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A phenomenological study : end of life decision making

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Graduate School
Knowledge Begins with Research

FINAL APPROVAL OF THESIS
Master of Science in Nursing

A Phenomenological Study: End of Life Decision Making

Submitted by

Carrie Genot

In partial fulfillment of the requirements for the degree of
Master of Science in Nursing

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A Phenomenological Study:
End of Life Decision Making

Carrie J. Genot

Medical College of Ohio

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CHAPTER I

Introduction

The end of life decision making process can be overwhelming and stressful for family members with a terminally ill loved one (Tilden, Tolle, Nelson, & Fields, 2001). Although death is inevitable for all humans, it is difficult for the patient and the family. It has been found that family members need understanding, comfort, and support from health care providers, to help them through the end of life decision making process (Hiltunen, Chase, & Medich, 1999; Swigart, 1996; and Yurk, Morgan, Franey, Stebner, & Lansky, 2001). End of life decision making involves the entire family (Hiltunen et al.). Involving the family may provide a sense of closure (Johnson & Bourgeois, 2003). Each family member's experience with the end of life decision making process is unique and offers insight into end of life care.

This chapter includes the statement of the problem and the purpose. The theoretical framework and the research question are identified. Conceptual definitions of variables are provided, along with assumptions, significance, and limitations related to this study.

Statement of the Problem

End of life decision making is a complex process with lasting effects that are positive and negative on family members with a terminally ill loved one (Hayes, 2003). Health care providers can reduce negative effects and increase positive effects by having a thorough understanding of the end of life decision making process. It is important for nurses and other health care professionals to provide accurate, timely, consistent

information and emotional support to family members that will help them move through the end of life decision making process in a sensitive, competent manner (Hughes & Oberle, 2001). However, some research indicates that health care providers tend to influence family members' decisions based on their own values (Hughes & Oberle, 2001 and Norton & Bowers, 2001). Physicians often fail to communicate with family members and provide explanations for decisions made during the end of life. As a result, family members lack the necessary information to make decisions, which may create a great deal of distress for the family.

The researcher's interest in the end of life decision making process is founded on her first experience as a nurse with end of life care. The researcher was required to attend all code blues called in the hospital in which she was employed, as part of the code team. One evening the researcher responded to a code blue in the intensive care unit. A team of nurses, a physician, and a nurse anesthetist were working with an individual who was experiencing complications and deteriorating rapidly. The team talked to one another about what bars were open in the morning, answered phones and pagers, laughed and joked, but never spoke directly to the patient to offer comfort or support. The researcher felt anxious as she watched the team work on, but not care for, the human life that was in their hands. Minutes later, the patient was pronounced dead. The team of health care professionals continued talking among themselves with no regard for the life that had just passed before them. The researcher felt shocked, sad, and extremely disappointed in the level of care that was provided to the patient. As she left the code, she wondered if the

patient would have been treated differently or if the team would have been more focused and concerned if it had been one of the health care team's loved ones.

“It is important to remember that the person dying is living and involved in living experiences with others until the cessation of physical life” (Johnson and Bourgeois, 2003). According to Watson (2003), a human life is sacred, yet the individual previously described, was not treated in such a caring and compassionate manner.

Statement of the Purpose

The purpose of this study is to explore the experiences of family members who participated in end of life decision making for a loved one who died of a terminal illness, in order to help nurses and other health care providers develop a greater understanding about the end of life decision making process.

Conceptual Framework

In this study, Watson's (2003) theory of human caring was used for the theoretical framework. This philosophical approach to nursing emphasizes the importance of humanistic caring, which is the foundational ethical principle of nursing practice (Watson). Human care provides the nurse with an opportunity to know themselves and the patient (Watson). According to Watson, the goal of nursing is to help the individual to acquire unity between the mind, body, and spirit.

Watson's (2003) theory promotes care which cultivates healing and increases awareness for both the nurse and the patient. Watson theorizes the importance for patients to share their experiences in a caring environment, and thereby, help the nurse connect

with the patients' feelings. Conceptualizing the study within Watson's theory helped the researcher to discover the participants' experience with end of life decision making.

Research Question

The research question addressed in this study was: What is the lived experience of a family member who was involved in the end of life decision making process for a loved one who died of a terminal illness?

Conceptual Definitions

The following are the conceptual definitions used in the phenomenon of end of life decision making for this study. A concept "is the basic element of a theory" (Burns & Grove 1999, p. 133). "A Conceptual definition provides a variable or concept with theoretical meaning and is derived from a theorist's definition of the concept or is developed through concept analysis" (Burns & Grove, p. 37).

1. Decision making is defined as the process of evaluating information from all aspects, to make a conclusion whereby wholeness, beauty, comfort, dignity, and peace are potentiated (adapted from Watson's theory 2003).
2. Terminally ill is defined as a state of health in which an individual is not expected to recover (adapted from Watson's theory 2003).
3. Family member is defined as those closest to the patient in knowledge, care, and affection, which may include the biological family, family of acquisition (related by marriage/contract) or family of choice and friends (adapted from Center for palliative care, 2003).

4. Lived experience is defined as a meaningful and personal moment which opens and attends to spiritual-mysterious and existential dimensions of one's own life (adapted from Watson's theory 2003).
5. Health care provider is defined as a person who is licensed or certified by law to develop and sustain a helping-trusting, authentic caring relationship with the one being cared for, to potentiate alignment of mind, body, and spirit (adapted from Watson's theory 2003).
6. End of life is defined as the final chapter of earthly existence for the one being cared for (adapted from Watson's theory 2003).
7. Transpersonal caring is defined as "seeking to connect with and embrace the spirit or soul of the other through the processes of caring and healing and being in authentic relation, in the moment" (Watson, 2003, p. 5).
8. Clinical carita is defined as "an emerging model of transpersonal caring that transcends conventional industrial and static models of nursing. It includes caring and love in our work and our life, and calls for a sense of reverence and sacredness with regard to life and all living things" (Watson, 2003, p. 3).
9. Caring occasion is defined as a coming together of the nurse and another with their unique life histories and phenomenal fields in a human-to-human transaction, which becomes a part of the life history of each person (Watson, 2003, p. 6).

Assumptions

Assumptions are “statements that are taken for granted or are considered true, even though they have not been scientifically tested” (Burns & Grove 2001, p. 38). In this study, it is assumed that end of life decision making for a terminally ill loved one is a difficult process. It is assumed that health care providers, particularly nurses, can help facilitate end of life decision making by having a greater understanding of this process. It is assumed that the support of health care providers will help family members feel more comfortable (Norton & Bowers, 2001). It is also assumed that this study will add to the growing body of nursing knowledge on end of life care for patients and their families.

Limitations

Limitations are “restrictions in a study that may decrease the credibility of the findings” (Burns & Grove, 2001). In this study, the inability to obtain true saturation is a limitation due to the small sample size. The researcher had four participants. Saturation is “the repetition of discovered information and confirmation of previously collected data” (Streubert & Carpenter, 2003, p. 25). The researcher’s inexperience with qualitative research also serves as a limitation to this study.

Significance

Understanding the needs of the family with a terminally ill loved one during the end of life decision making process may help nurses and other health care providers to appreciate the significance and impact of decision making at such a difficult time. As a result, health care providers may communicate with the family in a timely, compassionate manner, thus allowing the family to make decisions with appropriate information and

support (Hughes & Oberle, 2001). It is important for nurses to understand that decision making is a process (Hiltunen et al., 1999; Swigart, 1996; and Yurk, Morgan, Franey, Stebner, and Lansky, 2002). Identifying where the family is in the end of life decision making process will help determine their ability to be open to, and participate in, decisions regarding end of life care.

Summary

This chapter introduces the phenomena of the lived experience of family members who participated in the end of life decision making process for a loved one who died of a terminal illness. It also includes the statement of the problem and the purpose. The theoretical framework and the research question are identified. Conceptual definitions of variables are provided, along with assumptions, significance, and limitations related to this study.

CHAPTER II

Literature Review

Conceptual Framework

Watson's theory of human caring (2003) was the theoretical framework used to conceptualize this study. According to Watson, nursing is an art and a science which seeks to understand health and disease. Health is obtained through harmony of the mind, body, and spirit, while disease is the result of disharmony (Watson, 1988). The focus is not to cure; it is to provide holistic care. Health care providers who care for patients in a holistic manner are creating a "helping-trusting human care relationship" (Watson). Patients and family members will feel comfortable communicating their concerns in an environment where genuine care is being expressed.

As noted in Appendix A, holistic care, communication, and the nurse/health care provider-family relationship are important aspects that are intricately woven together in the lived experience of family members during the end of life decision making process for a terminally ill loved one. Watson's (2003) clinical *caritas* processes provide valuable guidelines for communication with family members, important aspects of holistic care, and effective nurse-patient and nurse-family relationships during the end of life decision making process. The word *caritas* is derived from the Greek word "meaning to cherish, to appreciate, to give special attention" (Watson, p. 2). Watson noted that nursing practice concentrates on the human to human connection, which is the necessary component for transpersonal care (Watson, 1988). Watson's holistic approach to nursing encourages health care providers to assess every aspect of the individuals' life that could be affecting

their health and well being. End of life decision making requires such compassion and sensitivity.

Transpersonal care is “seeking to connect with and embrace the spirit or soul of the other through the processes of caring and healing and being in authentic relation, in the moment” (Watson, 2003, p. 5). Clinical caritas and transpersonal caring create an opportunity for a caring occasion. A caring occasion is the coming together of the nurse and another with their unique life histories, which becomes a part of the life history of each person (Watson). All of these aspects are an important part in the end of life decision making process.

The clinical caritas processes combine caring and love to promote inner healing for others and self. Love is considered the foundation of nursing itself, and the essential element for future endeavors in caring-healing practices (Watson, 2003). Caring is something nurses have to cherish. It offers a moral, philosophical foundation for nursing, which is more than “just a job.” Watson identified the following 10 clinical caritas (pp. 3-4).

1. “Practice of loving-kindness and equanimity within context of caring consciousness.”
2. “Being authentically present, an enabling and sustaining the deep belief system and subjective life world of self and one-being-cared-for.”
3. “Cultivation of one’s own spiritual practices and transpersonal self, going beyond ego self.”
4. “Developing and sustaining a helping-trusting, authentic caring relationship.”

5. “Being present to, and supportive of the expression of positive and negative feelings as a connection with deeper spirit of self and the one-being-cared-for.”
6. “Creative use of self and all ways of knowing as part of the caring process; to engage in artistry of caring-healing practices.”
7. “Engaging in genuine teaching-learning experience that attends to unity of being and meaning attempting to stay within others’ frame of reference.”
8. “Creating healing environment at all levels, (physical as well as non-physical), subtle environment of energy and consciousness, whereby wholeness, beauty, comfort, dignity, and peace are potentiated.”
9. “Assisting with basic needs, with an intentional caring consciousness, administering ‘human care essentials’, which potentiate alignment of mindbodyspirit, wholeness, and unity of being in all aspects of care; tending to both embodied spirit and evolving spiritual emergence.”
10. “Opening and attending to spiritual-mysterious, and existential dimensions of one’s own life-death; soul care for self and the one-being-cared-for” (Watson, 2003, pp. 3-4).

Caring for family members with a terminally ill loved one using Watson’s theory (2003) will help healthcare providers maintain a holistic approach during end of life decision making.

Literature Review

A review of literature was performed to understand what has been documented regarding the issues patients and family members encounter while making end of life

decisions, how they cope while making these decisions, and the role of health care providers during the decision making process. An online search for the terms “end of life decision making” and “terminally ill,” was completed using the Cumulated Index for Nursing and Allied Health (CINAHL), and Nursing and Allied Health Collection. Inclusion criteria were research articles published in English and relative to the decision making process in the end of life. Fourteen articles were critiqued, compared and synthesized to determine the current level of knowledge regarding end of life decision making. The following is an in-depth discussion and analysis of those articles followed by a conclusion.

The Process of Decision Making

Health care providers have the opportunity to increase positive reflections on decisions made in the end of life, by having a clear understanding of the decision making process (Hayes, 2003). Hiltunen et al. (1999) analyzed 25 narratives submitted by 18 nurses to understand end of life decision making for critically ill patients and to understand the role of the nurse. Four stages of decision making in the end of life were identified: (a) recognition of a dilemma (b) period of vacillation (c) moving to a turning point, and (d) letting go. This process prepared the family to make an informed decision from a new perspective. Nurses assisted families in this process by listening, presenting information, being available, and giving consent to let go. Health care providers can assist in the decision making process by being aware that the family may vacillate and by understanding that the process takes time (Hiltunen et al.). These results supported how difficult it can be to make end of life decisions.

Similarly, Swigart, V., Lidz, C., Butterworth, V., & Arnold, R. (1996) interviewed 30 family members and 16 terminally ill patients to describe the process of end of life decision making for family members. The following three preparatory processes were identified: Cognitive, affective, and interpersonal. The cognitive process provided family members with a greater level of comprehension of the patients' condition. The affective process enabled the patient and or family to revisit and identify the patients' preferences for treatment. The interpersonal process allowed the family to continue relationships and roles within the family. This process helped the family understand that the patient would probably not recover and make a decision based on what they believed the patient would prefer.

Yurk et al. (2001) identified a process for helping critically ill patients and their family members arrange preferences for care in the end of life in a study with 32 terminally ill patients and their caregivers. Findings determined that as care shifted from curative to palliative, preferences for care were likely to change. As the patient communicated their preferences for end of life care they felt more in control of the decisions being made for them, and family members experienced less stress. Family members noted that the support they received from health care providers regarding end of life care gave them the reassurance needed to make a decision with confidence for their loved one. Yurk et al. noted that care requires individualized decisions specific to the patient and their circumstances in the end of life.

Collaboration

A nurse's role in the end of life decision making process is complex and requires working in collaboration with other health care professionals to provide optimal support to the family (Johnson & Bourgeois, 2003). Resources such as social services and chaplains provide additional support that is helpful to the family (Norton & Bowers, 2001).

Norton & Bowers (2001) interviewed 10 nurses, 5 physicians, and 5 family members to determine how end of life decisions were arranged among health care providers and family members for the patient. Findings indicated that health care providers who work in collaboration, allow consistent information to be communicated to family members regarding their terminally ill loved one (Norton & Bowers). Nurses emphasized the importance of collaborative care during the end of life decision making process. They also reported that conflicting information was conveyed to family members, when health care providers did not collaborate, which caused a great deal of distress for the family (Norton & Bowers). Swigart, (1996) also reported that family members expressed difficulty in obtaining a clear understanding of the patient's condition due to contradictory information received from physicians and nurses.

Communication with Patients

Good communication between physicians and nurses allows information to be conveyed to patients and family members in a consistent manner (Norton & Bowers, 2001). Hughes & Oberle (2001) interviewed 21 health care professionals to establish and contrast the viewpoint of physicians and nurses during the end of life decision making

process. Nurses expressed concern over the manner in which information was communicated to family members regarding a terminally ill loved one (Hughes & Oberle). Family members were often perplexed after speaking with the physicians due to the terminology they used when discussing the patient's condition. Good communication is instrumental in the patients' ability to understand their diagnosis, and prognosis (Sahlberg-Blom, Ternstedt & Johansson, 2000).

Similarly, Haidet et al., (1998) surveyed 520 patients to explore the physician-client connection between communication and comprehension of prognosis, and understanding of patients' preferences for treatment. Results indicated that information was often misunderstood and misinterpreted due to a lack of communication between the physician and the patient.

Mangan, Taylor, Yabroff, Fleming, and Ingham (2003) analyzed seven focus groups with 28 bereaved and 4 active caregivers to determine the needs of caregivers near the end of life and to identify potential solutions for health care providers to assist caregivers during this time. Results indicated that caregivers would benefit from additional information about their loved one's prognosis, increased attention to quality of life and communication with health care providers. Caregivers stressed the importance of good bedside manner, establishing good communication, and trust. Therefore, it is important for health care providers to develop interventions to help meet the needs of the caregivers and support them as they care for their love one during end of life.

In another study, Hines et al., (2001) interviewed 242 patients and their caregivers to understand why family members are unprepared to make decisions for a terminally ill

loved one. Findings indicated that the more conversations the patient had with the family member they designated to make end of life decisions for them should they become incapacitated, the more the family member understood the patients' preferences for end of life care. A lack of communication between patients and family member's increases stress levels for the family (Sahlberg-Blom et al., 2000; and Yurk et al., 2002).

Beliefs and Roles of Health Care Providers

Health care providers' beliefs may influence what information is communicated to patients and family members regarding the patients' diagnosis or prognosis. (Hughes & Oberle, 2001; Norton & Bowers, 2001). According to Hughes and Oberle, physicians struggled with making the best decision and whether or not their own values affected the information that was communicated to the family regarding the patients' condition. Nurses felt that physicians used their own value system as a guide for treatment rather than the beliefs of the patient and family members.

Johnson and Bourgeois (2003) analyzed one family's experience with end of life care to identify how healthcare providers can support the family. The analysis indicated that the values, beliefs, culture, and spirituality of the patients and family members guide the plan of care during end of life decision making. A holistic assessment of the patient and family's needs creates an environment for a dignified and peaceful death. A holistic assessment encompasses the spiritual, emotional, and physical realms within the family. Similarly, Yurk et al. (2002) identified that end of life care involves decisions which are specific and personal to the patient and family members.

A survey was conducted by Blackhall et al., (1999) to examine the attitudes of 200 people 65 and older. Results indicated that communication might be impaired if physicians and patients come from different cultural backgrounds. This study demonstrated a strong correlation between cultural values and beliefs and personal preferences for advanced directives. A better understanding of different cultural beliefs and practices may help providers as they interact with patients from different backgrounds (Blackhall et al.). These results support the importance of communication as previously discussed (Hughes & Oberle, 2001; Norton & Bowers, 2001), and the active role nurses and physicians need to play in this important process (Tilden et al., 2001).

Patient Outcomes

Researchers have conflicting results pertaining to how end of life decisions are made by patients and family members. Rosenfeld, Wenger, and Kagawa-Singer (2000) interviewed 21 individuals in the elderly community to identify what elderly individuals desire for end of life care and found that participants were more concerned about the long-term effects of illness rather than available treatment options. Participants expressed the importance of maintaining a quality of life that would allow them to continue in daily activities.

Contrary to these results, Cicirelli (1997) interviewed 388 elderly individuals living in apartments or homes in the community to determine their preferences for end of life care. The findings showed that the majority of participants wanted to continue living even with little chance of recovery and a poor health status. These results established that individuals could have multiple opinions about the end of life decision making process.

Another study conducted by Forde, Aasland, and Steen (2002) analyzed 76 questionnaires completed by physicians to understand the reasoning behind their medical treatment for terminally ill patients. Results indicated that the majority of physicians withheld treatment that would prolong life based on the patients' preferences. Prolonging treatment decreased the dignity of the patient and made death "unnecessarily technical" (Forde et al., p. 238). Treatment that supersedes the desires of the patient serves no purpose, and is therefore, meaningless (Forde et al.).

Stress and End of Life Decision Making

Family members are willing to participate in the end of life decision making process, although it can be overwhelming and stressful (Tilden et al., 2001; & Jacob, 1998). Tilden et al. interviewed 125 family members and 45 health care providers to determine the stress levels of family members associated with end of life decision making. Results indicated that stress levels are the highest immediately following the death of a loved one, yet decrease over time. Absence of an advanced directive and traveling a long distance to the hospital contributed to stress levels. In another study, Sahlberg-Blom et al. (2000) interviewed 37 family members to identify differences in how patients participate in the decision making process during the end of life. Findings determined that the highest level of stress occurred when there was ineffective communication between the patient and the family. This was usually due to the patient's unwillingness to discuss their illness or denial about their prognosis.

Summary

Numerous research studies were reviewed on the end of life decision making process. The analysis and discussion of the research findings were based on the literature reviewed. The findings provided valuable information that could be applied to nursing practice, such as the importance of good communication and collaboration. Research based literature reviewed in the area of end of life decision making is limited, yet forms a foundation for additional research. The majority of studies conducted on end of life decision making did not provide information on coping or support of the family during end of life care and after death occurs. Research articles focused on how patients and family members arrived at a decision, and the involvement of healthcare providers. Additional research is needed to provide nurses and other health care professionals with a greater understanding of the end of life decision making process.

End of life decision making can be difficult for family members. It is important for nurses and other health care providers to be knowledgeable about end of life care so that they can assist and support family members during the end of life decision making process. Family support is a powerful resource and important aspect of end of life care (Johnson and Bourgeois, 2003). Each family member's experience with end of life decision making is unique and offers insight into end of life care. It is the researchers' hope that this study may contribute to the growing body of knowledge to improve the quality of care family members receive during the end of life.

CHAPTER III

Method

The purpose of this study is to explore the lived experiences of family members who participated in the end of life decision making process for a loved one who died of a terminally illness.

Design

The phenomenological research method was chosen for this study in order to gain a better understanding of the end of life decision making process. “Phenomenology is a science whose purpose is to describe particular phenomena, or the appearance of things, as lived experience” (Streubert & Carpenter, 2003 p. 52). According to Burns & Grove (1999), phenomenology is an effective method to discover the meaning of a complex life experience. The phenomenological method requires the researcher to describe and clarify a phenomenon in a holistic manner and to portray experiences as the participant describes them because each experience is unique and qualitatively different (Streubert & Carpenter). Understanding that each individual has their own perception of the world and their own concerns about life is an important aspect of phenomenology (Burns & Grove). The phenomenological research design allowed the researcher to diligently explore the in-depth lived experience of caring for the whole person in order to add to the unique knowledge of nursing.

Materials

In this phenomenological research study, the researcher was the “instrument” in the data collection process. Using the researcher as the “instrument” in the interview

process allowed the researcher to listen to each participant's description and learn more about the end of life decision making process (Streubert & Carpenter, 2003). A tape recorder was used to record the interviews, and enable the researcher to review the interview over and over to identify feelings, non-verbals, and tone of voice, (Streubert & Carpenter).

Protection of Human Rights

Privacy of the participants was respected and protected. Fictitious names were assigned to each participant to keep their identity confidential. Audiotapes were identified by an assigned number and erased immediately after data analysis. A link was kept separately to correlate participants with their assigned number. At the conclusion of the study transcripts and the link were given to the principal investigator and placed in a locked file cabinet at the Medical College of Ohio to be held for 7 years to protect the participant's identity. Access to participants was obtained through the Director of Clinical Services at Hospice after the study was approved by the Institutional Review Board at the Medical College of Ohio and the Ethics Committee at Hospice. Upon approval, the Director of Social Services at Hospice invited individuals in the bereavement group to participate in the researcher's study on end of life decision making. The researcher's contact information was given to interested individuals. After the participants voluntarily contacted the researcher, the study on end of life decision making was described.

Data Collection & Analysis

The researcher obtained approval from the Medical College of Ohio Institutional Review Board prior to beginning the study. The researcher also obtained written

permission from the Director of Clinical Services at Hospice, the institution from which participants were selected. Purposive sampling was used to select four participants based on their experience with end of life decision making for a loved one who was terminally ill and died. Purposive sampling is used to “select individuals for study participation based on their particular knowledge of a phenomenon for the purpose of sharing that knowledge” (Streubert & Carpenter, 2003, p. 67). Information rich participants helped the researcher learn about the important aspects of the end of life decision making process. The inclusion criteria included the following: participants were the primary decision-maker for the terminally ill loved one, 18 years of age or older, agreed to participate, and spoke and understood English. Participants were selected from a Hospice bereavement group.

Upon receiving approval from the Institutional Review Board at the Medical College of Ohio and Hospice, the Director of Social Services at Hospice invited individuals in the bereavement group to participate in the researcher’s study on the end of life decision making process. The researcher’s contact information was given to interested individuals. After the participants voluntarily contacted the researcher, the researcher described her study on end of life decision making to the group and extended an invitation to participate in the study. Four participants accepted the invitation to participate in the study. Upon acceptance, the researcher answered any initial questions participants had, and scheduled an interview at Hospice at a time and date convenient for each participant.

The data were analyzed using Colaizzi's (1978) phenomenological research method. Colaizzi developed the method to guide the researcher's exploration of a phenomena using phenomenology in 1978. According to Streubert and Carpenter (2003) the following are the steps to Colaizzi's research method:

1. "Describe the phenomenon of interest."
2. "Collect participants' descriptions of phenomenon."
3. "Read all participants' descriptions of the phenomenon."
4. "Return the original transcripts and extract significant statements."
5. "Try to spell out the meaning of each significant statement."
6. "Organize the aggregate formalized meanings into clusters of themes."
7. "Write an exhaustive description."
8. "Return to the participants for validation of the description."
9. "If new data are revealed during the validation, incorporate them into an exhaustive description." (Streubert and Carpenter, 2003, p. 56).

To identify a phenomenon, the researcher must "begin by contacting that phenomenon as people experience it" (Streubert & Carpenter, 2003, p. 57). Unstructured interviews were conducted using the broad, open-ended question "What is your experience with end of life decision making for a loved one who was terminally ill?" Informed consent was obtained at the beginning of the interview at Hospice. Participants were given time to review the consent form and ask questions. The researcher determined that the participants understood the study on end of life decision making and their rights. After the study was explained, consent forms were distributed, reviewed, and signed, and

all questions were answered. One interview was conducted with each of the four participants. The interviews were face to face and lasted approximately 1 hour. The researcher utilized verbal and non-verbal prompts during the interview such as “go on. I hear what you’re saying,” maintaining eye contact and an open posture to demonstrate that each participant had the researcher’s full attention. The interviews were audio taped and transcribed verbatim for accuracy. Audiotapes were destroyed immediately after data analysis. A link was kept separately to correlate participants with their assigned number. At the conclusion of the study transcriptions and the link were destroyed to protect the participant's identity.

The researcher listened to the interviews while reading the transcription to become more familiar with the data and to ensure accuracy. This allowed the researcher to “acquire a feeling for them and try to make sense of them” (Colaizzi, 1978, p. 58). The researcher extracted significant statements and organized them into themes. Significant statements are “phrases that directly pertain to the investigated phenomenon” (Colaizzi, 1978, p. 59). Themes are “structural meaning units of data that are essential in presenting findings” (Streubert & Carpenter, p. 36). The researcher looked for recurring themes. According to Colaizzi, the researcher needs to verify that the description accurately portrays the participant’s experience. However, the researcher was not able to validate the descriptions with three out of four participants. These participants did not contact the researcher for a second interview as agreed upon during the first interview. In order to protect their privacy, the researcher did not have access to the participants contact information. Therefore, the researcher was not able to contact the participants.

Summary

This chapter identifies the research design and describes the data collection and analysis processes that will be used in this study. A phenomenological method was used to explore the lived experiences of family members who participated in end of life decision making for a terminally ill loved one who died. Colaizzi's (1978) method was used as a guide for data collection and analysis.

CHAPTER IV

Results

The purpose of this study is to explore the lived experiences of family members who participated in the end of life decision making process for a loved one who died of a terminal illness. This chapter describes the inclusion criteria used to select participants and presents the findings. Watson's (2003) theory of human caring was the theoretical framework used to conceptualize the study.

Sample

The sample consisted of four participants selected from a Hospice bereavement group. Privacy of the participants was respected and protected. Fictitious names were assigned to each participant to keep their identity confidential. Audiotapes were identified by an assigned number and erased immediately after data analysis. A link was kept separately to correlate participants with their assigned number. At the conclusion of the study transcripts and the link were given to the principal investigator and placed in a locked file cabinet at the Medical College of Ohio to be held for 7 years to protect the participant's identity. All of the participants were women. Participation was on a voluntary basis. Three of the four participant's husbands died from cancer. The fourth participant's mother died of a seizure disorder that had been diagnosed as terminal. The death of the participants loved ones ranged from 3-24 months prior to the study. It was the first experience with Hospice for all of the participants. Inclusion criteria for the study participants were: participants were the primary decision-maker for the terminally ill

loved one, 18 years of age or older, agreed to participate, and spoke and understood English. Each of the women experienced the loss of a loved one in the past 3-24 months.

Findings

The data was analyzed using Colaizzi's (1978) phenomenological method. According to Streubert & Carpenter (2003) the following are the steps to Colaizzi's research method:

1. "Describe the phenomenon of interest."
2. "Collect participants' descriptions of phenomenon."
3. "Read all participants' descriptions of the phenomenon."
4. "Return the original transcripts and extract significant statements."
5. "Try to spell out the meaning of each significant statement."
6. "Organize the aggregate formalized meanings into clusters of themes."
7. "Write an exhaustive description."
8. "Return to the participants for validation of the description."
9. "If new data are revealed during the validation, incorporate them into an exhaustive description." (Streubert and Carpenter, 2003, p. 56).

To identify a phenomenon, the researcher must "begin by contacting that phenomenon as people experience it" (Streubert & Carpenter, 2003, p. 57). The researcher collected descriptions by conducting unstructured interviews using the broad, open-ended question "What is your experience with end of life decision making for a loved one who was terminally ill?" The interviews were audio taped and transcribed

verbatim for accuracy. The researcher listened to the audio taped interviews while reading the transcriptions to become more familiar with the data and to ensure accuracy. The researcher extracted significant statements and eventually organized them into themes. According to Colaizzi (1978), the researcher needs to verify that the description accurately portrays the participant's experience. However, the researcher was not able to validate the descriptions with three out of four participants. These participants did not contact the researcher for a second interview as agreed upon during the first interview. In order to protect their privacy, the researcher did not have access to the participants contact information. Therefore, the researcher was not able to contact the participants. The following four themes were discovered:

Theme One: The importance of time and loving kindness in establishing authentic care to promote comfort and healing.

Theme Two: Creating a healing environment by assisting with basic needs in a considerate, consistent, caring manner, while viewing the family member's loved one as whole and complete regardless of illness or disease.

Theme Three: The importance of respecting family members by acknowledging, honoring and supporting their decisions and concerns to develop a helping-trusting relationship.

Theme four: Creating a healing environment for family members during denial, preparation, and letting go to potentiate beauty, comfort, and peace.

Theme One: The importance of time and loving kindness in establishing authentic care to promote comfort and healing.

The end of life decision making process is difficult for family members. Amy stated “if somebody said what was your whole experience during that whole period (end of life decision making process), as the caregiver, is that you never relax, never, never. Like you can’t ever sit down and not worry or cry or.....you just, you never do.” The participants appreciated the authentic care they and their loved ones received during such a formidable time. Amy recalled how thankful she was to have a nurse give of her time after her husband had a tumor removed in the hospital. Amy felt that the nurse genuinely cared for her because she took the time to listen, and comfort her by just being present:

And I remember that nurse sat in that room with me and I said....(tearful) I think that if God’s going to take you, that it’s okay, he can have you, but then you shouldn’t have to suffer anymore here. And I just remember she said yeah, I wish it could work that way. But she like sat there with me for two hours. Maybe it wasn’t two hours, but it probably just felt like. I mean, I think that that is like soooooo important.

Diane was having a difficult time dealing with her mother’s sudden terminal illness. She had to make end of life decisions for her mother while feeling confused and overwhelmed. She described the gratitude she felt when a physician took the time to listen and explain treatment options to help her through the end of life decision making process:

He (physician) was very good to my sister and I because we were constantly there. He took the time to explain everything. He’d stay in the room sometimes for an hour. He would stop in 3-4 times a day. I’d never seen a man so dedicated.

Ava expressed how thankful she was to have health care providers who were willing to take the time to provide explanations, and prompt, authentic care during her husband's terminal illness.

When we first went to the clinic out of town.....it was so different. They (health care providers) explained things to you, they helped you find what department you needed to get to. It made me realize how substandard the care was we had received all those years. They (health care providers) are really good at explaining about different stuff, and if I said we're down on something, they'd just call it in. It's really been a God send. They go out of their way.

Cora and her husband were married for 50 years before he was diagnosed with terminal cancer. She confirmed the importance of authentic care during this difficult time. Health care providers anticipated the needs of her husband, which allowed her to focus on her husband and the time that they had left, rather than worry about his care during the end of life decision making process:

Pretty much what they (healthcare providers) know, they can tell, or they can see. They knew what he (husband) needed and they done it. They would try and help him feel better. It was a blessing. It really was, because I didn't know what to do. You can't think because your main concern is them (loved one). What can I do to make them feel better? I hope he feels better. I hope he gets better. That is your concern. Where somebody else is thinking different.

Amy shared her experience with Hospice home care shortly before the death of her husband. Nurses provided timely care with loving kindness to assist with the needs of the family:

And if you run out people (nurses) will come here (to her home) in the middle of the night. If one of his lines would come out they would come right out, within an hour. I mean you would never wait. They were like right there. And the nurses were very upbeat and very responsive, and very helpful. The nurse that was here the day that my husband passed, umm, she was very supportive.

Ava recalled how comfortable and welcome the staff made her feel during her husband's stay at Hospice. The nurses were willing and kind, which was very comforting to Ava:

And they (nurses) are just wonderful. They don't make you feel like you're putting them out. They have been wonderful. They all, everytime they see me come in the building, they come over and give me a hug! It's so nice.

Diane expressed how important she believes it is for health care professionals to provide authentic care by making time for and showing kindness to family members during the end of life decision making process:

I think patience is really important, taking the time to explain things. I understand that they're (healthcare providers) busy and I know that everybody's short staffed anymore, but I just think that explaining stuff in a normal voice and in a normal

pattern would really help. Because you (family members) honestly don't understand.

Theme Two: Assisting with basic needs in a considerate, consistent, caring manner, while viewing the family member's loved one as whole and complete regardless of illness or disease.

The participants expressed how difficult and frustrating it was to have the needs of their loved one ignored, dismissed or denied by health care providers during the end of life decision making process. Participants felt disappointed and angry due to the lack of care they and their loved ones received from health care providers. Diane stated: "People need to understand that families are going through this stuff (end of life decision making) It wasn't important to them (healthcare providers) because she was just somebody taking up a bed."

Amy described an event that occurred when she took her husband to the oncologist for chemotherapy. He was very ill this particular day. Health care providers were more concerned with starting the treatment, than looking at her husband as a whole. Amy was concerned about her husband as a person. She needed someone else to be concerned as well:

He vomited this one day, I mean like continuously, just vomited, vomited, vomited. And I gave him a garbage can, and finally the one nurse came over and I remember thinking what the heck? Ya know? And finally somebody came over and said, well lets just try to get this (chemotherapy) started and then we'll have

one of the docs take a look. And I thought, so you'll go ahead and give the chemotherapy, but nobody's going to help him.

Amy recalled another incident that occurred after her husband was admitted to Hospice for terminal cancer. Again, the nurse did not look at the situation holistically. She acted out of duty, by following the doctor's order. Amy began to feel that health care providers simply did not care about her husband's care because he was terminal. What seemed obvious to her was being overlooked by health care providers. This was extremely upsetting to Amy during the end of life decision making process:

I walked in right after he was vomiting for days and he was eating red Jell-O, orange juice, milk, and he had had spaghetti. And I said who ordered all this food? And she said the doctor. And I said you know what..... get this out of here. Put in his chart he's not allowed to have anything red, he can't have any dairy products, he can't have any juices, and tell the doctor to call me. And she said here? Yes, in here. I mean that's ridiculous. And the nurse was just doing what she was told, you know, and dietary doesn't know if they don't specify. And I remember just thinking, they're all nuts! I mean here he's been bleeding for days and nobody knows where it's coming from and they're giving him spaghetti, jello, juice and milk. Ya know?

Diane stated how inconsistent nurses and other health care providers were during her mother's stay at Hospice. She wanted to be as involved with her mother's care as possible during the end of life decision making process. However, she received conflicting information from the staff as to what she could or could not help with. As a

result, Diane felt that the health care providers were not concerned with how difficult this time was for her mother or herself:

There would be nurses coming in the room telling me you can't do this for your mother. We have to do this. And it's as simple as maybe washing her up. But they didn't want me to take that on. And the next day the nurse would say, well we're going to need some help here. So, you don't know what you're supposed to do. Ya know, one time they want me to help, the next time they don't. One time they would leave her medicine in there for us to give it to her and the next time they're going you can't touch that. What are you suppose to do?! They really do need to be consistent with everything that they do.

Amy and her husband were shocked and upset when they received news about an abdominal tumor that went undetected for some time. Amy wanted to be notified and aware of her husband's condition. Instead, this news added to the difficulty of an already overwhelming situation during the end of life decision making process. Amy felt that health care providers were not very concerned about the tumor because he was terminal. However to Amy, every detail mattered:

The GI physician said it could be a tumor, and I mean nobody had ever said that, nobody. Not the oncologist, not the family docs, not the...nobody! And so we're looking at each other and we looked shocked. And he said, well, ya know somebody will be in to talk to you. Like he couldn't believe that nobody had told us. The surgeon said we have another tumor growing on the right side, and it's been growing since your first scan. But nobody pays attention. And I guess if you

look at the big picture it doesn't really matter, but when somebody's dying, everything matters. Every drug, any time a physician says anything. You hang on every single word.

Diane reflected on her feelings of disappointment with health care providers regarding the lack of consideration shown to her mother and herself during the end of life decision making process. Diane felt that health care providers did not look at her situation in a holistic manner, which added to the stress of an overwhelming experience:

They just don't take into effect that you have just gone 3 days without any sleep. And what they were doing was piling all this other crap on top of you that just really had no bearing on any of it.

Amy recalled an experience that occurred after her husband had abdominal tumor removed. She noted that health care providers did not consider the needs of herself and her loved one as a whole. They only focused on their assigned responsibilities, instead of how a change in health care status may effect the family and their loved one:

You walk in (after surgery) and there's this huge, huge bag connected. And my husband was sleeping, well, he was sedated. He was up, but he didn't know what was going on. And I remember looking at that and I said well, what is he suppose to do with that? And they said, oh you know, you can just put it on his belt loop. And I'm thinking who would walk around with this big fat thing on their belt loop?

Diane was very upset after the following encounter with a nurse the day her mom was transferred from the hospital to Hospice. Health care professionals did not provide

intentional care or view the situation holistically. The nurse was indifferent about the outcome of Diane's mother's illness, which was an insult to her because of how very important her mom was to her:

The nurse told me that day we left for Hospice, the guy said, ya know, I've seen people come out of there, I've seen people die, I've seen everything. So whatever's going to happen, going to happen. Ya know, it's just a very cold thing to say when you're dealing with something like that. I was not overly impressed with the hospital or the people that worked there. My mom could lay there for hours and we wouldn't even see anybody.

Diane went on to share her perspective of what is important to family members during the end of life decision making process:

They (health care providers) need to be a little bit more caring, I think that as family members, we're doing everything we can to help them (health care providers), because that means the best outcome for our loved one. It's not like we're in there trying to bother them or be a hindrance to them. And I think a lot of the time that's the way they (health care providers) made it seem. But I don't think it's a fixable problem, because it's just people.

Theme Three: The importance of respecting family members by acknowledging, honoring and supporting their decisions and concerns to develop a helping-trusting relationship.

All of the participants desired and appreciated the respect of health care providers during the end of life decision making process. Respect was shown by acknowledging, honoring, and supporting the family member's decisions and concerns. Participants were then able to focus on their loved one whose dignity they were trying to preserve.

Amy shared a difference of opinion she had with a nurse regarding appropriate communication between her children and husband during the end of life decision making process. Amy did not approve of the nurse's suggestion to have her children give their father permission to die. The nurse respected and supported Amy's decision:

Hospice kept talking about death like it was a matter of fact. And one of the things that they did that I totally disagree with is they just assumed, and they might have to do that, that we'll like let the kids tell him it's okay to go, and I think that's ridiculous for a kid, even an older kid. When your parent dies at a pretty young age I think that that's almost cruel. Maybe I'm just not somebody who's comfortable talking about things like that or about my feelings when things are going on. And when I did tell her that I didn't want to talk about it and I didn't want to hear it, I assumed that she wouldn't dare say it when I wasn't around. We understood each other perfectly, and I never heard another thing about it.

After Cora's husband was admitted to Hospice, she wanted to stay informed about his condition. The nurse respected Cora's concern by promptly providing the information she requested each day. This simple act greatly eased Cora's mind. As a result, she and the nurse made a meaningful connection:

I wanted his blood work, and I think the first three days that nurse kind of sighed but then after that she would just have it ready for me with a smile on her face.

Good morning, how are you? I just wanted to know what was going on, I wasn't questioning their abilities.

Amy wanted her husband to die in the comfort of his own home. The counselor talked with Amy and her husband about her concerns. The counselor honored Amy's decision to care for her husband at home:

We didn't want, I didn't want to be there (Hospice) when he died. But they (Hospice) had a counselor or somebody talk to him (husband) and that's when he said, well I want to stay here because I don't want to pass, you know with my wife and daughter. And they were good enough, you know when I said no, I want you at home. And the counselor asked questions and my husband asked questions. So it was a good idea all the way around.

Ava recalled the physician respecting her decision to forego her husband's chemotherapy:

The first kind of chemo they gave him turned him septic. So, they decided to try a different kind of chemo, and that again turned septic. The next time we had an appointment with the oncologist, I went in and I says look you've almost killed him twice (chuckles). I'd rather have him be him for as long as we can have it, so that we can go places and do things and not be running back and forth to the hospitals because of everything. And they suggested coming to Hospice.

Amy reflected on a decision she made regarding her husband's care during the end of life decision making process. Amy's husband became incontinent, therefore the nurse wanted to insert a urinary catheter. Amy did not want anymore invasive procedures to be performed on her husband. The nurse respected and honored that decision, which meant a great deal to Amy:

That day the nurse had said, she had said... that morning that he had taken a turn for the worse. And they wanted to cath him...and I said no. And she said he can't get up, and I said too bad, you know, put a Depend on him or something, and they did. I just didn't want anymore holes in his body or anything in him anymore.

In contrast, a lack of respect for the family's concerns or decisions during the end of life decision making process greatly grieved the participants. Disregarding how the family felt or what the family wanted, eliminated the family's right to participate, thus rendering them powerless.

Diane felt excluded from the end of life decision making process after a social worker informed her, instead of consulting with her, about what information would be communicated to her mother regarding her illness. Diane felt overwhelmed as she sat outside of the room, while a stranger told her mother she was dying:

I remember when my mom got to Hospice the social worker said, I'm going to go in and explain to your mom what's happening with her (dying), and I thought, ya know, you can't do that. Because, then I felt that if mom knew that, that she would just give up. So, we were sitting around this table and I remember looking at my brother and I said, really this is going to be it. Because I honestly believed

that if my mom knew, ya know that medical people, people she put her trust in thought she was dying, then, she would just give up. I think that was one of my hardest days at Hospice. And then I had to go back in and try and act like everything was okay.

Diane's mom was eating very little during the end of life. However, Diane could get her to eat very small amounts. She was angry when a nurse's aide withheld food from her mother directly against the family's expressed concern and decision to continue to feed her:

There was a little aide that worked there. And my mom had quit eating and she would eat a little bit, just whatever I could coax her into. And this girl was having a hissy fit because she said we were wasting food and she wouldn't even bring my mom a tray anymore. Which to me was just so stupid because.....ya know what is a tray? Ya know what is food if I can get her to eat 5 bites?

Amy confirmed these feelings of frustration. Her husband was in a tremendous amount of pain after undergoing surgery. A resident initially disregarded her concern and request to give him more pain medication, but honored her decision after further discussion:

And I remember he was in a lot of pain and he had never had surgery before that andya know he was moaning and...he was in pain. And I wanted them to give him more drugs and the resident said, well we don't want to gork him out. And I said well, I don't really care what you want, I want him gorked out until

he's out of pain. And he said, well, I can't do that. And I said well, I want you to give him more pain medicine, and he said okay.

Theme four: Creating a healing environment for family members during denial, preparation, and letting go to potentiate beauty, comfort, and peace.

Family member's thoughts and feelings changed as they moved through the end of life decision making process. Some participants needed time and support to move through the process, while others never did accept and prepare for the impending death of their terminally ill loved one. Diane was in denial throughout her mother's illness. She always believed her mom would recover, and therefore, was unable to prepare for her death. Diane is still having trouble letting go:

I think that...I know myself I never believed my mom was going to die. I still didn't believe it because she had been sick for so long that she always got better and I just assumed that she was going to get better again.

Denial prevented Diane from listening to her mom during the end of life decision making process. She experiences tremendous feelings of regret and guilt because she was unable to hear her mom and obtain closure:

We kind of couldn't even listen to my mom. The things she was trying to tell my sister and I towards the end, we couldn't even take that in. I don't think we could deal with both of em (her dying and hearing the information), to be able to do that for her, which I regret now. She was trying to tell us how much she cared and I couldn't even really take that in because to do that would admit that they (Hospice) were right and I

was wrong, and she was going to die. I couldn't even allow her (mom) to do that because it just wasn't something I was ready to deal with.

Amy shared her initial thoughts and feelings upon her husband's diagnosis of terminal cancer: "In the beginning you do all the things you think you can't do anymore, and then I guess I always thought he would get better somehow, like I was going to find that cure."

Amy expressed her need to prepare for the death of her husband. She felt that the decisions regarding her husband directly involved her and her family, making her an important part of the end of life decision making process. Because of this, Amy prepared to let go so that she could be at peace with the decisions she made during this difficult process:

My husband had a living will and I had said during that time that I would override that until I was ready. And Hospice sent a doctor here to talk to me, and I knew where she was coming from, but I felt that as long as he could think, I wasn't ready. When he was finally unable to think or to function at all, then I could see where it would be senseless for either of us, ya know, for him to stay alive.

As Amy reflected on her journey through the end of life decision making process she felt fortunate to have had the opportunity to say everything she wanted to say and prepare things exactly the way her husband wanted them before his death:

I think when somebody dies slowly.... we were given the opportunity to get ready. And that is a blessing in itself. My husband was able to get things put in

order the way that he wanted them done. I was able to let go, which I don't know if I would have been able to deal so well with it.

Ava's husband had suffered for many years due to multiple chronic illnesses. She felt that she had prepared during the many years her husband had been ill. Upon receiving the news that her husband had terminal cancer Ava expressed the sense of relief she experienced. She felt thankful that he would finally be without pain:

I thought, God's gonna take him home and make him better. Uhhhhhhhhhh, and I think that's my problem with the grieving thing. I grieved for 30 odd years (due to a long history of illness), and he was finally able to go, and he's not in pain anymore. It was a relief, it really was. Not that I wanted him to go, but he's out of pain now. He needed the rest. He needed to get out of this. I think it would be a lot different for someone else because like I said he had been in pain for a long time. So, for me it was a release, ya know. We had so many years to say goodbye.

Amy described her experience with letting go. When she gave her husband permission to die, she felt prepared. It had been a long journey for both Amy and her husband. She sensed he was ready and which gave her the peace, comfort and strength to let go:

I got up on the bed and I told Mark that it was okay to go.....that I would take care of the kids. And I told him that it was okay several times. And then he had died like 20 minutes later. I don't know about other people, but I wasn't, I wasn't relieved that he was gone, but I was. I mean I was really tired. Really, really tired. Ya know, did I wish he'd go.....no.....but it was okay.

Ava also was able to let go by giving her husband permission to die, which seemed to give him the release he needed. Ava was at peace as her husband began to relax:

So one morning it was like God woke me up and I noticed he was breathing kind of funny. And I went over by the bed and I just kept rubbing his forehead and saying I love you. And I said, now look, if God's ready for you, you don't tell God no. But if he's not ready for you, I'll keep ya (chuckles). And then he just seemed so much more relaxed. And I just kept rubbing his forehead until he quit breathing.

Cora explained how thankful she was that she participated in the care of her husband. It gave her the ability to say goodbye and be there for him during his last days:

And the nurse came in and said, well we're going to turn you over to Hospice. And right then I knew it wouldn't be long, and it wasn't. It was just about a couple of weeks after that. I took care of him the whole time, and I'm glad I did. I don't regret one second of it, not one. I would do it again.

Whatever the experience, all of the participants were glad they participated in the end of life decision making process for their loved one who was terminally ill and died. Each experience was unique and a valuable contribution to the study.

Exhaustive Description

In the seventh step of Colaizzi's research method an exhaustive description is required. An exhaustive description extracts the key aspects of each theme. The exhaustive description for this study on the end of life decision making process is the

following: Time and loving kindness helped establish authentic care to promote comfort and healing in a considerate, consistent, caring manner. Respecting family members by acknowledging, honoring, and supporting their decisions to create a healing environment throughout all phases of the end of life decision making process was important to the family. Nursing involves taking the time to consider all of the aspects that affect family members during this difficult time, which looks at the whole person, thus requires holistic care.

Summary

This chapter presented the findings of the phenomenological study on the lived experiences of family members who participated in the end of life decision making process for a terminally ill loved one who died. Colaizzi's (1978) method was used to analyze the data. After an in-depth examination of the transcriptions four themes were established. Significant statements were extracted from the verbatim to support each theme.

CHAPTER V

Discussion

The purpose of this phenomenological study was to explore the experiences of family members who participated in end of life decision making for a loved one who died of a terminal illness, in order to help nurses and other health care providers develop a greater understanding of the end of life decision making process. Four family members were interviewed regarding their personal experiences. Watson's (2003) theory of human caring was the theoretical framework used to conceptualize this study. The data were analyzed using Colaizzi's (1978) method. The emerging themes were as follows:

Theme One: The importance of time and loving kindness in establishing authentic care to promote comfort and healing.

Theme Two: Assisting with basic needs in a considerate, consistent, caring manner, while viewing the family member's loved one as whole and complete regardless of illness or disease.

Theme Three: The importance of respecting family members by acknowledging, honoring and supporting their decisions and concerns to develop a helping-trusting relationship.

Theme Four: Creating a healing environment for family members during denial, preparation, and letting go to potentiate beauty, comfort, and peace.

This chapter discusses the four themes identified in relation to Watson's (2003) theory

and research documented on the end of life decision making process. The conclusions and limitations are identified, along with implications for nursing practice, and recommendations for further research related to this study.

The participants experiences had commonalities, however, each experience was personal, unique, and meaningful. The researcher recognizes the value each individual experience offered to the study as a whole. All of the experiences contributed a vital componet, making it possible to analyze and explore the data and develop the themes as identified.

Theme One: The Importance of Time and Loving Kindness in Establishing Authentic Care to Promote Comfort and Healing

It is important for health care providers to “connect with and embrace the spirit or soul of the other through the processes of caring and healing and being in authentic relation, in the moment” (Watson, 2003, p. 5). Watson theorized that the clinical caritas are the center of nursing (Watson). Caritas means “to cherish, to appreciate, to give special attention, of not loving, attention to; it conotes something that is very fine, that indeed is precious” (Watson, p. 2). It is important for health care professionals to take the time to provide time and loving kindness to family members in developing authentic relationships that leave a positive, lasting impression. According to Watson’s clinical caritas two and four, the following are important aspects of care: “Being authentically present, and enabling and sustaining the deep belief system and subjective life world of self and one-being-cared-for”; and “Practice of loving-kindness and equanimity within context of caring consciousness” (Watson, pp. 3-4).

All four participants expressed how grateful they were to health care professionals for providing authentic care to their loved ones during the end of life decision making process. Gratitude was expressed differently based on the needs of, and what was important to, each participant. Two participants expressed how thankful they were when a nurse or other healthcare provider gave of their time to listen to their thoughts and feelings during such a difficult circumstance. A nurse sat with one of the participants at her husband's bedside, while a physician took time everyday to listen and speak to another participant about her mother's illness.

Two participants shared how important it was to have health care providers take the time to give directions, explain benefits and risks of treatment decisions, and describe the process of events related to the impending death of their loved one. Explanations provided peace of mind and helped family members make decisions for their loved ones. Three of the participants reflected on how important kindness was during the end of life decision making process. Nurses and other health care providers enabled the family to focus on their loved ones by anticipating the needs of the patient for the family in a loving fashion. The participants did not feel equipped to meet the needs of their loved one from a medical stand point, therefore, having the knowledge and assistance of health care providers was comforting. The family was extremely appreciative for the loving kindness that was bestowed upon them in this manner.

The following research supports the significance of time and loving kindness as they relate to authentic care: Hiltunen et al. (1999) identified four stages of decision making in the end of life that prepared the family to make an informed decision from a

new perspective. Nurses assisted families in this process by listening, presenting information, being available, and giving consent to let go. Health care providers can assist in the decision making process by being aware that the family may vacillate and by understanding that the process takes time (Hiltunen et al.). These results supported how difficult it can be to make end of life decisions.

Theme Two: Assisting with Basic Needs in a Considerate, Consistent, Caring Manner, while Viewing the Family Member's Loved One as Whole and Complete Regardless of Illness or Disease

It is important for health care professionals to provide holistic care that conveys a “sense of reverence and sacredness with regard to life” (Watson, 2003, p. 2). This type of care was demonstrated by providing consistent, considerate care. Watson explained that nursing surpasses “changing times, setting, procedures, functional tasks, specialized focus around disease, treatment and technology” (Watson, p 2). These aspects are important to care, however, nursing cannot be known by these qualities because they do not encompass the “professional ethic and mission of nursing (Watson, p. 3). Nursing involves looking at the whole person, and considering how the end of life decision making process is affecting the family.

Watson’s (2003) seventh and ninth caritas stated the following about human care: “Assisting with basic needs, with an intentional caring consciousness, administering ‘human care essentials’, which potentiate alignment of mindbodyspirit, wholeness, and unity of being in all aspects of care”, and “Creative use of self and all ways of knowing as part of the caring process: to engage in artistry of caring–healing practices” (Watson,

p. 4). These caritas emphasize the importance of providing holistic care in order to create a healing environment.

All four participants experienced a great deal of frustration and stress in addition to the burden they already carried with a terminally ill loved one, due to inconsistent, inconsiderate, and inattentive health care providers. Participants identified that nurses and other health care professionals failed to provide holistic care at times. One participant felt angry when her mother was treated like a patient in a bed, not an individual, who was important to the family or the health care providers. Another participant remembered an occasion when she hadn't slept in three days. Health care professionals expressed no consideration for what a difficult time she was going through. One participant acknowledged that health care providers need to be more caring, because family members don't understand what is happening to their loved one during the end of life decision making process.

Three of the participants remembered receiving inconsistent information from health care providers. One participant remembered the staff sending mixed messages to her regarding what she was able to help with involving her mother's care, which was very frustrating for her. Two participants explained that they felt like they were a hindrance to health care providers when they tried to meet the needs of their loved one by asking for help, which was frustrating for them.

Research confirms the importance of consistency and consideration as they relate to holistic care using an interdisciplinary team approach. Johnson and Bourgeois (2003) analyzed one family's experience with end of life care to identify how healthcare

providers can support the family. The analysis indicated that a holistic assessment of the patient and family's needs creates an environment for a dignified and peaceful death. A holistic assessment also encompasses the spiritual, emotional, and physical realms within the family.

A nurse's role in the end of life decision making process is complex and requires working in collaboration with other health care professionals to provide optimal support to the family (Johnson & Bourgeois, 2003). Resources such as social services and chaplains provide additional support that is helpful to the family (Norton & Bowers, 2001). Norton & Bowers determined that health care providers who work in collaboration allow consistent information to be communicated to family members regarding their terminally ill loved one. Nurses emphasized the importance of collaborative care. Nurses reported that conflicting information was conveyed to family members when health care providers did not collaborate, which caused a great deal of distress for the family (Norton & Bowers). Swigart (1996) also reported that family members expressed difficulty in obtaining a clear understanding of the patient's condition due to contradictory information received from physicians and nurses. These studies emphasized the importance of considerate, consistent care.

In a study conducted by Hughes & Oberle (2001), nurses expressed concern over the manner in which information was communicated to family members regarding a terminally ill loved one (Hughes & Oberle). Family members were often perplexed after speaking with the physicians due to the terminology they used when discussing the patient's condition. Good communication is instrumental in the patients' ability to

understand their diagnosis, and prognosis (Sahlberg-Blom et al. 2000). Similarly, Haidet et al. (1998) indicated that information was often misunderstood and interpreted due to a lack of communication between the physician and the patient.

Theme Three: The Importance of Respecting Family Members by Acknowledging, Honoring, and Supporting their Decisions and Concerns to Develop a Helping-Trusting Relationship

Although family members and health care providers may not agree on the course of action for a terminally ill individual, it is important for health care providers to respect and support the family's decisions when developing a plan of care. "Being present to, and supportive of the expression of positive and negative feelings as a connection with deeper spirit of self and the one-being-cared-for" is beneficial to family members during the end of life decision making process (Watson, 2003, p 3). Watson's fourth clinical carita stated the following: "Developing and sustaining a helping-trusting, authentic caring relationship." (Watson, p. 3). This carita conveys the importance of respect and support. Health care providers can demonstrate these qualities by acknowledging the family members concerns and honoring their requests whenever possible. The family has to live with the decisions they make for their loved one after their loved one dies and, therefore, it is essential for nurses and other health care providers to respect the family as they endeavor to make the best decisions for their loved one during the end of life decision making process.

All of the participants expressed differences in their values and beliefs and those of the health care providers regarding the end of life decision making process. One family

member felt respected when the nurse validated and supported her wishes regarding her husband's care. Another participant felt dominated by the physician who acted on his own beliefs, while disregarding the concerns of the family.

Most of the participants were with their loved one the majority of the time during the end of life decision making process. As a result they were very involved in the daily care of their loved one. One participant recalled how accommodating a nurse was when she wanted to see her husband's lab results. The nurse had the results ready for her upon her arrival everyday. Another participant described how thankful she was when a nurse honored her decision not to insert a catheter shortly before her husband's death. In contrast, a participant shared how upsetting it was to have food withheld from her mother because the staff didn't believe it was appropriate to waste the food due to a decreased appetite. This was difficult for the participant to understand and cope with.

Mangan et al. (2003) analyzed seven focus groups with 28 bereaved and 4 active caregivers to determine the needs of caregivers near the end of life and to identify potential solutions for health care providers to assist caregivers during this time. Results indicated that caregivers would benefit from additional information about their loved one's prognosis, increased attention to quality of life and communication with health care providers. Caregivers stressed the importance of good bedside manner, establishing good communication, and trust. Therefore, it is important for health care providers to develop interventions to help meet the needs of the caregivers and support them as they care for their love one during end of life.

Theme Four: Creating a Healing Environment for Family Members During Denial,

Preparation, and Letting Go to Potentiate Beauty, Comfort, and Peace

Health care providers who seek to understand and experience another's world "join in a mutual search for meaning and wholeness of being and becoming to potentiate comfort measures, pain control, a sense of well-being, wholeness, or even spiritual transcendence of suffering" (Watson, 2003, p. 5). As health care providers move through the end of life decision making process in a meaningful way, peace can be established making the experience more comforting for the family. Watson's eighth carita stated that "Creating healing environment at all levels, (physical as well as non-physical, subtle environment of energy and consciousness), whereby wholeness, beauty, dignity, and peace are potentiated" (Watson, p. 4). A healing environment considers all aspects of care in a compassionate manner. It is important for health care providers to consider the emotional aspect as well as the physical during the end of life decision making process.

Each participant handled the end of life decision making process uniquely. One participant was not able to accept the terminal diagnosis of her mother. She is still having difficulty with her loss and memories of the end of life decision making process. Another participant moved through the process quickly because her husband suffered for years due to multiple long term chronic illnesses. Two participants gradually journeyed through denial, preparation, and letting go as they received the terminal diagnosis of their loved one and journeyed through the end of life decision making process.

The initial shock of a loved one who is diagnosed with a terminal illness is unsettling, and often times unexpected. As a result denial often occurs. Initially, all four participants were in denial. After coming to terms with the terminal aspect of the

diagnosis, three participants began to prepare for the impending death of their loved one. One participant did this by arranging everything according to her husband's wishes, while another spent every last minute with her husband. She expressed that she has no regrets about the end of life decision making process. Another family member felt relieved when she received the news of her husband's diagnosis, because he had been in pain for many years due to multiple long standing illnesses. She felt prepared in every aspect upon hearing the diagnosis. One participant was never able to prepare for the death of her loved one. Her denial was too great to move through this portion of the end of life decision making process. Three participants were able to let go of their loved ones after time and preparation and have a peaceful goodbye, which was comforting for them. Two participants gave their loved one "permission to go." In both incidences, their loved one passed away within minutes. One participant, who only had a couple of weeks to prepare for the death of her husband, had difficulty letting go, while another was unable to let go altogether. As a result, she is experiencing a great deal of sadness and guilt.

Swigart, V., Lidz, C., Butterworth, V., & Arnold, R. (1996) identified the following three preparatory processes: Cognitive, affective, and interpersonal. Cognitive processes provided a greater level of comprehension of the patients' condition. Affective processes enabled the patient and/or family to revisit and identify the patients' preferences for treatment. Interpersonal processes allowed the family to continue relationships and roles within the family. This process helped the family understand that the patient would probably not recover and make a decision based on what they believed the patient would prefer. Family members were able to move through denial into

preparation by realizing and understanding that their loved one would die and accepting that on some level.

In another study Yurk et al. (2001) identified a process for helping critically ill patients and their family members arrange preferences for care in the end of life. Findings determined that as care shifted from curative to palliative, preferences for care were likely to change. Family members noted that the support they received from health care providers regarding end of life care gave them the reassurance needed to make a decision with confidence for their loved one. Yurk et al. noted that care requires individualized decisions specific to the patient and their circumstances in the end of life.

Conclusions

The end of life decision making process can be overwhelming and difficult for family members. It takes a great deal of courage to take on the job as the primary decision maker for a loved one who is terminally ill. The courage of the family should be admired and respected by health care providers. It is important for health care providers to take time to be patient and kind, in order to develop a helping-trusting relationship with the family as they move through the end of life decision making process. The participants expressed enormous gratitude for time, respect, support, and holistic, care. These qualities conveyed to the family that health care providers authentically cared and created a healing environment which promoted dignity, peace, and comfort.

Another important aspect of care was consistency. A nurse's role in the end of life decision making process is complex and requires working in collaboration with other health care professionals to provide optimal support to the family (Johnson & Bourgeois,

2003). Collaboration allowed care to be delivered in a consistent, caring manner. Health care professionals who provide inconsistent, inconsiderate care have possibly not been able to put themselves in the family's position and realize what a stressful, difficult time it is for them. Frequently, the care they provide is task oriented and lacks the support and reassurance the family needs. It is hurtful to the family when health care providers disregard the emotional hardship they experience as they participate in the care of a terminally ill loved one during the end of life decision making process. Emotions such as guilt, anger and regret are often expressed by the family after the death of a terminally ill loved one due to inconsistent care and lack of respect and support.

Consideration was also meaningful to the family. Health care providers, who disregard the concerns of the family or what the family wants, eliminate the family's right to participate in the end of life decision making process. To acknowledge and support the wishes and concerns of the family allows them to focus on their loved one whose dignity they are trying to preserve. Healthcare providers have the opportunity to increase positive reflections on decisions made during the end of life by having a clear understanding of the decision making process (Hayes, 2003).

Caring for family members with a terminally ill loved one using Watson's (2003) theory of human caring (2003) may help healthcare providers maintain a holistic approach during the end of life decision making process. Watson's holistic approach to nursing encourages health care providers to assess every aspect of the individuals' life that could be affecting their health and well being. The end of life decision making process requires such compassion and sensitivity. Health care providers who work with

the family members of a terminally ill patient will forever be in their memory based on the type of care that they provide.

Limitations

The inability to obtain true saturation is a limitation due to the small sample size. The researcher had four participants. A larger sample may reveal additional or different themes in the end of life decision making process. The researcher's inexperience with qualitative research also serves as a limitation to this study. All of the participants were obtained from Hospice. This may have presented a bias, and therefore may also be a limitation.

Implications for Nursing

In order to improve end of life care, it is important for nurses and other health care professionals understand the lived experience of family members who were involved in the end of life decision making process for a loved one who died of a terminal illness. The following are implications for nursing education and practice. Understanding the needs of the family with a terminally ill loved one during the end of life decision making process may help nurses to appreciate the importance and impact of the decisions that are made at such a difficult time. As a result, nurses may communicate with the family in a timely, consistent, considerate, respectful, caring manner, thus allowing the family to make decisions with appropriate information and support (Hughes & Oberle 2001). It is important for nurses to understand that decision making is a process (Hiltunen et al. 1999; Swigart, V., Lidz, C., Butterworth, V., & Arnold, R. (1996). 1996; and Yurk et al. 2002). Identifying where the family is in the end of life decision making process will help

nurses determine the family's ability to be open to and, participate in, decisions regarding end of life care for a loved one who is terminally ill.

Recommendations for Further Research

The findings provided valuable knowledge that could be applied to nursing practice. Time, consistency, consideration, and respect were important to family members during the end of life decision making process. Research based literature in the area of end of life decision making is limited, yet forms a foundation for additional research. The majority of studies conducted on end of life decision making did not provide information on coping or support of the family during end of life care and after death occurs. Research articles focused on how patients and family members arrived at a decision, and the involvement of healthcare providers. Additional research with diverse cultures is needed to understand the effects of end of life decision making for a terminally ill loved one, different issues family members encounter during the decision making process, and the beliefs and values of health care providers. It is the researchers' hope that this study will contribute to the growing body of knowledge to improve the quality of care family members receive during the end of life.

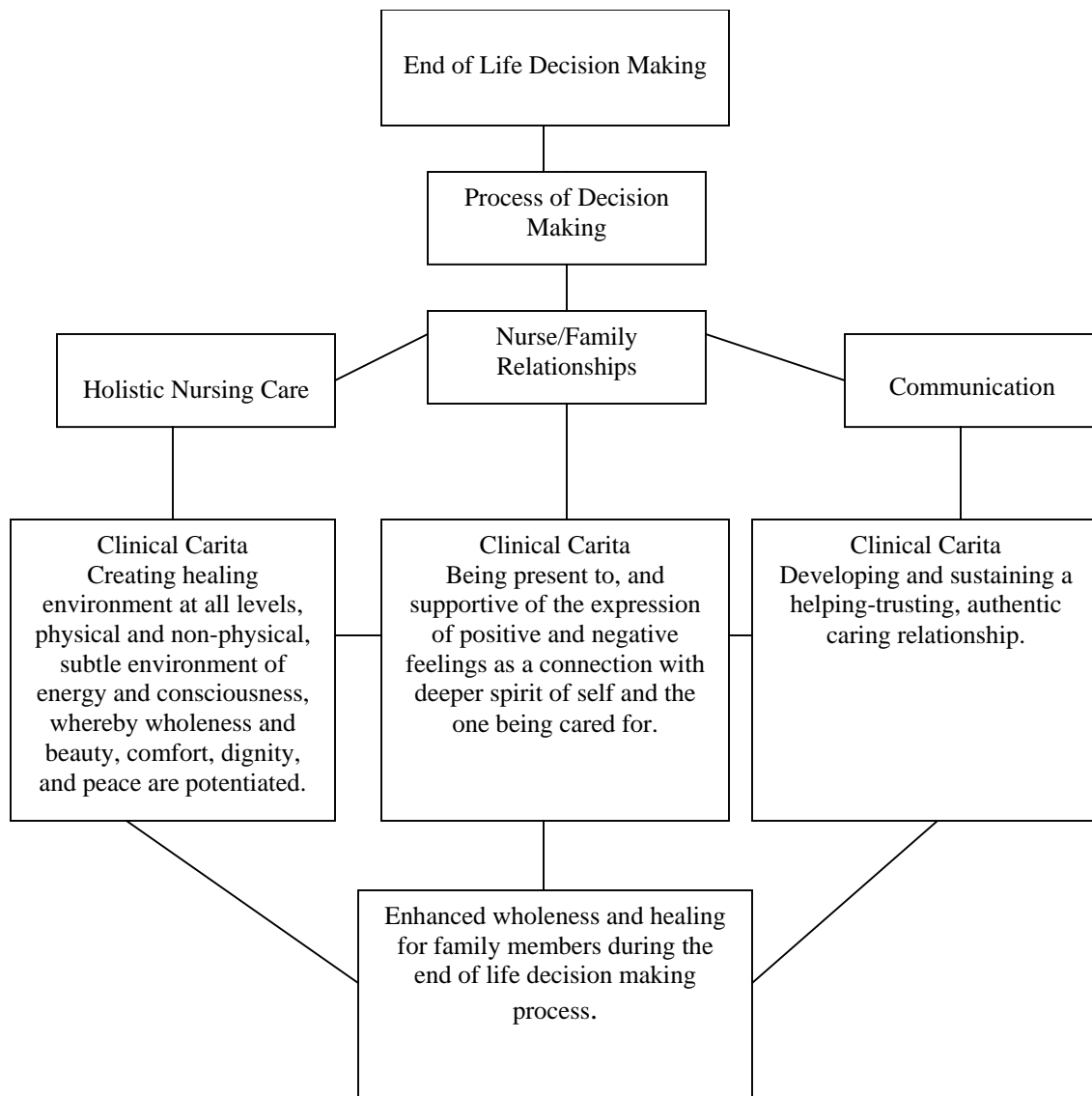
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Appendix A: Conceptual Framework



ABSTRACT

The purpose of this phenomenological study was to explore the lived experiences of family members who participated in the end of life decision making process for a loved one who was terminally ill and died using Watson's (2003) theory of human caring. The emerging themes were as follows: Theme One: The importance of time and loving kindness in establishing authentic care to promote comfort and healing. Theme Two: Creating a healing environment by assisting with basic needs in a considerate, consistent, caring manner, while viewing the family member's loved one as whole and complete regardless of illness or disease. Theme Three: The importance of respecting family members by acknowledging, honoring and supporting their decisions and concerns to develop a helping-trusting relationship. Theme four: Creating a healing environment for family members during denial, preparation, and letting go to potentiate beauty, comfort, and peace.