

**PALLIATIVE CARE AND IMPROVING QUALITY OF LIFE WITH END STAGE
RENAL DISEASE: AN INTEGRATIVE REVIEW**

Scholarly Project

Submitted to the

Faculty of Liberty University

In partial fulfillment of

The requirements for the degree
of Doctor of Nursing Practice

Natoya Nicola Bender

Liberty University

2021

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ABSTRACT

End-stage renal disease is a rising health care problem affecting more than 15% of the United States population. There are 700,000 patients with renal disease in the United States characterized by multiple comorbidities and increasing, distressing symptom burden. The necessity for palliative care for patients with end-stage renal disease is becoming the standard of care due to their complex medical needs and high symptom burden. The aim of this integrative review was to investigate the existing literature that evaluated the incorporation of palliative care to improve the quality of life of patients with end-stage renal disease. The goal of conducting this integrative review was to explore the benefit of integrating palliative care for patients with end-stage renal disease to improve their overall quality of life.

Keywords: Palliative care, end-stage-renal disease, improved symptom management, quality of life

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PALLIATIVE CARE AND IMPROVING QUALITY OF LIFE WITH END STAGE RENAL DISEASE: AN INTEGRATIVE REVIEW

SECTION ONE: FORMULATING THE REVIEW QUESTION

Chronic kidney disease poses a significant public health problem in the United States. Chronic kidney disease and end-stage renal disease continue to rise annually, costing millions in Medicare dollars (Grubbs, 2018). Both chronic kidney disease and end-stage renal disease confer significant mortality and morbidity to those affected by the disease. End-stage renal disease also causes patients significant symptom burden on those it affects, impacting patients' quality of life on many different levels and impacting patients mental, physical, and emotional health.

The Center for Disease Control and Prevention (CDC) defines chronic kidney disease as a condition in which the kidneys are injured and subsequently are unable to filter waste from the blood (2021). As defined by the CDC, end-stage renal disease is renal failure lasting greater than three months, requiring renal replacement therapy or renal transplant as a treatment modality to maintain a healthy life (2020). As a result, renal replacement therapy and renal transplants have contributed to increased healthcare expenses. Approximately 350 people every 24 hours in the United States begin treatment for kidney failure (Carney, 2020). Additionally, a decade ago, it was reported that the treatment of chronic renal disease to Medicare recipients costs over \$84 billion. In comparison, treatment of end-stage renal disease costs an additional \$36 billion due to renal replacement therapy needs (Ozieh et al., 2017).

The CDC and the National Kidney Foundation (2021) report that 15% of the U.S. adult population, approximately 37 million people, suffer from chronic kidney disease, while millions of others are at increased risk of developing end-stage renal disease. The CDC states that chronic kidney disease has risen from the world's 13th leading cause of death to the world's ninth leading

cause of death. Chronic kidney disease and end-stage renal disease cause many health problems that lead to increased risk of mortality and morbidity.

Background

A 2018 study identified 700,000 patients suffering from renal disease, which led to patients receiving hemodialysis for treatment for their failing kidneys (Li et al., 2018). As a result of end-stage renal disease, patients experience dry and itchy skin, restless leg syndrome, insomnia, fatigue, and joint and chest pain. If a kidney transplant is not available, end-stage renal disease can eventually lead to death. O'Hare et al. (2017) revealed that these symptoms are exacerbated by the lack of symptom management received by patients with end-stage renal disease, resulting in a short life expectancy, development of comorbidities, and poor quality of life, which may be enhanced with palliative care.

Palliative care is a specialized type of medical care delivered by providers trained to help people living with chronic diseases (Sturgill & Bear, 2019). This specialized treatment can help ease pain and suffering experienced by patients due to end-stage renal disease diagnosis (National Kidney Foundation, 2021). Furthermore, palliative care helps patients and their families understand their medical condition, prognosis, treatment goals, expectations of the care received and helps maintain their quality of life throughout their disease process. According to the World Health Organization (WHO), improved quality of life in any chronic disease state may be obtained by alleviating the strain and burdens of living with a severe medical condition (2020). The goal of this integrative review was to determine whether palliative care can help to improve the quality of life in those patients with end-stage renal disease.

Defining Concepts

Concepts that need to be defined for the purpose of this integrative review include palliative care, chronic kidney disease, end-stage renal disease, renal replacement therapy, hemodialysis, and symptom management. In this integrative review, palliative care has been described as a type of medical care that improves patients' quality of life and their families' understanding of disease processes when dealing with severe medical conditions such as end-stage renal disease (WHO, 2020). Palliative care is a holistic approach that provides relief from life-threatening illness through early identification and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual health problems. The palliative care goal is to improve the patient and the families' overall experience when dealing with their complex medical illness (Chiu et al., 2021).

Chronic kidney disease is defined as a slow progression of kidney damage leading to kidney failure caused by several underlying disease processes. Chronic kidney disease is a slow progression in which the kidneys are injured and subsequently are unable to filter waste from the blood (CDC, 2021). Chronic kidney disease, if not slowed, may lead to end-stage renal failure. If renal failure occurs, patients may require renal replacement therapy or kidney transplant as a treatment modality to maintain a healthy life (CDC 2020). End-stage renal disease impacts patients' quality of life due to the increased symptom burden of the disease.

Renal replacement therapy is a treatment method therapy that replaces the normal blood-filtering function of the kidneys for patients with end-stage renal disease. It is used when the kidneys are not working, also known as kidney failure, and includes acute kidney injury and chronic kidney disease (National Kidney Foundation 2021).

For this integrative review, hemodialysis is a form of renal replacement therapy where a machine called a dialyzer filter, or an artificial kidney is used to clean the blood. To get access to a blood vessel patient, a doctor needs to make access or entrance into the blood vessels to be dialyzed. Placing an entry is done with minor surgery, usually to the arm or a large vein in the body (National Kidney Foundation, 2021). Quality of life is defined as the level of comfort, health, and happiness experienced by an individual or a group (Britannica, 2020).

Symptom management is the control of a host of complaints experienced by a patient or witnessed by a patient's family or loved ones. These symptoms can vary and include pain, especially in the joints and chest, itching, fatigue, poor appetite, trouble concentrating, problem sleeping, muscle cramping, swollen feet and ankles, and nausea (National Kidney Foundation, 2021).

Rationale for Conducting the Review

According to the National Hospice and Palliative Care Organization (2021), palliative care is a care model of compassion and education focusing on improving the quality of life for patients with a life-limiting illness. It focuses on caring for the patient by providing for the patient's physical, psychosocial, existential, and spiritual health needs (Grubbs 2018). This approach to care ensures that dignity and quality of life are preserved during active care, especially for those patients with end-stage renal disease who undergo renal replacement therapy such as hemodialysis, peritoneal dialysis, or waiting for transplantation as the primary treatment (Grubbs 2018).

Patients with end-stage renal disease requiring renal replacement therapy treatments experience a heavy symptom burden. The median number of symptoms experienced by patients with end-stage renal disease is nine, with greater than 60 to 70% of those patients reporting

symptoms of dry skin, fatigue, itching, and bone/joint pain, with bone and chest pain as the most frequently occurring symptom (Li et al. 2018). Increased pain may lead to lower quality of life and, if left untreated, may lead to early death (Pham et al. 2017).

Palliative care provides an ideal opportunity to assess the wellness factors associated with end-stage renal disease and positively address them to provide comfort for patients undergoing treatment for end-stage renal disease (O'Halloran et al. 2018). Regrettably, palliative care has been sub-optimally utilized for patients with end-stage renal disease, thus causing increased patient suffering and poor quality of life (Li et al. 2018). Less than 20% of Medicare beneficiaries with end-stage renal disease receive palliative care referrals or interventions during an acute hospital admission, even when experiencing a worsening of symptoms (Sturgill & Bear 2019).

The history of palliative care is rooted in oncology because, at advanced stages, patients accept their mortality and forego treatments that postpone the inevitable and elect treatment which alleviates suffering (Cervantes Blanco & Jones 2017). Palliative care for patients with cancer has become a standard of oncologic care because it has been proven to be a clinical benefit in the alleviation of symptom burden, the enhancement of illness, understanding of disease process, and improvement of both the quality of life and overall survival for patients (Basch et al. 2016; Temel et al. 2017). The goal of conducting this integrative review was to explore the benefit of integrating palliative care for patients with end-stage renal disease to improve their overall quality of life.

Purpose and Review Questions

This integrative review was conducted to address the relationship between palliative care and quality of life of patients with end-stage renal disease. The aim was to investigate if the incorporation of palliative care would show an improvement in the quality of life of patients with

end-stage renal disease once introduced in their care (Taylor et al. 2016). This integrative review addressed the following clinical question: Does palliative care improve the quality of life in patients with end-stage renal disease?

Inclusion and Exclusion Criteria

The inclusion criteria for the literature review for this integrative review included studies written in English, studies that are peer reviewed, research that includes adult patients diagnosed with end-stage renal disease, which are patients diagnosed with stage four and five renal diseases, literature written in the last five years (2015-2021), patients requiring renal replacement therapy, and patients seen in both the acute care and outpatient setting. Databases searched included Cumulative Index of Nursing and Allied Health Literature (CINAHL) with PLUS Full Text, Medline, ProQuest Nursing and Allied Health Database, and PubMed. Keywords used in the search were end-stage renal disease, palliative care, symptom burden, quality of life, and improved symptom management. Research articles that were selected were published in the English language and published between the years 2015 to 2021 to ensure the use of the most current literature.

The exclusion criteria for this integrative literature review were the pediatric patient population and the patients with renal disease who *were* not diagnosed with end-stage renal disease (i.e., not receiving renal replacement therapy, renal disease stage two through three), publication before 2015 as data may be too old to align with the current study, and no use of data from editorials or news blogs to avoid biases and to avoid opinion-based data.

Conceptual Framework

This integrative review consisted of a rigorous, higher-level literature review using conceptual methods described by Whittemore & Knafl (2005). The integrative review is a

framework used to direct project leaders towards evidence-based practice change by extracting data and information from different sources of current literature. The model of an integrative review is essential to the practice of nursing research as it is the only form of research that combines multiple methodologies (both experimental and nonexperimental), as well as empirical and theological sources for more rigorous data capturing that plays a role in the improvement of evidence-based nursing practice (Whittemore & Knafl 2005).

Cooper (2021) explains that the purpose of an integrative review is to provide a summary of past research that addresses the phenomenon of the current problem which was investigated. The integrative review synthesizes published literature, both empirical and theoretical, that supports the integrative review topic. This literature review for this scholarly integrative review compiled evidence that suggested that palliative care impacts and improves the quality of life for patients with end-stage renal disease. The study supported the need to raise awareness for the subject matter via a five-stage synthesis process as defined: (a) problem formulation or identification of the patients' needs; (b) where the author reviews the literature to find what the literature says about the related topic; (c) data evaluation, compiling data from different resources, different literature sources on the topic of "end-stage renal disease and quality of life"; (d) analysis and interpretation, the formation of the literature matrix; and (e) presentation of the results or presenting the data to nephrology and palliative medicine as to the results of the literature matrix and a literature review (Whittemore & Knafl 2005). Toronto & Remington (2020) describe an integrative review as a type of research that looks broadly at a phenomenon of interest and allows for more diverse analysis from many different sources on a specific topic.

The aim of an integrative review involves a theoretical and methodological literature search to address the objective of the selected integrative review. The integrative review provides

the project leader with a more holistic understanding of their chosen area of research. According to Toronto & Remington, steps exist which should be followed by the project leader, which allowed for a well-developed integrative review (2020). The steps to follow when developing an integrative review as outlined are to first identify the current state of evidence; second, verify the quality of the evidence; third, find out what the gaps in the literature are; and finally, identify the future needs for research and practice development.

A PRISMA Diagram was used to show the results of how an integrative review was used to collect and categorize the results from the literature search process. The Melnyk's Level of Evidence tool was also used to level the literature and research to ensure that the studies were appraised for strength, content, and good quality (Melnik & Fineout-Overholt 2015).

SECTION TWO: COMPREHENSIVE AND SYSTEMATIC SEARCH

Search Organization and Organization and Reporting Strategies

According to Whitemore and Knafl (2005), search strategies must be defined and documented to ensure enhanced rigor and unbiased results that will support the review process. The purpose of a comprehensive literature review is to provide literature sources that best address the topic being investigated. The information sources and eligibility criteria for this scholarly project were defined comprehensively. The literature review started with the support of the Liberty University librarian, who helped with the narrowing of critical terms, the organization of wording, and advanced search techniques, which increased the rigor of search. The severity of the investigation was supplemented by combining words that were used to broaden the literature search to evaluate and critique the literature and methods used in the development of the analysis table.

Database Searches

The integrative review search strategy utilized in this research entailed a comprehensive computer-assisted search using the Jerry Falwell Library selected databases. The search engines included Cumulative Index of Nursing and Allied Health Literature (CINAHL) with PLUS Full Text, Medline, ProQuest Nursing and Allied Health Database, and PubMed. Keywords used in the search were: end-stage renal disease, palliative care, symptom burden, quality of life, and improved symptom management. Research articles that were selected were published in the English language and published between the years 2015 to 2021 to ensure the use of the most current literature.

SECTION THREE: MANAGING THE COLLECTED DATA

The research articles that were chosen for the final review maintained the integrity of the research question, which is, “does palliative medicine improve the quality of life in patients with end-stage renal failure,” providing an opportunity to evaluate the strength of the literature (Toronto & Remington, 2005). As a result, reliable studies helped the project leader conduct an integrative review that, when synthesized, provided accurate results.

The integrative review method was conducted using a comprehensive search process. As Toronto and Remington (2020) recommended, a citation manager was used to sort, collect, help identify, and eliminate duplicate studies. The Zotero reference manager was employed to keep track of research articles for the literature search and management. The initial search generated 791 research articles, of which 131 duplicates were removed, leaving 760 in which 61 were related to the integrative review topic. After the inclusion and exclusion criteria were applied and the duplicated studies were removed, 91 full text studies were assessed for eligibility. Of those

91 studies, 61 were excluded leaving 30 studies which were included in the qualitative synthesis and included in the final literature matrix (Table 1).

SECTION FOUR: QUALITY APPRAISAL

Sources of Bias

A rigorous literature search was used to evaluate the literature to determine relevance to palliative care for patients with end-stage renal disease. The study search was conducted using specific terms cited in the inclusion and exclusion criteria which minimize study bias (Whittemore & Knafl 2017). Identifying potential risk for bias when conducting an integrative review, as bias can occur at any point in the research study. Selection, attrition, measurement, and publication are examples of biases that can occur during an integrative review (Toronto & Remington 2020). The studies used in this integrative review have been evaluated to be free of bias.

Internal Validity

The validity of a study is measured by its transferability, credibility, and confirmability of the research results. Data saturations give credence to the fact of a study, and transferability means the study's results can be transferred to other situations and whether or not the findings can be generalized. Credibility ensures that only the findings are addressed, and confirmability means that others can confirm the results (Toronto & Remington, 2020).

The integrative review data collection and evaluation were limited, as only one reviewer was the primary project leader, increasing the risk for bias and internal validity (Toronto & Remington, 2020). For example, bias could be evidenced in the project leader's positive evaluation of evidence that supports the integrative review hypothesis and negative assessment

of the evidence that does not support the integrative review hypothesis (Whittemore & Knafl, 2005). In locating relevant studies for the integrative review, the project leader may include arbitrary search limiters, such as the geographical location or year of publication which can produce a biased sample because it might exclude a relevant body of evidence. Moreover, the project leader may limit their literature search to databases known to them or not fully include a representation of available databases.

Appraisal Tools

The data appraisal stage involved the development of a level of evidence matrix, which entailed the ordering, categorization, and summarization of data found in the literature selected. The process entailed collecting data that coincided with the review's focus, which was palliative care for patients with end-stage renal disease. The records of this analysis process are kept for integrity and transparency purposes. The level of evidence matrix entailed collecting and recording the citations, examining each source, and analyzing the purpose of the integrative review. The methodology used were relevant for this integrative review . According to Whittemore and Knafl (2005), this approach allows data collected from different studies with multiple methodologies. Additionally, this review adopted a quantitative approach that entailed analyzing the resulting themes within the results and is presented in a table format (see Table 1).

Applicability of Results

Applicability of results (also called external validity or generalization) contains a multidimensional concept, depending on the extent to which participants, the context of care, and the interventions (and comparators) evaluated in studies are representative of, or can be reproduced (Toronto & Remington, 2020). As a result, the applicability of a trial's results could

be limited if patients represent only a small portion of those being treated in normal practice. In ensuring the applicability of the results, this integrative review utilized inclusion and exclusion criteria in identifying the sources used to generate data. The research studies included those published between 2015 and 2021, resulting in the most current literature for the topic of the integrative review. The section was also limited to peer-reviewed journals addressing the topic of palliative care, symptom management, and improvement of quality of life in patients with end-stage renal disease. These measures ensured the applicability of the results across a larger population.

Reporting Guidelines

According to Li et al. (2019), the purpose of an integrative review is to provide an answer for a phenomenon or clinical question. A well-developed and written integrative review addresses a clinical question to improve clinical practice and, or, change clinical policies, which can impact patient care (Whittemore & Knafl 2005). Consequently, unlike other studies, an integrative review allows for a diverse methodology that plays a more significant role in evidence-based practice for nursing practice changes. Results from the integrative review are displayed in a Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) diagram (see Figure 1) to increase quality, transparency, and reporting, which would allow for ease of viewing, interpretation, and comprehension by readers (Toronto & Remington 2020).

SECTION FIVE: DATA ANALYSIS AND SYNTHESIS

A Thematic Analysis

The data appraisal stage involved the development of a level of evidence matrix, which entailed the ordering, categorization, and summarization of data found in the literature selected.

The data collection focused on research studies regarding the quality of life in patients with end-stage renal disease undergoing palliative care. Additionally, these research articles will be kept for 24 months for integrity purposes. The development of the level of evidence matrix involved collecting and recording the citation and analysis focus for each source, analyzing the purpose of the integrative review, the methodology used, its limitations, and its relevance for this integrative review. This approach allowed the project leader to collect data from different studies with multiple methodologies. This review adopted a quantitative approach that entailed analyzing the resulting themes within the results. The results are presented in a table format (see Table 1 for the results of matrix) (Toronto & Remington, 2020; Whittemore & Knafl, 2005).

The literature review revealed several positive factors about applying palliative care in patients with end-stage renal disease. The study review process identified themes that supported the topic of palliative care on quality of life in patients with end-stage renal disease. The process involved the development of the leveling of the evidence matrix that entailed the ordering, categorization, and summarization of data found in the studies selected. According to Whittemore and Knafl (2005), this approach allows for the project leader to collect data from different studies with multiple methodologies and organize and data to support the topic of interest. Overall, the literature review results reinforce the need for palliative care incorporation in the care of patients with end-stage renal disease, which will lead to an improvement in their overall quality of life. The summary is presented in Table 1 below.

Descriptive Results

The data identified while conducting research for this integrative review included themes related to factors that affected the care of the patients with end-stage renal disease and their improved quality of life. The information extracted from the literature search included outlines

and themes, building a link to help synthesize the results in such a way to help the reader to understand better the data (Whittemore & Knafl, 2005).

The themes which were extracted from the literature review are assessment tools identifying symptoms to improve quality of life in patients with end-stage renal disease, current barriers limiting palliative care consults, current practice related to symptoms assessment and management prior to palliative care, and lastly, the effectiveness of palliative care in the management of patients with end-stage renal disease.

Synthesis

The project leader reflected on a possible correlation between palliative care and improved quality of life in patients with end-stage renal disease. This is further explored under the four themes identified in the literature review and mentioned in the preceding paragraph.

Current Barriers Limiting Palliative Care Consult

The barriers limiting the application and effectiveness of palliative care by medical providers (especially nephrologists) other than palliative care providers were discussed in 11 of the 30 studies selected for this integrative review Alshamsi et al., 2018; Axelsson et al., 2019; Bates et al., 2017; Castro, 2019; Davis et al., 2015; Hawley, 2017; Jablonski, 2007; Jawed et al., 2019; Lazenby et al., 2017; Pommer et al., 2019; Sturgill & Bear, 2019. The research articles identified barriers, such as lack of training received by providers when discussing renal disease prognosis during end-stage renal disease, as well as providers not fully understanding the role of palliative care and how they can be of benefit in the care of patients with end-stage renal disease in active treatment. Additionally, nephrologists expressed fear related to the belief that involving palliative care will result in the premature withdrawal of hemodialysis from their patients. Alshamsi et al. (2018) concluded that 83% of the nephrologists in the literature continued to

provide dialysis to patients in a vegetative state due to this belief, and 48% of nephrologists reported that they would not withhold hemodialysis for patients who develop kidney failure to avoid having difficult discussions related to discontinuing treatment.

Axelsson et al. (2019) also identified challenges that limited the improvement of the patient's quality-of life related to the coordination of care of the end-stage renal patient, which included communication issues between the patient's hemodialysis setting as well as providers, which can have a negative effect on the patient's quality of life. Barriers also identified were based on the provider's experience with palliative care, beliefs, and knowledge, as these showed to be critical predictors of who will place palliative care consults which can affect the management of patient care and lead to poor quality of life. Such decisions are influenced by socio-cultural and religious beliefs, and hospital policies which can limit the use of palliative care for patients with end-stage renal disease, thus impacting the patients' quality of life. Jawed et al. (2019) noted that some barriers to palliative care in current practice include the lack of awareness of the palliative care option, symptom management needs of end-stage renal patients, time constraints of office visits, and inadequate patient assessments as well as the emphasis placed on hospital discharges.

Bates et al. (2017) explained that most patients have financial challenges that limit their access to care and treatment options for a better quality of life. The respondents of the study cited the change of roles from breadwinner to dependent as a significant psychological issue preventing them from seeking palliative care. Sturgill & Bear (2019) stated that there are clinical tools for clinicians to accurately prognosticate patients that will assist in making decisions regarding palliative care needs. Similar to the findings by Bates et al. (2017), most patients with

end-stage renal disease are less likely to utilize the palliative care benefit due to fears that their symptom burden needs would not be addressed. Thus, their quality of life will not be improved.

Lazenby et al. (2017) revealed that physicians avoid prognosis discussions with patients as they are under the assumption that patients do not want to discuss the prognosis. The literature review shows that by avoiding these discussions, these physicians are unknowingly limiting their patients' capacity to make informed decisions affecting their care, thus impacting their quality of life and their right to choose. Furthermore, the literature shows that advanced care planning is not commonly carried out, and end-of-life care discussions are seldom initiated before patient deterioration. The literature also showed that there is variability in the quality of life practices at end-of-life amongst nephrologists; some patients are felt to be withdrawn from dialysis too late, thus leading to poorer quality of life toward the end of life. Additionally, the options of withholding or withdrawal from hemodialysis are not commonly discussed with patients and/or families. Thus, when these treatments are discontinued, patients carry a heavy symptom burden which can have a negative impact on their quality of life toward the end of life. Castro (2019) revealed the factors that limit access to palliative care includes patients' age, increased comorbidity associated with end-stage renal disease, and patients' socioeconomic status. Furthermore, patients with end-stage renal disease should be managed by a nephrologist, and for symptom management, they should be managed by a palliative care specialist for improved symptom management and better quality of life outcomes.

Pommer et al. (2019) explained that physicians were not familiar with the utilization of palliative care services while patients were actively undergoing hemodialysis treatment. Moreover, palliative care was only utilized by patients undergoing conservative renal care, and when providers felt that their patients' condition was presumed fatal or had poor mental and

physical conditions, and hemodialysis would be contraindicated for survival. Patients only received a palliative care consult from the nephrologists when the end of life was near or when patients were ready for the withdrawal of hemodialysis—which led to late palliative care consults and heavy symptom burden towards end-of-life. Davis et al. (2015) stated that late palliative care consults decrease the benefits to patients and their families, which may be due to the team's lack of education in palliative care services or lack of resources and staff in the institution that provides palliative care services.

Hawley's (2017) study suggested that barriers preventing palliative care consults are ignorance regarding palliative care, reluctance to refer to the service, not fully understanding the positive resources of palliative care. Lastly, the fear of upsetting patients when the term "palliative care" is used, fearing that patients may confuse the word "palliative care" and "hospice" as being the same. The study also stated that providers did not want to turn their patients over to palliative care, fearing that the patient may feel that they were abandoning them to another service or the fear that their patients may see a palliative care referral as an admission of failure to cure or treat them.

This section concluded that providers should be educated on their ability to identify patients with end-stage renal disease symptom burden and the impact of those symptoms on their patients' quality of life. Nephrologists should be required to have the training to assess and treat the symptom burden that accompanies patients with end-stage renal disease, which may include pain, fatigue, muscle cramps, and nausea, among others. Additionally, for those nephrologists who are not appropriately trained or feel competent with managing these symptoms, referrals to palliative care for symptom management should be given, affording patients better access to improved symptom burden and a better quality of life.

Current Practice Related to Symptoms Assessment and Management Prior to Palliative Care.

Patients with end-stage renal disease have a significant symptom burden that most nephrologists fail to assess. Due to the failure to assess patients' symptom burden, patients suffer poorer quality of life during their disease trajectory, leading to increased symptom burden and recurrent hospitalization. These studies address the nature of these symptom burdens and how nephrologists make decisions regarding end-stage renal disease symptom management. The nature of the care provided to patients on hemodialysis related to symptom burden prior to palliative care was discussed in seven of the 30 selected studies. These studies include Alshamsi et al. (2018); Bates et al. (2017); Grubbs et al. (2017); Kwok et al. (2016); Jawed et al. (2019); Lowney et al. (2015); and Pommer et al. (2019).

Alshamsi et al. (2018) suggested that the decision-making of some nephrologists was influenced by factors such as socio-cultural beliefs, hospital policies, and religious beliefs regarding symptom assessment and symptom management, causing a lack of care toward patients with end-stage renal disease. The study by Kwok et al. (2016) revealed that the five most prevalent symptoms for end-stage renal disease patients were dyspnea (63.7%), fatigue (51.8%), edema (48.2%), pain (44.2%), and anorexia (38.1%). These symptoms were ascertained from study reviews as the most troublesome symptoms experienced by patients with end-stage renal disease. In addition, studies showed that these symptoms were poorly assessed and poorly managed by providers if palliative care was not involved in patients' care with renal disease. The five most prevalent interventions initiated by nephrologists in the treatment of patients with end-stage renal disease were oxygen administration (69.5%), parenteral infusion (67.3%), antibiotics (53.5%), bladder catheterization (44.7%), and analgesic (39.8%) in the last two weeks of life.

Lowney et al. (2015) reported that since nephrologists have unique relationships with

their patients for an extended period, they should be skilled with the basic symptom assessment and management skills to treat the complex needs of patient refractory symptoms properly.

Nephrologists should require the basic assessment skills to meet the multifaceted needs to care for their patients' baseline disease symptom needs. From the literature review, the most common causes of death for patients with end-stage renal disease were cardiovascular events (18.6%) and infection (17.2%), which carry a high symptom burden. Thus, there is an increased need for a nephrologist to be competent in their ability to assess for symptom burden in their patients, as well as have the ability to manage these symptoms throughout the disease trajectory to improve their patients' quality of life.

Bates et al. (2017) concluded that patients with end-stage renal disease complained of functional changes such as increased pain, insomnia, breathlessness, itching, fatigue, nausea, vomiting, and depression. The problem occurs when patients' symptom burdens go unassessed and untreated for years by their nephrologists. Jawed et al. (2019) states that reduced provider awareness of symptom assessment and management contributes to undertreatment. Research results suggest that nephrologists' current management approaches fail to identify patients with end-stage renal disease symptom burden, which leads to inadequately managed symptoms resulting in the undue suffering of patients. Further, Grubbs et al. (2017) research revealed that patients with end-stage renal disease, compared to other illnesses with similar Palliative Performance Scale (PPS), also reported moderate to severe anxiety and nausea. Based on those studies, a need for palliative care teams to manage patient symptom burden, especially patients with end-stage renal disease, is indicated. Palliative care will not only assess patient symptom burden. Still, it will also provide providers with the education and tools needed to be adequately trained and experienced to manage patient symptoms and distress on all levels. Symptoms may

include physical, emotional, and existential stressors. The study also showed that symptoms improved after consultation with palliative care providers.

The study written by Pommer et al. (2019) reported that physicians' decisions related to lack of symptom assessment were influenced by presumed fatal prognosis and poor mental and physical conditions of patients, thus leading to poor management. Lack of assessment of symptoms were left undone until patients were at end-of-life. Patients were not given any prognostication or direction of care to help them with decision-making until they were days away from end-of-life when they were referred to hospice care. Unfortunately, when patients were referred to hospice, they were already suffering from a heavy symptom burden.

This section reported that providers poorly assessed symptom assessment and management in patients with end-stage renal disease due to multiple factors. This section suggested that assessment tools, provider training, and palliative care were highly recommended to help improve the symptom burden and quality of life of patients with end-stage renal disease.

The Effectiveness of Palliative Care in the Management of Patients with End-Stage Renal Disease

While conducting the literature search for this integrative review, the data indicated that palliative care would be beneficial in the care of patients with end-stage renal disease to achieve an improved quality of life. These studies include Bates et al. (2017); Bonner et al. (2018); Davis et al. (2015); Gaertner et al. (2017); Grubbs et al. (2017); Jablonski (2007); Jawed et al. (2019); Kavalieratos et al. (2016); Lowney et al. (2015); Phongtankuel et al. (2016); Quinn et al. (2020); Rosansky et al. (2017); Siouta et al. (2016); Song et al. (2018); and Spilsbury & Rosenwax (2017). Thus, 15 of the 30 studies addressed the effectiveness of palliative care in patients with end-stage renal disease management.

The study by Bates et al. (2017) reveals that symptom burdens experienced by patients with end-stage renal disease could be better addressed through the use of a patient-centered palliative care team. Bonner et al. (2018) reported that palliative care was highly beneficial in the management of patients' symptoms and its impact on improving patients' quality of life. Additionally, this study concluded that patients' quality of life would be immensely enhanced throughout the disease process when symptoms are identified and appropriately treated. Other studies revealed that the advantage of palliative care is valuable to patients' physical, emotional, and social well-being and thus has a positive impact on patients' quality of life (Davis et al. (2015); Gaertner et al. (2017)).

In addition, Grubbs et al. (2017) suggested that there are positive effects for those who receive palliative care during treatment for their end-stage renal disease, and this research study also helped illustrate the need for improved symptom management, which may lead to an improved quality of life for patients with end-stage renal disease. Jablonski (2007) described that palliative care should be offered to all patients undergoing renal replacement therapy due to patients' high symptom burden. As a result of this burden, these patients would benefit from palliative care management throughout their disease process.

Jawed et al. (2019) revealed that palliative care providers are skilled in symptom assessment and managing end-stage renal disease patients. In contrast, non-palliative providers may not have similar training to provide these patients with the same level of care. Kavalieratos et al. (2016) concluded that palliative care interventions were associated with improvements in patient quality of life and symptom burden when introduced in patients with a life-limiting illness. The study by Lowney et al. (2015) supports those patients with end-stage renal disease do suffer from a high symptom burden and will benefit from the integration of palliative care as

part of their supportive medical management. Finally, Phongtankuel et al. (2016) reported that the integration of palliative care positively impacts patient quality of life.

Quinn et al. (2020) revealed that patients with end-stage renal disease who receive palliative care interventions had associated lower symptom burden, lower hospitalizations, and fewer emergency room visits; thus, they experience significant improvements in quality of life. Additionally, Song et al. (2018) explained that patients reported an overall improvement in cognitive functioning, emotional well-being, and spiritual well-being over time with incorporating palliative care interventions. In addition to benefitting the patient physically and emotionally, Spilsbury & Rosenwax (2017) explained that community-based palliative care providers help to reduce healthcare costs spending by 27% per patient per day and was associated with a reduction in the average inpatient hospital costs of nine percent per hospitalized patient, per day.

Assessment Tools Identifying Symptoms to Improve Quality of life in Patients with End-Stage Renal Disease

The need for effective assessment tools to identify patients' symptom burden to manage and treat patients properly was discussed in nine of the 30 of the selected studies Bonner et al., 2018; Davis & Hui, 2017; Gaertner et al., 2017; Jablonski, 2017; Kavalieratos et al., 2016; Lowney et al., 2015; Ng et al., 2021; Raj et al., 2018; Song et al., 2018. In general, the research studies addressed the need for adequate recognition and treatment of symptom management to improve quality of life, with the initial step being assessing patients' symptoms. In addition, the studies addressed a lack of standardized assessment tools for the patient with end-stage renal disease, which addresses their physical, psychosocial, and existential symptom burden.

Bonner et al. (2018) revealed that using an assessment tool is essential and beneficial to track a patient's symptom burden and quality of life toward the last year of life. The study reviewed five different tools in patient care. These include the Australian Karnofsky Performance Scale (AKPS), the Functional Assessment of Chronic Illness Therapy Palliative-14 (FACIT PAL-14), the Assessment of Quality of Life 6 Dimensions (AQoL-6D), the Sheffield Profile for Assessment and Referral for Care (SPARC), and the Chronic Kidney Disease-Symptom Burden Index (CKD-SBI). After implementing the assessment tools, nephrologists were better able to identify patients' symptom burden, which led to better treatment and improved quality of life. Bonner et al. (2018) also determined that for the patient with end-stage renal disease, a symptom assessment tool should be a part of their routine care and a routine palliative care consult. The study concluded that with an assessment tool, physicians were able to evaluate patient symptoms experienced and assess physical factors that impacted their quality of life. By this assessment, providers are better able to treat their patients, resulting in an improved quality of life. In addition, Kavalieratos et al. (2016) also utilized the Functional Assessment of Chronic Illness Therapy Palliative (FACIT PAL), as well as the Edmonton Symptom Assessment Scale (ESAS) to evaluate the effects of assessment tools on patients' symptom burden and quality of life. Research suggests that there was a steady improvement in symptom burden and a positive reported improvement in patients' quality of life associated with the use of the symptom assessment tool and the integration of palliative care.

Davis and Hui (2017) explained that palliative care aims to enhance patients' quality of life who suffer from chronic diseases. This study focuses on patients with end-stage renal disease and using assessment tools to assess their quality of life with the help of self-assessment questionnaires. These authors reviewed the use of the McGill Quality of life Questionnaire, the

EORTC-QLO-C30, and the ED-5D to assess patients with end-stage renal disease and their responses related to the quality of life. The study suggests that palliative care assessment tools are valuable in engaging patients when used, as they relate to the patients and improve their quality of life throughout their disease process.

Gaertner et al. (2017) conducted a systematic review and meta-analysis to assess the effectiveness of palliative care assessment tools in measuring the quality of life. The evaluation tools used for this research study were the EORTC QLQ-C3 which assessed functional status and quality of life in patients with end-stage renal disease, and the Multidimensional Quality of life Scale (MQOLS). These questionnaires identified the need for further development of clinical tools for symptom management and early palliative care integration in patient care. In addition, the authors noted that both palliative care and assessment tools are best used early on in patients' disease processes to achieve the best possible outcomes to better address patients unmet needs.

Jablonski (2017) states that palliative care is a total program designed to care for patients with chronic diseases (such as end-stage renal disease) to improve their quality of life. This research study investigated the use of a disease-specific assessment tool such as the Multidimensional Symptom Assessment Scale (MSAS), which assessed the intensity, frequency, duration, and distress associated with physical symptoms commonly experienced by patients with end-stage renal disease. The study suggested those patients with end-stage disease experience a high symptom burden both physically and psychologically. Those patients who scored higher had an increased symptom burden and reported lower quality of life. The research reflected that patients' appreciated being allowed to express themselves to the clinician, who was willing to listen to their otherwise neglected symptom burden. As a result, the study supports the integration of palliative care in patients with end-stage renal disease for the best patient

outcomes. For this population, it will be a managed symptom burden and improved quality of life.

A study conducted by Lowney et al. (2015) revealed that patients who have long-term relationships with their nephrologist had poor symptom management. Subsequently, due to these long relationships, nephrologists might overlook components of patient care at times, which may lead to increased symptom burden and decreased quality of life. Therefore, the authors used the assessment tool, the Palliative Care Outcome Scale (POS-renal), from the original POS and adapted it to meet the need of renal patients to help identify the symptom burden. The aim of the tool was to aid nephrologists in evaluating the severity of patient symptom burden. The completed surveys revealed that patients with end-stage renal disease had an increased frequency and severity of symptom burden and poorer quality of life. The authors also concluded that a multi-professional team approach is the best way to improve patient care and quality of life due to the patient population vulnerability.

Ng et al. (2021) conducted a research study that examined the factors that impact the symptom burden of patients with end-stage renal disease. Patients with end-stage renal disease on hemodialysis experience significant symptom burden and, due to those symptoms, may suffer a poorer quality of life. Identifying these factors may improve their quality of life. The tool that was used to assess symptom burden for this study was the Dialysis Symptom Index (DSI). The Dialysis Symptom Index assessed for the occurrences of distress from patients' physical, psychosocial, and sexual aspects of their life over a four-week period. The survey that was conducted showed that 46% of the 271 participants that took part in the study scored 30% or greater, which meant that they were experiencing a heavy symptom burden and poor quality of life. The higher the distress score, the poorer the quality of life. The authors concluded that, due

to the needs of the patient with end-stage renal disease, they require a holistic approach to symptom management for an improved quality of life.

The study written by Raj et al. (2018) stated that assessment tools are valid, reliable, and even necessary to capture patients' subjective symptom complaints to treat them appropriately. The assessment tool reviewed by this study was the Integrative Palliative Outcome Score Renal (IPOS) survey, which was developed from other pre-existing assessment tools. This assessment evaluated patients with end-stage renal disease and their views on quality of life in different domains. As noted in the study, assessment tools help minimize patients' hesitancy in mentioning their symptoms to their provider and assist providers to better assess patient symptom burden; thus, improving management and patients' quality of life.

The research written by Song et al. (2018) discusses the results of patients' quality of life from an overall symptom burden standpoint. The study reviewed several assessment tools, including the Edmonton Symptom Assessment System (ESAS), which measures overall symptoms (e.g., pain; fatigue; insomnia; and nausea). The Center for Epidemiologic Studies Depression Scale-Short Form (CESD-SF) measures emotional well-being, and the 12-item Functional Assessment of Chrome (FACT-Sp) measured spiritual well-being. The studies identified the need for patient assessment tools to evaluate symptom burden and quality of life. Unfortunately, both are subjective and can only be known by patient self-report. Nevertheless, the tools used were able to identify patients' symptom burden on the different domains over 12 months. Consistently, the continued use of the assessment tools revealed improvement in patients' reported quality of life.

End-stage renal disease is an illness that affects more than just the kidneys. It also affects the entire body on several different levels. In addition, patients with end-stage renal disease

manage many other health components that affect their physical and psychosocial being (Ng et al. 2021). It takes providers with a unique set of skills who can adequately assess, manage, and continuously treat patients with end-stage renal disease throughout their disease trajectory to meet their symptom management care goals. The evidence-based *studies* for this integrative review recommend that palliative care be woven into routine care for patients with end-stage renal disease to improve patients' symptom burden and quality of life throughout the disease process.

Ethical Considerations

This project is an integrative review that did not have human participants and did not contain personal patient information. This integrative review complied with the Liberty University Institutional Review Board (IRB) policies, and data was collected, analyzed, and stored in the project leader's computer, which is password-secured. A copy of both the Collaborative Institutional Training Initiative (CITI) certificate and IRB approval letters are provided in the Appendices (see Appendices A and B).

TIMELINE

	Start Date	Progress Remarks			
		Date Completed or Approved	Date Needs to Be Completed	In Progress	No Progress
Proposal					
Abstract	9/12/21				
Acknowledgement	9/13/21				
SSECTION ONE: FORMATULATING THE REVIEW QUESTION	8/31/20 revised 12/12/20				
Introduction					
Defining concepts and variables	9/7/20				

Rational for conducting the review	9/19/20				
Purpose and review question	9/27/20				
Formulate inclusion and exclusion criteria	10/3/20				
Conceptual framework	10/13/20				
SECTION TWO: COMPREHENSIVE AND SYSTEMATIC SEARCH	10/20/20				
Search organization and organization and reporting strategies	10/30/20				
Terminology	10/15/20				
Critical Appraisal	10/05/2020				
Synthesis	10/12/2020				
Theoretical Framework	NA				
Prisma	11/01/20				
Polit and Beck	11/01/20				
Cooper; Whitemore and Knafl	11/01/20				
SECTION THREE: MANAGING THE COLLECTED DATA	6/23/21				
SECTION FOUR: QUALITY APPRAISAL	6/30/21				
Sources of Bias	7/10/21				
Internal Validity	7/10/21				
Appraisal Tools (Literature Matrix)	7/21/21				
Applicability of Results	7/18/21				
Reporting Guidelines (Whitmore & Knafl)	7/30/21				
SECTION FIVE: DATA ANALYSIS AND SYNTHESIS	8/04/21				
Data Analysis Methods	8/09/21				
Descriptive Results	8/12/21				
Synthesis	8/15/21				
Ethical Consideration	8/15/21				
Timeline	9/8/21				
SECTION SIX: Discussion	8/14/21				
Implications for Practice/ Future Work	8/17/21				
Dissemination	8/17/21				

DNP Essentials	8/25/21				
DNP Project Oral Defense	10/18/21				
Comments					

SECTION SIX: DISCUSSION

Implications of Practice/ Future Work

The purpose of the Doctor of Nursing Practice degree serves to prepare the advanced practice nurse to conduct research activities that will improve healthcare practice and advance the practice of nursing. This degree plays a crucial role in implementing palliative care in caring for patients with end-stage disease processes by enhancing the practice of nursing through continued research and advanced practice (Edwards et al., 2018). The project leader has conducted a rigorous literature review that has identified themes that both impact and improve patients' care and the quality of life of patients with end-stage renal disease. The goal of this project was to explore the benefit of integrating palliative care for patients with end-stage renal disease to improve their overall quality of life, including physical, mental, and psychosocial health, and answer the question: Does palliative medicine improve the quality of life in patients with end-stage renal disease?

A review of the literature suggests that the incorporation of palliative care for every patient diagnosed with end-stage renal disease requiring renal replacement therapy which will require a potential practice change may help improve symptom management for patients with end-stage renal disease. Subsequent findings from this integrative review suggest that using a of a symptom assessment tool would improve patient quality of life with end-stage renal disease. Further research would need to develop and use a symptom assessment tool for patients with end-stage renal disease, as the literature review concluded that using a symptom assessment tool for patients with end-stage renal disease might help improve the quality of life by adequately

identifying symptoms. However, further research would need to be done in this area, as this was not the focus of this integrative review. Further research is also necessary to assess the ongoing impact of assessment tools in the care of patients with end-stage renal disease and their implications for patient care, mainly when used by nephrologists. Nevertheless, from the literature review, the assessment tool may be an effective tool to identify patient distress to treat sooner, improve symptom management, and improve their quality of life.

Dissemination

The findings from this integrative review will be disseminated to healthcare providers via PowerPoint presentation and as a poster presentation. The results will be shared with the palliative care department during Fellow Education week for the Georgia Medical Educational Department and the Georgia Kidney Association. This presentation will reflect the evidence from the literature of the positive impact that palliative care has on the quality of life in the patients with end-stage renal disease. The poster will also be presented at the American Academy of Hospice and Palliative Medicine (AAHPM) on February 9-12, 2022, in Nashville, TN.

Summary

End-stage renal disease carries a high symptom burden for patients who are affected by this disease. This integrative review aimed to explore whether the integration of palliative care improves the quality of life in those patients with end-stage renal disease. While palliative care provides an ideal opportunity to assess the wellness factors associated with end-stage renal disease, this integrative review was conducted to explore whether palliative care improves symptom burden in patients with end-stage renal disease, thus improving their quality of life.

The project leader has shown the correlation between improved quality of life by showing the four themes which are beneficial to the care of the patient with end-stage renal disease and how palliative medicine can positively impact patient care.

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Song, M.-K., Paul, S., Ward, S. E., Gilet, C. A., & Hladik, G. A. (2018). One-year linear

trajectories of symptoms, physical functioning, cognitive functioning, emotional well-being, and spiritual well-being among patients receiving dialysis.

American Journal of Kidney Diseases, 72(2), 198–

204. <https://doi.org/10.1053/j.ajkd.2017.11.016>

Sturgill, D., & Bear, A. (2019). Unique palliative care needs of patients with advanced chronic

kidney disease – the scope of the problem and several solutions.

Clinical Medicine, 19(1), 26–29. <https://doi.org/10.7861/clinmedicine.19-1-26>.

Taylor, F., Taylor, C., Baharani, J., Nicholas, J., & Combes, G. (2016). Integrating emotional

and psychological support into the end-stage renal disease pathway: A protocol for mixed methods research to identify patients' lower-level support needs and how these can most effectively be addressed.

BMC Nephrology, 17(111), 2–12. <https://doi.org/10.1186/s12882-016-0327-2>.

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- Toronto, C. E., & Remington, R. (2020). *A step-by-step guide to conducting an integrative review* (1st ed.). Springer.
- Whittemore, R., & Knafl, K. (2005). Methodological issue in nursing research: The integrative review-updated methodology. *Journal of Advanced Nursing*, 52(5), 546–553. <https://doi.org/doi: 10.1111/j.1365-2648.2005.03621.x>.
- World Health Organization. (2020). Palliative care: Key facts. <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.

Table 1

Table 1: Level of Evidence Table

Study 1 Alshamsi, F., Chaaban, A., Alrukhaiami, M., Bernieh, B., & Bakoush, O. (2018). Provision of renal care for patients with end-stage kidney disease in persistent vegetative state, in United Arab Emirates: A national survey of renal physicians. <i>Libyan Journal of Medicine</i> , 13(1), 1–9. https://doi.org/10.1080/19932820.2018.1490610	To assess the extent of withdrawing or withholding dialysis treatment during the provision of renal care at the end of life for patients with end-stage renal disease.	N= A random sampling of 29 nephrologists taking care of patients with end-stage renal disease.	A cross-sectional study	The study revealed that most nephrologists (83%) continue providing dialysis to patients in a vegetative state. Another 48% reported that they would withhold dialysis for patients who develop kidney failure. Such decisions are influenced by socio-cultural beliefs, hospital policies, and religious beliefs.	Level VI	The study sample size was too small to warrant the generalization of the findings.	The study provides key data on the care for end-stage renal disease. patients. It reinforces the need to provide early palliative care to avoid waste of resources as evidence. It also illustrates the need to develop healthcare policies that promote the proper allocation of resources in the renal department
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Study 2 Axelsson, L., Benzein, E., Lindberg, J., & Persson, C. (2019). End-of-life and palliative care of patients on maintenance hemodialysis treatment: A focus group study. <i>BMC Palliative Care</i> , 18(1), 1– 10. https://doi.org/10.1186/ s12904-019-0481-y	To describe nurses' and physicians' perspectives on end-of-life and palliative care of patients treated with maintenance hemodialysis	N= 17 renal nurses and five physicians in Sweden	A qualitative descriptiv e design using focus group interviews	There were challenges and barriers to providing quality palliative care in nephrology settings. The challenges identified challenges were related to coordination of care and different perspectives on care responsibiliti es that impacted symptom management and patients' quality of life, communicati on issues relating to the provision of palliative	Level VI	Small sample size.	Yes. It provides the barriers and perceptions of physicians to palliative care and the need to address them.
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				care where the hemodialysis setting was regarded as an impediment. Personal and professional experiences, beliefs and knowledge were considered of major importance.			
Study 3 Bagasha, P., Leng, M., Katabira, E., & Petrova, M. (2020). Health-related quality of life, palliative care needs and 12-month survival among patients with end-stage renal disease in Uganda: Protocol for a mixed methods longitudinal study. <i>BMC Nephrology</i> , 21(1). https://doi.org/10.1186/s12882-020-02197-7	The aim was to improve the understanding of quality of life amongst patients with advanced renal disease receiving care in a resource limited setting.	N=150-200 active hemodialysis patients receiving their care in an inpatient and outpatient settings of a government run facility.	A mixed longitudinal two arm study	Raising the awareness of patient needs and preferences, and the strengths and limitations of available health care services to care for the needs of patients with end-stage renal disease.	Level V	One main limitation is that the study sample came from one facility.	Yes, this study was able to draw the attention of the WHO in recognizing the need for improvement of quality of life in patients who suffer from end-stage renal disease. The study also showed that the use of outcome scale validated the need for symptom assessment for adequate treatment.

Study 4 Bates, M. J., Chitani, A., & Dreyer, G. (2017). Palliative care needs of patients living with end-stage kidney disease not treated with renal replacement therapy: An exploratory qualitative study from Blantyre, Malawi. <i>African Journal of Primary Health Care & Family Medicine</i> , 9(1), 1–6. https://doi.org/10.4102/pbcfm.v9i1.1376	The researchers undertook the study to identify the needs of ESKD patients not treated with Renal Replacement Therapy at QECH, Blantyre, Malawi to inform palliative care service providers and identify areas for future study	N= 10 adult patients (7 woman with median age of 60.5 years and of the seven, four were in treatment for HIV.	A qualitative explorative and descriptive design was used.	The study concluded four themes areas which requires further Are qualitative and quantitative research for patients with end-stage renal disease and the need for palliative care.	Level IV	The study sample size was small to warrant the generalization of the findings	Yes. This study reveals the symptom burdens that end stage renal disease patients experience and how they could be addressed through the provision of patient-centered palliative care. These findings will allow for the explanation of structure to improve the outcomes for patients with end-stage renal disease.
Study 5 Bonner, A., Chambers, S., Healy, H., Hoy, W., Mitchell, G., Kark, A., Ratanjee, S., & Yates, P. (2018). Tracking patients with advanced kidney disease in the last 12 months of life. <i>Journal of Renal Care</i> , 44(2), 115–122. https://doi.org/10.1111/jorc.12239	To describe symptom, quality of life, and support of care anticipated in the last year of life in patients with end-stage renal disease.	N= 19 patients	Observational, prospective, longitudinal design	The study concluded that regular assessment for quality of life and symptom management is needed for improved patient outcomes.	Level IV	Small study of sample. Patients were recruited from a single kidney health service.	Yes, this study was highly beneficial for both the proof that palliative care is effective in the symptom management and improved patient quality of life. This study proved that when symptoms are identified they can be treated appropriately for quality of life.
Study 6 Castro, M. (2019). Conservative management for patients with chronic kidney	To illustrate the metabolic alterations and symptoms arising	N= 60 journal studies.	Exploratory study	The results show 20-30% of the deaths of	Level VI	It is based on secondary data.	Yes. It reveals the need to address factors that limit access to early palliative care.

disease refusing dialysis. <i>Brazilian Journal of Nephrology</i> , 41(1), 95–102. https://doi.org/10.1590/02175-8239-jbn-2018-0028	from chronic kidney disease treated clinically without the aid of dialysis			patients with chronic kidney disease with indication to undergo dialysis occurs after refusal to continue dialysis, discontinuation of dialysis, or inability to offer dialysis on account of local conditions. Factors that limit access to palliative care include aging, increased comorbidity associated with chronic kidney disease, and socioeconomic status.			
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<p>Study 7 Couchoud, C., Arnaud, D., Lobbedez, T., Blanchard, S., Chantrel, F., Maurizi-Balzan, J., & Moranne, O. (2017). Access to and characteristics of palliative care-related hospitalization in the management of end-stage renal disease patients on renal replacement therapy in France. <i>Nephrology</i>, 22(8), 598–608. https://doi.org/10.1111/nep.12822</p>	<p>The researchers sought to analyze the access of palliative care-related hospitalization in the management of patients on dialysis in France by describing the characteristics of these hospitalizations, the clinical status of the concerned patients, and the use of palliative care in those stopping dialysis.</p>	<p>N= 51,834 patients aged 20 years and older who began dialysis from 1 January 2008 to 31 December 2013.</p>	<p>Systematic review & meta-analysis of randomized controlled trials</p>	<p>1865 patients (3.6%) had palliative care-related hospitalization, corresponding to a total of 3382 hospitalizations. Lower levels of serum albumin, active cancer, and impaired mobility were each independently associated with the probability of at least one such hospitalization. 4540 patients withdrew from dialysis (9% of the patients), 10% of them</p>	<p>Level I</p>	<p>The study was limited to hospitalizations, yet patients might have palliative care at home or in a nursing home after hospital discharge or directly without any hospitalization.</p>	<p>Yes. The findings will allow me to describe the need to train nephrologists and physicians in palliative care to enable them to identify patients who should be referred to palliative care.</p>
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				had a palliative care-related hospitalization.			
Study 8 Davis, M. P., & Hui, D. (2017). Quality of life in palliative care. <i>Expert Review of Quality of Life in Cancer Care</i> , 2(6), 293–302. https://doi.org/10.1080/23809000.2017.1400911 .	To provide an updated synopsis on the use of quality of life questionnaires in the palliative care setting.	N= several quality of life questionnaires, such as EORTC-QLQ-C30, MCGill QOL Questionnaire and EQ-5D have been used in the palliative care setting	Meta-analysis	Several quality of life questionnaires have been validated useful in palliative care settings. However there still are several gaps that impede their use in the clinical setting.	Level I	This study was not specific to a patient with end-stage renal disease.	Yes, this study could be adapted to focus on patients with end-stage renal disease and on the palliative care setting; we will define quality of life, discuss how quality of life instruments can be used clinically and in research, review approaches to validate these questionnaires, and how they can be used in utility analyses.

Study 9 Davis, M., P., Temel, J., S., Balboni, T., & Glare, P. (2015). A review of the trails which examine early integration of outpatient and home palliative care for patients with serious illness. <i>Annals of Palliative Medicine</i> ; 4(3), 99-121. https://doi.org/10.3978/j.issn.2224-5820.2015.04.04	The integrative review sought to investigate the benefits of early palliative care in the course of the disease trajectory for patients with serious illnesses as an outpatient and at home.	The literature search yielded 15 randomized control trials of outpatient palliative care and 13 randomized control trials of palliative home care. It also included 7 systematic reviews. These were collated into tables.	The methodology entailed a systematic review of palliative care randomized control trials.	The integrative review revealed advantages such as improvement in symptoms such as depression, improved patient quality of life, reduced aggressive care at the end of life, increased advanced directives, reduced hospital length of stay and hospitalizations, improved caregiver burden and better maintenance of caregiver quality of life	Level 1	The integrative review failed to identify what is meant by “early” palliative care.	Yes. The integrative review demonstrates the benefits of palliative medicine. It is useful to the DNP project and proves the need to provide palliative medicine consult in the care of ARD patients.
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				and reduction in the medical cost of care, as well as patient and family satisfaction. Some of the reviewed studies showed that symptoms and quality of life are not improved, and resource utilization and costs are not different from “usual” care.			
Study 10 Eckert, K., Motemaden, L., & Alves, M. (2018). Effect of hemodialysis compared with conservative management on quality of life in older adults with end-stage renal disease. <i>Journal of Hospice & Palliative Nursing</i> , 20(3),	How does palliative care improve quality of life in patients with advanced renal disease?	N=110-441. Studies conducted over a 2–3-year period. Patient with glomerular filtration rate (GFR) less than 15.	Systematic review	Discusses that patients who choose forgo hemodialysis may experience a better quality of life than those who	Level II	There was limited research on quality of life to guide this research related to hemodialysis	This study would help to build the that patients with advance renal disease do suffer from a higher symptom burdens and those symptoms will in fact impact patient’s quality of life. Nut when those symptoms

279–285. https://doi.org/10.1097/njh.0000000000000444 https://doi.org/10.1097/njh.0000000000000444				choose to undergo hemodialysis .			are addresses and manages patients can experience a better quality of life.
Study 11 Gaertner, J., Siemens, W., Meerpohl, J. J., Antes, G., Meffert, C., Xander, C., Stock, S., Mueller, D., Schwarzer, G., & Becker, G. (2017). Effect of specialist palliative care services on quality of life in adults with advanced incurable illness in hospital, hospice, or community settings: Systematic review and meta-analysis. <i>BMJ</i> , 357, 1-15 j2925. https://doi.org/10.1136/bmj.j2925	To assess the effect of palliative in patient with advanced illness.	N=3967 publication were reviewed with 10 randomized controlled trails with 2454 patients.	Systematic review and meta-analysis	Patients' quality of life in all aspects were improved with the incorporation of palliative medicine.	Level I	Many patients in specialized palliative care studies will die before the point in time of the primary quality of life analysis.	Yes, Patient's quality of life in all aspects were improved with the incorporation of palliative medicine, (physical, emotional, and social).
Study 12 Grubbs, V., O'Riordan, D., & Pantilat, S. (2017). Characteristics and outcomes of in-hospital palliative care consultation among patients with renal disease versus other serious illnesses. <i>Clinical Journal of the American Society of</i>	To compare rates of symptom severity and improvement and needs for advanced care planning between patients referred for palliative care consultation	N=33,183 patients, of whom 1057 (3.2%) had end-stage renal disease.	Observational study	Patients with renal disease or other illnesses had similarly low mean Palliative Performance Scale scores and reported	Level IV	Potential bias in a patient selection, where researchers concentrated on the sickest ones, which may not be reflective of the needs of the entire	Yes. It shows the effects of palliative care and the limitations that prevent its application to renal patients. It will help illustrate the need for the improved management and

<p><i>Nephrology</i>, 12(7), 1085–1089. https://doi.org/10.2215/cjn.12231116</p>	<p>because of renal disease and those with other serious illnesses.</p>			<p>similar moderate to severe anxiety and nausea. Symptoms improved similarly after consultation regardless of diagnosis except for anxiety, which improved more often among those with renal disease. Fewer patients with renal disease were referred to hospice than those with other illnesses.</p>		<p>hospitalized ESRD population</p>	<p>improved quality of life.</p>
<p>Study 13 Horton, J. R., Morrison, R., Capezuti, E., Hill, J., Lee, E. J., & Kelley, A. S. (2016). Impact of inpatient</p>	<p>Examined the relationship between palliative care and average hospital length in</p>	<p>N=295 hospitals with palliative care programs.</p>	<p>Observational study</p>	<p>Patient palliative care program alone not sufficient to</p>	<p>Level V</p>	<p>Patient palliative care program alone not sufficient to impact hospital</p>	<p>No, this study did not support project goal of proving improving quality of life, decreased</p>

palliative care on treatment intensity for patients with serious illness. <i>Journal of Palliative Medicine</i> , 19(9), 936–942. https://doi.org/10.1089/jpm.2015.0240	relation to improved quality of life.			impact hospital length of stay nor did it impact patient perceived quality of life.		length of stay nor did it impact patient perceived quality of life.	hospitalization, or decreased symptom burden.
Study 14 Jablonski, A. (2007). Level of symptom relief and the need for palliative care in the hemodialysis population. <i>Journal of Hospice & Palliative Nursing</i> , 9(1), 50–58. https://doi.org/10.1097/00129191-200701000-00010	The purpose of this study was to document the level of symptom relief of patients with end-stage renal disease treated with hemodialysis when they were treated by the palliative care services and the impact on their quality of life.	N= Two in-center dialysis clinics located in the Midwest US. The census of 281 patients. 51% male 49% female.	Descriptive cross-sectional design	The study concluded that with the incorporation of palliative care, patients showed improvement in symptom management and thus showed an overall improvement in their quality of life.	Level V	The measurement tool used to measure symptoms and level of relief as acknowledged, which was a disease-specific tool that assesses all symptoms and was not specific to those of renal disease only.	Yes, this paper concluded that palliative care should be offered to patients undergoing renal replacement therapy due to their high symptom burden. And due to their high symptom burden would benefit from palliative care management.
Study 15 Jawed, A., Moe, S., Moorthi, R., Torke, A., & Eadon, M. (2019). Increasing nephrologist awareness of symptom burden in older hospitalized end-stage	Improve the nephrologist awareness of symptom leads to symptom improvement, thus	N= 52 patients, with one who passed during the study.	Prospective multicentered interventional study	Improve the nephrologist awareness of symptoms leads to symptom improvement	Level IV	The limitations small sample size2nd Positions were aware that the study was taken	Yes, this study proved that without palliative care management, other providers are not skilled and are inadequate in the management of

renal disease patients. <i>American Journal of Nephrology</i> , 51(1), 11-16. https://doi.org/10.1159/000504333	improved quality of life.			, thus an improved quality of life.		place randomized.	symptom in patient with end-stage renal disease.
Study 16 Kavalieratos, D., Corbelli, J., Zhang, D., Dionne-Odom, J., Ernecoff, N. C., Hanmer, J., Hoydich, Z. P., Ikejiani, D. Z., Klein-Fedyshin, M., Zimmermann, C., Morton, S. C., Arnold, R. M., Heller, L., & Schenker, Y. (2016). Association between palliative care and patient and caregiver outcomes. <i>JAMA</i> , 316(20), 2104–2114. https://doi.org/10.1001/jama.2016.16840	To determine the association of palliative care with quality of life symptom burden, survival, and other outcomes for people with life-limiting illness.	N= 43 Randomized controlled trial provided data on 12,731 patients.	Systematic review and Meta-analysis.	Palliative care was associated with improvements in quality of life and symptom burden, but not with improved survival.	Level 1	The study limitations included what the author listed as missing data that could not be included after contacting authors such as quasi-experimental studies, several of which have demonstrated benefits of palliative care.	Yes; this study concluded that palliative care interventions were associated with improvements in patient quality of life and symptom burden.
Study 17 Kwok, A. O., Yuen, S., Yong, D. S., & Tse, D. M. (2016). The symptoms prevalence, medical interventions, and health care service needs for patients with end-stage renal disease in a renal palliative care program. <i>American Journal of Hospice and</i>	Evaluated the prevalence of symptoms and interventions initiated in the last two weeks of life, health care service utilization, and causes of death of patients with end-stage renal disease	N= 335 end-stage renal patients.	A retrospective study	The 5 most prevalent symptoms were dyspnea (63.7%), fatigue (51.8%), edema (48.2%), pain (44.2%), and	Level IV	The study was conducted in one center, which posed the limitation of generalization of the results. The response rate on the satisfaction survey was only	This study revealed the symptom burdens that end-stage renal disease patients experience and how they could be addressed through the provision of patient-centered palliative care.

<p><i>Palliative Medicine</i>®, 33(10), 952–958. https://doi.org/10.1177/1049909115598930</p>	<p>(ESRD under renal palliative care (RPC) program.</p>			<p>anorexia (38.1%). The five most prevalent interventions initiated were oxygen (69.5%), parenteral infusion (67.3%), antibiotics (53.5%), bladder catheterization (44.7%), and analgesic (39.8%) in the last two weeks of life. Each patient received 3.5 ± 4.4 outpatient clinic visits, 3.4 ± 10.3 home care visits, and 3.1 ± 2.7 hospital admissions.</p>		<p>around 65%, which may not be able to represent all bereaved patients' families.</p>	
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				The most common causes of death were cardiovascular events (18.6%) and infection			
Study 18 Lazenby, S., Edwards, A., Samuriwo, R., Riley, S., Murray, M., & Carson-Stevens, A. (2016). End-of-life care decisions for hemodialysis patients - 'we only tend to have that discussion with them when they start deteriorating'. <i>Health Expectations</i> , 20(2), 260–273. https://doi.org/10.1111/hex.12454	Identified the experiences and perceptions of doctors and nurses in nephrology for involving hemodialysis patients in end-of-life care decisions.	N= A sample of 15 doctors and five nurses in a large teaching hospital in Wales, UK.	A semi-structured qualitative interview study	Doctors and nurses avoid discussing prognosis with patients with the assumption that the latter does not want the information. Advance care planning is rarely carried out, and end-of-life care discussions are seldom initiated prior to patient deterioration. There is variability in end-of-life practices	Level VI	The sample size was small, which limits the generalizability of results. The dependence on interviews could have resulted in respondent bias.	The study provides profound insights into the management of end-of-life patients' renal care. It illustrates the need for improved care and new interventions to enhance clinical outcomes.

				amongst nephrologists ; some patients are felt to be withdrawn from dialysis too late. Furthermore, the possibility and implications of withdrawal are not commonly discussed with well patients. End of life care is not delivered well, which limits the quality of life			
Study 19 Lowney, A. C., Myles, H. T., Bristowe, K., Lowney, E. L., Shepherd, K., Murphy, M., O'Brien, T., Casserly, L., McQuillan, R., Plant, W. D., Conlon, P. J., Vinen, C., Eustace, J. A.,	The study describes the symptom profile of a large cohort of patients with end-stage renal disease on hemodialysis and evaluates how	N= total of 893 patients on hemodialysis.	Prospective Cross-sectional observational.	Patients with end-stage renal disease have a high symptom burden and experience a poor quality	Level V	Limitations include the absence of comorbidity indices and biochemical data from the analysis. A	Yes, this study supports the fact that patients with end-stage renal disease do suffer from a high symptom burden and can and will benefit from the incorporation of

<p>& Murtagh, F. E. (2015). Understanding what influences the health-related quality of life of hemodialysis patients: A collaborative study in England and Ireland. <i>Journal of Pain and Symptom Management</i>, 50(6), 778–785. https://doi.org/10.1016/j.jpainsymman.2015.07.010</p>	<p>symptom burden and other factors influence quality of life scores.</p>			<p>of life compared to the population of patients who do not suffer from end-stage renal disease.</p>		<p>decision was made not to include these data as comorbidity data, with the exception of diabetic status, were not recorded in a standardized format in the medical records in this study.</p>	<p>palliative care as part of their care.</p>
<p>Study 20 Ng, M., Wong, C., Choi, K., Hui, Y., Ho, E., Miaskowski, C., & So, W. (2020). A mixed methods study of symptom experience in patients with end-stage renal disease. <i>Nursing Research</i>, 70(1), 34–43. https://doi.org/10.1097/nnr.0000000000000479</p>	<p>The aim of this study was to explore factors that are associated with patient symptom experiences, using a symptom index to assess symptom burden.</p>	<p>N=271 participants to examine association of patient experience.</p>	<p>Mixed methods design using quantitative and qualitative components</p>	<p>Patients with end-stage renal disease receiving next dialysis experienced a significant symptom burden.</p>	<p>Level III</p> <p>The author noted that there was no difference in symptoms based on the types of dialysis received from patients. The second limitation was noted that there was only a limited number of demographics and clinical characteristics evaluated based</p>	<p>Yes, the study was able to conclude that there are several significant associations between patients reported symptom burden using correlation coefficients and multivariate regression analyses.</p>	

						on the review of literature.	
Study 21 Noble, H., Agus, A., Brazil, K., Burns, A., Goodfellow, N. A., Guiney, M., McCourt, F., McDowell, C., Normand, C., Roderick, P., Thompson, C., Maxwell, A. P., & Yaqoob, M. M. (2015). Palliative care in chronic kidney disease: The packs study—quality of life, decision making, costs and impact on carers in people managed without dialysis. <i>BMC Nephrology</i> , 16(104), 1–11. https://doi.org/10.1186/s12882-015-0084-7	The study sought to understand how patients make clinical care decisions and the impact of those decisions on caregivers regarding the application of conservative kidney management.	N= 112 patients is required.	The study is ongoing, and the study results have not been published.	A prospective multicenter, longitudinal study. It is a mixed-method study with both qualitative and quantitative components.	Level IV	The study will be based on self-reports by participants who will introduce tendencies of bias.	The study will reveal the needs of patients and the effects of their decisions on caregivers. It will show the importance of new approaches to care.
Study 22 Phongtankuel, V., Meador, L., Adelman, R. D., Roberts, J., Henderson, C. R., Mehta, S. S., del Carmen, T., & Reid, M. (2016). Multicomponent palliative care interventions in advanced chronic diseases: A systematic review. <i>American Journal of Hospice and Palliative Medicine</i> , 35(1), 173–	To assess the delivery of palliative care intervention on patient quality of life.	N=71 studies which detailed 64 unique palliative care interventions.	Systematic review	The study produced 71 studies, which detailed 64 unique multicomponent palliative care interventions.	Level I	The author listed limitations such as exclusions of articles not written in English, articles that excluded patients at end of life study may not reflect	Yes, this study shows that the integration of palliative care has an positive impact on patient quality-of-life.

183. https://doi.org/10.1177/1049909116674669						palliative care interventions first the author listed comprehensive search strategies which were studies excluded which were not written in English and intervention excluded that only targeted patients who were at end of life. published during the study period.	
Study 23 Pommer, W., Wagner, S., & Thumfart, J. (2019). Conservative care, dialysis withdrawal, and palliative care: Results from a survey of a non-profit dialysis provider in Germany. <i>Kidney and Blood Pressure Research</i> , 44(2), 158–169. https://doi.org/10.1159/000498994	To understand the practice pattern concerning conservative care, dialysis withdrawal, and palliative care support in renal patients	To understand the practice pattern concerning conservative care, dialysis withdrawal, and palliative care support in renal patients.	Randomized survey method	Most facilities and physicians were not associated with the utilization of conservative renal care and dialysis withdrawal. Palliative care varied between	Level IV	The study did not evaluate compliance with the fundamentals of palliative medicine, quality of caregiving, procedure, or documentation of decision-making process, which might	Yes. It reveals attitudes toward palliative care and barriers to effective palliative care. The findings will help identify the issues that should be addressed to make palliative care effective.

				facilities and physicians. Palliative care was only established in patients undergoing conservative renal care. Physicians' decisions were influenced by presumed fatal prognosis and poor mental and physical conditions of patients. Provision of palliative care was limited by lack of education in palliative medicine, shortness of staff, and lack of		contradict the responses provided by the participants.	
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				financial resources.			
Study 24 Quinn, K. L., Shurrab, M., Gitau, K., Kavalieratos, D., Isenberg, S. R., Stall, N. M., Stukel, T. A., Goldman, R., Horn, D., Cram, Detsky, A. S., & Bell, C. M. (2020). Association of receipt of palliative care interventions with health care use, quality of life, and symptom burden among adults with chronic noncancer illness. <i>JAMA</i> , 324(14), 1439. https://doi.org/10.1001/jama.2020.14205	The effect of palliative care on the importance on end-of -life outcomes in patients with noncancer illness.	N= 28 Randomized controlled trial of patients, 8 randomized clinical trials of patients with primarily noncancer illness.	Systematic review and meta-analysis.	Patients to receive palliative care interventions have associated lower symptom burden, lower hospitalization, and fewer emergency room visits.	Level I	The study included several other medical conditions, not just renal diseases. Many of the elements of palliative care were also present in usual care, which may underestimate the magnitude of the findings.	Yes, in one aspect but not related to quality of life as this study shows that palliative care compared with usual care, was statistically significantly associated with less acute health care use and modestly lower symptom burden, but there was no significant difference in quality of life
Study 25 Raj, R., Ahuja, K., Frandsen, M., Murtagh, F. E., & Jose, M. (2018). Validation of the ipos-renal symptom survey in advanced kidney disease: A cross-sectional study. <i>Journal of Pain and Symptom Management</i> , 56(2), 281–287. https://doi.org/10.1016/j.jpainsymman.2018.04.006	To assess the validity and reliability of the IPOS-renal survey (patient and staff version).	N= 81 patients (65 hemodialysis, 10 peritoneal dialysis, and six on supportive care; average ages are 64.9 years).	A cross-sectional study	The study resulted that the IPOS was able to collect the patient subjective illness concern and symptom burden.	Level III	None	Yes, very. Because symptom burden and quality of life are subjective an assessment tool is the best way to capture patients' most accurate responses for the most appropriate treatment..

<p>Study 26 Rosansky, S. J., Schell, J., Shega, J., Scherer, J., Jacobs, L., Couchoud, C., Crews, D., & McNabney, M. (2017). Treatment decisions for older adults with advanced chronic kidney disease. <i>BMC Nephrology</i>, 18(200), 1–10. https://doi.org/10.1186/s12882-017-0617-3</p>	<p>To understand how adult renal patients make decisions regarding dialysis initiation.</p>	<p>N= patient chart review from 1980-2012</p>	<p>Observational respective study</p>	<p>Older adults with advanced CKD are likely to die from non-renal failure related conditions before they are faced with a decision concerning dialysis. Most patients who initiate dialysis initiate treatment early. Most initiate dialysis because of acute renal failure. Dialysis does not provide survival benefits for older adults with poor mobility and</p>	<p>Level VI</p>	<p>None</p>	<p>Yes. The study shows the need for early palliative care and alternative treatments or older renal patients.</p>
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				high levels of comorbidity.			
Study 27 Siouta, N., Beek, K., V., van der Eerden, M., E., Preston, N., Hasselaar, J., G., Hughes, S., Garralda, E., Centeno, C., Csikos, A., Groot, M., Radbruch, L., Payne, S., & Menten, J. (2016). Integrated palliative care in Europe: A qualitative systematic literature review of empirically tested models in cancer and chronic disease. BMC Palliative Care; 15(56), 2-16. https://doi.org/10.1186/s12904-016-0130-7	To identify empirically evaluated models of palliative care (PC) in cancer and chronic disease in Europe, and develop a generic framework that will consist of the basis for the design of future models for integrated PC in Europe	14 studies were included: 7 models for chronic disease, 4 for integrated care in oncology, 2 for both cancer and chronic disease, and 2 for end-of-life pathways.	A systematic review of literature published from 01-01-1995 to 31-12-2013.	There is a strong agreement on the benefits of the involvement of a palliative care multidisciplinary team: better symptom control, less caregiver burden, improvement in continuity and coordination of care, fewer admissions, cost effectiveness, and patients dying in their preferred place.	Level I	The broadness of the topic under investigation.	Yes. The integrative review describes the benefits of palliative care and effective care models.
Study 28	The study evaluated the one-	N= 227 patients	Longitudinal	Patients reported	Level V	Study was conducted in a	Yes, this study was able to prove palliative

<p>Song, M.-K., Paul, S., Ward, S. E., Gilet, C. A., & Hladik, G. A. (2018). One-year linear trajectories of symptoms, physical functioning, cognitive functioning, emotional well-being, and spiritual well-being among patients receiving dialysis. <i>American Journal of Kidney Diseases</i>, 72(2), 198–204. https://doi.org/10.1053/j.ajkd.2017.11.016</p>	<p>year trajectory of patient reported dimensions of quality of life among patients on dialysis.</p>	<p>recruited from 12 dialysis centers.</p>	<p>observational study</p>	<p>overall symptoms, cognitive function, emotional well-being, and spiritual well-being improved over time with the incorporation of palliative care intervention.</p>		<p>single region of the US and included mostly patients with high level of function.</p>	<p>care positively impacting patients' overall quality of life, and decreases in their symptom burden when employed in their care.</p>
<p>Study 29 Spilsbury, K., & Rosenwax, L. (2017). Community-based specialist palliative care is associated with reduced hospital costs for people with non-cancer conditions during the last year of life. <i>BMC Palliative Care</i>, 16(1), 1–12. https://doi.org/10.1186/s12904-017-0256-2</p>	<p>To determine if community-based palliative care provided to people dying from non-cancer conditions was associated with reduced hospital costs in the last year of life and how this compared with people dying from cancer.</p>	<p>N= 12,764 decedents who, combined, spent 451,236 (9.7%) days of the last year of life in hospital.</p>	<p>A retrospective cohort studies.</p>	<p>All the decedents spent 451236 days of the last days in the hospital. Community-based specialist palliative care reduced their care costs by 27% per decedent per day. Community-based</p>	<p>Level IV</p>	<p>It is possible residual confounding by indication from the lack of clinical detail, particularly for non-hospitalized decedents, and motivations for accessing community-based specialist palliative care. The intensity of palliative care</p>	<p>Yes. It shows the effect of palliative care on the cost of healthcare, which reinforces the need for early palliative care.</p>

				specialist palliative care was also associated with a reduction of inpatient average hospital costs of 9% per hospitalized decedent per day. Hospital cost reductions were observed for decedents with organ failures, chronic obstructive pulmonary disease, and Alzheimer's disease.		was not assessed	
Study 30 Sturgill, D., & Bear, A. (2019). Unique palliative care needs of patients with advanced chronic kidney disease – the scope of the problem and several	Identified the barriers to effective palliative care and solutions to them.	N= 227 patients recruited from 12 dialysis centers.	Longitudinal observational study	There are few clinical tools for clinicians to accurately prognosticate	Level VI	The authors notes that they rely on past literature. There is a need for first-hand data to confirm the	Yes. The study illustrates the factors that limit effective renal care and the needs that will better address them, which

solutions. <i>Clinical Medicine</i> , 19(1), 26–29. https://doi.org/10.7861/clinmedicine.19-1-26				for individual patients. Patients with ESRD are less likely to utilize the hospice benefit than patients with other terminal illness.		validity of the results.	will then in turn improve patient care.
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Appendix A



Completion Date 15-May-2020

Expiration Date 15-May-2023

Record ID 36637548

This is to certify that:

Natoya Bender

Has completed the following CITI Program course:

Biomedical Research - Basic/Refresher (Curriculum Group)

Biomedical & Health Science Researchers (Course Learner Group)

1 - Basic Course (Stage)

Not valid for renewal of certification through CME. Do not use for TransCelerate mutual recognition (see Completion Report).

Under requirements set by:

Liberty University

CITI

Collaborative Institutional Training Initiative

Appendix B**LIBERTY UNIVERSITY**
INSTITUTIONAL REVIEW BOARD

June 17, 2021

Natoya Bender
Brenda Jessee

Re: IRB Application - IRB-FY20-21-1033 Palliative Care and Improving Quality of life in Patients with End Stage Renal Disease: An Integrative Review

Dear Natoya Bender and Brenda Jessee,

The Liberty University Institutional Review Board (IRB) has reviewed your application in accordance with the Office for Human Research Protections (OHRP) and Food and Drug Administration (FDA) regulations and finds your study does not classify as human subjects research. This means you may begin your project with the data safeguarding methods mentioned in your IRB application.

Decision: No Human Subjects Research

Explanation: Your study is not considered human subjects research for the following reason:

(4) "Scholarly and journalistic activities (e.g., oral history, journalism, biography, literary criticism, legal research, and historical scholarship), including the collection and use of information, that focus directly on the specific individuals about whom the information is collected," are not considered research according to 45 CFR 46.102(1)(1).

Please note that this decision only applies to your current application, and any modifications to your protocol must be reported to the Liberty University IRB for verification of continued non-human subjects research status. You may report these changes by completing a modification submission through your Cayuse IRB account.

Also, although you are welcome to use our recruitment and consent templates, you are not required to do so. If you choose to use our documents, please replace the word *research* with the word *project* throughout both documents.

If you have any questions about this determination or need assistance in determining whether possible modifications to your protocol would change your application's status, please email us at irb@liberty.edu.

Sincerely,

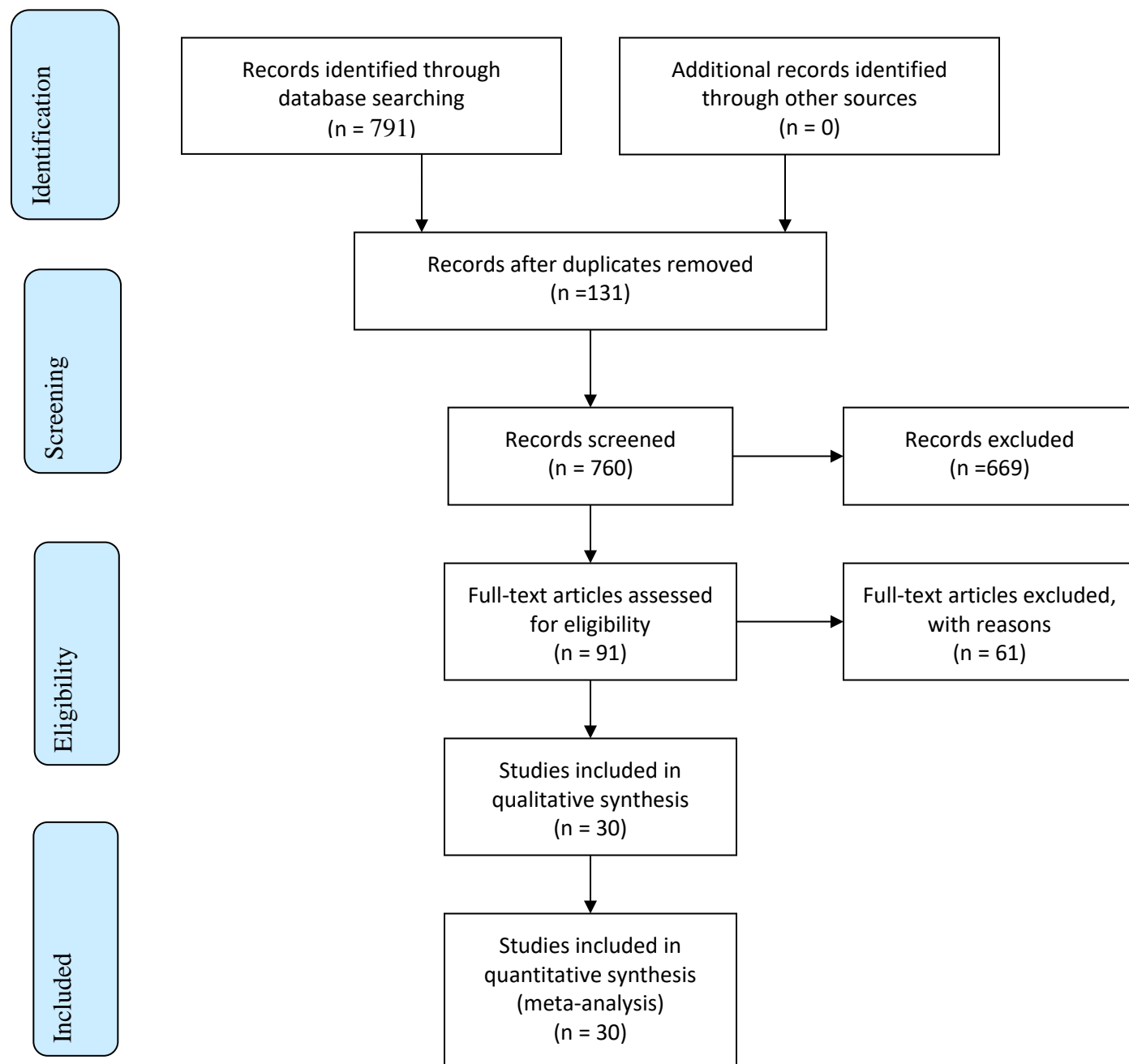
G. Michele Baker, MA, CIP
Administrative Chair of Institutional Research
Research Ethics Office

Table 2**Inclusion and Exclusion criteria applied to the literature review**

Inclusion	Exclusion
Peer reviewed articles	Patients of the pediatric population
Articles written in last five years	Patient with renal disease that are not end stage
Articles that have adult patients diagnosed with end-stage renal disease	Articles that are older than five years old
Articles written in English	Articles which are Editorials and or new blogs
Patients requiring renal replacement therapy	
Patients seen in both the acute care and outpatient setting.	

Table 3**Melnyk's Hierarchy of Evidence**

Level I: Evidence from a systematic review of all relevant randomized controlled trials (RCT's), or evidence-based clinical practice guidelines based on systematic reviews of RCT's
Level II: Evidence obtained from at least one well-designed Randomized Controlled Trial (RCT)
Level III: Evidence obtained from well-designed controlled trials without randomization, quasi-experimental
Level IV: Evidence from well-designed case-control and cohort studies
Level V: Evidence from systematic reviews of descriptive and qualitative studies
Level VI: Evidence from a single descriptive or qualitative study
Level VII: Evidence from the opinion of authorities and/or reports of expert committees

Figure 1**PRISMA 2009 Flow Diagram**

1: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org.