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Systematic Review of the Literature on Why There is Hospice Underutilization

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This is to certify that the doctoral study by

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Abstract

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MS, University of Texas Pan American, 2007

BS, University of Texas at Brownsville, 2004

Project Submitted in Partial Fulfillment
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Abstract

Despite hospice and palliative care services being available for patients at the end-of-life, it remains an easily accessible health care service which has been mostly underutilized and/or misunderstood. For this project, the practice problem was underutilization of hospice and palliative care services. A systematic review of the literature which focused on under usage of end-of-life care was conducted. MEDLINE, CINAHL, and ProQuest Nursing and Allied Source databases were searched (2005 to 2017). Studies that evaluated interventions for increasing hospice and palliative care services were selected. Conceptual variables included studies that addressed the under usage of end-of-life care. Kolcoba's comfort theory, Parse's theory of human becoming and Chochinov's dignity model was included to identify the issue, gather the data, and help transfer researched data into practice. The tools applied for analysis and synthesis were the appraisal of guidelines research and evaluation and the grading of recommendations, assessment, development and evaluation. The under usage of hospice and palliative care according to this systematic review, has resulted in (a)suffering negative effects on patients at the end of life, who do not receive adequate palliative or comfort care, (b) additional distress for families dealing with grief and denial, and (c) may result in unneeded acute care, adding significantly to the cost of care. This doctoral project formed a cogent set of recommendations consisting of, communication guidance and community education for a local hospice agency and the community. The contribution of positive social change in this community was through education and knowledge to bridge the gap into practice and improve end-of-life care in the community.

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Table of Contents

List of Tables

Section 1: Systematic Review of the Literature on Why There is Hospice Underutilization

Introduction

Hospice and palliative care (HPC) services refer to caring for those affected with a terminal diagnosis. The care is aimed at addressing pain and other distressful symptoms associated with the terminal diagnosis. HPC is specialized care aimed at providing comfort and continuity of care for patients and improving their quality of life once all curative measures have been used (Azami-Aghdash, Ghojazadeh, Naghavi-Behzad, Imani, & Aghaei, 2015). In these settings, health providers focus on comfort measures instead of curative ones (Mager & Lange, 2016). The care plan under hospice and palliative services concentrates on psychosocial, emotional, and spiritual issues faced during the end of life (Kelley, Deb, Du, Carlson, & Morrison, 2013).

The history of hospice care, according to Haak and Peters (2004) dates to the 11th century during the Crusades. Hospice is derived from the Latin word “hospes,” which means host/guest (Haak and Peters 2004). Today hospice is known as specialized end-of-life care (Kelley, Deb, Du, Carlson, & Morrison, 2013). Dr. Dame Cicely Saunders introduced the hospice philosophy at Yale University in 1963 (Haak & Peters, 2004). In 1969, Dr. Elisabeth Kubler-Ross published her book, “On Death and Dying” which was based on over 500 interviews with dying patients according to Dr. Kubler-Ross (Haak and Peters, 2004). Dr. Kubler-Ross placed great emphasis on care provided at home rather than at an institution (Haak & Peters, 2004). In 1974, Patricia Wald, in partnership with two pediatricians and a chaplain, founded the first hospice in the United States (Haak & Peters, 2004). In 1982, the Medicare hospice benefit was created. The

Medicare hospice benefit was enacted in 1986 and states were given the option to include hospice in their Medicaid programs (Haak & Peters, 2004). In the past decades, legislation has improved funding for hospice care and the Medicare reimbursement rates have increased. Because of these increased Medicare rates, the number of hospice care providers increased. In 2014, forty years after the first hospice opened in the United States, in the National Hospice and Palliative Care Organization (NHPCO) and its affiliates celebrated the delivery of hospice care in the United States for 4 decades.

Even though HPC services have been available for some time, they remain underused (MacPherson & Parikh, 2017). Underused end-of-life care services means that this care is not utilized to its potential. Beyea, Fischer, Schenck, and Hanson (2013) stated that despite growing availability of end-of-life care programs, these services remain totally and partially unused. No literature was found addressing a decline in hospice services, but the under usage of this important care was noted by many studies. Improving care and the quality of life for those diagnosed with a terminal illness is an important issue. Among healthcare professionals, poor communication skills, misconceptions, and limited knowledge may result in patients not being referred to hospice and/or palliative care services on a timely basis (Macpherson & Parikh, 2017). According to Kelley et al. (2013), a lack of collaboration between community members and the healthcare profession is another reason for the under usage of hospice services. Also, health care professionals may not have the proper tools needed to address the issue.

In addition to potentially adverse effects for patients, under usage of HPC services may have higher financial consequences for patients, families, and hospitals. Thomas and

Siaki (2017) found that the lack of HPC services resulted in an increased rate of hospital readmissions within 30 days of a prior admission. The number of hospital readmissions is a marker of a health care facility’s ability to provide effective, quality care (Thomas & Siaki, 2017). A high number of readmissions, according to Thomas and Siaki (2017), is viewed as an indicator of poor discharge planning and follow-up care. The Centers for Medicare and Medicaid Services (CMS; 2001) penalizes U. S. hospitals for having any readmissions within 30 days of a prior admission.

In this literature review, I gathered the evidence of quality of life at the end of life through research and knowledge about HPC. The findings provided guidance for health care professionals to implement and served as key factors for the translation of knowledge into practice (MacPherson & Parikh, 2017). Increasing knowledge of HPC services among patients may lead to positive social change in communities. HPC services provide access to culturally appropriate, quality health care for people who have a terminal diagnosis and their families and loved ones (Bray & Goodyear-Smith, 2013). According to Fine and Davis (2017), the implications for positive social change included educating patients, families, loved ones, nurses and doctors about end-of-life care and doctors having the skills needed to inform patients and families. Fine and Davis (2017) emphasized a shift from the acute care perspective to proactive, well-planned care. With planned interconnection and effective teamwork, they suggested a better outcome in provider-nurse-patient rapport Fine and Davis (2017) through planned interconnection and effective teamwork.

Problem Statement

According to MacPherson and Parikh (2017), the primary problem is the under-utilization of HPC services. HPC services are not well known in most communities. Many terminally ill patients suffer from poor quality of life because they lack access to end-of -life care services. According to Baines and Shearer (2015), hospice care services are cost-effective for all patients and are available continually (Baines & Shearer, 2015). Patients' misconceptions and lack of knowledge include the following:

- The, believe hospice care ends after 6 months.
- They are unaware of what medications, medical equipment, and care services are provided under the hospice option.
- They are unaware that other health care issues may continue to be treated.
- They don't understand their illnesses.
- They don't understand differences in treatment goals.
- They wait for physicians to talk about their illness and hospice, and physicians wait for patients to bring it up.
- There is a lack of clarity about who should handle end-of-life discussions (Baines & Shearer, 2015, p. 30).

There are many hospice agencies in our community who are ready to provide their unique services, but, due to various reasons, the services remain under used (Kelley et. al., (2013). The Dartmouth Atlas of Healthcare Data (2008) showed a gap in evidence-based practice in relation to end-of-life care. Per the Dartmouth Atlas of Healthcare Data (2008), the worst places to die are the following: Miami, FL, Los

Angeles, CA, East Long Island, NY, Stockton CA, Las Vegas, NV, Newark, NJ, St. Petersburg, FL, Manhattan, NY, McAllen, TX, and Bronx, NY. The project site location is in the McAllen, TX region. According to Smith et. al., (2012), due to underutilization of HPC services, there are numerous hospital readmissions within 30 days of a prior hospital admission. Many emergency room visits are from patients who are in the dying process. With preparation of patients, families, and caregivers and by early admission into hospice care services, it is possible to face death in a comfortable and dignified manner.

Purpose

The meaningful gap in evidence-based practice affects the quality of care and the quality of life for those affected with a terminal diagnosis along with their families and loved ones (Luckett et al., 2013). Nurses fail to recognize those patients who will benefit from early referral to HPC services. If nurses, doctors, and other healthcare staff have the knowledge and proper tools to identify those meeting the criteria for HPC, the gap between research and practice can be bridged. Providing care at the end of life is challenging (Luckett et. al., (2013), because many aspects of care need to be addressed properly. In a timely manner, end-of-life care needs to address distressful symptoms along with psychosocial and emotional issues (Luckett et. al., 2013). There is a gap in communication and practice regarding HPC services for terminally ill patients among physicians, nurse practitioners, discharge planners, and case managers at the acute care setting. These providers fail to recognize when HPC services are appropriate. Patients subject to a terminal diagnosis lack knowledge about end-of-life care, or they don't understand the concept of end-of-life services. Unfortunately, broaching the subject of care at the end of life is a topic that makes many health care professionals uncomfortable (MacPherson & Parikh, 2017). As a result, patients and their families are not well informed about the availability of HPC services, and how to access them (MacPherson & Parikh, 2017). The healthcare community consists of many professionals working together to provide quality healthcare. The purpose of this DNP project was to:

1. Complete a comprehensive and systematic review of the literature.
2. Provide patients, communities, and providers in the acute care setting with new evidence about HPC services.
3. An actionable set of recommendations to improve the under-usage problem.

In 2008 the National Priorities Partnerships (NPP) identified palliative and hospice care as one of six priority areas. Per the NPP (2008) palliative and hospice care can have a critical impact on improving patient-centered quality and utilization outcomes. There are barriers to access palliative or hospice care for those in need of these services which include, geographic location, inadequate workforce, and a workforce pipeline to meet the needs of patients and their families Meier, (2011). The NPP (2008) aims to ensure that all individuals have access to effective medical treatment, relief of discomfort symptoms, and high-quality palliative and/or hospice care services.

To bridge the gap from research to practice, adequate evidence-based research must guide (HPC) services, measure the quality of care, the lack of public knowledge, and the demand for, and benefits of HPC services. The questions that loom include how to tackle these barriers, how to acquire knowledgeable healthcare professionals to provide information to their patients. Barriers to effective access to end-of -life care need to be addressed by all healthcare professionals to ensure appropriate standards of care in the terminally ill (NPP, 2008).

The stigmas of shame and disapproval are also associated with end-of-life care, affecting patients, families and loved ones (Ricci & Dixon, 2015). They prevent, patients from seeking much needed services, such as hospice care (Ricci & Dixon, 2015).

Guiding practice focus was evaluated using the PICO system to formulate the clinical question for this systematic literature review: P means- patient/problem: -terminally ill patients, I means-intervention-: access to HPC, C means- comparison-appropriate plan of care, O- means outcome-effective care resulting in improved quality of life for the patient, the family/loved ones, and a decrease in hospital admissions.

Nature of the Doctoral Project

The nature of this doctoral project was a literature review of end-of-life services and quality of life. The goal was to evaluate the use of HPC services. The literature was selected for level of quality using the Finout-Overholt, Mazeurek-Melynk, Stillwell, and Williamson (2010) method for critically appraising of evidence. In their paper, Fineout-Overholt, et al., (2010, p. 48) categorized the literature into seven sectors:

1. Level 1 - consists of - systematic reviews and meta-analysis.
2. Level 2 - consists of random control trials.
3. Lever 3 - consists of control trials with no randomization.
4. Level 4 - consists of control and cohort studies.
5. Level 5 - consists of systematic reviews of descriptive or qualitative studies.

6. Level 6 - consists of descriptive or qualitative studies.
7. Level 7 - consists of expert opinion or consensus.

The use of Fineout-Overholt et. al (2010) was effective in the selection of research studies for this systematic literature review.

Sources of Evidence

Sources of evidence consist of primary and secondary methods. One was a systematic literature review to acquire evidence-based practice and knowledge from scholarly peer-reviewed literature. Rew (2011) described literature review as the plan and design for answering a clear, targeted research question. Evidence-based practice is based on research that incorporates relevance and methodology Rew (2011, p. 64). Rew (2011, p. 65) recommends the following steps when conducting a literature review:

1. Identify the specific research question(s) to be answered.
2. State the purpose of the review. What are its aims?
3. Identify inclusion and exclusion criteria.
4. Select the search terms to use.
5. Identify the appropriate database to search.
6. Conduct the electronic search.
7. Review outcome of search and match with inclusion/exclusion criteria.
8. Data extraction. Systematically retrieve data from each paper included.
9. Determine the quality of all studies reviewed.
10. Summarize findings in a table.
11. Interpret the meaning of the evidence retrieved.

12. Acknowledge the limitations and biases inherent in the process.

13. Publish and apply the findings in practice.

Using the recommendations as advised by Rew (2011) resulted in identifying appropriate research for this project.

For the purpose of this systematic literature review project, an expert panel was developed consisting of a chief of nursing, a director, and a staff member from a local hospice agency. The three experts for this panel were approached through phone calls, emails, and a meeting to discuss the project. Recommendations were generated following the presentation of the systematic review of literature through a Power Point presentation and providing each expert with a hardcopy of the project. Each expert provided feedback on the usefulness of the project within their facility.

This project provided, evidence that was put into practice to (a) bridge the gap, (b) provide for an effective point of care, and (c) improve the quality of life in the terminally ill. The resources discovered in this project included tools for nurses and other healthcare professionals to use to inform patients and the community on HPC services. These tools are used to identify and provide appropriate referrals to HPC services.

Significance

Terminal diagnoses occur frequently throughout the lifespan. Issues arise when a terminal diagnosis is initially made. One major issue is the delay of hospice services due to a variety of reasons (misconceptions/poor knowledge, etc.). Here the stakeholders are the patients, the nurses, the doctors, other healthcare professionals, hospitals, and the community. All would benefit from the translation of knowledge into practice. Hospitals will benefit from a decrease in hospital readmission rates. The terminally ill will have an increased quality of life. The significant goal here is having a win-win solution for all.

One major reason/issue is ethics. Ethical principles regarding full disclosure to the terminally ill are embedded in countries' patients' rights' act in the culture (Lorenson, Davis, Konishi, & Bunch, 2003). Disclosing the terminal prognosis is not the end but the beginning of the ethical dilemma for nurses, families, and patients (Lorenson et al., 2003).

Another issue for the delay of end-of-life services is communication and collaboration among healthcare professionals. Many healthcare professionals lack the knowledge of HPC and fail to refer to HPC services, assuming they will lose income. Patients have the right to quality, end-of-life care. Part of the care plan needs to be empowering people to learn about their care, so they can die with a comfortably, free of pain and other uncomfortable symptoms. For many patients, a discharge must be accompanied with a discharge referral to a hospice program (Kelley et al., 2013).

Finding effective solutions for all stakeholders is the answer to the problem. The solutions need to have support from the literature. Contributions from the review of literature yielded knowledge in the form of a checklist (toolkit) for appropriate and timely referrals to HPC services in the McAllen, TX region. Transferability of this project was an effective tool to use with different organizations. The local agency which received the results of this project has relations with other agencies and in other areas of the United States which could benefit from this project. The agency learned that HPC needs to be known in the community. Perhaps, by applying the methods Baines and Shearer (2015) used in their study, the use of hospice care services will increase.

Disseminating this systematic literature review project in the community resulted in progress for social change. HPC is now being more widely accepted in the community, resulting in closing this practice gap. According to the Dartmouth study, this region ranks poorly in being a poor place to die, at the end-of-life (MacPherson & Parikh, 2017).

Summary

Nursing care is vitally import. Lachman (2011) described the high importance of the nurse's role in increasing access to hospice care. According to Lachman (2011) "nurses as per the Code of Ethics for nurses, provision 1.4, addresses nurses having the moral and legal right to give accurate and complete information" (p. 200). I realized that even nurses lack the knowledge of end-of-life care. Many nurses view HPC services as giving up and no longer providing healthcare. Nurses have the duty to be involved in assisting patients and families in making important decisions about their end-of-life care (Lachman, 2011). The purpose of this paper was to focus on research into HPC services and to bring evidence-based research into practice. According to the American Nurses Association, nurses are obligated to be knowledgeable about the clinical issues faced by terminally ill patients (2001). Fine, Reid, Shengelia, and Adelman (2010) devised recommendations for improved communication among physicians, regarding palliative and end-of-life care. Fine et al., (2010) communication recommendations were as follows:

1. Initiate and explore emotional issues in life-threatening illness.
2. Prioritize emotional and quality-of-life issues to take precedence.
3. Take advantage of educational opportunities to expand the role as communicator.
4. Enlist the help of other health professionals.
5. Speak less, listen more.
6. Offer support and emotional validation.

These six recommendations according to Fine et. al (2010), provided appropriate guidance on how to communicate a terminal diagnosis and the healthcare options.

Baines and Shearer (2015) worked on a project called Targeting Resource Use Effectively (TRUE) in order to examine options to increase hospice services. The TRUE project resulted in the creation of brochures and wallets cards with the following information:

1. Do I have a serious or life-limiting illness?
2. Can my illness be cured?
3. If my illness can't be cured, are there treatments that can slow down my illness?
4. What kind of care is available that focuses on making me comfortable?

These brochures and wallet cards were left in churches, clinics, restaurants, schools, and senior citizen centers in the community. As a result, an increase in hospice care services was seen.

If the topic of HPC is not a comfortable situation for the healthcare provider or healthcare professional, the services of those who are experts in HPC need to be consulted. Through communication and collaboration within the healthcare profession, improvement and access to quality of life for those affected with a terminal diagnosis is attainable. Clinical practice guidelines, developed with concepts, models, and theories resulted in finding research studies focusing on underutilization of HPC services.

Section 2: Background and Context

Introduction

Under usage of HPC service continues to be a concern for providing care at the end of life (Hill, 2005). Even though HPC is considered the gold standard at the end of life Hill (2005), those eligible for this type of service never receive this care. Some reasons for the lack of utilization are as follows: culture, beliefs, and attitudes, lack of knowledge, and the policies and practices of the U. S. government health care system (Hoffman & Tarzian, 2005).

This systematic literature review encompassed concepts, models, and theories to clarify the issues of underutilization of HPC services. Frameworks set the foundation for this project for those at the forefront of research to receive the evidence-based knowledge and the tools to bridge this practice gap. In this review, qualitative and quantitative research studies on the underutilization of HPC were evaluated and dissected to help bridge the gap between the evidence-based and practice.

Concepts, Models, and Theories

A strong foundation is needed to develop a project that is transferable and has implications for social change. The problem analysis (or needs assessment) approach was used to develop the study's conceptual framework: overview (issue in question), research, methodology used for this study, study findings, discussion of findings, and implications of the findings. Theory was included in the review to identify the issue, gather the data, and help transfer the research data into practice. Three theories were presented: the comfort theory developed by K. Kolcoba in the 1990s, Parse's theory of human becoming (1981/1992), and Dr. Chochinov dignity model (2002). Dying with dignity is considered to be a basic human right (Guo & Jacelon, 2014). The dignity model, as pioneered by Dr. Chochinov, consists of three categories (factors) that affect a patient's sense of dignity (Ostlund, Brown, & Johnston, 2012). was also incorporated in this study. The Dignity Model consists of three categories (factors) which affect a patient's sense of dignity (Ostlund, Brown, & Johnston, 2012). Rationale for the concept model and theories used are the reason why these were chosen were to describe, explain, and bring forth interventions acquired through this literature review to address the reasons and barriers to HPC utilization.

Hospice and Palliative Care

Five research studies consisting of a quality improvement and quality measures, phenomenological research design, pilot observational study, and a randomized control trial were analyzed for this systematic literature review. Casarett et. al., (2005) conducted a randomized control trial of nursing home residents who qualified for HPC services to discover whether there would be an increase in hospice utilization. In their study Casarett et. al., (2005) concluded that, a structured interview to identify those nursing home residents meeting the HPC criteria resulted in an increase in hospice referrals and a decrease in acute care services. Highet, Hsieh, and Smith (2016) conducted a pilot trail study to evaluate whether an emergency department intervention for identifying those patients who were eligible for hospice care resulted in an increase in HPC enrollment. The pilot study Highet, Hsieh, and Smith (2016) resulted in an early identification of those patients meeting the criteria for hospice and resulted in an increase length of hospice care services. In the study by Melvin (2010) a phenomenological research design was used to find out the barriers to timely palliative care services in Western Australia and the effects associated with late referrals and quality of life. In her study Melvin (2010) found that due to late or no referrals to end-of-life care resulted in additional burdens being placed on patients as well as their families. Beyea, Ficher, Schenck and Hanson (2013) conducted a statewide Medicaid study in North Carolina to determine if quality improvement interventions resulted in an increase use of HPC in low income patients. The statewide Medicaid intervention study in North Carolina resulted in effective communication among the Medicaid primary care practice and an increase of referrals to HPC. Schellinger, Sidebottom, and Briggs (2011) evaluated the implementation of a model with participants and non-participants to determine if intervention was successful at improving increase of hospice services.

Underutilization

The literature review provided numerous studies in reference to HPC services. Most consisted of comfort measures to alleviate pain, such as medication and music therapy. For this review of literature, only those studies consisting of HPC under usage were selected. Kirolos et. al., (2014) found that, despite the evidence stating that HPC is effective during end-of -life care, it remains an underused service. Five research studies on the underutilization of HPC were chosen for this systematic literature review. The research studies selected are the following:

1. Integrating Palliative Care Information and Hospice Referral in Medicaid Primary Care. (Beyea et al., 2013).

2. Improving the Use of Hospice Services in Nursing Homes: A Randomized Controlled Trial. (Casarett et. al., 2005).
3. A Pilot Trial to Increase Hospice Enrollment in Ann Inner City, Academic Emergency Department. (Highet, Hseih, & Smith, 2016).
4. Patients' and Families' Misperceptions About Hospice and Palliative Care: Listen as They Speak. (Melvin, 2010).
5. Disease Specific Advance Care Planning for Heart Failure Patients: Implementation in a Large Health System. (Schellinger, Sidebottom, & Briggs, 2011).

Barriers to Effective Use of Hospice and Palliative Care

Barriers to HPC were found as a result of this literature review. Melvin (2010) found lack of knowledge among communities and health care professional resulted in under usage of end-of-life care services. Highet, Hsieh, and Smith et. al. (2016) found that early identification of patients at an emergency department who met HPC criteria at resulted in an increase rate of hospice admissions. Beyea et. al., (2013) concluded that their statewide intervention program aimed at the Medicaid primary care practice network was effective in communicating end-of -life care and referrals and admissions to HPC. A structured intervention in reference to a hospice informational visit at the nursing homes in the study it resulted in effective communication among the residents, the family, and the physicians (Beyea et al., 2010). As a result of the intervention, the end result was an increase in the rate of hospice referrals and a decrease utilization of acute care services (Beyea et, al., 2010). In their study Schellinger, Sidebottom, and

Briggs (2011) evaluated the implementation of Disease Specific Advance Care Planning (DS-ACP) for patients with heart failure in a large health system facility. The results of their study concluded that the DS-ACP is successful regarding positive documentation. participation, and an increase use of hospice services (Schellinger, Sidebottom, and Briggs (2011).

Strategies and Interventions

Through this systematic literature review strategies and interventions to increase the utilization of HPC were identified. Lack of knowledge, lack of identifying those patients who meet HPC criteria and effective communication skills about HPC were the main culprits in the under usage of end-of-life care. Strategies and interventions identified in this literature review point to evidence-based research to bridge the gap between research and practice. The study found that lack of knowledge needs to be addressed appropriately. The community, as well as our health care professionals, need to be knowledgeable regarding end-of-life care to effectively identify those meeting the criteria for this type of health care. If communication is an issue among health care professionals, the task may be done by experts in this field. Identifying those who benefit from end-of-life care and implementing the referrals in a timely manner resulted in an increase of hospice utilizations in the studies reviewed. This literature review acknowledged that society and the health care profession need to identify the barriers and use appropriate interventions to decrease hospital readmissions and increase end-of-life care health care services. Patients' perspectives need to be recognized in relation to end-of-life care. Their views need to be explored to dissect the issues and bridge the gap in practice associated with hospice care services.

AGREE II and Grade

Clinical practice guidelines, in reference to this systematic literature review regarding the under usage of HPC services, were accomplished through the Appraisal of Guidelines Research and Evaluation (AGREE) II. AGREE II was used to guide the development of this project and to assess the quality of the research studies reviewed. The scope and practice issue in question is the underutilization of HPC, resulting in poor quality of life for those affected with a terminal diagnosis and increased hospital readmissions. The population who benefits from end-of-life care is denied appropriate care due to under usage of HPC. This issue identifies the stakeholders involved and affected by the under usage of end-of-life health care services. Exclusion and inclusion criteria were utilized in this literature review to include only those research studies who addressed the barriers to under used of HPC services. The review of literature also included those studies which incorporated some system or implementation to identify those who met the criteria for HPC services. Clarity and Applicability was used in the inclusion and exclusion criteria to choose on which studies to include. Formation of the findings was graded for editorial independence to result in biased free research data. The Grading of Recommendations, Assessment, Development and Evaluations (GRADE) was also used for this systematic literature review. GRADE provides a view and clarifies key findings and interventions to address the issue in question. Through the GRADE system, the chosen studies were scored based on the type of evidence, quality points, consistency, directness, effect size, strength of the recommendation, and cost-effective solutions.

Summary

Through the use of concepts, models and theories, five research studies were selected. The selected studies were analyzed and synthesized through the use of AGREE II and GRADE to find the reason for the gap in evidence-based practice with regards to the under usage of HPC services.

Section 3: Collection and Analysis of Evidence

Introduction

The under usage of HPC services has resulted in negative outcomes for all stakeholders. The suffering due to discomfort at the end-of-life can be alleviated through appropriate and timely referrals to this type of care. Psychosocial, emotional, physical, and spiritual issues encountered during end of life are addressed appropriately with end-of-life care. Since hospice services are not used effectively, the result is hospital readmissions, which are costly, since at present hospitals are not reimbursed for readmissions within 30 days of a previous stay. Specialized care for the dying was introduced in the United States in 1963 by Saunders (Haak & Peters, 2004). In 1982 Congress added the Medicare Hospice Benefit, and in 1986 the Medicare Hospice Benefit was made permanent (Haak & Peters, 2004). This systematic literature review gathered the evidence of improved quality-of-life at the end of life through research and to brought forth this newly gained knowledge to an expert panel at an acute care site. It yielded recommendations aimed at translating knowledge into practice, which in turn, provided the health care staff with the appropriate tools for care at the end of life and has resulted in positive social change in the gradual acceptance of hospice care in the community.

Practice-Focused Questions

The under usage of HPC services has resulted in health care issues for all involved. Underutilized end-of-life care refers to health care services available which remain unused or are used too late according to Baines and Shearer (2015). Unused end-of-life care services may go unutilized for the following reasons (Baines & Shearer, 2015):

1. The hospice option is mentioned too late by health care professionals.
2. Patients (people) have misconceptions.
3. The benefits of HPC are not well understood by patients.
4. The benefits of HPC are not well known to patients.

Due to a gap-in-practice, (that is, a delay or lack of referral to hospice), those afflicted with a terminal diagnosis and their families have undergone unnecessary pain and suffering. Other stakeholders include hospitals, communities, and the health care profession. There is no reimbursement for hospital readmissions. Hospitals are also not reimbursed if terminally ill patients seek treatment for pain and other discomforts at the emergency room or if they become admitted for an inpatient stay (Feemster & Au, 2014). Patients and communities suffer increased health care costs. With the end-of-life health care services, the hospice option covers many medications and healthcare services. Bhatnager and Joshi (2013) stated that the fear of dying, along with the stigma associated with a terminal illness, prevents people from dying well. Most of us view death as a failure even though death must follow life. This feeling prevents planning a good death (Bhatnager & Joshi, 2013). HPC services have the tools needed to provide pain and symptom control management in the outpatient setting, without the need for trips to the emergency room or hospitalizations (Highet, Hsieh, & Smith, 2016).

This doctoral project called for the identification of a local issue which needed to be addressed to improve health care and result in positive social change. The issue in question is the underuse of HPC. The Dartmouth Atlas of Health Care data identified McAllen, TX as one of the worst places to die (MacPherson & Parikh, 2017). The systematic review of literature resulted in knowledge about appropriate tools resulting in improved quality of life for those affected with a terminal diagnosis and helped to decrease the hospital readmissions rate.

Sources of Evidence

Poor communication skills, limited knowledge, and misconceptions within the health care profession and among patients, have resulted in HPC candidates not being referred on a timely basis (MacPherson & Parikh, 2017). Kelley et. al. (2013) informed us that health care staff do not have enough knowledge about end-of-life care or appropriate tools to identify candidates for HPC. Late referrals have resulted in individuals being denied access to effective care at the end of life.

The review of literature clarified the facts regarding the under usage of HPC services. The underutilization of end-of-life health care services is a result of lack of knowledge, poor identification of those patients meeting HPC criteria, and ineffective communication skills. The result of this literature review has provided research data identifying strategies and interventions to address underutilized HPC services and decrease hospital readmission rates. The literature review demonstrated how the under usage of end-of-life care results in increased health care costs for patients as well as the health care community and the poor quality of life for those affected with a terminal diagnosis.

Published Outcomes and Research

The literature review for this projected included the MEDLINE, CINAHL, and ProQuest Nursing and Allied Health Source databases. Multiple terms were used for the research literature review search methodology. Terms used for the database searches were *HPC, interventions for the underutilization of HPC services, and increased hospital readmission rates due to underutilized HPC services*. The research articles retained consisted of those published in English between the years 2001 to 2017 that addressed the under usage of hospice care and the increased rate of hospital readmissions in relation to underutilized end-of-life care. The window period included all research studies found from 2001 until the present and only those that were peered reviewed.

AGREE and GRADE were used to grade the quality of the research articles in relation to the underutilization of HPC services. AGREE and GRADE also provided effective tools for practice guidelines in relation to appropriate research findings. The collection and analysis of the selected research studies have guided the implementation of evidence-based research into practice. The under usage of HPC resulted in negative outcomes for all stakeholders in the selected studies. The research data found improved access to end-of-life care resulted in improved quality of life, decreased health care costs for patients, and decreased hospital readmissions.

Evidence Generated for the Doctoral Project

This doctoral project yielded positive outcome for all stakeholders. The Dartmouth Atlas Health Care Study (MacPherson & Parikh, 2017) found this region to be one of the worst places to die. The researched data provides resources and tools to address the practice issue in question. The studies found that education for all, including patients on HPC services, resulted in an increase in end-of-life services. Strategies and interventions utilized in the studies resulted in an increase utilization of end-of-life care and in a decrease in hospital readmission which resulted in improved quality of life for those affected with a terminal diagnosis. The studies found a decrease in health care costs due to the increase in HPC.

Participants

The participants were provided with the findings from this systematic literature review. Hopefully, they will use the findings into practice at their health care organization (a local hospice agency). The participants consisted of three selected individuals for this expert panel. The expert panel consisted of a director and two employees from the agency. After reviewing the literature review and the PowerPoint presentation, the expert panel voiced any concerns, provided feedback, and approved the findings for use at their health care facility to improve the utilization of HPC.

Procedures

The collection of evidence incorporated the GRADE technique to acquire tools and useful techniques for selecting the evidence. When the review of literature was completed, the GRADE evaluation system was used to determine the value of the research studies found.

Recommendations

Using the Delphi technique for feedback from the expert panel, a set of recommendations was created. Recommendations because of this systematic review of literature called for the following:

1. Organizational health care delivery to result in high quality, efficient, and cost-effective services (Kutzleb et al., 2015).
2. Operational effectiveness and quality patient outcomes.
3. Formalizing partnerships between healthcare agencies including nursing homes and hospitals to promote patient-centered care through the following:
    - Educating patients/families/physicians/healthcare professionals on the availability and benefits of end-of-life care services.
    - Ongoing demonstration projects and models of healthcare delivery and cost effective, rigorous evaluations of hospice services and the impact on valued care.

Protections

This systematic literature review obtained approval from Walden University Institutional Review Board (IRB; Approval Number 07-13-17-0642525). After the approval process was in place and the Ethics Preapplication had been submitted, the approval to proceed was received.

Analysis and Synthesis

For this systematic review of literature, Zotero was used to keep my research data organized. I also used pen and paper to keep notes during the literature review process and to organize the selected research articles for this project. The Finout-Overholt, et al.,

(2010) method for critical appraising of the evidence was used. AGREE and GRADE methods were also used in this project to analyze and synthesize the research studies. The sources of evidence consisted of primary and secondary methods. Relevance and methodology were also used for the conduction of this literature review (Rew, 2011).

Summary

HPC remains a service not used to its full potential. Underutilization refers to specialized end-of-life care services which are not used by those who qualify for these services. The under usage of end-of-life care results in poor care and increased health care costs for those affected with a terminal diagnosis. This systematic literature review brought forth evidence of the issue of HPC services being under used. The studies selected for this literature review identified barriers as to why end-of-life care is not utilized to its full potential. A major reason for the under usage of HPC was lack of knowledge in relation to end-of-life care among patients, society and the health care profession. An increase in the Medicare Hospice Benefits may be evaluated by checking the number of patients which have opted for the Medicare Hospice Benefit. Positive outcomes associated with this review of literature were identified and brought forth. Maintaining human dignity is at stake here. Dying with dignity is the goal of quality care at the end-of-life (Guo & Jacelon, 2014). Patients' thoughts and feelings need to be considered when introducing hospice care services. We must listen to our patients. What are their questions, fears, beliefs, and attitudes about end-of-life care? Fine and Davis (2017) expressed the need for Medicare Hospice Benefit utilization, which are deeply linked to human needs and must include advances in medicine.

Section Four discusses the findings, implications, and recommendations of this systematic review of the literature in reference the under usage of HPC services. Strengths and limitations of the literature review are also discussed in Section Four.

Section 4: Findings and Recommendations

Introduction

The major barrier to the utilization of hospice care services was identified as a lack of knowledge by patients, health professionals and communities. The selected health care organization is a local home health and hospice agency located in Weslaco, Texas. The selected expert panel consisted of three individuals employed at this health care organization. The individuals were a VP of operations and two registered nurses from the selected local agency. The expert panel was given a copy of the research, a copy of the selected research studies, and a PowerPoint presentation. A timeline of three to four weeks was given to the panel.

Findings and Implications

The expert panel stated that the information I provided yielded insights on the underused hospice care services. The expert panel also agreed that lack of community education gives hospice a poor reputation. The most important information they learned from my research was the fact that this area was found by the Dartmouth studies to be one of the worst places to die. In the Rio Grande Valley, Texas according to Mr. Pena (2017) the local community doesn’t like to give up (on its loved ones) and will do everything possible for them. This community believes that accepting hospice care services means giving up. The lack of community education adds to this issue. Educating patients, the community, physicians, and other healthcare professionals will aid in promoting the hospice conversation at the appropriate time.

Recommendations

Recommendations from the research studies suggested that community education is the key to alleviating this problem. All five selected research studies suggested education. Education must start with physicians and other health care professionals. The fact that many health care professions find hospice care services uncomfortable discuss needs to be addressed. All health care professionals, especially those who work with patients at the end of life, need to be aware of hospice care services and how to address the topic appropriately. Actions need to be taken in a timely manner for those who are in need of hospice services in order to receive the full benefits of this type of care. Referral during the active dying phase benefits no one. The results of late hospice referrals or no referral at all, lead to pain and suffering for those affected with a terminal diagnosis and their loved ones. Teno et al. (2015) stated that significant unmet needs in end-of-life care remain. Recommendations as a result of this DNP project, as stated earlier, calls for the following:

1. Organizational health care delivery to result in high quality, efficient, and cost-effective services (Kutzleb et al., 2015).
2. Operational effectiveness and quality patient outcomes.
3. Formalizing partnerships between healthcare agencies such as nursing homes and hospitals to promote patient-centered care through the following:
    - Educating patients/families/physicians/healthcare professionals on the availability and benefits of end-of-life care services.

- Ongoing demonstration projects and models of healthcare delivery and cost effective, rigorous evaluations of hospice services and the impact on valued care.

Strengths and Limitations of the Project

The strength of this project is the fact that several research studies demonstrated the under usage of hospice care services. Most of the research studies pointed to lack of knowledge, misconceptions, and cultural issues among patients, being the culprit. The review of literature proved great evidence-based research regarding hospice care services.

The limitation of this DNP project is, that more research is needed for HPC services to be accepted as part of healthcare in our society. As the expert panel stated, our culture believes in doing everything to keep our loved ones alive. Opting for hospice care services means giving up. Continued research and strategies to increase knowledge about end-of-life care is required. Effective collaboration among the health care profession and our community regarding end-of-life care needs to be mastered effectively

Summary

Education and knowledge of HPC services was found to be the key in alleviating the under usage of end-of-life care. All the selected studies pointed to misconceptions and a lack of knowledge about HPC services.

Table 1

Characteristics of Selected Research Studies

	Casarett et. al (2005)	Highrt, Hsieh, & Smith (2016)	Beyea et. al (2013)	Melvin (2010)	Schellinger,Sidebottom and Briggs (2011)
Participants	Nursing home residents and their surrogate decision makers.	Emergency department staff and the identification of hospice and palliative care eligible patients.	510 Medicaid care managers serving severely ill Medicaid patients in North Carolina.	Interviewed 13 participants, 6 family members, and health care providers on hospice/palliative care experience	Chart audit of patients who participated in a study (the implementation of Disease Specific Advance Care Planning (DS-ACP)
Interventions	Structured interview identified residents whose treatment goals made them appropriate for hospice care.	Evaluation of the feasibility of ER staff to identify hospice eligible patients to accelerate hospice and palliative care enrollment.	Intervention was an educational model developed and delivered to the case managers through a conference training module system.	Interviews were conducted to evaluate hospice/palliative care knowledge.	The study evaluated the implementation of the DS-ACP model with the participants in the DS-ACP and those who did not. The chart audit examined differences in advance care planning documentation between participants and nonparticipants.
Outcomes	A simple intervention in communication resulted in an increased rate of hospice referrals and decreased the utilization rate of acute care resources	Collaboration of ERs and Emergency physicians provides a unique approach of early hospice eligibility identification and increased utilization of hospice care.	The statewide intervention for Medicaid case managers resulted in an effective practice network to increase communication and hospice/palliative care referrals.	Interviews showed lack of knowledge regarding hospice/palliative care. Misinformation was evident among all patients, family, and health care staff	The DS-ACP model proved to be successful when implemented among heart failure patients. The results also demonstrate the importance of referral method, results in positive participation, improved documentation and increased hospice utilization
Level of Evidence	Level 2 Randomized control trial study	Level 3 No randomization. Consists of a pilot study.	Level 4 Control/cohort study	Level 5, descriptive qualitative design method.	Level 2. Consists of randomized trials

Section 5: Dissemination Plan

Analysis of self

My analysis of this research project showed how lack of knowledge, miscommunication, misconceptions, and lack of education in this area (hospice care), leads to poor outcomes for all. The poor outcomes include ineffective comfort care at the end of life, increased rates of emergency and acute hospitalizations, anguish and pain for those afflicted with a terminal diagnosis and their loved ones, and an increase in healthcare costs, especially for patients.

This project showed how awareness, knowledge, and education can create positive social change in the community. The opportunity for transformative, evidence-based practice to take effect, resulted positive outcomes for all.

Summary

The need for acquiring knowledge through evidence-based research brought forth the need for a system of networking to improve health care access, especially specialized care such as end-of-life care. In south Texas, hospice care is not accepted as a part of health care by most people. Accepting hospice care is seen as giving up on their loved ones (Pena, 2017). More research is needed to focus attention on why this gap exists (Teno et al., 2015). Research leads to lack of education on this type of care, especially among health care professionals (IOM, 2014). Improved access to hospice care requires working with individuals and their loved ones and/or family to increase knowledge and comprehension of end-of-life care (Ornstein et al., 2016).

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