicates future decision-making and may undermine delivery of optimal care (Poole et al., 2018).

Nurses can advocate for care conferences which include the patient, informal caregiver, family, and health care team. Care conferences may improve care through identification of needs, discussion of ACP, and coordination of the interdisciplinary team. Nurses should work with GPs to develop a standardized PC referral tool for professional caregivers, and a decision aid for informal caregivers.

Identify specific needs of informal caregivers. This critical review identified specific interventions that bolster the efficacy of PC for people with dementia. One of the most impactful interventions can be accomplished by the nurse who helps informal caregivers identify their specific needs when caring for a person with dementia. PC interventions are likely to improve QOL if they are targeted to the specific needs (Carson et al., 2016). Supporting patients and caregivers in their transition from fully disease-focused care to fully comfort care can help caregivers better manage symptoms, avoid hospitalization, and reduce health care costs (Cassel et al., 2016). Informal caregivers require physical and emotional support as they care for the person with dementia. Nurses are in a unique position to both identify needs and provide support through available resources.

Recommendations for Nursing Research

As nurses consider the future of dementia care, it is important to further examine the role PC could play in improving QOL. High-quality investigations of large populations are needed in multiple countries to inform nurses of the needs of people with dementia and their caregivers and to identify how needs differ culturally. In addition, research is needed to understand how to improve dementia palliative literacy at the public health level to promote awareness of the trajectory of dementia and the PC option.

Future research is required to better understand the concerns of people with dementia and their caregivers, explore their views about QOL, and determine how PC can best support their care goals. Current research recommends integration of ACP into dementia care and future research can help nurses determine how to accomplish this (Sampson et al., 2011; Vandervoort et al., 2014; Chen et al., 2018; Poole et al., 2018). The effectiveness and value of the PC service model should also be investigated to accurately measure patient and caregiver satisfaction and understand the cost of PC.

Given the unique barriers and prolonged disease trajectory of dementia, there is a need to reexamine treatment approaches. Future investigations should examine how patients with dementia are cared for and how to best integrate PC with other expertise in a manner that promotes open communication about a dementia diagnosis, prognosis, and care between the disciplines.

Finally, research is needed to better understand professional perspectives about delivering quality PC to people with dementia. Current research has only identified barriers related to uncertainty about disease trajectory and when to initiate a PC conversation (Davies et al., 2014). Additional research is needed to understand how to address the needs of the wide variety of professionals and informal caregivers involved in delivering dementia care.

Integration of Theoretical Framework

Kolcaba's Comfort Theory was the theoretical framework utilized in this literature review because its holistic depiction of comfort closely aligns with the WHO palliative care definition which includes identification, assessment, and treatment of a person's physical, psychosocial, and spiritual needs to improve QOL (WHO, 2018).

Comfort Theory, a middle-range nursing theory first published in 1991, holistically depicts comfort in four experiential contexts: physical, psychospiritual, environmental, and sociocultural. Kolcaba posits that three types of comfort occur physically and mentally: relief, ease, and transcendence (Kolcaba, 2013). When Kolcaba's three types of comfort and four contexts of experience are considered together, attributes of comfort can be defined for the individual and they can achieve greater comfort.

This literature review identified that people with dementia are often subject to burdensome interventions that jeopardize comfort and their informal caregivers often lack the support and education required to identify and communicate comfort needs. The framework provided by Comfort Theory is an opportunity for nurses and other formal caregivers to introduce and approach this important work using language that is familiar, relatable, and effective for dementia patients and their informal caregivers.

Comfort Theory predicts that when a person is more comfortable, they will consciously or unconsciously engage in health-seeking behaviors (Kolcaba, 2013). For patients with dementia, actions may include expressing their wishes and concerns, spending time doing activities that bring comfort, spending time with people who bring comfort, and engaging in activities that promote symptom management such as positioning and oral care. For informal caregivers, actions may include expressing their wishes and concerns, having reliable respite care available to allow time for activities that bring comfort, and confidently participating in care decisions or hands-on care that effectively manages symptoms for the person with dementia.

Comfort Theory also conceptualizes that a good death is a health-seeking behavior. A good death occurs when symptoms are managed, conflicts are resolved, and dignity is protected (Kolcaba, 2013). When death is perceived as peaceful, and the individual and the family have found acceptance of death, QOL is validated.

Summary

This critical review of the literature includes evidence that supports the use of PC to improve QOL for people with dementia and their informal caregivers. Trends and gaps in the literature were identified along with implications for nursing practice and future research. As the world's population ages and the rate of dementia rises, it is critical to continue the investigation of PC as a plan of care that aligns health care with patients' wishes and supports caregivers. Kolcaba's Comfort Theory provides a holistic framework that helps nurses better utilize PC to address the multidimensional needs of people with dementia and their caregivers and improve QOL.

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Table

Evidence-Based Interventions for Dementia Palliative Care

Early Interventions	Later Interventions
Recognize dementia as life-limiting condition	Systematically screen for pain
Educate about natural dementia progression	Provide routine oral care
Identify needs of patient and caregiver	Organize care conferences on routine basis
Initiate conversations beyond DNR decision	Make timely referral to hospice services
Recommend palliative care consultation	
Support systematic advanced care planning	
Provide coaching by expert dementia nurse	
Use decision aids	
Provide practical and emotional support	

Appendix: Evidence Synthesis Matrix

Source: Abernethy, A. P., Currow, D. C., Shelby-James, T., Rowett, D., May, F., Samsa, G. P., Hunt, R., Williams, H., Esterman, A., & Phillips, P. A. (2013). Delivery strategies to optimize resource utilization and performance status for patients with advanced life-limiting illness: Results from the "Palliative Care Trial." *Journal of Pain and Symptom Management, 45*(3), 488-505.

Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
Purpose: Determine if palliative care (PC) is improved by better care coordination, optimization of function and comfort **Sample/Setting:** 461 adults with advanced life-limiting illness, pain, median baseline Australian-modified Karnofsky Performance Status (AKPS) score of 60 South Australia **Johns Hopkins Evidence Appraisal** **Level of Evidence:** I **Quality:** High	Randomized Control Trial (RCT) 3 simultaneous comparative randomized studies randomized to: 1. Individualized interdisciplinary case conference (n=167) 2. Education outreach for general practitioners (GPs) about pain management (n=230) 3. Structured educational visits for patients and caregivers about pain management (n=214) **Instruments:** AKPS Brief Pain Inventory	Case conference reduced hospitalizations by 26% (p=0.0069), better maintained performance status by 10% on AKPS scale (p=0.00368) Case conferences, patient/caregiver education maintained better performance status in patients with declining function (AKPS <70) (p=0.0143) **Conclusion:** Case conferences reduced hospitalization, maintained patients' functional status more so than specialist PC alone	**Strengths:** Randomized to three interventions Large sample size **Limitations:** Most patients had cancer diagnosis and lived in metropolitan area limiting generalizability Median survival was short at 179 days

Author Recommendations: Patients benefit most from PC when there is timely recognition of decline. When life-limiting illness is diagnosed, PC should be recommended.

Implications: Determine most effective elements of case conferencing and incorporate into PC best practices. Future research is needed to understand better ways to standardize PC referral data sets.

<table>
<tr><td colspan="4">Source: Ahronheim, J., Morrison, R., Morris, J., Baskin, S., & Meier, D. (2000). Palliative care in advanced dementia: A randomized controlled trial and descriptive analysis. <i>Journal of Palliative Medicine, 3</i>(3), 265-273.</td></tr>
<tr><th>Purpose/Sample</th><th>Design (Method/Instruments)</th><th>Results</th><th>Strengths/Limitations</th></tr>
<tr>
<td>Purpose: Determine if PC enhances comfort of patients with advanced dementia

Sample/Setting: Adults admitted to hospital with advanced dementia per score of 6d-7f on Reisberg Functional Assessment STaging (FAST) (n=99)

Intervention: Received PC consult, daily discussion with palliative team, meetings with patients’ surrogate (n=48)

Control: Usual treatment by primary care team (n=51)

New York

Johns Hopkins Evidence Appraisal

Level of Evidence: I

Quality: Good</td>
<td>RCT

Data gathered from patients’ charts

Instruments: FAST</td>
<td>Intervention patients more likely to receive PC plan, usually on discharge (p=0.008)

Intervention patients slightly less likely to receive IV therapy (p=0.025)

No significant impact on number of hospitalizations, average length of stay, mortality, use of specific treatments (i.e., cardiopulmonary resuscitation (CPR) in hospital p=0.65)

Conclusion: Consultation model of hospital PC does not change physician practice in hospital</td>
<td>Strengths:
RCT

Research assistant blinded to randomization

3-year study

Limitations:
Possible selection bias as families that chose to hospitalize relative with dementia may be predisposed to curative treatment

Data reflected only time since randomization when patients were hospitalized (average 1 week) and had established plan of care

Small sample size</td>
</tr>
<tr><td colspan="4">Author Recommendations: Identify patients prior to need for acute hospitalization when goals can be established with less urgency. Approach advanced dementia as an end-stage illness.</td></tr>
<tr><td colspan="4">Implications: Difficult to influence care of advanced dementia patients in hospital. Need to reexamine treatment approaches for patients with dementia given their unique barriers.</td></tr>
</table>

Source: Carson, S. S., Cox, C. E., Wallenstein, S., Hanson, L. C., Danis, M., Tulsky, J. A., Chai, E., & Nelson, J. E. (2016). Effect of palliative care-lead meetings for families of patients with chronic critical illness: A randomized clinical trial. *Journal of the American Medical Association, 316*(1), 51-62. doi: 10/1001/jama.2016.8474

Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Evaluate if family anxiety and depression are improved after participation in support meetings lead by PC clinicians **Sample/Setting:** Family surrogate decision makers related to 156 chronically ill patients age >=21 years who required >=7 days mechanical ventilation Intervention group (n=184) Control group (n=126) 4 medical intensive care units (ICUs) in Southeast U.S. **Johns Hopkins Evidence Appraisal** **Level of Evidence:** I **Quality:** High	Single-blind RCT Randomization stratified by study site **Instruments:** Hospital Anxiety and Depression Scale (HADS) Impact of Event scale (to measure Post-Traumatic Stress Disorder [PTSD]) Family Satisfaction in the ICU survey Hospital days 90-day survival	No significant difference found in anxiety and depression symptoms in decision makers (p=0.34) PTSD symptoms higher in intervention group (p=0.0495) Patients/families in intervention group had median of 4 less hospital days than control group (p=0.51) No significant difference in 90-day survival rate (p=0.96) **Conclusion:** Findings do not support routine PC-lead discussion of goals for all families of patients with chronic critical illness	**Strengths:** Randomized design in multiple hospitals Research personnel blinded to study group allocation **Limitations:** Unable to blind families to intervention

Author Recommendations: Palliative consultation may be more effective for challenging cases or when assistance needed for symptom management or disposition planning. When families get adequate support from primary medical team, additional focus on prognosis may not help and could further upset a distressed family.

Implications: Routine allocation of PC resources may be ineffective. Identify specific needs of family decision makers to better target PC interventions.

Source: Carter, G., van der Steen, J. T., Galway, K., & Brazil, K. (2017). General practitioners' perceptions of the barriers and solutions to good-quality palliative care in dementia. *Dementia, 16*(1), 79-95. doi:10.1177/1471301215581227			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Determine perceptions of GPs in regard to barriers and solutions to providing good-quality PC to people with dementia **Sample/Setting:** Cluster sampling using Quality and Outcomes Framework (QOF) data GPs in 174 practices caring for patients with dementia (n=340) Northern Ireland **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good	Non-experimental descriptive, pre-tested survey design using hermeneutic phenomenology qualitative design Thematic analysis of barrier statements and solutions **Instruments:** Postal survey "Care for Dementia Patients at the End of Life" Questions from European Association for Palliative Care (EAPC)	Identified five barriers: 1. Lack of knowledge, understanding, skills, education, training deficiencies 2. Limited availability of resources, lack of time, difficulty accessing community staff, resources, funding 3. Mismanagement of appropriate care, lack of standard guidelines, inability to recognize end-stage patients 4. Poor interdisciplinary team approach, inconsistent support 5. Family support and involvement, lack of respite care, difficulty discussing prognosis, unrealistic expectations **Conclusion:** Improved public awareness, enhanced training and education in the health care industry, and promotion of family involvement are essential to overcoming barriers to providing good-quality PC to people with dementia	**Strengths:** Strong participation at practice level (60.9%) **Limitations:** Sample limited to Northern Ireland Survey layout may have guided respondents' thinking Low individual GP response rate (40.6%)
Author Recommendations: Improved health care training and education, enhanced public awareness, and family involvement is crucial to improving the quality of PC for people with dementia. Future research should study replication of views in broader population.			
Implications: GPs and families play central roles in the care of people with dementia. Substantial multidisciplinary support is vital. Interventions to promote GPs knowledge and skills is important to match the complex requirements of dementia.			

Source: Cassel, J. B., Kerr, K. M., McClish, D. K., Skoro, N., Johnson, S., Wanke, C., & Hoefer, D. (2016). Effect of a home-based palliative care program on healthcare use and costs. *Journal of the American Geriatrics Society, 64*(11), 2288-2295.

Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
Purpose: Evaluate nonclinical outcomes of proactive multidisciplinary PC program (Transitions) for Medicare Advantage plan beneficiaries **Sample/Setting:** Propensity-based matching of patients with cancer, chronic obstructive pulmonary disease (COPD), heart failure (HF) or dementia with 2 years of usage data Intervention group received home- and clinic-based PC provided by interdisciplinary team (n=368) Control group (n=1,075) Southern California **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** High	Observational, retrospective chart review of medical records, billing and claims data Closed-ended 7 question survey of participants' experiences with program **Instruments:** Cochran-Mantel-Haenszel method used to compare groups Generalized estimating equations (GEE) to analyze number of hospitalizations GEE Poisson regression used to analyze of readmissions	In each disease studied, patients who received intervention had: 1. lower hospital costs and total costs per month (p=<0.002) 2. fewer hospitalizations and number of hospital days (p=<=0.001) 3. fewer hospital admissions in last 30 days of life (p=<0.001) 4. were less likely to die in hospital (p=<0.001) • Mean 30-day readmission rate was lower for intervention patients with dementia (p=0.01), COPD (p=0.005) and HF (p=<0.001) • Net Medicare savings average of $2,690/month for intervention patient with dementia **Conclusion:** Proactive palliative care program helped to avoid hospital use, lower costs commonly associated with final months of life	**Strengths:** Diseases studied represent a mixture of disease trajectories Large sample size **Limitations:** Possible selection bias due to study design Study limited to Medicare Advantage beneficiaries in single health care system Costs captured included health system costs and excluded some nonchemotherapeutic pharmacy costs and out-of-pocket costs Clinical outcomes not measured

Author Recommendations: Introduce PC earlier in disease course to reduce health care costs and help patients and families manage disease outside of hospital. Future research should include study of interplay between various forms of care and transition to hospice, and the relationship between clinical outcomes and positive financial return.

Implications: Programs designed to support transition of care from fully diseased-focused to fully comfort care (hospice) can be successful in lowering costs, helping patients and families manage symptoms, medications, complete advanced care planning (ACP), reduce hospitalization and ED visits.

Source: Chen, P., Liang, F., Ho, C., Cheng, S., Chen, Y., Chen, Y., & Chen, Y. (2018). Association between palliative care and life-sustaining treatments for patients with dementia: A nationwide 5-year cohort study. *Palliative Medicine, 32*(3), 622-630.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Analyze the use of palliative care and association with use of life-sustaining treatments between patients with dementia with and without a co-diagnosis of cancer **Sample/Setting:** Patients with dementia who received palliative care between 2009 and 2013 (n=1996) Comparative cohort (n=3992) Taiwan **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** High	Population-based matched cohort study Conditional logistic regression analysis **Instruments:** Charlson Comorbidity Index	Rate of PC use for patients with dementia was 1.64%, services limited to end-of-life (EOL) stage Dementia patients with PC had decreased use of invasive respiratory treatments and CPR, increased use of enteral tube insertion, non-invasive ventilator use Dementia patients with cancer and PC experienced significantly fewer life-sustaining treatments **Conclusion:** Patients without cancer are less well recognized in the traditional paradigm of PC	**Strengths:** National population-based approach Large study sample Comparative analysis matched for multiple factors **Limitations:** Absence of information on disease severity and functional status Exact date of PC initiation unknown Potential for under-reporting of symptoms due to patients' poor communication capacity
Author Recommendations: Shift paradigm for initiating palliative care in non-cancer patients from survival prediction to maximization of comfort through course of disease. Initiate ACP early for dementia patients. Improve awareness on the terminal nature of dementia. Improve public education about PC. Utilize randomized trials to evaluate the effectiveness of PC in reducing life-sustaining treatments.			
Implications: National Institute of Health eligibility criterial for PC are not applicable for patients with dementia. Withholding or withdrawing life-sustaining treatment is emotionally challenging especially for those without cancer who are less likely to be identified as terminally ill.			

Source: Davies, N., Maio, L., Vedavanam, K., Manthorpe, J., Vernooij-Dassen, M., & Iliffe, S. (2014). 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, 22*(4), 386-394. doi:10.1111/hsc.12094			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Determine professional perspectives about barriers to delivering quality PC to people with dementia **Sample/Setting:** 21 interviews: 2 group interviews (n=7, n=6) Individual interviews (n=16) Pairs of professionals with background in PC, dementia, PC research and policy making (n=5) England **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** High	Qualitative hermeneutic phenomenology design to identify patterns, themes from interpretation of professionals' perspectives Semi-structured interviews	Barriers relate to uncertainty about disease trajectory A wide-range of professionals work with patients with dementia in variety of care settings **Conclusion:** Four barriers exist to providing quality PC to people with dementia: 1) uncertainty towards systematization of PC 2) disconnection between services 3) different assumptions about training needs 4) negotiation of risk	**Strengths:** Included respondents from a variety of professions and care settings **Limitations:** Small sample size Study conducted in country with unique health care system Not all job roles included (e.g., social work, regulators)
Author Recommendations: Training for staff working with patients with dementia should address confidence, fear, skill development. Unique programs are necessary to address needs of caregivers in nursing homes and home care as they are the least educationally qualified and experience high levels of staff turnover.			
Implications: It is important to identify characteristics of practitioners, care settings and interdisciplinary support systems that support quality care.			

Source: Hanson, L. C., Carey, T. S., Caprio, A. J., Lee, T. J., Ersek, M., Garrett, J., Jackman, A., Gilliam, R., Wessell, K., & Mitchell, S. L. (2011). Improving decision-making for feeding options in advanced dementia: A randomized, controlled trial. *Journal of the American Geriatrics Society, 59*(11), 2009-2016.

Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Determine if decision aid improves quality of decision-making about feeding options for patients with advanced dementia **Sample/Setting:** Residents with advanced dementia and their surrogate decision-makers (n=256) Intervention group received audio or print decision aid on feeding options in advanced dementia Control group received usual care Nursing homes in North Carolina (n=24) **Johns Hopkins Evidence Appraisal** **Level of Evidence:** I **Quality:** Good	Partially-blind cluster RCT using: • In-person interviews with trained research assistants at enrollment • Phone interviews at 1 and 3 months • Chart reviews for follow-up on tube-feeding, weight loss, mortality at 6 and 9 months **Instruments:** Cognitive Performance Scale in the Minimum Data Set (MDS) Global Deterioration Scale Decisional Conflict Scale Expectation of Benefit Index Satisfaction with Decision Scale Decisional Regret Index	Surrogate decision-makers demonstrated: • Improved Expectation of Benefit Index score (p=0.001) • Lower Decisional Conflict Scale scores than controls (p=0.001) after 3 months • Increased likeliness to discuss feeding options with provider (p=0.04) Intervention residents more likely to receive dysphagia diet (p=0.04) and eating assistance (p=0.08) Tube feeding rare in both groups: intervention (n=1) and control (n=3) (p=0.34) **Conclusion:** When decisional aid is used, surrogates experienced reduced decisional conflict, increased knowledge, and more communication about feeding options with providers	**Strengths:** Partially-blind study design over 9-month period **Limitations:** Cluster randomization prevented double-blinding Possible bias due to clinician awareness that residents were enrolled in a trial addressing feeding options in dementia Research sites were within a single state

Author Recommendations: Decision aid interventions should support rather than replace communication with medical providers. Effectiveness of decision aids may be enhanced by clinical education. Future research should test the effectiveness of decision aids for seriously ill individuals and their families.

Implications: The use of decision aids is feasible and may reduce conflict and facilitate informed decision-making for a variety of healthcare choices. The effectiveness of decision aids can be enhanced by combining them with improved provider engagement and face-to-face communication.

Source: Harrop, E., Nelson, A., Rees, H., Harris, D., & Noble, S. (2018). The challenge pathway: A mixed methods evaluation of an innovative care model for the palliative and end-of-life care of people with dementia (innovative practice). *Dementia, 17*(2), 252-257.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Examine effects of new service model (The Challenge Project) on perceived quality of care (QOC) for patients with dementia; model included community PC nurse specialist and dementia support worker **Sample/Setting:** Healthcare professionals (n=20) Current caregivers (n=9) Bereaved caregivers (n=6) South Wales **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good	Mixed-methods approach **Instruments:** Surveys with open and closed questions Semi-structured interviews	75% increase in referrals of patients with dementia to the PC team (n=77) compared to the pre-project year (n=44) 69% of family caregivers state project lead to improvements in their knowledge, confidence, practical skills 70% of professionals rate project as ‘extremely helpful’ (n=13) or ‘quite helpful’ (n=1); specifically: creation of interdisciplinary care plans and ACPs, helping patients remain in preferred place for care, quality education, improved understanding of disease trajectory, benefits of early PC **Conclusion:** Innovative service models improve access to PC, advance knowledge, confidence, skills of caregivers and professionals	**Strengths:** Mixed methods approach **Limitations:** Small sample size and low number of survey responses limit generalizability Limited baseline data make it difficult to determine influence of project
Author Recommendations: Provide comprehensive training and education to health and social care professionals. Provide structured practical, educational and emotional support to caregivers. Future research should include more rigorous assessment of effectiveness and value of palliative service model.			
Implications: Involvement of a dementia specialist (nurse or social worker) can improve the knowledge, confidence and care skills of families and professional caregivers and help patients with dementia receive needed palliative services prior to EOL.			

Source: McInerney, F., Doherty, K., Bindoff, A., Robinson, A., & Vickers, J. (2018). How is palliative care understood in the context of dementia? Results from a massive open online course. *Palliative Medicine, 32*(3), 594-602.

Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
Purpose: Explore participants' literacy of PC at the end of online course about dementia **Sample/Setting:** Participant data from "Understanding Dementia Massive Open Online Course" 2014-2016 (n=1330) Participants were caring formally or informally for a patient with dementia or had a general interest in dementia **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good	Qualitative survey of students in online course Thematic analysis of open-ended response using topic modeling analysis **Instruments:** On-line survey 1-item short answer question: "Palliative care means…"	Course participants had general familiarity with traditional PC concepts Course participants had lack of awareness of relevance of PC for people with dementia Students did not discuss three themes relevant to PC: 1. Symptom relief 2. Multidisciplinary team 3. Holism **Conclusion:** Course participants incorrectly viewed PC as terminal care, and primarily correlated comfort with pain management	**Strengths:** Large international sample **Limitations:** Study data limited to one short answer response

Author Recommendations: Caregivers need improved PC education. Dementia palliative literacy needs to improve at the public health and policy level. Develop an evidence base for the role of PC for patients with dementia. Future research should include direct assessment of participant understanding and experiences of the relationship between PC and dementia.

Implications: There is a lack of awareness about how the PC approach could contribute to dementia care. Terminal care is only part of what PC can offer to patients and families. Dementia palliation health literacy may be improved through public health education and health care provider curricula.

Source: Nakanishi, M., Hirooka, K., Morimoto, Y., & Nishida, A. (2017). Quality care for people with dementia and professional caregivers' perspectives regarding palliative care in Japanese community care settings. *International Journal of Geriatric Psychiatry, 32*(12), 1342-1351.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Examine association between care quality and professional caregivers' perspectives regarding PC for patients with dementia **Sample/Setting:** Survey of 2,116 professional caregivers from 329 agencies about 3,603 people with dementia Home- and community-based settings under public long-term care insurance program Tokyo, Japan **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good	Cross-sectional paper-based questionnaire using 3 verified instruments **Instruments:** Japanese Quality of Life Instrument for Older Adults (QLDJ) to assess professional caregivers' knowledge and attitudes Cognitive Performance Scale (CPS) Activities of Daily Living Self-Performance Assessment Scale (ADL-H)	Lower levels of PC knowledge for employees of in-home or long-term care (LTC) (p=0.0110) compared to small-scale, multiple home care providers, group homes (p=0.001) Frequency of physical restraint use did not differ between patients treated with/without antipsychotics (p=0.080) Caregiver attitudes towards practicing PC in group homes was more positive (p=0.030) to those observed in in-home or LTC care (p=0.006) **Conclusion:** Positive association between dementia care quality and perspectives regarding PC for patients with dementia	**Strengths:** Measured professional caregivers' knowledge and attitudes regarding PC for dementia in relation to care quality **Limitations:** Cross-sectional design does not provide causal model of caregivers' views and dementia care quality Low response rate (25.6%) Possible sampling bias Staff ratings for quality of life (QOL) may differ from those of patients
Author Recommendations: A national strategy for advocacy and protection of adults is needed to integrate laws and guidelines to prevent the use of antipsychotics as a form of chemical restraint in patients with dementia. Future research should explore behavioral mechanisms, other than physical restraint and antipsychotic medication, and explore patients' and family's views on QOL and preferences in relation to PC and dementia.			
Implications: A focused educational approach is important to improving QOC for patients with dementia. Caregiving staff should be trained to use psychosocial interventions as the first-line treatment for challenging behavior.			

<table>
<tr><td colspan="4">Source: Poole, M., Bamford, C., McLellan, E., Lee, R. P., Exley, C., Hughes, J. C., & Harrison-Dening, K., & Robinson, L. (2018). End-of-life care: A qualitative study comparing the views of people with dementia and family carers. <i>Palliative Medicine, 32</i>(3), 631-642.</td></tr>
<tr><th>Purpose/Sample</th><th>Design (Method/Instruments)</th><th>Results</th><th>Strengths/Limitations</th></tr>
<tr>
<td>Purpose: Investigate EOL care factors important to people with dementia and family caregivers

Sample/Setting:
People with early stage dementia, (diagnosed within last 3 years and Mini Mental State Examination Score >20) (n=11)

Family caregivers (current and bereaved) (n=25)

England

Johns Hopkins Evidence Appraisal

Level of Evidence: III

Quality: Good</td>
<td>Qualitative approach using open-ended interviews, semi-structured interviews, focus groups

Instruments:
Q-sort exercise to seek views on important EOL factors prior to interviews</td>
<td>Identified 7 core aspects important to EOL care:
1. Remaining in preferred place
2. Ensuring comfort, minimizing distress
3. Skilled care team
4. ACP
5. Faith in family members
6. Trust in professionals
7. Care coordination
Patients and caregivers shared importance of aspects #1-3 and had divergent views on #4, #5, #7 and core competencies/skills needed by care providers to delivery good EOL care

Conclusion: Patients and families vary in their perceptions of dementia as a palliative condition complicating future decision-making and undermining delivery of optimal palliative care</td>
<td>Strengths:
Sought views of people with dementia themselves rather than proxy views of relatives after patients' death

Sought views of both current and bereaved carers

Limitations:
Topics discussed during Q-sort exercises may have influenced responses

Limited generalizability to people with advanced dementia and to greater population</td>
</tr>
<tr><td colspan="4">Author Recommendations: Engage in proactive ACP utilizing expert dementia nurses. Avoid overly aggressive, burdensome, futile treatments. Provide uninterrupted care, good communication, avoid transfer of setting. Improve dementia training for family physicians. Examine effectiveness of PC assessments in dementia. Identify EOL views of people at various stages of dementia. Determine how to integrate ACP into dementia care.</td></tr>
<tr><td colspan="4">Implications: People with dementia and family caregivers may not share views on aspects most important to achieving good EOL care. Patients and families need both practical and emotional support from professionals.</td></tr>
</table>

Source: Raymond, M., Warner, A., Davies, N., Nicholas, N., Manthorpe, J., & Iliffe, S. (2014). Palliative and end of life care for people with dementia: Lessons for clinical commissioners. *Primary Health Care Research & Development,* (15), 406-417.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Summarize information about management of EOL care for patients with dementia to construct theories grounded in research and generate practical methods to evaluate these effects **Sample/Setting:** Search of electronic databases of English-language, peer-reviewed journal articles published 2010-2011 using broad terms related to PC and dementia (preliminary search yielded n=6,167 papers) Titles and abstracts read by 2 authors and included in study if they were literature reviews of PC or EOL care as a process (n=36) **Johns Hopkins Evidence Appraisal** **Level of Evidence:** IV **Quality:** Low	Rapid appraisal Critical interpretive synthesis Titles and abstracts read by 2 authors and included if they were literature reviews of palliative or EOL for patients with dementia in any care setting at any age **Instruments:** 10 criteria for assessing the scientific quality of research reviews	Research lacks information about caregivers of people with advance dementia and their experience with proxy decision-making Little discussion in literature of person-centered care Family and professional caregivers lack education on PC and dementia **Conclusion:** There is a lack of specificity about research questions and priorities related to PC and dementia	**Strengths:** Methodology promotes debate about practical actions **Limitations:** Not a systematic review Review included 8 papers Authors' review was subjective
Author Recommendations: PCPs can influence the future of PC for people with dementia by participating in interventions-based research. Future research should include larger studies of people with dementia from diverse backgrounds and should follow participants to EOL. Research is needed to clarify what care homes need to improve EOL care for their patients with dementia.			
Implications: In addition to research evidence, political pressure, ideological stance and the need to act all influence health and social care initiatives. Researchers are challenged to conduct research that is relevant to society and policy makers.			

Source: Sampson, E. L., Jones, L., Thuné-Boyle, I. C., Kukkastenvehmas, R., King, M., Leurent, B., Tookman, A., & Blanchard, M. R. (2011). Palliative assessment and advance care planning in severe dementia: An exploratory randomized controlled trial of a complex intervention. *Palliative Medicine, 25*(3), 197-209. doi:10.1177/0269216310391691

Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
Purpose: Assess feasibility of implementing two-component intervention to improve EOL care for people with advanced dementia **Sample/Setting:** Patients age >=70 years with advanced dementia (FAST >=6d) and their caregivers and unplanned hospital admission for treatable acute illness (n=33) Intervention: PC assessment, ACP, discussion with caregiver lead by nurse specialist (n=22) Control: usual care (n=11) **Johns Hopkins Evidence Appraisal** **Level of Evidence:** I **Quality:** Good	Pilot RCT Random allocation by independent statistician Themes identified, extracted, analyzed using Medical Research Council (MRC) Complex Interventions Framework Measured at baseline, 6 weeks, 6 months, 3 months following bereavement **Instruments:** FAST Kessler Distress Scale Decision Satisfaction Inventory Client Satisfaction Questionnaire Euroqol-5D Satisfaction with End of Life Care in Dementia Scale (if patient died)	Palliative interventions not easily added to routine hospital care Information about function prior to hospitalization not always available Complex reasons for not making ACPs: family dynamics and unwillingness to address EOL issues **Conclusion:** Specific staff role may be necessary to address PC needs	**Strengths:** Used range of outcome measures **Limitations:** High drop-out rate (n=20) Difficulty accessing GP records to document care received at EOL

Author Recommendations: Specific staff role needed for patient assessment and PC discussion with caregiver. ACP should be done before patients lose mental capacity. More evidence is needed on the benefits of ACP developed by people with dementia before they lose capacity.

Implications: It is not optimal to perform ACP at time of hospitalization. A systematic approach to ACP may be more effective than individual approach. Older people who view video of person with dementia are more likely to include comfort in their plan of care. Many people do not wish to make ACPs despite recommendation to do so.

Source: Teno, J. M., Gozalo, P. L., Lee, I. C., Kuo, S., Spence, C., Connor, S. R., & Casarett, D. J. (2011). Does hospice improve quality of care for persons dying from dementia? *Journal of the American Geriatrics Society, 59*(8), 1531-1536.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Examine effectiveness of hospice services for patients with end-stage dementia from the perspective of bereaved family members **Sample/Setting:** Random sample of 1,111 death certificates from 5 states (AL, FL, TX, MA and MN) listing leading cause of death as dementia 770 family members were located, 545 (70.8%) participated in survey (of those participants, 260 (48.2%) received hospice services) **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** High	Secondary analysis of mortality follow-back survey **Instruments:** Telephone survey measuring family member perceptions of quality of care included: 1) 8 core items based on conceptual model of Family Evaluation of Hospice Care (FEHC) survey • Desired amount of physical comfort (2 items) • Received information on what to expect (3 items) • Desired emotional support (2 items) • Treated person with respect (1 item) 2) QOC (4 items) using 0-10 Likert scale 3) Quality of Death (QOD) using 1-10 Likert scale	Families of decedents who received hospice services were 51% less likely (CI=0.33-0.74) to report unmet needs, concerns with QOC compared to families of decedent who did not receive hospice services Families of decedents who received hospice services "at the right time" (not too early or too late) had higher ratings of QOC (CI=1.69-3.13) Receiving hospice services increased scores for peacefulness of dying (p=0.004) and QOD (p=0.008) **Conclusion:** Receipt of hospice services results in family perception of higher QOC, fewer unmet needs, and better QOD	**Strengths:** Survey measured satisfaction of surviving family members who are important consumers in EOL care **Limitations:** Survey relied on family member perception of care, patient perception not measured Sample drawn from only 5 states Potential sample bias, only cases in which physician recognized dementia as cause of death were studied Satisfaction rating scales may not be reliable when studying QOC
Author Recommendations: Timely referral to hospice services is important to improve quality of care and reduce unmet needs. Future surveys should ask factual questions, rather than rely on satisfaction measures to more accurately measure QOC. Medicare should continue payment for hospice services for nursing home residents who are dying of progressive, chronic illnesses such as dementia.			
Implications: Consumer perceptions are an important measurement of whether care is patient- and family-centered. Receiving hospice services "at the right time" influences family's perception of QOC. Bereaved family members of decedents with dementia report higher QOC and QOD when hospice services were received.			

Source: van der Steen, J. T., Radbruch, L., de Boer, M. E., Jünger, S., Hughes, J. C., Larkin, P., Gove, D., Francke, A., Koopmans, R., Firth, P., Volicer, L., Hertogh, C., & European Association for Palliative Care (EAPC). (2016). Achieving consensus and controversy around applicability of palliative care to dementia. *International Psychogeriatrics, 28*(1), 133-145. doi:10.1017/S104 1610215000824			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Identify GPs' perceptions of barriers and solutions to provision of quality PC in patients with dementia **Sample/Setting:** International panel of experts including: clinical practice professionals who provide PC to dementia patients, policy makers, and researchers (n=64) **Johns Hopkins Evidence Appraisal** **Level of Evidence:** V **Quality:** High	5-round Delphi study Ordinal regression analyses Instruments: Round 1: Core domains with relevant recommendations developed by group from 6 countries (n=12) Rounds 2 & 3: 27 countries evaluated domains and recommendations in online survey (n=89) Round 4: Decisions by core team Round 5: Input from EAPC Board and member associations	PC benefits patients with dementia based on the terminal nature of the disease Distinguish stages of dementia to target appropriate application of PC **Conclusion:** Controversy exists around: bringing up end-of-life issues prematurely, when to apply PC, and relabeling of dementia care as PC	**Strengths:** No evidence of response bias Delphi design helpful to identify controversies and improving guidance **Limitations:** Small sample size Applicability perhaps limited to western culture
Author Recommendations: Monitor benefits/drawbacks of early application of PC. Examine concerns about labeling care as "palliative." Study how to integrate PC with other expertise. Develop innovative solutions for practitioners that promotes open communication about dementia, prognosis and care needs between disciplines.			
Implications: Sensitivity is required when using the words "palliative care" due to association with dying or abandoning care. It is important to consider which expertise is responsible for dementia care.			

Source: Vandervoort, A., Houttekier, D., Vander Stichele, R., van der Steen, J., & Van den Block, L. (2014). Quality of dying in nursing home residents dying with dementia: Does advance care planning matter? A nationwide postmortem study. *PLoS One, 9*(3), e91130.

Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Examine the extent to which ACP relates to the quality of dying for nursing home residents with dementia **Sample/Setting:** Nursing homes, Flanders, Belgium (n=69) Deceased nursing home residents diagnosed with dementia (n=101), questionnaires sent to resident's: 1. Primary nurse (response rate 88.4%) 2. GP (response rate 52.9%) 3. Most closely involved family member or friend (response rate 53.2%) 4. Nursing home administrator (response rate 95%) **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** High	Cross-sectional study using random cluster sampling Post-mortem postal questionnaires **Instruments:** Comfort Assessment in Dying with Dementia scale (CAD-EOLD), subscales include: emotional distress, physical distress, dying symptoms Bedford Alzheimer Nursing Severity Scale (BANS-S)	Residents with ACP experienced less emotional distress (i.e., anxiety, fear) (CI 1.1-8.3) DNR order decreased the chance of experiencing emotional distress in last week of life (CI=1.1-11) Do not hospitalize order associated with less emotional distress (p=0.038) When nurses spoke with family member/friend in advance about desired direction of care, residents had lower ratings of discomfort (CI=0.09-0.60), restlessness (CI=0.17-0.98), gurgling (CI=0.1-0.8), dysphagia (CI= 0.1-0.6) **Conclusion:** Nursing home residents with dementia who have written their care wishes experienced lower levels of emotion distress at EOL	**Strengths:** High response rate Two-step screening protocol to identify study population Use of validated scale to measure QOD Measured outcomes from four participants in patient's care **Limitations:** Retrospective Data not reported by proxy, not by residents themselves Cross-sectional design establishes only associations, not causal relationships

Author Recommendations: A written ACP is important for the emotional wellbeing of people with dementia and their families; the process should begin as early as possible to enable reflection on options and facilitate psychological processing about EOL for the patient and family/friends. Nursing homes should establish a PC culture where ACP is encouraged.

Implications: Having a written ACP may lower levels of emotional distress for dying patients. Nurses play an important role in communicating with patients and families/friends about the dying process. Physicians should discuss EOL in advance and extend the conversation beyond the DNR decision.

Source: Verreault, R., Arcand, M., Misson, L., Durand, P. J., Kroger, E., Aubin, M., Savoie, M., Hadjistavropoulos, T., Kaasalainen, S., Bedard, A., Gregoire, A., Carmichael, P. (2018). Quasi-experimental evaluation of a multifaceted intervention to improve quality of end-of-life care and quality of dying for patients with advanced dementia in long-term care institutions. *Palliative Medicine, 32*(3), 613-621.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Evaluate effect of 5-component intervention to improve QOC and QOD in patients with advanced dementia living in LTC facilities. Interventions: 1. staff training 2. use of observational pain scale 3. routine mouth care 4. communication with families, educational booklet 5. nurse facilitator **Sample/Setting:** • 193 residents with advanced dementia and their close family members • Intervention group in two LTC facilities (n=97) • Control group (usual care) in two LTC facilities (n=96) • Quebec, Canada **Johns Hopkins Evidence Appraisal** **Level of Evidence:** II **Quality:** Good	Quasi-experimental study **Instruments:** FAST Functional Autonomy Measurement System Family Perception of Care Scale (FPCS) Symptom Management for End-of-Life Care in Dementia Scale (SM-EOLD) Comfort Assessment in Dying Scale (CAD-EOLD)	FPCS score higher in intervention group compared to usual care group (157.3 vs 149, p=0.04) CAD-EOLD higher in intervention group compared to control group (35.8 vs 33.1, p=0.03) SM-EOLD scores higher in intervention group compared to control group (34.7 vs 29.8, p=0.03) **Conclusion:** Multidimensional intervention in LTC for patients with terminal dementia resulted in improved QOC and QOD when compared to usual care	**Strengths:** Focused on clinically significant outcomes CAD-EOL scores correlated between families and nurses **Limitations:** Randomization of study participants not possible in quasi-experimental design Some questionnaires incomplete Response rate 57% in control group and 73% in intervention group
Author Recommendations: Systematically screen for pain. Perform routine mouth care. Utilize specially-trained palliative care nurse facilitators to coach facility staff about PC. Use verbal and written communication to educate families about issues related to PC.			
Implications: Coaching by nurse facilitator, in addition to training staff in PC, is key to improving QOC and QOD for patients with advanced dementia in LTC. Families experience greater satisfaction with care when they have received information about the natural evolution of advanced dementia and the PC option.			