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A Good Life: Palliative Care in the World of Dementia

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Abstract

Objective: The World Health Organization (2019) reports that dementia is the seventh leading cause of death with an estimated 50 million people worldwide with this disease. In the United States out of one and a half million Medicare patients on hospice in 2016, only 18% had dementia (The National Hospice and Palliative Care Organization, 2017). McAteer and Wellbery (2013) identified that while referrals to services seem to be on the rise, many are not made until the patient is close to death in the last weeks of an illness. The purpose of this project was to review the literature to identify if quality of life is improved if provided earlier in the disease process and discuss the major barriers that are preventing this type of care from being provided. **Methods:** Databases used for this literature review included CINAHL, Medline, Academic Search Complete, and ClinicalKey. The search focused on barriers to care including prognostication, communication, and misinformation. Over 4,000 articles were found. These were narrowed down to literature that was published within the last five years, in English, and peer reviewed. Twenty articles were identified as pertinent to this project and presented in the literature review to describe the identified barriers and solutions that promote early palliative care for dementia patients. **Conclusions:** Palliative care has been shown to improve quality of life and is a needed service for dementia patients. Multiple barriers include access to this type of care, issues with communication, collaboration between providers, lack of care continuity, education/skills deficiencies, personal bias, lack of guidelines/prognostication tools, and general misinformation about palliative care. Solutions include further education, emphasis on collaboration, use of guidelines, and ensuring that discussions about care are being done early in the disease trajectory.

Keywords: palliative care, dementia, non-hospice, Alzheimer's, and quality of life, communication, and prognostication.

Dementia is a broad term that covers many types of diseases that have an impact on memory, functional status, and the ability to communicate. According to the Alzheimer's Association (2019) the most common types of dementia include Alzheimer's disease and vascular dementia. Other types of dementia include Creutzfeldt-Jakob disease, Lewy body dementia, frontotemporal dementia, Huntington's disease, normal pressure hydrocephalus, posterior cortical atrophy, Parkinson's disease, and mixed types. Most of these have no cure.

Dempsey, Dowling, Larkin, and Murphy (2015) indicate the importance of being proactive to the needs of dementia patients and their families due to the terminal nature of the disease. As dementia progresses and causes further decline, it is anticipated that the care needs of the patient will increase. Hospice services (care given to patients who have a terminal illness with less than six months to live) can assist with symptom management, education, medical providers, nursing, social workers, pastoral care, grief counseling, respite services, and assistance with activities of daily living in order to improve quality of life during end-stage illness. However, if the disease is not advanced enough for hospice services the patient will not qualify for these additional supports.

Palliative care services improve quality of life for those suffering from chronic diseases but do not require an end stage diagnosis to qualify. This service bridges the gap between curative care and terminal illness. McAteer and Wellbery (2013) identified that while referrals to palliative care seem to be on the rise, many are not made until the patient is close to death in the last weeks of an illness. Dementia patients would benefit from earlier referrals to hospice services (as soon as eligible), but until then, this patient population would benefit from having non-hospice palliative care services in place. The primary gaps identified that prevent patient

access to such services include challenges with prognostication and timing of service initiation, communication/collaboration difficulties, and misinformation about palliative care.

Background

It is interesting to see the statistics relating to dementia patients. According to the World Health Organization (2019) dementia is the seventh leading cause of death with an estimated 50 million people worldwide who have the diagnosis. The National Hospice and Palliative Care Organization (2017) found there were almost one and a half million Medicare recipients on hospice in 2016, but only 18% of these were receiving this service for dementia. These patients had the longest mean length of stay, which was 104 days. However, half of all hospice recipients did not receive care until the last 30 days of their lives. This is concerning since there were so few dementia patients on hospice during the 2016 reporting period in comparison to the amount of people diagnosed every year. Furthermore, the mean length of stay for dementia patients is well under the initial six month period of the hospice benefit. The 2016 statistics only included Medicare patients; however, this is the main insurance provider for those over the age of 65. One would expect to see more patients qualified for hospice services with the amount of patients diagnosed and the anticipated decline.

Palliative care could potentially meet some of the additional patient needs and help bridge the gap in care until patients meet the guidelines for hospice care. The purpose of this project was to review the literature to identify if palliative care services are beneficial in improving the quality of life in dementia patients and to discuss the major gaps that are preventing this type of care from being provided.

Definition of Terms

Conceptual Terms

Palliative care refers to non-hospice-related palliative care that is provided to patients who have a chronic disease but do not yet meet the requirements of hospice services. These services are intermittent and intended to promote quality of life for the patient, which in turn can promote quality of life for family members as well. According to The National Hospice Foundation (2014), “All hospice is palliative care but not all palliative care is hospice.” For the purposes of this project, *palliative care services* refers to any such services provided in settings other than a hospice unit which is already providing services. *Hospice care* refers to similar services but only for those patients diagnosed with a terminal illness with six months or less to live. *Quality of life* is identified by patient and/or family perspectives as to what (if anything) is needed to meet or exceed physical needs, spiritual needs, emotional needs, and psychosocial needs.

Operational Terms

Dementia includes a broad set of diseases—such as Alzheimer’s disease, vascular dementia, and Parkinson’s disease—that can potentially impact cognition, functioning, and/or communication. For the purposes of this project, dementia is related to non-reversible causes. The *setting* is where the patient lives, which includes home, hospital, assisted/independent living facilities, nursing homes, correctional facilities, homeless shelters, street, group homes, etc. Hospice can also be considered a setting, such as at-home hospice or a hospice care center. *Life-limiting illness* refers to a disease that is expected to end in death. *Terminal illness* refers to a condition in which death is expected within six months or less.

Theoretical Framework

Katharine Kolcaba's (2001) Comfort Theory was used as the theoretical framework for this literature review. This middle-range theory focuses on the comfort needs of patients as well as the variables that can enhance or impede comfort. It originated with Kolcaba's own work with Alzheimers patients as a nurse trying to establish a more concrete definition about the concept of comfort. Comfort is a holistic term that includes physical, psycho-spiritual, environment, and/or sociocultural stimuli. Other concepts and variables were also identified by Kolcaba (2009) that promote or hinder the outcome of comfort. These include patient and/or family healthcare needs, comforting interventions, intervening variables, health seeking behaviors (internal behaviors, peaceful death, and external behaviors), and institutional integrity (best practices and policies). Comfort interventions are provided based on the subjective reports from the patient about their level of comfort or by the provider observing signs of discomfort. The concept of intervening variables includes the socioeconomic status, cultural values, comorbidities, and other variables that the provider may not have control over.

Comfort Theory applies to the topics of disease prognostication, appropriate timing of services, communication and correcting misinformation when it comes to the provision of early palliative care to dementia patients. Patients who are referred late to palliative care (and/or hospice) are at a disadvantage, as they may not benefit from the additional services that can be provided to enhance their comfort. Institutional practices and policies (or lack thereof) can create barriers to providing earlier referrals. Provider beliefs can also have a huge impact on the comfort of the patient due to differences of opinions about prognostication and when to initiate palliative care. Misinformation and communication problems on the part of the patient, family,

and/or provider can hinder the provision of patient comfort. Kolcaba's (2009) Comfort Theory encompasses the delivery of holistic patient-oriented care.

Problem Statement

The practice problem identified for this literature review is the underutilization of palliative care in dementia patients. The research question is as follows: In patients with dementia, does early palliative care promote improved quality of life when hospice is not appropriate? Furthermore, what are the major barriers found in the literature that inhibit the provision of palliative care in this population?

Literature Review

This project focused on identifying whether palliative care improves quality of life in dementia patients. Databases used for this research included CINAHL, Medline, Academic Search Complete, and ClinicalKey. Keywords used included palliative care, dementia, non-hospice, Alzheimer's, and quality of life, communication, and prognostication. Over 4,000 articles were found. These were narrowed down to literature that was published within the last five years, in English, and peer reviewed. Articles that focused solely on the provision of hospice care were excluded as much as possible while including ones that specifically discussed palliative care. These articles were further delineated to those that best focused on the key concepts of prognostication, communication, and misinformation about palliative care in order to narrow them down to those presented in this literature review.

articles were identified as pertinent to this project. Of these, seven studies specifically identified barriers with prognostication and the timing of referrals, five studies specifically discussed communication issues, and five specifically identified barriers with misinformation and/or lack of education about palliative care. The remaining three articles included more than

one of the topics. While most of the studies were specifically related to dementia patients, four were about palliative care in general, and one was specifically about patients with Parkinson's disease.

Prognostication and Timing of Referrals

Beernaert et al. (2015) conducted a multivariable logistic regression study of patients who had died during a six-month period in Flanders, Belgium to determine physician reasoning for or against the use of palliative care. The sample consisted of 3,751 cases. They found that 1,917 cases needed palliative care but only 29% actually received this service. Dementia patients made up 12% of the cases that needed palliative care, with 48% receiving the service. The median referral rate for dementia patients was eight days prior to death, compared to cancer patients who had a median referral rate of twice that. Physician-identified reasoning for not utilizing palliative care included the following: belief that the patient care needs were already being met (56%), services not considered beneficial or meaningful (26%), time constraints (24%), patient declination (6%), and family declination (4%).

Van Riet Paap et al. (2015) conducted a study using a case study vignette about a dementia patient in which 13 teams had to determine when a palliative care referral should be made. The sample included 84 professionals who worked in long-term care settings in six different countries in Europe, separated into teams. Three teams noted that they would refer early in the dementia diagnosis while the remainder would only consider a referral when the patient was in the advanced stages of the disease.

A mixed-methods study (qualitative and quantitative) performed by Bone et al. (2016) sampled 80 people to determine palliative care needs. Participants included 63 healthcare professionals and 17 elderly patients and caregivers. They found that the majority of participants

agreed about the benefits of implementing palliative care early but there was no consensus on when to initiate services.

Klok, Engels, Veldhoven, and Rotar Pavlic (2018) performed a small but important pilot study in 2016 regarding the importance of early identification of palliative care patients. They sampled 26 Slovenian physicians to assess the usefulness of a question tool to guide prognostication and timing of palliative care referrals. The tool required participants to ask themselves if they would be surprised if a patient died within the next twelve months, or if they would be surprised if the patient was still alive after twelve months. The authors found the question tools useful in prognostication and timing of palliative care referrals, especially in practice with a cancer patient case study. However, only eight participants were able to apply it to a patient with dementia. Lee, Bamford, Exley, and Robinson (2015) conducted a qualitative study in the United Kingdom with a sample size of 30 experts in palliative care and dementia. They found that one of the primary barriers to timing referrals was a lack of guidelines or care pathways.

Impacts of palliative care on quality of life were studied by Carpenter et al. (2017) using retroactive cross-sectional analysis. The sample consisted of 5,992 veterans (1,460 with dementia) who had died on hospice and in palliative care units in veteran hospitals in the United States during a two-month period. They found that families of patients who received palliative care consults at least a week prior to death reported improved quality of life. Additionally, they found the association between palliative care and improved quality of life was greater if services were implemented six months or more prior to the patient's death.

Singer et al. (2016) performed a systematic review of 14,961 randomized controlled trials that were published between 2001 and 2015. In this study dementia was found to be the second

most studied disease. Out of a sample size of 25 studies focusing on dementia, the authors found that 60% showed an improvement in quality of life with palliative care services. Seventy-three percent of the referrals in these cases were made based on clinician judgment.

Communication Barriers

Aerts et al. (2017) studied the palliative care needs of patients with neurological disorders who were seen by an inpatient palliative care department for approximately four years using both descriptive statistics and chi square. The authors found that out of 206 patients, 20% of them had dementia and were either discharged to palliative care in the home (7%) or died in the hospital (28%). Ten percent were found to either have been referred to hospice or had no referral at all. Seventy-two percent of all the patients in the study were unable to communicate at the time of their consultation. Palliative care referrals were mostly made at a time when the patient was close to end of life rather than early in the disease process. The authors indicated the need for improved communication with physicians, families, and patients about palliative care services in order to promote earlier referrals for both hospital and outpatient settings.

A study performed by Harrop, Nelson, Rees, Harris, and Noble (2018) examined the impact of a project established to improve palliative care and end-of-life services to patients with dementia. This project provided enhanced services that are similar to what hospice patients receive but included enhanced education and support to providers, family members, and patients. They used a sample size of 35 healthcare providers and caregivers. Using quantitative and qualitative methods, the authors found that more patients needed palliative support rather than end-of-life care. Sixty-nine percent of participants (n=11) reported that the project had increased their knowledge and confidence in caring for dementia patients while 95% of the participants reported the project improved understanding about the disease. Quality of life was reported to be

enhanced by 81% due to the additional services and support, and by the end of the project palliative care referrals were increasing.

A qualitative study done by Sampson et al. (2017) explored which factors had an influence on those making decisions for patients with dementia. The sample size included 10 caregivers and 24 healthcare providers who were given a topic guide to discuss that focused on symptom management, end-of-life decisions, individualized care, activities of daily living, and inter-professional communication. The authors found that the main barriers to decision making included lack of continuity, inability to make decisions, provider bias (internal or external), and providers delaying conversations. Other impacts included communication deficits of the patient, no advance directives, and lack of education to both providers, patients, and families, forcing last-minute decision-making. As a result, the authors recommended that while further education can be useful, a communication tool is needed to help encourage discussions between professionals, patients, and caregivers to help guide difficult decision-making. The authors also noted the importance of providers understanding their own biases and having conversations early with dementia patients and their families.

Van Den Noortgate et al. (2016) conducted a qualitative study with 32 researchers and providers in an effort to determine barriers to collaboration regarding the increased needs of the elderly population. They found multiple barriers, including lack of communication between providers, lack of skill and/or knowledge about what services the other disciplines provided, and limited use of palliative and/or geriatric specialty care. Both researchers and providers agreed that lack of communication was a huge barrier in providing patient care. One of the challenges identified was the general idea that palliative care was only for cancer patients or for patients

about to die. The authors indicated that improving communication, working together as a team, and advanced care planning are needed in order to promote collaboration between the specialties.

A cross-sectional study of 101 deceased dementia patients in Belgium nursing homes was performed by Vandervoort, Houttekier, Vander Stichele, Van Der Steen, and Van Der Block (2014) to identify if having advance directives in place enhanced quality of dying. They found that those who had advanced directives in place (17.5%) were three times more likely to have less fear and anxiety than those who did not. In 13.7% of the cases it was noted that a nurse-provided education about end of life had a negative connotation in the study, possibly due to these discussions happening at the same time that end-of-life symptoms (i.e. gurgling, dyspnea) were occurring. The main recommendation they had as a result of this study was to start the discussions about end-of-life planning for dementia patients as early in the disease process as possible.

Misinformation about Palliative Care

Brazil, Galway, Carter, and van der Steen (2017) conducted a cross-sectional observational study in the Netherlands and the United Kingdom in order to determine the barriers and facilitators of providing palliative care to dementia patients. The sample included 129 physicians experienced in providing care to dementia patients. The primary barrier they found was a lack of public and provider education leading to misinformation about palliative care. Participants emphasized the need for palliative care education to providers and the community as well as promoting awareness that dementia patients need this type of service. Additionally, they indicated the importance of patient-centered care, and a need for improved communication, shared decision-making, and increased access to spiritual and psychological support.

One qualitative study performed by Davies et al. (2014b) looked at the barriers that were preventing people in England with dementia from receiving high-quality palliative care. They explored the viewpoints of 26 multidisciplinary participants, which included nurses, geriatric psychiatrists, general practitioners, palliative care consultants, researchers, and managers. Barriers they found included mixed reactions about whether guidelines were needed and what type, lack of care continuity, and lack of collaboration between providers and specialists. Additionally, they found differences in educational needs, concerns about litigation, and lack of provider skills/confidence.

A study was conducted by McInerney, Doherty, Bindof, Robinson, and Vickers (2018) using topical modelling analysis as well as thematic analysis to study community palliative care perceptions. They sampled 1,330 people in the community, which included caregivers of dementia patients (paid and unpaid) and those who were interested in the disease. Participants completed a nine-week massive open online course that provided dementia education and the opportunity to discuss experiences and concerns. Education was provided on palliative care and participants were to individually identify their perceived meaning of the term “palliative care.” The top three responses included dignity and comfort, end-of-life planning, and quality of life. However, it was found that although the participants identified the need for palliative care, the services were equated more with terminal illness focusing on death. The authors expressed concern that palliative care services may not be identified early enough, thus limiting the amount of support available to the patient. They identified the need for increased education and awareness about palliative care services, and the importance of ensuring early access.

A mixed-methods study was conducted by Ouchi et al. (2014) over a one-month period to determine the number of dementia patients referred to palliative care following physician-

provided education about appropriateness of referrals. The sample included 51 dementia patients appropriate for palliative care who were over the age of 70 and had severe dementia. They found that 14 patients (27%) were discharged without a palliative care referral. The remaining 37 patients were admitted to the hospital with only 18 (35%) receiving referrals. Only four of the admitted patients (8%) were referred for palliative care by the emergency room physicians. Reasoning provided by physicians for lack of referrals included feeling the patient was inappropriate, time constraints, personal beliefs, and misperceptions that another was handling the referral (such as a hospitalist or the nursing home). The authors recommended further research on the benefit of outpatient palliative care and the misunderstanding that palliative care is not just for the dying.

Shearer, Monterosso, Ross-Adjie, Rogers, and Rogers (2016) conducted a year-long mixed-methods cross-sectional study in an Australian hospital to identify palliative care perspectives and educational needs of healthcare providers. The sample included 302 participants including 236 nurses and 49 healthcare providers (nurse practitioners and doctors). They found misperceptions about palliative care, including lack of awareness about what the term meant, what services it provided, and whether curative treatments would be continued. Additionally the authors found that many participants lacked education and understanding as to the usefulness of palliative care early on in the disease trajectory. In some cases, referrals were made very late in the diagnosis when the patient was unable to make decisions or were not made at all. The authors recommended that everyone in the healthcare setting have education and skills training in palliative care in order to promote optimal care and early referral.

Literature Identifying Multiple Gaps

Davies et al. (2014a) conducted a study to identify the challenges in providing palliative care services to patients with dementia. Their qualitative study was performed in 2012 with a sample size of 67 palliative care professionals from five European countries that included Germany, England, the Netherlands, Italy, and Norway. They found the major barriers to palliative care referrals were that dementia was not being viewed by all as a terminal illness and lack of awareness about the differences between hospice and palliative care. Multiple dementia classification systems and practitioner beliefs were noted as a barrier impacting prognostication and timing of service referrals. Other themes that emerged during the study included communication barriers (between services, providers, families and patients), lack of care coordination, funding difficulties, lack of education, and time constraints.

Another qualitative study performed by Fox et al. (2016) sought to identify the barriers and facilitators to palliative care needs of this patient population from the viewpoint of healthcare workers. The sample size included 30 healthcare workers in Ireland who were either working in a palliative care setting or working with patients with Parkinson's disease. They found communication difficulties, timing of referrals, and lack of education (amongst healthcare workers, families, patients, and the public) as the main barriers to palliative care provision. There was a lack of consensus about what palliative care represents, whether there is a need for it as a specialty, and when to begin the discussion about palliative care as an option. Additional barriers identified included personal beliefs and potentially negative connotations due to the subject matter. Participants did agree about the importance of providing education to families on what to expect, including being realistic about the disease trajectory.

Midtbust, Alnes, Gjengedal, and Lykkeslet (2018) performed a qualitative descriptive study in order to obtain insights about barriers to providing palliative care to dementia patients in nursing homes in Norway. The sample included 20 healthcare providers: 10 registered nurses, six licensed practical nurses, and four others whose role was not identified. The authors found the major barriers to providing palliative care included lack of continuity of care, time constraints, limited resources, lack of education, and use of agency staff not familiar with the patients. Mental and physical exhaustion was reported by participants due to the extra time required for symptom management or for the extensive physical needs of some of the dementia patients and not enough help. The participants indicated that extra staff was only hired at end of life to help meet the needs of the dying patient so that the patient did not have to die alone. Advanced care planning and staff continuity were found to be of importance in this population, especially if the patient was unable to make their wishes known.

Summary of Literature

One of the most confounding factors found in the literature review is the use of the words *palliative* and *hospice* interchangeably. This causes confusion as to whether the authors are discussing early referral needs to hospice or early referral needs to palliative care. Palliative care as a whole was found to have an impact on improved quality of life (Carpenter et al., 2017; Harrop et al., 2018; Shearer et al., 2016; Singer et al., 2016). Harrop et al. (2018) found in their study that palliative care was needed more than hospice while Carpenter et al. (2017) found a significant improvement in quality of life when palliative care was provided at least six months prior to death.

Multiple barriers were found in the literature that decreased access to palliative care. Lack of communication, coordination of care, collaboration between providers, and continuity of

care were found to be the greatest barriers (Aerts et al., 2017; Brazil et al., 2017; Davies et al., 2014a; Davies et al., 2014b; Fox et al., 2016; Midtbust et al., 2018; Ouchi et al., 2014; Sampson et al., 2017; Van Den Noortgate et al., 2016). This includes lack of communication between providers, between providers and patients/families, and even between patients and their families. Lack of provider/community education and skills in palliative care were found to be another major barrier (Brazil et al., 2017; Davies et al., 2014b; Fox et al., 2016; Harrop et al., 2018; McInerney et al., 2018; Shearer et al., 2016; Van Den Noortgate et al., 2016). Another barrier found was misinformation about palliative care, such as what it is, what the service does, and how one obtains access to the service (Brazil et al., 2017; Davies et al., 2014a; Fox et al., 2016; McInerney et al., 2018; Ouchi et al., 2014; Shearer et al., 2016; Van Den Noortgate et al., 2016). Fox et al. (2016) noted the importance of being realistic about the disease trajectory. Provider bias was found to have an influence on access in multiple studies (Beernaert et al., 2015; Davies et al., 2014a; Fox et al., 2016; Ouchi et al., 2014; Sampson et al., 2017). Other major barriers included lack of guidelines (Lee et al., 2015; Davies et al., 2014a; Davies et al., 2014b; Sampson et al., 2017; Shearer et al., 2016), uncertainty as to when referral is appropriate (Bone et al., 2016; Fox et al., 2016; Klok et al., 2018; Vandervoort et al., 2014; Van Riet Paap et al., 2015), inconsistency with prognostication tools currently available (Klok et al., 2018; Singer et al., 2016; Van Riet Paap et al., 2015), time constraints (Beernaert et al., 2015; Davies et al., 2014a; Midtbust et al., 2018), provider misidentification that needs had already been met (Beernaert et al., 2015; Ouchi et al., 2014), referrals made too late (Aerts et al., 2017; Shearer et al., 2016), lack of funding (Davies et al., 2014a; Midtbust et al., 2018), and patient inability to communicate (Aerts et al., 2017; Sampson et al., 2017).

The most common recommendation found in the literature was for early palliative care referrals (Bone et al., 2016; Fox et al., 2016; Klok et al., 2018; McInerney et al., 2018; Sampson et al., 2017; Shearer et al., 2016; Vandervoort et al., 2014; Van Riet Paap et al., 2015). A prevalent recommendation noted was the importance of having advanced directives in place and patient-centered care planning performed early in the disease trajectory (Brazil et al., 2017; Fox et al., 2016; Midtbust et al., 2018; Sampson et al., 2017; Vandervoort et al., 2014; Van Den Noortgate et al., 2016). Sampson et al. (2017) recommended having conversations early in the disease process to help prevent last-minute decision-making. Fox et al. (2016) found that these conversations had a negative connotation for the family when they were had while the patient was already exhibiting signs of being at end of life. They recommended being proactive in early care planning. Van Den Noortgate et al. (2016) found that both fear and anxiety were reduced (patient and family) when plans were made early in the disease trajectory. Other recommendations included utilizing a team approach for patient-centered care (Van Den Noortgate et al., 2016; Brazil et al., 2017) and the need for palliative care as a specialty (Fox et al., 2016).

Discussion and Synthesis

Recommendations

Palliative care should be available to all persons that are diagnosed with a life-limiting illness, regardless of whether the illness has a short or long disease trajectory. Education and skill development activities need to be available to healthcare providers for recognizing when palliative care is appropriate and how to avoid personal bias. Timing of palliative care should take into consideration the disease trajectory and what services the patient and/or family would benefit from, whether that be symptom management, education about the disease and caring for

the patient, change in setting, coordination of services (referrals, case management, personal care, etc.), or planning care.

The National Coalition of Hospice and Palliative Care (NCHP) (2018) guidelines recommend initiation of palliative care at the onset of diagnosis and transitioning to hospice when the terminal phase arrives. Early palliative care provides a way for patients and families to plan in advance for anticipated needs and make preparations for care. Fox et al. (2016) noted the importance of having early discussions because of the uncertainty of the disease trajectory. Having the end-of-life care discussion early on is important to establish what the patient's goals and wishes are while the patient can communicate for themselves. Educating healthcare workers and the public may help to reduce the stigma and negative connotation related to end-of-life discussions. Further research is recommended to identify tools that help measure quality of life for people receiving palliative care, especially for dementia patients, to help discover specific benefits. It is also recommended that further research consider the types of personal bias that are inhibiting palliative care referrals and end-of-life care planning, tools that help in prognostication, and sources of funding for palliative care services.

Application to Advanced Nursing Practice

It is important for nurse practitioners to recognize where a patient is at in the disease trajectory. As the disease progresses there will be a need for additional education, care, and services. If the patient does not meet hospice guidelines, the practitioner will need to identify which services would be most beneficial in meeting the patient's level-of-care needs. Referring a patient to palliative care early in the disease process will help to establish a partnership in which the patient is able to be an active participant in decisions about their own care. Advanced directives need to be discussed, not only with dementia patients but any patient with a life-

limiting illness, in order to establish goals of care early on. Although palliative care services can obtain directive paperwork, the nurse practitioner should begin the conversation about end-of-life wishes. The NCHP (2018) palliative care guidelines should be kept on hand to help discuss the benefits of palliative care and help with treatment and planning care.

Limitations

The primary limitation of this literature review was the lack of research in the area of non-hospice palliative care as it relates to dementia patients. Multiple studies were located that focused on palliative care for cancer patients but not for patients with non-cancer illnesses such as dementia. Furthermore, the majority of studies found were conducted in European countries despite the increased use of non-hospice palliative care in the United States, and many of the studies were limited by a small sample size. Finally, the majority of the studies were qualitative in nature and were based on participant opinions and experiences. While there was a general consensus in the literature that palliative care improves quality of life, there were no recent studies found that specifically identified quality-of-life measurements for dementia patients receiving palliative care or hospice services.

Conclusion

As evidences in this literature review, palliative care has been shown to improve quality of life and is a needed service for dementia patients. Multiple barriers have been identified that are limiting access to this type of care, particularly issues with communication, collaboration between providers, continuity of care, lack of education/skills, personal bias, lack of guidelines/prognostication tools, and general misinformation about palliative care. Some of these barriers could be avoided with education, collaboration, use of guidelines, and ensuring that discussions about care are being done early in the disease trajectory. Many of the people in the

studies in this literature review were referred late to palliative care or not at all, despite such services being appropriate for their needs. If palliative care is supposed to bridge a gap between curative care and hospice, why should it not be available for dementia patients who have a disease with no known cure?

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