



Caring behavior in hospice
by Teresa Dale Johnson-Smith

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Nursing
Montana State University

© Copyright by Teresa Dale Johnson-Smith (1997)

Abstract:

The purpose of this phenomenological study was to explore caring behaviors of hospice nurses as perceived by their patients. A review of the literature revealed the need for more study of caring behavior of nurses from the patient's perspective. A greater understanding and use of caring behaviors increases the effectiveness of nurses.

Jean Watson's nursing theory of Human Care, specifically the 'actual caring occasion' was used as a conceptual framework for this research. Watson's nursing theory argues for the use of phenomenology, the study of the lived experience of people. This nursing theory recognizes the human spirit within the person, an important component to the study of caring. Watson calls for the study of caring in relation to specific human conditions or health-illness experiences with identified populations.

The investigator conducted informal interviews on five patients. A qualitative analysis using Colaizzi's phenomenological data reduction method was used to extract themes from the interviews. The emergent themes from the participants' interviews were the staffs' way of being, welcoming availability, honest explanations and options, comfort using immediacy, honoring the uniqueness of the individual, being there for them, empathetic listening, human touch, spending time (attentiveness), and trust in competence. The experiences of caring as described by the participants are used to derive suggestions for nursing practice and nursing research.

CARING BEHAVIOR IN HOSPICE

by

Teresa Dale Johnson-Smith

A thesis submitted in partial fulfillment
of the requirements for the degree

of

Master of Nursing

Montana State University
Bozeman, Montana

May 1997

© COPYRIGHT

by

Teresa Dale Johnson-Smith

1997

All Rights Reserved

N378
J6379

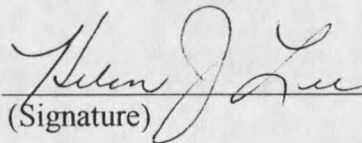
APPROVAL

of a thesis submitted by

Teresa Dale Johnson-Smith

This thesis has been read by each member to the thesis committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

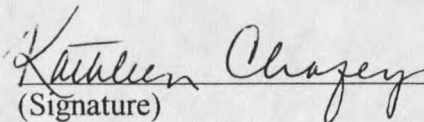
Dr. Helen J. Lee


(Signature)

5/3/97
(Date)

Approved for the Department of Nursing

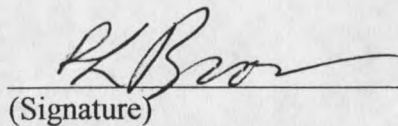
Dr. Kathleen Chafey


(Signature)

6/12/97
(Date)

Approved for the College Of Graduate Studies

Dr. Robert Brown


(Signature)

6/12/97
(Date)

STATEMENT OF PERMISSION TO USE

In presenting this thesis in partial fulfillment of the requirements for a master's degree at Montana State University-Bozeman, I agree that the Library shall make it available to borrowers under rules of the Library.

If I have indicated my intention to copyright this thesis by including a copyright notice page, copying is allowable only for scholarly purposes, consistent with "fair use" as prescribed in the U.S. Copyright Law. Requests for permission for extended quotation from or reproduction of this thesis in whole or in parts may be granted only by the copyright holder.

Signature Loren D. Smith

Date 5-31-97

VITA

Teresa Dale Johnson-Smith was born on August 25, 1952, to William Harrison and Leona Mae Johnson in Rodgersville, Tennessee. Teresa moved with her family to Maryland in 1955. After graduating from Overlea High School in Baltimore County, Teresa attended the Union Memorial Hospital School for Licensed Practical Nurses graduating in 1971. After working for over six years in coronary care, Teresa graduated from the University of Maryland in 1978 with a Baccalaureate degree in Nursing.

Teresa worked in intensive care and coronary care nursing for eighteen years in Maryland, Texas, Virginia, California, Washington and Montana. Teresa was a member of the American Association of Critical Care Nurses and held her AACN certification for five years. She was also an instructor in Advanced Life Support during that time. Teresa was a charge nurse in St. Patricks Hospital Special Care Unit for years and held her certification in Aortic Balloon pumping and post-surgical cardiac care as well as trauma care.

In 1988, Teresa married Jennings Hale Smith in Missoula, Montana where they currently reside with their three sons. From 1990 to 1997, she worked for Hospice in Missoula as hospice nurse case-manager and then as Hospice Patient Care Coordinator. During this time she was a member of the National Hospice organization and the Montana Hospice Organization. In 1994 through 1995 she held the office of Vice President and Legislative Chairperson. During this time the Legislative committee was working on regulatory rules for Hospice Inpatient facilities, a new service in Montana. The Missoula Hospice opened the first Hospice Inpatient facility in Montana during Teresa's tenure there. Teresa is currently a graduate nursing student at Montana State University.

ACKNOWLEDGMENTS

First, I wish to express my gratitude to my family for your loving support and encouragement. Thanks for your patience and for tolerating my constant pre-occupation with school. My husband, Jennings, and my sons, Cory, Timothy, and Daniel were my constant source of energy and love. My parents, William and Leona Johnson, and my husband's parents, Robert and Katherine Smith, were always interested, concerned, and supportive.

Secondly, I wish to express my gratitude to my thesis committee members, Dr. Helen Lee, Dr. Cathy Jenni, and Ardie Fraley for your professional support, kindness, and motivation through this learning and growing experience.

Thirdly, I wish to thank the Missoula hospice staff for their participation in this study and for their support through this very long and arduous journey. I would like to offer special thanks to Andrea Dreiling, a nurse who exemplifies caring behavior, and to Dr. Ira Byock, an enthusiastic leader in hospice, for mentoring me and for his model of care of the dying.

Finally, I would like to express my love and admiration for George and Lucille Jones, two hospice patients who taught me more about caring than anyone. I will always remember them for their openness, vulnerability, love and humor. They taught me how to be human in the face of death.

TABLE OF CONTENTS

	page
1. INTRODUCTION.....	1
Purpose.....	2
Conceptual Framework of Caring.....	3
2. REVIEW OF LITERATURE.....	6
Caring as a human trait.....	6
Caring as a moral imperative.....	7
Caring as an affect.....	7
Caring as an interpersonal relationship.....	8
Caring as a therapeutic intervention.....	9
Research studies involving terminally ill patients.....	9
Summary.....	13
3. METHODOLOGY.....	14
Design.....	14
Sample.....	15
Protection of Human Subjects.....	16
Procedure for Data Collection.....	17
Procedure for Data Analysis.....	18
Trustworthiness of Data.....	19
Credibility & Transferability.....	19
Dependability.....	20
Demographic Data.....	21
4. FINDINGS.....	22
Emergent Themes.....	22

TABLE OF CONTENTS-Continued

5. DISCUSSION.....	29
Limitations of Study.....	33
Implications for Practice.....	34
Implications for Research.....	34
Real Life.....	35
REFERENCES.....	37
APPENDICES.....	41
Appendix A: Consent form.....	42
Appendix B: Interview guideline.....	44

ABSTRACT

The purpose of this phenomenological study was to explore caring behaviors of hospice nurses as perceived by their patients. A review of the literature revealed the need for more study of caring behavior of nurses from the patient's perspective. A greater understanding and use of caring behaviors increases the effectiveness of nurses.

Jean Watson's nursing theory of Human Care, specifically the 'actual caring occasion' was used as a conceptual framework for this research. Watson's nursing theory argues for the use of phenomenology, the study of the lived experience of people. This nursing theory recognizes the human spirit within the person, an important component to the study of caring. Watson calls for the study of caring in relation to specific human conditions or health-illness experiences with identified populations.

The investigator conducted informal interviews on five patients. A qualitative analysis using Colaizzi's phenomenological data reduction method was used to extract themes from the interviews. The emergent themes from the participants' interviews were the staffs' way of being, welcoming availability, honest explanations and options, comfort using immediacy, honoring the uniqueness of the individual, being there for *them*, empathetic listening, human touch, spending time (attentiveness), and trust in competence. The experiences of caring as described by the participants are used to derive suggestions for nursing practice and nursing research.

CHAPTER 1

INTRODUCTION

Caring is a concept that has received much attention in contemporary nursing literature. Wolf (1992) defined the process of caring as "a characteristically interactive and inter-subjective human process which occurs during moments of shared vulnerability" between two or more people, "both a self and other directed process" (p. 3). Caring has been called the essence, core, and focus of nursing practice.

Nursing theorists, such as Leininger (1981, 1988), and Watson (1979, 1985), emphasized the central role of caring within the meaning of nursing and advocated its study (Morse, Solberg, Neander, & Bottorff, 1992). The University of Colorado has established the Center of Human Caring within the School of Nursing for research on caring. Leininger (1988) stated that caring is "the central, dominant and unifying feature of nursing" (p.153). A growing understanding of this concept is beginning to influence nursing theory, research, education, and practice.

However, debate surrounds this concept. Can 'caring' fully be described? Is it possible to teach nursing students how to be caring? How should caring be researched (qualitative vs quantitative)? Is caring unique in nursing? Rawnsley (1990) stated "if nursing is to substantiate its claim on caring as a domain construct, then it must assume the responsibility of articulating the ways in which caring and nursing are uniquely

integral” (p. 41). These are but a few areas of controversy.

While caring has been extensively described in clinical nursing and explored in nursing research, there remains a loose connection between definitions of caring practice and patient outcomes. More research is needed if caring is truly to be considered as the essence of nursing. Nurses need ways to connect the conceptual abstractions to the reality of the nursing and patient lived experience.

Watson (1990) stated, “specific theories of caring in relation to specific human conditions and specific health-illness experiences with identified populations” needs urgent research (p. 21). Hence, this research was conducted in a hospice context.

Purpose of Study

The purpose of this phenomenological study was to examine the caring behaviors of hospice nurses as perceived by the hospice patients. Utilizing this descriptive research approach facilitated understanding of caring behaviors of hospice nurses by exploring meaning in the lived experience of hospice patients. The impact of the caring behaviors was examined by eliciting patients’ thoughts and feelings following these behaviors. Themes emerging from this study were compared to current theories of caring in nursing research pertinent to dying patients.

Conceptual Framework of Caring

Watson's (1985) model of Human Care served as an organizing framework for this research. Specifically, the aspect of an "actual caring occasion" (Watson, 1989, p. 277) was used. In the model, Watson identified four conditions for caring. These include a) awareness and knowledge about one's need for care, b) an invitation to act, c) actions based on knowledge, and d) a positive change as a result of caring.

Watson's (1985) Theory of Human Care emphasized mutual, reciprocal and interactive experience directed toward the care of the sick (Morse et al., 1992). In this theory caring takes precedence. Human caring processes are an essential component of healing. Watson (1979) posed questions about what it means to a nurse to be caring, to be cared for, and to be healing. She postulated that caring is a moral ideal. In this theory, caring is the highest form of commitment to patients and the highest level of practice. Caring, in practice, allows the commitment and consciousness of the nurse to be expressed through the physical to reach the human center of the person (the spirit).

Nurses need to adopt a caring awareness and ethic. Watson (1988) illustrated this need in the following statement:

Nurse caring attends to the human center of both the one caring and the one being cared for; it embraces a spiritual dimension of the caring process; it is concerned with preserving human dignity and restoring and preserving humanity in the fragmented, technological, medical cure dominated systems (p.176).

How can we facilitate a change from the objective medical model to a more

humanistic approach to care? Dossey (1984) said we can do this through "the admission of both the care-provider and the care-receiver of the murky shadows within each--the woundedness of the healer and the latent healthiness of the (so-called) patient" (p. 204). Giving more recognition to the human-to-human connection and less recognition to the professional-to-layman relationship moves us away from the medical model. The medical model focuses on body systems rather than the person as a whole; mind, body and spirit. This recognition of the human-to-human connection is not without the risk of vulnerability, but it is a risk worth taking. Vulnerability of the nurse facilitates the human-to-human connection which in turn promotes healing (Watson, 1990).

According to Watson (1979), a person's concept of "self" influences the mind, body and soul. Harmony within these components of self underlies "health." The goal of nursing, in Watson's theory, is to assist persons to gain a higher level of harmony within these three spheres of being. Nursing activity centers around the human care process and strives for "actual caring occasions" (Watson, 1985). On such occasions a transpersonal relationship occurs allowing the nurse and the patient to move beyond physical reality and enter each other's phenomenal field (spiritual self). In these events the nurse and the patient expand their human capacities and gain greater knowledge of themselves. "The self learned about or discovered is every self; it is universal, the human self" (Watson, 1988, p. 180).

Sandelowski (1993) suggested theory may enter a qualitative research project "as the impetus and underlying rationale for the inquiry process itself, as an original product

of a study, or as an extant formulation brought into a study for organizational or interpretive purposes" (p. 217). Variances between themes and review of literature or theory should not be ignored and should be reported.

CHAPTER 2

REVIEW OF LITERATURE

There is variety within the very conceptualization of caring. The following review summarizes various theories and conceptualizations. Morse and her cohorts (1990, 1992) conducted an in-depth analysis of the concept of caring. Content from their two articles form the structure for the following discussion of caring.

Morse, Solberg, Neander, Bottoroff, & Johnson (1990) and Morse et al. (1992) organized the content about caring into five different theories or conceptualizations: a) caring as a human trait, b) caring as a moral imperative, c) caring as an affect, d) caring as an interpersonal interaction, and e) caring as a therapeutic intervention. They suggest that these conceptualizations are not mutually exclusive. The views of researchers in each area of conceptualization of caring are summarized in the following sections.

Caring as a human trait

Theorists from this perspective saw caring as "an essential way of being" (Griffin, 1983, p. 289). Leininger (1981) said caring is part of human nature and is essential to human existence. Leininger (1988) recognized all humans have the potential to care but this ability is not uniform. Roach (1987) suggested a person's experience with caring in childhood affects the ability to care as adults. According to these theorists, the human trait of caring was the central or principal motivator of nursing actions.

Caring as a moral imperative

Theorists in this category described caring as a "moral virtue" whose ultimate purpose is preserving "the dignity of the person" (Gadow, 1985, p. 33). Watson (1988) theorized that in caring, nurses "preserve the individual's humanity, inner harmony and potential healing" (p. 180). Caring to these authors was the central, foundational value in nursing practice. Theorists in this category did not believe caring can be described fully by a set of behaviors, or traits. "Caring is the adherence to the commitment of maintaining the individual's dignity or integrity" (Morse et al. 1992, p. 79). Caring was believed to take place in the metaphysical realm. Watson (1988) purposes that we cannot describe or measure caring. We cannot see this realm, but we can experience it. Caring is related to higher levels of professional ethics and practice.

Caring as an affect

Authors within this group described caring as an emotion, a feeling akin to compassion. This emotion motivated the nurse to caring behavior toward the patient. These theorists emphasized the reciprocity within caring. Gendron (1988) believed a "skilled" nurse was one who had developed the art or ability to create forms that express caring. The theorists' descriptions of caring were closely associated with the meaning of empathy. Forrest (1989) believed empathy precedes caring actions. McFarlane (1976) described caring as a feeling of concern, of interest and oversight with a view of protection. This is congruent with dictionary definitions of caring.

Bevis (1981) described caring as a feeling of dedication, and proceeds in four

developmental stages: attachment, assiduity, intimacy, and confirmation. Bevis said this process was necessary in full or caring had not taken place. Once caring occurs, it "enhances mutual self-actualization" (p. 51).

These theorists reported blocks to caring, including constraints on time, technological demands, and unattractive patient characteristics. Also, the lack of administrative support, warnings of professional boundaries, and becoming too involved can devalue the importance of caring.

Caring as an interpersonal relationship

This conceptualization suggested that the nurse-patient relationship was the essence of caring. Horner (1988), Knowlden (1988), and Weiss (1988) believed caring to be a mutual endeavor. The components of caring were reported to be communication, trust, respect, and commitment to each other. Again, these theorists affirmed reciprocity in the act of caring. They emphasized caring as feelings integrated with actions.

Benner (1989) defined caring as thoughts, feelings, and actions. Their definition required being "connected and concerned" with the client so that caring sets up the possibility of giving and receiving help. Further they suggested that caring helps clients cope, enabling them to successfully deal with whatever they find stressful and helping them find meaning in the situation. Benner affirmed the reciprocal nature of caring, saying that the nurse is enriched in the process.

Caring as a therapeutic intervention

Theorists in this category have studied nursing actions and described caring in the context of what nurses do. The focus was on the therapeutic intent of caring behaviors, such as attentive listening, patient teaching, patient advocacy, touch, being there, and technical competence (Morse et al., 1990). These theories of caring were patient-centered as compared with perspectives earlier in this paper. Researchers have studied patients' perceptions of nurses' actions they think demonstrates caring. Patients' feel cared for when "they are treated as individuals; they receive help in dealing with their illness experience; nurses anticipate their needs; they believe nurses are available; and nurses appear relaxed and confident" (p. 6).

Orem's (1985) theory of self-care was placed in this category. She expressed a highly developed theory in which self-care was asserted as necessary for the maintenance of life. Orem saw nursing as providing a helping service to accentuate self-care of patients. Caring is teaching patients to care for themselves.

Research studies involving terminally ill patients

A number of qualitative and quantitative research studies have been conducted to define caring and to identify caring behaviors most helpful to dying patients and their families (Degner, Gow, & Thompson, 1991; Fenton, 1986; Dobratz, 1990; Hull, 1991; Larson, 1984, 1986; Lewandowski & Jones, 1988; Raudonis, 1993). In these studies the most frequently identified caring behaviors of the nurse were placed into four categories. They were a) accessibility, b) effective communication, c) an accepting and non-

judgmental attitude, and d) practitioner competence (Hull, 1991).

Hull (1991) conducted a study using grounded theory to examine caring behaviors of hospice nurses, as perceived by family caregivers. The constant comparative method of content analysis was used. In a convenience sample of 10 families, 14 subjects were obtained. A total of 55 taped interviews were transcribed. Results of data analysis showed that in comparison to hospital nurses, hospice nurses were perceived as more caring, more open, more relaxed, and more attentive to the patient. However, the reason for this perception was not discussed.

Larson (1984) developed the CARE-Q instrument which asked subjects to rank caring behaviors from most to least helpful. She conducted two studies (1984, 1986), one with cancer patients and the other with nurses. The results of these two studies differed. Patients ranked the most important caring behaviors of nurses as a) monitors and follows through (competence), b) accessible, trusting relationship, and c) comforts the patient (Larson, 1984). The nurses identified differing behaviors as descriptors of caring (Larson, 1986). These behaviors included listening, touching, and talking. Perceived as evidence of caring were a) allowing the patient to express feelings, b) individually giving patient care c) realizing the patient knows himself the best, d) being perceptive of patient's needs, e) responding quickly, f) putting patients first and g) giving good physical care. A weakness in both studies was the use of a CARE-Q instrument because it limited the description of caring behaviors and may not have been all inclusive.

Degner, Gow, and Thompson (1991) took a different approach to the study of caring. They interviewed 20 oncology nurses and performed a content analysis on the findings. Positive critical nursing behaviors in care of the dying were described. Seven areas were thought by the nurses to be important: a) responding to the death scene in a calm, relaxed manner, b) providing comfort, c) responding to anger with respect and empathy, d) enhancing personal growth, e) responding to colleagues, f) enhancing quality of life of the dying, and g) responding to the family. Limitations of this study included input from one side of the caring relationship, the care provider, and none from the recipients of care.

Lewandowski and Jones (1988) conducted a study in which 120 questionnaires were mailed out to participants randomly selected from the telephone book. Each respondent answered questions based upon a vignette depicting a cancer patient in one of three phases of living with cancer. The participants (n=62) had not necessarily been a cancer patient or the recipient of nursing care, an obvious weakness of this study. In each of these phases nursing caring behaviors were ranked from most helpful to least helpful. The behaviors ranked most important included giving clear explanations of treatments and procedures, providing comfort, honest communication, providing good physical care, keeping patient/ family informed, showing interest, not abandoning the patient, calming the patient down, and providing things familiar and valuable to patients. The researcher emphasized the importance of having the "family" as the center of nursing interventions. Nonetheless, this study limited the description of caring to listing certain behaviors and having participants rank them.

Raudonis (1993) conducted a naturalistic study exploring the hospice patient's perspective of the nature, meaning and impact of empathic relationships with hospice nurses. Interviews were conducted with 14 hospice patients. The theme of "impact" of empathic behaviors came up repeatedly in descriptions of patients' experience and analysis of taped interviews. The researcher postulated the outcome of an empathic relationship was the improvement and maintenance of patients' physical and emotional well-being.

Dobratz (1990), Hull (1991), and Fenton's (1986) articles contributed to description of caring behaviors through comprehensive reviews of nursing literature. Lists of words and phrases thought to represent caring were compiled and organized in ways that resembled Larson's categories. These authors recommended further research to connect caring behaviors to patient outcomes.

Adkins and DeWitt (1997) at the University of Montana, did a research project on nurse-patient relationships in hospice. They conducted eleven interviews and thirty-five hours of observations in a hospice setting. They interviewed patients and nurses. They found touch to be an instrumental part of communication between hospice nurse and patient.

Touch was frequently used by hospice nurses with their patients. Both patients and nurses possessed strong feelings concerning touch used in a hospice setting. Touch not only strengthens the nurse-patient relationship, it also expresses the respect and caring a nurse has for a patient's feelings. (p. 10).

Touching demonstrated interest in another person. Some dying patients expressed some level of embarrassment regarding their appearance (weight loss, pallor or

jaundiced, etc.). Touch was a way to move toward the patient, to show interest and acceptance. These researchers discussed verbal and non-verbal immediacy. Immediacy communicates availability, expresses interest, and produces closeness between individuals. Touch was the most frequently observed non-verbal immediacy behavior in their study.

Summary

The concept of caring is elusive. The descriptions of caring change with persons and circumstances. Focusing on the processes and outcomes of caring may reveal recurrent themes. Study of the concept of caring is essential to nursing practice and may precipitate paradigm shifts within the discipline of nursing.

In the review of literature, there was considerable research on the concept of caring, utilizing both qualitative and quantitative methods. Studies have been conducted with the specific population of hospice and oncology nurses in regards to caring or helpful nursing behaviors. However, there had been infrequent research inquiry from the patients point of view. A phenomenological study on caring utilizing hospice patients as the sample population was not found. Use of this method provides an opportunity to study the phenomenon of caring from the perspective of patients' lived experience.

CHAPTER 3

METHODOLOGY

Design

The existential phenomenological method was selected for this study to elicit understanding of the essence of caring. As the review of literature demonstrated, caring is interpreted in many different ways and generally from the theoretical perspective of the caregiver. Reed (1994) pointed out that phenomenology was "anchored into the world of experience rather than the world of theory" (p. 336). The nature of the phenomenon of caring argues for the strengths of a methodology that acknowledges individual lived experience from the perspective of the person being cared for.

Phenomenology has its roots in the philosophical examination of the nature of being. Phenomenology allows for the personal, subjective experience of the person to emerge as the foundation of understanding. This research design provides a way of collecting descriptions while preserving spontaneity of the subjects' lived experience (Oiler, 1982) and minimized the researcher's influence on the subjects spontaneous expression. This was achieved by way of an interviewing method which follows the participant's lead. The researcher then searched the data for meaning. "The research design needs to access the meaning the experience has for the participant, and this needs to be preserved in identifying the 'essence' of the phenomenon" (Jasper, 1993, p.311).

Existential psychology and philosophy was made popular in the 1940's by, among others, Jean-Paul Satre (Morris, 1990). Existentialists were concerned with understanding people the way that they existed in the world. They supported the notion that people were "free" to make choices about how they live (Reed, 1994). When combined with the method of phenomenology the researcher attempted to "understand" the participant's choices and experience. To do this there was a "back and forth" conversation between participant and researcher regarding the phenomenon under study to clarify descriptions and themes.

Sample

The number of participants in phenomenological research is often limited because of the quantity and richness of data obtained, and the "extent to which the phenomenon is explored in the interview" (Drew, 1989, p.431). Seven participants were sought for this study. Participants were hospice patients in Missoula county. Hospice nurses assisted with participant selection according to the selection criterion below.

Selection criterion included terminally ill patients consenting to participate in the study who were a) oriented to time, place and person; b) possessed the ability to verbally express themselves clearly; c) had a prognosis of at least three months; d) were at least 21 years old; and e) on hospice services for at least three months. Participants were excluded from the study if uncontrolled symptoms prevented them from expressing themselves fully.

Protection of Human Subjects

Research conducted on dying patients must be done with sensitivity. Every effort was made during this study to protect the rights of human subjects. Hospice nurses inquired if potential participants would mind being contacted by researcher prior to telephone contact. Participation was strictly voluntary and participants were informed they could withdraw at any time. Participants were assured that withdrawal or refusal to participate would not in any way affect their relationship with their hospice program. They were informed the researcher had no affiliation with their hospice. The nature of the study was fully explained to each participant prior to obtaining written consent (Appendix A).

Confidentiality and anonymity were assured. Participants were informed their name would not appear on any written or verbal report. Pseudonyms were assigned to each participant and demographics, such as diagnosis and age, were changed in the report of data. Their signed consent forms would be kept in a locked file cabinet at Montana State University for five years. The researcher and committee chairperson were the only individuals who had access to audio-tapes of interviews and transcripts.

Risks and benefits were explained. The participants could have felt an invasion of privacy, anxiety, or fatigue during the interview. They were advised that they could stop the interview at any time. The participants were informed there would be no immediate benefit to them for their participation. Indirect benefits included the

knowledge that this study may provide information helpful to hospice staff in their care of the terminally ill. There was no deception of any kind used in this study.

Procedure for Data Collection

Seven participants were interviewed, asking them to describe their hospice experience. Wives of two patients came in during interviews. They added comments to what the patients were saying. Their input was accepted into the data. Open-ended questions were used to allow the true experience on hospice services to emerge (Appendix B). Patients were encouraged to express their personal thoughts, feelings and perceptions in an unstructured way. Further clarification of themes developed from analysis was sought by contacting participants a second time by phone.

All seven interviews were transcribed verbatim. Two interviews were not included in data due to lack of content. This decision was made after the transcription of the interviews took place and consultation with the committee chairperson. In both interviews communication blocks were present, which affected the participants' ability to articulate their experience. One participant was hard of hearing and misunderstood many of the questions even after repeating several times. The second interview eliminated was with a participant who changed the subject without articulating the lived experience.

Procedure for Data Analysis

Colaizzi's (1978) phenomenological method of data analysis was used as a model for this study. Audio-taped interviews were transcribed verbatim and read repeatedly until the researcher got a feel for the whole. Significant statements were extracted that pertained to the investigated phenomenon. Meanings were formulated from the significant statements using the participants own words. The researcher contemplated the meanings, organized them into clusters of themes and assigned them a name. An exhaustive description resulted from the integration of all meaning statements and themes. Their feedback was incorporated into a final complete description of the phenomenon in as explicit a statement of the essence of the phenomenon as possible with the data available.

A final validating step was achieved by returning to participants to ask how the description compared to their experience. Each theme was discussed with participants and they were asked, "How does my description compare to your hospice experience?" and "Have any aspects of your hospice experience been omitted?" The two participants eliminated from the study were not contacted. The five participants contacted agreed the below themes sufficiently described their hospice experience. This "back and forth" process was described by Colaizzi (1978) in order to validate data and to reach a saturation point in which no new information was obtained.

Trustworthiness of Data Analysis

In a phenomenological study the researcher strives to establish trustworthiness in the results. Koch (1994) explained this was accomplished by establishing credibility, transferability, and dependability.

Credibility and Transferability (Validity)

Guba and Lincoln (1989) claimed that a study was credible when it presents faithful descriptions and the reader confronting the experience can recognize it. Jasper (1993) referred to two issues related to extrapolating "meaning" from data obtained utilizing phenomenological methods. This author referred to these issues as the risk of "interpretation" and the use of "pre-reflective descriptions" (p.311). Interpretation and analysis of data can be affected by the researcher's previous experience and pre-conceptions of the phenomena under study. To diminish the effect of this bias the researcher [brackets] data reflecting their own beliefs about the phenomena and temporally suspends these to the extent that this is possible (Rather, 1992). The meaning of the experience comes directly from transcribed interviews, "not reworded or changed" (Jasper, 1993, p. 311).

Jasper (1993) described the other issue of concern with phenomenology was "pre-reflective experience" (p. 312). The researcher strives to select participants with lived experience of the phenomena and makes efforts in the research process to "preserve the natural spontaneity" (p. 312) of the experience. Preferably, study participants will be

articulate and possess verbal skills adequate to describe their experience. Still, there are risks the participants will exclude parts of the experience that they consider to be too painful or too confidential to share. This tendency may be overcome by initial establishment of a good rapport with the participants and by spending time with them so they can fully explore the phenomenon.

Transferability was a term used by Guba & Lincoln (1989) to describe the degree to which a phenomenological research study can be applied to other settings. Koch (1994) suggested that transferability can only be judged by the readers. Sandelowski (1993) said that a study was transferable when readers view its findings as meaningful and applicable in terms of their own experiences. To meet this criterion Koch (1994) suggested that researchers must provide sufficient contextual information in reports of their work.

Threats to credibility and transferability can include maturation of data over time, observer effects, selection and mortality (LeCompte & Goetz, 1982). Several strategies to control threats to validity discussed earlier were a) initial establishment of a good rapport with participants prior to interviews, b) temporarily suspending own beliefs by bracketing all findings that are consistent with own beliefs, and c) providing sufficient contextual information in the report of findings.

Dependability (Reliability)

LeCompte & Goetz (1982) identified several threats to dependability. They included a) researcher's status, b) participant choice, c) social situation, and d) methods in procedure. Strategies to control these included a) describing participant

characteristics and b) delineating the context in which data are generated.

In this study meticulous recording of field notes and verbatim transcription of audio-taped interviews supported dependability. A precise record of strategies for collection, analysis, and reporting of data was kept. Asking participants to respond to the data analysis was another strategy that was employed. Finally, findings were compared to published qualitative studies investigating the same phenomena.

In summary, every effort was made in this study to obtain fullness of data regarding caring behaviors of the hospice nurse and regarding the impact those behaviors have on the hospice patients. Simultaneously, the researcher exercised caution to maintain the trustworthiness of the results. Using phenomenology provided rich data in the study of this transcendent concept--caring.

Demographic Data

Seven participants were interviewed. Their ages ranged from 44 to 84 years. Three were female and four were male. All had completed high school except for two females. All participants were retired. Their previous occupations included bus driver, nurses aide, housewife, farmer, ranch hand, and two worked in a variety of blue collar jobs. Data was used from five interviews due to communication blocks in two interviews.

CHAPTER 4

FINDINGS

Emergent Themes

Ten themes emerged from patients' descriptions of the caring behaviors of hospice staff. They were a) generosity of self, b) welcoming availability, c) honest explanations and options, d) comfort with immediacy, e) honoring the uniqueness of the individual, f) being there for *them* (participant emphasis), g) empathetic listening, h) human touch, i) spending time or attentiveness, and j) trust in competence.

A theme present in all five interviews was repeated descriptions of the hospice staff's way of being or **generosity of self**. Among the descriptors used by patients were loving, kind, caring, friendly, and professional. One young man, Dennis, dying from lymphoma said, "I haven't run across anyone from hospice that I didn't like. I mean they are all very friendly people. All are very professional no matter what it is." All five patients made remarks about staff attributes.

Grace, an elderly woman dying of colon cancer, used to work as an aide in a nursing home when she was younger. She compared the nurses she worked for to hospice nurses. Grace commented that hospice staff “seem so loving. . . .” “If they didn’t love taking care of the people they wouldn’t be doing this work. I think they do it because they care.”

Cliff, a patient at the hospice house, seemed particularly impressed by the hospice staff. “You couldn’t ask for better kindness in words or actions.” “They love you.” “There is a lot of caring here” he proclaimed. One of his final parting comments seemed to summarize the feelings of all five patients. “I enjoy the people (from hospice).”

Another theme that received comments from all five participants was **welcoming availability**. This twenty-four hour availability was characterized as ‘welcoming’ because most of the comments were directed toward being invited and encouraged to use the hospice on-call nursing service. Dennis’ wife, April, commented,

Before hospice, I would sit up all night afraid that if I went to sleep that something bad would happen and I would miss it. I just couldn’t sleep. But with hospice, they keep reassuring me that any hour is a good hour to call and that there are no silly questions. Just knowing that they are there and I can call them anytime, I can sleep.

Other patient comments reflected this same sentiment. “They are taking a big relief off me, just knowing they are a phone call away.” “I appreciate when I can get a nurse in a hurry.” “I am thankful to have them. I can call them day or

night.” Finally, Ann, another patient’s wife, stated, “Things change so quickly for him. It’s just nice to know they are there.”

The third theme which received comments from all five participants was **honest explanations and options**. This seemed a highly valued approach from the hospice staff; “no beating around the bush, just cut to the chase”. Three patients seemed to emphasize ‘truthful’ responses from hospice staff was appreciated.

Dennis had been hospitalized for an infection just prior to his hospice referral. While hospitalized and on IM antibiotic injections, he had been complaining to the nursing staff about the pain of these injections. April, his wife, had gone to the nurses on several occasions to ask them to call the doctor to get the order changed. The nurses said they had done that, but the physician on his rounds claimed he received no such call. They chose to believe their physician. They were both very angry about this experience to the point of signing Dennis out of the hospital against medical advice. April said,

They (hospital staff) figure they have you in there, they can do any damn thing they want. Where hospice always asks, ‘Would you like to try this or that’. It’s more question, question, question. They explain a little better what is going on. They don’t leave you hanging. Hospice staff doesn’t lead you around. You ask them a question, they are going to give you a direct answer. And they let you know what you are asking. They always let me know what my options are.

Other patient comments under this theme follow. “She explains things to me.”

“We would have been lost without them. They came and showed us what

needed to be done. We depend on them a lot.” “If you question a medication, they have been good at going to the doctor and finding the answer.” “They always answer my questions.” Being truthful and direct in educating patients about their disease, spelling out their options and the consequences of those options suggested to these patients that hospice staff cared for them personally. This was what hospice staff at the hospice house called, “putting patients in the driver seat.” Patients were allowed control, knowledge, and authority over their care while allowing for dependency.

Comfort and responding with **immediacy** was the fourth theme to arise from the data. All five participants mentioned the word ‘comfortable’ or ‘comfort’ during the interview. “They are there to make you comfortable.” Another patient claimed, “They always focus on comfort.” The staff were perceived as moving in closer proximity, and becoming more interested in a supportive way, to patients who were in pain.

Jerry was a 50-year-old man with tremendous pain around his very enlarged liver. One night he had more pain than usual. This time his pain was not responding to his pain medication. His wife, Ann, was “feeding him Dilaudid in handfuls.” “I just knew I was going to overdose him.” She called the on-call hospice nurse. Jerry said, “He (hospice nurse) saved me when he brought this in,” pointing to his continuous automatic delivery device (CADD) pump infusion. “He (nurse) called the doctor and encouraged her (physician) to go with an IV infusion.” Ann was impressed that, “even after he got Jerry all set up on the

pump and his pain controlled, he stayed here a while until I felt comfortable for him to go.”

At the Hospice house Cliff stated,

I would think when you are dealing with the terminally ill, it would be hard to have to deal with that person, to make that person feel comfortable. It's not an easy job, at least it wouldn't be for me. But these nurses do it so well.

Four out of five participants mentioned feeling unique and respected for who they were. Cliff emphasized several statements in this next theme, **honoring the uniqueness of the individual**. Cliff is “a loner”. He went through a “hostile” divorce. His two daughters were told by his ex-wife that he was dead and they moved out of state. He had many estranged relationships, both with family and friends. Now, he was dying from lung cancer. Many things changed for him. He joined a church, where he developed some new friendships. Cliff started to soften. He desired to have some closure with his family and to seek their forgiveness. Thus far they have not responded to his requests.

Cliff mentioned several times during his interview feeling unworthy, and guilty for taking up hospice staff time. “I think all of them want to care for *me*,” he said. Cliff continued,

They (hospice staff) just let each of us (patients) be ourselves. I think they want to make everyone to feel that way, all the patients. That they are there for you, that you are special to them. But you have to receive. I don't think they are treating me better than they treat someone else. They are doing the best for everyone they can. They are there for you, not for them, but for you.

Jerry and his wife said, "Hospice nurses, they have several patients they see during the day. But each time they show up its like you are the first patient they've seen." Ann went on to say, "They (hospice staff) keep reassuring us that they are there for us." For this Jerry and Ann felt relieved and that they were important to the hospice staff. **Being there for *them*** (participant emphasis) was another overarching theme that ran throughout the data.

The seventh theme to come out of the data was **empathetic listening**. Four out of five participants interviewed made statements about being able to talk to hospice staff easily and feeling understood. Grace stated, "She (her hospice nurse) is a nice person to talk to." Dennis' wife April claimed, "They always listen, they don't mind if I want to talk". Cliff said very eloquently, "they can hug you with their words". Jerry and Ann seemed to place a high value for empathetic listening. Ann said,

I was leery of people coming into my home at first. But now, she (hospice nurse) has been my buddy. She has helped me out a lot. I can talk to him (Jerry) but sometimes I don't know how he will feel about it. Just say something I'm feeling and I want to talk about it, but I don't want to upset him. I can talk to her. No matter what the topic, she can help. So, she helps me with my stress.

Jerry commented that a male nurse, Jim, helped him a lot. "He's someone I can talk to. I've been down and I've talked to Jim a couple of times about how I was feeling." Ann added, "He likes Jim because he can understand him better, the male end of things."

Four out of five participants mentioned **human touch** as important. "She gives me a big hug when she comes and when she leaves." "She has a personal touch." Cliff proclaimed, "If you can't accept hugs, you have more than cancer". This topic often brought smiles to the participant's faces as they discussed it. These patients seemed to enjoy this level of intimacy. This was another area where immediacy was observed by the patients.

The next theme was **spending time or attentiveness**. Participants made the following statements. "They get to me as soon as possible. That's the neat part of the gift of being here (hospice house)." "They don't rush in and out. They spend time with you." Ann explained how she perceived this.

Just the attention they give you and the way they handle his needs. They do it in a very caring, very caring way. I don't know, it's kind of like, well if he needs anything, they just jump in there and do it for him as if it were me doing it. That's what makes that connection.

Another theme mentioned by participants was **trust in competence**. Grace claimed, "If they are not sure about something they check it out." Margaret was an elderly woman living alone. Margaret had stage four lung cancer. She added, "They are always very thorough." Cliff also valued this in the hospice staff.

I'm sure there're are days that it's not easy on them. But, I can trust I will get adequate medical care. They would go out of their way to do that for you, I feel that. When you have a terminal illness, I can't think of anything else a person needs more than trust, and they give it to you.

CHAPTER 5

DISCUSSION

This study was of caring behavior in hospice. These themes emerged from the participants descriptions of what caring was to them: a) the hospice staff's generosity of self, b) welcoming availability, c) honest explanations and options, d) comfort with immediacy, e) honoring the uniqueness of the individual, f) being there for *them*, g) empathetic listening, h) human touch, i) spending time or attentiveness, and j) trust in competence.

The participants in this study described what they thought was caring behavior. These actions or behaviors were interpreted as caring not only because they met some need of theirs, but also because of the way in which the actions were carried out. The observations of the hospice staff's **generosity of self** were discussed by the participants more than any other topic and accentuated all other themes discussed. Conceivably, this alone may be the essence of caring. The way in which a nurse approaches a patient, not what they do, may be specifically what patients recognize as caring.

Different studies have focused on the specific action or behavior performed by the nurse at the time they were perceived as caring. Yet how caring is availability, provision of comfort, explanations, etc., if these actions are

performed in a devaluing, rude way? In the concept analysis on caring, Leininger (1981) talks about caring as "an essential way of being." The finding of hospice staff's generosity of self demonstrates this portrayal of caring.

Many of the specific caring behaviors identified by these hospice patients were consistent with results of other research on caring, particularly those studies involving hospice patients. Many of the caring behaviors identified point toward a desire on the part of hospice patients for some level of intimacy with their hospice nurses. Human touch, comfort with immediacy, honoring the uniqueness of the individual, trust, spending time and attentiveness help establish this level of intimacy. When interacting with patients, the way in which the hospice nurses conducted themselves influenced the patient's perception of caring, deep respect for the patient combined with allowing whatever level of dependence or independence the patient may need in the moment.

The hospice nurses twenty-four availability seemed of utmost importance to patients and caregivers. The fact that these hospice patients felt invited by their nurses to "call anytime" decreased anxieties felt by caregivers and patients alike. This finding was discovered in other studies on caring, particularly Hull (1991) and Larson (1984). Would patients in these studies have perceived twenty-four hour availability with a tired, grouchy nurse as caring behavior? The fact that the participants in this study were invited to use the on-call system, and were welcomed when they used it. "No hour is a bad hour. No question is a silly question." This may be what caring meant to them.

Many patients in this study expressed that human touch was important to them. Human touch was identified as a specific action in Larson's Care-Q sort but was not identified as an overall theme in any previous study. However, conclusions in Atkins & DeWitt (1997) study on communication emphasized touch as the most frequently observed non-verbal immediacy behavior. They postulated that touch demonstrated "respect and caring," a hypothesis affirmed in this study. Atkins and DeWitt discussed immediacy behaviors, both verbal and nonverbal. Immediacy behaviors are ones that communicate availability and interest, involve most of the senses, and encourages closeness between individuals (p. 3).

Responding to the patient's discomfort with immediacy was another behavior perceived as caring. Providing comfort was mentioned in all the studies on caring this researcher reviewed (Degner, Gow, & Thompson, 1991; Fenton, 1986; Dobratz, 1990; Hull, 1991; Larson, 1984, 1986; and Lewandowski & Jones, 1988). Is it caring behavior when a hospice nurse takes two or three hours to respond or tells the patient over the phone to take another pill? In both instances they may be providing comfort, at least eventually.

Responding with immediacy and compassion may be how these behaviors are perceived as caring. The hospice nurses moved closer to these participants while they were in pain with touch, gentle reassurance, and a calm voice. The participants' gave recognition to the nurses for **being there** for them in time of need.

This study and Lewandowski & Jones (1988) emphasized the need for honest communication regarding patient's disease, its course, and their options for treatment as highly important. Patients clearly saw honest communication as caring behavior. In the face of death, patients and their caregivers wanted to be prepared for what is to come. Honest education with *sensitivity* for what the patient is going through was essential to the caring relationship between nurse and patient.

Other themes identified could be classified as aspects of good communication. These were empathetic listening, spending time and attentiveness. Also, findings in studies by Hull (1991), Raudonis (1993), and Atkins & Dewitt (1997). Again, the nature of listening and attentiveness was in the patient's descriptions. Atkins & DeWitt discuss both listening and attentiveness as immediacy behaviors. Spending time attending to patient's needs was another overarching theme of caring.

Trust was identified as an integral part of a caring relationship. In this study patients felt cared for if they could trust their caregivers. Trust was established by the competent performance of duties. Trust was also established by consistently being there for the patient with actions based on compassion and caring. Patients who see nurses "going out of their way to provide comfort" or "doing their best for everyone they can" may have an easier time establishing trust.

The themes in this study are congruent with Watson's theory of an "actual caring occasion" (Watson 1989, p. 277). The descriptions of the hospice patients leads one to believe this process was present in their interactions with their nurses. The hospice nurses became aware of a need for care, the hospice patients were open to interventions, the hospice nurse intervened based on their knowledge of the patient, and there appeared to be a positive change as a result of caring.

However, missing from the description of this process was a differentiation of how these actions were carried out and in what manner, with compassion and concern? These study results suggested to the researcher that the manner in which interventions are performed would be a better indicator of caring. That is, the 'what' of care is insufficient it must be combined with a particular 'how'. Nurses need to examine their motivations for performing duties and responsibilities. Other motivators, other than caring, (such as earning a paycheck or getting a good evaluation) may not necessarily be 'bad' but they are not ideal for hospice patients.

Limitations of study

Limitations to this study exist. Patients have differing perceptions of reality and differing abilities to communicate that reality. These findings may not be

generalizable. However, other hospice patients may recognize the caring descriptions.

Implications for Practice

The findings in this study suggests that caring is an integral part of a helping relationship, if not the base on which a helping relationship is built. These caring behaviors, identified by patients, give hospice nurses a map or guide to establish a therapeutic, helping relationship with their patients and families. Knowing behaviors considered valuable to dying patients increases the hospice nurse's effectiveness in establishing a caring relationship.

The information in this study may cause nurses to ask some hard questions. What is the motivation of a specific nursing action? How might we increase the effectiveness of our interventions? In the present day health care system, how might we preserve a humanitarian approach to illness and death? These are a few questions that could be contemplated when reading these findings.

Implications for Research

It appears the only uniqueness of 'caring' within nursing are the unique opportunities that exist. Opportunities to care and be cared for exist in all areas

