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Referral Patterns from Long-Term Care Services to Palliative Care: Perceptions of Directors of Nursing

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Referral Patterns from Long-Term Care Services to Palliative Care: Perceptions
of Directors of Nursing

Presented to the Faculty of the School of Nursing

The George Washington University

In partial fulfillment of the

requirements for a

Doctor of Nursing Practice Degree

Spring, 2018

DNP Project Team

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Abstract

Background: Palliative care referrals are important in long-term care facilities because they are the first step in generating the services that the patient may need. This study looked at the phenomena of how Directors of Nursing in long-term care facilities that had access to palliative care services determined if a referral was needed.

Objectives: The purpose of this study was to gain a deeper understanding of the decision-making process used by Directors of Nursing for referrals. The study's aims were to determine what factors prompt a referral in long-term care settings. The primary research question was: How do Directors of Nursing determine which long-term care patients should be referred for palliative care.

Methods: A telephone interview was conducted with seven Directors of Nursing. An interview protocol used a planned behavior theoretical framework and interviews were recorded and transcribed for analysis.

Results: Telephone interview transcripts were analyzed from Directors of Nursing from two skilled nursing facilities and five assisted living facilities. Monthly referrals varied from one to four, and interview responses were grouped in three categories: physical, cognitive, and administrative decisions. Responses were analyzed for content and saturation.

Conclusions: This study demonstrates a lack of understanding of palliative care services by Directors of Nursing in long-term care. Physical symptoms were often cited as a reason for referral, but there was no mention of the other domains noted in the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care (2013). Study findings support a need to integrate national guidelines for initiating palliative care for more patients who may benefit in long-term care facilities.

Background

As people are living longer, the prevalence of chronic diseases and the need to manage them increases (Hui, Kim, Roquemoire, Dev, Chisholm, and Bruera, 2014). By 2030, 20 percent of the United States population will be over the age of 65. Most adults will develop one or more chronic illnesses that will persist until death (Hui, et al., 2014). These later years are often characterized by physical and psychological symptom distress, progressive functional dependence, and frailty. Many older people with serious illnesses reside in long-term care facilities. Yet, it is estimated that only 10% of residents who meet eligibility in long-term care facilities receive palliative care (Hanson, et al., 2001).

Palliative care encompasses a set of services aimed at improving the quality of life for people with physical and psychological symptoms regardless of their diagnosis (Teno, et al., 2013). Palliative care extends the scope of hospice care, which focuses on end of life care to institute these supportive services earlier in the course of illness (Teno, et al., 2013).

Referrals for palliative care come from a variety of sources including the community, primary care providers, specialty medicine providers, skilled nursing facilities, assisted living facilities, inpatient settings, individuals, and families. A person can also become ineligible for hospice as a result in stability of illness or improvement in his or her condition. Palliative care can meet the continuing needs of these patients to enhance quality of life during stable disease (National Hospice and Palliative Care Organization, 2018).

Residents of long-term care are particularly well-suited for palliative care because of conditions that cause debilitation and chronicity, which affect quality of life and cause symptom burden. It is estimated that by the year 2030, 40 percent of all deaths in the United States will be in nursing homes (Stephens, Hunt, Bui, Halifax, Ritchie, and Lee, 2018). There is substantial

evidence that palliative care services are underutilized and patients experience significant symptoms and side effects that are ineffectively managed in long-term care (Hui, et al., 2014).

This research explored beliefs and attitudes of long-term care Directors of Nursing toward palliative care referrals. These interviews provide understanding of the “lived experience” of those who made referrals in long-term care facilities and insight as to how palliative care services can be made more available.

Purpose and Aims

The purpose of the DNP project was to gain a deep understanding of the decision-making process by Directors of Nursing when making referrals to palliative care in long-term care nursing facilities. The study’s aims included the exploration of the referral process for palliative care services, including knowledge, attitudes, and beliefs of how this service could help long-term care patients.

Research Question

The primary research question was, how do Directors of Nursing determine which long-term care patients should be referred for palliative care.

Significance of Study

This study provided a meaningful contribution to nursing knowledge through the exploration of the factors that influence referrals for palliative care services made by Directors of Nursing in nursing homes where palliative care services are available. The national guidelines for palliative care identify the domains of care to be provided, including physical function and symptom management, psychological and psychiatric aspects, spiritual care, social well-being including support of family caregivers and bereavement support. The elderly population in long-term care settings is a population which can especially benefit from these services often having multiple

chronic conditions, high symptom burden, and diminished social support. Thus, improving the referral to care can significantly benefit the patient.

Literature Review

A literature review was conducted pre and post data collection to examine the evidence regarding palliative care referrals from long-term care facilities. Search terms included palliative care, skilled nursing, referrals, processes, criteria, and qualitative studies. The studies reviewed included studies in the United States, qualitative studies, descriptive studies, studies of long-term care facilities and nursing homes, randomized controlled trials, quality improvement projects, and quasi-experimental studies. Three databases were accessed in an effort to find the latest information that was supportive of the hypothesis and of significance to the project. They included CINAHL, PubMed, and Scopus.

Initially, twenty-two articles were found with the key terms of palliative care, skilled nursing, and referrals. An additional 30 articles were reviewed from primary data sources related to the articles. These articles were searched for duplicates and articles' titles were read and eliminated based on content. Article abstracts were read and those studies that did not meet criteria were eliminated. (See the Prisma Diagram, Appendix A). Eight articles were also researched for results within each citation. This search yielded seven articles relevant to this topic.

Although each study used a different study method for analysis, all seven studies looked at referrals to palliative care for patients in a care setting. Three studies analyzed data on the perceptions of the family in prompting a referral to palliative care. Each study concluded that the family has a significant bearing on the decision by caregivers to refer to palliative care. In the study in the emergency department (Stephens, et al., 2015), caregiver perceptions as to the influence of the family on decisions to refer to palliative care revealed insecurities with care,

unpreparedness for end of life, inadequate or absent advance care planning, and lack of communication between family members as major influences on determination to refer. In a quasi-experimental pre and posttest study (Hermans, De Almeida Mello, Spruytte, Cohen, Van Audenhove, and Declereq, 2018), family anxiety was also measured with the use of a care instrument. The tool was used to measure baseline and post intervention after one year and included pain management and family anxiety. Although the use of referrals increased in this study, staff participants who were knowledgeable about palliative care thought the use of the tool was a “waste of time” because participants felt they knew when to refer (Hermans, et al., 2018). In a quality improvement study (Stephens, Hunt, Bui, Halifax, and Ritchie, 2018), the use of a tool in semi-structured interviews with family and residents, staff, and medical record reviews compared residents with and without a comfort order over one year in three nursing homes. The study looked at the families’ understanding of advance care planning, the use of the POLST form, and included hospice patients. Ninety-eight percent of families in this study reported that they did not have an understanding of these elements. Additionally, the findings showed that there was a lack of professionals with hospice and palliative care understanding and a lack of available services that may impact referrals.

Two studies looked at referrals over a defined range of time from six months to two years. A longitudinal study (Lima & Miller, 2018) evaluated mean survival rates of residents in 54 nursing homes after a palliative care consult was written. The results of this study support that six-month survival rates did not differ significantly ($p < 0.05$) in those residents with a palliative care consult when compared to residents who did not receive palliative care. In a retrospective review (Berkowitz, et al., 2011), an intervention was used to evaluate discharges to skilled nursing units with the use of a standardized template. Results of the study concluded that for

1,775 patients discharged over a 2-year period of time, 20 percent showed a decrease in hospital readmissions for those patients who had three or more hospitalizations in six months ($P=.03$).

Although all seven studies had the objective to measure referrals to palliative care, none measured all patients without limitations. Four studies included hospice referrals in the results, one study was limited to the emergency department (Stephens, et al., 2018), two studies only focused on a subset of patients with a specific diagnosis of cancer or heart failure (Lima, & Miller, 2018) or specific indicators of patient age, complexity of illness, and delays in communication (Berkowitz, et al., 2011). One descriptive study (Lester, et al., 2014), described the referral rate to palliative care, comfort care, and hospice care based on a nationwide survey of Directors of Nursing. The design methodology was a national survey online that was completed by 316 Directors of Nursing of skilled nursing facilities with an 11% response rate. Specifically, questions were asked about the use of palliative care versus hospice, and results concluded that hospice is significantly more available than palliative care. In the survey, social workers were found to be more likely to refer patients to palliative care. All studies show a gap in the literature of failure to look at all patients who meet criteria. Each study concludes that deaths and outcomes could be contributed to by other factors, which may not be directly related to palliative care referrals.

Three studies used a tool to trigger early referrals and improve communications between caregivers and long-term care facilities. In a quasi-experimental pre and posttest study (Hermans, et al., 2018), the use of interRAI palliative care instrument was used for baseline and post intervention after one year. Measurement data included symptoms such as pain management and family anxiety. Results for those with no prior knowledge of the tool were more favorable ($n=8/15$) with the use of the tool. A tool to measure chronic pain, weight loss,

and decrease in activities of daily living was used by Berkowitz, R. (2011). This study concluded that the use of a standard tool could help improve communication and trigger early referrals. In both studies (Hermans, 2018 & Stephens, 2018), tools were used to capture patients that met requirements for palliative care and to help those who did not have an understanding of palliative care or hospice services make the referral.

A Cochran review (Petkova, Froggatt, Hall, Higginson, Kolliakou, and Froggatt, 2011) looked at research to determine the effectiveness of interventions in care homes for older people in long-term care homes. Key journals were hand-searched and Pub Med was used with selection criteria, including randomized clinical trials, controlled clinical trials, controlled before and after studies and interrupted time studies. Articles included the use of assessment and management of physical, psychological, and spiritual symptoms, and advanced care planning. Seven hundred and thirty-five participants were included in the study results, and all studies were conducted in the U.S. with several sources of bias noted. Few outcomes for residents were assessed in the reviewed studies related to palliative care, and there were variations in satisfaction scores between the studies. The review supports conclusions that there are few studies that show high-quality trials of palliative care interventions. Recommendations in the review are for further research to look at measuring standardized outcome tools and the need to reduce bias and increase the knowledge about palliative care services, which is an aim of this study.

After a thorough review of the literature, research indicates that there are not enough informational studies published to date that expand on referrals from long-term care nursing facilities to include palliative care service. Gaps in the literature support that there is published information on hospice referrals, but often, palliative care information is included in this

information. Current literature indicates that a lack of participants in key roles in the referral process, such as nurses and caseworkers (Lester, Stenfanacci, and Feuerman, 2014) can hinder or delay services to residents. The literature supports that there is defined criteria that is used in intensive care and the emergency department (Stephens, et al., 2015), but such defined criteria are isolated to these care areas. The use of these criteria in long-term care may be beneficial. Additional studies indicate that the lack of available services for palliative care can impact access to care. Research also indicates that although some studies recommend the use of an interventional tool with defined criteria, there is no agreement on which tool or which criteria to use as a standard measurement or reference to a body of knowledge.

The central phenomenon of this study will add to the body of nursing knowledge by providing a key, missing component in the literature, i.e. palliative care referrals in long-term care. The existing literature often cites that there are processes in nursing homes to trigger a palliative care referral for a specific disease process, such as cancer, but the scope of palliative care embodies a larger set of chronic diseases and conditions that can be managed by encompassing all domains of palliative care. This study builds on existing evidence by exploring the perceptions of a key referral role, the Directors of Nursing. Information about the knowledge and attitudes of these referrers for determining who to refer was identified as a gap in the existing literature and forms the basis for this study.

Theoretical Foundation

This study used the theory of planned behavior (TPB). This theory was developed in 1985 and it is among the most widely used theories to predict cognitive behaviors in decision-making (Côté, et al., 2012). The model explores personal motivation to perform an action. This theory is applicable to the process used by long-term care facility Directors of Nursing to make a

palliative care referral.

In this theory, intention supersedes the behavior. The theory asserts that if there is a strong intention, there is increased likelihood that a behavior will be performed (Rashidian & Russell, 2011). It is important to note in this theory that subjects always have the control over whether or not to perform the behavior (Rashidian & Russell, 2011). Attitudes motivating behavior are often seen as either positive or negative, and ultimately directly relate to behaviors. Subjective norms are also important to measure because they are perceived social pressures that arise from one's own behavior. The interview protocol included items addressing the relationship between behavioral intention and behavior.

Methods

Research Design

This qualitative study utilized grounded theory to describe the lived experience of Directors of Nursing for determining what patients may need, or could benefit from, with palliative care referrals. The use of a guided interview questionnaire with open-ended questions allowed for the ability to gain insight to explore the depth, richness, and complexity inherent in the phenomenon of interest. Because grounded theory allows for the development of concepts as the interviewing continues or advances, each interview builds on the previous interviews to gain a deeper understanding. Interview questions were refined as concepts developed (Gillespie, Chaboyer, St John, Morley, and Nieuwenhoven, 2015). The use of this study design allowed the researcher to adapt the interview guide when it became apparent what was important to the participants (Sbarani, Carter, Evans, and Blinkhorn, 2011). Results were expressed as a substantive theory whereby the concepts contained in the data were related to one another in a cohesive whole. This was an appropriate approach to this study as the interview questions aligned with attitudes

and beliefs that were then related to behavior, in this instance referral of long-term care residents to palliative care.

Study Population, Sample and Sampling

Setting

Ten facilities were approached that were within the service area of a county-based palliative care program in a rural region of the east coast in the United States. The ten facilities represent a portion of the facilities that offer long term care services to the county population that is maintained by one palliative care program. Of the ten facilities approached, seven facilities agreed to participate in the study, including five assisted living facilities and two skilled nursing homes. All facilities in the study were Medicare dependent, with the skilled nursing homes having less than 250 residents and the assisted living homes having less than 50 residents. All facilities in the study had similar 24-hour care delivery models, with professional and para-professional staff caring for residents. All facilities in the study were at one-hundred percent occupancy during the time of the study and had a similar mix of chronic disease and dementia patients. All facilities in the study had access to hospice and palliative care services, and employed Directors of Nursing. The DON's at three facilities, including two assisted living facilities and one skilled nursing home, declined to participate in the study due to not having enough time for the interview.

Participation

Names of staff in the Director of Nursing role and their email addresses were obtained from direct conversations with participants or from telephone contact through the facility. An email was sent to each person individually with details of the study and time line for commitment with

a due date to respond back. After confirmation of willingness to participate verbally, a follow-up email and the researcher's contact information was sent via secure email to each subject.

Sampling

Seven Directors of Nursing were interviewed based on their involvement with the palliative care referral process in the facilities where they worked. The study inclusion criteria were that the participants were involved in the referral process in the role of Director of Nursing in a long-term care facility named for study and facilities that were located within the referral region of one palliative care service area. Exclusion criteria were that the individuals were not in the role of Director of Nursing or that they did not work at one of the facilities named in this study.

Instrument and Measurement

A demographic questionnaire and a guided interview questionnaire were developed for this study. The demographic questionnaire, Appendix C, was provided to each subject for completion prior to the interview to capture age, gender, race, educational level, experience, and service specialty. The Guided Interview Questionnaire, Appendix D, provided an interview format that flowed from one question to another in an established order for each subject to obtain specific information and stimulate additional dialogue. The interview protocol also involved the researcher recording any additional information about the interview, such as interruptions, distractions, feelings, ideas, thoughts, secondary data, and questions from the subject (Rosenthal, M., 2015). If a new question was asked by the researcher that clarified an additional point or a new area of study, it become part of the interview for other participants from that interview forward. Questions related to how decisions regarding referrals were made, along with questions on who else might be involved in the process. See Appendix D for Guided Interview Questionnaire.

Ethical Consideration

Permission for this study was obtained by the Institutional Review Board at George Washington University. The study qualified as an exempt study.

Data Collection

Interviews were scheduled with each subject at a time that was convenient for both parties, and they were conducted via telephone. Interviews were approximately 6 minutes in length, and audio recordings and written field notes were used for data collection and analysis. The point of saturation was considered reached when no new information was gleaned from the opinions of the interviewees and there were no opposing views. Throughout the study, all interview information was sent via a secured website with a link to minimize the risk of information being breached or exposed.

Before the interview began, each subject was afforded an opportunity to ask questions about the study, the interview process, and other aspects of the project. The demographic questionnaire was reviewed with each subject for completion before the interview. Any questions, concerns, or comments made during the interviews were recorded by the researcher in field notes, in case they were relevant for inclusion in the data analysis.

Interviews were recorded using an IPHONE application, Call Recorder, which was installed on the researcher's cellular phone. Each subject was notified when the recording began. Permission to record the conversation was obtained verbally prior to the interview starting. Written field notes, which were taken from the interview protocol, were used to supplement audio recordings. The audio file on Call Recorder was transcribed when all interviews were complete.

Data Analysis

The researcher reviewed the audiotapes produced from each interview to ensure complete, usable recordings were obtained, and no supplemental information was needed. Interview audio files were sent electronically in a secured, encrypted delivery to a third-party vendor (Transcripts to Go.com), to transcribe each interview verbatim, and they were returned to the researcher electronically in a secured, encrypted format within 24 hours. Upon receipt and after review for accuracy, Dedoose was used for qualitative data analysis to identify key terms, words, and phrases in relation to the aims of this study. The results of each research question were analyzed and evaluated for themes and commonalities. Specifically, responses were analyzed for each participant and results were first organized in large groups or broad categories and were later grouped into smaller categories with similar patterns, as patterns emerged.

The methodology for data analysis was appropriate for this study because it allowed for the emergence of common themes. Generalizations were made in responses to themes identified based on common major themes and subthemes. Quotes from those interviewed were included within the final results to show validity and rigor to support themes. Generalizations about the feelings, attitudes, beliefs, and experiences of subjects with palliative care referrals were described in the context of existing literature (Criswell, 2014).

Results

The aim of this research was to explore the referral process for palliative care services. The knowledge, attitudes, and beliefs of how this service could help long-term care patients by discussing referral practices by Directors of Nursing was evaluated by interviewing seven Directors of Nursing. All participants were Caucasian, female, and over the age of 50. All participants had greater than 10 years of experience in healthcare and all had a Bachelor's

Degree in nursing. All seven respondents indicated that they had over 10-15 years in long-term care, and 2-5 years of experience with palliative care services. Two participants worked in a skilled nursing facility and five participants worked in assisted living facilities.

The analysis of Question 1, the number of referrals monthly, showed a varied response with two participants indicating they refer 3 to 4 patients a month, while two participants indicated they refer one or two a month, and two participants stated they refer 1 a month. One participant stated that she has not had a referral in “quite a while”, however, when asked about the last patient she referred, the nurse recalled that she referred “1-2 recently”.

Findings regarding referral criteria were divided into three broad categories of physical decline, cognitive decline, and administrative decisions. Based on these common themes, all responses from participants fell into these broad categories. Data analysis support that most referrals are generated based on physical symptoms or functional decline and the theme drawn from this was Physical Decline. Decrease in functioning was reported by three participants, weight loss was reported three times, loss of appetite was reported once, “sleeping a lot” was reported once, as was dialysis, “started having falls”, and “stopped eating”.

The second major theme was Cognitive Decline. The phrases of “altered mental status” and “cognitive decline” were reported by two participants. The additional response of “becoming more agitated” was added to this category to capture the patient that had an increase in confusion. The Directors of Nursing recognized these cognitive changes as indicative of overall decline and they also sought palliative care consultation to manage these symptoms.

Administrative decisions were made for referrals, with one response of “I like to get an extra set of eyes to look at the patient, when we are doing all we can”, and “when the patient is no longer hospice eligible and still needs following closely”. “Not hospice eligible” was reported

twice as a reason for an administration decision for a referral and “sometimes the doctor orders” was reported once. One participant reported that a reason for a referral could result from policy to involve palliative care with a “change like an altered mental status.”

Within this category of Administrative Decisions, the Directors of Nursing also voiced interest in this study. The discussion included when referral to palliative care was based on the facilities’ procedures or policies and how they, as Directors of Nursing, could learn to improve care. Their comments included: “I am grateful for palliative care, it is a huge benefit to anybody with a terminal illness and dying”, “I am interested in your findings, if there is something that you think I need to know”. The participants also shared positive experiences with their use of palliative care services. Comments included, “We use them (palliative care referral or care) more than we used to”, “I think we use palliative care and hospice and know when to use them”, “We go back and forth with them (palliative care) and hospice when the patient needs it”, and “Palliative care was a substantial benefit to many residents throughout the death and dying process and even the time that lead up to that”, and “Palliative care is familiar to me.”

Discussion

The findings of this study support the literature reporting that only a small percentage of patients who could benefit from palliative care actually receive referrals to palliative care. The role of Director of Nursing in this study was selected as a key stakeholder in facilitating outside services for patients in each of their organizations. Their involvement in the referral process is crucial in helping to get patients the services they need. In each of these long-term care facilities, the Director of Nursing is aware of the referrals written and helps with the implementation of such referrals. When compared to literature findings, this study also supports the underutilization of palliative care and lack of clear policies to trigger such referrals.

Physical symptoms were the primary reason that referrals were generated in this study, but there was no discussion of a standardized tool for symptom assessment (Berkowitz, et al., 2011). A standardized template could be used to assess patient symptoms and policies to determine when the facility/patient needs palliative care consultation. The literature regarding palliative care and hospice referrals supports that Palliative Care services and Hospice are not always readily available to patients. It also suggests that there is a lack overall of understanding of palliative care and when to use or request service. In this study, findings related to Directors of Nursing responses of “hospice or palliative care” suggest that there is a lack of understanding that palliative care services are distinct from hospice and that palliative care should be implemented early in the course of disease. Extensive literature has documented the barriers that arise when palliative care is associated only with terminal illness and death and when there is a lack of understanding of the scope of palliative care.

Limitations

There are limitations and weaknesses identified with this study design. The sample size for this study included only seven interviews in two care settings. While data obtained did provide common themes and important insights regarding palliative care referral, future research should include more diverse settings such as skilled nursing, assisted living, or specialty units (such as dementia units) which would provide diversity and perhaps additional knowledge. It is also important to recognize that participants in this study were similar in demographics variables such as age, education, and gender and a more diverse sample might have provided different results.

Telephone interviews did not allow the researcher to assess body language and some of the interviews were completed at a time when the participants stated they were busy. Saturation was achieved with the general physical symptoms criteria used to obtain referrals, but there were no

definite parameters reported for each symptom as to when these symptoms should lead to palliative care referral. More specific criteria regarding weight loss, insomnia, pain intensity, and other uncontrolled symptoms could provide structure for more consistent and earlier referrals for palliative care consultation. The settings for this study were either skilled or assisted living, and future focus on this topic should include institutional factors such as staff numbers, patient acuities, number of residents housed, etc.

Personal bias was also a consideration and potential limitation in this study. The researcher has 17 years' experience in healthcare caring including hospice and palliative care settings. Telephone interview recordings were reviewed several times in an attempt to monitor any unintended biases and to remain objective in reporting of findings.

Implications/Recommendations

This study is important to nursing research and to the future of palliative care in an aging society. Study findings can be used to improve practice by linking to the national guidelines for palliative care. Ongoing education to review criteria, reasons for, and goals of care should be implemented and embedded in nursing documentation to objectively trigger a response for generating an early referral. It is important to note that despite nationally accepted guidelines and well-defined domains for palliative care, no Nursing Director interviewed mentioned their use. Ongoing education related to palliative care and the standards or guidelines for care are needed in these settings. The education should emphasize the distinctions between hospice and palliative care, the evidence regarding patient benefit from this care, and how to communicate with older adults and their families about palliative care.

Conclusions

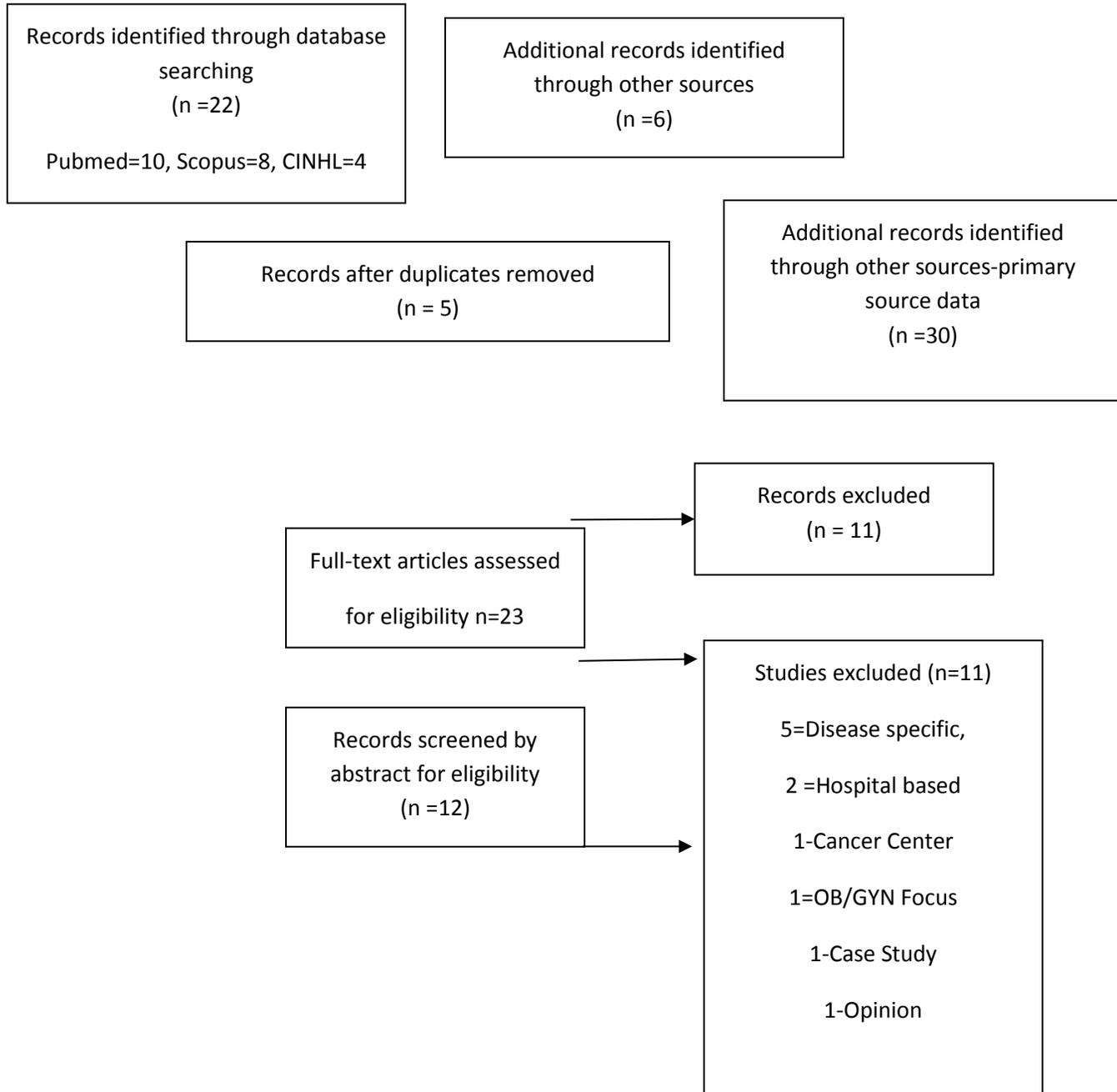
This study is reflective of the lack of understanding and underutilization of palliative care

services in long-term care. There is variability in the number of referrals and palliative care is deemed to be an option only or when the facility is unsure what next steps are available for the patient. Physical symptoms are cited as the primary reason for palliative care referrals with no mention of the other domains of palliative care, such as spiritual, social, cultural, end of life, ethical, or legal, as noted in the National Guidelines for Palliative Care (2013). Study findings support the need for clear criteria to guide practice.

This study supports a need for improved understanding and education in long-term care facilities with defined criteria through the use of the National Clinical Practice Guidelines. The perspectives in this study by nursing directors add important knowledge in settings known to care for seriously ill elders where such care could greatly impact quality of life.

Recommendations for further research include testing interventions, such as the potential inclusion of guidelines into electronic health records to automate a trigger for referrals and to increase the knowledge of all staff to better support access to palliative care.

APPENDIX A: PRISMA DIAGRAM



Appendix B: Variable Table with Theoretical and Operational Definitions:**Qualitative Study of Referrals for Palliative Care Variables**

Variable Name	Variable type and form	Theoretical Descriptive Definition	Operational Definition/Specification
<i>Dependent Variable</i>			
<i>Demographic Variable (Independent Variables)</i>			
Age	Demographic/Explanatory Interval	Age of Participant	Age of referee in years from 18-65
Gender	Demographic/Explanatory/Binary	Sex	Male=1, female=2
Race	Demographic/Explanatory Category	Race	1= Caucasian 2=Black 3= Asian 4=Hispanic 5= Other
Education	Demographic/ Explanatory Category	Education Level	1=Associates Degree 2=Bachelor's degree 3=Master's degree 4=Doctorate degree
Experience in LTC	Demographic/Explanatory Interval	Experience in LTC in years	1 = less than 1 year 2= 2-5 yrs. 3=5-10 yrs. 4=10-15 yrs. 5=15-30 yrs.
Previous Experience with PC	Demographic/ Explanatory Interval	Experience with PC in years	1= less than 1 yr. 2=2-5 yrs. 3=5-10 yrs. 4= > 10 yrs.
Environment	Demographic/Explanatory Category	Area of patient care where referral is generated	1. Skilled Nursing Floor 2. Independent living unit 3. Assisted living unit 4. Dementia Unit

APPENDIX C: Demographic Questionnaire**Participant Name:** _____

What is your age?	
What is your Gender?	Male=1, female=2
What is your Race?	1= Caucasian 2=Black 3= Asian 4=Hispanic 5= Other
What is your level of Education?	1=Associates Degree 2=Bachelor's degree 3=Master's degree 4=Doctorate degree
What is your Experience in LTC?	1 = less than 1 year 2= 2-5 yrs. 3=5-10 yrs. 4=10-15 yrs. 5=15-30 yrs.
What is your Previous Experience with PC?	1= less than 1 yr. 2=2-5 yrs. 3=5-10 yrs. 4= > 10 yrs.
What are of nursing do you write the most referrals?	5. Skilled Nursing Floor 6. Independent living unit 7. Assisted living unit 8. Dementia Unit

APPENDIX D: Guided Interview Questionnaire

Participant's Name

Questions for Interview:

1. About how often, or how many referrals do you make for nursing home residents for palliative care services each month.

2. How do you decide who should be referred for palliative care.

3. Do you have specific criteria that you use for determining eligibility for palliative care services?

4. Tell me about the last person that you referred for care...what were the circumstances?

5. Tell me more? If applicable.

APPENDIX F Information Form

THE GEORGE WASHINGTON UNIVERSITY

WASHINGTON, DC

Information/Consent Form

Title of Research Study: Referral Patterns from Long Term Services to Palliative Care: Perceptions Directors of Nursing

Investigator: *Karen Sharrah, MSN, FNP-C*

Investigator Contact Information: *Karen Sharrah, Cell phone 717-377-5669*

Why am I being invited to take part in a research study?

We invite you to take part in a research study because this study focuses on the phenomena related to the role of Director of Nursing in the palliative care referral process

What should I know about a research study?

- Someone will explain this research study to you. You may ask all the questions you want before you decide whether to participate.
- Participation is voluntary; whether or not you take part is up to you.
- You can agree to take part and later change your mind.
- Your decision not to take part or to stop your participation will not be held against you.

Who can I talk to if I have questions?

If you have questions, concerns, or complaints, or think the research has hurt you, talk to the principal investigator, Beverly Lunsford PhD, RN, FAAN @ 201-994-6726.

This research is being overseen by an Institutional Review Board (“IRB”). You may talk to them at 202-994-2715 or via email at ohrirb@gwu.edu if:

- You have questions, concerns, or complaints that are not being answered by the research team or if you wish to talk to someone independent of the research team.
- You have questions about your rights as a research subject.

Why is this research being done?

This research is looking in depth at how Directors of Nursing make referrals to begin palliative care services for their patients in long term care facilities. Current research suggests that approximately 10% of patients in long-term care receive palliative care services. This under utilization demonstrates a significant impact to patients who typically have comorbidities and may benefit from palliative care. This study will look at the knowledge, attitude and belief of DON (Directors of Nursing) to better understand how and why this is happening in an effort to explain these results for future research.

How long will I be in the study?

We expect that you will be in this research study for 2 months. Your involvement will be in a one-hour telephone interview, filling out a brief demographic questionnaire

How many people will take part in this research study?

We expect about 10 people will take part in the entire study.

What happens if I agree to be in this research?

After you agree to participate, you will meet with the researcher at a predetermined time over the telephone to answer 4 questions related to referrals for palliative care services. This phone interview will be recorded and will last for a maximum of one hour. You will be given an opportunity to ask questions and the interview will follow a conversation format where you will be encouraged to share your thoughts, beliefs and attitudes about referrals for PC (palliative care). Information recorded will be reviewed by the researcher and for transcribed in a secured, encrypted format to be typed verbatim. All interactions for this research project will be between yourself and the researcher only. If you decide not to participate, the study will continue with the number of DON who does agree to participate.

What happens if I agree to be in research, but later change my mind?

You may refuse to participate or you may discontinue your participation at any time without penalty or loss of benefits to which you would otherwise be entitled.

If you decide to leave the research, please contact the researcher so that she may destroy any and all information regarding your involvement.

Is there any way being in this study could be bad for me?

All research studies have some risk. The following table outlines risks under the following categories of minimal, moderate or significant

Physical Risk	Minimal	Interviews are conducted via telephone
Psychological Risk	Minimal	All information is confidential and all information will be stored in a secured electronic file. Information will only be aggregated with other respondents' with all identifiable information removed.
Privacy or confidentiality Risk	Minimal	“ “
Legal Risk	Minimal	“ “
Social Risk	Minimal	“ “
Economic Risk	Minimal	“ “

The risks and discomforts associated with participation in this study are not expected to be greater than those ordinarily encountered in daily life or during the performance or routine physical or psychological examinations or tests.

What happens if I believe I am injured because I took part in this study?

You should promptly notify the research team in the event of any injury as a result of being in the study.

You will not receive any financial payments from GWU, GWU Hospital and/or the GWU MFA for any injuries or illnesses. You do not waive any liability rights for personal injury by signing this form.

Will being in this study help me in any way?

You will not receive any benefits from participating in this research. Findings of this study, however may improve the quality of care of nursing home residents who may receive palliative care services.

What happens to my information collected for the research?

To the extent allowed by law, we limit your personal information to people who have to review it. We cannot promise complete secrecy. The IRB and other representatives of this organization may inspect and copy your information.

Data obtained for research will be kept in the possession of the researcher in a locked area in the office where the researcher resides. All electronic data will be stored in a secured file on a flash drive that only the researcher has access to in a locked file cabinet. At the end of a 5 year period, the flash drive will be smashed by the researcher

Are there any costs for participating in this research?

There are no costs for you to participate in this research

Will I be paid for my participation in this research?

You will not be paid to participate in this research.

How will I be informed of the results of the research?

The researcher will make a copy of the final analysis and it will be available upon request.

Name of Participant

Date Consent obtained

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