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Shared Presence: Caring for a Dying Spouse

by

Lana Sue McLouth Kanacki, M.S., R.N.

A dissertation presented to the

FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE

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Dissertation Committee

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ABSTRACT

Shared Presence: Caring for a Dying Spouse

There is limited research on female spouses and their end-of-life experience with their dying husbands. The purpose of this study was to explore wives' perceptions of hospital and hospice care at their husbands' end-of-life. The grounded theory method was used for this study. Data were collected over thirteen months and then transcribed and coded for meaning.

Participants were 25 elderly widows (62-103 years of age) with 19 husbands' deaths in a hospice setting and 6 in the hospital. They were widowed from 6 months to 10 years after the death of their spouses. They were good informants with excellent recollections about their husbands' death.

Going through this journey with their husbands, widows experienced awareness of impending death, forming connections, and realizing sense of self. Although present in distinct categories, these three categories also overlap with each other and the relationship between them forms the emerging theory. These categories point to the more abstract core phenomenon of being there. All these pieces emerge into a theory of Shared Presence: Caring for a Dying Spouse at the end-of-life. It was in this time and in this place for this, to occur, the transition to the end-of-life for the wife and husband.

One implication for further research is to explore the value of the wife's human touch for her husband at the end-of-life. Also there is some indication that laughter and humor could be of benefit for widows during the bereavement process and this could be further explored. Cultural and religious differences could be of significance as well so

that will be another direction in forthcoming studies. Finally, it would be of interest to study if timing of death had any impact on the grief process.

DEDICATION

To the widows who gave of themselves

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Chapter I: FOCUS OF THE INQUIRY

Wives' thoughts about the care of their husbands at the end-of-life would be valuable to know. The literature is not forthcoming in studies exclusively about wives' perceptions of this challenging time. In this study, their husbands died in hospice, hospice type settings and the hospital.

The reality is most people still die in hospitals (Hoffmann, 2005) and "one in five Americans die using ICU (intensive care unit) services" (Angus et al., 2004, p. 638). In America prior to World War II, a person died at home with family nearby (Krisman-Scott, 2003). But hospitalization changed this location and terminal care was then administered by strangers (Krisman-Scott, 2003). Care then came back to the family in the form of hospice. As we have known it, the modern American hospice has been around since 1974 (Nicoll, 2002).

With the focus on technology and critical care in the 1950s, 1960s, and 1970s in the hospitals (Fairman, 1992; Kalisch & Kalisch, 2004), there had to be a place for the dying person and their families to go. Families needed a place for their loved ones to die. To meet this need the modern hospice was conceived. With all the technology in the hospital, the hospice was one answer for the dying person. Hospice truly

changed the dying experience because instead of focusing on “cure,” it focuses on “comfort” (Stoddard, 1978, p. 28 as cited in Hoffmann, 2005).

Recent investigations have focused on end-of-life care in acute care, home care, and hospices, and these studies have provided mixed findings. In a phenomenological study on the experiences of families (including spouses) with loved ones receiving palliative care in an acute care hospital, family members revealed or reported it was not a place to die (Dunne & Sullivan, 2000).

In contrast, Keegan, McGee, Hogan, Kunin, O’Brien, and O’Sioran (2001) viewed relatives’ (including spouses) responses to health care in the last year lived. Care was given at hospital, home care, and hospice in this study. Through semi-structured interviews with 155 relatives, it was found, overall, relatives were very happy with the care given to their loved ones. Finally, Kirchhoff and associates (2002) conducted focus groups with family members as well as widows to elicit information on family experiences in the critical care unit. Their study revealed how difficult decisions were for the family members with the prognoses and with so many sad events in succession.

We know some of what families desire at end-of-life, but we do not know what the experience is of the surviving wife in caring for her husband at the end of his life. There is research in this area of end-of-life but not many studies about spouses’ perception, in this case female spouses.

Lines of Inquiry

The purpose of this study was to explore widows’ perceptions of care at the end of their spouses’ lives. To better understand this phenomenon, the following lines

of inquiry were developed: 1) What is the experience of soon-to-be widows during the time of spousal death? 2) What are the perceptions of widows of end-of-life care in the hospital and hospice/home care? 3) How does this experience affect their own lives? This study will explore widows' perceptions of both hospital and hospice/home care using a grounded theory approach.

Method

Grounded theory is useful for this study on spouse's transitional experience at the end-of-life as there is limited research in this area. In the "practice-theory strategy" presented by Meleis (1997, p. 230), the phenomenon deserves attention due to its importance to practice and the need for a theory to further understand this phenomenon.

As a qualitative research method, grounded theory studies social phenomenon and is "data in the form of words" (Schwandt, 2001, p. 213). Creswell (1998) builds on that view by conveying the importance of the naturalistic setting and finding meanings from people in the social phenomenon. Because of the focus on social phenomenon, social interactionism is the philosophical base (Charon, 2004).

The data analysis of constant comparison has a focused approach including open coding, axial coding, selective coding, and finally the conditional matrix (Creswell, 1998). Constant comparison (Morse & Richards, 2002) looks at a concept and how it relates to another concept. Designs become apparent and categories are developed (Morse & Richards, 2002) at every stage of theory development (Charmaz, 2006). In constant comparison, data are looked at for "relevance" and how they are "similarly categorized" (Schwandt, 2001, p. 30).

In open coding the whole of the phenomenon is broken into parts. In axial coding these parts are put together in a novel way to view the “central phenomenon” (Creswell, 1998, p. 57). This central phenomenon is also referred to as a core phenomenon (Strauss, 1987). Each piece of coding leads back to this core phenomenon. Codes then go to the next step conceptually, relationships among concepts are made, and theory develops (Strauss, 1987, p. 242).

The researcher uses logical reasoning (induction) and explanation (deduction) and links smaller sections together for relevant theory. Researchers make particular note of how “the pattern varies dimensionally” (Strauss & Corbin, 1998, p. 67), and when no additional new data are seen, saturation is reached (Creswell, 1998; Strauss & Corbin, 1998).

Then, very carefully, the “story line” (Creswell, 1998, p. 57) is presented in “selective coding” (Creswell, 1998, p. 57). The “story line” is pulled from the axial coding and the theory is connected. Heretofore undiscovered ideas become the theory. As it develops, “the data talks” (Strauss & Corbin, 1998, p. 68). Theory is derived from the data and provides insight about a chosen topic. As the researcher looks at his/her data, a conditional matrix is visualized and diagrammed (Creswell, 1998).

In this study a commonality of experience or thought could arise from the data and contribute to a new understanding of the dying. As the theory evolves from the ground up, it may shift one way or another with each interview. This shifting will occur until there is some consensus and balance is reached. This emerging theory becomes more apparent.

Philosophical Underpinnings

Interestingly, pragmatism is seen as an American philosophy, and although different in its presentation, it is acutely concerned with “the union of theory and practice” (Schwandt, 2001, p. 204). The basis for this social/psychological theory is that “people create shared meanings through their interactions, and those meanings become their reality” (Patton, 2002, p. 112). Symbolic interactionism is seen as the foundation of grounded theory (Beck, 1999). First was Mead (1934; Schwandt, 2001) a pragmatist and a psychologist of social phenomenon in his work as a philosopher. He is considered an originator of symbolic interactionism (Reynolds, 1993).

Symbolic interactionism is a theory influenced by Blumer (1969) and named by Blumer (Stryker, 1980). Blumer (1969) put forth three thoughts that shaped symbolic interactionism. First, things have significance and people relate to that significance. Second, the relationship people have with other people will influence the value of things. And last, the “meanings of things” are influenced by an “interpretative process” (Patton, 2002, p. 112). Because of these thoughts, Blumer realized the importance of qualitative research (Patton, 2002) and its importance to inquiry into the “meaning of human action” (Schwandt, 2001, p. 213).

Charon, professor emeritus from Minnesota, presents five central ideas of symbolic interactionism. These five ideas are the “role of social interaction,” “role of thinking,” (2004, p. 28) “role of definition,” “role of the present,” and “role of the active human being” (p. 29). The “role of social interaction” is seeing the person in engaged interaction with others and with society. With this engagement comes change, constant living change, as the human is ever-changing.

“Role of thinking” (Charon, 2004, p. 28) is the individual’s interaction within one’s self. The thinking process is reflected in what he/she does. The “role of definition” is how the individual makes meaning of a situation. He/she makes the definition based on “interaction and thinking” (Charon, 2004, p. 29). The individual will respond depending on how that person defines a situation.

In the “role of the present”, the individual acts to current situation not to past situations. So, “interaction, thinking, and definition” impact what is happening right now. Finally, the “role of the active human being” is at the core of symbolic interactionism (Charon, 2004, p. 29). Active changes are made because of interaction, thinking, and defining as the individual is energetic and effective.

Symbolic interactionism is a part of the social sciences, sociology and social psychology with human beings the focus whether in small or large units. Humans are social beings and they respond to different situations in different ways (Charon, 2004). It is the understanding of the individuals’ interaction and human behavior in an evolving state such as the end-of-life. Symbolic interactionism is a philosophy and grounded theory is a method.

Like symbolic interactionism, grounded theory focuses on the essence of an experience (Morse & Richards, 2002). Within the social environment of this study are the woman and her dying spouse. Grounded theory provides the opportunity to conceptualize the wife’s perceptions of end-of-life care of her spouse in a social setting. Grounded theory is an avenue for theory development in this needed area of research with symbolic interactionism as the undergirding of the grounded theory (Morse & Richards, 2002). This study may provide new insights and new direction for end-of-life care.

Significance of the Study

The need to know more about the experience of the wife in caring for a dying spouse is the focus of this study. There is a significant gap in the literature when it comes to developing theory and linking research topics to theory. Widows' perceptions of end-of-life care of their spouses is an area that has received little attention in the literature. When studies have been done in this area, they have not been linked to a theory. For example, Redinbaugh, Baum, Tarbell & Arnold's (2003) study on family caregiver coping and Tolle, Tilden, Rosenfeld, & Hickman's (2000) study on obstacles for caregiving to the dying, do not link their research to theory. Thus, it may be helpful to establish a theoretical link to inform further research and possible intervention.

Qualitative methods uniquely look at data in a fresh way from the participants' view and are theory building. For this study, a qualitative method has been selected because there is a paucity of research in this area of end-of-life.

Research on female spouses experiencing the death of their husbands is limited. Other studies have focused on other family members and spouses together. Although not unrecognized, wives are not well researched, yet they have significant and insightful ideas to express as they hold one of the more important social ties, the one of being a wife.

End-of-life management is a health priority for nurses. Nurse leaders have pinpointed five areas to be of great importance for nursing research. Among them is the end-of-life and its impact on the client and the client's loved ones (NINR FOCUS, 2006; National Institute of Nursing Research, 2006).

Nursing is well positioned to assist the dying and their families, with compassion, empathy, and support. Being knowledgeable about the events leading up to the death may improve nurses' ability to intervene positively during this time of transition. From this study's focus on end-of-life this qualitative research study may indirectly inform nursing interventions that widows deem valuable. A greater understanding of wives engaged in the end-of-life transition in hospital and hospice needed to be more fully examined.

Chapter II: CONTEXT FOR THIS INQUIRY

This chapter provides an overview of the extant literature on end-of-life and spouses' experiences with hospice and hospital. The chapter will also have studies further from the central idea of this proposed study, studies which have received the most research support, and particularly ones more similar to the proposed study in concept and methodology. Topical areas in this literature review include family caregiving, experiencing the care of a family member, experiencing the death of a family member, and family adjustment after the death of a family member.

Although it is beyond the scope of this chapter to review all articles, selected articles related to family experiences with hospice and hospital are discussed. Readers are especially referred to the seminal works by Hanson, Danis, and Garrett (1997), Seale and Kelly (1997), and Tolle, Tilden, Rosenfeld, and Hickman (2000). These same works are reviewed in this paper.

Family Caregivers

At the end-of-life, family caregivers have expectations and dreams. In this qualitative work, a prospective exploratory study by Wennman-Larsen and Tishelman (2002), themes were discovered and confirmed in a study of caregivers. Eight

caregivers were spouses; one was in a partnership and the other two were parents. Data were collected over a one-year period in Stockholm, Sweden. Ten interviews were taken from 3 hospices. Most interviews were at the caregiver's home. No questions were developed prior to meeting with caregivers. Direction was given to the caregiver to talk of the patient's illness. After transcribing some initial audiotapes, ideas for further discussion were apparent for the next caregiver's interview.

The themes developed by constant comparison are "role transition in becoming a family caregiver" and "transition to a new life situation of the caregiver" (Wennman-Larsen & Tishelman, 2002, p. 242). For "role transition in becoming a family caregiver" (p. 242), family members saw themselves as the ones responsible for care and didn't see professionals as giving primary care or assistance. For "transition to a new life situation of the caregiver" (p. 242), the caregivers looked ahead to when the sick member was no longer with him/her, and they were afraid. The sick member was often the one the caregiver talked to, but with illness, there was no longer someone to talk with (Wennman-Larsen & Tishelman, 2002).

In one descriptive study, nurse researchers looked at caregivers of hospice home patients and the worries they had (Newton, Bell, Lambert, & Fearing, 2002). The instrument was a questionnaire which included semi-structured questions drafted by the researchers. The instrument was not named and no reliability and validity data were reported. There was also an opportunity for caregivers to write about their care for troubling symptoms of their loved ones or how they did without the immediate availability of hospice personnel. Data analysis included frequency distributions and non-parametric tests. Thirty-three participants/caregivers were recruited from

Midwest hospices. Most caregivers were 70-79 years of age, and all were related to the patient with 52% being spouses. Seventy-three per cent of caregivers were female.

Unable to move freely and control of bladder were major concerns of caregivers (Newton et al., 2002). The majority gave care from 12-24 hours a day even with the aid of members of the family and hospice. What caregivers liked best was the whole care from hospice. Nurses' advice followed in importance, as nursing personnel was highly esteemed. They looked to the nurse for emotional care giving, and researchers recommended more relief time for these caregivers.

Redinbaugh et al. (2003) examined how families, who gave care, cope. In this quantitative study to ascertain coping, researchers used an instrument, the Family Crisis Oriented Personal Scales. In addition, researchers utilized the McGill Quality of Life Scale, Patient ADL Needs, Brief Symptom Inventory, and Caregiver Burden Screen.

Family Crisis Oriented Personal Scales ascertained coping with 29 "items" within subscales. These subscales had the following internal consistencies: "acquiring social support $\alpha = 0.75$, seeking spiritual support $\alpha = 0.83$, mobilizing family to acquire and accept help $\alpha = 0.50$, reframing $\alpha = 0.78$, and passive appraisal $\alpha = 0.38$ " (p. 904).

Within the McGill Quality of Life, the internal consistencies were "psychological symptoms $\alpha = 0.94$, physical symptom distress $\alpha = 0.77$, existential well-being $\alpha = 0.77$, and social support $\alpha = 0.02$ " (p. 903). For the Brief Symptom Inventory, internal consistency was .93. Caregiver Burden Screen had reliability at .78.

Participants were 31 caregivers and their dying family members in home hospice. Seventy-one percent were spouses and 77% were married. If the patient had more day-to-day demands and was psychologically needy, these factors contributed to less coping by

the caregiver. But, as shown in a regression equation, if the caregiver could reconcile to himself/herself the family member's disease course, less stress was evident.

Stress of caregiving correlated with ADL at ($r = 0.51$), with psychological disharmony ($r = 0.42$), and quality of life at ($r = -0.65$). The greater the demand for aid with activities of daily living (ADL) the greater the score. "Internal consistency for the ADL score was 0.75" (Redinbaugh et al., 2003, p. 903).

Experiencing the Care of a Family Member

Family Satisfaction with Care

What constitutes positive care in the last 24 hours of life from the caregivers' perspective? What are characteristics of the family and client that show contentment for care given at the end-of-life? To answer these questions, Casarett et al. (2003) utilized a survey instrument for their study. Caregivers responded and completed a survey between "two to six weeks after death" (p. 206) regarding their loved ones' care. For data analysis, nonparametric tests were done as well as qualitative analysis for the open portion of the study.

There were 112 participants with caregivers' spouses numbering 39% and caregivers' children at 36%. These participants were selected as their family members were receiving hospice care and were identified as caregivers. Ninety percent were very pleased with hospice services. The better the symptom management, the more satisfied the caregivers were. Place of death did not affect satisfaction, but communication was more likely for caregiver and patient in the home setting.

The same hospice personnel were desired at death as were available during hospice experience. It was uncomfortable to get someone unfamiliar close to the time of

death, in these instances in the last 24 hours. Caregivers wanted pain and agitation to be managed well. All caregivers were able to reach hospice when the patient died, and almost all were able to reach hospice in the remaining 24 hours of the family member's life.

Families' positive perspectives of end-of-life care their family members received were identified in a study by Miceli and Mylod (2003). The instrument these researchers used was the Press Ganey Hospice Care Family Survey. Of the 43 questions, 38 questions zeroed in on "arranging hospice care," "dealing with the hospice office," "hospice team," and "personal issues" (p. 363). The last 5 questions gave a chance to give broader impressions. Cronbach's alpha for "arranging hospice care was (.90), dealing with the hospice office (.92), hospice team (.96), personal issues (.97), and overall assessment (.93)" (p. 363).

In this national study, participants numbered 1839 from 17 affiliations in the United States. Forty-six percent were spouses, adult children 32%, and other relationships 19%. A vast majority – 89% – was having his/her first experience with hospice. If hospice referral was not timely, satisfaction was lessened with all hospice care. However, it was reported that families were pleased with hospice care. They gave it a score of 92.82 out of 100. Top areas that were appreciated by families were "availability of the entire hospice," the "degree to which staff addressed emotional needs of patient and family," "availability of hospice staff when needed," and "staff's concern to keep you informed about the patient's condition" (p. 366).

Family Satisfaction with Hospital Care

Receiving ideas from families who had lost a member on how to make tertiary centers more therapeutic places to die was the focus for Pierce (1999), a nurse researcher. Pierce conducted a qualitative study by way of questionnaires of 8 key questions with probes. For example, Pierce asked what aid healthcare workers provided that was beneficial for the family member. In addition, the researcher inquired about what family members would wish for themselves if they were dying. These interviews were analyzed for 15 themes with a constant comparative method.

Participants were obtained from 4 Southern counties and then further selected randomly by coin-toss. There were 29 family members from a possible of 75 family members, total. Families wished to see three major areas improved. The dying family member and family must have time and space together and they must be physically near. It was deemed important to have quality relationships between the health provider and the dying member/family, and it is essential for the dying person and his/her family to be in a therapeutic environment.

Family Satisfaction with Hospice Care

Another study, Nolen-Hoeksema, Larson, and Bishop (2000), examined family satisfaction as related to the hospice experience. This quantitative study had participants completing 5 measures including the Inventory to Diagnose Depression with test-retest reliabilities from .64 to .71, and the Spielberger State Anxiety Scale with test-retest .54 to .67. Also assessed was the dimension of post-traumatic stress symptoms with test-retest of .57 to .68. Of further interest was the Hamilton Rating Scale for Depression with

intraclass correlation coefficient at .74. The final measure for this group of people was the structured Clinical Interview for DSM-III-R.

There were 287 subjects who were interviewed before the patients' deaths and four times after, coinciding with 5 measures. Subjects were obtained from 11 hospices from the San Francisco Bay vicinity.

In this study of family satisfaction and the hospice experience, ninety-five percent found hospice beneficial. The physical aid was important, but families appreciated the emotional support even more. Since hospice personnel have seen people die previously, they are able to aid families in knowing what to expect as their loved ones expire. Interestingly, "people who said hospice should have done something differently reported less satisfaction with the support they were receiving from their families" (Nolen-Hoeksema et al., 2000, p. 38). Also, these people had a tendency to be more depressed overall, even before this death.

Families believed hospice could be improved by preparing them more for the physical alterations in their dying family member. Other family members felt like they were getting too much support when the hospice was supposed to be more for the patient. Conversely, families wished to see more active involvement from hospice with baths every day for the patient instead of two times a week. As far as gender, men were more appreciative of hospice than women.

Researchers in another study asked whether sooner referrals to hospice were better (Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005). Interviews were with family members with patients' input at admission and then with family members after the patients' deaths. A descriptive study was done with two semi-structured interviews as

well as examination of medical records. These 275 subjects were also first time users of hospice.

With longer hospice stay, families felt like they received more from the service than from a shorter one. This support could be pain control and telephone service availability. Based on both of these findings, an earlier recommendation to enter hospice would be important.

If patients and caregivers are very pleased with end-of-life care, does that mean it is of high quality? That area was the question of a study by Steele, Mills, Long, and Hagopian (2002). This retrospective work was conducted with patients and caregivers. Two instruments were utilized: a patient survey and a caregiver survey. For the patient survey, the "alpha reliability co-efficient was .84" (p. 22) and for the caregiver survey .77. In addition, some remarks were solicited for qualitative analysis.

This retrospective work was conducted with 321 patients and 444 caregivers. Both patients and caregivers have high opinions of hospice care which includes how care was given, control of symptoms, and communication with hospice personnel. Caregivers would talk positively of hospice to others, and they knew what hospice provided. Particularly, caregivers were pleased with pain management and least pleased with the aid hospice gave if the family member needed hospitalization. Generally, caregivers were pleased with hospice services. The qualitative data revealed nurses as being "nice" and "knowledgeable" (p. 23).

Family Satisfaction with Hospital and Hospice Care

Spouses describe the hospice and hospital care their dying spouse received in a study by Seale and Kelly (1997). Data were gathered with both quantitative and

qualitative methods. Interviews were conducted 8-9 months after death. Open-ended questions as well as structured questions were used.

These British researchers interviewed 66 living spouses with 33 spouses describing hospice care while 33 spouses described hospital care. All the dying spouses had cancer and the majority was male (61%). To obtain the hospice sample, death certificates were chosen randomly. For the hospital sample, 3 health authorities were utilized.

Compared to the hospital group, more hospice individuals had knowledge of their impending death. Relaying information to patients were hospital doctors at 89%, general practitioners at 38%, hospital nurses at 12%, hospice doctors at 12%, hospice nurses at 5%, and a district nurse at 2%. Both hospital and hospice individuals were treated well for pain, nausea, and shortness-of-breath. Hospice personnel were able to communicate more effectively than hospital physicians, however hospice had a family environment while hospitals were seen as hectic. Over the years, hospice has retained its edge with its superior psychosocial atmosphere (Seale & Kelly, 1997).

Experiencing the Death of a Family Member

Pain Management

Did the clinician hear where the dying wish to die and what treatments were acceptable to them? Was the dying pleased with the assistance of clinicians? Lastly, how was pain managed in the last week? These questions were of interest to researchers Tolle et al. (2000).

By telephone survey, family informants completed a researcher-generated questionnaire of 58 questions. The study included 475 family members who were

instrumental in the care of deceased family members. This sample was obtained by death certificates' information leading to these family members.

Treatments acceptable to them such as deciding about care were an alpha .72. With assistance of clinicians, there was an alpha .85. Finally, with pain management there was an alpha of .62. Although families were generally pleased with care from clinicians, pain was a concern for one third of the dying. It was noted nurses are considered more accessible than physicians.

Family Presence

Differences in the received end-of-life hospital care for a dying family member if a family member was present or not present at death was the question Tschann, Kaufman, and Micco (2003) asked. A retrospective cohort analysis design was utilized. Medical documentations were reviewed retrospectively from a community hospital in an urban setting. The 370 patients had all died within one year.

When a family member was with the patient at death, it showed involvement during the course of hospitalization. Family being present at death lessened technological intervention such as ventilators and antibiotics and promoted measures of comfort. If the family was there at death, DNR (do not resuscitate) orders were transcribed and the patient would die sooner. Family presence at death also meant narcotics were given and treatments were withheld from the dying.

Communication with Family

What are families' impressions of a loved one's care in his/her last month of life? Families were queried about such matters as "treatment intensity, decision-making, and symptom relief" by Hanson et al. (1997, p. 1339) in a qualitative and quantitative study.

Families' responses were gathered and coded. Interviews involved children, spouses, siblings, and other connections to the dying family member. Four hundred sixty-one informants participated. Most of the clients died in hospitals, many died in nursing homes, and some died at home.

Furthermore, families gave ideas for better care for the terminal time of life. Family members felt they were not involved enough in the discussion with decision making about course of treatment. Treatment is an individualized matter of whether the family wants more or less treatment, so communication is vital to know what to do for each family.

Unfortunately, pain remains a constant problem with 78% of dying family members encountering it (Hanson et al., 1997). Pain was a grave concern for them, and comment was made that hospital nurses did not manage pain sufficiently.

In addition, the findings revealed hospitals were less favorably because of delayed admissions for the dying family member. Hospice, however, was praised as were the nurses. Nurses were seen as strong with "attentiveness and assessment skills and the emotional support they offered after death" (p. 1341). Ideas for better care included "improved communication by physicians" (p. 1342), better access to physicians, better pain management, and better health delivery in the areas of finance and insurance.

Curtis et al. (2005) uncovered occasions when the family was not fully assisted with end-of-life management of their family member in the critical care setting. This qualitative study was done at 4 Washington hospitals by having conferences with family members, patients, and health care workers. These conferences were led by physicians;

however, nurses, social workers, and clergy were in attendance as well. Conferences were audiotaped and then themed using the grounded theory method.

One hundred sixty-nine family members and fifty-one patients were represented in 51 conferences. Fifteen conferences (29%) had occasions when the family expressed they were not fully assisted by the physicians. Missed opportunities were not hearing the family, not responding to emotions, and not responding related to education of medical ethics and palliative care.

Family Expectations/Experiences with Nurses

One study looked at end-of-life events from a very specific perspective. Carey and Forbes (2003), two British researchers, looked at the experience of family members who donated corneas from their deceased family members. These researchers utilized semi-structured interviews, and the study was themed in a qualitative manner.

Ten bereaved families were the sample coming from 2 palliative wards in Southern England. Most families thought patients with cancer could not donate their corneas. Families believed nurses approached them with care in asking for this donation, and they were pleased with their decision to donate.

The documented caring behavior of nurses dates back to the late 1800s and early 1900s. A historical study was conducted by Wolf (1991) using content analysis to examine periodicals from the last century. Findings indicated relatives had a need to be near the dying person (Montagu as cited in Wolf, 1991), and families wanted nurses to give special aid to their loved ones (Hospital Nurse as cited in Wolf, 1991). A nurse needed to be prepared to administer spiritually if a family requested this service.

Expectations were to have prayers memorized or to have ready a book of prayers if needed (Wolf, 1991).

Some nursing cares are considered more beneficial than others by caregivers and nurses of hospice patients (Ryan, 1992). For the purpose of this current study, caregivers are of interest. "A Q-sort of 60 nursing behaviors ranked from most to least helpful was completed by 20 caregivers" (p. 22).

Each participant was given cards describing needs, or "nursing behaviors" (p. 24) that they divided into different significance, whether it represented himself/herself, whether it was true or not, and what its importance was. Seventy-five percent of the subjects were female spouses who came from an urban area and were at their homes.

Three large categories were "patient's physical needs" with "reliability coefficients of .97," "patient's psychosocial needs" with reliability coefficients of .92 and "psychosocial needs of the caregiver" with reliability coefficient of .95 (p. 25). The caregivers listed top nursing behaviors as listening to the sick and responding to emergency situations. Providing information on constant availability of care to patient and caregivers was also deemed important. This related to being available every day around the clock.

Other top nursing behaviors were being honest with patients and caregivers' inquiries and alleviating fears. Family members wished to know what to do if the patient dies. Other nursing behaviors were being present with the patient and educating on how to keep the patient comfortable in a physical manner.

The highest ranked nursing behavior by the caregiver was the psychosocial needs of the patients. The lowest ranked nursing behavior was the psychosocial dimensions of the caregiver.

At the bottom of the list for the caregiver was talking to the patient about his/her guilt, crying with a patient, and making funeral plans. Visiting the patient at the funeral home was not considered very helpful. Developing a plan for organizing medications, teaching how to reposition a patient, and changing linens were not all that helpful. Talking about things other than death, letting the patient come to terms with dying, and education about possible hospital admittance were also not seen as helpful.

Family Reaction to Dying

In a qualitative interpretive study Yates and Stetz (1999) examined families' reaction and acknowledgement of the dying of their loved ones. For about one hour and a half, participants had semi-structured interviews. The sample was randomized from 105 family members. Of the represented sample of 20 (9 males and 11 females), 16 were spouses, 2 were daughters, and 2 were mothers.

Two overarching spheres were "being uncertain" (p. 115) which was not knowing what to expect and "agonizing" (p. 116) which represented overwhelming feelings. To cope with these uncertainties and overwhelming feelings, family members hoped, pretended, and prepared. "Hoping" (p. 117) was demonstrated when the family wanted their loved one to become well. "Pretending" (p. 118) was not acknowledging death would happen. "Preparing" (p. 118) was getting ready for the inevitable death and making plans.

Family Adjustment after Death of Family Member

Looking at the personal adjustment of relatives after the death of a family member to cancer was the focus of a descriptive, non-experimental study by Eriksson, Somer, and Lauri (2001). These Finnish nurse researchers gave a questionnaire developed from an existing instrument of one of the researchers to 258 relatives, and instrument reliability was measured.

Nearly fifty percent of relatives were spouses. Relatives were upheld with emotional caring prior to and after the death of their loved ones. "Relatives were most content with how they were accepted (93%), listened to (89%), and given time by staff when they needed it (84%)" (pp. 441- 442). Seventy-seven percent stated they were informed about their loved ones' sickness.

Initial bereavement insights were the focus of a descriptive correlational study from St. Mary's Hospice in Tucson, Arizona. Longman, Lindstrom, and Clark (1989) had participants all complete the Bereavement Survey Questionnaire. These 97 participants had lost a spouse or significant other with most having lost spouses and then parents.

For these respondents, their health was stable at 13 months. Thirty-two percent received help from counselors. A majority were lonely. Ninety-one percent were religious. Particularly troublesome times for these family members were "time of diagnosis" and "time of active dying" (Longman et al., 1989, p. 33).

"Concern, consideration, and support were common themes" (Longman et al., 1989, p. 34) of how hospice aided them. Ninety-six percent felt hospice was beneficial with 21% thinking initiation of hospice could have been sooner.

In another study, “investigation was made of the relationship between hope, concurrent losses, coping style, setting (hospital, hospice, nursing home), and grief resolution” (Herth, 1990, p. 109). A general information form was utilized as well as the Herth Hope Scale, the Jalowiec Coping Scale, and the Grief Resolution Index. Seventy-five spouse participants in this descriptive study were obtained from hospices, hospitals, and nursing homes.

Herth Hope Scale had a reliability of .78 to .94 (Herth, 1990). Also, utilized was the Jalowiec Coping Scale with the reliability .88 to .94. The Grief Resolution Index had an alpha .87 in a previous study and .89 in the current work.

Hope aided in grief recovery. Some of the factors that aided hope were good income, health, and visits each week by family/friends. Spousal participants had superior grief recovery and hope if their spouses died in hospice instead of the hospital or the nursing home.

Synthesis of Literature

Family members, nearly 50%, who were spouses, were upheld emotionally prior to and after death of their loved ones by health professionals (Eriksson et al., 2001). They valued the nurses’ presence (Ryan, 1992). In the studies of families and their experiences with hospice, hospice nurses were found to aid families favorably with emotional care (Newton et al., 2002; Nolen-Hoeksema et al., 2000) and letting families know how their loved ones would die (Nolen-Hoeksema et al., 2000). In addition, Seale and Kelly (1997) did a study on both hospice and hospital care, and hospice patients were more likely to know of their pending deaths than hospital patients. Communication was more likely for caregiver and patient in the home setting (Casarett, Hirschman, et al., 2003).

In another study, health professionals did not respond to emotions. Although the study focused on physicians, it would be critical to know in what way and how nurses would perform in a similar context (Curtis et al., 2005). Caregivers saw the psychosocial needs of the patient as the most important and their own psychosocial dimensions as the lowest (Ryan, 1992).

Emotional support is important because caregiving is stressful to the family (Redinbaugh et al., 2003). Again, hospice received high marks with nurses strong in “attentiveness and assessment skills and the emotional support they offered after death” (Hanson et al., 1997, p. 1341). Hospitals and nursing homes were received less favorably. Nurses’ sensitivities and emotional caregiving were influential in corneal donations after the death of loved ones in the study done by Carey and Forbes (2003).

Children and spouses whose loved ones died primarily in hospitals desired more decision making (Hanson et al., 1997) and more communication (Hanson et al., 1997; Curtis et al., 2005). Over the years hospice as compared to the hospital has retained its edge with its superior psychosocial atmosphere (Seale & Kelly, 1997).

Relatives wanted special involvement from the nurse with their dying family members with frequent baths (Nolen-Hoeksema et al., 2000) and being allowed to be near the dying individual (Montagu as cited in Wolf, 1991; Pierce, 1999).

Troublesome times were “time of diagnosis” and “time of active dying” (Longman et al., 1989, p. 33) for this sample group of mostly spouses and then parents. Family members (mostly spouses) were looking ahead when their loved ones were no longer there, and they were afraid (Wennman-Larsen & Tishelman, 2002). Nurses were seen as alleviating fears (Ryan, 1992), but, in one troubling international study, Swedish

health care professionals were not seen as giving primary care or assistance in hospice with loved ones (Wennman-Larsen & Tishelman, 2002).

In yet another study (Yates & Stetz, 1999) of mostly spouses, caregivers were getting ready for the death of their loved one, after hoping for wellness and even denying death for this loved one. Making funeral plans with them by hospice personnel was not considered helpful; however, spouses and caregivers did wish to know what to do when their loved one died (Ryan, 1992).

According to several studies, hospice could be started sooner (Longman et al., 1989; Miceli & Mylod, 2003; Rickerson et al., 2005) as it was felt more benefits were forthcoming such as pain control and telephone availability (Rickerson et al., 2005). If hospice referral was not timely, satisfaction was lessened with all hospice care (Miceli & Mylod, 2003).

Pain management did receive lower marks and was a concern for one third of the dying (Tolle et al., 2000). Family viewed pain management as a grave concern and commented that hospital nurses did not manage pain sufficiently (Hanson et al., 1997). But in another study in a hospice setting, the caregivers were pleased with pain management (Steele et al., 2002) although patients did not rate it as high.

When family was present, more comfort measures were employed (Tschann et al., 2003). The better the symptom management, the more satisfied the caregivers, as they wanted dyspnea and pain to be managed well (Casarett, Hirschman, et al., 2003). Families desired education on how to keep patient comfortable (Ryan, 1992).

It is deemed important to have quality relationships between the health provider and the dying member/family (Pierce, 1999). Nurses were seen as “nice” and

“knowledgeable” (Steele et al., 2002, p. 23). Top nursing behaviors from the caregivers’ view were listening to the sick and responding to emergency situations (Ryan, 1992). Further, support for responding to emergency situations was not forthcoming at this time in other studies.

Critique of Literature

This critique of the literature emphasizes the need for the link between research and theory and the importance of researchers identifying their affiliations. The literature talks of widows being primary subjects to study and the importance of the nurse. Furthermore the current discussion speaks to a variety of research methodologies that were utilized in this review. The quality and findings of the synthesis of literature are rich and give insight to nursing practice, but there are areas for improvement.

For example, although articles in this review came from reputed journals such as *Journal of Palliative Medicine*, *American Journal of Hospice & Palliative Care*, and *Nursing Research*, some of the research was atheoretical. There was not the linkage between research and a developing theory; this lack lessened the research quality. In addition, some quantitative studies did not have the theory base, and it affected the quality of the study and its impact on a larger field of knowledge. Some studies, by contrast, showed strength by having a theoretical base.

Even though most authors identified their affiliations and credentials, not all did, and this missing information is another area for improvement. That lack raised the question of who these authors are and what their intentions are. Studies come from a multidisciplinary and nursing approach. We need to understand the lens these researchers are looking through and how they are looking at the identified research interest. Some

occupations mentioned by authors were nurses with different specialties and other specialties e.g. medicine, geriatrics, psychology, ethics, sociology, and public health. However, a major disappointment is the limited emphasis on nursing care mentioned and its importance to the dying and the bereaved.

Although female spouses were represented in many of the studies, research was not completely about their experiences. Female wives of the dying spouses have not been studied by themselves. Instead the samples have included parents, siblings, children, or others creating mixed samples. When spouses are included, all are not specified by gender. It is not always clear who are male and female in the demographics. Thus, research needs to be conducted where the focus is only on female spouses to enrich the knowledge for end-of-life from their unique perspective.

In this literature review qualitative, quantitative, and mixed methods are all represented. With qualitative studies, findings are not able to be generalized or transferable while quantitative studies have a limited focus. Sample sizes tended to be large for quantitative studies and were done to saturation for qualitative studies. Mixed methods give perspective qualitatively by perceptions and quantitatively by statistics. The variety of research methods gives an overall strength to the underpinnings of this research for end-of life and bereavement.

Instrumentation was also not always strong in studies cited earlier. There were concerns about reliability and validity. But, on the other hand, there were strong psychometrics with high internal consistencies and test-retest reliabilities. Different ways were utilized to obtain the data. For example, a survey was utilized as well as

retrospective work was undertaken. Correlational work was cited as well as one historical study identified.

These varying perceptions from journals, methodology, researchers, subjects and disciplines add needed dimension and direction to the current research study, helping to shape its flow.

Importance of the Synthesized Findings to Current Study

The current study will be contextualized within the synthesized findings of the literature review. This review focuses on widows and their time with hospital and hospice. The researcher will present the need for additional study on end-of-life research related to widows' perceptions of hospital and hospice care of their spouses.

Emotional support at the end-of-life is demonstrated to and appreciated by family members (Eriksson et al., 2001; Hanson et al., 1997; Carey & Forbes, 2003). In one study emotions were not tended to by physicians (Curtis et al., 2005) and were especially noted in the findings.

Hospice nurses, however, excelled at giving emotional care (Newton et al., 2002; Nolen-Hoeksema et al., 2000). In addition, nurses were specifically mentioned with how strong they were with "attentiveness and assessment skills and the emotional support they offered after death" (Hanson et al., 1997, p. 1341). However, nurses were not mentioned enough specific times and in enough specific ways, leaving an area in the literature that needs to be addressed.

Pain continues to be a problem and also needs more focused research attention. Perceptions by spouses of the pain management in those final days and hours of life of

their spouses would be beneficial. Unfortunately, in the literature and in real life there are lapses by nurses with pain care, and these lapses need to be studied.

With the rich literature based on family experiences with hospice and hospitals, researchers still haven't made a priority the exploration of spouses' experiences with hospice and hospital, specifically the female spouses and their journey with their spouses at the end-of-life. In the research literature the participants are the family members and most often included spouses, but they also include parents and other significant people in the studies (Eriksson et al., 2001; Ryan, 1992; Hanson et al., 1997). With end-of-life being such a significant traumatic occurrence, it behooves researchers to give this topic the attention it needs and deserves. When mentioned, hospice and hospice nurses seemed to fare better than hospital and hospital nurses. What are the perceptions of the widows of end-of-life care in the hospice and hospital? What are the perceptions of widows of nursing care? It is important to gain clarity on this subject and to fill this gap in the literature.

The end-of-life experience should be positive in hospital as well as hospice. The reality is most people still die in hospitals (Hoffmann, 2005), and "one in five Americans die using ICU services" (Angus et al., 2004, p. 638).

This proposed study of widows' perceptions of hospital and hospice nursing care of their spouses as they were dying will answer some initial questions. This is a large area for potential nursing knowledge development in end-of-life care. This initial research project could have information that would guide and direct focused inquiry for the benefits of dying patients and their spouses.

Chapter III: METHODOLOGY OF THE INQUIRY

There are many points in the cycle of living and dying whereby the nurse intervenes; end-of-life is one of them. The end-of-life experience of the dying spouse and the perceptions of the surviving spouse of these experiences are a rich source of information on this process. It is a time of spousal interaction and a time of active terminal nursing interventions, yet it has not been clear what enhances the dying process for a dying spouse and the role nurses play.

Grounded Theory Method

Grounded theory, a qualitative design, was the choice for this research as the researcher explored an area of nursing interest which had not been studied sufficiently. To study the perceptions of widows by process questions in interviews was the way this grounded theory research was conducted.

Grounded theory starts from the very beginning, that is coming up from the very ground that supports it. Grounded theory is a rigorous procedure concerned with detail that leads to a significant theory. To produce theory takes "induction, deduction, and verification" (Schwandt, 2001, p. 110). By using logical reasoning, explanation, and decisions whether something is suitably correct, theory can be produced.

Glaser and Strauss (1967) in their landmark book, *The Discovery of Grounded Theory: Strategies for Qualitative Research*, differentiated between “substantive theory” and “formal grounded theory” (Polit & Beck, 2004, p. 255). “Substantive theory” looks at a particular phenomenon while “formal grounded theory” compiles the results of many phenomenon into a theory (p. 255). Substantive theory is more specific to what is directly studied as compared to formal theory which is more abstract and broader (Strauss & Corbin, 1998). Substantive theory will inform nursing practice.

From these early beginnings, grounded theory evolved. As this theory developed, Glaser and Strauss looked at their work differently, and, eventually, they went their separate ways. Then, Strauss, the sociologist, and Corbin, a nurse went on to publish books that aid researchers in understanding the technique of grounded theory. From their work flows this researcher’s study.

Grounded theory is a qualitative method studying social situations. Creswell (1998) contributed to the early work of grounded theory by his focus on social situations and people in their natural settings. Because of the focus on social phenomenon, social interactionism is the philosophical base (Charon, 2004).

Grounded theory is the bringing out of new theory from the data collected (Schwandt, 2001). It employs “constant comparison” (p. 110). The researcher gathers word data and then begins the process of clustering into sets. These clusters may become larger or they may collapse as the theory develops (Liehr & LoBiondo-Wood, 2006).

As theory develops, the themes are sharpened. Data from the last interviews conducted are further sharpened for clarity (Liehr & LoBiondo-Wood, 2006). When data becomes “saturated” (Creswell, 1998, p. 56) and no new insights are apparent, the

researcher will develop both a narrative and a “conditional matrix” (Creswell, 1998, p. 57). The “conditional matrix” visually summarizes and highlights the relevancy of the new theory (Morse & Richards, 2002). The theory may be the end-point or there may be further testing empirically (Creswell, 1998).

Participants

Twenty-five female widows were interviewed. They had been widowed for at least six months. Even when surveys are done within weeks of death, family members are not adversely affected relates researchers (Casarett, Crowley, & Hirschman, 2003). Participants were actively sought until saturation was reached, that is when no new insights are revealed (Chiovitti & Piran, 2003; Creswell, 1998).

Participants came from Southern California from a core community of 21,000 and the surrounding cities. The community setting allowed for a wide variety of people. Inclusion criteria are to be a woman, been widowed for at least six months, be able to read and understand English, be able to understand the consent form, and be able to participate in the study by describing experience. Potential participants would have been excluded if they were not able to articulate their experience. Age range was 62-103 years of age for these widows.

Generally, hospice enrollment is higher for Caucasians than Black/African Americans, Asians, or Hispanics (Smith, Earle, & McCarthy, 2009). Although the diversity of the participants was somewhat limited, every attempt was made to recruit from various locales, churches and senior centers.

Table 1
Characteristics of Widows

25 Participants

Age in years	62-103
Religion	
Protestant	21
Catholic	4
Race	
Caucasian	23
Black/African American	1
Mexican American	1
Years Married	6-76
How Long Widowed	6 months – 10 years
Care Facility where husband died	
Hospice (home)	12
Hospice (facility)	3
Hospital	6
Nursing Home	4

Recruitment Strategies

In some local churches' bulletins or on church bulletin boards, an ad was placed for recruitment of participants. The ad ran for several subsequent weeks in church bulletins (see Appendix A for Recruitment Advertisement and Appendix B for Flyer). Senior citizens' centers and bereavement support groups were also used as sources of participants. Thus, the widow phoned the researcher and the researcher phoned the widow (see Appendix C for Telephone Response to Potential Participant Calling Researcher and Appendix D for Researcher Calling Widow).

For qualitative studies, "theoretical sampling" and "snowball sampling" were utilized. "Theoretical sampling" is attempting to have specific people involved who would benefit the developing theory (Morse & Field as cited in Morse & Richards, 2002, p. 173). These would be widows who have been widowed at least 6 months and relate to the theory that is becoming apparent. "Snowball sampling" was also utilized where one widow would suggest another widow for the study (Morse & Richards, 2002, p. 173; Polit & Beck, 2004, p. 732). This method would be advantageous for getting the desired sample size which meets the criteria.

Participants entered the study from the recommendation of their friends and acquaintances. The study drew participants from all walks of life, life experiences, and various health care settings because there are many hospitals and hospice providers in the area. They did not all have the same experience at the same hospital or hospice. However, they were from the same geographic area, Southern California, and there were some similarities among participants such as their widowed experience and nurse involvement in their end-of-life care.

Demographic information included age, race, religion, how many children they have, and individuals who give them social support. Also included are life occupation, where home is, where widow and husband lived, years married, medical diagnosis of spouse, and whether spouse's death was sudden or lingering. Finally, whether the spouse was cared for in the hospice (home), the hospice (facility) or the hospital was included. Demographics give perspective and depth and understanding to the researcher's findings (see Appendix E for Demographic Questions).

Human Participants' Consideration

Widowhood is a very difficult time for these participants. Widows are honored and treated with sensitivity, respect, and empathy by the researcher. Acknowledging their losses in a serious manner is one way to show empathy.

The researcher listened carefully to whether these widows wished to be a part of this study. If they chose not to participate, this choice was respected (see Appendix F for Research Participant Consent Form and Appendix G for Typist's Confidentiality Pledge).

Before the widows were asked any questions, informed consent was obtained. After acknowledgement of their understanding of the study, the consents were signed. Of the two consents gathered from each participant, one was placed in a locked file in the researcher's office. The other consent including contact numbers was given to the participant. Before, during, and after they these women are subjects, confidentiality will be maintained and no names are associated with data. Identifiers will be assigned to distinguish replies from others for note taking and for reporting purposes. Interviews and related research materials are in a locked file in the researcher's office.

Some respondents may feel some catharsis by talking about their perspectives. On the downside, the widows may become tired during the interview process. Although there is truly little direct benefit to them other than a listening ear, their participation will aid nurses in the direct nursing care of spouses and their dying husbands and could impact bereavement outcomes. Because of the sensitive nature of the topic, if participants felt they needed further assistance with emotions, the researcher was willing to aid them in calling the San Bernardino Access Unit (909-381-2420) and stay with them until they have the needed assistance. No one needed this service. Also, available was a local support group at the First Baptist Church of Redlands.

As a small service to the widow participants, the researcher provided information to a link in the community for widows called "Grief Share Support Group." Meeting on Monday evenings at the First Baptist Church of Redland, the group is free and the goal is to support people with loss. This information was given to the widows as well as a \$10.00 gift card to Target.

Data Collection

Data collection and data analysis occur at the same time. "It is the analysis that drives the data collection" (Strauss & Corbin, 1998, p. 42). Interviews are the chosen method as they get to the "interviewee's experience" (Schwandt, 2001, p.136). A semi-structured interview was conducted with widows. The interview guide has 12 questions for an individual to answer with this researcher. These questions derive from the lines of inquiry (see Appendix H). By focusing the questions, the answers are channeled on the designated topic (Schwandt, 2001).

Questions and memos evolved as more participants were interviewed. The interview guide was updated continuously and a memo was written after each interview (Charmaz, 2006). Thus, questions for interviewee #2 were different from those for interviewee #10.

This project required doing sufficient interviews until ideas were comfortably developed. Interviews were continued until saturation was reached (Creswell, 1998). In addition, to supplement these questions, demographics were obtained by the researcher (See Appendix E).

The purpose of interviewing and doing a demographic sheet were to gather data on widows' perceptions of end-of-life care of spouses who died in the hospital or hospice. Audiotapes were made of the interviews and the data were gathered from January 2008 – January 2009.

Data Analysis

As previously noted, data collection and data analyses occur at the same time. The interview was transcribed, coded, and analyzed by grounded theory method in a timely manner. The audiotapes were transcribed completely and accurately.

Coding was done on all interviews. After each interview, the interview tape was transcribed and coding initiated. When major themes were identified, all interviews were re-read several times and coded. Theme coding resulted in major themes and sub-themes (Morse & Richards, 2002). Constant comparison was done “comparing ... concept with concept” (Morse & Richards, 2002, p. 158).

There was further development in data, however. Concepts were put together in a construct and they were affirmed with more data. In the methodology, concepts are

generated then relationships were suggested between concepts which form the theory, and finally, more data confirmed the theory (Schwandt, 2001).

Confidence of the Inquiry

Lincoln and Guba (1985) note that for the study to have trustworthiness, it must have truth value, applicability, consistency, and neutrality. Another word for truth value is believability and is the counterpart for empirical research's internal validity. There is the thought of different realities that needs to be represented and if they are there, there is truth value.

Applicability is found to be conflicting for the naturalistic inquirer because of the difficulty to make inferences. What naturalistic inquirers do is pull out working hypotheses. They note that transferability and external validity are more of an empirical science concern. The primary investigator does not have to be the one to prove transferability. The qualitative researcher's responsibility is "providing sufficient descriptive data" (Lincoln & Guba, 1985, p. 298).

Consistency is also something for the researcher to consider. With empirical research the expectation is for findings to be predictable and congruous. But with qualitative research, the results can not be neatly reproduced. Humans are unique and cannot always be seen as consistent.

Neutrality occurs when there is space between participant and researcher. When the research is value free, it is objective and empirical. But the qualitative researcher expects the importance not to be on himself/herself but on the data itself. The question is about the data being confirmable.

To meet the standards of trustworthiness in qualitative inquiry, there must be “credibility,” “transferability,” “dependability,” and “confirmability” (Lincoln & Guba, 1985, p. 300). For the research results to be credible, Lincoln and Guba (1985) suggest “prolonged engagement, persistent observation, and triangulation,” “peer debriefing,” “referential adequacy,” and “member checking” (p. 301).

Concerning prolonged engagement, this researcher has worked for years with women who have lost their spouses. The researcher is immersed in that culture of loss and has over time gained acceptance and been deemed trustworthy by the spouses and their wives. Persistent observation is determining what is of utmost importance in the research and spending time with that. The caution is not to engage prematurely.

Peer debriefing is collegial listening and giving feedback on the research. The researcher needs to be clear in his/her focus to withstand the scrutiny of a colleague. Besides the four listed researchers, the primary investigator had other doctorally prepared nurse scientists give suggestions and insights.

Referential adequacy has its objective to save different recorded material and at a future time have it reviewed against a larger body of material or be used as a reference point. Educated, interested persons could even look at archived raw material and compare findings (Lincoln & Guba, 1985).

Member check is a way to see if what one purports to say is what the widows felt they actually said to the researcher. This check also could be done in the course of the interviewing, in saying what previous participants said and if it rings true for current participants. Or right after the interview, the researcher can relate to the widow what she heard the widow say to her.

Transferability gives other researchers an opportunity to review thick descriptions on the research topic and make a decision whether the study may be transferred. Thick description flows from a purposeful sample but each situation is different as to whether the study's results may be used at a later time.

Dependability and confirmability are achieved together. By the process of reviewing how the research occurs dependability happens. The product is supported by data and thus confirmability. Confirmability is obtained by the confirmability audit. Halpern's work on the "confirmability audit" (as cited in Lincoln & Guba, 1985, p. 318) suggests leaving a trail that may be retraced with "raw data," "data reduction and analysis products," "data reconstruction and synthesis products," "process notes," "materials relating to intentions and dispositions," and "instrument development information" (pp. 319-320). In the case of this researcher, audiotapes, transcribed interviews and notes are included in the data set. Memos after interviews and summaries as the theory is developed are also safe guarded. The progression of interpretations and linking of theory to literature with drawings of conceptual diagrams are held in a locked file. Completed theory and "conditional matrix" will be published (Creswell, 1998, p. 57).

Researcher's Role

Reflexivity is an important part of qualitative research. Because I, the primary investigator, am intimately involved in the research process, I needed to recognize any particularities or preconceptions which could influence the study (Polit & Beck, 2004). Creswell (2003) talks of the researcher having "a sustained and intensive experience with participants" (p. 184). I asked questions and responded to their answers and, thus, I was

part of the research process. The data informed me and I informed the data (Strauss & Corbin, 1998).

Memos were written after each interview. They revealed the quality of participants' responses. In turn, this writing enhanced the credibility of the study. Other nurse researchers verified data so the primary investigator interpretation was moderated.

I was an instrument in doing the interviews (Janesick, 2000). Thus, the quality of the research was dependent on my ability (Patton, 2002) to listen and be interested in the participants' experiences. I tried to be sensitive and to repeat questions as necessary. Professionalism and developing a common understanding are also important.

I saw firsthand the effects of widowhood on my mother who lost her spouse at the age of 53; he was 58. This experience gave me additional insights from the perspective of a daughter. Now, I celebrate my parents and how valuable they are to me and this experience during the research gave me some insights of widowhood. But these insights could also be a disadvantage. Experiencing my mother's widowhood made me more empathetic but this knowledge needed to be balanced with an open mind as I listened to what my participants had to say about their own experiences. In addition, I have worked with many new widows in my 28 years of experience in oncology and critical care nursing. Because of my career, I have awareness of the death experience, acute reactions, and the feelings about the future without a spouse. I, the primary investigator, have recognized I have a bias to help the widowed.

Chapter IV: PRESENTATION OF FINDINGS

The participating wives and their husbands all seemed to have enduring and loving relationships. They had journeyed through life together and were coming together in these sacred moments, last hours, and days of life. Their always being together seemed to give a certain intensity of the developing death experience. At the center of this theory were the man and woman in their final time together on this earth. It was how they were as they entered into the medical environment either by way of hospice or hospital. It was there that their experience could be shaped best by healthcare professionals.

At the last, the participants described Shared Presence: Caring for a Dying Spouse (see Figure 1), the wife and husband as a dyad together in their moments of end-of-life experience. Most of these wives had long marriages with their husbands. They had spent decades together, many of them, and now they were together in this final time. Being there at death was a chance to have a special togetherness of shared presence.

It appeared the wives valued this time. Some were there and some were not at the moment of passing, but all were there in thought and spirit. This emergent theory has a core phenomenon of “being there” which includes physical contact and saying good-bye. Also, the theory has as its parts context, process and consequences (Corbin &

Strauss, 2008). The context includes the awareness of impending death whether it be lingering, sudden or traumatic. The process includes forming connections, dividing into family relationships, care and comfort, and spiritual solace. Family relationships are either supportive or non-supportive. Care and comfort are interacting with healthcare personnel and communicating at the end-of-life. Spiritual solace involves clergy visits and prayers and personal faith.

Consequences are the realizing sense of self. The subcategories of this are disturbing situations, aloneness, experiencing peace and finding meaning. Context, process and consequences are a way of categorizing data to do theory building.

Awareness of Impending Death

These participants had experienced life's challenges, illnesses, and triumphs, and now their final journey was beginning. This was the span of life until death. The wives came to the enormous realization that the death of their life partners was quite near. Some of the husbands' deaths were lingering due to chronic disease such as Parkinson's. Others seemed or appeared more sudden as in cancer, and others were traumatic due to accidents. Widows remember hearing the news and their disbelief. But there was an awareness that death could be very near. The time was not right for an event that no one wanted to happen.

Core Phenomenon: Being There

Physical Contact Saying Good-bye		
Context / Conditions	Process	Consequences
Awareness of Impending Death <ul style="list-style-type: none"> - Linger - Sudden - "Traumatic death" 	Forming Connections Family Relationships <ul style="list-style-type: none"> - Supportive family - Non-supportive family Care and Comfort <ul style="list-style-type: none"> - Interacting with healthcare personnel - Communicating at the end-of-life Spiritual Solace <ul style="list-style-type: none"> - Clergy visits and prayers - Personal faith 	Realizing Sense of Self Disturbing Situations Aloneness Experiencing Peace Finding Meaning

Figure 1: Shared Presence: Caring for a Dying Spouse

One husband went in for a cardiovascular workup and was diagnosed with cancer throughout his body. The situation had changed dramatically.

They told me we'll have to keep him overnight and I said ok ... no problem and ... then I went ... back in the next morning thinking that they were going to do the procedure ... and ... they told me ... they hadn't been able to stabilize the blood pressure and that they were going to run some tests on him and ... that's when they discovered that he had cancer throughout his body.

He had some cancer in his past, but this diagnosis was totally unexpected. "An oncologist came in and ... said he has three weeks to live." The wife, though shocked, had the wits about her to call hospice.

Another spouse reflected on a very difficult experience with a treatment protocol.

She said:

I had no idea though that he was dying ... I figured this was another up and down spot from the chemotherapy range. His last three months of chemotherapy were just very painful it was a very painful three months I think he knew that the end was near, but I...didn't want to face it.

At the time of his death, although her husband's perceptions about his impending death were unknown, he was actively teaching a class under these trying circumstances.

Although there was an awareness of a serious situation, the decline seemed sudden.

Or as another widow relayed, it "didn't really register that he was going to go."

Her husband showed some physical symptoms of jerkiness and was still responding, but something wasn't quite right, so she called hospice.

Another spouse's health changed suddenly and worsened. Unfortunately, in this case the man had lung cancer.

It was very fast and it was very traumatic. Everything happened from diagnosis which was on a Friday till his death was about four and a half, almost five weeks It was sudden. At the time it felt ... everyday was stretched out, prolonged, everyday was almost a crisis in the way it happened so rapidly... one thing after another would happen. They would do an operation; they have to drain the lung.

It was almost a surreal experience how fast it went for this wife and her husband. She did mention previous husbands dying, so she was all too familiar with losses.

Traumatic death occurred quickly or had a disturbing element to it. A husband fell from a ladder suffering trauma. He had been healthy up to that point enjoying mission service and retirement. The accident was a serious setback and then caused his untimely death.

Regardless of the length of time, the wives seemed to have a sense of disbelief or even denial of the impending death when they first heard or became aware of their spouses' nearness to death. It always seemed difficult for widows to assimilate all of these events and potential losses into their lives.

Forming Connections

Forming connections were key components in the Shared Presence: Caring for a Dying Spouse theory. They were essential to the widow traveling through this journey. Essential to her successful navigation were these connecting ties to family, care and comfort, and spiritual bonds. Forming connections involved reaching out for sustaining relationships during this time of change. Spouses sought support from family relationships, health care providers, and spiritual solace from clergy. Inwardly, each wife had a personal faith giving her strength.

Family Relationships

The relationships of love, respect, and honor between the children and the widows were apparent. These were important as expectations were high for family support during illness, death, and bereavement. Family relationships were seen as supportive or non-supportive.

Supportive Family

By and large, the widows reported positive relations with their families, particularly with sons and daughters. Widows expected this support, and the family reciprocated generously and unconditionally with care and love for the widow at the time of death with sustaining family relationships.

In those last moments of life, one daughter who was also a nurse stayed with her dad who was breathing heavy in his room and had come “to comfort” her mom. She used her nursing expertise to enhance her role as daughter as she saw the difficult struggle her mom was having in coming to terms with her husband’s death. Although the wife had petitioned the Lord for her husband to pass, it was still so very hard to go through this experience.

One husband’s condition warranted the wife and his son to take shifts to meet his needs. His illness, Lou Gehrig’s disease, was prolonged over a five year period. This progressive disease starts with difficulty swallowing and culminates in paralysis. It involves much physical care from others and he was no exception as he required total care. He didn’t want to go to sleep at night, and he kept his family awake as he needed something every 10 or 20 minutes. The wife said:

And a whole year or so he was bedridden and in a wheelchair. He was afraid to sleep because he was afraid he would choke. And so he kept himself up day and night and my son actually stopped school and moved in to help me.

In another case, before his death, the husband was content to see his estranged daughter who stayed for a week close at hand for her father. At the moment of death, his nurse stepdaughter assessed her stepfather’s circulation by feeling his carotid and called hospice. Although the stepfather had seen his estranged daughters before he died, his

stepdaughter was the one who stepped in to assist her mother and his wife. "I yelled for Karen and Karen came right in and ... checked ... carotid artery ... she said no, no he's not breathing and she said I'll call hospice and that's what she did."

For another woman, all the kids were there with her as her husband died. "I was there and I saw the thing going down, I called the nurse, they called all the kids and they came in and I ... knew he was going then." Now all four of her children try to care for her. From another family, one daughter spoke to her dad, "she said, Daddy, it's okay. I'll take care of Mother." He was in his 90s, elderly and they had tried to ease his passing.

In the immediate bereavement, children surrounded their mothers when they had heard their fathers had passed, but not all were there right at the death occurrence. "She [daughter] came in right after and then my son and his wife came as soon as they could get there.... in fact, they didn't get there until after he died, but they were on the way." This support from the children was not taken for granted and was truly appreciated.

A grandson and his mom turned around from going to church to support the new widow. In this case, after the death of a beloved husband at home, the children and grandson assisted with purchasing a new mattress for the widow. They thought of the difficulty she might have sleeping in the same bed after her husband's cancer death.

They had all gotten together, my son and daughter and grandson and his wife and they decided already which I didn't even know ... that I would get a new mattress ... and a new bed and they had already looked all around they knew where the mattresses were the best.

Most of these widows said they would have had a harder time without the support of their family. One widow stated, "My daughter who has a PhD in nursing also came and ... she helped and it was very helpful to have that support...I don't know if I could

have made it without the support of the family.” The daughter helped with making the bed and giving of herself emotionally. She stayed on at her stepfather’s request.

Non-supportive family

In another case, a new widow arrived at the hospital after her husband died from an overwhelming pneumonia and discovered his first family in the room. “When I walked in there and nobody said anything. He was laying on the ...gurney there on the bed.” She had hoped to be there at the moment of death but was caught in traffic. The two families met at his death, and even though the two families were important to him, they couldn’t connect at this point, at least, at that time, in that moment. The experience of missing the moment of death, confronting this loss as well as another family was a very difficult experience for the widow.

Even if they had children, widows were at times disappointed. In one instance, there was some trouble with a daughter during the crisis, and the widow said, [I had] “trouble with my daughter.” In the middle of the night the mom summoned help from her. At first the daughter wasn’t cooperative, but she did arrive before the passing of her father. “So she arrived before he died. But I don’t think she thought that he knew that she was there.”

Another widow, because of no support from her children, regretted having them and, unfortunately, the one child who would have given her support had recently died. She lamented that she would go by another son’s home and wave, but they hadn’t talked for nine or ten years. “I have a son who’s a medical doctor who lives three houses up, but ... he and his wife once I was done babysitting their kids they cut Bob and I off.”

Some spouses, however, did have to go it alone without sons and daughters to rely upon; instead they depended on a more distant network of friends and extended family. However these women were not the majority. Interestingly, almost all these widow participants said they had maintained cohesive healthy relationships with family and others. These positive relationships were also reflected in their interactions with health care personnel.

Care and Comfort

The wives interacted with healthcare personnel and communicated at the end-of-life with these same personnel. These professionals were expected to be competent and caring. If they were not, the widows were disappointed.

Caring concern was shown by the nurses by asking if the wife was doing okay in those final minutes.

So I sat there. I watched the nurses as they prepped him with their gown and diaper and all that stuff and I just sat there very sad. Finally a nurse looked at me and she said, 'Are you alright?' By that time the tears were beginning to run.

Arrangements had been made for him to arrive at the institutional hospice when he deteriorated. And now she had this time of sadness. A nurse quickly picked up on her deep sorrow and put comforting arms around the wife. Concern is shown by not being in a hurry and being supportive psychologically. "She was always very, very kind" and "the attitude was just wonderful."

Interacting with Healthcare Personnel

One widow noticed how prompt the nurses were in attending to her husband and how she appreciated this care. "They just gave excellent care. If a patient needed ... a

nurse to do something and the nurse was doing something else she or he would stop what they were doing and ... attend to the problems of the patient.” The nurse put the patient first.

Being reaffirmed by nurses that wives were giving good care to their husbands felt good to several widows, the wives reported. Unfortunately, there were a few nurses who were unkind or short with the wife or did not offer any special care. “No, I didn’t feel anybody offered me special comfort. I’m sad to say that,” said one wife, a retired nurse and her husband a physician. If these former medical personnel didn’t deserve personalized care from healthcare providers, who would?

One wife was caught at 6:30 in the morning during report. “I didn’t realize I wasn’t supposed to be in the room...the nurses were a little short with me.” A kind nurse realized the woman’s predicament and placed her behind the curtain until it was okay to come out. Families don’t know the regimented regime of the hospital; this lack of knowledge may make a traumatic situation even more dire.

One of the nurses ... came in and said, ‘We’re going to move him immediately’ and I just made the comment ... that I had understood that he was not to be moved until the next morning. And there was a nurse coming on that night her name is Cathy and my son had talked to her the night before when she had been on with [my husband] and she just was so kind to him and I know Cathy was coming on and I said I rather he just stay right here if that’s possible. She said, ‘It’s not.’

So the husband was moved to another unit on a different floor. The wife was left to ponder what this all meant, the move, the attitude of the nurse, and her own feelings.

In contrast, for those under hospice care, wives were to call when there was a “marked decline,” when it looked like the loved one was in his final time. [When] “the patient looked as though they were going into the last stages of their life ... a particular

nurse ... would go out on that particular call.” These signs could take different forms such as “couldn’t swallow” and “unresponsive” and difficulty getting blood pressure or heart rhythm. Unfortunately for this wife, that call was made for her husband too, with his pneumonia and coma.

“He was having hard breathing ... it just got to me, and so we kept the bedroom door closed and ... that night I cried the whole night long.” Being in the room was too painful for her and someone else had to be there, in this case her daughter. With this widow the anticipated grief was overwhelming. Their friends and daughter saw her through to death.

A nurse colleague of her physician husband gave the wife a private phone number to call if needed, which she did. “She gave me her private phone number of her house. She said, ‘During the night anytime you want me I’m on the phone.’ ” That nurse had been a colleague for years. Very often, the nurse was in the picture to show concern in the multiple settings of hospital and hospice.

One widow said, “There was one nurse that came in there and talked to him as if he could hear, that he would know it was okay for him to go.” Even though she had conflicted feelings about this nurse, she still recognized the nurse’s positive input in this situation. Her conflicted feelings resulted from the nurse holding her husband’s hand while he was dying instead of the nurse realizing she, the wife, wanted this privilege.

From a different perspective, one widow who was a nurse said she was impressed with a nurse educator who was teaching about her husband’s clinical condition while he was dying. “His pulse, his temperature, all the various reactions, every one of his organs

were being recorded there and she was teaching this to her students. I'm sure that's what she was doing."

Different physicians made their "presence" known by making house calls before their patients passed away. In one instance, besides having a physician visit her terminally ill husband, this wife had a physician neighbor who assisted with morphine administration. This wife seemed to be truly blessed to have both a professional physician and physician neighbor.

Another physician was called because the wife thought her husband was dying. The physician thought the husband was dying, too, and came right over to their house. He "had prayer over him" and the husband became better. "And then later the doctor said, 'Didn't you think he was going to die?' I said, 'Yeah I sure did,' and he thought so too."

Raving about her husband's physician, one widow said, "I don't know why he was there on Sunday morning, but he came in and he stayed over Alan until he passed away.... It meant a lot to me that the doctor was so caring." The widow was so pleased with the doctor's caring. "What kind of person he was to care, to be there on a Sunday morning for no reason other than maybe just to be there with my husband I don't know." She was so taken by his caring she has him now as her private physician.

Referring to her hospice doctor, a widow said, "He was so good; he was such a kind man, compassionate person. I can't say nothing bad about him." She had such a rich time with her hospice nurse and hospice physician.

Some husbands received visits from their physician colleague friends. Physicians were noted for their compassion and expertise. For example, a physician was trying to help one family stay informed about hospice and whether or not to insert a tracheostomy

or gastric tube. He was an esteemed hospice doctor, and the widow so wanted to talk to him more after her husband died. But she recognized the professional relationship had ended even though emotionally she wanted that connection. "I think I would've liked to talk to the doctor again, but I felt like he had to go on and take care of other patients and ... his work with me had concluded."

Another widow noted, "They wanted him to be comfortable." The nurse said, "I think he'll be more comfortable with a foley and than he won't be wet." For additional comfort measures at the end-of-life, little drops of water placed in the mouth were refreshing. One nurse friend was particularly appreciated: "she would give him medication under his tongue as he couldn't swallow." All these measures of comfort nurses did for their patients, all with the purpose of making the passing more comfortable for the husband and wife.

Remembering how the nurse comforted her was positive for a widow in the retelling. The nurse "came over, she put her arm around me is there anyone you can call?" Human touch seemed to be healing and it was a comforting memory.

In another case after the death of her husband, the nurse asked the widow if she wanted to put pajamas on her husband. This wife had decided to be in the house but not in the room when he expired his last breath, but the widow wanted to help with the pajamas. It seemed keeping the husband clean was important before and after death for both the wife and nurse.

In one case, when the wife said she felt she should have been closest to her husband and holding him as he died, the nurse was in the wife's place holding her husband's hand. "At first I resented her; I thought I wanted to be up there closer to him

... and I could see that thing just get flatter and flatter [monitor] I thought I should be up there doing that.” The wife was behind the nurse, and she indicated she wanted her rightful place by him. “Behind her, I was behind her, right behind her. She was in front of me.” Although, nurses are generally or known to be concerned and kind, their compassion may make them overstep their boundaries, and they need to know their sense of place.

One wife saw no dilemma. “I went to the other side [of the bed] because I wanted to be right there, and she was on one side and I was on the other.” She was able to be close as her husband’s “breathing got shallow and each breath became a little bit farther apart.” She was assertive enough to take her place besides her husband, but other widows may need encouragement in taking in what they believe to be their rightful place.

In one very sad situation, the hospice nurse cut into the family’s time with the deceased husband and father.

The way she came in ... we thought she was going to ... check him out and say I’m sorry he is gone or whatever from a professional ... she didn’t all she did was say, ‘I need to check him out for bruises, make sure he wasn’t abused.’ We were very, very unhappy with her.

The family was dismayed by her implication. If only she could have presented herself more professionally in her communication. Particularly, it was sad as they had a very positive experience with hospice throughout the husband’s illness and yet now it ended with a seemingly unwarranted accusation.

That incident is not the general view of hospice. Largely, hospice was seen by the wives as positively, though there are a few suggestions to make the service even better. More than one widow expressed that hospice could do more, and there need to be more follow-up and grief support groups. “I wished that they could have had a list of people

that I could have called,” said one widow. She was by herself, childless with three close college friends. She needed assistance; she couldn’t do it alone. Unfortunately for her, her caregiver died of a heart attack during the time of her husband’s illness.

For another wife, she needed a personnel change: “She was just negative, she wasn’t as gentle with my husband as the others were. She was very blunt in her approach which no one from hospice had been,” and the wife requested a change of personnel.

Another widow said, “You know, they’re there two or three times a week, then all of a sudden everybody clears out and there is nobody.” This wife became very attached to her hospice nurse and wanted the relationship to continue after her husband passed away. Even though all hospice personnel came to see her right after her husband died, she still felt abandoned and disappointed. “Finally about three months later the nurse called to see how things were. The chaplain never called ... actually the head nurse ... she did call, but that wasn’t real meaningful to me. I wish that the people I knew called.” For the personnel who provided services, a gradual transition away from the widow is indicated.

“Even after, he was unconscious in hospital/hospice, they were very careful with him. They were very tender with him just like he knew what was happening,” one woman reported. This tenderness and kindness helped this widow. She had an ideal situation with hospice at home then with institutional hospice. Indeed, when she could no longer care for him at home, she had an alternative.

“I really don’t think I could have done it without hospice” was another widow’s sentiment. Another wife stated, “They didn’t treat you like a stranger, they tried to comfort and all that so they were very good.”

“The few days that I was involved with them, I have nothing but the highest regards for them,” said one participant. Hospice personnel were noted by the wives for great attitudes, phone availability, and mental support. For one family, hospice personnel had their favorites; one was more supportive to the wife and one more supportive to the husband.

Oh, I thought they were so good. They had the purpose of helping the person not to suffer, and if they saw that the person was suffering they would do something immediately to help him to not feel the pain.

In another case, a husband was made comfortable during his final days with morphine, but he had a clear mind before his death. At times hospice would even get needed medication in the middle of the night for the husband.

Summing it up, one widow shared, “I felt really good about it. I’m glad that I chose to do hospice even if it was just briefly ... but as it turned out they were there when I needed them.” Even though her husband had a lingering illness, he went downhill fast before his immediate death, and hospice became very important for both.

Out of 25 participants, only 6 widows lost their husbands in a hospital setting. “They were very, very good to me at the hospital.” Flexible visiting hours helped with all the husband’s friends coming from the Knights of Columbus. The wife desired these flexible visiting hours and she received them. When her husband needed dialysis, she was able to stay in the hospital room.

Conversely, for one wife, her husband needed a hospital bed, but none was found after going to three emergency rooms. In his last days, he was very ill, and he was a very important person, but no bed was available for him. The following day he went to ER and finally a bed was secured for him. Healthcare is complex, and apparently with the further

financial downturn, ERs are severely impacted and overwhelmed. Negative health care delivery may occur under this burden.

A widow firmly said on the final hospital admission of her husband, "My husband is 84 years old and he deserves some respect. He better not be in the hall when I get there." He wasn't. She was familiar with the health care systems, the backlog of patients waiting in the ER hallway and wished to prevent this indignity for her husband.

Much to one wife's dismay, her husband was discharged too soon from the hospital. She blamed herself as well, for not managing his rib fractures better from a fall. When he was readmitted, he contracted a hospital infection and with his current weakened state, he died. This outcome was not expected, and she was greatly stricken over her loss.

Another widow, a nurse, saw all the learning opportunities available in the hospital for nursing education. "No, I think they knocked themselves out. They really did. Since it was a teaching hospital, they really did their best."

With her husband's placement in the hospital, one wife appreciated "the concern and the gentleness and the questioning as to whether are you comfortable, is there anything else I can do for you."

Communicating at the End-of-Life

One wife had a nurse whom she indicated she valued and was looking forward to having her return on her next shift to care for her husband. But her husband was moved abruptly to another floor and away from this valued nurse. As it turned out, one of the downstairs' nurses followed her up to his new room. And when the husband gurgled, she said, "Oh, he's dying." This comment was very stressful to the wife and the wife said, "It

was very hard.” The wife reported problems with this nurse on her husband’s first assigned unit and then her next unit as well.

Further, this same wife said she was put in an awkward situation when a different nurse complained about her husband who was coughing up blood. The nurse said, “He has been spitting at me all night.” Because of his declining condition, they put “a breathing mask over his mouth and nose. When I took it off, it was full of blood.” She said she knew her husband was not being uncooperative.

The wife seemed distraught over what was happening to her and her husband. With the high acuity of patients and nurses working long shifts, it impacted the widow personally and thus her memory of the event. Fortunately, this scenario did not occur regularly to these widows. However, it caused this one wife great emotional pain because it happened to her and her husband.

In being present at death, another wife was affected emotionally. She said she was guided to take him to an institutional hospice during the night time. When she contacted one of her daughters, initially the daughter was not supportive of her mother, so the support she received from hospice was especially valued.

First I had called the hospital actually because that is the number I had, they told me to put him in an ambulance and bring him in. I said I can’t do that because he is too weak and I am scared and I am here just with he and I.

But she did follow the ambulance to the hospice. Her daughter arrived before he died and supported her mother while her father went through this passage.

In another case, breaking the news of death to a wife in person was important to the doctor. He searched the neighborhoods and other people trying to locate the new

widow. Finally, he reached her. "The doctor wanted to be with me. I could tell by his eyes," she reported.

In some cases, health professionals came in and pronounced death without causing discontent in the family. One family prepared a meal for the nurse who did the pronouncement while they waited for the mortuary personnel to arrive. Registered nurses were seen as compassionate in breaking the news of death by some widows.

In one case, a husband died after having a head injury. Voicing her feelings, the wife wished the physician would have been more compassionate. "One doctor could have been more sympathetic," she said. What bothered her was his attitude and not receiving a word or two of sympathy from him. This woman and her husband were quite elderly, had been together many years, and a more compassionate stance would have been appreciated.

Another widow, a physician herself, was so disappointed in the unsympathetic response at how her husband was pronounced dead by the physician that she swore. Later, she said, "I think you can be sympathetic, but I think you have to have a certain reserve." Interestingly, she had gone to medical school with this physician's father some years back.

In one instance, there was not an established relationship between the nurse who came to pronounce the death and the new widow. The nurse "did the best she could but it was very cold and very difficult."

Both physicians and nurses were esteemed as most significant by the wives when caring for their husbands. A hospice physician who acted with conviction in caring for

one woman's husband gained her respect. The doctor who was there on a Sunday tending to one participant's husband also earned her trust and admiration.

A nurse who was in charge of the unit of one husband was looked upon with favor said his wife. Another nurse was a daughter who was available emotionally for her family and was esteemed by her stepfather. Another nurse gained the confidence of one wife by helping with medications and being sweet. With a husband's decline one hospice nurse came to spend the night turning the husband and giving him cooling measures. In one instance, the nurse, the aid, physician and chaplain all came the next morning after the passing of one woman's husband. This visit showed support to the widow and respect to the deceased. Thus, positive relationships were formed with physicians and nurses.

Spiritual Solace

The wives by and large sought spiritual support from their clergy. Indirectly, they said they found it important and meaningful. Most talked of their personal faith in a Higher Being. Spiritual solace was reflected by clergy intervention and personal faith of the widows. Each widow in her own way expressed her spirituality.

Clergy Visits and Prayers

Priests had a most significant role in offering spiritual care and sacraments during frequent visits. Pastors and one of their wives came right after the husband's death, and this visit seemed to be a most important care from the widow's perspective. Clergy visits and prayers with the family were seen as important. Several husbands were anointed with oil by the clergy in keeping with religious traditions.

One widow felt the visits were too late from the clergy, and she didn't want them at the end. She said, "And the time to visit was early on, I think, when he could have talked and maybe enjoyed it a little bit... he didn't want people to see him in that way [very sick]." She went on to say, "Well, there was about a year and a half we didn't see anybody.... the head pastor thinks they met the needs and they really did not."

Something special that helped one widow, she said, was that her pastor played the harmonica during those last moments of life. For this wife and her husband he played, "His Eye is on the Sparrow," creating a very special memory for the widow.

[My husband] had tears coming out of his eyes so we knew he heard us, we were talking to him and about an hour after he [the pastor] got there, he started breathing very, very heavily... faster and then it began to slow down.

For a different widow, a different pastor who was a friend also selected hymns to play on his harmonica for the wife and her husband. "He was calm. I could tell that he enjoyed it." With being new in town, one widow wasn't able to make the needed spiritual connections to ensure a spiritual memorial service. She forged a relationship with the hospice chaplain, but when his car broke down, he wasn't able to get to the memorial service. "He called and he said he had broken down on the freeway and he wouldn't be here." She was disappointed and she felt that the spiritual comfort she needed simply wasn't there.

Church members could be a source of spiritual connection with their visits. However, church members were not mentioned often by the participants. After the death of her husband, one widow stated her church family to be "very sympathetic."

Personal Faith

“Just God and believe me He’s been good to me” is what sustained one widow since she didn’t have the support of her children. But she indicated she did have her personal faith.

Personal faith was whatever gave the widow a spiritual path between her and God. It gave her the ability to remain strong during the journey of the unknown. This sentiment of relying on God was echoed by a widow, “God. I lean on no one else. He’s my guide.”

For one woman with a hospitalized husband, she said, “I prayed the rosary every day down there hoping he would come through.” Her husband had picked up a bad infection on vacation and returned to California where he died in an ICU. His death had an impact as he had been active in his community and was a devoted husband.

Realizing the gravity of her husband’s condition, one wife petitioned the Lord for her husband to die. He couldn’t swallow in his last months due to Parkinson’s. “There was nothing that they would do to make him well and towards the end, it was like I prayed that the Lord would help him go to sleep.” With some time, her husband passed on. She indicated she had no regrets and was relieved he was at rest.

But she wasn’t the only wife who petitioned the Lord for her husband to finish his time on earth. Another widow said, “I prayed, so did my daughter that he be mercifully laid to rest you don’t want people in pain to be living.” He had been a community leader in his time, respected then and now. In his last months he had pain from ruptured diverticuli and was bedfast and miserable. He wanted to die at home and he did peacefully.

Being There

Being there is the core phenomenon of the theory Shared Presence: Caring for a Dying Spouse. It is central to this theory. Within the core phenomenon is physical contact and saying good-bye. Generally, a widow had been with her husband throughout a marriage, being a part of his life. And now she desired to be with him during his death transition. She wanted to be there. As mentioned, some participants were there at the moment of death and some were not. One participant missed the moment but was in the house.

I was around the house and I walked by his bed, and I looked at him, and I thought I think something is wrong here, I think he's dead. So I went and put my hand on his heart, wasn't beating, nothing in his pulse, so I called my daughter. I think Daddy is dead.

Many loved ones gathered around after his death including friends, nurse and physician colleagues.

"I felt privileged to have been able to be there with him right up to his last breath," said one widow. In the institutional hospice, the widow "was there to hear him do the last expiring of his breath." Another wife chose not to be with him in his room for his last breath, but she was nearby in the house.

Finally, a wife gathered the support of her family to be with her as her husband died. "I saw that my husband was dying, I wakened my nephew and he and his wife came in and were with me when my husband died so I'm glad that somebody was there." She said her daughter was a source of emotional support, but she wasn't there when her father died.

Still another wife found the last week difficult. She wept when the end was coming closer. "I wasn't shocked when he died; I knew it was going to come."

One exhausted wife slept right through her husband's moment of death. She was physically there but asleep, but she was there throughout the years of his declining health. "I had fallen asleep and when I woke up, I don't know about an hour or so, checked on him and he was gone I knew it was going to be within a few days." The widow had sensed right about when her husband would pass. Still another widow who was attentive to her husband during his last days lamented being in traffic and not being with him when he died.

Another wife was a part of her husband's last days. "I was with him all the time. In fact, I think it kind of helped them a little bit, you know for me to be with him." She was set up with a chair around the clock to be with him in the hospital.

Physical Contact

To touch and hold her spouse were important for some of these wives and for one wife in particular. She said she gave human contact to her spouse. She had gone through several hospital deaths of her husbands and made note of the good cares each received.

One wife helped her husband by supporting his head as they moved him up in bed. It was one of the last things she could do for him. For another husband, the wife gave him food and "saw that he was well cared for."

Holding their husbands as they died was a helpful idea whether suggested by a nurse or initiated by the wives. One widow stated, "He died in my arms." In another instance, a nurse encouraged a wife to hold her husband. "They fixed him and I had him in my arms," she said. Another widow took the initiative to hold her husband of 57 years in her arms as he died.

Being widowed multiple times, one woman reported she had held in her arms each of her husbands as he died in the hospital. She recognized that the nurse encouraged her this past time with her husband, "She was there. She was right there." Would it be appropriate for nurses to suggest this intervention? One widow communicated it would be. For another, her husband died in the hospital, "Well, it was...kind of hard 'cause when you're hooked up to all those tubes and then trying to get over on that bed," it is difficult to do. She said she liked the idea of "combing his hair and talking to him all the time."

Even though he "slept most of the time at the end," one wife stated she would try to see her husband three times a day. When he slipped away, she had her hand under his neck. "Well ... I put my hand under his neck right there so he could feel it."

Saying Good-bye

Saying good-bye was an opportunity for closure in the relationship on this earth. Good-byes were spoken of but never really said. During the time of spousal death, a good-bye didn't always happen as expected or the opportunity was missed. So what was the experience of saying good-bye? Not everyone said or wanted to say good-bye to her husband. For some wives, they said they knew bringing up the topic of death or saying good-bye would upset their husbands, so they never did say a formal good-bye to each other. "No. I didn't say good-bye to him. He would have just gone into shock."

For an elderly widow, she said she regretted the heavy sedation that impaired communication and interfered with her good-bye. "You know I never did get to tell him good-bye." She was right there at his death, but a good-bye wasn't possible. The nurse also missed her opportunity to encourage the widow to talk to her husband. This was the

case where the nurse stood in the way holding the husband's hand and checking the monitor. The nurse seemed to take the primary position according to this woman, and the widow is very disappointed.

Sometimes the health changes were so sudden such as with a cardiovascular collapse no good-byes were said. One wife didn't know her husband was slipping away so fast, and a good-bye did not take place. One widow said sadly, "He never did talk to me again after he told me that his head hurt."

Because of another widow's spiritual beliefs, she felt she would see him again, death was a temporary situation, "and his going was more of a good-bye." She voiced her belief, in a life hereafter and that she would see him soon. Other widows believed in the life hereafter but didn't voice it in this way.

Regardless of setting, personnel invited them to stay with their expired spouses. This action seemed to promote positive relationships with the wife and the caregivers. One woman reported, "The hospice people told me take your time; you don't have to rush." She further said, "They kept reassuring me even after he died you do not have to call mortuary right away. Sit here as long as you feel you need to. So I was very pleased." Another participant stated, "They let me stay with him as long as I wanted I was with him for about an hour." There was a good-bye to be said after the husband was deceased. Widows need this sacred time with their spouses.

One participant noted that the one of the most helpful interventions was being permitted to be with him after her husband died. "They let us stay there in the room with him. We were there probably for two to three hours." He died suddenly, and she needed

that time to view him, to touch him, to reflect and to pray. Being with her expired spouse by herself was appreciated by this new widow, "I went by myself back to the room."

Realizing Sense of Self

The consequence of a spouse's death promoted the realizing sense of self. It is a new way of experiencing oneself and the experiences that come along with it. In realizing sense of self, there were disturbing situations, aloneness, experiencing peace, and ultimately, finding meaning.

For one wife, a disturbing situation was that she couldn't bear to hear her husband's breathing at the end and to know she was alone. For another, to not hear the voice of her spouse talking to her left its sad mark. Being together most of their lives, it was a real tragedy to suddenly be apart and alone. These widows sought to experience peace and to find meaning in their new sense of self.

Disturbing Situations

Participants reflected on their journey to establish a sense of peace in their lives. However, that sense of peace was disrupted by disturbing situations. Many participants stated that their thoughts were interrupted by memories of unpleasant or difficult situations. For the most part, they felt they needed to deal with these issues by themselves as they lost their major supportive relationship. These recurrent thoughts were unsettling and gave a troubled experience. The widows found it challenging to put these thoughts into perspective. Each widow, however, was in a different place along this continuum. There were often reoccurring regrets, and this further compounded an already traumatic occurrence.

One wife voiced regrets in not returning to the hospital when her husband's condition had changed for the worse. She just didn't know he was going to change so fast. Events that occurred in the hospital she said were disturbing to her. "Those were very hard experiences for me and I kind of mulled through those for quite awhile." Thankfully this widow had some peace with the playing of the harmonica for her and her husband. It seemed the impact of that negative experience was tempered by the peacefulness of his passing.

One participant said she recognized a different self than she thought she was. For this woman, stress-induced palpitations kept her from her husband's funeral. Instead of being at her husband's funeral, she found herself in the hospital. "I'm not aware I'm that kind of person, but evidently I am."

Mortuary personnel were also found to be challenging. When they came to pick up her husband, one participant stated his prized necklace was lost. This was a major regret as it was her husband's treasure and meaningful to her. The people from the mortuary and the widow looked everywhere for the necklace. "We looked everywhere, we looked at everything and I know that woman took it out of the house. I know she did." She frequently reflected on this situation. The loss was difficult for her and she could not let go of this negative experience.

In another instance, the widow stated she wasn't pleased that the mortuary personnel parked in front of her neighbor's house and they appeared to be arguing. "They parked, they parked over here, instead of pulling in the driveway, which I thought was very inappropriate you know why take a body in front of my neighbor's house. I thought they could've pulled in the driveway." So, despite everything going well with healthcare

personnel, there were negative experiences with the mortuary. Negative memories repeatedly occurred.

The hospital infection that took one woman's husband was a particularly tragic regret. The widow stated she just wished she would have known he would have complications from his rib fractures. "If I realized how bad the ribs were broken, I would have put one of these ... binders on him." But, there was no way for her to know this. This widow associated her husband's death with complications related to his rib fractures from a fall. She voiced indirectly that somehow she thought this could have been prevented by her. Reoccurring regrets and his diagnosis and management of his care continued to trouble her.

Another widow voiced she was disturbed by her experience with an untrained caregiver. "She wasn't trained," and "Look, I went to wake her up one night, we were in trouble. She says, 'Oh, wait until morning'" In spite of this situation, the widow said she has no regrets. Still, she continues to discuss this situation and ruminates about it.

Nightmare occurrences were voiced by only two widows, but they could perhaps be speaking for more. No matter how the husband died, the experience it seemed was anguishing for her, the widow. But this particular widow commented, "I had nightmares, dreams for quite a while." Her husband's experience moving around the hospital and the "events at the very end" contributed to these nightmares. Her husband had difficulty finding a hospital placement, and when he did, his wife had some negative encounters with some nurses.

Night terrors plagued another widow after her husband died. Her husband had suffered with pain. She would relive everything in her sleep.

I appealed to my husband's physician, an internist, to give me some medication because I was having a terrible time sleeping. I just had such I called them night terrors. I would just waken and relive everything and everything and I couldn't get it out of my mind long enough to even get any rest.

Despite the disturbing situations, the widows seem to come to terms with these events. They appear to be less traumatized, and with time the nightmares are lessened for one widow. Certainly, there is a developing progression to finding meaning.

Aloneness

Alone. Aloneness was the fear and vulnerability that unnerved some widows. Fearing to be by herself, "Because John and I were always together" was one widow's comment. To be alone by herself in a new assisted living arrangement took courage. She had to make this transition by herself when she had always done things together as a couple.

The fear of being alone and old all by herself was another issue. "They treat all older people bad; I don't know of anyone that's really good to anybody that's old," said one woman. For unclear reasons, she appeared to have lost faith in people and her children, but not in God. She lived by herself with a connection to the church but struggled with grief because of her husband's and son's deaths.

Another woman was cared for by her husband. Now she is alone and had to be a new self. "I [am] just trying to pick up and do things on my own now because I'm not used to it." Her husband handled the finances, and now she had to do her own with the assistance of her brother. She had never handled finances before, but her husband had provided for her well, and she lived a comfortable life in assisted living.

One widow expressed her vulnerability as a woman alone; she felt she could be preyed on. In her new self, a different widow denied depression, but said:

It's like I'm in a canoe without a paddle, you know. Everything keeps going. I keep doing what I need to do, but there's no way for me to direct it. I just have to take it as it comes.

Another widow said, "It was just like he wasn't there, but he was because he couldn't do things and I had to take over doing all of those things and so the loss was already there." With his demise, the widow stated, "I just feel sort of empty." She had had a long time marriage, 57 years, and four children with him.

Although being alone wasn't where the widow expected to be, ultimately, she appeared to accept her aloneness. The widows seemed to come to terms with this aloneness, each in a different way. This was part of the realizing sense of self in experiencing self in this new way, by herself.

Experiencing Peace

These women indicated that a sense of peace was the acceptance of the death of their spouses and how the death occurred. This sense of peace was not wishing things to change but accepting them as they were. One wife said:

I feel that I did everything that I could possibly do.... I felt that I didn't have to say I wish I had, I wish I had done this. I wish I had done that...I think I just did everything I possibly could.

Another widow said, "I don't worry or fret over what could have been done because I felt like everything was done that should have been." That thought echoed again with another widow who commented, "Everything was done that could be done for him."

Another widow said, "I miss him terribly, but I wouldn't want him back the way he was." Her husband had deteriorated over time with Parkinson's culminating in swallowing difficulty and shallow breathing. It was a hard transition from this life to the next reality for this man and his wife.

Because of her husband's spiritual transformation, another widow said she is at peace and with no regrets. Her husband made a spiritual commitment before he died. "I am confident I know where Karl is" and "that has given me much peace, much peace." Most of the wives stated that their husbands were spiritually minded except for two, and this lack caused considerable heartache to them.

Another woman came to a fuller realization of her situation, "I didn't realize he had been taking care of me all these years. I thought I'd been taking care of myself." She said she saw the tremendous need from her husband for her. "I was taking care of him." Although he had taken care of her during the marriage, now she had cared for him in his illness. Because of the tragedies that had come her way, this well-educated and independent widow said she desired to become a better person. "You just kind of become bitter or you become more understanding of other people." She spoke from experience as she had lost multiple husbands and a child. Peace may be elusive, but these widows actualized it in their lives. In realizing a sense of self, there was the satisfaction of this peacefulness and then finding meaning.

Finding Meaning

How to make sense of this loss was something each widow seemed to ask herself. They sought meaning and obtained strength from their religious faith and beliefs.

One resilient Catholic woman related, "I have a strong faith and I ... think there were times when God was there just pushing people in front of me." She saw God's leading during her difficult transition to widowhood. Another widow said, "I feel so grateful that God was just with me every step of the way, every step of the way. He answered every prayer I offered and still does."

"And, ah, I thank God that he didn't suffer the way we were told he was going to," commented one wife whose husband's pain was under control through medications. A very elderly woman was thankful in the way that her husband died without suffering. Just to not see her husband suffer with his disabling illness, she was "happy he is at rest."

Another husband was a man of faith and was not afraid to die. At his bedside, one wife told her husband when he died he would then open his eyes and see Jesus. This comment calmed him, he went into a sleep, into a coma and then into his death. This experience seemed comforting to the widow.

Another widow said, "I'm a Christian and he was a Christian so we believed that, you know, if we die, then when Jesus comes, He will resurrect us, so I look forward to seeing him again." Even though her husband was terminal, he witnessed to his nurse and desired that she would become a Christian. "He was more concerned with her giving her heart to the Lord ... he wasn't concerned about himself, he knew he was going to die, but he wanted to ... invite her to be a Christian."

Watching her husband suffer made one widow say, "I just felt like this was not fair, the world was not fair, where are you God?" With her husband's suffering and death, her faith seemed to have sustained a major blow. She is a woman of great spirituality, but it seemed within her spiritual journey it was a time of despair.

Some women voiced their emotional pain as their husbands did not share their views of spirituality and faith. As they sought meaning in their own lives, they kept their faith in spite of their husbands' differing views.

Unfortunately for one husband, he thought it was too late for him spiritually and for spiritual intervention. He observed, "I think it's too late for that." He wasn't happy with his life decisions of drinking and being estranged from his daughters. The widow seemed to find his spiritual decision devastating. Another widow had a husband that wanted no exposure to spiritual interests; this decision appeared to be heartbreaking for the widow then and now. He even didn't want to hear her talk of spiritual topics on the phone to friends. She says, "I'll have to wait and see." This was a topic that caused emotional pain for these two widows and this was seen by their serious facial expressions as they reflected on their husbands' spirituality.

For another widow on the loss of her husband, she said, "I don't come to tears over it a whole lot because I just know that he believed in God and that we have a Blessed Hope." Conversely, one widow says she is joyful because of her husband's spiritual transformation before he died. "All of a sudden he started praying and he asked the Lord to forgive him any of his sins for his whole life." Despite her loss, she has joy and is exuberant.

Her husband's end-of-life care has made one respondent seem to appreciate what she had. "I miss him, but I'm sure that he would have wanted me to carry on, just what I've done." She is active in her church and says she contributes to worship books. She says she knows what the journey is all about and she is able to help other wives and their husbands.

These widows found meaning in their spirituality and faith traditions and had a new realizing sense of self. This new awakening occurred because of their life-transforming experience of widowhood.

Shared Presence: Caring for a Dying Spouse

Going through this journey with their husbands, widows experienced awareness of impending death, forming connections, and realizing sense of self (See Figure 2). Although present in distinct categories, these three categories also overlap with each other and the relationship between them forms the emerging theory. These categories point to the more abstract core phenomenon of being there. Within these categories and through the process of developing this theory, the three lines of inquiry are illuminated.

All these pieces emerge into a theory of Shared Presence: Caring for a Dying Spouse at the end-of-life. It was in this time and in this place for this, to occur, the transition to the end-of-life for the wife and husband.

Awareness of impending death is important because that is where the theory started with the widows involved in the last moments of their husbands' lives and they became cognizant of their husbands' ensuing death. This category overlaps with forming connections. Because of the death experience, there is an acute need for involvement from family, health care providers, and spiritual leaders. There wouldn't be such a great need for connections if this death event were not occurring.

Forming connections are important in their own right because of the acute needs of the widows. Realizing sense of self relates to these other categories. Because of the impending death and relationships to others, the widow realizes her own sense of self. Although there are disturbing situations and feelings of being alone, she ultimately finds

peace and meaning. All of these categories and the core phenomenon support the theory

Shared Presence: Caring for a Dying Spouse.

Figure 2: *A Theoretical Model: Shared Presence: Caring for a Dying Spouse*

Chapter V: DISCUSSION OF FINDINGS

Presence is vital in a disconnected world. An enduring relationship such as that of a husband and wife in shared presence is very important in this time. More attention to presence is being given by researchers. In this current research there was a vital connection between the husband and wife, the experience of Shared Presence: Caring for a Dying Spouse. Theoretical perspectives which are close to shared presence are grief and presence.

Theoretical Perspectives of Grief

Sigmund Freud, a ground-breaking psychiatrist, is seen as a significant figure in “the theoretical understanding of grief” (Walsh-Burke, 2006, p. 46). Freud wrote of attachment that develops in infancy and then letting go of that attachment at death. In this current research, this attachment was the relationship between the husband and wife. They had gone the road together throughout life and now the time was here, unfortunately, to relinquish that important attachment.

Although there is not a typical loss (Kübler-Ross & Kessler, 2005), the early work by Kübler-Ross (1969) gives some direction on the stages of grief in her enduring classic *On Death and Dying*. These stages are denial, anger, bargaining, depression and

acceptance.

These stages are seen as close to shared presence as the widow makes the journey with her spouse. Some widows had denial that their husband would die, and one thought it was moving fast. Several widows were angry, one because her children were not available emotionally to her. Then another was angry because of a lost item that occurred during the time the mortuary personnel came for her husband. She thought the personnel had taken this item, and she wanted it back.

Instead of bargaining, in one example a widow petitioned the Lord for her husband to die. In time he did pass, and she was at peace he was no longer suffering. Depression was seen in one woman as she shared her story, but when questioned, she denied depression. For another widow, she admitted to struggling with depression and still struggles with it. Most widows found acceptance or peace in their comforting religious beliefs, in their spiritual and faith traditions.

Mahoney's (2003) theory may be used as a constructivist perspective on grief. There are "active agency," "ordering processes," "personal identity," "social-symbolic processes," and "dynamic dialectical development" (p. 5).

Active agency reflects humans' participation in their own lives. Our choices influence us and others. Ordering processes relate how we need organization in our world. Often we do this without being conscious of it. Personal identity comes by an organized world and then an organized self. Social-symbolic processes recognize our sense of self in a relationship. It is "what we feel with one another" (p. 7). Dynamic dialectical development reflects the ebbs and flows of life as we try to achieve a balance,

but balance is elusive. Thus, a constructive view focuses on a “meaningful action by a developing self in relationship” (p. 5).

Ultimately in this research, its meaning is in understanding the widow’s experience. Mahoney (2003) saw the body and mind interacting, giving an individual her sense of identity in the grief encounter. Dramatic change occurs when the wife loses her husband. There is a significant upheaval psychologically, and its impact is also on the philosophical core. “It entails a search for an accepted meaning of the event so it can be an integral part of the reconstructed belief system” (p. 77). Thus, basically the philosophy that guided a widow undergoes change. This constructivist perspective makes a way to find meaning without the spouse.

*Theoretical Perspectives of Presence

Presence is a fundamental concept for nursing. In Hines’ (1992) classic piece, a concept analysis for presence in nursing is captured. She found the attributes to be “time with another ... unconditional positive regard ... transactional speaking with, being with, doing with ... encounter that is valued ... connectedness ... and sustaining memory” (p. 294).

Further, she describes how a nurse may use presence. Recommendations are to use the patient’s name, make eye contact, and hear the patient out. Continuity of care is also pivotal. This presence is related to the nurse-patient relationship while Shared Presence: Caring for a Dying Spouse is the dyad of husband and wife.

Fingeld-Connett (2006) relates that presence, although not completely understood, should not be seen, for example, as the same as caring. Presence is known by “sensitivity, holism, intimacy, vulnerability and adaptation to unique circumstances”

(p. 708). Both nurse and patient must be open to the idea of presence for it to materialize.

Regarding family presence, which is a kin to Shared Presence: Caring for a Dying Spouse, several related research studies were done in the critical care setting. The majority of emergency and critical care nurses welcome family presence for CPR and other procedures. Nurses recognize families want to be with their loved one even during codes and invasive procedures (MacLean, Guzzetta, White, Fontaine, Eichhorn, Meyers et al., 2003). However, only 5% of units have written policies for family presence.

In a similar study of family presence occurring during resuscitation, the nurses who supported them had higher self confidence and felt they could handle the situation. “Nurses who invited family presence during resuscitation were significantly more self-confident in managing it and perceived more benefits and fewer risks” (Twibell, Siela, Riwitis, Wheatley, Riegle, Bousman, et al. 2008, p.101). If the nurse saw more benefit for family presence, it was because she works in the Emergency Department, is certified, or is a member of a professional organization.

Stokes (1999) did a thought provoking study on “ministry of presence” and “presence of the Spirit” (p. 193). In her study they may happen separately. But with good presence of the chaplain, the Spirit may happen naturally. However, Stokes found the Spirit only occurred if the patient had that experience before. She concluded in her piece that “ministry of presence ... refer[s] to more graced and mutually experienced ministry (p. 199).

Bereaved Widows

Other research strands are in the works of different researchers interested in the lives of widows. Rodger, Sherwood, O'Connor, and Leslie's (2006-2007) study focused

on the “sudden death of a partner” (p. 107). In their study they found it is distressing to maintain tasks of everyday for the survivor. While coping with grief they had to function with day-to-day details. From another perspective, the widows could see a life anew with prospects of perhaps a new partner and a new future.

Grief experiences of older women whose husbands were under hospice care have also been explored (Jacob, 1996). Stressors were the husbands’ declining health and then their deaths. The widows quickly had to take on new responsibilities. Older widows needed to be encouraged to have a “voice” in seeking support. Loneliness was a big area of need – with grief going longer than one year and the widow replaying sad pivotal events.

Stroebe, Stroebe, and Schut (2001) reviewed gender differences in bereavement. Both genders have increased illness and death, but widows do better than widowers in that initial phase after the death. Women have a better network of friends than the widowers, and thus, more social support.

The benefit of laughter and humor for the newly bereaved is the study conducted by Lund, Utz, Caserta, and deVries (2008-2009). Most of their sample were women (61%) and over the age of 50. The widowed valued humor, laughter, and happiness. Interestingly, it was a bigger part of their lives than they foresaw. These positive emotions lessened grief and depression for the widows. In this current study and during these interviews, a few widows saw humor and laughed at some memories of their husbands. Since there is minimal data from this current study, the role of humor and laughter may be an area of further exploration.

Research Supporting the Dimensions of Shared Presence: Caring for a Dying Spouse

Awareness of Impending Death

There is some related support for awareness of death. In an earlier work Redinbaugh et al. (2003) found there is less stress if a family could reconcile themselves to the disease course and manage “illness-related problems” (p. 901). Hospice personnel have the ability to share with family what to expect as their loved ones face impending death as they have both knowledge and experience (Nolen-Hoeksema et al., 2000; Waldrop, Kramer, Skretny, Milch, & Finn, 2005). This knowledge aids in hearing the news and accepting the impending death. Even so, hospice personnel could still give more information.

Farber, Egnew, Herman-Bertsch, Taylor, and Guldin’s (2003) research revealed how the caregivers, most of them wives, looked at the awareness of death. So while they did their caregiving, they knew their lives would shortly be fundamentally and dramatically changed by the loss of their spouses.

This study is also reflected in Francke and Willems’ (2005) research. The subjects were “relatives of deceased patients” (p. 241) and terminally ill patients who stated their degree of awareness as death was approaching. Realizing too late that death was imminent gave less time to have resources available for the family and a home ready for a very sick person. In this current research, the reality was that some of the wives were more ready for the death of their spouses than some other wives.

Family Relationships

Their roles as wives were critical and demanding (McMillan, 2005) as they cared for their husbands at the end. Many of the widows in this current study were with their

husbands as they died and, thus, a part of that experience. For example, one would not allow hospital workers to leave her loved one in the hospital corridor. In the research of Tschann et al. (2003), if the families were there at death, they were more likely to be there during the hospitalization. Families impacted the direction of health care and even the time of death for DNR (do not resuscitate) orders were written with family there and made a way for a “shorter time to death” (p. 835).

Family has been important throughout time. Wolf reviewed periodicals in the 1800s and 1900s where it was revealed families had a need to be with the dying person (Montagu as cited in Wolf, 1991). This presence reinforces this theme of sustaining family relationships and how the extended family helps the widow at the death of her husband. Family was available at his passing and was actively involved in the widow’s life.

For these older widows in this current study, they received vast social support from their children. Many of these widows had fewer people in their lives, but they were quality social support. Bishop, Martin, and Poon (2006) reflect that the quality of the social support is more important than contact and network size.

In a systematic review of the literature, Andershed (2006) shared her findings for families and their loved ones at the end-of-life. These findings reinforced families’ need to be present and their need to do positive things for their loved one. Both in this reviewed study and the current study were the importance of relationships between the professionals and family caregivers.

Care and Comfort

Hospice is valued both by participants in this study and by those in others. Caregivers appreciated the wholistic care which hospice provided (Newton et al., 2002). Wholistic care included psychological support, management of problematic symptoms and formation of positive relationships.

As noted, bathing was a priority by nurses and widows in this current research. This finding was supported in the research by Nolen-Hoeksema et al. (2000) where families wanted their family members to receive baths more than two times a week. If the family didn't get the needed daily care for their loved one, they were dissatisfied.

Pain remains the problem as reported in Tolle et al. (2000). Professionals' attention to controlling pain was appreciated by the family. In this current study pain was controlled and was not as large an issue as it could have been. Husbands had minimal, controlled, or no pain although one husband had pain at the end.

Each widow wanted something different done. It may be how her loved one was approached, how often he got bathed, or the involvement of healthcare professionals after he died. Open lines of communication were needed to ensure this quality of care. The research of Hanson et al. (1997) substantiated that communication is important for seeing what the family needs. For end-of-life care to be more beneficial, family members rated communication as a key factor.

Spiritual Solace

Widows in this study talked of praying constantly, petitioning the Lord, and having faith in God. Spirituality was very important to all widows in this study. Their

spirituality is at their core across religious affiliations. They have strong faith from their various religious traditions. In Yoon's (2006), study it was revealed that "elderly individuals who reported looking to God for strength and comfort or deciding what to do with God were more likely to have greater life satisfaction" (p. 70). The research of New York psychologists Frantz, Trolley, and Johll (1996) views bereavement and religious beliefs and practices in adults. Religious beliefs aid positively with coping with bereavement. A belief in the life hereafter is also noted to be a comfort to the bereaved in this published study.

Other reviewers found it is true that "older women use religious coping" (Michael, Crowther, Schmid & Allen, 2003, p. 145). Also, they are shaped by their beliefs of spirituality to aid them in the transition to widowhood (Michael et al. 2003). Lobar, Youngblut, and Brooten's (2006) qualitative work viewed death rituals and "death of a loved one" (p. 44). Families' beliefs shaped the rituals and the ceremonies they did to ensure "passage to God, the 'light,' or another life" (p. 44).

Daaleman, Usher, Williams, Rawlings, and Hanson (2008) studied spiritual care at the end-of-life. How do clinicians and healthcare workers view spiritual care given to those at the end-of-life? They see spiritual care as an important part of end-of-life care. Spiritual care is seen "as a series of highly fluid interpersonal processes in the context of mutually recognized human values and experiences, rather than a set of prescribed and proscribed roles" (p. 406). Being present is the major theme.

Core Phenomenon: Being There

Casarett et al.'s (2003) study concerns the last 24 hours of life. If symptom management is satisfactory, family members are pleased. This satisfactory symptom

management supports the qualitative findings in the current study. Whether managing a fever or keeping the mouth moist, widows were pleased with this nursing care for their husbands.

Also, widows wished to be near their loved ones, and the environment must be therapeutic for them. This finding was supported by the work of Pierce (1999) where she stated the dying family member and family must have time and space together.

In this current research, a widow talked of phone availability which she appreciated and that she utilized. In one instance a wife called a nurse colleague of her physician husband in the middle of the night for assistance. This helpfulness of phone availability of nursing personnel was supported by the research of Rickerson et al. (2005).

Warren's (2002) research communicated that family members whose loved ones die in critical care discussed their dissatisfactions. "Not being present at time of death" (p. 54) was one of these concerns. Other dissatisfactions were availability of the doctor, the reason for death, insufficient intervention and staff who didn't care. Being there is very important in Warren's research as well as the current research.

Wives showed deep caring by being there at their husbands' deaths. "Being present with others is truly the gift of caring" (Authier, 2004, p. 276).

Physical Contact

Even though a husband may be dying, he still feels the importance of touching and being touched. In this current study widows held their husbands in their arms as they died. Some wished to hold his hand or comb his hair. This touching is able to affect him positively (Cort, Monroe, & Oliviere, 2004). Further, these authors state:

as they approach death people's need for physical closeness, to touch and be touched, may be much more significant in terms of quality of life ... It is essential to regard sexuality and intimacy as fundamental, integral aspects of palliative care.

When AIDS patients at the end of their lives had meditation and received massage, it improved their spiritual and overall quality of life. These researchers (Williams et al., 2005) point out with the stigma of the disease, there is physical isolation. It was found that massage is a necessary component for the aspects of spirituality to be recognized. Perhaps in this current research these husbands were aided spiritually by being touched at the end-of-life.

In another study, it was discovered that massage in cancer patients is helpful with pain and mood. Even simple touch proved beneficial (Kutner, Smith, Corbin, Hemphill, Benton, & Mellis, et al., 2008). The therapy of touch aided these husbands and wives.

Traditionally, touch is not seen as appropriate for psychiatric patients because of the fear of aggression or the thought of destructive sexuality. However, in this study, touch was seen as important to this small research group of four psychotic patients. Touch is "a path through which one feels acknowledged as a human being" (Salzmann-Erikson & Eriksson, 2005, p. 843). From person to person there is physical communication. From wife to husband there is physical communication.

Saying Good-bye

In this current study, the widows discussed good-byes, but they were not said for a variety of reasons. A husband didn't want his wife to say good-bye. Some husbands died suddenly. One husband was heavily medicated. And for many wives, the opportunity was simply lost. However, other researchers, Frantz et al. (1996) found it was

important to say good-bye to their loved ones, not just a half-way good-bye, but one that was good, right, and complete. It gave positive closure with the loved one and “related to positive coping and outlook” (p. 151).

A good-bye is also important for the husbands. It was found to be the biggest worry of patients if they were “vegetable-like” and could not “say good-bye to someone” (Matters that Worry, 1998, p. 8).

The moment of home death was discussed by ten families. They spoke of the “breathing” of the terminally ill and the “mystery” (Donnelly, Michael, & Donnelly, 2006, p. 352). With the last breath death occurred for the family and the mystery was the supernatural experience of his parting.

Rituals are important to saying good-bye. For one chaplain (Berndt, 2004), it was making arrangements for the nursing home staff and residents to say good-bye to a deceased resident. There is “a bedside prayer service” (p. 53). A chime would ring three times and the deceased’s name would be announced. Instead of going out a back door, the deceased would leave through a main door of the nursing home with his/her casket draped with perhaps a quilt. One resident said, “I know that how you remember and take care of my neighbors is how you will remember and take care of me” (p. 54).

Final moments are also important for the husband and wife. It was not possible for all to achieve that intimacy at the end-of-life, but those final moments may be sacred and memorable (Valentine, 2007). With the current study widows gave physical contact and there was music for some of the husbands.

Disturbing Situations

New widows have a 40% increased chance of hospitalization according to Laditka and Laditka (2003). "Social connectedness measured by having phoned a friend/neighbor or family member in the period prior to the baseline survey, significantly decreases hospitalization risk for the recently widowed" (p. 7). In the current study this situation was one widow's experience as she was hospitalized for cardiac palpitations and missed her husband's funeral.

In addition, mental health may be adversely impacted as well for the new widows (Wilcox et al. 2003). "Married women reported better physical and mental health and generally better health behaviors than widowed women" (p. 513). In this current study, one widow freely admitted her ongoing depression since her husband's death. Another widow seemed depressed, denied it, but felt adrift.

There is support for the finding of disturbances in sleep as some widows had night terrors and nightmares (Longman et al., 1989). With intrusive dreams the widows did not have proper rest at night.

Warren (2002) relates a disturbing situation which is an uncaring staff. One participant felt they didn't care for the elderly man. They found him useless. One wife in our current study also worried about how she would be treated as an elderly woman. Further, a participant didn't feel a doctor was available when her loved one was in a critical condition. In this current study doctors were available but how one pronounced death was disturbing to the widow as he seemed unsympathetic.

Aloneness

Loneliness is a part of everyone's experience; it is a human condition (Killeen, 1998), and it is felt acutely at different moments of one's life. As expected, it was difficult for some widows to go on without their spouses. They were alone now, making their own decisions and planning their own life course. This loneliness was supported by the research of Kowalski and Bondmass (2008).

Husbands and wives had been a couple and now they were not, they had done everything together and now that was ended. This finding relates back to Wennman-Larsen and Tishelman's (2002) study of caregivers. Often the person who dies is the major person for talking and support. The husband was the wife's main support and now she was alone.

In Porter's (1994) study, she stated how widows made "aloneness acceptable" (p. 21). The widow depended on extended family. Also, the companionship of pets was very important. The widow would leave the home when she felt confined and return to the empty house feeling okay. Finally, she began new ways with her daily routine. These current widows also had new places to live, some of them had dogs and were active in their faith communities.

Experiencing Peace

The literature was not strong with the connection between peace and widowhood. Actually, there was a dearth of research literature regarding peace and widowhood. In an early study, Thompson, Gallagher-Thompson, Futterman, Gilewski, and Peterson (1991)

found that widows have grief for 30 months or more. Thus, it is difficult to have peace until there is resolution of this grief.

These widows in the current study had been widowed for 6 months to 10 years. Some were further along in experiencing peace in their widowhood. One widow cried throughout the interview but was thankful for the time we spent together.

An even earlier study by Carey (1977) looked at widows' adjustment one year after the loss; those who adjusted best were older and better educated. In this current study, most of the widows were professional women and are older. They had a range of occupations from gas station manager, switchboard operator, teachers, nurses and physician. All were on the trajectory to having peace.

Finding Meaning

The widowed need time to grieve and to reformulate new lives without their partners. Winter (1999) recommends to not spiritualize bereavement. It is appropriate for "spiritual" people to manifest their sorrow even when their ultimate hope is of life in the world to come. In other words, it is quite acceptable to have grief and to express it even if one is a person of faith. Widows expressed their sense of loss, their feelings, and their strong faith. "Spirituality is common to all people of any or no belief" (Heyse-Moore, 1996, p. 297.)

Balk (1999), an Oklahoma family relations and child development professor, wrote of bereavement and spiritual change. Spiritual change may occur if there is a crisis, a crisis such as bereavement. "Life crises are dangerous opportunities," states Balk (1999, p. 486). A person's spirituality is challenged.

Three events may happen. First, there may be a psychological imbalance that isn't easily corrected. Second, there may be time for contemplation, and, thirdly, this bereavement event changes a life fundamentally. For a surviving spouse, this spiritual change could give a whole new way of seeing the world, a new world view. Because of these happenings, spiritual change has the opportunity to occur.

Guttmann (2001) states "human beings are motivated first and foremost to finding meaning in life" (p. 117). This meaning is best attributed to how we feel about others and God. A major disappointment such as a loss of a spouse is an opportunity to find meaning, and each person will come to a different meaning.

Interestingly, Foley (2000) found women who had good health and were college educated had high scores in spirituality. Spirituality becomes more important as people age. This spirituality aids in finding meaning in life.

Concluding Thoughts

Research on these widows' end-of-life experiences fit in centrally with published research. It reinforced positively family relationships, spiritual solace and the theory of Shared Presence: Caring for a Dying Spouse. Also, this current research adds to the literature of aloneness and experiencing peace as there is a paucity of support in the research literature for these dimensions.

In thinking about hospice and hospital, hospice seemed to have a more serene backdrop than the hospital for the wife and husband. Within the hospital was movement from unit to unit. One gentleman had difficulty finding an available bed. The institutional setting such as a nursing home can cause the confusion of room-mates when a family may only want a peaceful place to be together such as what is provided through hospice.

Both hospice and hospital had positive and negative things said about them concerning caregivers. As mentioned earlier, there were some isolated events which were negative. Relating pronouncement of death could be difficult in both settings. Both places allowed the wives to hold their husbands as they died. In one instance the hospital nurse didn't know her place, taking the wife's rightful place at the bedside. Both settings were needed and physicians and nurses shone as they attempted to meet the needs of the wife and husband during the end-of-life transition in Shared Presence: Caring for a Dying Spouse.

Chapter VI: IMPLICATIONS

In this study a very sad event was discussed, the loss of a husband. By sharing their experiences, the widows will help other wives as they make this journey in saying good-bye to their husbands. The widows were transparent in relating their experience and in their desire to transform hospital and hospice care for others.

In addition, this study begins to fill a gap in the literature about widows' perceptions of hospital and hospice care of their spouses. It starts the dialogue on the theory, Shared Presence: Caring for a Dying Spouse, and the discovered categories: awareness of impending death, forming connections, and realizing sense of self.

Critique of the Study

Data was collected in a largely Christian community. Participants all tended to have strong marriages and religious beliefs. For the most part, all 25 were excellent historians. All widows appreciated being a part of the study as they believed they would help other widows. There are some restraints due to its limited ethnic diversity and geographical boundaries of being based only in Southern California. In a similar study it would be telling to have other faith traditions such as Jewish and Muslims or even those who do not adhere to a faith, participate.

Implications for Practice

A greater substantial focus on palliative care is needed in academic nursing curriculums. Programs from associate degree to doctorate need to address the topic of palliative care for all populations. Nurses are in a unique leadership role to serve those in need of palliative care whether as staff, advanced practice, education or research. Widows perceive nurses as caring and competent. Indeed, nurses have a unique ability for establishing relationships and performing well clinically. They have the widow's comfort and welfare in mind.

In this study, participants viewed nurses as kind, having positive attitudes and positive interactions. Cleanliness and help with baths by nursing personnel were appreciated by the widows as it was difficult for a wife to provide the necessary care. Nurses knew how to keep a husband comfortable with medication, drops of water, and turning. All of this expertise was appreciated by the wives.

A widow also needs to be encouraged to take her rightful place by her husband as he dies. The nurse needs to step back and let the widow have this prominent place; indeed, it is important that the nurse know her place. The nurse may gently guide the wife to be at her husband's side and hold his hand.

Consistency and sensitivity for all death pronouncements are important from both doctors and nurses. These are pivotal moments for a surviving spouse. The pronouncement of death created a contented or discontented widow. Caring professionals need to be aware how important this passage is to a family. To break the news compassionately, to be sympathetic to the widow, and to not be in hurry seemed to be appreciated approaches.

Lacking referrals for follow-up bereavement support, widows may opt to go it alone. Community resources are needed, and churches could take a greater lead in offering this important bereavement support outreach. A chance to share emotions and events could only be beneficial for the newly bereaved widows. If there are community resources, the word needs to be better relayed from nurses in the hospitals and hospices so the widows have the opportunity to go if they so desire.

Implications for Further Research

A larger quantitative descriptive study is indicated related to pronouncing death in a loved one (Lobiondo-Wood & Haber, 2006). In this current research, doctors and nurses were seen as either being sensitive or lacking compassion in giving the death news to different families. Unfortunately, doctors and nurses have seen death before, but most widows don't have routine exposure to this sad experience. Happenings in the hospital are not regular occurrences to them. The transition needs to be more sensitive and health professionals need to see more of what the family is experiencing. Further study is indicated regarding the way death is pronounced and how the family is treated during this sensitive time.

In this study the researcher saw more of what nurses do that is considered therapeutic. It would benefit wives for researchers to do an intervention study to see what a difference it is for a spouse to die in the arms of his wife. Several widows talked of their experience with this situation. One time this holding was suggested by a nurse, and other times the wives initiated it. It may be beneficial to suggest this holding to other wives; the nurse could suggest wives' human touch with their husbands at the end-of-life and note the wives' perceptions.

The shared experience of illness and death by spouses and their decision-making process about goals of care also need to be further explored. To examine post-bereavement adaptation is also a need with a continued focus on satisfaction with hospital and hospice care.

The literature suggests that laughter and humor may have a positive effect on the bereavement process. Although there was indication in this study that was of benefit, the data are insufficient. Further exploration of this phenomenon is indicated.

This study captured mainly Caucasian, with the addition of one Black/African American and one Mexican American. The diversity of Southern California could include more Black/African Americans and Hispanics as well as Asians. For the continuity of this research, it could be ideal to start in different ethnic churches or ethnic social gatherings. It would also be of great interest to have only a Black/African American group or a Mexican American cohort to see the richness of their tradition, faith, and culture play out in an engaging qualitative study of widows' perception of hospital and hospice care of their spouses.

There could be a difference in perceptions when the wife loses her spouse suddenly or as a lingering experience. What is her satisfaction with care at the end-of-life related to this? Also of interest is when the wife has to transition her husband to hospice or hospital. What would make this change go more smoothly and positively for the wife? A lack of bereavement care seems to be a concern. Follow-up models that have been successful need to be identified and evaluated.

As there are no instruments readily available, as a catalyst from this study's theory, they could be developed. One could explore the benefit of touch in those last days

of life. It would see how the widow could be supported in holding and touching her spouse at the end-of-life. Another instrument would see how she may be best supported by her family and friends. Perhaps another instrument could view what nursing cares widows' desire most for their spouses and their subsequent satisfaction. These instrumentations could be beneficial in bereavement care.

Refinement of Theory

Qualitative results provide thought and direction for other studies. The emergent theory Shared Presence: Caring for a Dying Spouse needs to be further explored and tested. A series of focus groups would be considered an appropriate follow-up. First of all, gathering widows who have not been a part of this study, researchers could present the model for discussion. Secondly, would be focus groups with other ethnic backgrounds. And last, some widows who have had several husbands could be included in a different focus group than the one-time widowed. However, the decisive question is: Does this emergent theory represent the widow's experience as seen by the model?

Bereavement outcomes continue to be of interest. They need to be further conceptualized and tested. Positive and negative bereavement outcomes by health care professionals may be ascertained by noting how frequently grief is identified, depression treated, and medication recommended for sleep disturbances.

The hospice's caring model of offering bereavement services such as individual counseling and/or support groups remains important. Many hospitals offer community-based bereavement support groups as well. Effectiveness of these approaches needs to be further evaluated.

Widows could be encouraged to talk more about negative experiences after the loss of their husbands and how it has affected them. Collaborative efforts could be made with other helping professions such as counselors or marriage and family therapists for complicated grief reactions.

Conclusion

The importance of being together at end-of-life was a part of the journey of marriage for the widows and their spouses. Sharing these sacred moments as husband and wife together in a mostly supportive medical milieu contributes positively to the end-of-life experience and then the immediate bereavement period.

Coming through the experience of their husbands' illnesses, the widows were supported by their families. Together the husbands and wives benefited from the care and comfort of healthcare personnel. The wives also had their personal faith to see them through, and it was reinforced by clergy for themselves and their husbands. Disturbing situations arose as well as aloneness, but, ultimately, there was peace and finding meaning.

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Appendix A

Recruitment Advertisement

Participants are needed in a Research Study regarding

A Widowed Woman's Experience of her Husband's Last Days of Life

I am seeking women who have been widowed for over one year for a research study. Doctoral nursing student wishes to ask you a few questions about your husband's last days in a hospice/home or hospital. It should take about one hour and can be at a location convenient for you. Please contact Lana RN 909-796-1246 for more information. Leave a message and repeat your name and phone number slowly. I will return your call.

Appendix B

Flyer

**Are you interested in participating in a
study on the last days widows spend with
their dying husbands?**

- If you have been a widow for over one year and your spouse died in hospice or in the hospital, you are invited to share your experiences
- Sharing your experiences would educate nurses in providing better care for the dying male client and his wife
- Your involvement would consist of a 60-minute audio-taped interview

A University of San Diego graduate nursing student needs 30 widows for study participants and would like to meet you.

**If you are interested or would like more information,
please contact**

Lana S. Kanacki, MS, RN

909-796-1246 or e-mail: llkanacki@llu.edu

Appendix C

Telephone Response to Potential Participant Calling Researcher

Hi, this is Lana Kanacki.

What is your name? Thank you for showing interest in my research study about widows.

Pause.

I am a doctoral nursing student at the University of San Diego and an RN. This is a difficult time for you and I appreciate you calling me.

Pause.

Have you been a widow over one year?

Pause.

OK. I would like to ask you if you would consent to a taped interview for about 60 minutes. We could meet in your home, in a quiet public place or in a private conference room on the campus of Loma Linda University. What would work best for you?

Pause.

What would be a good time and day for you?

Pause.

(Make appropriate arrangements, including driving and parking directions) I'll see you then. Please call me anytime at 909-796-1246 if you need to contact me before then or cancel. It's OK if you decide this is not for you.

Appendix D

Researcher Calling Widow

Hi, you don't know me personally, I'm Lana Kanacki and a doctoral student at the University of San Diego and an RN. I am calling you because your friend gave me your name as a referral.

Pause.

My research is on widows and I'm conducting individual interviews of about 60 minutes a piece in a quiet public space.

Pause.

Would that be something you would be interested in?

Pause.

Appendix E
Demographic Questions

1. What is your age?
2. What is your race? ___ White ___ African American/Black ___ Hispanic/Latino
___ Asian ___ Native American ___ Other
3. What is your religion?
4. Do you have children? ___ Yes ___ No
5. If yes, how many children do you have?
6. Is there anyone whom you can depend on for emotional support?
7. What is/was your life occupation?
8. Where do you consider your home?
9. Is this where you and your husband lived?
10. How many years were you married?
11. What was your spouse's medical diagnosis?
12. Was your spouse's death sudden or lingering?
13. Was he cared for in a ___ hospice (home) ___ hospice (facility) ___ hospital?

Appendix F

Research Participant Consent Form

Widows' Perceptions of Hospital and Hospice Care of their Spouses

Lana Kanacki RN is a doctoral student in nursing at the Hahn School of Nursing and Health Science at the University of San Diego. You are invited to participate in a dissertation research project she is conducting for the purpose of exploring widows' experiences of the care their husbands received in a hospital or hospice during the last days of life.

The project will involve one interview that asks questions about what it was like for you during the last days of your husband's life. The interview will last about 60 minutes and also will include some questions about you, such as your age. If it's OK with you, Lana may also contact you once by telephone in a few weeks after the interview for about 10 minutes to clarify what you told her.

The interview will be at a time and place convenient for you. Participation is entirely voluntary, and you can refuse to answer any question and/or quit at any time. Should you choose to quit, no one will be upset with you, and your information will be destroyed right away. Your health care and other social services you might receive will not be affected at all if you decide to quit.

Your interview will be audio-recorded, written, analyzed, and studied in a manner that protects your identity. This means that a fake name (pseudonym) will be used instead of your real name. A transcriptionist (a person who types your words while listening to your audio-recordings) will sign a pledge of confidentiality before doing this work. Any information provided and/or identifying records will remain confidential

and safeguarded in a locked fireproof safe/file in Lana Kanacki's home/office for a minimum of 5 years.

The results of the research project may be made public and information quoted in professional journals or meetings, but your real name will never be used. Deciding not to participate or answer some of the questions will have no effect on your healthcare or any other services you might receive from doctors, nurses, or social services. There may be a risk that talking about the experience during the interview may bring up sad memories or make you feel tired. **If you would like to talk with someone about your feelings, you can call the San Bernardino Access Unit 909-381-2420, 24 hours a day.** Remember, you can stop the interview at any time you feel tired or for any other reason.

If you participate in the study, you will receive a Target gift card worth \$10. Lana will give you this card whether you decide to complete the interview or not, or even if you decide you don't want to be in the study. The other benefit to participating will be in knowing that you helped nurses learn how to help wives better during the last days of their husbands' lives in a more effective way.

If you have any questions about this research, please contact Lana Kanacki at (909) 796-1246 or her research advisor (an impartial third party) at the University of San Diego School of Nursing, Dr. Patricia Roth at (619) 260-4572.

I have read and understand this form, and consent to the research it describes to me. I have received a copy of this consent form for my records.

Signature of Participant

Date

Name of Participant (Printed)

Signature of Principal Investigator

Date

Appendix G

Typist's Confidentiality Pledge

I will be typing Lana Kanacki's typed notes from her transcriptions of her interviews for her dissertation research.

Widows' Perceptions of Hospital and Hospice Nursing Care of Their Spouses

I promise to hold all individuals' interviews confidential and to maintain their anonymity. I will not talk of the interviews to anyone. To do so would otherwise be a serious ethical breach.

Signature of Typist

Date

Signature of Principal Investigator

Date

Appendix H
Interview Guide

Widow #1

1. I would like for you to tell me about your experience. That is, your experience about your husband's final days before he died.
2. What initiated hospice/hospital care? Tell me about it.
3. Tell me about your perceptions of the facility (hospice, hospital) where your husband died.
4. How would you describe the comfort measures your husband received? Probe: Was there anyone in particular who assisted you with his comfort?
5. How was his comfort level in his last hours?
6. How were emotional and spiritual care administered to your husband? Probe: Who?
7. If there is one, tell me about the significant person who cared for your husband.
8. What was helpful about the care your husband received?
9. What was most helpful about the care you received right after your husband died?
10. What care would you have liked seen done for your husband?
11. How do you feel your husband's end-of-life care has affected your personal outcome? Probe: How have you been?
12. Is there anything else you would like to share with me?
13. How long have you been a widow?