Dying as an individual: A call for a patient-centered approach to hospice care research

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DYING AS AN INDIVIDUAL: A CALL FOR A
PATIENT-CENTERED APPROACH TO
HOSPICE CARE RESEARCH

by

Sarah Nicole Nebel

Bachelor of Science
Northern Arizona University
2006

A thesis submitted in partial fulfillment
of the requirements for the

Master of Arts Degree in Communication Studies
Hank Greenspun Department of Communication
Greenspun College of Urban Affairs

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ABSTRACT

Dying as an Individual: A Call for a Patient-Centered Approach to Hospice Care Research

by

Sarah Nicole Nebel

Dr. Tara Emmers-Sommer, Examination Committee Chair
Professor of Communication Studies
University of Nevada, Las Vegas

This investigation focuses on patients’ perspectives of hospice care as relating to the communication of the wholistic\(^1\) health care approach defined in the mission of hospice care. Given research reveals that the communication of wholistic health care is affected by factors such as individual patient health, social support systems, and interdisciplinary teams (IDTs), this study aims to examine whether the original hospice mission has been met, maintained, or communicated to hospice patients. Semi-structured, open-ended interview questions explore patients’ perceptions of wholistic care and interdependence with the participants, in their health care. Responses reflected that patients are unaware of all the services offered under wholistic care. Furthermore, through the lens

\(^1\) Patients perceived *holistic* health care to be synonymous with Eastern healing philosophies, which incorporate medical practices “outside the mainstream of scientific medicine” (holistic, n.d.). To emphasize hospice holistic care as comprehensive care for the whole individual, this study utilizes an alternative spelling of *wholistic.*
of relational dialectics, patients are unable to receive this comprehensive care and struggle between the tensions of openness and closedness, autonomy and connectedness, and uncertainty and certainty as they attempt to create and maintain interdependence with IDTs and social support systems.
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“What sign?”

I waited for her to reveal that there was some kind of sign informing visitors of rules about perfume and cologne, as she had just finished scolding me about the scent I was wearing. She didn’t respond, but simply began to pull out a journal and pen. She turned to a blank page and wrote the date at the top, along with my name. I sat there stunned, trying to figure out what she was writing, when she turned to me and said, “Go out of the room and come back in again. Read the sign.”

I hesitated for a moment, trying to figure out if this was really happening. She continued writing notes, nonverbally expressing that she was not going to offer further explanation and simply assumed I would follow her directions. I walked out into the hallway, turned around and looked back into the room. In the few seconds I stood in the doorway, I scanned as much of the room as I could, knowing my next test had already begun. *Look for the sign*, I kept lecturing myself.

Finally, I noticed it. There on the wall by the door frame hung six unassuming cut-out letters, spelling Purell. The humble letters looked as if they had been crafted by a small child in an elementary art class. The sign above the letters read: *During cold and flu season, use the Purell by*
the door. I glanced to my left and on small chairs sat the hand sanitizer. I looked back at “Ginny”, who by this time had finished writing in her journal, and without offering any affirmation, she stared blankly back at me. I washed my hands.

To: “Ginny” and all of the hospice patients who taught me the true etiquette of a researcher and reminded me “to do no harm”, that I might have done them justice.

To: Dr. Tara Emmers-Sommer and Dr. Erin Sahlstein who are equally the two most influential mentors during my educational career.

To my committee: Thank you so much for helping me “make this a work I can be proud of.” For your insight into more clear, thoughtful writing and hospice knowledge.

To my colleagues: Sarah, Daniel, Desiree, Michele, Brittney, Jonathan. I can never express to you how much you’ve helped me and how I am forever changed by the impact each of you have had in my life. I cannot verbalize these years more eloquently than: “Everyone remembers the experience quite truly... And everyone was centered around this thing, that we suffered. No one forgot that. Everyone had that in common” (Bruce Springsteen).

To my family: Thank you for always believing in me and encouraging future successes. And for yelling, “Finish your thesis!” at my graduation ceremony.

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CHAPTER 1

INTRODUCTION

Scholars argue that homes have become “inhospitable to birth, sickness, and death” (Illich, 1976, p. 41). Centuries ago, women gave birth to babies at home and loved ones died in family settings; but, both birth and death have now become hospitalized. Scholars claim that self-care is equated with delinquency (Illich, 1976). Rather than allow individuals to work through suffering on their own, life has become medicalized and generally ignores the patient perspective (Ragan, Wittenberg, & Hall, 2003). In order to overcome the pervasiveness of a medicalized world, hospices were created, focusing a wholistic approach to care (Mount, 1976).

Wholistic care is defined as an approach to health in which providers “enhance the integrity and the spirit of dignity in the healing encounter between careseekers and caregivers”, “empowering patients to participate in their own health care” (Benor, 1999, p. 1). Through a wholistic approach, patients are offered “complementary therapies [that] introduce philosophies and methods of health care that promote whole-person care” (Benor, p. 1). Hospice’s wholistic mission includes a “team-oriented approach to expert medical care, pain management, and
emotional and spiritual support expressly tailored to the person's needs and wishes" (National Hospice and Palliative Care Organization website, 2008). Although the goal of hospice is to return to this person-centered care to address patient needs on a more intimate level, researchers relatively ignore the patient's perception of the success of this approach. Researchers instead review the success of patient-centered health from the critiques of families and providers (Coopman, 2001; Hines, 2001; Iedema, Sorenson, Braithwaite, & Turnbull, 2004; Karlsson, Ehnfors, Ternestedt, 2006; Kim & Kim, 2003; Ragan et al., 2003; Riggio & Taylor, 2000; Wittenberg-Lyles, 2006; Wyatt, Ogle, & Given, 2000; Zimmermann & Applegate, 1992).

Anderson (2001) reviewed patient narratives describing minor medical issues, or non-life-threatening procedures, although her research lacked insight into how patients negotiate their health during major medical situations or life-limiting circumstances. Conversely, Emanuel, Alpert, Baldwin Jr., & Emanuel (2000) gathered "first-hand information from a national cohort of 988 terminally ill patients" (p. 420). However, while this study has contributed much to palliative and end-of-life (EOL) care research, Emanuel et al.'s interviews were conducted between 1996 and 1997. As changes in biomedical research have taken place since the study's publication, a more current review is needed.

While the hospice wholistic mission reads as "generous control of symptoms, attention to the patient's psychological and spiritual needs,
care and support for the family as well as the patient” (The hospice experiment, 2002), recent palliative care “focuses on selected physical aspects of suffering, such as pain, or on selected aspects of decision making, such as the do-not-resuscitate order, which may be important to physicians but are of less concern to patients” (Emanuel et al., 2000, p. 420). Attention to the patients’ needs “enhance patients’ abilities to achieve agency in their interactions with their health care teams, their support system, and the health care system in general” (p. 201). As hospice patients have additional needs beyond strictly physical concerns, the lack of attention to these alternative needs suggests that patients do not have a voice in obtaining comprehensive care (O'Hair, Villagran, Wittenberg, Brown, Ferguson, Hall, & Doty, 2003), given Houck, Avis, Gallant, Fuller, Goodman (1999) argue that “unless specifically asked, many patients may not offer QOL [quality of life] concerns” (p. 401).

Rationale

This study is focused on creating a comfortable environment in which hospice patients can activate communicative agency over their health care concerns. The hospice care mission of whole-person centered treatment suggests the promotion of agency; therefore, it is vital to examine whether patients perceive this encouragement. Thus, research questions are designed to understand patients’ perceptions of the communication of the wholistic approach, acknowledging wholistic
health care as a whole-person approach encompassing the physical, emotional, psychological and spiritual needs of the patient. Furthermore, as this wholistic care is attended to through a system which includes patients, social support, and hospice interdisciplinary team members (IDTs), research questions are also designed to understand patients’ perceptions of interdependence. Through a semi-structured interview format, patients are given a voice to discuss these perceptions.

This study also continues the scholarly conversation in health communication by addressing patients’ use of relational dialectics in managing agency within the comprehensive care environment. Specifically, dialectical tensions might be present as patients attempt to negotiate their identities as both care recipients and active participants in addressing their health needs. As patients are reliant on IDTs for medication, patients might perceive requesting additional services as inappropriate, as if they are asking for too much. Thus, rather than openly use their voice to obtain wholistic services; patients might attempt to close this communication, concluding in the receipt of merely standard physical care. A review of relational dialectical theory could provide insight into how patients negotiate these tensions while obtaining care throughout their chronic illnesses.

The following literature review includes recent research involving patient characteristics that might affect how the wholistic health care approach is communicated, while providing insight into patients’
possible additional needs, which contribute to understanding wholistic care. Furthermore, research concerning interdisciplinary teams and social support systems should reveal insight into interdependence and the role other health care participants play in a patient-centered care approach.
CHAPTER 2

REVIEW OF RELATED LITERATURE

Hospice History

In order to understand a patient-centered health care approach, a brief history of the hospice movement is required. The hospice idea is not a novel approach to dying (McNulty & Holderby, 1983; Paradis, 1985). 1,500 years ago hospitals were primarily places of care not cure, as the facilities existed to provide shelter for various kinds of needy individuals, while Christian hospitals accepted individuals needing refuge or spiritual care, and “provided charitable services to the needy” (A. Fontana, personal communication, July 2007). However, when fear of sicknesses and disease became politicized and the hospital became “a mark of status for the upper classes to be affiliated with,” physicians became focused solely on cures, and not respite or refuge care (p. 100). Thus, while some illnesses were treatable and required physician care, other individuals with life limiting illnesses were refused admission or over medicated in an attempt to cure rather than care (The hospice experiment, 2002). Death was viewed as an enemy that needed to be conquered. As death is inevitable, this denial of mortality was deemed unacceptable. Mary Aikenhead attempted to return to the original
mission of hospitals as places of refuge, focusing on the terminally ill persons by providing care for both the body and soul of the patient, by opening the first ‘modern’ hospice of the dying in Dublin. Upon the success of the Dublin hospice, Aikenhead’s religious order founded St. Joseph’s hospice in London in 1950 (Fontana, 2007).

Cicely Saunders, another advocate for maximizing comfort and quality of EOL treatment, received her medical degree and practiced at St. Joseph’s before opening St. Christopher’s hospice in the 1960s. The first hospital-based hospice, Royal Victoria Hospital in Montreal, opened in 1975 resulting from Saunders’ success. Since the 1960s and 1970s, “more than 3,000 hospice programs serve about 900,000 patients a year in the United States”, with “8,000 programs in over 100 countries around the world” (The hospice experiment, 2002). Although there have been advances in biomedical technology in the past thirty years, given hospice is a philosophy not simply a facility, the hope is that original wholistic mission of hospice has been maintained: “generous control of symptoms, attention to the patient’s psychological and spiritual needs, [and] care and support for the family as well as the patient” (The hospice experiment, 2002). This mission exists to help patients “have the greatest possible pleasure, to make it possible for [patients] to enjoy social and family relationships and to help [patients] maintain a positive self-image, so that [patients] may die with dignity” (McNulty & Holderby, 1983, p. 7). Although the history of hospice reveals that the hospice mission is a
fitting response to overcome the denial of mortality and that many modern hospices have emerged to carry out this mission, again current hospice research lacks patients' evaluations of whether they are being cared for wholistically. In order to understand whether the above-noted goal has been met, maintained, or communicated to hospice patients, research regarding patient characteristics is necessary as each patient's wholistic care is affected by their unique circumstances.

Factors Affecting Wholistic Health Care

In his research regarding cancer patients, Kreps (2003) claims, “Due to the broad range of different cancer conditions and issues, a great deal of specific information needs to be conveyed to different individuals depending on their unique situations” (p. 163). A review of research regarding quality of life factors, spirituality and religiosity, patient attitudes, gender and relational status, marginalization, and finally self-concept factors provide insight into understanding how hospice patients experience wholistic care.

Quality of Life Factors

Primarily, patient views of quality of life have been known to affect EOL decisions. Tarzian, Neal, and O'Neil (2005) found that a continuum exists in regard to machinated life. Many individuals commented that prolonging life was more important than quality of life. For instance, one participant mentioned “I just want to just keep holdin' on, I don't want to
go out . . . just let me live a little more, long as I can” (p. 38). On the
other hand, some patients privileged quality of life over prolonging life.
These individuals stated “When I get sick, if I have to be on machines
and everything, just let me go. . . I do not want to be hooked up to no
machines” (p. 38). As evident in these opposing opinions regarding
machinized assistance, patients’ perceptions of QOL affect the type of
care they receive, as well as their EOL decisions.

**Spirituality and Religiosity Factors**

The previous research regarding EOL decisions and machinized
assistance, reveals that patients consider God’s role in EOL decisions,
which provides insight into how patients’ wholistic experience is affected
by spiritual or religious factors, as “spirituality is central to the care of
the dying” (Puchalski & Romer, 2000, p. 134). Egbert, Mickley, and
Coeling (2004) claim that religiosity can help an “individual cope with life
stress” (p. 15). Puchalski and Romer make similar statements, claiming
that “patients learn to cope with and understand their suffering through
their spiritual beliefs, or the spiritual dimension of their lives” (p. 129).
Other researchers have found that often, in the context of EOL care,
conversations about a spiritual afterlife will precede discourse about
death (Puchalski & Romer, 2000; Tarzian et al., 2005). More specifically,
Tarzian et al. found that while caregivers and family members wanted to
respect the patients’ wishes, they often made statements about leaving
decisions “in God’s hands” (p. 40). Given that some patients feel more
comfortable discussing EOL decisions in the context of spirituality, patients' spiritual histories provide insight into the communication of a wholistic health care approach.

**Patient Attitude Factors**

Beyond QOL and spirituality, research suggests that patients' overall attitudes affect their hospice experiences. Kim and Kim (2003) conducted a study in order to understand cancer patients' perspectives of hospice and found that the participants who held positive beliefs were likely to be more involved and benefited most from hospice care. Likewise, Kim and Kim discovered that hospice care providers were more likely and willing to participate in their roles if they shared a more positive approach to cancer treatment with the patient.

Correspondingly, negative opinions about illnesses also affected healthcare. Collins, Crowley, Karlawish, and Casarett (2004) examined patients' health care as contingent upon the patients' levels of depression. Collins et al. concluded that "depression may have a substantial but underappreciated influence on patients' willingness to share health care decisions with others" (p. 531). Thus, depression affects the patient's health and also communication with their social support network. As the wholistic hospice mission focuses on making it "possible for [patients] to enjoy social and family relationships," this research reveals how patient attitudes might affect this mission (McNulty & Holderby, 1983, p. 7).
Gender and Relational Factors

Other factors known to affect health care, besides spirituality and attitudes are gender and marital status (Wachterman & Sommers, 2006). Primarily, biological sex affects the health care process in terms of life expectancy, as science concludes that, on average, women have a longer life expectancy than men. As a result, at the end of life, women “may be sicker, have less social support, and have fewer financial resources” (p. 344). Furthermore, concerning marital status, research indicates that women are more likely to be widowed than men. As mentioned, because single or widowed individuals are less likely to receive informal care, marital status has a substantial impact on health care. Single individuals, whether never married, widowed, or divorced, are less likely to receive informal care, from family or loved ones (Wachterman & Sommers, 2006). Consequently, single individuals might experience little social support and are more likely to die in a nursing home or palliative facility.

Karlsson et al. (2006) also examined the effects of marital status in relation to gender, though they also incorporated factors such as age, “diagnosis, referral source, and length of stay (LOS)” (p. 113). Karlsson et al. found that the inpatient cancer hospice they studied mostly consisted of elderly individuals, with a mean age of 75 years. For both men and women, the mean LOS was listed as 29 days, although women reported their LOS as 4 days longer than the men. Karlsson et al. found that the
proportion of single women was higher than that of single males, with 70% of men reporting being married. Karlsson et al.’s findings that female cancer hospice inpatients experienced a longer LOS and impacted the proportion of single individuals, combined with Wachterman and Sommers (2006) research that single individuals were more negatively affected, provides insight to how gender and marital status, can truly affect EOL care, thus suggesting the need for more research that includes all aspects of a individual’s life to gain more insight into the hospice wholistic health care approach.

**Marginalization Factors**

Tarzian et al. (2005) argue that along with gender and marital status, additional traits that cause individuals to belong to marginalized groups also affect EOL care. Tarzian et al.’s research consisted of individuals from two marginalized focus groups: homeless persons and people living with HIV/AIDS (PLWHAs). Because these groups were identified as marginalized, their access to health care was often affected by their status. Many patients reported hesitation from seeking health care, because they feared they would be discriminated against, because of their age, race, cultural expectations, or specifically in this study, the social stigma from their socio-economic and health statuses (O’Hair et al., 2003). As death is relatively denied in Western culture, terminal patients might be considered a marginalized population as well (The hospice experiment, 2002). Given that these factors affected whether
patients were willing to communicate their health care needs, research in palliative care should focus on the possible marginalized status terminal patients might adopt.

**Self-concept Factors**

Two final factors, intrapersonal and interpersonal self-concepts, also affect the way patients might negotiate their health (O'Hair et al., 2003). More specifically, "cognitive overload, affective arousal, uncertainty, misguided expectations, inadequate interpersonal functioning, and low self-efficacy" can alter the choices patients make when confronted with life-limiting illnesses (p. 199). In regard to uncertainty, Hines (2001) claims, "because serious illness entails multiple interconnected uncertainties, how a person attempts to cope with one uncertainty also depends on their expectations about how these coping strategies will affect other issues" (p. 502). Again, this research indicates that patients alter how they receive health care based on personal factors. As such, research addressing how the nuances of each patient are attended to by hospice personnel from patient perspectives should help to present a more thorough examination of hospice care. Specifically, are each patient's particular needs purposely attended to when the wholistic hospice health care approach is communicated to them? The aforementioned literature regarding factors affecting wholistic health care provides insight into the first two research questions:

RQ1: What was the patient's reasoning for choosing hospice care?
RQ2: From the patient’s perspective, how is the wholistic hospice experience communicated to them?

Interdisciplinary Teams (IDTs)

Although patient characteristics might provide insight into how wholistic health care is communicated to patients, it would be remiss to assume that this comprehensive health care perception results from the patients’ nuances alone. More specifically, this idea of wholistic care is affected by the channels and senders through which it is communicated, such as members of hospice personnel. Thus, in order to further ascertain whether the original goal of hospice is enacted and maintained, a review of specific health care professionals’ communication is necessary.

Given that wholistic care incorporates the physical, psychological, emotional, and spiritual needs of each patient, it is reasonable to assume that simply one physician per patient would be insufficient. Moreover, even if one physician could address each of the patient’s issues, given the inevitable nature of the terminal illness, research shows that physicians struggle with interpersonal communication. Iedema et al. (2004) attribute this communication difficulty to the dichotomy between the biomedical talk and empathetic discussions about the patient’s personal experiences in health care. Iedema et al.’s research focused on the discourse occurring within the intensive care unit (ICU) at a hospital in Sydney,
Australia. The researchers found that conversations regarding the futility of treatment become confrontational, because physicians believe, “what medicine does well [...] is [facilitate] dying for unconscious patients” (p. 89), but “anguish takes over when conscious patients refuse to accept they are dying” (p. 89).

This conversation difficulty becomes extremely problematic as patients benefit greatly from engaging in this talk with their physicians. While physicians might believe they are doing the patients favors by maintaining the perception of hope and avoiding these conversations, these discussions are incredibly valuable. Terminal patients who are able to discuss their options “were less likely to spend their final days in hospitals, tethered to machines. They avoided costly, futile care. And their loved ones were more at peace after they died” (CNN website, 2008, np).

However as Iedema et al. (2004) found, several doctors claimed, “I still have real difficulty with that [telling conscious patients that they are dying]’ or ‘It is just too daunting to go up to a patient” (p. 89). Buss (1999) claims that these feelings of inadequacy could result from a lack of proper medical training for physicians. Buss (1999) argues that “during clinical years of training [...] students learn to apply factual knowledge and develop clinical acumen by participating directly in patient care and by observing others provide patient care” (p. 391). Furthermore, training “fails to define the physician’s role in caring for the
dying and creates an environment that discourages students and residents from addressing patients' palliative needs" (p. 391), as the aforementioned hospice history illuminates. Thus, medical education during the clinical years should incorporate palliative care studies to ensure that these future medical professionals are aware of how to address hospice patients' needs.

Other scholars attribute this physician inadequacy communicating about EOL decisions or nonphysical suffering to the fact that physicians are often so fraught with time, stress, and technical learning (Puchalski & Romer, 2000). Puchalski and Romer report that physicians spend approximately 15 minutes with patients and lacked the closeness needed to really 'know' the patients. These physicians might not take adequate time to get to know patients because they are more comfortable discussing the technical and medical aspects of health rather than the personal experiences (Wyatt, Ogle, & Given, 2000).

Again, as highlighted in the history of hospice development, much of a physician's inadequacy in properly communicating with patients can be traced back to the economical focus of health care and presently the concept of managed care. Street (2003) explains "in the 1980s, managed care generally meant care provided by HMOs (health maintenance organizations) or prepaid health plans" (p. 72). While aspects of managed care have changed since the beginning of the 21st century (i.e., recently model HMOs provide care for a fixed amount per person per year and
hybrids of prepaid plans have been created, the overall concept remains the same: many patients have limited choice in physicians and their access to proper health care is limited because of the policies involved in healthcare insurance. Street argues that "the influence of managed care could [...] result in greater clinician control of the interaction, less trust between provider and patient, and more frequent discussion of topics related to health promotion" (p. 73). Thus, because "practically all medical care is 'managed' in some way, shape, or form," it is often impossible for physicians to spend adequate time with each individual patient (p. 72). However, as the aforementioned research findings indicate, even if time is available, physicians experience difficulty in communicating with patients regarding futile health circumstances (Buss, 1999; Iedema et al., 2004). Given that it would be nearly impossible for the current medical care system to return to its pre-managed focus, health care could benefit with a more thorough examination of how communication might be improved within these managed circumstances, focusing on the patients' more detailed needs without the added time constraints.

Although it appears that many demands are placed solely on the physician, Riggio and Taylor (2000) argue that hospice nurses also need to have technical knowledge as well as empathy for patient concerns. Iedema et al. (2004) reviewed nurse narratives and highlighted the importance of their discourse in discussing EOL care with ICU patients.
Similar to the findings regarding physician discourse, Jedema et al. discovered that nurses experienced a disjunction between communicating the futility of treatment and emotional support. One nurse commented, “We give them these poor, like these sad prog... negative prognoses when they first come in but we demonstrate the opposite and to me if I was the lay person, I would find that very conflicting” (p. 91). Nurses explained the terminality of conditions to patients, but these nurses then struggle with providing empathy to patients. Thus the nurses’ attempts to support and encourage patients were an act in opposition to the terminal medical circumstances.

Similar to physician dissonance, nurses’ communication discomfort in EOL situations might occur from lack of time or training. However, specifically regarding hospice or EOL care, nurses’ communication discomfort might also relate to the transitory nature of the hospice environment. As patient death is inevitable with terminal prognoses, medical personnel might refrain from developing closer relationships or improving their communication comfort with the patients to “obtain emotional space” (Baverstock & Finlay, 2006, p. 508).

Fortunately because the hospice philosophy includes the incorporation of IDTs, patients do not need to rely solely on medical doctors or nurses to meet their physical, psychological, and emotional needs, especially if these health care professionals have difficulty doing
so (Salt & Robinson, 1998). Anderson (2001) explains, “when researchers expand thinking of the medical interview beyond the physician and patient relationship, they are free to include other professionals and staff who come in contact with patients during interviews” (p. 63). For example, in Sweden the inpatient hospice ward consists of 14 team members including: “doctors, nurses, assistant nurses, an occupational therapist, a physiotherapist, a priest, a social worker, and volunteers” (Karlsson et al., 2006, p. 114). Within the interdisciplinary team, Riggio and Taylor (2000) argue, “while nurses and other hospital medical personnel focus primarily on helping patients to get well, hospice workers administer to the physical and psychological needs of the dying patient, and to the emotional and psychological needs of the patient’s family” (p. 352). In sum, medical staff members are not isolated.

Overall, previous research suggests that doctors and nurses are often uncomfortable in communicating with patients empathetically, especially when an illness is labeled incurable. With the existence of IDTs within the hospice care philosophy though, the hope is that social workers, volunteers, spiritual counselors, and comfort care specialists can assist in communicating with patients. However, because so many individuals share the responsibility in presenting the patient with a wholistic type of care, disjunction might also occur among IDTs in communicating health prognoses to patients. Iedema et al. (2004) found that when nurses experienced dissonance when discussing the
impending mortality with patients, rather than demonstrate interdependence with the medical team through support or a shared responsibility with physicians, nurses would emphasize their separateness from doctors by altering their language. Specifically, rather than using inclusive talk such as “we” or “us” (p. 91), nurses use the word ‘they’ when referring to the doctors. Nurses are “fixing the distinction between how [they (nurses)] perceive these dying patients and how ‘they’ (doctors) treat them” (p. 91). Thus, Iedema et al.’s study reveals potential issues concerning hospice interdisciplinary teams, as several health care participants are included in caring for the patient.

Generally, given that so many individuals share the responsibility in presenting the patient with wholistic care and as a result IDTs might cause stress for the patient when negotiating communal decision making, patients might experience difficulty in understanding the overall hospice philosophy. These potential IDT issues and the initial research focus of patient factors, prompt research question 3:

RQ3: How do patients experience interdependence with IDTs regarding the wholistic health care approach?

Social Support

While researchers have found that volunteers have more access to patients than most physicians and nurses, additional research indicates that family members or social support systems potentially have the
greatest impact on hospice health care, because they have a central focus on the patients' well-being, whereas IDTs and volunteers might have a peripheral focus on the patient with a central focus on the hospice organization. More specifically, social support systems might deal with fewer politics in dealing with the patient, as IDTs are working for a paycheck and volunteers are helping secure those paychecks, as their unpaid hours help to fulfill Medicare requirements (A. Martinez, personal communication, 2007). Thus, a view of social support systems might provide added insight into how patients perceive wholistic health care beyond what IDT research can offer.

Unspecific to health care, “social support matters: It is the cornerstone for the quality of human life” (Albrecht, Burleson, & Sarason, 1992, p. 149). Social support becomes increasingly important when negotiating through health concerns, as “patients with advanced serious illness must make numerous complex health care choices,” such as “whether to undergo diagnostic procedures, about treatment options and medications, and about goals and plans for care” (Collins et al., 2004, p. 527). Patients then “must weigh uncertain risks, potential benefits, and outcomes,” which might cause additional emotional distress, thus the presence of social support systems is essential (p. 527).

When strong support systems are present, patients should experience a feeling of comfort. Comforting communication occurs when
one individual acknowledges another's difficult circumstances and encourages the individual to seek understanding of the situation (Zimmermann & Applegate, 1994). Comfort might also occur in the form of advocacy, which O'Hair et al. (2003) explain readdresses the balance of power. Rather than solely rely on the interdisciplinary team to meet the patient's needs, supporters advocate for the patient to have control in EOL decisions. The need for advocacy is evident because often patients might be hesitant to make EOL decisions based on their own needs and desires. In Tarzian et al.'s (2005) research, narratives reflected that many homeless individuals became concerned for the burden EOL decisions placed on their family members. For instance, one individual claimed “I've already made people suffer a lot, through my addiction, and burnin' my bridges” (p. 38). While this narrative seems specific to the individual's identity as homeless, this feeling might be shared by other dying persons.

Given that social support systems can both provide comfort and/or advocate for patients, supporters generally adopt multiple roles when interacting with the patient. Arrington (2005) claims that, “Regardless of how a survivor's partner adjusts to the caregiver role, he or she also creates a new relationship with the survivor. That relationship evolves as the duties of the caregiver change. As the caregiver's role is redefined, so is the caregiver-survivor relationship” (p. 144). For instance, Arrington explains that many caregivers begin by taking on the role of practical
support. Using patients’ narratives about their wives’ role in their health care, Arrington found that often the wives explored the emotional role and were responsible for encouraging their husbands to consult physicians. The wives’ role changed to a more practical role, through the monitoring of medication, once the men were diagnosed. When practical aspects were stabilized, wives reverted back to the role of emotional supporter. Because new roles and relationships develop through the health care process, communication between the individuals is likely to change as well (Miller & Apker, 2002). However, many social supporters admit that they are unaware of appropriate discourse when communicating with a dying individual. Tarzian et al. (2005) found that some individuals claimed to have difficulty controlling their emotions. One study participant explained that because his family knew how emotional he was, he was often excluded from the decision-making process when discussing his mother’s health care. Other individuals seemed to make decisions for their loved ones, based on thoughts they had about their own mortality, often summarizing events in which they experienced extreme dissonance when their parents requested to have the ventilator removed.

While many individuals admitted their concerns in communicating with the hospice patient, other individuals reported being able to decipher between “good” care and “bad” care (Tarzian et al., 2005, p. 41). These individuals claimed that simply offering to listen with compassion
was most appropriate when conversing with dying individuals, which seems to be a similar doctrine taught in hospice volunteer training (A. Martinez, personal communication, 2007). Although all of these accounts seem to be representative of the palliative care setting, research was not collected from the hospice patients themselves. More specifically, while this research might provide insight to how social supporters feel about hospice care, the feelings of the actual hospice patients about the support they receive is not provided.

Overall, hospice patients rely on social supporters to assist in decision making, although the aforementioned research highlights social supporters difficulty in EOL discussions or maintaining proper roles when interacting with the hospice patient. Thus, future research would benefit from exploring how hospice patients negotiate their relationships with social supporters in the context of wholistic care, resulting in research question 4:

RQ4: How do patients experience interdependence with social support networks regarding the wholistic health care approach?
CHAPTER 3

METHODOLOGY

Grounded Theory

As the aforementioned research highlights, hospice patients might encounter diverse situations as factors affecting health care such as interdisciplinary teamwork, inadequate physician knowledge on dying, social support issues, quality of life, spirituality and religiosity concerns, patient attitudes, gender and relational statuses, marginalization factors, and self-concept needs relate to the dying experience. Given that so many factors can emerge for this vulnerable population during such a tenuous time, it is imperative for communication scholars to not only acknowledge the broad range of previously determined factors, but to sift out those factors that are most prevalent for hospice patients. Thus, a grounded theory approach will be utilized so that I can locate common factors affecting how wholistic health care is communicated to hospice patients.

Grounded theory was first developed by Glaser and Strauss (1967) as a means to counteract the critiques of qualitative research. Scholars argued that qualitative findings were not generalizable, so Glaser and Strauss developed a method to use induction as a means of building
theory from data. Following this method, researchers begin by making observations from within a large area of study (Potter, 1996). After making these observations, researchers look for emergent themes or explanations. The ultimate theory is “discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon” (Strauss & Corbin, 1990, p. 23). This grounded theory approach can be utilized in the present study in order to understand hospice patient experiences with interdisciplinary team members and social supporters while communicating their physical, psychological, and spiritual/emotional needs. Although the data will dictate the resulting theory, this study will be guided by the aforementioned research questions regarding wholistic health care communication and interdependence.

Interview Format

The present study uses a semi-structured interview format to collect data. Open-ended or nondirective questions are designed to open interviews up to broad topic areas (Potter, 1996). Scholars claim that interview responses “may work allegorically, which means that they may tell not just about what they are manifestly telling but also about something else” (Mol & Law, 2002, p.15). More specifically, open-ended interviews allow patients the opportunity to reveal information nonspecific to forced questions. Scholars who placed more constraints on
interviews also acknowledged the benefit open-ended questions offer. Emanuel et al. (2000) collected their information from focus groups, rather than interviews. The authors note that the study was limited in the fact that the nature of the interview questions “was determined in large part by the hypothesized conceptual framework, which may have constrained the range of dimensions in the data analysis to those identified in the focus group” (p. 429). Consequently, Emanuel et al. suggest that the data may not include all factors that contribute to EOL care. Karlsson et al. (2006) also confess that a limitation of their study is that the variables they collected “were solely determined by the information available in [...] registers,” thus information resulting for personal interviews could provide more insight to factors influencing hospice patient care (p. 119).

Given the comprehensive nature of open-ended interview questions, the present study utilized nondirective questions in a semi-structured interview format in order to gather a patient-centered understanding of hospice care. Semi-structured interviews consist of a combination of both unstructured and structured elements. Primarily unstructured interviews are present when “scientifically useful interviewing is sometimes carried out in less formal or structured manner” (Singleton & Straits, 1999, p. 241-2). Unstructured interviews include very general objectives, spontaneous questions, and comprehensive discussions. These interviews are often preferred because
the interviewer can adapt questions to focus more on the individual experiences and insights. On the other end of the spectrum exist structured interviews. Structured interviews offer specific questions, designed to meet specific objectives. Each participant in the study is asked the exact same questions in the exact same order. Furthermore, the interviewer may not probe the respondent to gain a deeper perspective, but must adhere to the interview script.

Semi-structured interviews, as expected, combine the previous two interview types. As partly structured, these interviews have clear and specific objectives with predetermined questions. Semi-structured interviews allow the interviewer to ask follow-up questions that would aid in an expansion in the respondents’ answers. In the present study, a semi-structured interview format is most appropriate, as the structure will provide consistency in data collection and also sensitivity in the types of questions asked of the hospice patients, while unstructured interview elements will allow for probing and flexibility for patients to elaborate on their interpretation of hospice care communication.

Solicitation of Participants

Participants were solicited from a non-profit hospice in the southwest. This particular facility specialized in home-care. Facilities with an in-home focus operate by sending IDTs to patients’ houses, only housing patients on cite, under three circumstances: hospital to home
transition, severe pain and symptom management, or family respite care. Patients may only utilize the in-patient unit for a maximum of three to five days, and then they must return to their home-care program, unless symptoms or medical management needs attention beyond what can be provided in a home setting. In the latter case, patients will stay in the in-patient setting for an indiscriminate time period. Patients included in this study were currently in their home-care settings.

I contacted the facility manager, providing a copy of the interview questions, with the understanding that hospice personnel had the opportunity to offer input before the questions were finalized. Once the hospice staff and I agreed, the interview protocol and questions were then submitted to the Office for the Protection of Research Subjects (OPRS). Before beginning the interviews, I completed the required eighteen hours of Hospice Volunteer Training Program, in order to understand the sensitivity of the hospice environment and utilize the techniques learned in the training session to maintain a supportive environment for the hospice patients.

Approval was granted by OPRS after minor revisions and I contacted the hospice facility manager again to assist in the recruitment of 10-20 willing hospice patient participants. During weekly IDT meetings, the facility manager asked team members for names of possible study participants. The facility manager also informed volunteers of the study for additional recruitment. Participation was
limited to (a) patients age 18+ and (b) hospice patients defined as individuals diagnosed with a noncurative illness with less than six months to live. As the aforementioned literature review suggests, all aspects of patient demographics impact how individuals communicate about health. Thus, provided that the patients met the above noted parameters regarding age and diagnosis and were regarded as in appropriate health, the patients were allowed to participate. Appropriate health was defined according to the same protocol the hospice facility utilizes to determine a patient’s eligibility to meet with standard volunteers. Specifically, patients are eligible for standard volunteers, until the ‘eleventh hour’ (closing stage of life), at which time only the volunteers who are designated as ‘eleventh hour’ are permitted to meet with the patients. Once the facility manager obtained the names, she informed the patients about the study procedures and after gaining consent from the patients, she forwarded the names and phone numbers to me.

Participants

The final sample consisted of 10 home care hospice patients, ages ranging from 60 to 90 ($M = 73.6$, $SD = 8.114$). Participants had been utilizing the hospice program between 1 and 14 months ($M = 6.2$, $SD = 3.789$). Patient health diagnoses in the final sample included tongue cancer, stomach cancer, chronic obstructive pulmonary disease (COPD), colon cancer, debility, lung cancer, breast cancer, and ovarian cancer.
Data Collection

Once the patients agreed to participate, I called each patient, introduced myself, briefly reiterated the research design, and initiated a discussion to schedule a mutually agreed upon interview time. All interviews were conducted in the patients’ homes, based upon the patients’ needs or requests. The interview began with a pre-interview statement, describing the focus of the research and the guidelines of the conversation. I verified the participants’ hospice patient status and distributed the consent form. After the patient read and signed the consent form and I set up the digital audio recorder and prepared the interview materials, the interview commenced (refer to Appendix A for Interview Consent Form).

The interview questions were designed to solicit responses regarding how patients perceived the communication of the wholistic health care approach (for example: ‘Describe how hospice is treating your physical pain’ and ‘Describe how hospice is treating your emotional/psychological needs’). Questions were also designed to solicit responses regarding how patients experience interdependence with social support networks: ‘Describe your strongest emotional supporter.’ ‘What do you talk to your support system about?’ Patients were asked to describe their interactions with the IDT members regarding the wholistic health care approach: ‘How do you see your relationship with your hospice doctor (nurse, spiritual mentor, comfort care specialist)?’ ‘What
is the communication like from your perspective?' Finally, patients were generally asked: 'What would you change or want to improve with your current hospice treatment?' (refer to Appendix B for Interview Protocol).

The length of interviews ranged from 20.20 minutes to one hour 2 minutes ($M = 39.24$ minutes). One interviewee, "Ginny", requested to handwrite her answers, as she experienced difficulty projecting her voice and speaking at length. "Ginny's" interview was still audio-recorded as she spoke briefly while writing her answers. After all ten interviews were completed, I transcribed the one written and nine taped conservations verbatim, producing 126 pages of typed text-based data for content analysis. All names in the interview transcripts were changed to ensure patient confidentiality.

Analysis of Data

As evident in the aforementioned research, EOL care generally encompasses several characteristics relating to the patients' specific needs and lifestyles. Changes in relationships with IDTs and social supporters occur as patients attempt to negotiate their physical, emotional, and psychological, and spiritual needs. Given all these factors become evident under the dying patients' needs, communication scholars are presented with the charge to explore whether the overall wholistic care, consisting of these four areas are communicated and as a result, help to maintain the overall hospice philosophy.
The first step in the analysis of the patient interview data was an open coding qualitative analysis of the transcripts (Emerson, Fretz, & Shaw, 1995). I began by reading through each transcript and paraphrasing the patients' responses. Then, I read through each paraphrase and selected key words. After all the key words were extracted, I organized these ideas into overarching themes. A constant comparison analysis was utilized to determine whether certain themes consistently emerged (Goetz & LeCompte, 1984). When incidents emerged from the transcripts that did not fit the constructed themes, a new theme was constructed. Finally, the data underwent an intercoder reliability check by another researcher. The reliability checker and I generally agreed on the emergent themes although the language of the labels differed. For example, instead of the theme focus on positives concerning patients' relationships with IDTs, the other coder titled these comments ambivalence with the subheading limited details about communication. The coder explained that she perceived the patients' brief comments to communicate their ambivalence about the details of their care. However, I explained that I defined ambivalence as uncertainty and indecisive and although patients' comments were brief and general, they still responded with a positive evaluation. Thus the coder and I agreed that focus on positives provided more detail about patients' relationships with IDTs.
The coder and I also differed with the terms *independence* and *autonomy*. We considered these words to be interchangeable and selected *autonomy* as the appropriate label to correspond with the language of relational dialectics. Conversely, both the coder and I used the same language *burden for social support* to describe patients' comments about their relationships with their support teams, *unnecessary* to describe spiritual needs, and commented that patients' were focused on pain management as primary concerns regarding physical needs. Finally, the coder included notes that patients discussed how their communication might differ with various social support members. Specifically, few patients spoke with close family members about their health and refrained from these conversations with others. However, this theme did not appear to be consistently articulated by patients. Thus, despite the variations in language and interview evaluations, the coder and I concluded that no additional themes needed to be added or present themes removed.
CHAPTER 4

FINDINGS OF THE STUDY

Research Question 1

Analyses of the 10 interview transcripts with regard to RQ1, 'What was patient’s reasoning for choosing hospice care?', reflected patients’ medical history. Specifically, some patients communicated they had encountered a problem that could only be helped with a medical procedure, while others had been engaging in ongoing curative treatments for chronic illnesses. While patients were advised by health care professionals to either engage in medical procedures to overcome the catalyst or continue their previous treatments for their chronic illnesses, transcript analysis reflected the theme, decision to end current treatment. Under the theme, decision to end current treatment, two additional themes emerged revealing, as the transcript analysis reflected patients’ perceptions of pain and perceptions of unlikely success of the curative treatment plan.

Insight into patients’ medical history first emerged when patients told about how a medical experience became a catalyst for more medical procedures or a life altering surgery. “Beatrice” had some complications with COPD, which affects the lungs and impairs breathing. However,
“Beatrice” explained that it wasn’t until she had a heart aneurism that hospice became an option. The head cardiologist told her:

Beatrice: ‘You have 30 minutes to make up your mind. If you want to live, you have to have open heart surgery and you have to make up your mind within a half hour’ (B, p. 1).

Although “Beatrice” was living with a chronic illness, her aneurism acted as a catalyst for her to choose a noncurative route to deal with her medical condition.

“Beatrice’s” comments suggest that patients negotiate between curative and noncurative treatment when a new medical concern prompts a decision between cure and care; however, five patients explained that chronic medical conditions, rather than a medical event, encouraged them end current treatment and seek noncurative care.

“Henry” had been suffering with prostate cancer for four years, while “Fran” was fighting ovarian cancer for eleven years. Regardless of whether patients perceived a recent medical event as a catalyst, or patients were living with chronic illnesses, transcripts reflected an emergent theme of patients making a decision to end current treatment.

Decision to End Current Treatment

After fighting illnesses for years, four patient responses reflected that their reason for choosing to end curative treatment developed because of their dissatisfaction or tiring of current treatment plans.
Edward: I decided that after ten years of chemotherapy and radiation and all of that that I wasn't going to do anymore (E, p. 1).

Perceptions of Pain

One of the reasons patients chose to end current treatment or forego a medical procedure was because they had experienced or perceived the process to be painful and exhausting. "Beatrice" explained how having heart surgery would be more harm than it was worth, while "Fran" commented on the pain and exhaustion chemotherapy and radiation caused during her bout with cancer.

Beatrice: The healing is impossible and at my age, and they cut you in the back and in the front. You end up on dialysis and it's very painful (B, p. 1).

Fran: It was wearing me down and it was gonna kill me before the cancer did and so um, I didn't want to do anymore. [...] Plus with the pain and that kind of thing and I thought that they would be able to help me (F, p. 1).

Perceptions of Unlikely Success

Beyond enduring the pain and recovery of the medical procedures associated with their illnesses, the second theme that emerged under decision to end curative treatment was that patients perceived curative treatment to be unsuccessful. Although "Beatrice" was told that she needed to choose surgery in order to live, "Beatrice" had called her son's friend, a cardiologist, who told her:

Beatrice: 'You have a 50-50 chance [of living] if you have surgery.' [...] Which means you got no chance, I know. When they say '50-50,' it's all over, I know (B, p. 1).
Like “Beatrice”, “Henry” recalled the physician's comments regarding the unlikely success of curative measures.

**Henry:** He says, ‘You should you should’ve been in ten years ago. You’re way too late. You’re beyond chemotherapy. You’re beyond radiation. It’s too late. It’s too late’ (H, p. 1).

Despite the apparent despair conveyed in this prognosis, “Henry” actually attempted chemotherapy for a while. Like “Henry,” “Fran” had fought cancer through radiation and chemotherapy, hoping that the curative treatments would work.

**Fran:** I had, I’ve been fighting cancer for 11 years. Over 11 years now. Ovarian cancer and it just came back, metastasized and came back in 2004. That’s at least when we found out that it was back. And so I've come back from every time. See, my husband just thought, ‘Well, she’s okay. She’ll be okay, because she beat it before and she can beat it again’ (F, p. 1).

However, after going through chemotherapy treatments with little relief, both “Fran” and “Henry” chose to end curative treatment. “Fran’s” story reflected her frustration and exhaustion with the treatments, which she conveyed as the reason to stop engaging in curative measures.

**Fran:** Well I did. I kept beating it, but it kept getting worse and it kept coming back, so, it was time (F, p. 1).

As evident from interview transcripts, patients associate curative measures with pain and perceive ongoing medical efforts as futile. However, the aforementioned themes merely provide insight into why patients opted against curative measures, but not why hospice was chosen as the alternative. Additional emergent themes exposing patients’
overall perceptions of hospice care provide insight into why they chose hospice as a health care plan.

_Hospice as the Alternative_

The aforementioned three themes merely provide insight into what prompted hospice patients to end or forego curative treatment, but do not address the initial research question concerning why patients are choosing hospice care. Moreover, if a patient decides against curative measures, one cannot automatically assume that the individual will opt for hospice care as the alternative. Emergent themes reflect that individuals who chose to begin hospice care had prior knowledge about hospice through work or family experiences, were seeking monetary or general help that they perceived could be provided through hospice, or associated noncurative treatment with death and so they chose hospice as a “place” to die. Thus the following themes: 1) _prior knowledge of hospice care_, 2) _monetary assistance_, 3) _general help_, and 4) _hospice as representative of mortality_, are attended to below. As related to the latter theme regarding the association of hospice with death, the additional theme of _hope_ emerged suggesting that patients’ initial perceptions of hospice as signifying their mortality changes into hope.

_Prior Knowledge of Hospice Care._

As mentioned, research is unclear as to whether the primary mission of hospice care is communicated to patients today. However, the
current study reveals that patients have knowledge regarding hospice care through work experiences within the health care field.

Donna: I knew about it. When it first started. It started in Connecticut. And I lived in Connecticut, so it was nothing new to me, because one of the boys who was working with us on the home care program for the city, left us to join the hospice when it first opened up in Connecticut, so I knew all about it (D, p. 3).

"Edward" also communicated his knowledge of hospice.

Edward: I was the chief executive officer of two health care companies and as, I had my own, for thirteen years, my own medical billing company. So I know that what the framework of health care is from pediatrics to geriantol, geriatrics (E, p. 1).

While these accounts of prior affiliation hospice programs suggest that patients are aware of the purpose of hospice through personal knowledge of hospice, these comments do not convey patients' complete understandings of the hospice mission, nor do they suggest that their information came from the actual hospice with whom the patients were currently affiliated. Specifically, while “Donna” explained that the hospice philosophy was not new to her, she did not provide any information about the focus or quality of hospice care. “Edward” also did not provide any information about the hospice mission. In fact upon further discussion, “Edward” acknowledged that he only became aware of the current hospice facility through a discussion with his wife.

Edward: The only way I'm familiar with any hospice in town is because I happened to drive by [hospice] and I knew that there was one there. So my wife, my ex wife, checked out some of these and we thought that this
one was the best one, so that's the only reason why I went in (E, p. 1).

Again, although “Edward” articulated his prior knowledge of hospice claimed the current facility “was the best one,” he did not provide any details about the hospice mission or services offered.

“Ira” provided insight about the type of care he knew he wanted to avoid, but he also did not explicitly discuss how the current hospice could meet his needs or how hospice differs from other facilities that experience blatant complications with care.

Ira: My wife heard about it [hospice]. And she heard about it and thought about it as being very good, because a lady over here had a problem with her husband. And she put her in those units up at the corner and she’s paying like 4 or $5,000 a month. [...] He had to be fed through the stomach and she pulled the blankets back and here all this food was laying there. A disconnect. So she whipped him out of there. I don’t know where he is now, or, he’s probably passed away, but it didn’t sound too good for paying that kind of money (I, p. 1).

“Ira” did not give evidence to support his theories that the hospice program was better than the care facility his neighbor was in, rather he concluded that through hospice he could expect better care.

Overall, while some patients might have been introduced to hospice through personal knowledge or family history, patients’ previous experiences with hospice reveal little knowledge about the focus of the philosophy or the quality of care. However, other emergent themes provide insight into patients’ more detailed understanding of hospice care focus.
Monetary Assistance

To begin with, two patients indicated that while they opted against curative treatment, they ultimately chose hospice care as a means to meet their monetary needs. One patient explained that she couldn't afford curative treatment. "Ginny" looked to hospice as a way to combat these financial issues.

Ginny: We have [zero] money. The insurance ran out and we were in desperate shape. I actually used NAH as my insurance policy (G, p. 1).

Like "Ginny", "Ira" also associates hospice with financial assistance. He opted to forego curative treatments and chose hospice for his ongoing health problems, and as a result "Ira" relies on hospice for monetary support as well.

Ira: Now hospice has taken the whole thing over. And we're just in the business of gearing up the bills that remain in between that time. [...] She's [social worker] working on them and I think we'll get it cleared up in about a month (laughter) (I, p. 1).

General Help

While "Ginny" and "Ira" comment on their fiscal relationship with hospice, other patients explain that they needed hospice for general assistance. "Fran" describes the conversation she had with her oncologist when she had decided to stop chemotherapy and radiation, while emphasizing her self-sufficient/self-reliant personality.

Fran: So, I think two months in a row, she had mentioned it to me about hospice and I kept thinking, 'Well, I'm okay and I'm doing okay. I can take care of myself. I can do this and that, whatever. I don't need hospice
right now. Down the road I will, but right now, I don’t' (F, p. 1).

However, when “Fran” realized she was unable to complete her daily tasks without some assistance, she looked to hospice for support.

Fran: Finally I said to her ‘I think I’m ready for hospice.’ [...] I think because I could, I felt myself not being able to do things like I always had before. And I’m one of those people that I’ve got to do things. I don’t ask people for help. I do whatever needs to be done and that’s it. And then it kept getting to the point where there were more and more times when I couldn’t do some of the things that I wanted to, so I thought well, I’d better get some help (F, p. 1).

Like “Fran,” “Joe” also chose hospice care for assistance, although he did not emphasize his independence as “Fran” had. Rather, “Joe” appears to adhere to the paternalistic patient/provider health communication model, as he maintains limited patient control and encourages high provider power by trusting hospice IDTs know what is best for his care.

Joe: Not much to explain. They just came over and said it was the best thing for me. Switch to hospice and I said that’s fine with me. I said as long as I’m taken care of (J, p. 1).

“Joe” had little input into what services or care hospice could provide, and he simply depended on hospice personnel to take care of whatever needs they saw fit. Both “Fran’s” and “Joe’s” experiences provide insight into how self-concept factors affect the receipt of health care. Given “Fran’s” reluctance to give up her independence by relying on hospice, one can suspect that she will attempt to maintain a high level of agency
while utilizing hospice services. However, in a paternalistic health care model, in which “Joe” appears to be involved, “patients become those who are marginalized” (O’Hair et al., 2003, p. 198) as paternalistically-minded patients lack the voice needed to achieve the most comprehensive health care (Geist & Gates, 1996). Thus although this theme reflects patients begin hospice care to gain assistance, this distinction between “Fran” and “Joe” reveals insight into how self-concepts can affect perceptions of assistance, which affect the receipt of the wholistic experience.

Hospice as Representative of Mortality

While “Fran” and “Joe” note help/assistance as the primary reason they sought hospice care rather than curative treatment, “Fran’s” comments reveal her belief that hospice is one of the only options in health care when the diagnosis is terminal. Specifically, “Fran” referred to needing help “down the road” and described her condition as “getting to the point” when she was unable to function as before. Five other patients offered the perspective of a linear health experience, in that there are points within the terminal diagnosis when the condition worsens and patients are unable to return to their previous self-sufficient health stages. “Edward,” like most patients, saw a dichotomous health care choice: either continue chemotherapy and radiation as curative treatments with little success and much pain and discomfort, or forego curative treatment and use hospice to die.
Edward: That I simply was going to let nature take its course. So when you do that, then hospice is that only answer and how you ease your way out of this life (E, p. 1).

“Beatrice” also perceived hospice as associated with death when she describes how she surrendered to the hospice alternative. Rather than see hospice as a wholistic health care approach, focused on life, “Beatrice” explicitly shared her belief that hospice was representative of mortality.

Beatrice: So he says, ‘I’m going to put you in hospice.’ In other words, I’m not going to live long. [...] The only thing I said, ‘Well, I guess it’s all over, I guess I’m dying.’ [...] ‘I guess this means I’m on my way out’ (B, p. 2).

Like “Beatrice”, “Henry” also saw enrolling in the hospice program as an acknowledgement of his terminal condition.

Henry: ‘Well, here’s what we can do,’ I said, ‘I wasn’t ready to be in a room by myself, staring at a wall the rest of my life. And that’s impossible.’ And she said, ‘Henry. It’s done. No no.’ so she says, ‘well, we can send you home and send a nurse. [...] and come to the house. And see how that works out’ (H, p. 1).

Also, like the other patients, “Henry” saw this option of giving up and dying as his only one, when he was informed that he was “too late” to have a fair chance at fighting cancer. A distinct part of “Henry’s” response, however, is his portrayal of the medical provider’s reassurance. “Henry” suggests that his perception of a solitary death experience was negated by the provider. He was not going to be in a room by himself, “staring at a wall.” Conversely, “Henry” was encouraged that someone would come to his house, so he would not be alone, and together they
would “see how that works out.” Thus, an element of hope has been introduced to “Henry” and is further attended to below.

Hope

The final theme of hope emerges within patients’ reasons for choosing hospice care as the alternative to curative treatment. While responses suggest that patients choose hospice for monetary or general help or as a place to die, this theme of hope provides insight into how patients’ perceptions of hospice change once they become involved with the program. Again, hope is not a primary reason patients chose hospice care but emerges as a theme as a result. “Beatrice” describes how she no longer associates hospice with death.

Beatrice: The only thing I said. Well, I guess it’s all over, I guess I’m dying.’ But I don’t feel that way now. Even though I do have bouts […]. I hope – I’ll make a bet. I’ll live longer than that. I will bet anybody (B, p. 2).

“Ginny” responds in the like, as she conveys herself and other hospice patients as more than just dying people, but as still living.

Ginny: No one should ever be thrown away, there is value in every living soul (G, p. 3).

Furthermore, “Ginny” cringed at the word ‘progression’ when asked if she talks about the progression of her illness, and elaborated by explaining:

Ginny: Nothing is incurable. Disease – if you believe, is Dis. Ease. Incurable – if you believe, is Cure from within. Dis-ease/in-curable (G, p. 6).

This theme of hope reflects that patients adopt new understandings of hospice care once becoming involved. While these
newfound feelings of hope might suggest that the hospice mission is being communicated to patients, the hope patients are discussing here does not necessarily reflect the hospice mission of wholistic care. Rather, this hope appears to contradict patients’ terminal prognoses, as patients reveal their determination to outlive their prognoses or be cured. Thus, as this theme of hope suggests that patients are focused on outliving their terminal prognoses, perhaps the original goal of hospice, “a peaceful and comfortable death” and wholistic services are not communicated accurately (NHPCO website, 2008).

Research Question 2

In order to develop RQ2, ‘From the patient’s perspective, how was the wholistic hospice experience communicated to them?’, wholistic health care must be operationalized. As mentioned, the original wholistic mission of hospice is “generous control of symptoms [physical], attention to the patient’s psychological and spiritual needs, [and] care and support for the family as well as the patient [emotional]” (The hospice experiment, 2002). To elaborate upon the definition of wholistic care that was presented at the onset of this study, wholistic health care is defined as encompassing the physical, psychological, emotional, and spiritual needs of the patient, and these four areas have emerged as themes which provide insight into how patients perceive the wholistic hospice experience.
Physical Needs

Physical needs are defined as issues "of or relating to the body as distinguished from the mind or spirit" (physical, n.d.). As part of the wholistic health care experience, physical concerns were perceived by patients as needs met through the use of medication, prompting the theme medication to emerge. While the definition of physical suggests medication fits as a response to patient concerns, hospice facilities also attempt to meet physical needs through the provision of the following therapies, pet, energy, massage, and aromatherapy, under the heading comfort care services. Thus the theme knowledge of comfort care services provides insight into patients' understanding of the physical element of the wholistic care experience.

Medication

The theme medication emerged as a method by which patients perceived hospice as meeting physical needs, suggesting that patients associate physical concerns with pain management. When asked about physical needs being met, "Beatrice" commented on how hospice provided medical equipment and that she only called the facility to help when she was in physical discomfort.

Beatrice: I have all the equipment [...] and I know what to do in case of an emergency and I have, I call hospice if I'm in real distress and they respond right away (B, p. 2). They come in, they do what they're supposed to do (p. 4).
“Beatrice’s” articulation of hospice coming in to do “what they’re supposed to do” suggests “Beatrice’s” belief that the extent of hospice care is to provide physical support by relieving discomfort. “Edward” and “Ira” responded similarly, noting hospice’s provision of medication as attending to their physical needs.

Edward: They come in and take my vitals and I tell them what has happened since the last visit. And pretty much it’s a matter of whether my pain level has increased to a point where I need more medication. And then they take care of getting that, they call the doctor and get that approved (E, p. 3).

Ira: Physical pain? I’ve been taking some pills for it, but I’ve been telling them, ‘I don’t have any pain.’ [...] And I’m thankful for that. That’s what I asked [the nurse], I said, ‘Will there be pain?’ and she said, ‘We’ll take care of it’ (I, p. 11).

Patients’ comments about medication, when asked about their physical needs, suggest that patients are unaware of the multiple methods hospice uses to attend to physical needs. Thus, interview responses regarding comfort care services provided reflect patients’ misunderstandings of the physical element of wholistic care.

Knowledge of Comfort Care Services

Although physical needs include attention to pain management and medication, hospice facilities also provide aromatherapy, pet therapy, massage therapy, and energy therapy in order to address the physical comfort of patients. However, the theme knowledge of comfort care services, reflects patients’ misunderstandings of the purpose of comfort care services. To begin with, “Henry’s” question indicated that he
perceived comfort care to be associated with cure. Specifically, when asked if he used aromatherapy, pet therapy, or massage therapy, “Henry” responded sincerely:

Henry: Are those good cures for prostate cancer or lung cancer? (H, p. 6).

“Edward” also considered comfort care had possible curative purposes and were not simply options or services to enhance his comfort.

Edward: There’s not much, I should say, there’s not much needed really. I’m not trying to be cured. So there’s not much he can do for me (E, p. 3).

“Henry’s” and “Edward’s” confusion concerning the focus of comfort care suggests that these services as components of the physical wholistic experience are not being communicated to hospice patients. As “Edward’s” and the previous theme, *medication*, suggest that patients’ primary concern might be pain management and thus comfort care services seem superfluous, as patients are not seeking curative treatment. However, comfort care services are not aimed at curing, rather these services, like medication, can be utilized to reduce physical pain as well. “Albert”, a stroke patient, is paralyzed on one side of his body and is unable to move from his bed. As a result, his mobile side becomes sore from maintaining the stationery position. As part of the wholistic experience, many hospice facilities offer massage therapy as a comfort care service. If “Albert” could perceive this therapy as part of meeting his physical needs, he might engage in massage therapy and as a result he might experience wholistic health care more adequately.
Psychological and Emotional Needs

The theme psychological and emotional needs reflect that like physical needs, patients also do not fully rely on hospice to treat the psychological and emotional aspects of their wholistic health care. Specifically, patients perceive having psychological needs as being unstable or crazy.

Albert: I have no trouble with myself. [...] No trouble with other people. [...] And I feel [...] fine (A, p. 13).

Edward: I don't think I have any psychological needs for them to take care of. I'm an extremely self-reliant person. I don't need a lot of help from anybody. The only help I need is to make sure I'm pain free and they do that (E, p. 7).

Similarly, "Fran" and "Ira" communicated their negative connotations of psychological needs as they made jokes in reference to their mental states.

Fran: Psychological, huh? Okay, so now this is my mind. Well, sometimes I think I'm losing my mind, but that's beside the point I guess (F, p. 11).

Ira: I'm pretty well settled. My mind is not crazy yet (laugh) (I, p. 11).

"Beatrice" also conveyed that turning to others for assistance with emotional or psychological issues suggested weakness or instability, when she explained that she doesn't use hospice to meet her emotional or psychological needs.

Beatrice: They don't treat my emotional/psychological needs. I haven't felt the need. Like I say, I have a family. I got a life. I direct these gir- these people that help me. I'm not a cry baby. Even when I'm in pain, I
can't cry. I complain. And I curse, but I don't cry (B, p. 11).

These perceptions of psychological needs or issues are detrimental, especially because the subtext in some patient responses indicates that patients do have psychological needs and could benefit from looking to hospice to fulfill those needs. For instance, “Albert” made a few comments about ‘morbid’ talk, suicidal thoughts, and withholding certain conversations from his wife about his experiences. I asked “Albert” if he had conversations with his wife about what he was going through.

Albert: Never had. [...] No sense of getting there. I have upset and what happens. She, I have things to say, but I don't say them. [...] Some things are left better unsaid (A, p. 10).

Later, I asked if he wanted to talk about any of those “unsaid” topics with his social support. “Albert” relayed a hypothetical conversation he would have with a social worker, if he addressed those topics.

Albert: ‘Candice, you ever thought about suicide?’ ‘No.’ [...] ‘Have you ever thought about it before?’ ‘No.’
Interviewer: And who do you have those conversations with?
Albert: Candice.
Interviewer: Who’s Candice?
Albert: No reason to have that conversation (A, p. 12).

“Albert’s” wife commented about how she thinks “Albert” gets upset when he thinks he might be a burden to her. I asked “Albert” if his wife being upset was a concern to him. Visibly upset, “Albert” responded in the affirmative, saying that his wife said it all, and attempted to turn on the television. After his wife left the room, “Albert” continued talking.
Albert: No. Everything's fine. [...] Everything's fine. [...] Except never should have moved here.
Interviewer: Never should have moved here? To Las Vegas?
Albert: Yah. This here place. Dead man (A, p. 17).

At this point, “Albert” if we could call it a day. While originally, “Albert” claimed that everything was fine and that he did not have psychological needs for hospice to fulfill, further probing and follow-up questions reflected that “Albert” had some concerns that might be addressed as part of his wholistic experience but that he was not currently utilizing these services.

Other patient responses also indicate that they have underlying emotional or psychological concerns, but don’t think they can be helped in this area. When I asked what conversations they would prefer to have with their support system, they answered:

Edward: What I don’t want to talk about much is the fact that I’m dying. That’s a given (E, p. 6).

Henry: There’s nothing other than they can do. We both know and the hospice people know that I’m just hanging by my fingernail on the prostate and on the lung, so it’s very temporary touchy. There’s not much they can do they do as good a job as they possibly can, I’m sure. And they answer the questions as they come up. Naturally, it’s very depressing knowing that you’re going to die and it could be a week, could be two weeks. A month. Who knows (H, p. 11).

“Edward” and “Henry” explained that they did not want to dwell on their illnesses, but they did admit that they wanted to live forever or didn’t want to talk about their health, even though they know their conditions are terminal. Thus, hospice patients might experience
emotional or psychological distress because they do not want to die, though they know death is inevitable. Therefore, while these patients say they do not have emotional or psychological concerns, their views of death might be considered as part of these needs and thus they might benefit from utilizing these aspects of their wholistic experience.

"Henry" also implied some underlying psychological needs when he spoke about how he wanted to learn more about his condition. He claimed that he would find books about his cancer, but he needed someone to explain the information to him.

Henry: Well I've got some information. I'd like more information, I'd like but it's too hard to get to. I don't have one of them [...] even to connect into. I'd like to know more about my disease, but a lot of these books that I get, they're over my head. I don't understand them. They're more for a doctor to read, so only 50% help me, 50% don't (H, p. 9).

Again, like the other patients, "Henry" has intellectual or psychological needs that could be fulfilled through the help of a professional or hospice care giver, but he has yet to utilize these services as part of his wholistic care. Research indicates that patients could benefit from engaging in frank discussion about their thoughts and emotions. Specifically concerning EOL care, Combs Lee (2008) explains, "people crave these conversations [about death], because without a full and candid discussion of what they're up against and what their options are, they feel abandoned and forlorn, as though they have to face this alone" (CNN website, 2008, np). Thus, as abstinence from these
conversations might increase loneliness, the wholistic experience which includes the relational elements in patients' lives, cannot be properly attended to if emotional and psychological needs are not addressed.

_Spiritual Needs_

Concerning spiritual needs, patients perceive spiritual concerns to be associated with God and religion although hospice defines spirituality more broadly. Hospice explains spiritual needs as "a way of describing the organizing center of a person's life" (Irion, 1988 as cited in Derrick, 1996). Furthermore, spirituality also concerns the elements that give meaning to life. However, responses reflect that hospice patients are either unaware of what spiritual needs consist of or associate spirituality with religious beliefs, claiming they do not have spiritual concerns and thus are not utilizing these services as part of their wholistic care experience.

_Limited Knowledge of Spiritual Services_

Primarily, these patients were unaware of the spiritual element of their wholistic health care. "Albert" said that he did not meet with a spiritual mentor or advisor; however later, when asked how hospice was treating his spiritual needs, he seemed confused by spiritual needs were.

Albert: Hope so. They're doing well.
Interviewer: They're doing well? Okay. Do you talk with them about your spiritual needs? Do you talk to hospice about your spiritual needs?
“Albert’s” wife contradicted “Albert” and said “no.” To which, “Albert” changed this answer.

Albert: No I’d rather not (A, p. 14).

While it can be argued that perhaps “Albert’s” wife was unaware of “Albert’s” spiritual needs, and thus immaturely altered “Albert’s” understanding of his own hospice care, “Albert” had already explained that he did not meet with any spiritual personnel at hospice. Given that “Albert” did not elaborate on any other ways hospice met his spiritual needs, his responses indicate that he is not sure what his spiritual needs consist of or how they might be met through a wholistic experience.

Like “Albert”, “Chris” also indicated that he was unaware of how hospice could address his spiritual needs. He shook his head when asked how hospice was meeting his spiritual needs. I then asked a follow-up question:

Interviewer: Do you feel that if you had those spiritual needs, would hospice be able to provide those for you?
Chris: No (C, p. 15).

Like “Chris”, “Fran” also did not know what to anticipate if she had spiritual needs for hospice to meet. While “Fran” was asked about her religious needs during the initiation phase of her hospice care and declined assistance, she conveyed that she was unaware of hospice’s role in meeting her spiritual needs if she had them, claiming she didn’t know who would come or how they would help. Similar to patients’ knowledge of comfort care services, patients are unaware of spirituality as part of
the wholistic experience, which indicates that these various elements are not being communicated to patients.

*Refusal of Spiritual Services*

Patient responses reflect that while some patients are unaware of what constitutes spiritual needs or how hospice can address those needs, other patients expressed that they do not have these needs. “Beatrice” communicated quite plainly that this service was not necessary in her health care.

Beatrice: I don’t have a therapist, and I don’t have a spiritual mentor, and I don’t think I need one (B, p. 5).

Like “Beatrice”, “Fran” also claimed that she did not need spiritual services; however, as “Fran” continued talking about her spirituality, she expressed a possible underlying need for assistance from hospice, as she utilized similar services while in the hospital.

Fran: In the hospital, now I did have people come. They were Catholics and they came, they came to my bed and everything and prayed with me, that kind of thing, but ya know it’s cool. But it isn’t something that I need, ya know all the time. I can pray on my own, kinda [...]. Well, I think when you, when you sign in [to the hospital], I think they, well they want to know what your religious preference is, or if you have one or whatever. And then they ask if you would like to have somebody and I, I guess I must have said or whatever, but anyway, they were there (F, p. 10).

“Fran’s” comments suggest that at one point during her bout with cancer, she had accepted religious or spiritual support. Given that “Fran” was unaware of the process through which hospice addresses patients’ spiritual needs, but that she had accepted spiritual assistance previously
during her health care, it is reasonable to assume that if “Fran” had more knowledge of how hospice could meet her needs or understood that hospice could meet those needs on her own terms, she might be more inclined to accept this aspect of the wholistic health care approach. This assumption is especially a possibility, given “Fran’s” suggestion of the importance of religion in her life. She mentioned all her friends of various religions who were praying for her.

Fran: They all had people that they knew praying for me. The churches, the synagogue, the temple, whatever they went to [...] It’s just amazing. And I believe in the power of prayer. It’s why I’m still here (F, p. 5).

Religious Needs

While the previous themes reflect that hospice patients were either unaware of how hospice could meet their spiritual needs or claimed they did not have spiritual needs, six patients associated their spiritual needs with religion.

Fran: And of course, they asked me about the religion kind of thing. We are Catholic and that kind of thing, but I didn’t want people coming all, ya know to talk about that or whatever. I felt that I was okay with that, I can do it myself, or whatever (F, p. 2).

Similarly, “Beatrice” elaborated on her limited religious views when asked how hospice met her spiritual needs.

Beatrice: They don’t. I don’t need them. I’m not a religious person anyway. I don’t believe in dead spirits, I don’t believe in, the only spirit we have is when we’re living. I don’t know how religious you are, but I don’t, ya know? (B, p. 11).
“Edward” also explained claimed that he didn’t utilize hospice for spiritual needs, because like “Beatrice”, he associated spirituality with religion. When I asked him if he could comment about how hospice met his spiritual needs, he asked:

Edward: Does it help to tell you that I’m either an atheist or agnostic?
Interviewer: Well, I mean it helps, but I just thought any kind of, some people define spirit, spirituality in different ways, so I wanted to just make sure I gave you the opportunity to talk about that (E, p. 8).

Although it seemed that “Edward” understood this new articulation of spirituality, he did not elaborate any more on spiritual needs or hospice’s part in meeting those needs. Like “Edward”, “Donna” and “Henry” also perceived spiritual needs to be related to religion and hospice’s part, or lack thereof, in meeting those needs. When I mentioned spirituality as part of the wholistic health experience “Henry” spoke about his relationship with the hospice chaplain.

Henry: Chaplain? [...] Just a standard relationship. He prays and he’s protestant. He says a little prayer and that’s about the way it is (H, p. 5). Just a regular minister to uh the congreg, to uh the parishioner. And he prays with me and asks forgiveness and that’s about it, I guess. All basically, ‘Don’t give up hope, keep going’ (H, p. 6).

“Ira” also considered spirituality to be associated with religion and he conveyed that he did not have any spiritual needs, as he no longer went to church.

Ira: Not spiritually. I stopped going to church about 40 years ago.
“Ira” elaborated about his skepticism when people turned to Jesus before they died.

Ira: Because not, I’m not into it. And I don’t think I will be. Even when it comes time to, if you’re gonna die ya know because there are a lot of things I cannot believe in the biblical stuff and to have someone telling you or pushing you on it (I, p. 12).

“Ira” claims that he does not want or need hospice to meet his spiritual needs; however, when referring to these needs, he only associates them to going to church or believing in Jesus before people die. “Ira’s” comments suggest that if there was another way to operationalize spirituality as not being related to religion, “Ira” might have use of this element of wholistic care in hospice. This assumption can be made, as “Ira” conveys later that he does believe in a God.

Ira: Well, I don’t know if it’s so hard to understand. The way I feel it, if God made us in the beginning Adam and Eve. He made the two: ‘Here’s the good side, here’s the bad side. You choose, whichever.’ And people have ya know. So if there’s gonna be a something, punishment after, well so be it (l, p. 14).

Although the previous patient responses suggest that one reason spirituality is not necessarily considered as part of the wholistic health care experience is because patients associate spirituality with religion, like “Ira” “Ginny” suggests that patients have a difficult time articulating exactly what their spiritual needs are, in order to obtain that assistance from hospice personnel. “Ginny” wrote about surrendering to God as being difficult, when asked about her interaction with a hospice spiritual mentor.
Ginny: I speak with Ellen. She is just awesome. To totally surrender to God is not an easy thing to do (G, p. 4). I go to God. I can only open my Christ light, the glow that says I am never alone (G, p. 6).

“Ginny” went on to explain that she asks God for guidance and listens. She refers to her cancer as “negativity” and says she prays, if God wills, for the cancer to go away, but found difficulty in trying to convey these thoughts and feelings to me.

Ginny: It’s hard to explain (G, p. 7).

“Ginny’s” comments suggest that while she does speak with a hospice spiritual mentor, she thinks surrendering to God or explaining how she uses spirituality to assess her health status is difficult to talk about and address. Thus, it is reasonable to assume that because patients confine spirituality to the parameters of religion or find difficulty in expressing spirituality as they personally experience it, this aspect of wholistic health care is not being communicated as effectively as possible.

Research Question 3

Analyses of the 10 interview transcripts with regard to RQ3, ‘How do patients experience interdependence with IDTs regarding the wholistic health care approach?’ reflected that patients perceived interdependence with IDTs in their hospice care, as they indicated they had strong connections with various hospice personnel and knowledge of the medical equipment. However, patient responses also reflected that there
were often changes in hospice personnel and limited visits and time with hospice physicians. Furthermore, patients had difficulty expanding on the type of care they received; instead they offered generic statements referring to positive aspects of their care or blind trust in the health care decisions hospice personnel made. Thus, while patients claim they felt interdependence in their care through the two emergent themes of connectedness with hospice personnel and active participation, two additional themes of patients' reliance on providers and lack of provider consistency reflected a lack of interdependence.

**Connectedness with Hospice Personnel**

Interview responses indicated that patients experienced interdependence in their health care as they emphasized the close relationships they had with their hospice care providers. As the previous literature review indicates health is becoming more medicalized, minimizing the relationships patients have with their health care providers. Comments about the relational aspect of care reflect that patients desire a return to a more interdependent type of care. When asked about his communication with the hospice spiritual adviser, "Henry" responded:

> Henry: And he prays with me and asks forgiveness and that's about it, I guess. All basically. 'Don't give up hope, keep going.' And it's a good relationship (H, p. 6).

"Edward" indicated that he had close relationships with both his
nurse and volunteer, as he emphasized their unique and developed connections.

Edward: There was a nurse named C.M. uh. [...] Got along with her very well. She became almost a friend (E, p. 2). I had, I have one [volunteer] that comes in every week to meet with me. We've become good friends. He's been coming in for about a year, close to a year (E, p. 4).

"Donna's" comments also indicated that a uniqueness to their relationships with IDTs. Despite the constant changeover in personnel (forthcoming), "Donna" believed that her nurse would stay with her.

Donna: As I said! She says she's never gonna leave me (D, p. 6).

"Fran" also distinguishes her relationship with her doctors from relationships other patients might experience, as she communicated that she was "lucky" with her interactions.

Fran: I have been very lucky with the doctors that I've had throughout the years. Every one of them has cared about me and I knew that they did and they were always looking out for my best interest (F, p. 4).

Patients also highlighted their connections with IDTs when they recounted compliments they had received about their patient identity.

"Donna" discussed the mutual liking between she and her doctor, while "Beatrice" spoke about her and her doctor's ability to share humor.

Donna: She [doctor] comes out at least once a month. She thinks I'm super. I think she's super. The feeling is mutual (D, p. 4).

Beatrice: They were laughing and laughing because he gets a kick out of me. He said he never enjoyed a patient so much. Of course I know that's his bedside manner, it doesn't matter (B, p. 4). So I asked my doctor, I said,
‘Why is it that I’m the oldest and my youngest siblings are all dead?’ He said, ‘Ya know why? Only the good die young. Bad people like you, they go on and on and on.’ So, we had a joke on that (p. 7).

Patients’ responses reflecting strong connections with hospice personnel relate to health communication research in the United States concerning positive patient/physician relations. Anderson (2001) argues “physicians have benefited from skills training in how to show concern for patients through verbal and nonverbal behaviors, such as listening and being friendly” as patients feel more comfortable to discuss their health situations with their physicians (p. 68). Thus, patients’ understanding of the wholistic experience might be enhanced through the development of connections with IDTs.

Active Participation

While the emergent theme of connectedness with hospice personnel reflected that patients appreciated, and could potentially benefit from, the close relationships they formed with IDTs, interdependence also includes a level of mutuality. Thus the theme active participation emerged reflecting a more comprehensive feeling of interdependence. Patients’ discussed their own roles in addressing their health care concerns and communicated personal knowledge of their medical treatments. “Ginny” specifically emphasized her agency, by explicitly commenting how IDTs did not act unless she requested their assistance.

Ginny: At 3AM – at 4AM – what ever (l) (l) needed/ what ever I needed comfort – listening – to calm me down when I
was scared (G, p. 3). [...] By Request – my Request (p. 5).

“Edward” and “Chris” also emphasized their control in their health care when they explained the process of obtaining what they need.

Edward: So they arranged last to week to have this taken care of. So I need to say that as far as my interaction with them, they respond very quickly to what I tell them (E, p. 3).

Chris: Whatever they offer, I can either take it or leave it (C, p. 6).

“Ginny’s”, “Edward’s”, and “Chris’s” comments suggest that patients believe they play an active role in the kind of care they receive. This control was further emphasized when patients told me details about certain medical procedures. Although I did not specifically ask any questions that related to medical technology, patients consistently informed me about their medications and equipment. “Henry” spoke about his lung cancer and emphysema, explaining that he needed to exercise more and be in the sun to mitigate his health problems, while emphasizing that the nurses tell him a lot. “Donna” also provided information about her tumor and her expectations of the growth or the tumor’s descending nature. Finally, “Beatrice” educated me on the specifics of her condition.

Beatrice: Well, an aneurism in the heart is usually fatal. It’s a growth in the heart that keeps growing and eventually it will affect the aorta vein. Do you know what the aorta is? And uh mine is growing. And that is an aneurism. Then there is an embolism. That is on the surface, around, like this. The other one is inside the heart (B, p. 1).
Patients’ emphasis of their medical knowledge reflect that patients seek to be stronger participants in their health care and possibly, as a result, patients feel more in control (Street, 2003). However, with much control also comes much responsibility. Guttman (2003) claims “health messages that emphasize lifestyle factors and personal responsibility may implicitly characterize those who do not adopt recommended practices as unwilling, lazy, or weak of character and at fault for their medical conditions” (p. 661). Given that medical knowledge might increase responsibility, patients might opt for relying on providers, which prompts the third theme under patients’ perceived interdependence with IDTs.

**Reliance on Providers**

While the previous two themes, *connectedness with hospice personnel* and *active participation*, indicate that patients experience interdependence as they value their close, mutual relationships with IDTs and participate in their own care, other responses suggest that patients have little or relinquish much control in their care, by relying heavily on hospice providers to meet their needs. When asked about how hospice was meeting their various wholistic concerns, patients gave vague answers about the overall quality of care, suggesting that although patients asserted that they were knowledgeable about their medical situations, patients were not able to elaborate about how their needs
were specifically met. Thus, the theme reliance on providers suggests an apparent lack of interdependence.

"Beatrice's", "Joe's", and "Chris's" comments explicitly reflected a possible reliance on physicians and lack of interdependence, as they emphasized their lack or investment in signing medical papers and engaging in medical procedures.

Beatrice: I don't know myself, to tell you the truth. The doctor he came here yesterday and he says, 'Where is your aneurism. Is it on the lower part?' cause you can have it here, 'It's up there?' I said, 'I don't know. I'll sign any papers you need so you can investigate it with the hospital, I don't know' (B, p. 1).

Joe: Not much to explain. They just came over and said it was the best thing for me. Switch to hospice and I said that's fine with me. I said as long as I'm taken care of (J, p. 1).

Chris: They just came over here. I laid back and let them take care of it, everything (C, p. 1).

Another method patients seemed to use to emphasize their reliance on IDTs, became apparent in their abstinence from communicating with providers about negative issues with their care or vague answers about the quality of care. When asked about the type of communication and care patients received from their IDTs, patients gave vague positive feedback, claiming everything was fine, good, and satisfying.

Joe: They treat me good (J, p. 7).

Chris: She was great. I'm, everybody was great. I don't know what to tell you, but they were all great! (C, p. 3).

Albert: I feel fine (A, p. 5).
While patients responded positively about hospice, the ambiguity of these answers suggest patients are either unaware of the details concerning their care or that they are withholding their negative feedback so as not to upset their circumstances. For instance, when “Albert” is asked about how hospice treating his spiritual needs, he answers that they’re doing well, although previously he commented that hospice did not address his spiritual needs.

Albert: Hope so. They’re doing well.
Interviewer: They’re doing well? Okay. Do you talk with them about your spiritual needs? Do you talk to hospice about your spiritual needs?
Albert: Uh, yah.
Interviewer: Yah?

“Albert” automatically answered that he was satisfied with a hospice service he had previously admitted he wasn’t even receiving. Similarly, before “Donna” even knew what question she was being asked, she responded with positive feedback about her circumstances.

Donna: My initial experience with them?
Interviewer: Who was the most memor-
Donna: -I was totally happy! [...] Satisfied! Happy! Content! What can I say? (D, p. 4).

“Donna’s” quick answer suggests that she was determined to respond positively about the care she was receiving regardless of what I asked.

Inasmuch, “Fran’s” comment reflects even more clearly the fact that patients do not want to address any problems they perceive with their care. Even though “Fran” admits she doesn’t see the doctor much,
she counteracts this possible negative situation to highlight the positives of her care.

Fran: Maybe seeing the doctor. I don’t know if it would do, well probably not. I don’t think it would make any, much difference, cause he does what he has to do if he needs to (F, p. 12).

“Henry” comments on his late medication, but like “Fran”, he also minimizes this concern.

Henry: And the drugs that I need, that they have to deliver medicine, a couple times they were a little late overnight, but they have worked out for the best and it’s worked out good (H, p. 10).

One possible reason patients refrain from expressing any negative concerns about the wholistic experience is that patients might adhere to the paternalistic model of health communication, which emphasizes trust in physicians and appropriate patient behavior. Beck’s (2001) research, regarding an increase in patients’ acquisition of information on the internet, reflects that some physicians are threatened by patients who are highly motivated to seek their own medical knowledge. Patients who adhere to a more paternalistic health communication model might believe in this stigma against proactive patients and choose to be more passive in their health care approach, by minimizing any problems with their care. “Ira’s” comments possibly emphasize this idea that patients should not report problems with their health care after he explains that he and his wife hadn’t had any problems with the hospice program.

Ira: That’s the thing. That’s the way it should be (I, p. 11).
Given that patients rely so heavily on IDTs to provide their care, it is reasonable to assume that patients do not want to ‘bite the hand that feeds them’ by making requests about their care. These concerns become even more apparent as responses reveal the theme that patients acknowledge the importance of good patient depictions.

Good Patient Depictions

Several patients claimed that they were unlike the other patients, whom they perceived to be extremely sick or frail.

Beatrice: It’s easy because I’m not a needy person. I’m not as needy as some of the others. Like my doctor was amazed, he said, ‘You you should see what the patients that I have to see.’ [...] I’m not a cry baby (B, p. 11). I’m not a needy person so I don’t have to call them a lot, just if my meds have run out or something like that. So I’m satisfied. [...] Well I hope you don’t have any bad patients. Do you, are you able to get enough information from your very very sick patients. [...] A lot of them are very depressed (p. 13).

Similarly, “Fran” emphasized her strength as a patient and communicated her perception that other hospice patients were needy, wanted special treatment, or complained a lot.

Fran: I know that (nurse) takes what I say very seriously because she says, ‘You don’t complain about all the different things’ ya know. [...] I know there are people that are like that, I mean they complain about e v e r y t h i n g, ya know and you don’t know for sure, are they really ya know whatever (F, p. 10)?

Again, by the patients’ depictions what constitutes a ‘good patient,’ responses further supported the theme reliance on providers. This strong dependence on physicians or paternalistic framework, suggests minimal
patient control. Consequently, any sense of interdependence with IDTs is

diminished as high provider control and low patient control does not

reflect a mutual relationship (Roter & McNellis, 2003).

Lack of Provider Consistency

To further inform about patients’ perceptions of interdependence

with IDTs the third theme, lack of provider consistency, becomes

significant. Patients comment that they rarely see their physicians, are

unaware of who certain IDT members are, and often experience a

changeover in which personnel visit them. Consequently, I argue that

patients cannot experience interdependence with IDTs due to this level of

inconsistency. Four patients primarily commented on their brief

encounters with the hospice physician.

Ira: I only saw her once, Dr. S I think. Is that her name? (I, p. 3).

Fran: Well, actually the only time I ever talked with him was

that first time when he was here. In the initial visit. So

I really don’t have any kind of, except for then and he,

ya know, he was a nice man. (F, p. 3).

Beyond articulating their limited physician visits, patients also

reflected that the personnel were constantly changing. “Henry” and

“Donna” spoke about the chaplains they met with previously, although

they were both unsure of when they would see the chaplain again.

Henry: He [chaplain] was coming every week and he was doing

a good job. A nice job. I think he’s a little sickly now,

but I’m sure he’ll pop in one of these times (H, p. 5).

Donna: No, I haven’t had a spiritual adviser since he left and

joined another one. I must ask about that (D, p. 6).
Similar to the chaplain inconsistency, patients suggested that there was a high turnover of nurse personnel as well.

Beatrice: They (nurses) change a lot. See, I don’t know why they have a turnover. Even, I’ve never seen the same nurse twice. Of course I’m new (B, p. 4).

While this changing of nurses might be unavoidable given the emotionally laborious nature of the position, problems might arise as patients are unaware of the reasons for the high turnover and as a result, they might blame themselves, as “Fran” reveals.

Fran: It almost seemed like I had two or three, I don’t know if it was two or three. That I was beginning to think, ‘Well, ya know, was it something I said, or what?’ ya know? But they just didn’t keep coming back, or whatever (F, p. 4).

Like “Fran”, “Donna” was also confused about the high turnover.

Donna: I’ve had so many changes of nurses, it isn’t funny. They leave, now I’m gonna lose my [nurse] in the middle of this month. March. She going back to New Mexico. Another one left to go to work for the Veterans in Boulder city. Another nurse left for... never knew the reason. (nurse) says she is not gonna leave. She’s happy here. I said ‘Sure, til they push you... too far.’ (laugh) then you’ll leave. ‘No, no, no, I’m not leaving’ (D, p. 4).

Overall, limited physician time, lack of knowledge about IDTs, and changes in personnel might not seem detrimental, as patients still reported satisfaction with their care. However, the research question was guided to ascertain whether patients experienced a level of interdependence with the IDTs. “Henry’s” experience with the nurse turnover reflects that patients do not experience this interdependence.

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Henry: Well, we had, I had three of them in here. Once they was in charge, 'I do it this way.' 'I do it this way.' 'Well, I do it this way.' But it's been off and on. It's hard. These are mild indifferences. There's no, there was no fighting. If you have two people you're gonna have two varying opinions (H, p. 4-5).

In order for interdependence to be achieved, patients and IDTs must establish common goals with mutual effort. However, as "Henry's" comments suggest, the lack of provider consistency introduces a varied and unpredictable environment, which is not an ideal foundation on which to build interdependence. Furthermore, as the personnel are constantly changing and patients are confused as to why, it is evident that shared goals are not present. Thus, while patients might indicate that they sense of level of interdependence, satisfaction with care and trust in their providers, given the limited details about their care and lack of provider consistency, it is reasonable to conclude that interdependence with IDTs during the wholistic health care experience does not readily exist.

Research Question 4

Analyses of the 10 interview transcripts with regard to RQ4, 'How do patients experience interdependence with social support networks regarding the wholistic health care approach?', reflected that three major themes: autonomy, connectedness, and burden for social supporters. Specifically, hospice patients asserted their own independent roles in their wholistic care, while also emphasizing the help they receive from
their social support networks, suggesting that patients and supporters work as a team for comprehensive care. However, as the theme burden for social supporters emerged, it can be argued that patients attempt to reduce their interdependence with support networks in order to reduce the impact of the burden on their supporters. Consequently, three additional themes emerged as patients worked to reduce the burden: focus on positives, abstinence from health care conversations, and value as relational partners. The final theme, definition of social support, reflected that even as patients attempt to enhance or decrease interdependence with social networks, confusion in who is included in these networks reflects that interdependence is an impossibility.

Autonomy

Similar to interdependence with IDTs, transcript analyses reflected that patients possibly experienced a tension between wanting to be in control of their care and needing to rely on their social support teams. To begin with, patients emphasized their autonomy by asserting their independence or involvement in decision-making. “Ginny” constantly emphasized that the wholistic care was her personal experience.

Ginny: My decision – totally MY decision! (G, p. 2) You first don’t rush into a situation where you are Not welcome – this is about “Ginny” and her Comfort (G, p. 3). If my family was there – or anybody else – they shared. If not they missed out! (G, p. 5).

“Beatrice” also articulated her independence by explaining that she was in charge of supervising her help. Furthermore, although “Beatrice”
admitted that she would discuss decisions with her supporters, she adamantly conveyed that the decision was solely hers to make.

**Beatrice:** [The helpers are] very nice. And if they’re not, ‘Goodbye, Adios’ (p. 5). I’ll make a decision, I’ll discuss it with you, but my decision is made. If you have, if you have an input, good,’ otherwise I don’t want them around me (p. 6).

Similarly, “Edward” conveyed that he sometimes includes his ex-wife, but again asserts his autonomy as he comments on the rarity of her involvement.

**Edward:** Generally, I do it myself, but sometimes she gets agitated when things aren’t done in a hurry and so she’ll take the reigns and take care of it herself (E, p. 6). And there would be a rare case when she would have to get involved (p. 9).

*Connectedness*

While patients spoke about their personal control in their healthcare, patients also commented on the involvement their support systems have in the wholistic experience. “Joe” acknowledges the teamwork aspect of his care when he discusses how his personal involvement affects his family’s role in his care.

**Joe:** I get to thinking I can do more than I can do and all of the sudden I kick myself back about six months. That’s okay. But we’ll get through it (p. 8).

“Albert” and “Donna” also use the term “we” to indicate the interdependence with their support systems.

**Albert:** I know what we did, discuss it (A, p. 3).

**Donna:** Right, right right. We did everything together (A, p. 3).
Four other patients articulated their connections with their social support teams as they spoke about the assistance their supporters provide.

Fran: That if I need help with something and I have a problem that I can go to them and talk with them about it (F, p. 11).

Edward: My wife's very involved in my care (E, p. 2). We talk about how I feel with what my pain level is and all that and how I'm being taken care of here and that's it (E, p. 5).

Although "Edward" previously asserted his independence in his health care when he mentioned the rarity of his ex wife's involvement, here he comments that she is very involved in his care. Thus it is important to note that "Edward's" claims illustrate an apparent tension between autonomy and connectedness, suggesting that a relational dialectics framework might elucidate understanding in this study.

Similarly, "Henry" spoke about turning over his control to the VA and his caretaker friend but indicated that he might be able to take care of himself.

Henry: She [caretaker] has been doing that and keeping my pills straight, which I would have a hard time doing, because I cannot see and reminding me some and the meals, I couldn't get up to fix a meal. Well, I might be able to, but then I might not (H, p. 7).

Both "Edward's" and "Henry's" responses highlight that in order to reconcile the interdependence between themselves and their support systems, patients must assert their independence while simultaneously emphasizing a connection with their loved ones. One reason patients
might feel compelled to find a balance between these two needs became apparent as another theme emerged relating to social support networks: *burden for social supporters*.

**Burden for Social Supporters**

Patients described struggling with feeling as though they are a burden for their social support networks. Several patients commented that they didn't want their families to change their lives to take care of them.

Donna: He’s so good. But I don’t want to take advantage of him. It’s not fair to him. He should have a life of his own (D, p. 11).

“Fran” also spoke about not wanting to take advantage of her loved ones.

Fran: My husband was the one who was driving me. Mainly to the doctor, but ya know with his job, I hate to keep asking him to ya know leave work and come and take me to the doctor (F, p. 6).

“Albert” also commented that he considered himself a burden to his caretaking wife when he spoke about his concerns that he was upsetting her. After “Albert” mentioned these feelings, he changed the subject.

“Albert’s” attempt at redirecting the conversation suggests that patients attempt to reduce these feelings of burdening their social support teams, by increasing levels of interdependence. Specifically, as patients spoke about being a burden to their loved ones, three additional themes emerged, as patients attempted to 1) *focus on positives* of social support care, 2) abstain from *health care conversations* and 3) emphasize their *value as relational partners*. 77
Focus on Positives

Similar to the vague responses patients gave concerning the quality of care they received from hospice IDTs, patients mainly focused on only the positive aspects of care provided by social support. Patients might provide these affirmations as a means to counteract their feelings of burdening their loved ones. “Joe” claimed several times that he had no complaints and that he was well taken care of.

Joe: I have no complaints (J, p. 4, 8, 9). I don’t think there’s much more they could do for than they do. They try their best to take care of whatever I need (p. 7).

Similarly, “Donna” relayed only positive evaluations of her supporters.

Donna: No. They don’t fail to meet my needs. They’re supportive in every which way (D, p. 15).

“Chris” also noted how positively his family reacted when he chose to enter the hospice program.

Chris: They just they just reacted all of the sudden perfect (C, p. 2). They know about it and they’re very supportive. [...] Everything is fine (p. 7).

When patients didn’t comment on the quality of care they received, they emphasized instead the strength of their relationships, as “Donna” discussed her communication with her son and “Edward” spoke about his continued ties with his ex.

Donna: Everyday! On the phone, I’ll tell him. This happened today, that happened yesterday, this is happening today, bye bye. We have a very good relationship (D, p. 12).
Edward: Just my ex, my wife. That’s all. When I say wife, it’s my keep, it’s my ex wife. I don’t think of her in that sense (E, p. 5).

**Abstinence from Health Care Conservations**

The aforementioned responses indicate patients felt as though they were a burden to their social networks, and as a result I argue that patients tried to reduce the impact of the burden by highlighting the positives aspects of their social support networks. Furthermore, interviews suggest that patients also refrained from having conversations about their health with family and friends, as another method of reducing the burden. “Fran” commented that she knew it wasn’t positive to ‘unload’ on her husband all the time.

Fran: He’s the one who’s here with me and he usually takes the brunt of when I’m not feeling too well. And I take it out on him, which is not the good thing to do, but that’s the way it works (F, p. 5).

Six other patients spoke about how they refrained from talking about their health or illnesses.

Ira: We don’t. We don’t mention anything about dying or getting really sick or anything like that (I, p. 6).

Beatrice: I don’t bother my children (B, p. 7).

Albert: We don’t talk a lot. [...] No, other than morbid talk (A, p. 9).

When asked if he could describe the morbid talk, “Albert” switched subjects and made a joke. As mentioned, “Albert” explained that he refrained from conversations that dealt with depression and suicidal thoughts.
Albert: No reason to have that conversation (A, p. 12).

Thus, while "Albert" said he and his wife talked about his terminal condition, during the interview he switched topics any time death or suicide were addressed.

Patients' abstinence from discussing health concerns with social supporters has been examined in studies focusing on disclosure. Derlega, Winstead, and Folk-Barron (2000) explain that persons living with HIV and AIDS (PLWHAs) will refrain from having frank discussion with relational partners for other-focused reasons. Specifically, patients might try to "protect the other person from having to make sacrifices or to keep her or him from becoming upset" (p. 54). Given that this study interviewed home-care patients, the assumption is that the patient's primary caregiver lives in the home and is taking care twenty-four hours a day. Thus, patients might believe they are burdening their caregivers and consequently attempt to limit disclosure about their health to lessen this burden.

**Asserting Value as Relational Partners**

Aside from refraining from discussions about their health, patients also asserted their value as relational partners, again possibly to spare social support networks from the burden of their illnesses. I argue that patients spoke about the ways in which they helped their social supporters to show that they are still valuable participants in the relationship. "Ginny" explicitly stated the value of all individuals,
regardless of their health conditions. "Beatrice" asserted her value when she spoke about providing emotional support to her daughter who didn't want "Beatrice" to die.

Beatrice: She'll say, 'Ma, I don't want you to die. What am I gonna do without you?' I said, '(Daughter) everybody dies. That's, from the moment we're born, we're only here for a visit. So there. It's a very natural thing. So please, don't be sad about it' (B, p. 7).

"Ira" also commented on the emotional well being of his social support, when he conveyed concern for his wife.

Ira: Not really, but she, I feel worried about leaving her, ya know? I used to look after the house, payment of the bills and the whole works, do the shopping, everything (I, p. 8). But she cries a lot, when she thinks that she's gonna be by herself. It's normal. [...] I don't know, but it's a hard for her and then with the daughter on her mind for the last ten years, it was really bothering her. I know it was (p. 9).

"Edward" spoke about the professional support he provides for his ex-wife to assert his value as a relational partner.

Edward: That's pretty much it, I mean she has a situation right now involving an organization in which she's become an officer and I've been giving her guidance on how to handle the interaction with people in that organization (E, p. 5) And how she handling certain aspects of her business and whatever I can do to help her. It makes me feel relevant again if I do that. My daughter also calls me from Los Angeles with questions about her business and I help her (p. 6).

"Ginny" also told a story of how she provided comfort to a woman from the insurance company, even though as a hospice patient, "Ginny" is technically supposed to be the recipient of emotional support, rather than the provider.
Ginny: I knew she was hurting and wanted to talk to her. Yet she finally came to me. That's the way it should be (G, p. 4).

**Definition of Social Support**

As patients attempted to gain more interdependence with their social support systems, a final theme emerged concerning patients' interdependence with social supporters. Specifically, patients seemed unaware or confused about who to consider in their social networks. When asked about their social support teams, two patients commented on relationships with hospice personnel, one discussed financial support, and one commented about her limited number of familial roles.

Donna: No, and he my [son] isn't married, so I'm not even a mother-in-law, or a grandmother for that fact. I have a cleaning lady (D, p. 10).

Patients' varied answers and apparent confusion regarding social support, which prompted this final theme, provide additional insight into how language might affect communication with hospice patients. If hospice IDTs ask patients about their relationships with their social support teams, yet there is a discrepancy between the social supporters IDTs and patients are each referring to, communication will be affected. Communication scholars are called to use principles from the field to identify the language that individuals use to create shared meaning, as language “shape[s] the perceptions that people have of illness in general and their own bodies in particular” (Edgar, Freimuth, & Hammond, 2003, p. 630). Thus, before agency can even be promoted with hospice
patients, communication scholars should focus on applying knowledge about a symbolic construction of reality to the health context.

Overall, patient responses reflect a desire to be interdependent with their social support teams, although the responses also reflect an imbalance of dependence. Specifically, while patients emphasize their connectedness/interdependence with social support teams, they also highlight their feelings of burdening their supporters. Given these apparent feelings of burden, patients indicate that they attempt to decrease additional supporter stress by focusing on the positive ways their supporters are present and abstaining from health conversations (Derlega et al., 2000). Furthermore, patients communicated their value as relational partners, which I read as an attempt to highlight that they can be depended upon and not simply dependent.
CHAPTER 5

SUMMARY, CONCLUSIONS, RECOMMENDATIONS

Reflection on Findings

Participants in this study identified that they first entered into hospice care because they chose to forego or end curative treatment. Specifically patients commented that they either experienced a medical problem which served as a catalyst for a medical procedure or had chronic health problems that could be addressed through the use of ongoing medical treatment. Patients’ assumptions that either the medical procedures or ongoing treatments would be extremely painful or unsuccessful led to the decision to refrain from taking curative measures. However, these themes simply reflected why advanced curative treatment was not pursued, although the primary research question was designed to gain insight into patients’ reasons for choosing hospice care. Thus, additional themes emerged concerning patients’ reasons for choosing hospice: prior knowledge of hospice care, monetary assistance, general help, and hospice as representative of mortality. While patients confessed their initial association of hospice with morbidity, a final theme emerged revealing patients’ new perceptions of hospice as providing hope for life. This final theme of hope indicates that hospice is
able to communicate to patients the overall philosophy of wholistic care, as patients begin disassociating hospice from death. However, the wholistic health care experience consists of more than just rearticulating the idea of hospice from denial of mortality into a place of hope. Rather, as mentioned, wholistic health care strives to meet the patients’ physical, emotional, psychological, and spiritual needs during their dying experience. Thus, research question two was designed to uncover patients’ perceptions of hospice’s wholistic mission.

Patients primarily associated physical concerns with pain management and/or medication, and while comfort care services are aimed at providing additional physical comfort, the majority of patients were unaware of these services, at times confusing them with curative treatment. Although it might be argued that patients consider pain management to be their greatest physical need, patients are not aware that comfort care services might also address their pain as well. For instance, given “Albert” is unable to get out of bed or turn over, he lays in the same position while sleeping or awake. When his leg was sore from his immobility, “Albert” needed his wife to massage him to relieve the tension. Throughout the massage, “Albert” instructed his wife on the preferred technique, but after many unsuccessful attempts both “Albert” and his wife seemed frustrated and ended the massage. Massage therapy is one aspect of comfort care services hospice facilities offer, however, if patients fail to recognize that comfort care services are provided to meet
their physical needs, this aspect of the wholistic experience is not being articulated effectively.

As part of the wholistic experience, psychological and emotional concerns were also not being met as comprehensively as possible. Under this eave of wholistic care, patient responses reflected that they considered psychological and emotional issues to be weaknesses and thus did not utilize hospice services to meet these needs. These perceptions of psychological and emotional issues might not be an area of concern if a patient did not have needs in these areas that might be helped if addressed. However responses reflected that patients struggled with emotional and psychological concerns, regarding their relationships with social supporters and their unease with their terminal conditions, though for fear of being considered unstable or crazy, they did not seek hospice to meet these underlying needs.

Finally, few patients utilized hospice spiritual care services. Primarily, some patients are simply unaware of what spiritual consist of or how hospice might be able to meet such needs. Other patients communicated that these services were unnecessary, as they either consulted others regarding their spirituality, or felt they did not have any spiritual needs to address. One of the more telling themes regarding spiritual concerns however, comes from patients’ association of spirituality with religion. Responses reflected that patients considered spiritual needs as going to church. As societal religious demographics
suggest, however, spirituality can be varied, wide-ranging, and comprehensive, thus limiting spirituality to church attendance is problematic. Consequently, it is reasonable to question how these services are communicated to patients.

Given the themes of associating spirituality with religion, along with physical needs associated with medication, and psychological/emotional needs associated with instability provides insight into holistic care communication. Patient responses reflect that hospice facilities might not be effectively communicating their overall mission to patients. While the holistic experience incorporates the use of interdisciplinary teams including volunteers, spiritual counselors, and comfort care providers, these patients were overwhelmingly unaware of these services or have vague understandings of the services they provide. Concerning the aforementioned spiritual concerns, it is reasonable to question whether hospice is defining spiritual needs “a way of describing the organizing center of a person’s life” (Irion, 1988 as cited in Derrick, 1996) or as needing to meet with a chaplain or religious personnel. As this spiritual needs definition was taken from the hospice handbook, the assumption might be made that hospice uses this statement to explain to patients what “spiritual needs” might incorporate. However, “Fran” stated, “And of course they asked me about the religion thing,” suggesting that regardless of how hospice communicates these services to patients, “Fran” still perceived that IDTs asked about her religion. This
possible discrepancy provides insight into the age-old debate of intent vs. effect. Regardless of the hospice facility’s intent in communicating spirituality, patients perceive spiritual needs as hospice chaplain associated. Thus, it is imperative that changes be made in the communication of the wholistic health care approach so that patients do not perceive physical needs as only met through medication, psychological and emotional needs as unstable, or spirituality as church oriented. By addressing this communication, patients might receive the comprehensive care hospice was originally designed to provide.

Beyond simply changing the way wholistic services are communicated, research needs to address the time in which these services are communicated. While patients conveyed they initially had misconceptions about hospice representing a place to die, their understanding of hospice changed as they met with the IDT. However, given that patients claimed they would utilize certain services when their illnesses progressed to a certain point, it is reasonable to question if this explanation of hospice and the services provided takes place during the beginning phase of hospice care and that patients are expected to request services when needed. As “Fran” articulated, every one from hospice (doctors, nurses, social workers, chaplains, etc.) initially came to her house when she began hospice treatment. While “Fran” was negotiating her decision to forego curative treatment and come to terms with her prognosis, she implies that she was offered the many wholistic
services simultaneously. Obviously the presentation of so many services could prove to be extremely overwhelming for a person who recently accepted her terminal condition. Furthermore, offering these services in the first stage of hospice care would be irresponsible as patients might not have these needs right away. For instance, “Chris” indicated that he didn’t feel any pain or real discomfort. “Chris” might be offered massage therapy in the first week, but have no use for this service until his condition progresses. If wholistic options are offered during the initial period of hospice care, it is reasonable to question whether patients must then seek out these services for themselves. Given that “Donna” and “Henry” conveyed that they met with the chaplain previously but were unaware of his whereabouts, the assumption might be made that patients are expected to ask for the different wholistic services. However, relying on patients to voice their own concerns could prove to be problematic as evident in the theme of good patient depictions. Patients continuously articulated that they were not needy, suggesting that they were afraid to make waves by requesting services. Thus rather than rely completely on the patients to initiate discussion about their health care requests, wholistic health care must be communicated constantly and accurately. Even if “Fran’s” understanding of being offered every wholistic service during her first visit is inaccurate, this depiction again speaks to intent vs. effect. Specifically, even if hospice is asking patients about their needs throughout their hospice experiences, the perception is
that wholistic services are being offered only in the beginning and patients are seen as needy if they ask for anything beyond medication.

In regard to research question three the themes connectedness with hospice personnel and active participation reflected how patients experience interdependence with IDTs. Specifically, patients asserted their relationships with IDTs to move away from the medicalized form of health care. These strong relationship depictions were further illustrated as patients tell about how they are active participants in their health. By using "I" statements and explaining their medical conditions, patients demonstrated their own involvement with their care. To achieve a level of mutuality that must be present for interdependence to exist, patients explained how they relied on IDTs for the most comprehensive care. However, vague positive comments and the value patients placed on being a "good patient" suggests that patients are not vocal in requests concerning their health care and do not complain about the care they receive. These characteristics became more evident as patients continuously commented on the lack of provider consistency, as they rarely saw their physicians, were unaware of IDT roles, and experienced drastic changeovers in nurses. Specifically, repetition of the provider consistency issues and the generic statements "I feel fine" and "everything's perfect" combined with their apparent reliance on hospice to provide medication for pain management suggests that patients do not want to upset the system for fear of losing the care they currently receive.
Thus, while patients claim they experience interdependence with IDTs through relationships and active participation, interview subtext reveals that patients do not perceive that they are in control of their care.

Finally, research question four highlights patient's perceptions of interdependence with social support networks. The themes autonomy and connectedness emerged highlighting that patients tried to assert a level of interdependence, although as burden for social support emerged as a second them, patients conveyed that they felt more reliant on supporters than a mutually dependent. As the themes, focus on positives, abstinence from health care conversations, and value as relational partners emerged, it became apparent that patients attempted to gain interdependence with social support teams by using communication techniques to reduce burdens. Similar to the results in research question three, patients seem to refrain from discussing negative elements of their care or diagnoses with their networks, which again proves to be problematic as patients are not able to receive comprehensive care if they feel they cannot articulate their concerns. Again as research suggests, relational factors affect how patients experience EOL care, as patients rely on social networks to negotiate their health concerns (Karlsson et al., 2006; Wachterman & Sommers, 2006). Thus, reliance on social support teams is necessary, but given the current study reveals patients' concerns of burdening their social support teams, patients needs' might not be met for fear of imposition.
The theme *value as relational partners* also becomes a concern as patients discuss instances in which they had to help their loved ones come to terms with the terminal prognosis. These responses reveal that patients are only able to experience interdependence with their social support teams by addressing the emotional concerns of their loved ones. As evident in research question two, patients are not even utilizing hospice for their own emotional and psychological needs, yet they are worried about their supporters and as a result, patients might suppress their own needs to meet those of others (Murray, Boyd, Kendall, Worth, & Benton, 2002). Hackl, Somlai, Kelly, and Kalichman (1997) discuss how women living with HIV/AIDS experience care for the emotional wellbeing of their families, which causes added stress beyond the usual pressures of the illness and could pose a problem as care recipients become emotional-care givers.

*Relational Dialectics as a Theoretical Framework*

As mentioned, the current study utilized a grounded theory approach so that emergent themes might reveal a theoretical lens in which to view the data. Through an examination of the results, I conclude that relational dialectics might provide additional insight into the communication of hospice's mission of wholistic health care and should be considered as a framework for future research in this area. Baxter and Montgomery (1996) argue that "social life is a dynamic knot
of contradictions, a ceaseless interplay between contrary or opposing tendencies" (p. 3). Baxter further defines contradiction as occurring when two tendencies or forces are interdependent [...] yet mutually negate one another” (Baxter, 1988, p. 258). These basic tensions require individuals to communicate in order to change and develop the relationship. While many tensions can be present in relationships, Baxter argues the presence of three prominent pairs: openness/closedness, autonomy/connectedness, and certainty/uncertainty.

**Openness and Closedness**

Within a relationship, Baxter (1988) claims that individuals might experience a tension when disclosing information. While intimacy increases when relational partners disclose to one another, most individuals exhibit a need to maintain a level of privacy. Openness and closedness provide insight into why patients talk about their care with vague positive statements, why patients refrain from discussing about their health and why patients do not utilize all of the offered wholistic services. While patients want to experience interdependence with IDTs and social supporters by asserting their involvement in their care, patients also struggle with being perceived as needy or as a burden, as evident in research concerning health disclosure with partners by PLWHAs (Derlega et al., 2000). Furthermore, although patients need to discuss their emotional and psychological concerns, these patients might also refrain from utilizing the offered wholistic opportunities for fear of
being perceived as unstable. Thus, the current study reveals that while patients desire to be open and active participants in their health care, they also strive to maintain a level of closedness that might prove to hinder their reception of the wholistic mission hospice facilities strive—at least in philosophy—to fulfill.

*Autonomy and Connectedness*

A second pair “which meet[s] the conditions of both unity and negation, thus constituting [a] dialectical tension” concerns autonomy and connection (Baxter, 1988, p. 259). Baxter claims that this contradiction might be considered the most prominent contradiction, as “no relationship can exist by definition unless the parties sacrifice some individual autonomy” (p. 259). Paradoxically, too much autonomy or separateness, without regard to the relationship, causes a problem as well. Thus, individuals must negotiate this tension. The current study highlighted this tension between autonomy and connection in patients’ expressions of interdependence with social support networks and IDTs. While primarily patients claimed they consulted their family in their health care decisions, they also attempted to assert their independence by minimizing their reliance on these social support networks. Patients again refrained from conversations about their health care to decrease the burden for their loved ones, but perhaps they limited these conversations in order to make their dying experience their own and regain some semblance of control or autonomy. Concerning
interdependence with IDTs, patients constantly emphasized their close relationships with the personnel, commenting on the friendships they formed. However, patients also expressed their control or autonomy when they explained that IDTs came when summoned.

**Certainty and Uncertainty**

The third prominent tension Baxter (1988) claims is evident in relationships concerns the uncertainty vs. certainty dialectic. Citing uncertainty reduction theory (Berger & Bradac, 1982) and pragmatic systems theory (Fisher, 1978), Baxter (1988) argues that while individuals need certainty in a relationship in order to quell fears and doubt, too much of a pattern might cause the “ultimate emotional deadening of a relationship” (p. 259). As with the aforementioned contradictions, the relational partners must negotiate between certainty and uncertainty through “strategic communicative choices” (p. 260).

The current study reveals this tension in the basic nature of the hospice environment. Given the eligibility for hospice care relies on a terminal prognosis, patients experience certainty in knowing that they are fatal. However, as some patients commented that they had surpassed the six month mark, a sense of uncertainty is evident as they are unaware of when the time of death might come. The tension of certainty and uncertainty is also evident in patients’ relation to IDTs and thus might provide insight into why patients do not take advantage of wholistic services.
As IDTs attempt to manage pain noncuratively, patients expect IDTs to bring medication and treat their physical needs. A level of uncertainty is apparent in the lack of provider consistency, however, such as nurse changeover or limited doctor/patient time. Patients might fear the lack of IDT consistency. Moreover, “needing and achieving relational uncertainty may require that particular uncertainties, such as opposition, at least temporarily vanish” (Sahlstein, 2006, p. 149). Thus, in order to maintain the assurance of constant medication, patients assert identities of good patients, which might affect their desire to ask for the various wholistic services.

Conclusions

As mentioned, Baxter and Montgomery (1996) argue that contrary or opposing tendencies are ever-present. Given that these tensions always exist, Baxter provides four main management strategies to minimize the negative effects of opposition. As dialectical tensions emerged in the present study, the strategies patients used in managing these tensions provide insight into how hospice patients perceive wholistic care and interdependence with IDTs and social support networks.

The current study reveals that one such dialectical tension management strategy that patients utilize is selection. The strategy selection occurs when an individual chooses to emphasize one tension
over the opposition, virtually ignoring the latter (Baxter, 1988). The use of selection is evident in the current study as patients reporting choosing connectedness over autonomy, certainty over uncertainty, and closedness over openness. Although patients attempted to assert their control in their health care, they select connectedness by emphasizing their relationships with IDTs, maintaining a good patient status with few requests, relying on IDTs to make the ultimate decisions, and asserting their value as relational partners with social supporters. Patients select certainty over uncertainty as they withhold concerns of provider inconsistency to ensure the predictable receipt of medication. Finally, patients select closedness over openness when they refrain from health conversations to minimize the imposition to their social supporters.

While selection can be beneficial in managing tensions, the current study reveals that patients’ use of selection is quite possibly hindering their receipt of wholistic, interdependent health care.

Two praxis strategies that might help patients increase their agency are segmentation or balancing. Segmentation allows individuals to isolate spheres in which they will highlight each tension (Baxter, 1988). For instance, patients might choose to highlight autonomy when interacting with their social supports to first articulate their own health concerns and needs. Then patients might select connection and interdependence with social supporters when interacting with IDTs, so they can present a united front on health care decisions, as social
supporters advocate for and with them. Balancing is another method patients might use to manage tensions and increase agency. Balance allows individuals to find a middle ground between the tensions (Baxter, 1988). Ideally, balancing could help patients find a compromise between openness and closedness, so that they could communicate their needs to providers, but also maintain dignity as they are allowed some sense of privacy.

By allowing dialectical tensions to be present or choosing alternative methods of managing tensions such as segmentation or balancing, patients’ levels of autonomy, uncertainty, and openness could develop. With an increase in autonomy, patients would feel that they have agency and control in having their needs met. Allowing for uncertainty would provide patients with the freedom to experience more of the wholistic services beyond the predictable pain management. Finally, attention to a level of openness rather than relying on closedness would provide patients with more voice in their health care and possibly more open and honest communication with their social supporters. However, tension management should not be solely the patient’s responsibility. Rather hospice care providers and social support members must learn techniques to effectively communicate the wholistic approach and interdependence so that patients feel comfortable enough to build agency.
Limitations and Future Research

Although this qualitative analysis proved to be rich with data concerning the communication of the hospice mission, no study is without limitations. One limitation is the small sample size. While telling themes emerged that provide information that could improve hospice care in the future, ten interviews is not representative of the hospice patient population. Furthermore, as the participants were patients from the same hospice program, these results do not necessarily speak to the greater hospice philosophy. However, considering that the ten participants were varied as far as personal circumstances and diagnoses were concerned, they nevertheless shared some similar experiences and the data extend prior research in wholistic health care communication.

Another limitation concerns the language utilized throughout the interview script. While spiritual, physical, emotional, and psychological needs were all defined, the questions were asked as “Physically, are there any areas in which you feel that your social support team fails to meet these needs?” While the word “fails” was intended to mean unsuccessful or falls short, given that patients focused on the positives of their care and were hesitant to talk about the negatives, “fails” might be considered to be very loaded. Consequently, in the future I would consider changing the language to: “are there any areas in which your social support team might be able to address your physical needs?”
A final limitation concerns the sample demographics in this study. The nine of the ten participants were Caucasian and all ten were over the age of sixty. As evident in previous research many factors such as gender and marital status affect how patients negotiate through their illnesses (Karlsson et al., 2006; Wachterman & Sommers, 2006). Fontana (2008) argues age and race are also important differentiating factors. Patients and providers adopt different ideals concerning the use of intensive care and EOL decisions, as demographic diversity becomes evident (Fontana, 2008). As these factors might influence the patients' perceived levels of interdependence with IDTs, future research should focus more on these factors by including a larger and more diverse sample to better understand how demographic characteristics differentiate the use of interpersonal communication and EOL decisions.

The current study reveals several concerns regarding the communication of wholistic care to hospice patients. While the original mission of hospice is designed to meet patients' wholistic needs, interview responses reveal that patients do not experience this comprehensive care as the wholistic services are either misunderstood or perceived as unnecessary. Furthermore, while patients claim they experience interdependence with IDTs and social supporters, dialectical tensions exist suggesting that patients struggle between being the good patient or being an active participant in their health care. Although patients claim they are active participants, the tension management
strategy of selection suggests that patients do not emphasize their autonomy, openness, or uncertainty, and thus exhibit a lack of agency in their own care and the inability to enjoy a truly wholistic dying experience.

Given the history of the medicalization of the dying process, the hospice philosophy has been rightfully acclaimed as a successful solution. However, this study’s findings suggest that the communication of the original wholistic hospice mission and services are either absent or lost in translation with patients. Perhaps hospice staffs are assuming that patients were already aware of what hospices offer and thus, that is why the hospice was chosen as a place of respite. Regardless, if unaware of this mission and services, patients are unable to articulate their agency in attaining the most comprehensive experience possible. Thus, future hospice training should be guided to more appropriate and constant communication regarding the services offered to patients, and IDTs should focus on encouraging patients to achieve agency in their health care. With a stronger emphasis on a patient-centered approach to hospice care, IDTs, social supporters, and patients might work together to cultivate the type of care hospice was originally designed to provide.
APPENDIX A

INTERVIEW CONSENT FORM

TITLE OF STUDY: Dying as an Individual:
A Call for a Patient-Centered Approach to Hospice Care Research

INVESTIGATOR(S): Tara Emmers-Sommer and Sarah Nebel

CONTACT PHONE NUMBER: 895-2633

Purpose of the Study
The purpose of this study is to understand whether holistic health care is communicated to you as a hospice patient. Also, Ms. Nebel is attempting to understand how the network/system including the patients, social support, and hospice interdisciplinary team members (IDTs) operate to meet your needs.

Participants
Ms. Nebel is interested in the idea of holistic care within hospice. Ms. Nebel has heard from patient family members and hospice team members about the comprehensive care patients receive, regarding physical, emotional, psychological, and spiritual comfort. Today, as a participant of the study, you will be interviewed by Ms. Nebel, so that she might understand how you feel this holistic care is presented to you.

Procedures
If you volunteer to participate in this study, you will be asked to participate in an interview, which will take about one hour, unless at any time you would like to end our conversation. Ms. Nebel will ask open-ended questions, allowing you the chance to elaborate on your needs and concerns with your care.
1) First, Ms. Nebel will need to verify that you are currently considered a Nathan Adelson Hospice patient.

2) In order for Ms. Nebel to be able to pay attention to your experiences, she will be recording the conversation. Your name and identity will not be linked to any of the information you provide, and only Ms. Nebel and a transcriber will hear the tape for accuracy.

3) Third, all research conducted at Ms. Nebel’s university requires that participants read a this standard Informed Consent document prior to participation. Will you read this sheet and sign it if you are willing to participate in the study? If you prefer, Ms. Nebel can read it aloud. Ms. Nebel will then hand you the sheet, or read it aloud if necessary, and give you time to sign while she sets up the recorder and prepare the materials.

4) Remember that this participation is voluntary and you do not have to answer any questions that make you uncomfortable. Ms. Nebel will then allow you time to ask answer questions you might have.

5) Finally, Ms. Nebel will turn on the tape recorder and then begin asking questions.

**Benefits of Participation**
There may not be direct benefits to you as a participant in this study. However, if patient interviews reflect that holistic care is not being communicated effectively to hospice patients, hospice might be able to alter the way in which they address patient health needs, thus providing better health care to the patients in the future. Also, patients have the comfort and forum to offer their voice about their experience.

**Risks of Participation**
There are risks involved in all research studies. This study may include only minimal risks. Nathan Adelson Hospice will derive a list of potential voluntary participants based on their knowledge of these individuals. They will not include a name of someone who is in compromised health. Participation is completely voluntary. Individuals can choose not to participate or discontinue from participation once the interview has started if they so choose. Also, participants may choose not to answer any question they wish not to answer for whichever reason.

**Cost/Compensation**
There will not be financial cost to you to participate in this study. The study will take approximately one hour of your time. You will not be compensated for your time.

**Contact Information**
If you have any questions or concerns about the study, you may contact Sarah Nebel at 702-774-7032. If you have questions for the primary investigator, you may contact Tara Emmers-Sommer at 702-895-2029. For questions regarding the rights of research subjects, any complaints or comments regarding the manner in which the study is being conducted you may contact the UNLV Office for the Protection of Research Subjects at 702-895-2794.
**Voluntary Participation**
Your participation in this study is voluntary. You may refuse to participate in this study or in any part of this study. You may withdraw at any time during the interview without prejudice to your relations with the university. You are encouraged to ask questions about this study at the beginning or any time during the research study.

**Confidentiality**
All information gathered in this study will be kept completely confidential. No reference will be made in written or oral materials that could link you to this study. All records will be stored in a locked facility at UNLV for at least 3 years after completion of the study. After the storage time the electronic and paper copies of the data will be destroyed.

**Participant Consent:**
I have read the above information and agree to participate in this study. I am at least 18 years of age. A copy of this form has been given to me.

______________________________                        ________________
Signature of Participant    Date

______________________________
Participant Name (Please Print)

**Audio/Video Taping:**
"I agree to be audio or video taped for the purpose of this research study."

______________________________                        ________________
Signature of Participant    Date

______________________________
Participant Name (Please Print)

**Participant Note:** *Please do not sign this document if the Approval Stamp is missing or is expired.*
APPENDIX B

INTERVIEW PROTOCOL

Upon the research board’s approval of the study, the researcher will contact Barbara Taylor at Nathan Adelson. During a weekly meeting, Ms. Taylor will ask interdisciplinary team members for names of possible study participants. Ms. Taylor will also inform volunteers of the study for additional participant recruitment. Ms. Taylor will inform the participants about the study, gaining their approval and then will forward the names and numbers of the patients to the researcher. The researcher will then call the patients, introduce herself, and discuss a mutually appropriate interview time and place. The researcher will arrive at the predetermined location and begin the interview process.

See below interview sequence:

Accounts of Hospice Patient Experiences

Parameters for interviews and patients:
1) Patients can be encouraged by Interdisciplinary team members (IDTs) to participate.
2) All participants must be voluntary.

Procedures:
1) All interviews must be recorded.
2) Interviewer will read “Pre Interview Statement” (below) to the participant before starting the interview.
3) The goal is to conduct 10-15 interviews.

Pre Interview Statement:
Hello. My name is Sarah Nebel and I will be interviewing you today. First I want to start by thanking you for allowing me to do this research. I believe you have valuable stories to tell about your experiences, and I look forward to hearing more about your life.
I am currently conducting this study through the University of Nevada, Las Vegas, to understand more information about individual experiences with hospice care. I'm interested in how you feel hospice team members (doctors, nurses, volunteers, comfort care practitioners) communicate with you about your health, and whether you feel that those involved in your health care are working together in a system, to provide you the best care possible.

The interview will take about one hour, unless at any time, you would like to end our conversation. I will ask open-ended questions, allowing you the chance to elaborate on your needs and concerns with your care.

Before we get started with the interview, I have a few housekeeping items to go through and then I can answer any questions you might have.

1) First, I need to verify that you are currently considered a Nathan Adelson Hospice patient.
2) In order for me to be able to pay attention to your experiences, I will be recording our conversation. Your name and identity will not be linked to any of the information you provide, and only myself and a transcriber will hear the tape for accuracy.
3) Third, all research conducted at my university requires that participants read a standard Informed Consent document prior to participation. Will you read this sheet and sign it if you are willing to participate in the study? If you prefer, I can read it aloud. [Hand them the sheet to read and give them time to sign while you set up the recorder and prepare the materials.]
4) Finally, remember this is voluntary and you do not have to answer any questions that make you uncomfortable. Do you have any questions before we begin?

Explanation and purpose:
Ok, now that we are finished with the housekeeping issues, we can begin the first part of the interview. Again, I am interested in the idea of holistic care within hospice. I have heard from family members and hospice team members about the comprehensive care patients receive. More specifically, the goal of hospice is to provide you with physical, emotional, psychological, and spiritual comfort, and today I would like to know how you feel this holistic care is presented to you. Do you have any questions about the term holistic care or about this research?

[Turn tape recorder on now]

Before we begin discussing each element of holistic care, I would like to hear about how you came to utilize hospice care. When was that and
how was the decision made? Did you and your family discuss this option?

Describe your first experience once becoming a hospice patient. Who is the most memorable person from that initial period and why? Describe your family's involvement with this interaction. Did you and your family discuss this interaction?

Tell me how you see your relationship with your hospice doctor. What is the communication like from your perspective?

How do you see your relationship with your hospice nurse? What is the communication like from your perspective?

Describe your relationship with your hospice spiritual mentor/therapist. What is the communication like from your perspective?

Have you met with a volunteer during your experience with hospice? What is the communication like between yourself and your volunteer from your perspective? Describe how your family interacts with the volunteer.

Have you utilized any of the comfort care services (aromatherapy, pet therapy, energy therapy, massage therapy)? Describe your interaction with the comfort care specialist. Describe the involvement from any other hospice or family members.

Describe your relationship with your social supporters. How do you and your social supporters communicate? What do you talk to your support system about? Describe your strongest emotional supporter. Do you talk to your emotional supporter about your illness or its progression? How often do you have these conversations? Describe your strongest medical needs supporter. What would you prefer to talk to your supporters about? Describe the interaction between the hospice members and your social supporters. Describe your ideal support.

Describe how hospice is treating your physical pain.

Emotional and psychological needs concern your thoughts and feelings about your diagnosis, relationships with others or relationships with yourself. Describe how hospice is treating your emotional/psychological needs.

Hospice describes spiritual needs as “a way of describing the organizing center of a person’s life” (Paul Irion, professor emeritus of pastoral theology and hospice chaplain – 1988, cited in Derrick, 1996).
Spirituality also concerns the elements that give meaning to your life. Describe how hospice is treating your spiritual needs.

Overall, describe how your social support team is treating your physical pain. Physically, are there areas in which you feel your social support team fails to meet this needs? Describe how your social support team is treating your emotional needs. Emotionally, are there areas in which you feel your social support team fails to meet this needs? Describe how your social support team is treating your psychological needs. Psychologically, are there areas in which you feel your social support team fails to meet this needs? Describe how your social support team is treating your spiritual needs. Spiritually, are there areas in which you feel your social support team fails to meet this needs?

What would you change or want to improve with your current hospice treatment?

[When the interviewer has asked all the questions, paraphrase the information covered and ask her/him if there is anything else they feel they need to talk about regarding hospice care.]

Debriefing
Those are all the questions I have. What questions do you have for me?

I have a few more interviews I'll be conducting with other patients. After I've met with all the participants, I will listen to the tape and try to determine what some of you might have in common regarding your hospice care. I believe your experiences can offer insight into how hospice and your social support networks can tailor their actions to fit your needs even more closely. Your participation truly will benefit hospice care in the future.

Thank you so much for your participation. I really appreciate hearing about your experience. If you have any questions or concerns, please let me know.

[turn off tape recorder]
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