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THE EXPERIENCES OF HEALTH CARE PROVIDERS PROVIDING COMFORT FOR
NURSING HOME PATIENTS AT THE END OF LIFE

by

HERMA BAKER

Master of Science in Nursing, University of Central Florida, 2004

A doctoral thesis submitted in partial fulfillment of the requirements
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ABSTRACT

Research shows that healthcare providers (HCPs) are not adequately prepared to provide comfort care for patients who are at the end of life. Since the 1990s, numerous legislative, research, and clinical initiatives have addressed concerns about improving care at the end of life. The purpose of this study was to describe the experiences of HCPs providing comfort for patients in the nursing home who are at the end of life. This study focused on physicians, nurse practitioners, nurses and nurses' aides at a central Florida nursing home. A descriptive qualitative design was done utilizing a focus group discussion, individual interviews, and a self-administered questionnaire. The findings indicated that a lack of facility support, inadequate staffing, inadequate end of life care education, family and patient denial of prognosis, as well as decreased primary care physician involvement affect the delivery of comfort care for patients at the end of life in the nursing home. This study supports the need for end of life education to HCPs and the need for adjustments in staffing to meet the complex needs of patients in the nursing home who are at the end of life. A new finding of this study reflects the use of an angel cart to aid in the provision of comfort care for patients at the end of life. Recommendations for future research were made based on study results

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CHAPTER I

Introduction

Medical advances, coupled with public health strategies, have resulted in a 30-year increase in life expectancy since the dawn of the previous century (Centers for Disease Control and Prevention, 2008). People are living longer with increased expectations about their health and quality of life. These expectations extend to wanting to ensure that the last months and years of life are lived as fully as possible with comfort and dignity. The National Institute on Aging (NIA) (2009) have stated that comfort care at the end of life (EOL) is an essential part of medical care. The goal of EOL care is to relieve suffering as much as possible while respecting the dying person's wishes.

Since the early 1990s, several legislative, research, and clinical initiatives have addressed concerns about improving care at the EOL (End-of-Life Nursing Education Consortium (ELNEC), 2008; National Institute of Nursing Research (NINR), 2007). For example, the ELNEC project is a national education initiative designed to prepare nurse educators to integrate evidence-based content into the curricula of nursing schools and into practice. In addition, the NINR has identified EOL research as one of its five main research priorities.

The transition in the nursing home (NH) setting from routine to comfort care at the EOL can be delayed by a lack of awareness about the signs of terminality, indecision, inaction, or inadequate communication on the part of key decision makers. The term EOL care is often used interchangeably with hospice or palliative care. Many studies support the fact that Health Care Providers (HCPs), which include physicians, nurses, nurse practitioners, and nurses' aides, are not adequately prepared to provide comfort care at the EOL (Ersek, Grant, & Kraybill, 2005).

Accordingly, there is evidence that dying patients experience inadequate relief of pain and other undesirable symptoms and that their wishes concerning end of life are not always taken into account. Reasons for these gaps in care need to be understood in order to design strategies to improve care. The perspective and experience of the people actually delivering EOL care in the nursing home setting has not been well described. Understanding this perspective can lead to improved preparation and support for the people who work most closely with the dying.

Problem and Significance

Nursing homes represent a major component in the continuum of long-term care and are a common setting for delivering EOL care. For the purposes of the present research, the term EOL refers to a point at which it has become clear that the patient is in a progressive state of decline. As the population ages, increasing numbers of older Americans will receive EOL care in NHs. The mortality rate for NH patients is approximately 25% per year, and 66% of permanent residents will stay in the NH setting until they die rather than enter a hospital for their final days of life (Reynolds, 2004). By 2040, it is estimated that 40% of deaths will occur in NHs (Ersek et al., 2005) . Ironically, despite the frequency of death in the NH, there is much evidence to suggest, however, that many NHs are ill-prepared to provide high quality EOL care (Ersek, et al., 2005)

According to Waldrop and Kirkendall (2009), federal and state agencies have established universal standards for routine NH care, but procedures for NH-based EOL care are not regulated and, as a result, vary widely. While EOL care is provided in all health care settings, it has not routinely received specific focus within NHs. Care at life's end is defined by the

regulatory environment, but the interchangeable use of the terms EOL care, palliative care, comfort measures, and hospice care may contribute to uncertainty about what constitutes NH-based EOL care (Waldrop & Kirkendall, 2009)

There are many barriers to providing EOL care in NHs. Specific challenges include lack of physician involvement and poor communication between NH staff and physicians (Ersek et al., 2005). Approximately 60% to 70% of NH nursing employees are nursing assistants (NAs) who provide 70% to 90% direct care (Ersek et al., 2005). Typically, NAs have a high school education or less. Among licensed NH staff, licensed practical nurses (LPNs) generally outnumber registered nurses (RNs) (Ersek et al., 2005). LPN training programs usually take 12 to 24 months to complete and include only limited content on geriatrics and EOL care. For these reasons, the educational needs of NH staff may be greater than those of clinicians in other settings (Ersek et al., 2005).

In order to provide adequate EOL care, it is evident that current standards of care need to be explored for patients who are expected to die in NHs. The steps in improving the situation are to examine the current practice patterns, to determine what HCPs perceive as barriers to providing comfort care to patients at the EOL, and lastly to explore how they think that care can be improved. The purpose of this research is to describe the experiences of HCPs with providing comfort for patients in the NH who are at EOL. A better understanding of this phenomenon may result in improved comfort and EOL care. The HCP's identified as nurses will include LPN's and RNs.

Objective and Aims

The objective of this research was to describe the experiences of HCPs providing comfort for patients in the NH who are at the EOL. Study findings will be used to provide a direction for educational change. The study was guided by the following research questions:

1. How do HCPs define comfort care for patients at the EOL in the NH?
2. How is comfort care addressed differently by different types of HCPs in the NH?
3. What are the facilitators identified by HCPs that affect the delivery of comfort care for patients in the NH at the EOL?
4. What are the barriers identified by HCPs that affect the delivery of comfort care for patients in the NH at the EOL?
5. How are NH HCPs educated to provide comfort care for patients at the EOL?
6. How do HCPs feel they can deliver better comfort care?
7. How are HCPs providing comfort for patients at the EOL?

Definition of Terms

Conceptual Definition

The terms comfort care, EOL, and HCPs represents the phenomena of interest for this proposed research:

- 1) Comfort care is considered in nursing as an intervention, conversely using the term comfort measures is a process, such as providing comfort. Comfort measures are a means to a state of comfort that is the desired outcome of comfort care (Siefert, 2002). In this study, comfort care is operationalized by the immediate state of being strengthened, as well as having the human needs

for relief, ease, and transcendence addressed physically, psychospiritually, socioculturally, and environmentally (Kolcaba, 1994). In addition, comfort care can be the cessation of all active curative treatments

2) EOL is considered to be the period of time marked by disability or disease that is progressively worsens until death (National Institute on Health, 2004). In this study, EOL is operationalized as the final stage of the journey of life when death, whether due to terminal illness, acute or chronic illness, or age itself, is expected (Dyer, 2006). It is the point when it has become clear to HCPs that the patient is in a progressive state of decline. Specific indicators of that decline would be cessation of eating as well as change in consciousness or breathing patterns.

3) HCPs are providers of medical or health services, and any other person or organization who furnishes, bills, or is paid for health care in the normal course of business (HIPAA, 2009). In this study, the HCPs are the physicians, NAs, NPs, and the nurses which are the LPNs and RNs.

Operational Definition

1) Comfort is considered to be measured by nursing using the general comfort questionnaire. This measure assesses quality in terms of comfort and the extent to which the person is experiencing comfort at that point in time (K. Kolcaba & Dowd, 2000). In this study, comfort is operationalized by the report of the patient or the observable decrease in posturing which is the subspace of the full range of the physically possible. (Kolsch, Beall, & Turk, (n.d.)).

2) EOL is considered to be measured by quality indicators, such as worsening physical function and weight loss which are expected aspects of terminal illness (American Geriatrics Society,

2002). In this study, EOL is operationalized by prognostic assessments of the patient by HCPs or family members, diagnosis, symptom expression, and functional decline.

3) HCPs are measured and operationalized by the services they provide.

Assumptions

It is the assumption that the participants in this study will be able and willing to express their experiences and feelings regarding EOL care. It is possible, however that this will be difficult for them. These beliefs can provide guidance to the development of the educational preparation of nurses. However, according to previous literature, educational preparation for EOL care is insufficient. One of the purposes of this research was intended to explore these deficiencies.

Overview of the Study

This qualitative study about experiences of HCPs providing comfort for patients in the NH is described in detail in the following chapters. Chapter II summarizes the literature that provided a basis for the study. Chapter III describes the methodology used to conduct this qualitative study. This includes the design of the study, the sampling decisions, and the data collection and analysis procedures. Chapter IV presents the results of the data collected. Chapter V discusses the findings and presents the conclusions and implications of the study as well as recommendations for further related projects

CHAPTER II

Literature Review

Health care providers (HCPs) are increasingly faced with EOL situations in nursing homes and assisted living facilities, and there are reports of frustration and lack of sufficient training in these areas. This literature review will focused on the experiences of HCPs providing comfort for patients in the NH at the EOL. A computerized search of MEDLINE, CINAHL, PubMed, PsychInfo and Cochrane was conducted using keyword searches for the following terms: comfort care, EOL care, and nursing homes, long term care (LTC). Major concepts found in the literature were studies regarding differing perceptions and knowledge of EOL care, barriers to progress in improving EOL care, facilitators associated with quality EOL care, and educational deficiencies regarding EOL care.

HCP Perceptions and Knowledge of EOL Care

Several researchers have explored HCPs perceptions of providing EOL care to patients in the NH (Bern-Klug, Dessert, Cerner, Beaver, & Smirched, 2004; Denham, Meyer, Rat bun, Tabor, & Thornton, 2006; Good ridge, Bond, Cameron, & McKean, 2005; Tyree, Long, & Greenberg, 2005). Bern-Klug et al. (2004) performed an exploratory qualitative study (N=12) in which NH physicians were interviewed regarding their perspectives on EOL care. The researcher's ultimate goal was to improve understanding of NH physician perspectives regarding EOL care and suggest directions for further research. Four themes were identified in the analysis of the 12 interview transcripts: (a) extensive familiarity with dying, (b) consensus is integral to good EOL care, (c) obstacles can interfere with consensus, and (d) advance directives set the

stage for conversations about EOL care. The findings for this study revealed further research is needed to determine if other members of the health care team (i.e., nursing staff, residents, family members, etc.) also value consensus highly. In addition, a refinement of the general education for physicians on EOL describing the relationship between curative and palliative care is proposed for NHs (Bern-Klug, et al., 2004)

Similarly, Tyree et al. (2005) performed a survey (N=607) with a convenience sample of NPs attending a national conference to examine their beliefs, practices, and perceptions when discussing EOL care discussions. Out of the total number of NPs, 30 worked in a NH setting. The survey included 20 liker-type questions, 11 demographic questions, and 20 open-ended questions. The study concluded that education and experience contribute significantly to the comfort level of NPs who initiate EOL discussions. Although the NPs felt that experience was a contributor to their comfort level when initiating EOL care conversations, they also felt that additional education would be beneficial (Tyree, et al., 2005)

According to Denham et al, (2006) little is known about the role of NAs in rural long-term-care facilities or their impact on the process of death and dying in rural healthcare environments. They conducted a study utilizing focus groups with NAs, which were held in six rural countries located in five states to assess attitudes and perceptions about EOL care and training needs. Four themes about the needs of rural NAs around EOL care were identified in the focus groups; (a) a need for more education, (b) a need for better communication skills, (c) close bonds between NAs and clients, and (d) organizational problems that more training might ameliorate. The findings for this study that revealed there is a need for additional NA training about EOL care in

rural areas with attention to unique concerns. A computer-based training on EOL training holds great promise as a way to offer low cost and meaningful education to many rural NAs (Denham et al., 2006).

Goodridge et al. (2005) performed an exploratory descriptive study in which the author's utilized semi structured interviews. They examined the perspectives of RNs and NAs as well as family members regarding the last 72 hours of NH resident lives. The sample consisted of 14 RNs, eight NAs, and four family members. Thematic analysis was conducted independently and through consensus themes and subthemes that emerged from the interviews. Two major themes that emerged from this study were: (a) the staffs' caring behaviors and (b) the resident's unique experience of dying. The findings revealed dyspnea was a more common EOL symptom than pain. Caring behaviors of staff were central to the resident's dying process and involved assessment, coordination of care, physical care, family education, and nurturance. Family members' ambivalence about the resident's death and fear of the resident dying alone were frequently noted. The authors concluded that appropriate and timely symptom management and a range of caring behaviors of staff are critical elements in the dying experience of NH residents (Goodridge, et al., 2005).

It is the perception of HCPs that further education is necessary and crucial to providing adequate care (Flacker, Won, Kiely, & Iloputaife, 2001). A study by Flacker et al. (2001) interviewed physicians, nurses, and NAs (N=27) to assess their perceptions of EOL in the NH. Areas assessed were pain, comfort, emotional support, quality of death, number of symptoms present at the EOL, and whether direct care needs were met. An analysis of the data revealed the

areas of differences were pain and emotional support. The NAs perceived more resident pain compared to physicians or nurses. In addition, the physician's perception of the importance of emotional support provided to families was lower than that of NAs or nurses.

The authors concluded an explicit individualized care plan should be utilized by care providers to better understand how their perceptions of EOL care differ (Flacker, et al., 2001)

Summary

In summary, the findings of these studies revealed knowledge deficits and differing perceptions on what constitutes quality EOL care. Effective team functioning requires an understanding and recognition of the different perceptions of HCPs. In addition, clarifying and addressing the reasons for these differences may improve both job satisfactions on the part of the care provider, as well as the quality of EOL care delivered.

Barriers to Quality EOL Care

Several researchers have explored barriers to progress in improving EOL care in NHs (Hanson, Henderson, & Menon, 2002; Stillman, Strumpf, Capezuti, & Tuch, 2005) . Focus groups and surveys were conducted by Hanson et al. (2002) with experienced NH staff and physicians (N=77). Participants described lack of training, regulatory emphasis on rehabilitation, a resource-poor setting, inadequate staffing, staff turnover, and physician disregard for EOL issues as important barriers to high-quality care of the dying in NH (Hanson et al., 2002). Three major themes emerged to define a good death in a NH: (a) highly individualized care based on continuity relationships with caregivers, (b) effective teamwork by staff, physicians, and family,

and (c) comprehensive advanced care planning that addresses prognosis, emotional preparation, and appropriate use of medical treatments (Hansen, et al., 2002)

Stillman et al. (2005) looked at NH staff perceptions concerning barriers and facilitators to EOL care in the NH. The researcher's ultimate goal was to determine whether the presence of an 18-month comprehensive palliative care program would affect the knowledge and attitudes of the staff. The study was part of a larger palliative care initiative with more than 300 NHs. The chief findings concerning barriers, attitudes, and knowledge of NH staff regarding EOL were regulatory concerns focused on functional outcomes, communication with family, uncertainty regarding pain management, and appropriate care of the dying. Staff at each NH was asked to complete an investigator-developed post questionnaire. A total number of 539 questionnaires were completed. The study suggests that a palliative care program within NH increases knowledge about care for the dying (Stillman, et al., 2005)

A more recent mixed methods study explored the burden of being confronted with death and dying for NH staff. (Jenull & Brunner, 2008). Findings from open-ended interviews with 17 representatives of different occupational groups informed the design of a questionnaire used to conduct a survey in 52 NHs. In total, 894 questionnaires were returned, yielding a response rate of 49%. Results indicated it was more difficult to talk about death with family members of terminally ill residents than the dying themselves (Jenull & Brunner, 2008). The researchers concluded that the need for EOL training regarding death and dying is not only essential for nursing staff but is also needed for other ancillary staff that is also substantially strained by the dynamics of death and dying.

Summary

Inadequate staffing, lack of administrative support, lack of staff training, regulatory issues, and physician disregard for EOL care issues have been identified as the major barriers for quality EOL care. NHs are and will continue to be the site of death for many Americans. It is therefore essential that barriers and attitudes to quality EOL care be addressed in order to improve the problems faced in caring for the dying.

Educational Interventions

Research has demonstrated worldwide that there are major EOL educational deficiencies among HCPs and insufficient training in care at the EOL. A number of researchers (Braun & Zir, 2005; Easom, Galatas, & Warda, 2006; Keay, Alexander, McNally, Crusse, & Eger, 2003; Paice, Ferrell, Coyle, Coyne, & Callaway, 2008) evaluated the effects of each educational interventions designed for HCPs. It has been demonstrated that providing educational in-service to HCPs has been successful in increasing their knowledge and improving the quality of dying for patients at the EOL (Braun & Zir, 2005; Easom et al., 2006; Keay et al., 2003; Paice et al., 2008)

Nurses' aides (NAs) play a critical role at the bedside of seriously ill and dying residents, and they can make the difference between a good and poor dying experience (Braun & Zir, 2005). Braun and Zir explored the effectiveness of an eight-hour training curriculum related to dying, death, and bereavement with NH NAs (N=42). Participants demonstrated high scores on posttests of training content, and they significantly improved their scores on personal comfort

with providing EOL care over the course of training. This was not an experimental design, and that is a limitation of this research. However, the researchers concluded that the use of this interactive learning curriculum provides an effective way to provide EOL training to paraprofessionals (Braun & Zir, 2005).

A similar study by Easom et.al (2006) with RNs and LPNs (N = 9) in the NH setting tested the effects of a classroom presentation as an intervention to increase knowledge of EOL care. Purposive sampling guided the selection of the sample, which was deemed appropriate in order to maintain nursing coverage on all units. The results revealed posttest scores were significantly higher than pretest scores regarding overall knowledge on EOL care. The attitudes and perceptions changed in defining what constitutes a good death. The researchers identified study limitations due to size, which impedes the ability to generalize these findings. Likewise, the participants who volunteered and completed the study were probably self-motivated and already had an interest in EOL care. The researchers concluded that future studies should be conducted with a larger number of participants in multiple NH settings (Easom et al., 2006)

An earlier study by Keay et al. (2003) tested whether an educational intervention designed for physicians (N = 12) in NHs improves the quality of dying for patients. Physicians participated in a half-day adult education outreach program including audit and feedback. The main outcome measures were determined through chart documentation and included: (a) total patient comfort, (b) pain control, (c) bereavement support, (d) dyspnea, (e) control of uncomfortable symptoms during the dying process, and (f) presence of advance directives. The four NHs that completed the intervention all had significant improvement in EOL care outcomes,

which was measured from a pre-education and post-education program. The researchers concluded that important terminal care outcomes can be significantly improved by targeting key nursing home physicians with an adult educational program that includes auditing and feedback (Keay et al., 2003)

A more recent study by Paice et al. (2008) explored global efforts to improve palliative care with the ELNEC. A course evaluation form and post-course activity evaluation was completed by a convenience sample of 38 nurses from 14 eastern and central European and Asian countries. Content experts in palliative care revised the original ELNEC curriculum to reflect the specialized needs of nurses in a global arena. The researchers concluded that the first ELNEC international training program demonstrated the feasibility of providing high-quality care, essential education to nurses from a variety of countries (Paice et al.)

Summary

HCPs experience and educational backgrounds have shown to be important factors in the ability and confidence level of HCPs providing comfort for NH patients at the EOL worldwide. HCPs consistently reported insufficient training in the care of patients at the EOL. Educational interventions have proven to be successful in improving knowledge and quality of life for patients at the EOL

Conclusion

A number of researchers have studied differing perceptions, barriers, and knowledge of EOL care in the NH setting with HCPs. The methods used by these researchers included structured interviews, focus groups, questionnaires, and surveys. The researchers' ultimate goals

were to gain an understanding of the different views on EOL care by HCPs that may influence their perceptions of that care. Areas of differences include how to approach pain management, comfort, emotional support, supportive care, quality of death, and time spent with the resident. The most common areas of differences were pain control and emotional support.

Similarly, HCPs consistently reported a need for EOL training and expressed feelings of inadequacy in EOL care knowledge and a lack of experience related to EOL care. It is apparent according to previous literature that HCPs who are expected to care for patients at the EOL do not have all of the tools necessary to meet the multifaceted comfort needs of dying patients. Research findings support the conclusion that education on EOL care is essential and crucial in the provision of care worldwide.

CHAPTER III

This chapter presents the methods that were used for the study, including the design, selection of the participants, sample, setting, and data collection procedures. In addition, inclusion and exclusion criteria are discussed. The data analysis is described as well as the methods used to assure protection of the participants.

Methods

The primary purpose of this study was to explore HCPs experiences of providing comfort to NH patients who are at the end of life. Factors that facilitate or barriers that prevent the HCPs ability to provide this comfort were of particular interest. The study was conducted in one local NH in central Florida. Data were obtained by the researcher via a self-administered questionnaire, audio-taped individual interviews, and an audio-taped focus group discussion.

Design

A descriptive qualitative design was used in this research. A descriptive design is used to describe an event, experience, or concept about which little is known (Oman, Kregman, & Fink, 2003). In essence, a broader synopsis of actual experiences is presented and defined in common language.

Sample

The participants for this study were a convenience sample of HCP's (nurses' aides, registered nurses, and licensed practical nurses) employed at a one large central Florida NH. Physicians and nurse practitioners (NPs) who have privileges at the NH were also invited to

participate in this study. Inclusion criteria included NH HCPs who were caregivers for patients who are at the EOL and are receiving care either with or without hospice services and are receiving comfort measures only. Data exclusion criteria included NH employees that were unable to communicate in English. Recruitment of participants was accomplished with a flyer placed in each of the three nursing units, and a flyer placed in the physicians' and NPs' communication book (see Appendix A) which was located in each nursing unit announcing the research study. The flyer asked any interested participant to contact the researcher by telephone or e-mail if interested in completing a questionnaire and/or participation in a focus group discussion. However, the researcher did not receive an e-mail or telephone call from any staff requesting to participate in the study. Hence, recruitment of participants in the study resulted from the researcher being onsite at the facility and personally asking HCP's if they wanted to participate. To further announce and recruit participation for the study, the researcher attended the NA staff meetings. However, due to facility limitations, the researcher could not attend the nurse's staff meeting.

The researcher's goal was to conduct one focus group discussion with the nurses and one focus group discussion with the NAs. The researcher intended to recruit the focus group participants from the questionnaire respondents. It was also expected by the researcher that nursing supervisors and physicians and NPs would have limited availability to participate in a focus group discussion and thus this was not considered in the design of the study. However, all HCPs, to include physicians and NPs were invited to complete study questionnaires. The facility director allowed one focus group discussion to be conducted with NAs after their routine

scheduled staff meeting at the facility. One focus group discussion was completed with NAs that volunteered. However, the focus group discussion was held at the end of the day and there was facility concern regarding compensation for overtime. Due to the time constraints, the researcher was not able to obtain demographic information from the NAs participating in the focus group discussion. In addition, the facility director allowed the researcher to conduct individual interviews with nurses that volunteer to participate during their work hours.

Setting

The targeted participants for this study included HCPs working at a central Florida nursing home. The NH has a high rating for overall inspection, quality of care, quality of life, and administration according to the Agency for Health Care Administration (ACHA) survey conducted in 2009. This NH has a total of 180 beds and typically has a 94% occupancy rate. There are 100 NAs and 50 nurses employed at this facility. The number of nurses (LPNs and RNs) and nurse's aides on each shift are as follows: 1) there are eight LPNs, three RNs, and 28 NAs on the day shift 2) there are seven LPNs, one RN, and 23 NA on the evening shift, and 3) there are eight LPNs and 28 NAs on the night shift. The number of nurses and NAs did not change for the weekend evening and night shift. However, the number of RNs was decreased to one on the weekend day shift with no change in the number of LPNs and NAs. In addition, there are five physicians and three NPs who are not employed by the NH but have credentialing privileges. Credentialing privileges refers to the detailed information concerning the provider qualifications and the extent of the care that provider is permitted to provide care in a health care setting ("Joint Commission," 2010).

Protection of Human Subjects

Approval from the University Central Florida (UCF) Institutional Review Board (IRB) and the NH was obtained (see Appendix B and C). All participants were made fully aware of the purpose of the study and full explanations of the methods were provided to them (see Appendix D, E, and F). Confidentiality was maintained at all times. No identifying data was used throughout the study. Participants were given an identifier number at the beginning of the focus group discussion and were not asked their names on the self-administered questionnaire or during the individual interviews. All questionnaires, tape recordings, and transcriptions of the interviews and focus groups were locked in a file at the researcher's office. Only the researcher had access to this data. According to the UCF IRB, the questionnaires, individual interviews, and focus group discussion were exempt from the informed consent process since consent was implied by the HCPs' agreement to participate.

Data Collection and Instruments

Data were collected through a self-administered questionnaire (See Appendix G), audio-taped individual interviews of nurses, and an audio-taped focus group of NAs. The self-administered questionnaire was constructed based on the expert review from the researcher's thesis committee members and a review of the relevant literature. The beginning of the questionnaire included demographic information such as age, gender, race, shift worked, and educational level. The demographic section of the questionnaire was followed by 15 open-ended questions that focused on current practice patterns with patients at the EOL, knowledge of EOL care, and facilitators, and barriers that affect comfort care delivery at the EOL. The participants

who volunteered to complete a questionnaire were given an envelope along with the questionnaire and were allowed to take it home to complete and then asked to return it within two weeks. The participants were directed to place the questionnaire into a sealed envelope that was provided and place it into the communication book at each nursing station upon return of the questionnaire.

The facility director approved participants to be interviewed or participate in the focus group during working hours and in designated locations and at designated times that were convenient to the facility. The focus group discussion and interviews provided additional information on perceptions of EOL care experiences. These data collection tools included 12 open-ended questions (See Appendix H). The open-ended questions were developed to further explore specific responses from the self-administered questionnaire regarding EOL care. The questions consisted of the participants EOL care experiences. The researcher asked all of the questions in both the focus group discussion and interviews and all of the participants were allowed to answer each question freely without interruption from the other participants or the researcher. Each participant was assured of confidentiality. The participants in the focus group discussion were identified by coded identifiers specific to the focus group.

Each interview of the nurse participant was conducted individually at separate times. Before the questions began, demographic information was obtained from each of these participants and included age, job title and years of experience working with EOL patients (See Table 2).

All data collection occurred during a one month period of time. Each interview and the focus group discussion lasted approximately 30 minutes.

Data Analysis

Qualitative data analysis began immediately following completion and collection of questionnaires. Within two days of the completion of the focus group discussion and individual interviews, the data was transcribed verbatim by a professional transcriptionist. The researcher assessed the transcription for accuracy by listening to and comparing it with the audio-tapes. Quantitative analysis of the demographics from the questionnaires and the individual interviews were conducted by the researcher. The narrative data from the questionnaires as well as the transcription from the interviews and focus group discussion were analyzed by carefully reading and rereading in order to identify common meaning from the participants' responses to support interpretation. The interpretations were then compared for similarities, and differences as well as consistency among the various data collection forms. A list of themes related to the participants' responses were identified as well as several verbatim quotes that are included to support the interpretations and allow for validation of the findings.

Limitations

Traditionally, self-administered questionnaires allow large numbers of individuals from widespread geographical locations to be sampled cost effectively (Polit & Beck, 2008). However, the major limitation to this approach has always been poor response rates, which can restrict researchers in their quest to generalize findings to the population (Coughlan, Cronin, & Ryan, 2009). Other limitations that are associated with self-administered questionnaires are the

possibility that the participant either did not complete the questionnaire him or herself or sought help to do so. This may interfere with the representativeness of the sample. Also, difficulty reading, interpreting words, or writing can exclude particular groups from participating and thus bias the study (Coughlan et al. 2009). The focus group and interviews were intended to further explore the questionnaire responses.

Conclusion

A better understanding of the reasons for the differing perceptions, associated barriers and gaps in educational knowledge with EOL care is necessary for quality EOL care. The researcher will utilize the research findings to make recommendations for educational strategies that will improve comfort care at the EOL in the NH setting.

CHAPTER IV

This chapter presents the results of the study which includes a description of the sample. The results were organized according to the research questions that were discussed in the objective and aims section as well as the themes that were identified.

Results

Of the 51 questionnaires distributed to NH participants, a total of 15 (29%) were returned completed (see Table 1) The majority of the participants completing the questionnaire were NAs, worked on the day shift, were African Americans females between the ages of 35 to 40 years old, and, had zero to five years of EOL care experience. The researcher had difficulty with interpretation of some of the questionnaire responses. For unknown reasons, the responses did not always correlate with the questions. The questionnaire was purposefully designed at a sixth grade reading level and was piloted with HCPs at a different NH to ascertain content validity

A total of six participants who were all female nurses completed the interview. In addition, they were all white, worked the evening shift, were between the ages of 20 to 25 years old and, had zero to five years of EOL care experience (see Table 2). Nurses that were on the day or night shift did not volunteer to complete an interview.

Lastly an audio-taped focus group discussion was conducted with seven NAs. Demographics of the group were not obtained due to facility concerns that the discussion might take too long and would result in overtime.

The exact number of participants completing the study or representative sample could not be determined. Due to the maintenance of study anonymity, some participants may have

completed more than one part of the study which in turn might result in repeated or redundant responses. This overlapping of answers from the questionnaires, focus group discussion, or the individual interviews could affect thematic impressions.

Table 1

Sample Characteristics of Participants Completing Questionnaire (n = 15)

Characteristics	n	(%)
Female	14	(93)
Male	1	(7)
Age group (years)		
<30	1	(7)
31-34	2	(13)
35-39	6	(40)
40-44	1	(7)
45-49	2	(13)
50-55	3	(20)
Race		
White	5	(33)
African American	7	(47)
Biracial	1	(7)
Indian	2	(13)
Job title		
LPN	2	(13)
RN	2	(13)
NA	10	(66)
NP	1	(7)
Job shift		
Day	10	(66)
Evening	4	(26)
Night	1	(7)
EOL care job experience (years)		
0-5	5	(33)
6-10	4	(26)
11-15	3	(20)
16-20	1	(7)
21-30	2	(13)

Table 2

Sample Characteristics from Nurses' Interviews (n = 6)

Characteristics	n	(%)
Female	6	(100)
Age group (years)		
20-25	3	(50)
40-49	2	(33)
60-69	1	(17)
EOL care job experience (years)		
0-5	3	(50)
15-20	2	(33)
> 20	1	(17)
Job title		
LPN	5	(83)
RN	1	(17)
Job shift		
Evening	6	(100)

The rest of the discussion in this chapter describes a compilation of the data taken from the questionnaires, focus group discussions and individual interviews. Themes that emerge related to the data compilation are identified.

Comfort Care Definition

The first research question explored how the participants defined comfort care for patients at the EOL in the NH. There were similarities among all of the participants in relation to how comfort care is defined. The definitions of comfort care were determined from the participant's responses from the focus group discussion, interviews, and the questionnaires (see Table 3). The following is an excerpt by a nurse from her interview defining comfort and her experience with a dying patient who had no family:

The definition of comfort is making sure that the patient is pain free, physically comfortable, and [sic] no respiratory distress. Also letting the patient know that someone is there for them. I remember back when I was a NA and there was a patient that was dying and had no family members. Every day I would clock out of the NH and come back into the room and sit with the patient. It was a good experience to be able to be there for the patient and let him know that he was not alone.

It is notable that the nurse reports that she provides her presence on her own time and not as a part of her paid responsibilities. Care and support for the person who is dying is essential and focuses on making the patient comfortable.

Several nurses completing a questionnaire reported comfort care is “just to make the patient comfortable and pain free.”

One NA completing the questionnaire defined comfort care as, “The patient should always be made comfortable.” Another definition of comfort care from a NA the completing the questionnaire states: comfort care is not just pharmacological, it is ensuring that the mouth is kept moist, positioning the patient for comfort as well as offering a relaxing environment.”

Overall there were similarities by the participants from different data collection methods on how comfort care was defined.

Comfort Care Provision

The second research question focused on how comfort care is addressed by different types of HCPs in the NH. In addition, research question number seven focused on how the participants provided comfort for patients at the EOL. Although there were similarities about how comfort care is defined among all HCPs there were also noted differences based on the HCPs job title or role. All participants described comfort care as basically making the patient feel comfortable and inclusion of family involvement. All of the participants indicated that comfort care provided to the patient on hospice is no different than comfort care provided to a patient who is on comfort care only without hospice services. The NAs felt that more time is needed to care for patients that are on comfort care when there is no hospice involvement in the patient’s care. The NAs description of comfort care had a more task oriented focus concerned with the patient’s personal care. The nurses’ associated EOL comfort care with a greater emphasis on physiologic processes

and medication administration. The following is an excerpt from a NA during the focus group discussion:

What I would describe as keeping the patient comfortable is keeping them clean and dry. I would reposition them as often as possible, and if family members are there, I would offer them a cup of coffee, a danish, or whatever just to make them comfortable so they don't leave the patient to go get a cup of coffee. Sometimes they leave the patient to go get a cup of coffee and that is the time when the patient passes. I would try to have extra chairs and extra things there for them to relax.

A reflection from another NA from the focus group referred to comfort care while the patient is on hospice: "There is no difference in how we care for patients that are on hospice except we spend [sic] less time with them because they have hospice aides."

During an interview, a nurse participant description of providing comfort was reported as "keeping the patient comfortable and pain free." Another nurse who completed a questionnaire states "providing comfort care means taking the family and patient needs into account."

A questionnaire NA respondent's description of comfort care provided to a patient on hospice was reported as: "I am sure there is no difference in care. The patient is still treated with love, caring, compassion, kindness, and perhaps a little extra tender loving care."

Overall this section described how different types of NH HCPs addressed EOL comfort care for patients who were or were not receiving hospice services. Task oriented descriptors of

comfort care were offered by the NAs and emphasis on physiologic processes and adequate medication administration was described by the nurses.

Table 3

Definitions of Comfort Care

Nurses' Aides	Nurses'
Patient is made comfortable	Patient is made comfortable
Follow patient wishes	Prevention of bed sores
Loving touches and smiles	Eliminate extreme measures
Providing care that makes patient pain free	Patient is pain free
Ensure room quiet	Patient is never left alone
Positioning for comfort	Give patient full attention
Offer patient a relaxing environment	Make sure patient relaxed
Keeping patient clean	Patient is anxiety free
Doing whatever makes patient happy without causing harm	All aspects of care
Patient is without respiratory distress	Patient is comfortably breathing
Soft strokes to hair	Not taking extreme measures
Involve family with care	Family involvement
Mouth care	Symptom management

Good and Bad Death Reflections

Providing adequate comfort care at the EOL was reflected as an integral part of a good death. The nurse and NA participants in the interviews and focus group discussion were asked to describe their views of a good and a bad death. The following is a reflection of a good death from a NA in the focus group discussion:

I would have to say an example of a good death is when either a loved one or a person that you are dealing with does not die alone. I mean if someone is in the room with them at that point in time, and they just don't go by themselves. I would consider that a good death, because, I mean when I go, I would like preferably family, but I would like somebody to be there at my bedside.

The description of a bad death from another NA during the focus group discussion indicated:

The worst death I ever saw is of the denial from the family that this person can fight it and they are going to make it through. Everyone knows that this person is dying, they have all the symptoms. There were two women in their sixties, and their mother was dying, and they absolutely denied the fact that she was dying. They were trying to force her to eat, trying to force her to drink and she was nothing but skin and bones. She had already started shutting down, and they insisted on getting her up and putting her on the toilet and doing this and that. They just kept saying come on mama, you know you can do it. They were just in complete denial and the moment that she passed, they crawled into the bed with her and held her body, both of them on either side of her, just holding her and weeping and clutching their chest. We thought we were

going to have to send them to the hospital, they would not let go.

A nurse from the interview reported a good death as: “when the family is there” and a bad death is “when the death is unexpected and family is not present.” Another nurse reported a good death as “is one that does not linger” as well as “someone that goes peacefully out with no suffering.” One nurse reported a good death as “no sign of anxiety or showing any pain and patient is relaxed with no suffering.” Lastly, a nurse also from the interview reported a bad death as “when the death is unexpected and family is not present.”

Overall, this section describes the participant’s views of what constitutes a good death or a bad death. The nurses from the interviews and the NAs from the focus group provided different reflections of a good and bad death with an over-riding theme of not being left alone during the dying process.

Facilitators of EOL Care

The third research question involved the identification of facilitators that affect the delivery of comfort care for patients in the NH who are at the EOL. Key themes that were identified by all participants during the focus group sessions, individual interviews and self-administered questionnaires were related to the effects of positive staff teamwork and the use of the angel cart to aid with the provision of comfort care. The angel cart was designed by the nursing director and is used with EOL patients when death is suspected to be imminent within three days. The nurses report that signs of impending death are when the patient’s breathing becomes more irregular and slower, breathing becomes loud and rattling, and the hands or feet become discolored with a purplish hue. The NAs reported that the nurses let them know when the patient

is near death because they are not always sure how much of the life span that is left for the patient. The angel cart provides aroma therapy, soothing music, and books that the family could read to the patient. In addition, the participants indicated that everyone pulls together to help each other and there was no discussion of impediments to teamwork. The following are nurse participants' reflections from the interviews on the use of the angel cart and teamwork:

One nurse's viewpoint that was reported during an interview related to the use of the angel cart to help facilitate the quality of care given to the patient at the EOL. It was stated that, "with the use of the angel cart, it makes the patient more relaxed and comfortable and they breathe better with no moaning or groaning."

Participants believed that the shortage of staff has a negative impact on the quality of care they are able to provide to the patient but working together as a team results in higher quality of EOL care. For instance, one nurse said: "Although, there are staffing issues, I think the nurses here work as a team as best as possible."

NAs in the focus group discussions had similar responses on teamwork and the use of the angel cart as positive facilitators of comfort care. For instance, a NA reflection during the focus group on the use of the angel cart: "There was a lady who we brought the angel cart in her room because we were sure she was ready to pass on. However she just bounced right back every time we would bring the cart in the room." The NAs contributed the patient's bouncing back due to the angel cart comforting the patient.

A reflection regarding teamwork by a NA in the focus group:

I would say there is team work in this facility. If there is a patient that is going down,

One set of us will go down and you know speak to the patient, talk to them, clean them up, turn them, sit down for a few minutes and hold their hand. And if there is no problem, then another set of staff will come in and do the same thing.

Overall, this section describes the facilitators to EOL care reported by all of the participants as teamwork and the use of the angel cart.

Barriers to EOL Care

The fourth research question focuses on the current barriers identified by the participants that affect the delivery of comfort care for patients in the NH at the EOL. Themes identified by all participants included: 1) lack of time to spend with the patient to provide quality EOL care, 2) inadequate staffing related to the staff -patient ratio that is not adjusted according to the acuity of the patient, 3) patient and families in denial of the prognosis, 4) lack of prior formalized education on EOL, 5) lack of primary physician communication with patient and family regarding the patient prognosis, 6) lack of administrative support related to staffing and finally 7) lack of EOL care facility policy related to EOL care. The following are nurses' comments from the interview:

It is so frustrating to not be able to care for the dying patient especially when family is present. The nurses are given the same amount of patients to care for regardless if one of those patient is critically ill. Taking in the angel cart while the family is in the room seems to take the pressure off a little.

Having enough time to care for the patient appears to improve the quality of EOL care. One nurse stated: There just is not enough time to give attention or take care of the needs of the

patient or families due to staffing problems.”

Another nurse reported, “If there is a critical patient, I feel that the patient load should be less for that nurse because the patient needs that extra attention.”

One nurse reported inadequate education on EOL care as a barrier: “I had no prior training for EOL care, just the experience on the job”

The following is a nurse reflection of inadequate communication by physician regarding patient prognosis at the EOL:

The patient is terminal, and the primary care physician just keeps on treating the patient as usual, not interacting with [sic] patient or being honest about their terminal prognosis. Then the hospice physician comes in and tells the patient that he or she is terminal and cannot be fixed, which causes the family to be in denial. The primary care doctor needs to get on the same page as the hospice doctor and be more honest.

In regard to administrative support one nurse stated: “There is no administrative support.”
"Also there are staffing issues with regards to implementing decrease staff-ratio when taking care patients who are at the EOL”

A NA participant that completed the questionnaire also reported barriers to quality EOL as: “Not having enough staff to ensure adequate time spent with the dying patient and the family being in denial that the patient is dying.”

All of the participants reported no knowledge of a facility policy that guides EOL care. In addition, participants did not suggest that such a facility policy would be a facilitator of EOL care or a barrier.

Overall this section described the multiple barriers identified by the participants that affect the delivery of comfort care to patients at the EOL. Included in these barriers were: 1) lack of time, 2) inadequate staffing, 3) lack of EOL education, 4) lack of physician communication, 5) lack of administrative support, 6) patient and family denial of EOL prognosis and, 6) lack of EOL care policy.

EOL Training

The fifth research question addresses the participant's preparation and education to provide comfort care for patients who are at the EOL. None of the participants had any formalized EOL training in their school curriculum prior to employment. They indicated all of the knowledge learned about EOL resulted from on the job experience while working with staff members who appeared to be more experienced in EOL care. The facility has yearly classes on EOL that are presented by a hospice physician. However, staff members feel more education is still needed. A few staff felt prepared with EOL care because of prior experience working with hospice patients. The following is a focus group excerpt from a NA reflecting on EOL education:

I was never trained in school. What little training that I ever received was from whatever nurse that I was working with at the time. Whatever facility that I was working with, with the exception of this one, which I have been at for five years, other places I worked before never gave any kind of in-service like we have here. It is very difficult to not have adequate training because you are realizing your own mortality at the same time that you're watching this person pass on.

All of the nurses participating in the interview expressed a lack of EOL care training and more education would be beneficial. One nurse reported, “no previous formalized EOL education, just on the job training.”

A NP who completed a questionnaire indicated: “I do not have enough training in EOL care. I learn about expected issues of EOL care as they come up.”

Overall this section described the participant’s views on preparation and education in providing comfort for patients at the EOL as inadequate.

Improving EOL Comfort Care

The sixth research question involves how participants feel they can deliver better EOL comfort care. Four themes were identified: 1) the importance of education, 2) administrative support, 3) grief counseling related to NAs emotional attachment to patients, and 4) staff consistency and continuity. All of the participants expressed that more EOL care education will be beneficial to provide optimum care to patients who are at the EOL. Participants also indicated that there should be a policy to allow for decreased staff- patient ratios assigned when HCPs are taking care of a patient who is in the last stage of dying or critically ill.

The NAs in the focus group discussion indicated that they develop a very special close bond to the dying patient and they have a need for grief counseling when that patient dies. The following is a reflection from a NA in the focus group:

There was a lady who died at the end of last year, and I did not know because I work on all three wings, and I had not been over to her side in some time. When I went to see her, I found out that she was dead and it broke my heart. Nobody had

told me she had died. Nobody really thinks of the caregiver. We are here to do a job, and there is a relationship that you build with people that you take care of.

Wish I had been there to offer her some type of comfort. So, I feel that this facility should provide some type of grief counseling for the staff

In addition, all NA participants in the focus group discussion and nurses who were interviewed felt that if the dying patient was assigned a regular NA at all times, it would provide continuity of care with staff consistency and the patient will then never be left alone.

Summary

The focus of this study was to explore the experiences of NH HCPs providing comfort for patients at the EOL. Participants who care for patients at the EOL volunteered to complete a questionnaire, take part in an audio-taped interview, and/or participate in an audio-taped focus group discussion. Comprehensive analysis of the data identified multiple challenges in EOL care. Exploration of the data revealed eight negative themes: 1) inadequate education on EOL care, 2) lack of administrative support with regard to staffing, 3) need for staff grief counseling due to emotional attachment, 4) need for staff continuity, and consistency, 5) lack of EOL care facility policy, 6) lack of physician communication with family and patients regarding EOL care issues, 7) lack of time allotted with patients to provide quality EOL care and, 8) family and patient denial of EOL prognosis. The positive themes that were identified included: 1) use of the angel card to aid in the provision of comfort to the patient and, 2) staff teamwork

From the themes identified, there was a positive reflection of teamwork among staff when providing EOL care and the use of the angel card in the provision of comfort care to the patient.

From the perspectives of the participants, it is apparent that EOL care takes time and attention, requires a team approach with sufficient EOL knowledge, and must have communication among all NH HCPs and families that is essential to EOL care decision making. A detailed discussion of the above findings in reference to previous literature is presented in the following chapter.

CHAPTER V

Discussion

A qualitative, descriptive study was completed using data from audio-taped individual interviews, a self-administered questionnaire and an audio-taped focus group discussion. The purpose was to better understand the experiences of HCPs providing comfort for patients in the NH at the EOL. The findings of this study reinforced that the factors influencing comfort care at the EOL are multi-faceted, and are in need of interventions that promote quality EOL care. From the compiled data sources, several themes were identified and will be discussed and compared to the relevant literature related to EOL care. Additionally, limitations of this study, implications and recommendations for practice changes and future research will be discussed.

Comfort Care

In this study, all participants defined comfort care similarly. However, there were also noted differences in the way participant's operationalized the term comfort care. These differences appeared to be based on the participant's job title or role in the NH. The NAs' description of comfort care had a more task oriented focus concerned with the patient's personal care. The nurses' associated EOL comfort care with a greater emphasis on physiologic processes and medication. Similar findings by Goodridge, et al., (2005) also revealed different perspectives regarding coordination of care for patients at the EOL by the various roles of the HCPs. The overall consensus by the participants in this study was that comfort care is essentially making the patient comfortable to allow them to die with dignity.

Facilitators of EOL Care

Facilitators identified by both the focus group discussion and the interview participants was that teamwork and the angel cart improved the ability to provide EOL comfort care. The angel cart was utilized for patients deemed to be close to death. The nurses in the interview expressed that that they often are unable to spend quality time with the patient and by taking the angel cart into the patient room it calms the patient's and family members that are present. No previous research has been identified on the use of an angel cart or a similar tool for the provision for comfort care at the EOL.

All participants completing a questionnaire, participating in the focus group discussion or interviews were in agreement that there is adequate teamwork in the facility. It was the consensus that everyone works well together and that the support they receive from coworkers contributes to good teamwork and improved EOL care. Teamwork and support has been shown to affect the quality of care provided in NH (Forbes-Thompson & Gessert, 2005).

Barriers of EOL Care

Lack of Time

Lack of time to deliver quality EOL care was repeatedly indicated by all participants attributed to inadequate staffing. In particular, the angel cart was used to supplement EOL care when there was insufficient quality time available to spend with the patient. All of the participants expressed that they needed more time to take care of a patient who is critically ill or at the EOL. This lack of time has also been identified in the literature as a barrier to quality EOL care (Goodridge et al., 2005). Participants in the Goodridge et al. study also felt that they should

have fewer patients to take care of when they are taking care of a patient that has increased needs.

Inadequate Staffing

The lack of adequate staffing was repeatedly identified by all of the participants in this study. The participants in the focus group discussion and the interviews consistently described feeling overwhelmed because of inadequate staffing. The assigned staffing ratio was thought inadequate to provide quality EOL care. In addition, the participants in the focus group discussion and the interviews felt that the dying patient should be assigned a consistent staff member to ensure continuity of care so that optimum EOL care is delivered. Previous literature indicates that inadequate staffing is an important barrier to high-quality health care (Hanson et al., 2002)

Lack of EOL Education

Recent research has demonstrated worldwide that HCPs have EOL educational deficiencies and insufficient training in care at the EOL (Braun & Zir, 2005; Easom et al., 2006; Keay et al., 2003; Paice et al., 2008). All of the participants express feelings of unpreparedness to provide EOL care and indicate a desire for more EOL education regardless of their length of employment. The lack of EOL education of staff in NHs has been identified in previous research as a barrier to adequate EOL care (Ersek et al., 2005). Additionally it has been demonstrated that providing education in-services to HCPs has been successful in increasing their knowledge of EOL care (Braun & Zir, 2005; Easom et al., 2006; Keay et al., 2003; Paice et

al., 2008) A few of the participants felt prepared to provide EOL care because they had worked with hospice and had prior experience working with EOL patients.

Lack of Physician Communication

The participants in the interviews felt that the lack of physician communication of a patient's prognosis to the patients and families was a barrier to EOL care. The nurses reported that the patient and families were in denial because they were not well informed of the patient's prognosis by the physician. The nurses also stated the physician just keeps treating the patient with a curative focus. It is typically the hospice physician that reveals the terminal diagnosis, and often, the diagnosis is not accepted by the patient and family. They remain in denial and the family wants everything done to prolong life resulting in unnecessary tests and treatments.

Previous research indicates that ineffective communication with families of NH residents is a barrier to quality EOL care (Forbes-Thompson & Gessert, 2005). In addition, research has shown that physicians are reluctant to speak to their patients about the terminal nature of their illness (Ersek et al., 2005)

Lack of Administrative Support

In this study, all participants felt that they could provide better comfort care to patients who are dying if they had the support of the NH administration. Administrative support was described as needing to be in three forms: staffing in terms of decreasing staff-ratio with regard to the patients acuity, the provision for staff grief counseling, and the provision for staff continuity of assigned staff to specific patients who are at the EOL. Previous research reveals

that HCPs do not feel supported by the administrators when caring for patients at the EOL (Denham et al., 2006; Flacker et al., 2001).

Lack of EOL Policy

All of the study participants reported that they had no knowledge of an EOL policy at the facility. How a facility EOL policy would impact EOL care was not suggested by the participants. In addition, no previous literature was identified regarding current policies and regulations that guides EOL care in the NH. However, the experiences of HCPs with providing care to patients at the EOL in this study indicates an EOL care policy in the NH might provide a direction for quality EOL care

EOL Care Improvement

The positive factors that all participants identified as likely to be beneficial to improving EOL care were the importance of EOL care education and administrative support. In addition the participants in the focus group discussion and the interviews felt that staff consistency and continuity were associated with EOL care improvement. Lastly, the NAs in the focus group discussion indicated staff grief counseling would greatly improve EOL care and assist them in dealing with their feelings of emotional attachment to the dying patient. Previous research reflects the emotional attachment of NH staff with patients who are at the EOL and the benefits of emotional preparation with counseling (Denham et al., 2006; Flacker et al., 2001; Hanson et al., 2002) . In addition, this is consistent with previous research that indicates NAs need education on ways of dealing with emotional attachment (Denham et al., 2006; Ersek & Ferrell, 2005)

Limitations

One limitation of this study is that the study was conducted in only one NH. This impedes the ability to generalize the findings. This limitation suggests the importance of future comparative studies of different types of NHs. An additional limitation was that there was no representation of the physician and only one representation from a NP perspective. Direct interviews with physicians and NPs who provide NH EOL care would have enhanced the findings. The voices of residents and family members are missing from this study. These perspectives would offer greater understanding of EOL care from their viewpoints.

There was a low response rate for participation in the study especially from the nurses. The study findings might be different in regards to the experiences of nurse's ability to provide comfort for patients at the EOL. Several steps were taken to improve the response rate. Flyers were placed throughout the facility explaining the study in detail. The survey was short in length with a minimum of 15 minutes to complete and the researcher was available to answer questions related to the questionnaire.

Another limitation was the researcher's difficulty with interpretation of the HCPs responses to the questionnaire. The questionnaire responses did not always correlate to the question asked despite efforts to assure content validity and appropriate questionnaire literacy levels.

Lastly, a limitation of this study is the researcher's relationship with the NH. The researcher has worked at this NH for the past five years and has developed a close relationship

with some of the staff. That relationship may have had an effect on how the questions were answered by the participants.

Conclusion

The researcher explored the experiences of NH HCPs who provide comfort for patients at the EOL through a self-administered questionnaire, audio-taped individual interviews, and an audio-taped focus group. A better understanding of the reasons for the differing perceptions of comfort care, facilitators, barriers, and gaps in educational knowledge of EOL care was identified. This study found that HCPs perceptions of defining comfort care and providing comfort to patients at the EOL were similar. However, the focus or the way they operationalized comfort care did differ. Nurses were more focused on physiologic and medication needs. The NAs focus was more task oriented concerned with person care. Similar findings by Goodridge et al. (2005) also revealed different perspectives regarding coordination of care for patients at the EOL by the HCPs.

Although all of HCPs reported adequate teamwork among staff, there were communication difficulties with some families and patients who were in denial of the patients' prognoses. The staff attributed this denial to the physicians' lack of patient and family interaction regarding EOL discussions and communication. These results are similar to previous research regarding the physicians' difficulty with discussing death and dying with patients (Ersek et al., 2005)

This study found inadequate staffing, lack of formalized education and lack of time to be barriers to EOL care. Administrative support with staffing issues was reported by participants to be inadequate. These barriers to EOL care are in direct correlation with previous studies. Focus

groups and surveys were conducted by Hanson et al. (2002) with experienced NH staff and physicians (N=77). Participants in the Hanson et al. study described a lack of training, regulatory emphasis on rehabilitation, a resource-poor setting, inadequate staffing, staff turnover, and MD disregard for EOL issues as important barriers to high-quality care of the dying in NHs.

From the perceptions of the participants not everything is being done to meet the complex needs of patients at the EOL. The result of this study corroborates with the previous research findings on HCPs experiences with providing comfort for patients in the NH at the EOL. In addition a new finding from this study reflects the use of an angel cart to aid in the provision of comfort care for patients at the EOL. Comprehensive analysis of the data revealed multiple problems, and supports the need for change. It is imperative that patients who are at the EOL be allowed to die with peace, comfort, and dignity. Implications for practice as well as recommendations for future research are discussed below.

Implication for Practice

The study has implications for clinicians that could be used to develop 1) mandatory EOL educational program for HCPs, 2) policy changes in terms of adjustments in staff assignments, 3) facility policies that guide EOL care, 4) the provision of grief counseling for staff, 5) career track training for RNs and 6) increased funding for EOL care training and facility staffing.

Continuing educational programs for EOL care should be considered mandatory for HCPs, nursing administrators and physicians. Specific content on EOL care that might include: 1) the care of dying patients to include: 1) managing their physical symptoms, 2) communication with

patients and families at the EOL as well as describing what to expect in the dying process, and 3) identification of decision points in the dying process.

Policy changes that include the implementation of consistent staffing patterns should be considered. This will promote the development of patient and staff relationships that could contribute to a higher quality of EOL care. In addition lower HCP-to-patient staffing ratios should be reconsidered in situations where HCPs are caring for EOL patients. Administrators of NHs should better recognize and understand the complex needs of patients at the EOL and provide adequate staffing with adjustments in staff assignment based on the acuity of the dying patient.

The implementation of facility policy regarding EOL care in collaboration with hospice should be considered as well as grief counseling for staff. Coordination of care with hospice services will provide comprehensive interdisciplinary services.

Career track training for RNs with special emphasis on the role of supervising the LPNs and NAs, and managing nursing care could be recommended. It is the role of the RN to be responsible and accountable in the coordination of the nursing staff work environment.

A sustained effort on many fronts, including increased funding for EOL training and adequate staffing is needed to improve EOL care in the NH. Recommend redirection of the state's approach to funding with emphasis on quality EOL care consistency and safety in the NH setting opposed to the current financed reimbursement mechanism.

Recommendations for Future Research

To further validate the findings from this research, additional studies should be conducted with larger sample sizes to include additional NHs and other perspectives such as physicians, NPs, patients, and families. Also studies on attachment of NH staff and its effect on the care they give would be important in determining whether attachment hinders or promote quality EOL care in the NH. Another recommendation is studies on the use of an angel or comfort cart to aid in the provision of EOL comfort.

APPENDIX A: NURSING HOME FLYER

“Experiences of health care providers providing comfort for patients in the nursing home at the end of life”

Would you like to take part in a research study?

The purpose of this study is to explore the experiences of health care providers providing comfort to nursing home patients at the end of life.

The study will involve completing a questionnaire (15 minutes) and/or
Taking part in a focus group discussion (1 hour)

Physicians, Registered Nurses, Licensed Practical Nurses, Nurse Practitioners or Nurse’s Aides
are eligible for participation.

**Researcher: Herman Baker, MSN, FNP-BC, Doctoral of Nursing Practice student at the
University of Central Florida**

**If you are interested please call or email me: Herman Baker (352) 572-1411 (cell), or
hbaker6897@aol.com**

Thanks



Sounds Exciting?

APPENDIX B: IRB APPROVAL



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To: **Herma L. Baker**

Date: **March 31, 2010**

Dear Researcher:

On 3/31/2010, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Initial Review
Project Title: The Experiences of Health Care Providers Providing Comfort For
Nursing Home Patients At The End Of Life
Investigator: Herma L. Baker
IRB Number: SBE-10-06836
Funding Agency: None

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Joseph Bielitzki, DVM, UCF IRB Chair, this letter is signed by:

Signature applied by Janice Turchin on 03/31/2010 08:52:46 AM EST

A handwritten signature in black ink that reads "Janice Turchin".

IRB Coordinator

APPENDIX C: LETTER OF APPROVAL FOR STUDY



March 11, 2010

Herma Baker, MSN, ARNP, FNP-BC student at UCF

Re: Proposed Research Study

Dear Ms. Baker:

I have reviewed your proposal to explore EOL care in nursing homes. I find it very interesting and would be willing to allow you to proceed with your planned study. Please contact our Director of Nursing, Tina Vanaman for EOL policies that are currently in use at Palm Garden of Ocala.

I anxiously await your flyer that will be used to announce the study, procedures and selection criteria. Please forward to me at your earliest convenience so that I may approve for posting in the facility.

Respectfully,

A handwritten signature in blue ink, appearing to read 'Jennifer Mikula', is written over the printed name.

Jennifer Mikula, NHA
Administrator

Palm Garden of Ocala

2700 S.W. 34th Street • Ocala, Florida 34474

Phone: 352.854.6262 Fax: 352.854.0010

www.cypresshealthcare.net

APPENDIX D: EXPLANATION OF RESEARCH (QUESTIONNAIRE)

What is title of this study? The Experiences of Health Care Providers Providing Comfort for Nursing Home Patients at the End of Life

What is the purpose of this study?

The purpose of this study is to explore and describe the experiences of health care providers giving comfort for nursing home patients at the end of life. Past studies show health care providers are not prepared to give comfort care at the end of life. This study will help show areas that need to be changed for patients at the end of life

Who is in charge of this study?

The study is being done by Principle Investigator: Herma Baker, MSN, FNP-BC, Doctoral of Nursing Practice student at the University of Central Florida

What will I be asked to do?

You will be asked to complete a questionnaire about your experiences in giving comfort for patients at the end of life. The questionnaire will take about 15 minutes to complete and you do not have to answer any question that makes you uncomfortable

Are there any risks to me for taking part in this study?

There are no foreseeable risks or discomforts involved in taking part in this study

What are the benefits of my participation in the study?

There are no direct benefits to participants in this study.

Will my identity and the information I share be kept confidential?

All information shared with the researcher will be strictly anonymous. Anonymous means that no one will know the information you gave came from you. The questionnaire will be kept in a safe locked file at the researcher's office and destroyed after the data is analyzed.

Will I be compensated for my participation in the study?

There is no compensation or other payment to you for taking part in this study

Can I stop participating at any time?

You taking part in this study is voluntary. You may choose to stop at any time and there will be no penalty. If there is data already collected, it will be used.

Whom do I contact if I have questions?

If you have any questions, concerns, or complaints about the study, please contact the researcher, Herma Baker at 352-572-1411, or e-mail hbaker6897@aol.com. You may also contact the chair of this research, Elizabeth Rash, at 407-823-1055. Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF IRB). This research has been approved by the IRB. If you have questions about your rights as a research participant you may contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL. 32826-3246 or by telephone at (407) 823-2901

APPENDIX E: EXPLANATION OF RESEARCH (FOCUS GROUP)

What is title of this study? The Experiences of Health Care Providers Providing Comfort for Nursing Home Patients at the End of Life

What is the purpose of this study?

The purpose of this study is to explore and describe the experiences of health care providers giving comfort for nursing home patients at the end of life. Past studies show health care providers are not prepared to give comfort care at the end of life. This study will help show areas that need to be changed for nursing home patients who are at the end of life.

Who is in charge of this study?

The study is being done by Principle Investigator: Herma Baker, MSN, FNP-BC, Doctoral of Nursing Practice student at the University of Central Florida

What will I be asked to do?

You will be asked to take part in one focus group discussion session which will be audio taped and last for one hour at the respective nursing home. During the group discussion, you will be asked to share your experiences as well as give opinions and suggestions regarding providing comfort for patients at the end of life. You will also be asked to keep confidential all information shared by other participants in the group discussion

Are there any risks to me for taking part in this study?

There are no foreseeable risks or discomforts involved in taking part in this study. There is a chance that another participant of the focus group could tell something about you that they learned in the discussion. All focus group participants are asked to respect the privacy of other group members

What are the benefits of my participation in the study?

There are no direct benefits to participants in this study.

Will my identify and the information I share be kept confidential?

All information shared with the researcher will be strictly confidential. The audio taped information will be kept in a safe locked file at the researcher's office and destroyed after the data is analyzed.

Will I be compensated for my participation in the study?

There is no compensation or other payment to you for taking part in this study

Can I stop participating at any time?

This study is strictly voluntary. You may choose to stop at any time and there will be no penalty. If there is data already collected, it will be used.

Whom do I contact if I have questions?

If you have any questions about the study, please contact the researcher, Herma Baker at 352-572-1411, or e-mail hbaker6897@aol.com. You may also contact the chair of this research, Elizabeth Rash, at 407-823-1055. Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF IRB). This research has been approved by the IRB. If you have questions about your rights as a research participant you may contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL. 32826-3246 or by telephone at (407) 823-2901

APPENDIX F: EXPLANATION OF RESEARCH (INTERVIEW)

What is the title of this study? The Experiences of Health Care Providers Providing

Comfort for Nursing Home Patients at the End of Life

What is the purpose of this study?

The purpose of this study is to explore and describe the experiences of health care providers giving comfort for nursing home patients at the end of life. Past studies show health care providers are not prepared to give comfort care at the end of life. This study will help show areas that need to be changed for nursing home patients who are at the end of life.

Who is in charge of this study?

The study is being done by Principle Investigator: Herma Baker, MSN, FNP-BC, Doctoral of Nursing Practice student at the University of Central Florida

What will I be asked to do?

You will be asked to take part in an interview session which will be audio taped and last for approx 30 minutes at the respective nursing home. During the interview session, you will be asked to share your experiences as well as give opinions and suggestions regarding providing comfort for patients at the end of life.

Are there any risks to me for taking part in this study?

There are no foreseeable risks or discomforts involved in taking part in this study.

What are the benefits of my participation in the study?

There are no direct benefits to participants in this study.

Will my identify and the information I share be kept confidential?

All information shared with the researcher will be strictly confidential. The audio taped information will be kept in a safe locked file at the researcher's office and destroyed after the data is analyzed.

Will I be compensated for my participation in the study?

There is no compensation or other payment to you for taking part in this study

Can I stop participating at any time?

This study is strictly voluntary. You may choose to stop at any time and there will be no penalty. If there is data already collected, it will be used.

Whom do I contact if I have questions?

If you have any questions about the study, please contact the researcher, Herma Baker at 352-572-1411, ore-mail hbaker6897@aol.com You may also contact the chair of this

research, Elizabeth Rash, at 407-823-1055. Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF IRB). This research has been approved by the IRB. If you have questions about your rights as a research participant you may contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL. 32826-3246 or by telephone at (407) 823-2901

APPENDIX G: DATA COLLECTION TOOL/QUESTIONS

Part A

Date: _____

- 1). What is your gender? _____
- 2). What is your age in years? _____
- 3). What is your race? _____
- 4). What is your job title? _____
- 5). What language(s) do you speak? _____
- 6). What is your highest level of education? _____
- 7). What shift do you work? _____

Part B

- 1). How do you describe comfort care for patients at the end of life?
- 2). How is end of life comfort care given to patients at your facility?
- 3). How do you know what type of end of life comfort care to give to patients?
- 4). How do you include families in end of life comfort care for patients?
- 5). Is a team approach used to give end of life comfort care? If so, how is the team approach used?
- 6). What things might get in the way of giving end of life comfort care?
- 7). What things might help you give end of life comfort care?
- 8). How do facility policies help you give end of life comfort care to patients?
- 9). How do facility policies get in the way of you from giving end of life comfort

care to patients?

- 10). How does current facility staffing change how you give comfort care to patients?
- 11). How does the physical environment in the facility change how you give end of life comfort care?
- 12). Do you feel that your training in end of life comfort care is enough? If not, what would help you improve your comfort care skills?
- 13). How many years experience have you had with patients who are at the end of life?
- 14). How is giving comfort care different when the patient is on hospice?
- 15). How is giving comfort care different when the patient is comfort measures only?

APPENDIX H: INTERVIEW AND FOCUS GROUP QUESTIONS

1. Begin with thanking the participants for agreeing to share their experiences with me as part of my research study. Explain the purpose is to explore and describe their experiences with providing comfort care for nursing home patients who are at the end of life. My intent is to identify what educational needs are in need for improvement. Please tell me a story about what that experience has been for you.
 2. Do you feel that you have had adequate training to deal with patients that are dying?
 3. Tell me an example you feel that is a good death.
 4. Tell me an example you feel that is a bad death.
 5. A team is a group of staff working together for a common interest. Do you think that there is a team approach used in this facility, and if yes, how is it used?
 6. What are obstacles or things that might prevent you from giving comfort care to patients that are dying?
 7. Sometimes patients are under hospice care and others time they may just be on comfort measures only. Is there a difference in the comfort care to the patient that you provide?
 8. What is your definition of comfort care for patients at the end of life?
 9. Is there a facility policy on providing comfort care to patients at the end of life?
 10. How do you involve the family members with providing comfort care for end of life patients?
 11. Do you feel that there is a staffing issue that prevents you from giving good comfort care to patients at the end of life?
 12. How does the physical environment here at the facility change how you give comfort care?
-

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