

PREDICTORS OF TIMING IN HOSPICE UTILIZATION:
THE ROLE OF FAMILY IN THE DECISION
FOR HOSPICE CARE

by

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Abstract

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Patients and families coping with a terminal illness are faced with a number of decisions over the course of their disease. The decision to continue further treatment versus utilization of a palliative approach, such as hospice, is often one of the most difficult and complex. There are many barriers to hospice care, causing the service to be underutilized. Family is a significant force in patients' choice for palliative care and patients place greater importance on communications related to end-of-life care with their family than with health care professionals. However, dying remains a taboo conversation, a key barrier to end-of-life care. Using an exploratory, cross-sectional approach, this study utilized multiple regression to examine the extent to which family communication about illness and death (FCID) and referral source (family referral versus medical referral alone) predicted both decision time (number of days between hospice referral and admission) and hospice length of stay within the context of other barriers to hospice.

The sample of this study (N = 90) consisted of primarily Caucasian patients ($n = 74, 82.2\%$) with high levels of both self-reported spirituality (mean = 8.08 on a scale from 0 to 10) and family communication (mean = 4.05 on a scale from 1 to 5). Though 14 different diagnoses were represented, 63% of the sample had cancer. Patient ages

ranged from 37 to 96 with an average age of 71. Patients were admitted to hospice during stages of advanced illness as 86.7% scored a 50 or below on the PPS, meaning that they needed considerable assistance and mainly sat or stayed in bed. 40% were completely bedbound and in need of total care at the time of admission. 60% of the sample enrolled in hospice within a week, likely due to an advanced stage of illness, and just over half (51.5%) died within just over a month of admission (34 days).

Overall, this dissertation brings a new perspective to hospice utilization through the use of decision time as an outcome variable. Decision time was correlated with a number of barriers to hospice from within literature and prior research. Referral source was also predictive of decision time for hospice, suggesting that when a patient is referred by a family member or a close friend in addition to or in lieu of a medical professional, decision times for hospice were longer. This was likely due to these patients starting a conversation about hospice as an option earlier during the illness process. However, referral source was overshadowed by the impact of functional status at the time of hospice admission and use of treatment. These were the largest predictors of decision time for hospice reinforcing the role of late referrals and current policy restrictions (limiting patients' abilities to seek treatment while accessing hospice care) on hospice utilization.

This dissertation also provides a number of connections among barriers to hospice as a starting point for future research. Both the meaning of hospice and spirituality presented as impactful variables requiring more in-depth follow up about how patients and their families define and understand these constructs in relation to the decision to enroll in hospice. Involving family members early in discussions for care will help clinicians to identify and provide support to families who may be struggling to make timely decisions. Obtaining access to end-of-life care is important in improving quality of death, symptom management, and bereavement for family.

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Chapter 1

Introduction to the Study

Statement of the Problem

Patients and families coping with a terminal illness are faced with a number of decisions over the course of their disease. The decision to continue further treatment versus utilization of a palliative approach, such as hospice, is often one of the most difficult and complex. Family is a significant force in patients' choice for palliative care (Casarett, Crowley, & Hirshman, 2004; Zhang & Siminoff, 2003) and patients place greater importance on communications related to end-of-life care with their family than with health care professionals (Meeker & Jezewski, 2005). However, dying remains a taboo conversation, a key barrier to end-of-life care (Nelson, 2006). The challenge with denying the reality of death is that it directly relates to delaying the conversation of one's wishes at the end of life (Eues, 2007). Communication between patient and family is an important type of communication that can serve as either a barrier or a facilitator within the transition to hospice care (Waldrop & Rinfrette, 2009). According to the National Hospice and Palliative Care Organization (NHPCO, 2010), for every patient on hospice there are two others with terminal illness eligible to benefit from these services. Many of these missed patients continue to "endure costly and ineffective treatments" and many die "alone or in pain" (para. 3). Barriers and facilitators to end-of-life care are important considerations for helping patients and families to access timely and appropriate services.

Background Information

SUPPORT Study

One study that drew great attention to the need for improved communication and for end-of-life care in general, funded by the Robert Wood Johnson Foundation, was The

Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). The SUPPORT study was conducted in two phases between 1989 and 1994 and documented multiple problems for adults dying during acute hospitalization (Connor, 2009). The goal of the study was to “improve end-of-life decision making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying” (SUPPORT Principal Investigators, 1995, p. 1591). Phase I of the study included 4301 patients within five teaching hospitals and focused on the following objectives: describing outcomes, developing prognostic models, identifying shortcomings of care, establishing adjustment methods, and designing an intervention. Results documented “substantial shortcomings in communication, decision making, and outcomes” (p. 1593).

Phase II of the study provided an intervention focused on improving communication and decision making by providing physicians prognostic models to assist in estimating likelihood of disability or death, in addition to the use of a clinical nurse who was trained to meet with patients and families in order to discuss and document wishes. Results of Phase II did not produce any significant differences between the control (care as usual) and intervention groups (randomized by physician group) across any of the five outcomes studied, one of which included patient-physician agreement on CPR preferences (SUPPORT Principal Investigators, 1995). Ultimately, results of the study demonstrated that providing additional information to physicians alone did not make any difference in outcomes of care at the end of life (Schroeder, 1999) or in increased communication between patients and physicians, as it appeared that physician behavior was unchanged (SUPPORT Principal Investigators, 1995).

Since the SUPPORT study highlighted so many unmet needs at the end of life there was a push to improve care, and philanthropic foundations provided opportunities for research and education (Bern-Klug, 2004). The SUPPORT study had major

implications on hospice care, as hospice is one program designed to promote better outcomes at the end of life (described further below). Results suggested that information on hospice and other end-of-life choices were not being provided to patients until much too late, if presented at all. The need for this information to be accessible to patients and families much earlier during hospitalization and illness became apparent (Greipp, 1996). Though much of the literature within end-of-life care that stemmed from results of the SUPPORT study has focused on barriers to care and decision making at the end of life, a small amount has explored the important role of family communication within this process. Understanding the pertinent role of family communication as it relates to the decision for end-of-life care is crucial in working to find additional ways to overcome barriers to hospice and to address the problematic outcomes emphasized by the SUPPORT study.

What is Hospice Care?

According to the Electronic Code of Federal Regulations (2012), the codification of all of the administrative rules from Federal Government departments and agencies, hospice care is defined as “a comprehensive set of services described in 1861(dd)(1) of the [Social Security] Act, identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members, as delineated in a specific patient plan of care” (Title 42 section 418.3). Connor (2009) defines interdisciplinary care as care that “draws on the skills of people in a variety of disciplines who work collaboratively in meeting the patients’ various needs” (p. 8). Section 1861(dd)(1) of the Social Security Act (SSA) further defines interdisciplinary team as a group including at least one physician, registered nurse, social worker, and a pastoral (or other) counselor. This section also describes the services provided under hospice care as nurse and physician care, physical, occupational, or

speech therapy, social services, home health aide services, medical equipment, counseling, and short-term inpatient services.

In addition to these services, Connor (2009) summarizes the qualities of hospice care as care that is available around the clock, is provided wherever the patient lives, and is focused on symptom management. The patient and family are recognized as the unit of care (instead of just the patient) and the interdisciplinary team treats the whole person (instead of just the illness). Other qualities noted are the inclusion of volunteers, the availability of services regardless of ability to pay, and the provision of bereavement services after the death of the patient (Connor, 2009, pp.7-8), each of which is also outlined within the Act. Goals of hospice care are to provide an alternative to intensive end-of-life care in the hospital, to provide focus on quality of life and symptom management instead of treating disease, and to provide psychosocial support to both the patient and the family. The goal is not to hasten death or prolong life, but to provide comfort and support quality of life during the natural process of dying. It is also clear that the hospice benefit is meant to be less costly to Medicare than conventional care at the end-of-life (Neuman, Mathews, & Gaumer, 2009).

In addition to the definition and services of hospice care, section 1861(dd) of the SSA states that in order to receive hospice care, a patient must be certified by a physician as having a life expectancy of six months or less. However, as noted by Jennings and colleagues (2003), just because a patient's life expectancy is more than six months, does not mean that the patient would not benefit from hospice care. However, due to the political climate to limit Medicare spending in the passing of this legislation in 1982, this limitation in eligibility was set to provide assistance within the last six months of life and not in ongoing care for a chronic condition.

Section 1812(d)(2) of the SSA defines the second main hospice requirement, the restriction that when electing hospice care, a patient must choose to forego any active treatment, or curative care, of his or her terminal condition. Benefit periods for coverage are explained along with requirements for recertification of continued hospice care from one benefit period to the next. The patient has the right to revoke hospice care at any time without penalty, allowing him or her to seek treatment for the condition if desired. A patient may also transfer hospice care from one provider to another if dissatisfied with the care.

Demographics of Hospice Patients

In 2013, between 1.5 and 1.6 million patients within the US were recipients of hospice care (NHPCO, 2014). Of these, 83.9% were ages 65 years or older, with 41.2% ages 85 or older. Over the past several years the total number of patients served by hospice has steadily increased and though it will likely continue to increase due to our aging population, the number of patients lacking access due to various barriers will increase as well. Today there are 40 million seniors in the US, which are expected to double in the next 30 years as the baby boomers' generation ages (NHPCO, 2010). Elders are by some definitions "among the most vulnerable in any society" (DeChesnay & Anderson, 2012, p. 5).

Primary hospice diagnoses consist of cancer (36.5%), debility (5.4%), dementia (15.2%), heart disease (13.4%), and lung disease (9.9%), among other non-cancer diagnoses (stroke, kidney disease, liver disease, amyotrophic lateral sclerosis, HIV/AIDS, and others; NHPCO, 2014). Another key consideration of the population being served by hospice is the lack of ethnic diversity. In 2013 only 19.1% of hospice patients were members of minority communities and 80.9% were Caucasian (NHPCO, 2014). 8.4% of hospice patients were African American, 2.9% were Asian American, and 7.5% identified

themselves as multiracial or other. Though barriers to hospice exist across ethnicities, additional barriers within different cultures are an important consideration for exploring this lack of diversity in hospice care. For example, cited cultural barriers within African Americans include religious/spiritual value conflicts (such as the belief in a cure or the role of suffering), distrust in the healthcare system (Bullock, 2011; Schmid, Allen, Haley, & DeCoster, 2009; Shrank et al., 2005), and belief in the importance of preservation of life over quality of life (Shrank et al., 2005). Barriers for immigrants include geographical distance from family members, language differences, lack of insurance or fear of deportation, and discrimination (Smith, Sudore, & Perez-Stable, 2009).

Consequences to Delayed or Absent End-of-Life Care

Obtaining timely access to end-of-life care is important in improving quality of death, symptom management, bereavement for family, and cost of services. Each of these is explored further here. A number of studies provide evidence that hospice improves outcomes at the end of life across settings: hospitals, nursing homes, inpatient hospice, and home care. Contrary to public belief that hospice equals death (Andruccioli et al., 2007; Feeg & Elebiary, 2005), one study demonstrates that Medicare hospice patients survived, on average, 29 days longer than non-hospice patients (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007). Another study compared quality of death in cancer patients across hospice and non-hospice groups. Researchers developed their own measure of quality of death and compared the two groups using analysis of covariance while controlling for variables they found as significantly correlated to quality of death: age, family income, and extent of disease at first diagnosis. Results demonstrated that quality of death scores were higher for hospice patients than for patients receiving conventional care (Wallston, Burger, Smith, & Baugher, 1988). In a study examining family perspectives on end-of-life care across the location of death,

families where patients received hospice care were more satisfied with quality of care. This population was also found to be more likely to report satisfaction of emotional support for both the patient and for themselves (Teno et al, 2007).

Another recently developed scale evaluating the quality of experiences at the end of life is the Caregiver Evaluation of The Quality of End-Of-Life Care (CEQUEL) Scale (Higgins & Prigerson, 2013). Results of this validation study indicated that higher scores were positively associated with hospice care and negatively associated with post-loss indicators of regret and psychological trauma. Like the studies discussed above suggest, hospice services are likely to improve experiences at the end of life. Results from Higgins and Prigerson's (2013) study also demonstrate that poor end-of-life experiences are likely to end in more difficult bereavement. In a separate study that considered end-of-life discussions, medical care, and caregiver adjustment, researchers discovered that poor patient quality of life and poor caregiver adjustment post-death were both associated with aggressive care (Wright et al., 2008). Metzger and Gray (2008) considered a relationship between bereavement and factors prior to the loss, including the impact of pre-loss communication between the bereaved and the deceased. Bereaved family members that developed greater acceptance of an expected loss through increased communication experienced less distress during bereavement (as measured by scores of depression, complicated grief, and posttraumatic stress). One of the goals of hospice care is to address psychosocial needs of patients and families, creating a supportive environment where pre-loss communication can occur.

National Hospice and Palliative Care Organization provides several performance measures related to assessing the quality of hospice care. In 2013, 73.5 percent of individuals rated hospice care as "excellent" on the Family Evaluation of Hospice Care (FEHC) measure and according to the Comfortable Dying Measure, nearly 7 of 10

patients with pain upon admission, had pain resolved to a comfortable level within 48 hours of the initial assessment (NHPCO, 2014). Pain management outside of end-of-life care however has been a great cause for concern, as indicated within hospital systems in the groundbreaking SUPPORT study (SUPPORT Principal Investigators, 1995) and as identified by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO, Zhang et al, 2009). According to the Health and Retirement Study, the proportion of people who experience pain increases from 25% during the final two years of life to 46% in the final four months of life (Smith et al, 2010). Pain, alongside poorer quality of life at the end-of-life, appears more likely to occur outside of the support of specialized end-of-life care.

Cost of services at the end of life is potentially another important consequence of delayed or absent end-of-life care, as Medicare estimates that over a quarter of expenses is spent during the last year of patients' lives. Several current studies attempted to examine the efficiency of hospice services, but there is some discrepancy about whether the use of hospice care actually saves money at the end of life compared to non-hospice users. Researchers recognize the difficulty in making cost-comparisons due to selection bias in retrospective studies and inability to implement true experimental designs due to ethical issues in denying patients access to services for the purposes of research. One study found that the use of hospice care decreases Medicare expenditure among younger patients with cancer, but that expenditures increased with other diagnoses and for patients over 84 (Campbell, Lynn, Louis, & Shugarman, 2004). Yet in a similar study that used an alternate method of matching with careful considerations in accounting for selection biases, investigators found lower costs for hospice patients compared to those not in hospice care. This study also found that patients choosing hospice lived longer than the matched patients (Pyenson, Connor, Fitch, & Kinzbrunner, 2004). A second

study also provided conflicting results from the Campbell and colleagues study, supplying findings that did not suggest increases in Medicare expenditures among dementia patients or among patients over 85. Their study, which focused on nursing home residents, suggested “cost neutrality” among long-stay dementia patients, a 9 percent savings in expenditure for long-stay cancer patients, and 22 percent lower expenditure for short-stay nursing home patients across diagnoses (Gozalo, Miller, Intrator, Barber, & Mor, 2008). A study attempting to learn from limitations in previous studies, matched patients with considerations accounting for the length of hospice use in exploring Medicare expenditures on hospice care. This particular study found that patients who died in hospice saved Medicare an average of \$2309 for each patient in comparison to non-hospice patients (Taylor, Ostermann, Van Houtven, Tulsy, & Steinhauser, 2007).

Importance to Social Work

Social workers are a critical component to the teams that work with patients facing end-of-life issues across a multitude of settings: hospitals and clinics, long-term care facilities, home health and hospice organizations, and disaster response teams. In fact, hospices, home health organizations and long-term care facilities are required by the Federal government to include social workers on the interdisciplinary team providing care to patients and families (Social Security Act, 1982). Both Holloway (2009) and Payne (2009) highlight the appropriateness of social work as a profession to influence developments within end-of-life care due to its long-standing traditions in advocacy and its position between medical processes and social services.

In discussion about a program specific to medical decision making at the end of life, Bomba and colleagues (2011) relate the core social work competencies identified as essential within end-of-life care (Gwyther et al., 2005) as the same competencies important for meeting the goals of the specified program (Bomba, Morrissey, & Leven,

2011). With the inclusion of family as a primary component in palliative care, social workers are vital team members who have specific training in group dynamics, family systems and in developmental needs of various family members (Fineberg, 2010). Social workers are central to aiding patients and families in communication, decision making, and in accessing quality end-of-life care.

Purpose of the Study

The research question that guided this study was what is the relationship of family referrals and family communication among other barriers to care on the timing of the decision for hospice? While the role of physicians and healthcare communication has been a primary focus within the literature on hospice utilization, research suggests that the influence of family communication has greater significance on patients than communication with physicians (Meeker & Jezewski, 2005). The importance of family in decision making has been explored across the lifespan and should not be overlooked at the end of life. This study contributes to gaps within existing literature related to the role of family within the decision for hospice enrollment. Decision time for hospice, or more specifically the length of time between initial hospice referral (learning about hospice as an option for care) and hospice admission, was a central dependent variable in this study which provides a new perspective to existing literature on hospice utilization and barriers to care. Results of this study have potentially strong implications in end-of-life research, practice and policy. Findings can help researchers identify the extent to which family contributes to how and when patients enroll in hospice services. Understanding this role will help clinicians to identify and provide support to families who may be struggling to make decisions. Failing to recognize the role of family within decision making at the end of life could cause further delay in access to much needed services at the end of life.

Chapter 2

Literature Review and Theoretical Framework

Literature Review

Hospice Enrollment and Hospice Utilization

As discussed above, in order to qualify for hospice a person must have a terminal diagnosis with a likely prognosis of six months or less to live (as determined by a doctor, though it is okay for patients outlive this prognosis and remain on services), and must forgo further active treatment for the hospice diagnosis. Once hospice has been contacted (by either a medical professional on behalf of a patient or by the patient and/or family themselves), a hospice representative usually sits down with the family to explain hospice as well as complete a further assessment of the patient's appropriateness for hospice care. It is often during this initial visit that the patient and family decide they would like to access hospice care, and the patient (or legal representative) can sign the admission paperwork. This decision, and official documentation, indicates the date of hospice enrollment, or the time agreed upon between hospice and the patient/family for hospice to begin providing services. Though this marks the active decision for hospice, there is generally a lot that has occurred prior to this visit with the hospice representative. Patients and families also sometimes take time to consider this decision before scheduling a second meeting with hospice prior to enrollment. The timing of hospice enrollment is likely impacted by multiple factors, which are discussed throughout this dissertation and central to this investigation. Hospice utilization is another term in the literature applied to discuss the use of hospice care. Often, hospice utilization and hospice enrollment are used interchangeably.

In addition to considering the timing of enrollment and of hospice utilization, researchers have also considered the timing of the hospice referral itself, or rather when

patients first learn about hospice as a potential option for their care. The hospice referral is also discussed in terms of contacting hospice about a potential patient for care. As discussed above in the introduction, hospice care is underutilized and often characterized by late referrals and short lengths of stay. Longer lengths of stay in hospice provide patients and families a greater opportunity to receive the full scope of benefits that hospice care has to offer. In one study that conducted interviews with family members of 275 patients both upon admission and after death, families of patients with longer lengths of stay “reported receiving more hospice services and reported that those services were more helpful” than families of patients with shorter lengths of stay (Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005). However, no ideal length of stay has been identified (Quill, 2007) and suggestions of minimal lengths of stay to receive optimal benefits have varied (Kapo, Harrold, Carroll, Rickerson, & Casarett 2005; Rickerson et al., 2005; Christakis & Iwashyna, 1998). In contrast to calculations of the ideal length of stay, the family members’ perceptions of being referred “too late,” are associated with unmet needs for both patients and family members, in addition to greater dissatisfaction with quality of care (Teno, Shu, Casarett, Spence, Rhodes, & Connor, 2007). Much of the literature on hospice utilization and enrollment considers the factors, or barriers, that contribute to these late referrals.

Barriers to Hospice Use

Hospice eligibility and election

In the United States, the four highest causes of death include heart disease (24.6% of total deaths in 2009), cancer (23.3%), chronic lower respiratory disease (5.6%) and cerebrovascular disease (5.3%; Heron, 2012). The landmark book *Awareness of Dying* (Glaser & Strauss, 1965) discussed the trend that individuals were moving away from dying from a short trajectory to one from chronic illnesses over longer periods of

time. Lunney and colleagues (2003) tested these trajectories of dying (sudden death, terminal illness, organ failure, and frailty), finding that predictability of death related to a terminal illness, such as cancer, accounted for only 21% of deaths within the study. Without a predictable terminal period prior to death, timely access to end-of-life care is difficult. This concept is similar to Bern-Klug's (2004) discussion of the "ambiguous dying syndrome," which is the reality that many people living with chronic illness are not considered dying until they are on final days, if dying is recognized at all. Or from the observations of a nurse in a relatable study, "these people really die very, very slowly, inch by inch" (Hanson, Henderson, & Menon, 2002, p. 119).

Traditional hospice services were initially meant to target cancer patients in their last six months of life. While originally over 90% of hospice patients had a primary diagnosis of cancer (Connor, 2007), in 2013 only 36.5% of hospice patients had a cancer diagnosis (NHPCO, 2014). Cancer typically provides physicians with a clear death trajectory enabling fairly appropriate prognoses, while most other diagnoses are not as clear cut, making it difficult to discern when a referral is appropriate. Another change that has occurred over time includes shorter lengths of stay with nearly 35% of patients receiving end-of-life care for less than a week and 50% of all hospice patients receiving care less than 19 days (NHPCO, 2014). This reflects late referrals, which is contributed by both limitations in eligibility and in forcing patients to choose between curative and palliative treatments, among other variables. One study that considered whether patient's preferences for low-burden or high-burden treatment impacted hospice use found that many patients did not have preferences that make them eligible for hospice care, and that those who do are not accessing hospice in a timely manner (Casarett, Van Ness, O'Leary, & Fried, 2006).

Death denying culture

While the developments of medications and technologies have contributed to longer life expectancies as well as longer periods of disability before death (Lynn et al., 2008), they have also contributed to the existing death-denying culture within our society. In the early 1900's people took care of their loved ones at home until death. Bodies were laid out in the front room of the house and the community came by to pay their respects. In urban culture during this time, many families were multi-generational, so even from a young age "aging and mortality were present and even normal" (Kiernan, 2006, p. 10). Since the 1900's, due to economic changes and industrialization, people moved away from the farms and women were needed to work outside the home, making them unavailable to care for their loved ones who were sick or dying (Krisman-Scott, 2003). In 1920, 75 percent of people died within the home as opposed to 75 percent who died in hospitals or institutions in the 1990's (Lynn et al., 2008). With the removal of death from homes and the normalcy of everyday social interactions, death became something that was scary and removed from that of normal living. The inability to communicate about death makes it difficult to prepare or to receive the appropriate care and support.

Meaning of hospice

In 2002, Freidman, Harwood, and Shields conducted a study interviewing 30 hospice experts from around the country to identify contributing factors that limit patients' admission to hospice care. Responses demonstrated a consensus in the belief that patients and family members "associate the word 'hospice' with 'giving up.'" Other studies have similar findings indicating that the belief by both patients and professionals that hospice and palliative care equals death is a barrier to end of life care (Andruccioli et al., 2007; Feeg & Elebiary, 2005). Another variable that contributes to the association of hospice and palliative care with death, are the many misconceptions and myths about

end of life care. One article discusses common myths and provides information and education about the truths of hospice care. Several of the myths reviewed are that a discussion of death takes away a patient's hope, that hospice care is only for patients with advanced cancer, that increases in pain medications causes a hastened death, and that hospice or palliative care begins at the very end of a patient's life (Peden, Hill, & Powell, 2005). Results from a qualitative study examining perceptions and utilization of palliative care in the hospital setting, supported that some health professionals continue to believe the myth that palliative care is only appropriate in the final days of life (Rodriquez, Barnato, & Arnold, 2007). Though untrue, these beliefs about hospice contribute to the decision to delay enrolling in services.

Cultural barriers

Cultural factors may also serve as a barrier to choosing hospice. Type of caregiver involvement in addition to location of care, may be one area in detecting racial differences in hospice utilization. For minority patients with a formal caregiver, length of stay in hospice was significantly shorter than non-Hispanic White patients (Chung, Essex, & Samson, 2008). Authors suggest this racial disparity may exist due to the disparity in the quality of nursing homes (as this is where most formal care giving occurred), rather than suggesting that they enrolled later in their illness since no significant difference in length of stay was detected in those with informal caregivers. Another study considered location of care prior to hospice admission and found that African Americans were more likely than Whites (48.6% vs. 32.3%) to be referred from the hospital setting than in all other locations and that regardless of race, patients who were referred from the hospital were more likely to die within seven days of hospice enrollment (Johnson, Kuchibhatla, & Tulsky, 2011). In retrospective data looking at hospice length-of-stay in Asian-American and Pacific Islander cancer patients, all ethnic subgroups were less likely to enroll in

hospice than Whites, though there were variations in length-of-stay once enrolled (Japanese Americans had shorter length of stay in comparison to Whites, while Filipino Americans were longer; Ngo-Metzger, Phillips, & McCarthy, 2008). Each of these studies call for further research in order to understand the differences noted as national rates of hospice utilization among minority groups have not changed within the past five years (Bullock, 2011). Other recent studies found no significant differences when considering length of stay between minorities and whites (Hardy, Chan, Liu, Cormier, Xia, Bruera, & Du, 2012; Park, Carrion, Lee, Dobbs, Shin & Becker, 2012) though the disparity in the overall number of participating minority patients remained apparent.

Communication with healthcare providers

Inadequate communication with physicians has been identified as a significant barrier influencing quality at the end of life (Eues, 2007). In a study examining 100 patients already enrolled in a hospice program, 30% were not aware of their diagnosis and 62% had no awareness of their prognosis (Andruccioli et al., 2007). When examining views and attitudes of primary care physicians, researchers found that “only 65%...agreed they were comfortable communicating a prognosis” (Snyder, Hazelett, Allen & Radwany, 2012). Physicians’ inability to communicate clearly about diagnosis and prognosis with patients are due to a variety of reasons. Hospice experts identified physicians’ personal discomfort with death and lack of training and experience in end-of-life care as barriers to communication and work with dying patients and their families (Friedman et al., 2002). Physicians’ reluctances to inform patients about impending death due to anxiety about their own mortality is another suggested reason (Feifel, 1969 as cited in Neimeyer, Wittkowski & Moser, 2004). Higher death anxiety in physicians is related to greater difficulty disclosing prognoses (Kvale, Berg, Groff, & Lange, 1999) along with consideration of more factors before breaking bad news to patients (Eggerman

& Dustin, 1985). An additional concern is that minority patients may receive this information at an even lesser rate. Thornton (African-Americans get less end-of-life discussion, 2008) found that after reviewing data from SUPPORT, physicians reported having prognostic conversations with only 41% of African Americans compared to 58% of white patients.

Other barriers that contribute to problematic communication between practitioners and patients include our death denying culture, patient denial, and the focus within the American health care system on cure (Hickman, 2002). Ultimately, patients and families cannot talk or make decisions about something they are not even aware of. Hickman (2002) suggests that the inclusion and involvement of family members is one way to overcome barriers and to enhance decision making at the end of life.

In contrast to the literature that documents physicians' lack of communication many empirical studies attempt to evaluate effectiveness of the communication that does occur. In interviews with family members who experienced the loss of their loved one in an acute hospital, decision making in family meetings was one of three salient experiences that relate to emotional burden for caregivers (Radwany et al., 2009). Additional identified barriers to effective provider-family communication include multiple or alternating physicians in acute settings (Baggs et al., 2012), inadequate time conversing with family, inconsistent use of multidisciplinary teams, and lack of frequent communication (Ahrens, Yancey, & Kollef, 2003). Promoting excellent communication between physicians and family members is one way to lessen caregiving burdens (Rabow, Hauser, & Adams, 2004). Normal communication typically happens in an informal fashion and not until care providers have already reached a consensus that restoration or survival is unlikely (Lilly & De Meo, 2000) or until a decision has to be made (Hines, Babrow, Badzek, & Moss, 1997). The use of communication interventions

involving interdisciplinary team meetings shortly following admission and daily communication from consistent team members has shown to decrease the length-of-stay in critical care, lower hospital costs, and allow for earlier access to palliative care (Ahrens et al., 2003; Lilly & De Meo, 2000).

Family and Decision Making at the End of Life

Though several barriers to choosing hospice care are outlined above, the importance of family in decision making cannot be minimized. Researchers have documented the role of family involvement as a critical component at the end of life. Within palliative care, the patient and the family are recognized as the unit of care (Connor, 2009), versus focusing on the patient alone. Outside of palliative care, some argue that family-centered care or collaborative approaches that involve family members are more appropriate than the traditional client-centered approach (Hardwig, 1990; Hidecker, Jones, Imig, & Villarruel, 2009). While patient autonomy is a core value in Western medicine, other cultural groups may not share this value suggesting an even greater need for involvement of family members (Ballard-Reisch & Letner, 2003; Volker, 2005). Research has shown that Whites are more likely to prefer autonomous decision making than Blacks (Bullock, 2011) and are likely to be more exclusive regarding who to include in discussions, whereas Blacks were more inclusive, often extending participants beyond family to close friends and spiritual leaders (Shrank et al., 2005). A number of studies have also shown family-centered models of decision making as preferred by Mexican Americans and Korean Americans (Ballard-Reisch & Letner, 2003). Merging person-centered planning with family focused care is offered as one suggestion for enhancing end-of-life care and transitions for patients with intellectual disabilities (Kirkendall, Waldrop, & Moone, 2012).

One of the other considerations in determining the role of family at the end-of-life is the prevalence of caregiving. In the US, a family member in 31.2% of households reports serving as an unpaid caregiver (National Alliance for Caregiving, 2009). For recipients of care, family members are most likely to be the designated caregiver, making them an integral part of health care decisions. In addition to this involvement, family influence plays a dominant role in a person's development of values, health attitudes and behaviors (Pecchioni, Thompson, & Anderson, 2006), all of which are key variables in decision making (Shrank et al., 2005). The understanding of family within this proposed study is approached within an inclusive framework as determined by patients and the loved ones who surround them.

Importance of family communication at the end of life

With the prominent role of family during illness and at the end of life, family communication is an important consideration. Segrin and Flora (2005) define communication as "a transactional process in which individuals create, share, and regulate meaning" (p. 15). Though multiple definitions of family communication exist, the one accepted in the context of this review is "the act of making information, ideas, thoughts and feelings known among members of a family unit" (Olson & Barnes, n.d., p. 1). Much of the literature on family communication provides insight to its importance at the end of life. This portion of the review examines the content of end-of-life conversations, important outcomes of family communication, in addition to challenges within family communication.

Conversations at the end of life. Both patients and caregivers desire more communication at the end of life (Fried, Bradley, O'Leary, & Byers, 2005). Even though multiple studies suggest the absence or difficulty of family communication at the end-of-life (Boehmer & Clark, 2001; Fried et al., 2005; Gotcher, 1995; Zhang & Siminoff, 2003),

others provide insight into the content of final conversations. Final conversations are defined as any familial communication between the time of diagnosis and death (Keeley, 2007). Badr and Taylor (2006) characterized four different areas of relationship talk which emerged from separate interviews with patients and their spouses. The quality of the relationship, relationship memories, planning for the future, and problem solving all became topics of conversation during the cancer experience (Badr & Taylor, 2006). These areas highlight a connection between family communication and decision making. In addition to these areas, messages about love, personal and relational identities, faith, routine interactions, and the difficulty of past relationships are conveyed in final conversations between dying patients and their family members (Keeley, 2007). Conveying love, gratitude, forgiveness and farewell in conversations at the end of life are also considered important (Byock, 1996).

The impact of conversations directly related to end-of-life topics was a significantly stronger indicator for lower distress and increased quality of care than agreement between patient and family member about the need for communication (Abbey, 2009). In other words, whether patients and families agree on the desired amount of talking does not matter as much as whether the conversation about end-of-life occurs at all. This also suggests that family communication about illness, or end-of-life topics, may be a separate construct than family communication more generally. Results from Wittenberg-Lyles and colleagues (2012) support the above finding in that “conformity in family communication [does] not equate with family agreement or open communication” (p. 25).

Outcomes of family communication. A number of studies have considered the impact of family communication on patient and/or family functioning through a variety of approaches. Increases in frequency, honesty, and satisfaction of family communication

along with emotional support, had positive impacts on effective adjustments of terminally ill patients (Gotcher, 1993). Other studies considered the positive effect of family communication on psychosocial adjustment resulting in increased communication about the relationship (Badr & Taylor, 2006). In the opposite direction the lack of communication between patients and families was found to have an increased risk of poor adjustment for prostate cancer patients (Boehmer & Clark, 2001). The ability to express emotion, like within the definition of family communication provided, was associated with a decrease in pain for cancer patients (Dalton & Feuerstein, 1989). Increased discussion of end-of-life topics was associated with less distress and increased quality of life (Abbey, 2009).

Communication constraints, which developed due to the desire to protect patients or family members, has been documented as a predictor to family conflict (Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2010). Other studies considered the impact of family communication on the caregivers instead of on the patient themselves. End-of-life conversations have multiple positive functions for bereaved family members, such as affirmation of their relationship with the patient, sense of closure of the relationship, validation of beliefs, and reconciliation (Keeley, 2007). Self-efficacy and increased lengths of caregiving was associated with greater perceived levels of open communication by caregivers, while emotional exhaustion and depression of caregivers was associated with lower perceived levels of open communication (Bachner & Carmel, 2009).

Challenges in family communication. In addition to positive outcomes, research also presents challenges in family communication. Findings across multiple studies show a large prevalence of patients and families that experience communication difficulties. In a study that surveyed 193 terminally ill patients and their caregivers, 39.9% of caregivers

desired more communication along with 20.2% of patients (Fried et al., 2005). Within the same study 37.3% of caregivers and 22.3% of patients reported that communication was difficult. Two-thirds of a sample of 26 lung cancer patient-caregiver dyads reported communication problems (Zhang & Siminoff, 2003), where in a sample of 78 breast cancer patients and their significant others, one-fourth reported strained communication (Lichtman, Taylor, & Wood, 1987).

The nature of terminal illness itself causes potential for communication difficulty due to the physical progression of illness, diminishing the ability of patients to communicate normally (Planalp & Trost, 2008; Stone, Mikucki-Enyart, Middleton, Caughlin, & Brown, 2012). Patient impairments, alongside geographical distance of family, are situational influences of difficult communication (Stone et al., 2012). Other natural responses to terminal illness, such as a wide range of emotions (Planalp & Trost, 2008; Zhang & Siminoff, 2003), denial (Planalp & Trost, 2008), and family conflict (Kramer et al., 2010; Planalp & Trost, 2008) also make family communication more challenging. Relational influences, for example role changes and the influence of multiple family members are cited as increasing communication difficulty (Stone et al., 2012). Avoidance, belief in the power of positive thinking, and psychological distress (Zhang & Siminoff, 2003), along with the belief that talking about concerns might hasten death or reoccurrence (Lichtman et al., 1987) are other variables that contribute to complexity in communication.

Family and Decision Making at the End of Life

Research on decision making at the end of life has invariably discovered family members to be at the center (Cohen, McCannon, Edgman-Levitan, & Kormos, 2010; Hiltunen, Chase, & Medich, 1999; Karasz, Sacajiu, Kogan, & Watkins, 2010; Tschann, Kaufman, & Micco, 2003). Though Hiltunen and colleagues (1999) anticipated studying

accounts of patients' decisional conflict in their review of narrative accounts from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), they discovered that the majority of decisions were actually made by family members. The presence of family members at the time of death when compared to patients who died alone is an indicator for greater presence of DNR orders, documentation of withdrawn treatments, and use of pain medication prior to death (Tschann et al., 2003). These findings suggest that family involvement increases the use of comfort care within the hospital for dying patients, also implying that family members played a role in making these decisions.

While it is often assumed in the American healthcare system that patients will make care decisions when they are alert and able to, multiple cultures prefer family decision making, or collectivism and interdependence versus individualism and independence (Candib, 2002; Johnstone & Kanitsaki, 2009). In a milestone study regarding culture at the end of life, Blackhall and colleagues (1995) found great variation across cultures within the United States (Korean Americans, Mexican Americans, European Americans, and African Americans) about whether or not a patient should be told of their diagnosis (47%, 65%, 87%, 88% respectively) or of a terminal prognosis (35%, 48%, 63%, and 69%). Ultimately suggestions for providing culturally competent care at the end-of-life involve the inclusion of family and assessment on the role of cultural preferences related to decision-making and other values and beliefs (Bullock, 2011; Stein, Sherman, & Bullock, 2009).

Eight informal roles for family members across four differing intensive care units emerged during an ethnographic study spanning from 2001 to 2004: primary caregiver, primary decision maker, family spokesperson, out-of-towner, patient's wishes expert, protector, vulnerable member, and health care expert. Each of these roles was tied to the

decision making process for families at the end of life, often creating a complicated dynamic (Quinn et al., 2012). Within this context of decisional conflict (Hiltunen et al., 1999), a decision making process was identified involving several stages: recognition of a dilemma, a period of vacillation, moving to a turning point and letting go. Additional challenges in decision making for families included the need for multiple decisions throughout the process, multiple perspectives of family members, and presence of family members at different stages within the decision making process at any given time (Hiltunen et al., 1999). A second identified process for family decision making at the end of life includes cognitive, affective, and interpersonal steps guiding family members to understand the patients' condition, identify patients' preferences for treatment, and continue familial roles respectively. These processes ultimately help family members to understand the patients' unlikelihood of recovery, enabling them to make a decision (Swigart, Lidz, Butterworth, & Arnold, 1996).

Proxy decision making

Family members are often called upon to make decisions with or on behalf of patients with advanced illness (Meeker & Jezewski, 2005). Though historically medical decision making was in the hands of physicians under the Hippocratic Oath (Meeker & Jezewski, 2005), current models are based upon a model of rational choice, which emphasizes a patient's stated wishes first, followed by substituted judgment about what a patient would decide, and lastly the patient's best interest (Drought & Koenig, 2002; Karasz et al., 2010; Meeker & Jezewski, 2005). One of the challenges with this model is the overwhelming lack of implementation of Advance Directive and Living Will paperwork, designating someone's choices at the end of life (Bomba et al., 2011; Fagerlin & Schneider, 2004; Glass & Nahapetyan, 2008; Lang & Quill, 2004). Minorities are often cited as completing advanced directives at even lower rates than Caucasians (Bullock,

2011; Cohen, 2008; Volker, 2005). In observation of the decision making process between staff and family members of 26 patients, results suggested that consideration of best interest took precedence over a patient's wishes (Karasz et al., 2010). Additional arguments against the use of living wills in decision making include unpredictability of complex conditions and potential choices, ambiguous understanding of one's wishes prior to facing the need for decisions, and proxies' ability to interpret their loved ones documented choices (Fagerlin & Schneider, 2004). An evaluation of published reports from the SUPPORT study showed that surrogate understanding of their loved ones' preferences was barely better than chance (Covinsky et al., 2000), perhaps indicating a lack of family communication about such issues.

Prior to the need of proxy decision making, multiple studies have considered whether or not patients and their designated proxy match regarding end-of-life preferences (Ditto et al., 2001; Parks et al., 2011; Schmid, Allen, Haley, & Decoster, 2010). In a systematic review examining family decision making experiences, results showed that proxies demonstrated low to moderate accuracy in predicting choices (Meeker & Jezewski, 2005). Proxy accuracy was significantly higher when a spouse or partner served as proxy versus an adult child or other and increased accuracy across proxy types was associated with lower family conflict (Parks et al., 2011). Other variables that increased accuracy included conditions of forced choice and directed use of substituted judgment (Meeker & Jezewski, 2005).

Advance planning and end-of-life preferences

While Advance Directives are meant to be useful in decision making, the complementary variable of communication provides additional benefits. In fact, planning for care at the end of life and making decisions are "fundamentally relational" (Jennings & Morrissey, 2011). Group decision making among a family was preferred over use of an

individual surrogate, indicating the need for communication between family members (Meeker & Jezewski, 2005). Open family communication was an indicator for improved congruence in care preferences between terminally ill patients and their caregivers (Gardner & Kramer, 2009). Family members who discussed patients' advance directives with them also reported greater confidence in their ability to serve as a proxy, even though it did not improve accuracy in predicting patients' choices (Ditto et al., 2001). Overall family communication about end-of-life preferences serves a greater purpose for decision making than completion of advanced directives alone. Barriers to these discussions, also discussed above under challenges in family communication, include fear of death, trust in others to make decisions, and challenging family dynamics. Prior experiences of death, acknowledgement of the reality of death, and spirituality are facilitators to family communication about end-of-life preferences (Elliott, Gessert, & Peden-McAlpine, 2009).

Family communication and decision making

Unfortunately, there are no consistent patterns of how family communication and decision making are studied in relation to one another, though both family and communication are regularly considered in relation to decision making. Babcock and Robinson (2011) present a model of "Seven Core Components of Communication and Decision Making," which includes specific interventions for counselors to assist the family unit in navigating the process of decision making. This model provides further support for the important role that social workers can play within family communication and decision making at the end of life. The seven components include getting ready to work with the family and other systems, assessing the situation, managing conflict, providing information, identifying roles, processing familial responses, and follow through. While this model provides a framework for helping families to communicate during the decision

making process, the processes specific to how the patient and family members communicate amongst themselves is not considered.

Waldrop and Meeker (2012) considered the role of family in their study on understanding decision making surrounding hospice enrollment. In order to be enrolled in the study, patients had to score a 40 or above on the Palliative Performance Scale (PPS), indicating an ability to communicate. Family members were also involved in the interviews, due to the authors understanding of family involvement within the decision making process. Using the conflict theory model (CTM) of decision making as a framework to guide the study (appraisal of the challenge, surveying alternatives, weighing alternatives, deliberations, and adherence to the decision), authors discovered that the decision making process prior to the hospice encounter varied between cancer diagnoses and other chronic illnesses (Waldrop & Meeker, 2012). For patients with cancer, there was a distinct turning point when treatment was no longer effective that indicated an appropriate referral to hospice care. For non-cancer diagnoses, the appraisal of the challenge was characterized by multiple trips to the hospital and exacerbations of symptoms; with no distinctive parameter for facilitation between treatment and palliative care, the referral for hospice was more likely to be delayed (Waldrop & Meeker, 2012). The study's results provide a useful framework for understanding differences in the process of family decision making for hospice by diagnosis, but the role of communication within the family surrounding this process was not explored.

Scott (2010) uses a theoretical perspective of multiple goals to consider how the quality of family communications about end-of-life decision making is more important than the quantity. Outside ratings of communication from observing family communication were positively associated with reports from patients and their loved ones on satisfaction

with the conversation and decision making efficacy. More research is needed related to informal communication between older adults and their family members (Hopp, 2000).

Review of Methodology and Research Design

Research at the end of life presents multiple challenges. One of the first challenges is in regards to the vulnerability of terminally ill patients. Worries about terminally ill patients' participation in research include their debilitating physical and psychosocial symptoms, dependency on others for care, and potential cognitive impairment or inability to provide consent (Fine, 2003; Reyna, Bennett, & Bruera, 2007). However, the concern over patients' vulnerable state and inability to participate in research has stunted the growth of evidenced based knowledge about end-of-life care (Casarett, 2005; Gysels, Evans, & Higginson, 2012). In a systematic review of 20 studies considering the impact of end-of-life research on participants, positive outcomes were seen across each of the different parties and very few experienced any distress (Gysels, Evans, & Higginson, 2012). While certainly the focus on potential risk to terminally ill patients should not be minimized, it is also important to recognize the benefit of such research to dying patients, their families, and the field of end-of-life care at large when appropriate measures are taken to limit risks (Fine, 2003).

In addition to discussion about vulnerable patients inclusion in research is a secondary consideration about the challenges faced with participation that can impact the research design. For example, recruitment and retention of participants, attrition, and poor health status impacting data collection are all challenges faced (Addington-Hall, 2007). Due to the relative newness of palliative care research and the subjective constructs often studied, optimal measurement techniques are not agreed upon, making validity a particular challenge (Casarett, 2005). Longitudinal designs are difficult due to high rates of attrition or drop-outs and quasi-experimental and experimental designs are

difficult as they “may be too regimented for clinicians accustomed to flexible, patient-centered care” (Head & Ritchie, 2004, p. 40). Some clinicians even worry whether randomization in relation to end-of-life care is even ethical (Connor, 2009). Though pure experimental models are always desirable, other approaches are also appropriate and valuable (Head & Ritchie, 2004). In fact, with the nature of palliative care utilizing a team approach, it is natural that end-of-life research also be approached across interdisciplinary fields using a combination of qualitative and quantitative designs (Addington-Hall, 2007; Lloyd, White, & Sutton, 2011).

The SUPPORT study, described earlier, demonstrated that collection of large quantitative data utilizing a randomization design is possible in end-of-life research. Feasibility of such a study though is an important consideration. While funding was obtained through the Robert Wood Johnson Foundation, a huge funding source within end-of-life research, the study was their most expensive venture costing over \$29 million; a normal funded project with The Robert Wood Johnson Foundation is generally less than \$500,000 (Schroeder, 1999). Another feasibility concern in research at the end of life is with hospice patients, where the average length of stay is short, causing concern over involving them in a process of informed consent and data collection (Head & Ritchie, 2004). In prospective studies, even patients who are able to consent upon enrollment may lose that ability at a later point within the study (Casarett, 2005). These challenges are all aspects that need consideration within the methodology of a research study.

Though there has been recent growth, end-of-life research efforts overall are still considered to be relatively small in comparison to other topic areas, leaving “many unanswered questions” (Addington-Hall, 2007, p. 2). Much of the research on decision making and family communication at the end of life are exploratory and descriptive, demonstrating there is still much we don’t know about these constructs. Qualitative

research methods are common, utilizing focus groups (Bullock, 2011; Elliott et al., 2009) and guided or semi-structured interviews (Badr & Taylor, 2006; Gardner & Kramer, 2009; Keeley, 2007; Stone et al., 2012), with grounded theory (Badr & Taylor, 2006; Bullock, 2011; Radwany et al., 2009; Wittenberg-Lyles et al., 2012) and/or content analysis (Bullock, 2011; Waldrop & Meeker, 2012) in data analysis. Cross-sectional designs are common (Kramer et al., 2010; Waldrop & Meeker, 2012), as longitudinal data is difficult to obtain due to short prognoses of terminally ill patients. Quinn and colleagues (2012) utilized a prospective ethnographic approach to study trends in decision making within four ICU's over an extended period of time from 2001 to 2004. Some studies are retrospective utilizing bereaved family members to portray the end-of-life experience (Stone et al., 2012). Critiques of this approach are that it does not capture the experiences from the perspective of terminally ill patients themselves. The amount of time passed from the experience may also have an influence on how bereaved family members remember it.

Due to the exploratory and descriptive nature of studies on decision making and/or family communication at the end of life, measurement tools and scales are not extensively used. The Life Support Preferences Questionnaire (LSPQ) was used in quantitative studies about decision making as a measure for treatment preferences when considering proxy accuracy in predicting patient's choices (Parks et al., 2011; Schmid et al., 2010). In both quantitative and qualitative designs, questions about and presence of advance directives were often used as an indicator for decision making (Bullock, 2011; Schmid et al., 2010; Tschann et al., 2003; Young & Rodriguez, 2006). Hospice enrollment, representing the decision for hospice care, has been measured simply by yes (enrolled) or no (not enrolled), or in other studies by calculating rates of hospice enrollment across particular demographics (duPreez et al., 2008; Sexauer et al., 2014;

Zheng, Mukamel, Caprio, & Temkin-Greener, 2013). The timing of hospice referral, hospice enrollment, and hospice utilization have all used hospice length of stay as an indicator (Miller, Kinzbrunner, Pettit, & Williams, 2003; Sexauer et al., 2014). Timing of enrollment has also been measured by asking families to choose from predetermined categories, “too soon,” “too late,” or “at about the right time” (Kapo et al., 2005).

Researchers using qualitative methods have considered the process of decision making from multiple perspectives of patients, family members or clinicians (Elliott et al., 2009; Gauthier & Swigart, 2003; Quinn et al., 2012). In studies considering family communication at the end of life, self-report measures are most commonly used (Harris et al., 2009). While these tools provide flexibility to family researchers, they collect general impressions of communication versus actual occurrence of behaviors (Metts & Lamb, 2006). The use of previously validated scales to study family communication at the end of life is uncommon. Another consideration when studying family communication at the end of life is whether or not one is studying general family communication versus family communication about the illness itself. Though the two are highly correlated, the use of general family communication scales “may not be appropriate for assessing illness-related” communication (Arden-Close, Moss-Morris, Dennison, Bayne, & Gidron, 2010, p. 544).

Gaps in Knowledge

While family communication is recognized as both a barrier and facilitator (depending upon the quality) to the transition to hospice care, the research surrounding this connection is limited. Research related to the role of familial communication within the decision making process is warranted, along with further research about how families communicate about their illness in general (Harris et al., 2009). Little is known about the decision making process for hospice at all (Chen, Haley, Robinson, & Schonwetter,

2003). While a number of studies describe family members' feelings that communication and information were insufficient, what is meant by communication is not adequately discussed. How this fits together with the way families communicate amongst themselves about illness seems to be an important consideration that remains overlooked. The role of family in comparison to other identified barriers is also lacking.

Another gap within the literature considered within this review is that the majority of studies were related specifically to cancer rather than across the spectrum of terminal illness. While cancer patients continue to make up close to half of the patients served in palliative programs, these studies do not provide an inclusive picture of other types of patients served by end-of-life care. A methodological gap includes the use of a recognized measurement scale on either decision-making or family communication that is validated for use with terminally ill patients.

Understanding the role of family and communication in decision-making about hospice at the end-of-life will help clinicians to identify and provide support to families who may be struggling to make decisions. Failing to recognize the important role of family within this process could cause further delay in access to end-of-life care and in the overall quality and satisfaction with the experience.

Theoretical Framework

Due to the shortage of literature that directly studies the relationship between family communication and decision making, scholars have not identified an optimal or generally accepted theory. However, a number of theoretical frameworks and models have been used to explain family communication and decision making separately. Within family communication textbooks, decision making is a topic readily discussed (Segrin & Flora, 2005) and within texts on decision-making, family communication is discussed (Werth & Blevins, 2009). While these texts suggest that these concepts are each

important within the context of the other, further research is needed to consider the relationship between them. Theory is useful in exploring this relationship, specifically in demonstrating the general importance of the family within decision making processes. Family systems theory and the epigenetic model of family processes are guiding theories for this study which suggest the importance of family within the process of complex decision making. Each of these theories is discussed below along with an application related to decision-making within the context of families and illness at the end of life.

Family Systems Theory

Historically, family systems theory originates from General Systems Theory (GST) within fields of engineering and biology (Segrin & Flora, 2005). GST is credited mainly to Ludwig von Bertalanffy (2008), who introduced the theory as a response to previous scientific theories which attempted to “resolve the phenomena of life into parts and processes which could be investigated in isolation” (p. 134). In the simplest of explanations, Bertalanffy (1968) described GST as “a general science of ‘wholeness’” (p. 37). Family theorists related to GST, recognizing the family as a system, defined by Bertalanffy (1975) as a “set of elements standing in interrelation among themselves and with the environment” (p. 159).

Though GST is rooted within fields of formal and hard sciences, its application in social sciences and family therapy is based upon the use of three core assumptions (Whitchurch & Constantine, 1993). First, one of the major aims of GST was to assist in unifying branches of science through a theory applicable to the “similar problems and conceptions [that] have evolved in widely different fields” (Bertalanffy, 1968, p. 30). Bertalanffy explained that though the entities across disciplines are completely different, viewing them as systems “leads to a correspondence in general principles and even in special laws when the conditions correspond” (p. 33). This means that regardless of

whether the systems are biological, mechanical, or the functioning within a family, the concepts and processes of GST are equally applicable to each (Segrin & Flora, 2005).

The second core assumption discussed by Whitchurch and Constantine (1993) was the idea of holism, or that a system must be understood as a whole and that it “cannot be comprehended by examining its individual parts in isolation from each other” (p. 328). When considering families, this suggests that each member is interconnected with other members of the family. In other words, change occurs due to interactions between various members of the whole family, or when one member changes, every other member is impacted as well (also known as interdependence or mutual influence).

The third assumption of GST as applied to social sciences and family therapy is related to the rudimentary concept of cybernetics; systems are able to monitor processes through feedback and then make corrective adjustments (Whitchurch & Constantine, 1993). Cybernetics is “concerned with the communication and manipulation of information in controlling behavior” within a system (p. 332). All cybernetic systems are self-monitoring, or within human systems, “characterized by self-reflexivity” (p. 329). Self-reflexivity is the idea that as humans we can “develop our own goals and monitor our own behavior” (Segrin & Flora, 2005, p. 28), which occurs through the process of communication (Whitchurch & Constantine, 1993). Therefore, family communication is an important consideration towards both goal development and behaviors, such as decision-making, within a family.

Key concepts within family systems theory include boundaries, open and closed systems, input and output, rules, goals, and feedback (Sabourin, 2006). Each of these helps to explain and understand interactions within a family. Systems theory is a dominant theory within all perspectives of family communication (Sabourin, 2006). Described as a meta-theory within the study of communication, systems theory allows us

to view the family as a whole (Sabourin, 2006). Though our medical system often views patients through a lens of autonomy, the use of a systems approach makes it difficult to remove the family from considerations of a particular patient, including decision-making processes. Medical decision making is viewed as an interpretive process within a family systems approach, where family serves as support to the patient (Kuczewski, 1996). The patient, the family, and the medical team are all operating systems with differing boundaries, goals, and rules that govern behavior (King & Quill, 2006). Babcock and Robinson (2011) used a systems approach to guide them in a counseling model for assisting patients in making decisions within the transition to palliative care. In this proposed study, systems theory guides us to look at the family as an entire system, recognizing that the patient cannot be separated from the influence of other members within the system.

Epigenetic Model of Family Processes

In understanding this model it is important to understand the concept of epigenesis, or the epigenetic principle. The word epigenesis can be defined as “referring to events of ‘becoming’ (‘genesis’) that build ‘upon’ (‘epi’) the immediately preceding events” (Wynne, 1988, p. 83). Singer and Wynne (1965) describe this as their view of human development, suggesting that transactions within each stage of development build upon outcomes from previous stages. So if development is “distorted or omitted” within one stage, it can impact development and interactions in other stages moving forward (p. 208).

Social workers are most familiar with the idea of the epigenetic principle through Erikson’s stages of development (stages of the individual life cycle), which guides understanding of human behavior. Researchers normally examine family development based upon the problems that occur for individuals who are not “developmentally or

experientially ready” for normal patterns within the family life cycle (Wynne, 1988, p. 81). Wynne is more interested, however, in the problems within the relational systems and processes that occur perpendicularly to the normal family transitions, which will expectedly be out of synch at times. As illuminated above in the discussion on systems theory, families are relational systems where series of relationships and interactions among its members create a uniquely defined system that cannot be understood outside of the context of the entire system (Wynne, 1988). Wynne was the first to apply the epigenetic principle to the level of relational systems, instead of to cell or individual levels of systems organization. However, understanding levels of organization from systems theory is central to Wynne’s development of the epigenetic model of family processes. Wynne is actually seen as an important contributor within the historical development of systems theory, as in the 1950’s he (along with other researchers around the country) began examining schizophrenia from the perspective of the family unit versus as an individual pathology (Schultz, 1984).

In the epigenetic model of family processes, Wynne (1988) theorizes that there are four relational processes within family systems, where each builds upon the processes from the prior levels: attachment, communication, joint problem-solving, and mutuality (see Figure 2.1; An epigenetic model of family processes, Wynne. 1988. Copyright Guilford Press. Reprinted with permission of The Guilford Press). The two relational processes most applicable in this proposed study are those of communication and joint problem-solving. For each process, Wynne provides alternative negative aspects, which imply relational distance or difficulty. Fluctuation along the positive and negative poles within a process is expected over the course of relationships, though achieving positive patterns in one level leads to the ability to create positive processes within the next stage. For example, families who have achieved positive attachment are

more likely to share a social reality which allows them to form a basis of understanding within their communication (Wynne, 1988). Relational processes between family members are transactional. Similar to the understanding of systems theory above, persons within the family system “undergo internal change during the course of interchange with one another” and “all parts...are interdependent, each modifying the rest through recursive (circular) feedback” (p. 87). So in addition to positive attachment influencing communication processes, the quality of communicating within family members will modify attachment and caregiving.

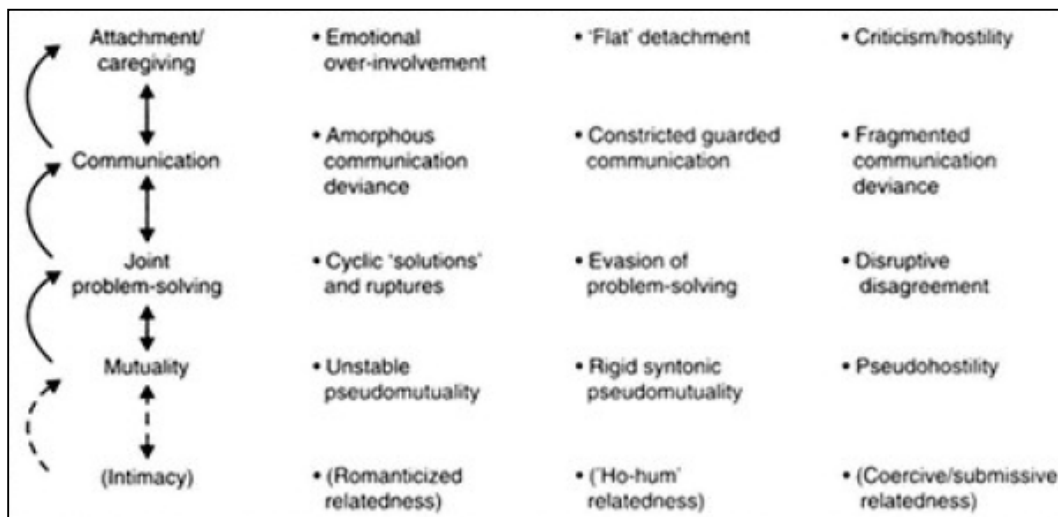


Figure 2.1 Wynne's Epigenetic Model of Family Processes

Though attachment is often studied in relationship to infancy and young childhood, the concept is applicable across the life span (Wynne, 1988), creating a basis for application in later life development, such as at the end-of-life. Though previously untested, King and Quill (2006) suggested that this model “has direct relevance to medical decision making” (p. 706) and provides a good fit for “understanding and responding to a range of common family dynamics encountered in palliative care and hospice settings” (p. 704). The role of communication in problem-solving (as outlined in

further detail below) is identified within the model. Negative patterns alongside communication processes include amorphous or fragmented communication deviance (CD) and constricted guarded communication (Wynne, 1988). CD is defined as when a family member is unable to construct a consistent meaning or similar visual image as the member speaking (Singer & Wynne, 1966).

Joint problem-solving (or decision making, as referred to within this study) is most likely to be navigated positively when families have a positive background of communication. Without this foundation, disruptive disagreements, indecisiveness (or evasion of problem-solving), and cyclical problems with no long-term solutions are likely to result (Wynne, 1988). Within the context of decision making for hospice care, each of these negative processes would likely delay or deter that decision. Families often avoid making decisions in end-of-life care until a crisis event, or turning point, occurs (Waldrop, 2006; Wallace & Adorno, forthcoming). With the polarization between active treatment and palliative care that comes along with a decision for hospice, families often find themselves in 'disruptive disagreement,' causing for a delay in any decision at all. This model suggests that in order to help families navigate these problem-solving difficulties, it would be prudent to first address family attachment and communication.

In this study, Wynne's epigenetic model of family processes provided a framework stating that positive processes of communication (sharing of information, ideas, thoughts and feelings) about illness allows for complex decision making. This also suggests that families experiencing negative processes of communication (avoidance, constricted, or fragmented communication) may have more difficulty making these decisions. The model suggests a strong connection between processes of communication and decision making in families and that in order for families to be successful in joint problem-solving, there must first be a positive attachment and second

a quality of communication. It is using this assumption, that this study suggested the importance of family communication in the decision for hospice care, as poor communication would likely result in delayed decision making (or evasion of problem-solving) or disruptive disagreement about the right course of action (leading to a delay in the decision for hospice).

Chapter 3

Methodology

Introduction

Of course we know that there are a number of important factors that contribute to how patients and families make decisions about hospice care. We also know that family is an important influence in decision making. What needs further exploration is how the role of family impacts decision making about hospice care among these other noted factors. The purpose of this study was to examine the extent to which family impacts hospice utilization, or the timing of the decision for hospice care. This study used an exploratory, cross-sectional approach. A quantitative analysis using multiple linear regression examined the extent to which family communication about illness and referral source (family versus medical professionals) predicted both the amount of time between referral and enrollment and hospice length of stay. Based upon the search of the literature and this author's pilot study, a number of additional variables served as control variables. This research was carried out in partnership with Community Hospice of Texas, a local hospice agency that was willing to assist with access to potential participants and with data collection (see attached letters of research support, Appendix A). Prior to any data collection, I obtained approval through the University of Texas at Arlington's IRB (see Appendix B for IRB approval letter).

Qualitative Pilot Study

During the spring and summer of 2013, I completed 18 qualitative interviews with hospice patients and/or their family members (Wallace and Adorno, forthcoming). This study served as a pilot study for this dissertation and considered how and when patients and families make the decision to begin hospice care. The two research questions guiding the study were as follows: (1) How do patients (and/or families) make the

decision to begin hospice care? (2) Do family relationships and family communication inform decisions about a patient's care at the end of life? Both patients and family members were asked to participate in the study. If patients were unable to consent due to their illness, family members were asked to participate after permission was obtained from the Power of Attorney or primary decision maker on behalf of the patient. The resulting sample of interview participants across 18 patients was 27, 5 patients and 22 family members. Using a structured interview guide, I asked participants about the development of the patient's illness, the transition to hospice care, how they communicated about the illness within their family, and about their decision making processes. In addition to the qualitative interviews I conducted preliminary field testing on a potential family communication measure (untested in this population) and the research questionnaire developed for this proposed study. Pretesting is important in order to explore validity and reliability of a measure, in addition to gathering information about content and administration (Waltz, Strickland, & Lenz, 2010).

Using grounded theory, five overarching themes contributing to hospice decision making emerged from the 18 qualitative interviews: families seeking hospice, turning point, communication, experiences, and meanings. Multiple subthemes existed across these five overarching themes. While an extensive report of methods and results from this pilot study are outside the scope of this proposal, it is important to consider how the findings contributed to the development of the current study. Resulting subthemes confirmed much of what we already know about barriers or facilitators to hospice care from the literature, such as the roles of the following: crisis or decline prompting a decision about hospice (resulting in late referrals), exhaustive medicine (aggressive treatment), insurance or financial restraints, health communication, and the meaning (or patient and family members understanding) of hospice. However, in addition to

supporting what is already known in current empirical literature, two additional findings, the role of families seeking hospice and of family communication, contributed to the importance of studying them as predictors within the current study.

The Role of Families Seeking Hospice

When considering the cases of the sample as a whole, we noticed that the sample split almost in half across a variable based upon referral source. Forty-four percent (8/18) of our sample fell into a group that we termed “families seeking hospice.” This was defined as patients (or family members responding on their behalf) who first learned about hospice as an option for their illness from a family member or a friend and/or patients whose family member made the initial contact to the hospice company (as opposed to a referral from a physician or healthcare professional). When a patient first learns about hospice from family or a friend it suggests that there is an advocate for hospice care presenting hospice in a positive light. This was supported by evidence from the qualitative interviews. Two patients within this group actually had family members who served as hospice volunteers. The thing that stood out most about this group in relation to the current proposal, was regarding hospice length of stay. Patients who fell into the group of families seeking hospice (8/18) were on hospice more than three times longer than the group referred by a physician or medical professional (average of 194.5 days compared to 53.1 days). Though these findings are not generalizable due to the small sample size, they certainly warrant evaluation in a larger study and support the important role of families in decision making about hospice care.

Family Communication

The second key finding important to highlight in relationship to the proposed study, is the theme of family communication, which surfaced within the overarching theme of communication. Transmission of values and patterns of communication were

two subthemes to family communication. Within the qualitative interviews, family members often spoke about apparent values that contributed to their decisions about the patient's care. Though these values may not have been discussed out loud within the family, they were transmitted between members in the other ways they communicated with or related to one another. In one case, a daughter spoke about the tradition and role of the daughters in taking care of aging parents. In another case a daughter spoke often about the value of protection through the need to stay strong and positive, or to protect particular members from the possibility of death within the home. Spirituality was another value that was often discussed. Though it would be difficult to capture these values with a quantitative measure, it is important to recognize how they contribute to the way families communicate about illness and how this may shape the decisions made about end-of-life care.

In addition to the importance of values, patients and family members spoke about the process of communicating about illness, providing clues about their patterns of communication. Some participants shared their process of gathering for discussions, holding formalized family meetings, or talking things through until they were "on the same page." These behaviors suggested more open patterns of communication. Other families described withholding information about an illness until being "forced" to share the information due to decline, or coming up with circular ways to indirectly suggest ideas in order to help facilitate a decision. These descriptions from patients and family members suggested closed patterns of communication. Both types of communication seemed to play a role in how decisions were made about hospice care. Though the effect of these different types of communication was not considered within the pilot study, results suggest that this is a second factor worthy of further investigation.

Sampling and Data Collection

Sampling

This study used availability sampling, or convenience sampling, due to the time-sensitive nature and turnover rate within hospice care. Though probability sampling is a preferred method within research, obtaining a randomized sample based upon an ever-changing population would have been problematic. Potential subjects for inclusion in this study were legal adults enrolled in hospice care in the partnering agency, Community Hospice of Texas. Though Community Hospice of Texas has seven offices across the state, potential subjects were identified from the offices located within the metroplex: Fort Worth, Dallas, and Cleburne. The Fort Worth office also includes two inpatient hospice units, one freestanding house located on the campus of Texas Health at Huguley Hospital, and a second located within James L. West Alzheimer's Center. An additional inclusion criterion for participants was that they must be conversant in English. Patients living at home or staying in one of the Community Hospice inpatient units were able to consent to participation at any time. Those within a facility (nursing home, assisted living, or hospital), were not able to participate until an administrator from the facility gave written permission for the research to occur within their building (per UTA's Institutional Review Board). Community Hospice preferred for their marketers to be the ones to make this contact with facility administrators.

Prior to any data collection, hospice nurses, social workers, and chaplains from each collection site were trained by this researcher on the referral procedures of the study. Hospice staff introduced the study to patients and/or patients' legal decision maker during their regularly scheduled hospice visits (see Appendix C for the initial recruitment script provided to hospice personnel). Staff then referred patients to me and I contacted patients about setting up a research visit. As an incentive for staff to make referrals, I

provided \$5 gift cards for any staff member that made five or more participant referrals. I also provided food during their training session about the study. Each staff member received a laminated copy of the recruitment script.

Upon referral staff designated whether or not it was the patient or legal decision-maker who would be participating in the study. In the event that a patient was incapacitated and unable to make a decision about participation due to the nature of their illness (as documented within the normal procedures of hospice care), the legally designated decision-maker was able to provide assent for the patient and then participated within the study on their behalf. Due to the nature of late referrals and often short lengths of stay in hospice care, it was important to include this subset of the hospice population within the study. If it was the patient who participated and there was a caregiver involved, I checked with the patient and the caregiver to assess their ability to participate at the time of the research visit. I was willing to reschedule the visit if the patient was not feeling up to participating at the time of the scheduled visit. At any time the patient was able to decline to participate, ask that a family member assist them in answering the questions, or ask that a family member participate in their place. In the case that a family member assisted the patient, I obtained an informed consent from both individuals. As an incentive for participation in the study, participants were placed in a drawing for one of five \$20 donations to be made in their honor to the charity of their choice.

In addition to considering the sampling methods, determining an adequate sample size a priori was important. Without a large enough sample the probability of obtaining a type II error (or failing to reject a false null hypothesis) is much higher (Mayr, Erdfelder, Buchner, & Faul, 2007). Generalizability of results to the population is also at risk without an adequate sample size (Abu-Bader, 2010). There are varying suggestions

in determining an appropriate sample size, several of which are discussed here and related to the current study. One long-standing rule of thumb in determining sample size for multiple regression is to use a minimum of 10 cases for each independent variable (Draper & Smith, 1998; Miller & Kuncze, 1973). Application of this rule in the proposed study called for a minimum sample size of 90 cases as there are a total of 9 independent variables. Another source suggested that the minimum sample size should be a bit higher than this, or $50 + 8m$, where $m = \#$ of factors (Abu-Bader, 2010). This called for a minimum of 122 cases in this study ($N \geq 50 + 8 * 9$). Through the use of G*Power, a software program that can be utilized to perform an a priori power analysis for different statistical tests (Faul, Erdfelder, Lang, & Buchner, 2007), 107 cases was suggested, where $\alpha = 0.05$, power ($1 - \beta$ err prob) is set at 0.95, and a medium effect size is chosen. Though there was a range of a suggested sample size from 90-122 cases using the suggestions outlined, 90 was the target minimum for this study with hopes of reaching the higher range during the projected data collection time period (August – December, 2014). The resulting sample for this study was 90 participants with the data collection ending in early January.

Informed Consent and Confidentiality

Once the study was introduced to a patient or family member and he/she expressed an interest in participating, the hospice staff member referred the patient to me. Once a referral was made either myself or my research assistant contacted the patient (or primary decision maker) to schedule the research visit. Participation in the study involved completion of a five-page questionnaire (developed by this researcher), a short measure on Family Communication about Illness and Death (FCID), and permission to access the patient's hospice chart. Private Health Information as related to the study (age, diagnosis, date of admission, referral sources, etc) was collected from the

regularly obtained information in the patient's chart as a way to minimize burden to the participants. Both the questionnaire and the FCID scale were administered by the researcher to minimize missing data and any further burden to patients who may have experienced difficulty sitting up or writing due to their illness.

At the beginning of the research visit, I (or my research assistant) presented and explained a detailed informed consent form (see Appendix D for approved Informed Consent form). The study was designed for either the patient or a designated decision maker to participate and provide information about the patient. In the case that a patient was unable to consent, the decision maker assented on their behalf (as access to the patient's chart was needed to collect study information) in addition to signing a consent form for themselves to complete the study's questionnaire and survey. If a patient completed the questionnaire with the assistance of a family member, informed consent was obtained from both individuals. Regardless of study participation, hospice services were administered as usual and participants were aware of their rights to stop research at any time during the process without consequence. All confidential materials were safeguarded according to the requirements of UTA's Institutional Review Board (IRB). Risk to participants was minimal, though patients and/or family members could have potentially become emotional due to the nature of the questions as related to illness, hospice, and family communication. Hospice psychosocial staff (social workers and chaplains) continued to be a supportive source for patients and family members both during and after completion of data collection. Patients and families may have benefitted from consideration of family communication during the illness process, in addition to gaining satisfaction in contributing to potential benefits for future patients in need of making decisions about hospice care.

Variables and Measurement

During the pilot study for this dissertation, a research questionnaire was developed to collect data on relevant variables from empirical literature. After initial development of the questionnaire, two additional researchers reviewed the questionnaire and provided feedback, one of whom has extensive clinical practice and knowledge in end-of-life care. Prior to use the questionnaire was approved by UTA's IRB (see Appendix B for approval letter). During the pilot study I administered the questionnaire to 28 individuals (a combination of patients and family members). During this process I made notes about which questions needed further clarification from participants as well as examined whether the participants were responding to the questions in a way that matched the constructs I hoped to measure. This provided invaluable information about the validity of the questionnaire and allowed me to make appropriate changes in preparation for the dissertation study. Specific questions from the questionnaire are provided throughout the text in relation to corresponding variables, but the questionnaire in totality is attached at the end of this proposal (see Appendix E). Prior to use of this revised questionnaire it was reviewed for accuracy by clinical directors at Community Hospice of Texas and approved by UTA's IRB.

In addition to the questionnaire filled out by participants, some demographic variables were collected from the patient's chart. The information from patient's chart form (see Appendix D) designated that all of the data obtained was from regularly collected information in the hospice chart. Some of these questions are also discussed in further detail as related to corresponding variables. All variables can be reviewed in Table 3-1.

Table 3.1 Description of Variables

	Variable	Measurement
Dependent	Time between Referral and Enrollment	# of days (ratio)
	Hospice Length of Stay	# of days, including date of enrollment and date of discharge/death (ratio)
Independent	Family Communication about Illness	FCID Scale, total sum or average score (interval)
	Referral Source	Family/friend or medical professional (dichotomous)
Control	Age	Based on the time of hospice enrollment (ratio)
	Diagnosis	Cancer or Non-cancer (dichotomous)
	Race/Ethnicity	White or Non-white (dichotomous)
	Spirituality	Self-report on a likert scale question (interval)
	Satisfaction with Physician Communication	Self-report on a likert scale question (interval)
	Use of Treatment	Use of treatment after learning about hospice as an option (dichotomous)
	Illness Trajectory	Score on Palliative Performance Scale upon admission (ratio)
	Meaning of hospice	Self-report on a likert scale question (interval)

Demographic Variables

Demographic variables collected for this study included patient's age, gender, race/ethnicity, diagnosis, religious affiliation, level of education, veteran status, and household income. The location of care and number of participating patients versus their designated decision makers (along with their relationship to the patient) were also reported. These demographics were used to describe the overall sample within the study as well as to examine differences between different subpopulations. Several of these demographic variables were also used as controls based upon their relevancy to the criterion variables discussed within the literature.

Dependent Variables

Decision Time

Decision time was defined as the amount of time between initial referral for hospice (when patient or family member becomes aware that hospice is an option for the patient's current care or condition) and enrollment in hospice care (date that care began). Though hospice records the date that an official referral is made (the day someone contacts hospice on behalf of the patient about interest in enrolling in hospice care), this date does not capture how much time has passed since first learning about hospice as an option. Sometimes the official referral is made at the same time as the initial referral, however, other times patients continue to pursue other options even after learning about hospice. Since one of the concerns about care at the end-of-life is that patients are accessing end of life care much too late in their disease progression, it was important to consider what factors may contribute to the amount of time it takes for patients and families to decide to enroll in hospice care.

Though the exact date one learns about hospice as an option is difficult to pinpoint, asking participants to recall and report the information was the most accurate source that was available for this study. An alternative might have been to review medical records, but it was unlikely that hospice had access to the records of the initial referral and this would not have captured the incidences where the initial referral came from personal friends or family members. This variable was measured by the following question located within the research questionnaire (attached as Appendix E): "How long before enrolling in hospice did you FIRST learn about hospice as a potential option for your (the patient's) care/current illness?" The question provided several example responses so that it was apparent it was referring to a measure of time. Once participants reported an amount of time I translated their responses to number of days. Seven days

was calculated for each reported week and 30 days was used for each reported month. Though this was an approximate number, it allowed the data to be scaled as a continuous variable for use with linear regression.

Hospice length of stay

The second criterion variable was hospice length of stay. Discussed above in Chapter 2, this variable has been used as a proxy for both hospice utilization and timing of hospice enrollment. A continuous variable, hospice length of stay was measured using the number of days a patient was on service with hospice care. This was calculated by figuring the duration between two dates (the date of admission/enrollment and the date of death or discharge), including both the start date and the end date. Both the admission date and the date of discharge (or death) are included in the hospice chart and were obtained on the information from patient's chart form (Appendix F). For patients who were still living and enrolled in hospice at the time that data analysis was conducted, the length of stay was calculated using the date of analysis as the date of discharge. This was a small subset of the sample ($n = 12$), due to the quick turnover rate in hospice care.

Predictor Variables

Family communication about illness and death

Though initially I planned on using a general family communication scale to measure family communication in my dissertation, results from the pilot study caused me to reconsider whether or not this fit. In addition to the qualitative interviews in the pilot study, I also tested the use of a general scale measuring family communication, Olson and Barnes' (n.d.) Family Communication Scale (FCS). Though the scale captures my understanding of family communication, it does not capture how well the family communicates during times of stress or how the family communicates specifically about the illness or death. Arden-close and colleagues (2010) discuss this same dilemma in

their validation study for the Couples' Illness Communication Scale (CICS), stating that measuring couple communication generally "may not be appropriate for assessing illness-related couple communication" (p. 544) due to the impact chronic illness has on relationships, along with evidence that differences in desires for communication about illness may result in decreased marital adjustment.

When examining results from the FCS within my pilot study, and examining those next to the qualitative interview transcripts for each family, it did not appear that the scale provided an accurate representation of the communication challenges or practices described within the interviews. This led me to re-consider measuring family communication generally to measuring family communication about illness instead. Results from the pilot study also led me to consider openness of family communication about illness, as open and closed patterns of communication emerged as important themes.

Family communication about illness in this study was measured using the Family Communication about Illness and Death (FCID) Scale (see Appendix G) which was adapted from Bachner & Carmel's (2009) Caregiver's Communication with the Patient about Illness and Death (CCID) scale. According to the developers, the CCID measures the caregiver's perceived level of open communication with the patient about topics surrounding illness and death. Researchers developed the scale from qualitative interviews and partially based on the Openness to Discuss Cancer in the Nuclear Family Scale (Mesters et al., 1997). The CCID scale was validated among bereaved caregivers of cancer patients. An explanatory factor analysis resulted in one factor of all six statements and Cronbach's α equaled 0.80 (Bachner & Carmel, 2009). I contacted the author of this scale in order to obtain written permission for its use and adaptation within this study (see Appendix H for this statement). I followed the six statements that have

been previously validated, but altered the language to include an evaluation related to the family as a whole rather than the relationship specific to one caregiver and patient. See Table 3.2 for these changes.

The adapted scale, FCID, includes two versions within the same page: a patient version and a family version. I altered the questions so they are written from the perspective of the respondent completing it. There are six statements with a 5-point scale of responses that applies to each statement, ranging from 1 (strongly disagree) to 5 (strongly agree). The scale is scored using an average of all responses and then reversed so that higher scores represent greater levels of perceived open communication. Cronbach's alpha was reported as part of the results to measure internal validity of the scale.

Referral source

The referral source was assessed based upon two questions. The research questionnaire asked participants, "How did you learn about hospice as a potential option for your (the patient's) care/current illness?" Respondents chose "Family/friend," "Medical professional," or "other." The second question assessing referral source, "Who FIRST contacted hospice about patient referral," was answered based upon information from the patient's chart. The same three responses (family/friend, medical professional, or other) were provided as choices. This variable was then dummy coded based on nonfamily referral (0) or family referral (1). If family/friend was checked on either of the two questions, the referral source was coded as a family referral.

Table 3.2 Changing CCID to FCID

CCID Questions:	FCID Patient version:	FCID Family version:
1. I hardly talked with the patient about his illness because I did not want to make him sad.	I hardly talk with my family about my illness because I do not want to make them sad.	I hardly talk with my loved one (or other family members) about his/her illness because I do not want to make him/her (them) sad.
2. Conversation with the patient about his illness made me very uneasy.	Conversation with my family about my illness makes me uneasy.	Conversation with my loved one (or other family members) about his/her illness makes me uneasy.
3. I was afraid to talk with the patient about continuing my life without him.	I am afraid to talk with my family about their lives continuing without me.	I am afraid to talk with my loved one (or other family members) about my life (our lives) continuing without him/her.
4. I avoided talking with the patient about his feelings and fears.	I avoid talking with my family about my feelings and fears.	I avoid talking with my loved one (or other family members) about his/her (their) feelings and fears.
5. I didn't know what to do or say to the patient in his suffering.	My family doesn't know what to say or do when I am feeling down.	I don't know what to say or do when my loved one (or other family members) is (are) feeling down.
6. I avoided talking with the patient about his impending death.	I avoid talking with my family about my illness and future death.	I avoid talking with my loved one (or other family members) about his/her illness and future death.

*FCID adapted from Bachner & Carmel's (2009) CCID

**Responses changed from 1 (*not at all*) – 5 (*to a great extent*) to 1 (*strongly disagree*) – 5 (*strongly agree*), matching the original responses from Mesters et al. (1997) Openness to Discuss Cancer in the Nuclear Family Scale

Control Variables

Age

Age is a continuous variable that was collected from the patient's hospice chart at the time of hospice enrollment.

Diagnosis

Diagnosis is another demographic variable that was collected from the patient's hospice chart. Though diagnosis is a nominal variable, this variable was dummy coded in

order to run a regression analysis. Zero was used to designate noncancer diagnoses (dementia, congestive heart failure, stroke, Alzheimer's, debility, liver disease, etc) and one was used to designate cancer diagnoses. This categorization was chosen due to research suggesting that decision making about hospice care differs based upon non-cancer versus cancerous diagnoses (Waldrop & Meeker, 2012).

Race/ethnicity

Patients and/or the responding family member designated the group that most closely described the patients' ethnicity based upon current categories from the US census: where 0 = Hispanic, Latino, or Spanish origin; 1 = White (non-hispanic), 2 = Black or African American; 3 = Native Hawaiian or other Pacific Islander; 4 = Asian; 5 = American Indian or Alaska Native; and 6 = other. Since race is also a nominal, categorical variable it was dummy coded where zero equals nonwhite and one equals white (non-Hispanic). This allowed the variable to be included in linear regression.

Spirituality

Spirituality was measured using a single scaled question on the research questionnaire: "Using a scale from 0 – 10, rate the level of importance that spirituality plays within your daily life."

Satisfaction with physician communication

Satisfaction with physician communication was measured using the following five-response, likert-scale question on the research questionnaire: "Rate your level of satisfaction with how your (the patient's) physician communicated with you about your (the patient's) illness, diagnosis, and prognosis prior to hospice care." Available responses ranged from greatly unsatisfied (0) to greatly satisfied (4).

Use of treatment

Use of treatment is a dichotomous variable, measured through the use of a question on the research questionnaire. Participants were asked, "After recognizing hospice as a potential option for your (the patient's) current illness, did seeking additional treatment delay your decision to start hospice care?" Responses were coded zero for "no" (non-treatment) and one for "yes" (treatment).

Functional status

The patient's functional status was measured using the Palliative Performance Scale (PPS; see Figure 2 reprinted with permission; Wilner & Arnold, 2006), which is a regularly assessed measure within the hospice chart both upon admission and throughout the patient's stay in hospice care. The score is reported on a scale of 0-100, with 0 representing death and 100 representing full and normal functioning across five observer-rated domains: ambulation, activity level evidence of disease, self-care, intake, and level of consciousness (Anderson, Downing, & Hill, 1996). The scale is correlated to the Karnofsky Performance Scale in addition to "actual survival and median survival time for cancer patients" (Wilner & Arnold, 2006, p. 994) representing strong criterion validity. The PPS is a useful tool in predicting length of survival in hospice programs (Head, Ritchie, & Smoot, 2005). The PPS score recorded upon admission for each patient was obtained as a measure for functional status at enrollment within this study.

%	Ambulation	Activity level evidence of disease	Self-care	Intake	Level of consciousness	Estimated median survival in days ^{a-c}		
100	Full	Normal <i>No disease</i>	Full	Normal	Full			
90	Full	Normal <i>Some disease</i>	Full	Normal	Full	N/A		
80	Full	Normal with effort <i>Some disease</i>	Full	Normal or reduced	Full	N/A		
70	Reduced	Can't do normal job or work <i>Some disease</i>	Full	As above	Full	145	108	
60	Reduced	Can't do hobbies or housework <i>Significant disease</i>	Occasional assistance needed	As above	Full or confusion	29	4	
50	Mainly sit/lie	Can't do any work <i>Extensive disease</i>	Considerable assistance needed	As above	Full or confusion	30	11	41
40	Mainly in bed	As above	Mainly assistance	As above	Full or drowsy or confusion	18	8	
30	Bed-bound	As above	Total care	Reduced	As above	8	5	
20	Bed-bound	As above	As above	Minimal	As above	4	2	6
10	Bed-bound	As above	As above	Mouth care only	Drowsy or coma	1	1	
0	Death	—	—	—	—			

a Virik, K, & Glare, P. (2002). Validation of the Palliative Performance Scale for inpatients admitted to a palliative care unit in Sydney, Australia. *Journal of Pain and Symptom Management*, 23(6), 455-457.

b Anderson F., Downing, G.M., & Hill J. (1996). Palliative Performance Scale (PPS): A new tool. *Journal of Palliative Care*, 12(1), 5-11.

c Morita, T., Tsunoda, J., Inoue, S., et al. (1999). Validity of the Palliative Performance Scale from a survival perspective. *Journal of Pain and Symptom Management*, 18(1), 2-3.

Figure 3.1 Palliative Performance Scale (PPS)

Meaning of hospice

The meaning of hospice for patients or their family members was captured in the following question on the research questionnaire; “Which of the following best describes your perception of hospice at the time that you first learned about hospice as an option for your (the patient’s) care/current illness?” Responses ranged from “Very Positive (supportive care and services to manage needs)” to “Very negative (sure or sudden death; overuse of medications, etc)” and were scored on a corresponding scale from 0 (very negative) to 4 (very positive).

Hypotheses

Hypothesis 1

Family communication about illness and death is a predictive factor in hospice length of stay. More open family communication will predict longer lengths of stay.

Hypothesis 2

Family communication about illness will predict the length of time between referral and admission to hospice. Families with more open family communication about illness are more likely to make quicker decisions about enrollment to hospice care.

Hypothesis 3

Referral source is a predictive factor in hospice length of stay. Family referral sources will predict longer lengths of stay on hospice in comparison to medical professional referrals.

Hypothesis 4

Referral source is a predictive factor of the length of time between referral and enrollment. Family referral sources will predict shorter time between referral and admission in hospice care.

Hypothesis 5

Family as a referral source will be a greater predictor of hospice length of stay than family communication.

Hypothesis 6

Family as a referral source will be a greater predictor of the length of time between referral and enrollment than family communication.

Data Analysis Strategy

Data analysis was conducted using the Statistical Package for Social Sciences Software (SPSS), version 21.0 (IBM, 2012). Prior to running any data analysis, I examined the data for any errors or missing values. To examine for errors, I ran a frequency distribution for each variable to look for any responses that fell outside the possible range of responses. Once those were identified I referred back to the original data source to correct any mistakes made during entry. The frequency distribution also

identified the percentage of missing data. Missing data can be problematic within palliative care research due to sensitive patient conditions and can cause great difficulty in procuring accurate results in data analysis (Reyna, Bennett, & Bruera, 2007). Due to administering the scales myself, there was no missing data except for one participant who stopped prior to completing the FCID scale due to becoming emotional. Since missing data was way less than 5% and randomly missing, I excluded that one case from the analysis, which is suggested as a general rule (Abu-Bader, 2010). If missing data had exceeded 5%, was missing disproportionately from within a subset of my sample, or if my sample size had not met the minimum determined above, I would have replaced missing data with a predicted value using a regression analysis (Abu-Bader, 2010). In addition to the frequency distributions for each variable already run, I ran descriptive statistics of the demographic variables. This helped provide a descriptive understanding of the sample.

Next I ran descriptive statistics for criterion variables (and of the residuals) to test for normality, as this is one of the assumptions for multiple regression (Abu-Bader, 2010). In order to determine whether the distribution is normal, I examined a histogram and considered Fisher's skewness and kurtosis coefficients. A distribution is considered to be severely skewed "if its skewness value (S) is more than twice its standard error (SES, standard error of skewness)" or "if its kurtosis value (K) is more than twice its standard error (SEK, standard error of kurtosis; Abu-Bader, 2010)." If skewness was slight, or within the recommended range (± 1.96), I proceeded with no further changes. If skewness was severe I transformed the data using the guidelines outlined by Abu-Bader (2010, p. 61): square root, logarithm, or inversion.

Additional assumptions that require testing in multiple regression are homoscedasticity and multicollinearity (Abu-Bader, 2010). Homoscedasticity refers to a

normal distribution of predictor variables at any level of the criterion variable. This can be detected by examining a scatterplot of the two variables. If results form a fan pattern, heteroskedasticity is present and can be corrected with a log transformation.

Multicollinearity “occurs when independent variables are highly correlated,” or greater than .80 (Abu-Bader, 2010, p. 102). In this study I tested for multicollinearity by running Pearson correlation coefficients between independent variables. If present, a large sample size can reduce multicollinearity or one of the correlated variables can be dropped from the regression. Linear regression is also known to be robust even when a violation is not met.

Prior to running the regression, I also used Cronbach’s alpha to determine the internal consistency for the FCID. A score of .70 or higher indicates that items are most likely measuring the same construct (Vogt & Johnson, 2011). In order to test the hypotheses I used the following methods. First, I tested for a bivariate relationship between each predictor and criterion. Though I have picked my control variables based upon empirical research and my pilot study, if a relationship does not occur then “it is unlikely that one would predict the other” (Abu-Bader, 2010, p. 103). In those cases I excluded that variable from initial regression equations. The level of significance was set at 0.05 ($p = .05$) and I used multiple linear regression to test the hypotheses.

Chapter 4

Data Analysis and Results

This chapter presents the results of the quantitative data analysis methods described in Chapter 3. The research question guiding this study was how do family relationships and communication impact the timing of the decision for hospice care? The overall purpose was to consider the role of family in the context of other barriers to hospice utilization, or the timing in the decision for hospice. Data analysis was conducted using the Statistical Package for Social Sciences (SPSS), version 22.0 (IBM, 2013). First, a description of the sample is provided followed with a description of each of the study variables and how the data was prepared for bivariate and multivariate analysis. This section also includes a description of testing for internal consistency of the Family Communication about Illness and Death (FCID) Scale. Next, bivariate analyses were conducted to examine some of the relationships between main variables and any differences within the sample population. Finally, hypothesis testing was conducted along with a summary of the findings.

Description of the Sample

Demographic Characteristics

The sample for this study consisted of 90 hospice patients. 32 of the 90 patients were able to participate independently (35.6%), while the remaining 58 were too ill to answer questions, requiring a decision maker (either the power of attorney or legal next of kin) to participate and consent on their behalf. Inclusion of these patients was important due to the nature of late referrals to hospice care and the number of hospice patients that are admitted so near the time of their death. Participating decision makers ($n = 58$; 64.4%) consisted of adult child ($n = 27$; 30%), spouse ($n = 25$; 27.8%), parent ($n = 3$; 3.3%), and other relationship (grandchild, POA not related, and sibling; $n = 3$; 3.3%).

Though the decision maker participated instead of the patient in these cases, the information collected was the same, with the patient as the focus of the response (ie patient age, diagnosis, race, household income, use of treatment, etc). Other important variables were collected from the patients' hospice chart, such as date of enrollment, referral source, and functional status. The only variables where there was a potential difference in how a family member might respond compared to a patient were those requiring scaled responses based upon the perception of the respondent: family communication about illness, satisfaction with physician communication, or the meaning of hospice. However, there were no statistically significant differences between FCID scores completed by patients (mean = 4.01) versus those completed by a family member (mean = 4.06). There were also no significant differences among satisfaction with physician communication (patient mean = 3.0; family member mean = 3.02) or the meaning of hospice (patient mean = 2.61; family member mean = 3.07).

Ages across all 90 patients ranged from 37 to 96 (mean age = 71, SD = 15.55) and 14 total diagnoses were represented in the sample, though 63% were some form of cancer (see Table 4.1 for a full description of demographic characteristics). The sample was primarily Caucasian ($n = 74$, 82%), which is reflective of the national hospice population. Eight patients were African American (8.9%) and 4 were Hispanic (4.4%). 63% of the sample was female ($n = 57$). Much of the sample was living on Social Security income (due to age or advanced illness). 40% ($n = 36$) had an annual income of less than \$25,000 and 66.4% ($n = 59$) made less than \$50,000 per year. Only 9.1% had incomes above \$100,000 ($n = 8$). Over half of the sample had at least some college experience (55.6%) and around 1 out of every 5 patients (21.1%, $n = 19$) was a veteran. Just over half of the sample ($n = 47$) had prior exposure to hospice care (through a family member or close friend on hospice where the respondent was involved with patient's care).

Table 4.1 Demographic characteristics of the sample

Descriptor		n	%
Respondent	Patient	32	35.5%
	Adult Child	27	30%
	Spouse	25	27.8%
	Parent	3	3.3%
	Other	3	3.3%
Age (37-96)	< 50	10	11.1%
	50 – 64	21	23.34%
	65 – 84	38	42.4%
	85+	21	23.34%
Gender	Male	33	36.7%
	Female	57	63.3%
Diagnosis	ALS	1	1.1%
	Alzheimer's/Dementia	5	5.6%
	Anoxic Brain Damage	1	1.1%
	Cancer	57	63.3%
	CVA	8	8.9%
	Heart (Disease/Attack/CHF)	8	8.9%
	COPD	2	2.2%
	End-Stage Renal Disease	1	1.1%
	Parkinson's	1	1.1%
	Pneumonia	1	1.1%
	Liver Disease	1	1.1%
	Pulmonary Fibrosis	1	1.1%
	Respiratory Failure	1	1.1%
	Swelling Mass	1	1.1%
Race	White	74	82.2%
	Black	8	8.9%
	Hispanic	4	4.4%
	American Indian	2	2.2%
	Other	2	2.2%
Level of Education	Some high school	12	13.3%
	High School graduate	28	31.1%
	Some College	25	27.8%
	College Graduate	15	16.7%
	Graduate Degree	10	11.1%
Income	Less than \$25,000	36	40%
	\$25 - \$50,000	23	26.4%
	\$50 - \$75,000	10	11.5%
	\$75 - \$100,000	10	11.5%
	\$100 - \$125,000	2	2.3%
	\$125 - \$150,000	3	3.4%
	\$150,000+	3	3.4%
Veteran	Yes	19	21.1%
	No	71	78.9%
Prior Hospice Exposure	Yes	47	52.2%
	No	43	47.8%

Frequencies of Dependent Variables

Decision time

Decision time was calculated as a continuous variable by the number of days between initial referral to hospice (or the first time patient and/or family learned about hospice as a potential option for care) and hospice enrollment. 60% ($n = 54$) of the sample made the decision to enroll in hospice within one week of an initial referral. Decision time ranged from same day admission (0 days; $n = 10$; 11.1%) to 2 years (720 days; $n = 2$; 2.2%), though 90% ($n = 81$) of the sample made the decision within 4 months and the overall mean was 53 days.

Length of stay

The average length of stay for participants in this study was 84.63 days (SD 120.7) with a range from 2 days ($n = 3$, 3.3%) to 730 days ($n = 1$, 1.1%). Though nationally, 1 in every 3 patients dies within a week in hospice care, in this sample it was closer to 1 in 4 (24.4% within 8 days). Just over half of the sample (51.1%) died within 34 days compared to the national average of around 18 days. However, like the national sample, this sample was heavily skewed towards shorter lengths of stay (see original histogram in table 4.7 below).

Table 4.2 Description of Outcome Variables

Variable	Min-Max	Mean	S.D.	Kurtosis/SE	Skewness/SE
LOS	2-730	84.63	120.7	9.42/.503	2.678/.254
Decision Time	0-730	53	127.533	17.345/.503	3.954/.254

Frequencies of Predictor Variables

Family communication about illness and death (FCID)

Openness of family communication about illness and death was measured using the FCID scale described in Chapter 3. The total scale score is an average of all

responses to the six statements that make up the scale. Responses range from 1 (*strongly disagree*) to 5 (*strongly agree*) and are then reversed so that higher scores represent greater levels of perceived open communication about health and illness within the family. Chronbach's $\alpha = .79$, suggesting high internal consistency across all 6 items of the scale. The mean for all participants was 4.05, and 55.1% of participants ($n = 49$) had a score greater than 4 (on a scale of 1-5), suggesting that perceived levels of communication within this sample are relatively high. 15.7% ($n = 14$) had an average score of 3 or lower suggesting lower levels of open communication about illness and death. There were only 89 completed scores, as one participant became emotional during completion and did not finish.

Table 4.3 Description of FCID

Variable	Min-Max	Mean	S.D.	Kurtosis/SE	Skewness/SE
FCID	1.33 - 5	4.045	.86	.587/.506	-1.016/.255

Referral source

73.3% ($n = 66$) of the sample was referred by a medical professional alone, while the remaining 26.7% ($n = 24$) were additionally (or solely) referred by a family member or a friend.

Table 4.4 Referral Source

Variable		N	%
Referral	Family/friend	24	26.7%
	Medical Professional	66	73.3%

Frequencies of Control Variables

Age

Age was normally distributed with a range from 37 – 96 and a mean age of 70.61 (S.D. 15.55). See demographic characteristics above for further information about

participants' ages, along with information for diagnoses and races/ethnicities, other demographic variables that also served as control variables. Table 4.5 provides a full description of continuous control variables.

Table 4.5 Description of Continuous Control Variables

Variable	Min-Max	Mean	S.D.	Kurtosis/SE	Skewness/SE
Age	37-96	70.61	15.55	-.724/.503	-.292/.254
Spirituality	0-10	8.08	2.57	-1.443/.254	1.326/.503
Satisfaction with Physician Communication	0-4	3.01	1.2	.287/.503	-1.128/.254
PPS	10-70	38.89	15.32	-.431/.503	-.097/.254
Meaning of hospice	0-4	2.91	1.338	-.157/.503	-1.015/.254

Spirituality

Spirituality was measured through the use of one question asking participants to rate the level of importance that spirituality played within their daily lives on a scale from 0 to 10. 82% of the sample ($n = 74$) rated spirituality above the number 5 and the mean was 8.08 (S.D. = 2.57).

Satisfaction with physician communication

Participants' responses on a question about satisfaction with physician communication related to the patient's diagnosis and prognosis ranged from 0 (greatly unsatisfied) to 4 (greatly satisfied), with a mean of 3.01 (S.D. = 1.2). Nearly 3 out of 4 (74.4%, $n = 67$) were either satisfied or greatly satisfied and only 14.4% ($n = 13$) were either unsatisfied or greatly unsatisfied. 11.1% were neither satisfied nor unsatisfied ($n = 10$).

Use of treatment

21.1% of participants ($n = 19$) delayed the decision to enroll in hospice care in order to pursue further treatment for their diagnosis. Treatment was not a factor for the

remaining 78.9% of participants in this study ($n = 71$). Table 4.6 shows a description of categorical control variables.

Table 4.6 Description of Categorical Control Variables

Variable		N	%
Use of Treatment	Yes	17	21.1%
	No	71	78.9%
Diagnosis	Cancer	57	63.3%
	Non-Cancer	33	36.7%
Race	White	74	82.2%
	Non-White	16	17.8%

Functional status

Functional status was measured using the Palliative Performance Scale (PPS) described in Chapter 3. Scores ranged from 10 – 70 (on a potential scale of 0 to 100), with a mean score of 38.89 (S.D. = 15.32). Upon admission to hospice 86.7% ($n = 78$) of participants scored 50 or below on the PPS. A score at 50 represents a patient with an extensive disease process who mainly sits or lies down and needs considerable assistance. 40% ($n = 36$) of participants scored a 30 or below, which represents patients who are completely bedbound and in need of total care. Only 13.3% ($n = 12$) scored a 60 or 70 which suggests that the patient has reduced ambulation and is unable to participate in normal work or household activity, though they may still be fully able to meet self-care needs or need only occasional assistance.

Meaning of hospice

This variable captures patients' (or their decision makers') perceptions about hospice care at the time of the initial referral to hospice on a scale from 0 (very negative) to 4 (very positive). Nearly half of participants (48.9%, $n = 44$) already felt very positively about hospice care upon initial referral, and an additional 18.9% ($n = 17$) had a somewhat positive perception. 15.6% perceived hospice in either a very negative way

(10%, $n = 9$) or a somewhat negative way (5.6%, $n = 5$). The overall perception of hospice at the time of referral among this population was more positive than negative with a mean of 2.91 (S.D. 1.34).

Summary of Sample Demographics

The sample of this study ($N = 90$) consisted of primarily Caucasian patients ($n = 74$, 82.2%) with high levels of both self-reported spirituality (mean = 8.08 on a scale from 0 to 10) and family communication (mean = 4.05 on a scale from 1 to 5). Though 14 different diagnoses were represented, 63% of the sample had cancer. Patient ages ranged from 37 to 96 with an average age of 71. Patients were admitted to hospice during stages of advanced illness as 86.7% scored a 50 or below on the PPS, meaning that they needed considerable assistance and mainly sat or stayed in bed. 40% were completely bedbound and in need of total care at the time of admission. 60% of the sample enrolled in hospice within a week, likely due to an advanced stage of illness, and just over half (51.5%) died within just over a month of admission (34 days).

Data Preparation

After screening my data for any data entry errors and looking at frequencies, I looked at each of my variables independently to check for normality of the distribution. In order to test for normality, I examined a histogram and considered Fisher's skewness and kurtosis coefficients for each continuous variable (see Figure 4.1). A variable was considered skewed if it fell outside of the suggested ± 1.96 (S/SES or K/SEK) for normality. I also evaluated whether there were any outliers within each of the continuous variables by computing Z-scores. Any z-score that was outside of 3 standard deviations of the mean was identified as an outlier (as suggested by Abu-Bader, 2012). Age and palliative performance scale (PPS; indicator for functional status) were both normally distributed with no outliers. Decision time, length of stay, family communication about

illness and death, and spirituality were positively skewed and each contained outliers. I ran Fisher's skewness and kurtosis variable both before and after dropping the outlier for each variable to see if normality was impacted. Since dropping the outlier(s) did not correct normality for any of the variables I used a log transformation. Similarly I used a log transformation for satisfaction with physician communication and meaning of hospice, neither of which had any outliers. Both were negatively skewed so I reversed these variables prior to a log transformation. Table 4.7 shows histograms and Fishers' coefficients for each of the variables both before and after log transformations. I did not discard any of the cases based on outliers, as none of the outliers impacted the outcome of normality after log transformation.

In addition to looking at univariate outliers, I also tested for multivariate outliers using Mahalanobis distance. Testing across all continuous variables, initially four of the 90 cases had multivariate outlier values. However, when I retested for multivariate outliers after log transformation of individual variables, no multivariate outliers were identified.

Table 4.7 Histograms

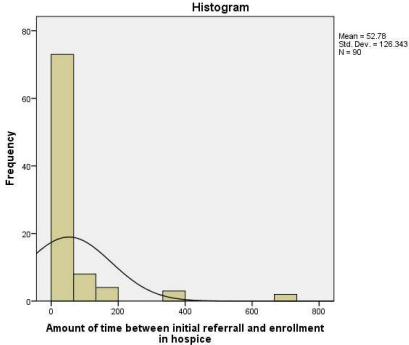
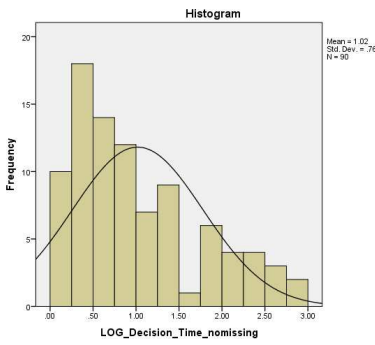
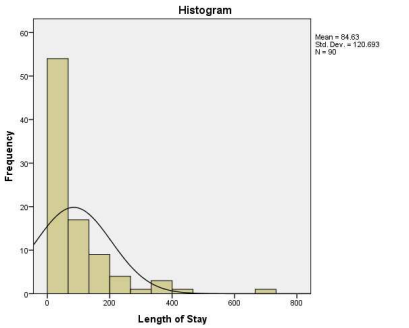
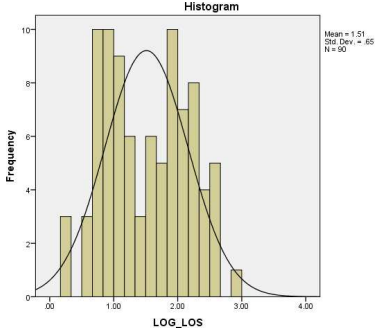
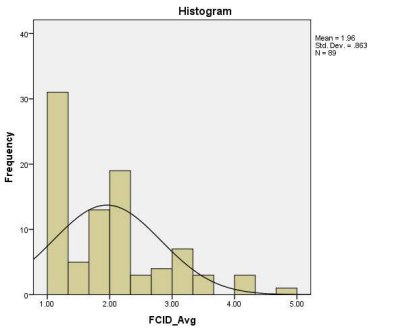
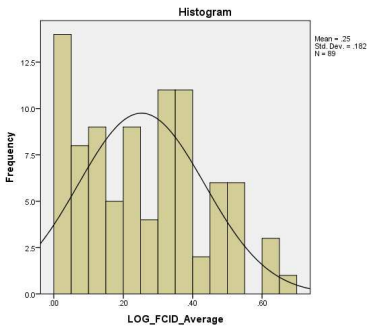
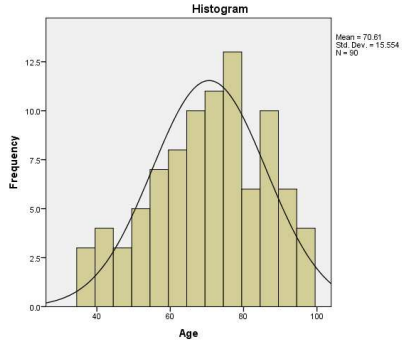
	Original Histogram with Fischer coefficients	Histogram after log transformation with Fischer coefficients
Decision Time	 <p>Mean = 52.78 Std. Dev. = 126.343 N = 90</p>	 <p>Mean = 1.02 Std. Dev. = .76 N = 90</p>
	15.43 (S/SES) and 33.82 (K/SEK)	2.59 (S/SES) and 0.95 (K/SEK)
Length-of-Stay	 <p>Mean = 94.63 Std. Dev. = 120.693 N = 90</p>	 <p>Mean = 1.51 Std. Dev. = .65 N = 90</p>
	10.54 (S/SEK) and 18.73 (K/SEK)	0.16 (S/SES) and -2.24 (K/SEK)
FCID	 <p>Mean = 1.96 Std. Dev. = .663 N = 89</p>	 <p>Mean = .25 Std. Dev. = .182 N = 89</p>
	3.98 (S/SES) and 1.16 (K/SEK)	1.04 (S/SES) and -1.7 (K/SEK)

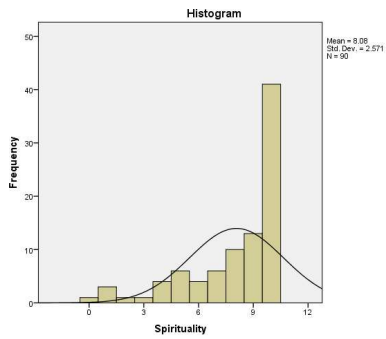
Table 4.7 – continued

Age

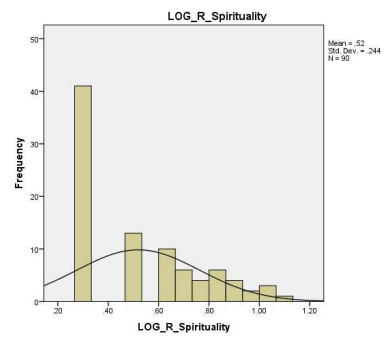


-1.16 (S/SES) and -1.44 (K/SEK)

Spirituality

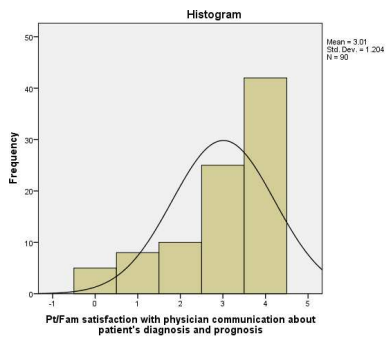


2.64 (S/SES) and -1.44 (K/SEK)

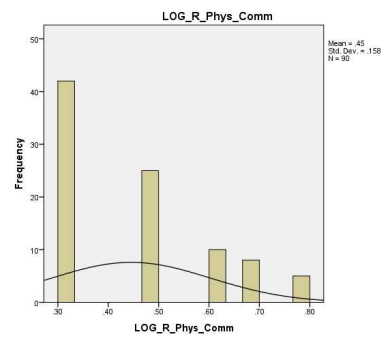


-1.537 (S/SES) and 2.87 (K/SEK)

Satisfaction with Phys. Comm.



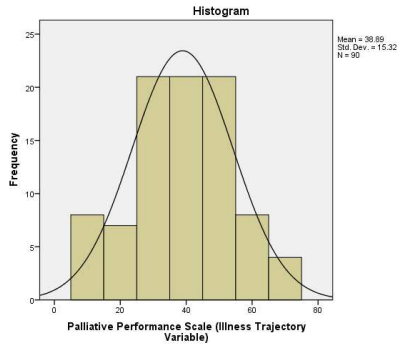
-4.44 (S/SES) and .57 (K/SEK)



2.87 (S/SES) and -1.537 (K/SEK)

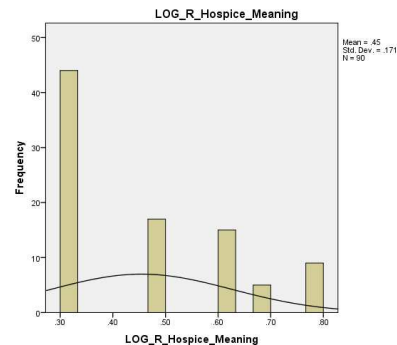
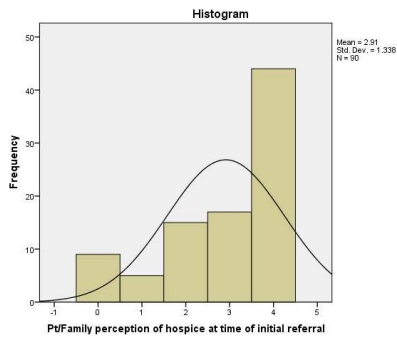
Table 4.7 – continued

Functional status



-0.38 (S/SES) and -0.86 (K/SEK)

Meaning of hospice



-3.996 (S/SES) and -.31 (K/SEK) 2.42 (S/SES) and -2.057 (K/SEK)

Bivariate analysis

Correlations with Outcome Variables

Prior to running regression to test my hypotheses, I used Pearson’s r correlation test to see which variables are correlated with the dependent variables. Table 4.8 shows these results. Length of stay was correlated (at .01 level) with two of the control variables, functional status (PPS; .318) and spirituality (-.272). Neither family communication about illness or referral source, my independent variables of interest, had a significant correlation with length-of-stay on hospice. However, referral source was correlated (at .01 level) with decision time (.247), along with the following control variables: age (-.301),

diagnosis (cancer/noncancer, .265), functional status (PPS, .318), and the use of treatment (.633). Spirituality was also correlated with decision time (.199) at the .05 level. A one-tailed test of significance was used as this is an exploratory study considering some of these relationships for the first time.

Table 4.8 Correlations with Outcome Variables

	Decision Time	Length-of-Stay
Family Communication about Illness (FCID)	.052	.029
Referral	.247**	.091
Age	-.301**	.004
Diagnosis	.265**	.006
Race	.170	-.033
Spirituality	.199*	-.274**
Satisfaction with Physician Communication	-.010	.006
Use of treatment	.633**	.010
Functional Status (PPS)	.318**	.571**
Meaning of Hospice	.113	.045

*Correlation is significant at the 0.05 level (1-tailed)

**Correlation is significant at the 0.01 level (1-tailed)

Differences in Decision Time

After looking at correlations, I also wanted to consider any differences in decision time across demographic variables. There were no statistically significant differences in decision time for hospice across gender, age, level of education, spirituality, or veteran status. Using an independent-samples t-test I compared decision time across patients with cancer diagnoses and non-cancer diagnoses. There was a significant difference in decision time for those with cancer (mean = .756, SD = .77) and those with non-cancer diagnoses (mean = 1.17, SD = .72); $t(88) = -2.58, p < .01$. This suggests that there may be differences in the decision making process based on diagnosis. More specifically, these results suggest that persons with cancer diagnoses take longer before deciding to enroll in hospice (56.75 days) than those with non-cancer diagnoses (45.91 days). Table 4.9 provides results for each of the t-tests run.

Other differences were found in decision time across race. Levene's test for equality of variances was violated, $F = 7.98$, $p = .006$. After conducting an independent-samples t -test (using the t statistic not assuming homogeneity of variance) there was a significant difference in decision time for white patients (mean = 1.08, SD = .787) compared to minority patients (mean = .66, SD = .79); $t(26.9) = -2.75$, $p < .01$. These results suggest that white patients take significantly longer to make the decision to enroll in hospice from initial referral to hospice admission (60.36 days) than minority patients (7.85 days).

Though income was an ordinal variable with multiple categories, more than half of the sample ($n = 59$) fell into the two lowest income categories (< \$25,000 and \$25,000 - \$50,000). I chose to collapse these two categories (< \$50,000) in addition to collapsing the higher income categories (> \$50,000) due to the low number of participants who fell into each of the original higher categories. Levene's test for equality of variances was violated, $F = 5.62$, $p = .02$, so I ran an independent samples t -test using the t statistic not assuming homogeneity of variance. There was a statistically significant difference in decision time for patients with an annual income lower than \$50,000 (mean = .85, SD = .66) compared to those with higher annual income (mean = 1.37, SD = .86), $t(-2.83)$, $p < .01$. These results suggest that those with higher incomes take significantly longer to enroll in hospice after learning about it as an option than those with lower incomes (114 days on average compared to 25 days).

A final demographic variable where differences were found were in patients' prior exposure to hospice care. This was a simple yes or no question where respondents stated whether or not another family member or someone close to them had experienced hospice in the past where they had some involvement with the care. I used an independent samples t -test and compared those who had prior hospice exposure to

those who did not. Those with prior exposure to hospice had a mean decision time of 27.23 days (log mean = .82, SD = .69) and those without prior exposure had a mean decision time of 76.15 days (log mean = 1.2, SD = .79). This was a statistically significant difference, $t(88) = 2.41, p < .05$.

Table 4.9 Decision Time t-test Results

	<i>n</i>	<i>T</i>	<i>df</i>	<i>p</i>	Mean (in days)	Mean (log)	SD (log)
Diagnosis		-2.58	88	.01			
Cancer	57				56.75	1.17	.095
Non-Cancer	33				45.91	.76	.134
Race		-2.75	26.9	.01			
White	77				60.36	1.08	.79
Non-white	13				7.85	.66	.44
Income		-2.829	42.76	.007			
< \$50,000	59				24.86	.85	.66
> \$50,000	28				113.68	1.37	.86
Prior Hospice Exposure		2.41	88	.018			
Yes	47				76.15	.79	.115
No	43				27.23	.82	.689

Differences in Length of Stay

Similar to my exploration of differences in decision time across demographic variables, I also looked at differences in length of stay. However, no differences existed across any of the demographic variables except spirituality. Though overall this sample reported strong spiritual beliefs (mean = 8.08) an independent t-test showed a significant difference in length of stay based upon high spirituality (7 or above) from those who rated importance of spirituality at a 6 or below, $t(88) = 2.76, p < .01$. Though spirituality was a scaled variable (0 – 10), there was not enough patients within each category to run an ANOVA so I grouped responses 0 – 6 for low levels of spirituality and grouped responses 7 – 10 for high levels of spirituality. Those who rated spirituality at higher levels of importance were on hospice nearly twice as long (94.96 days versus 48.5 days).

Table 4.10 Length of Stay t-test Results

	<i>N</i>	<i>T</i>	<i>Df</i>	<i>p</i>	Mean (in days)	Mean (log)	SD (log)
Spirituality		2.759	88	.007			
7 – 10	70				94.96	1.61	.63
0 – 6	20				48.5	1.17	.62

Relationships between Independent Variables

I also used Pearson's *r* to test for multicollinearity between independent variables. Multicollinearity is not a problem, as no independent variables are highly correlated at .80 or greater. Table 4.11 shows significant correlations between independent variables.

Table 4.11 Correlations with Independent Variables

	FCID	Refer	Age	Dx	Race	Phys. Comm.	Use of Tx	PPS	Hospice Meaning	Spirit
FCID	1	-.139	.045	.037	.12	.094	.099	.072	.16	.033
Referral		1	.075	.042	.015	.11	.18*	.093	-.17	.15
Age			1	-.41**	.19*	-.13	-.24*	-.2*	-.37**	.02
Diagnosis				1	-.03	.15	.17	.41*	.31**	-.06
Race					1	-.06	.2*	-.01	-.15	.28**
Physician Comm						1	-.07	.18*	.17	.05
Use of Treatment							1	.15	.23*	.26**
PPS								1	.17	-.24**
Hospice Meaning									1	-.12
Spirituality										1

*Correlation is significant at the 0.05 level (1-tailed)

**Correlation is significant at the 0.01 level (1-tailed)

Hypothesis Testing, Multivariate analysis

In order to test my hypotheses I ran four univariate regressions to see if the main independent variables of interest predicted either of the dependent variables. Each of these is described below under the corresponding hypothesis. If the independent variable of interest was not predictive, then the hypothesis was not supported and no further steps were taken. If the variable was predictive I used multiple regression and added only the control variables were correlated with the dependent variable (at 0.01 or 0.05 levels). In a final step I added any remaining control variables. Since I had already transformed the variables using a log transformation, violations of homoscedasticity was not a concern.

Hypothesis 1

My first hypothesis was that family communication about illness and death would be a predictive factor in hospice length of stay. Or more specifically that open family communication would predict longer lengths of stay. To test this hypothesis, I ran a linear regression with FCID and LOS variables. First I looked at R^2 to see if family communication explained any of the variance in LOS ($R^2 = .001$). Less than 1% of LOS was explained by family communication. Not surprisingly then, family communication about illness and death was not a statistically significant predictor of length of stay, $\beta = .029$, $t(87) = .271$, $p = .787$. This hypothesis was not supported. The output for this regression model is listed below in table 4.12.

Table 4.12 Linear Regression Results for LOS and FCID

Variable	B	S.E.	B	df	t	p	R²
FCID Average	.103	.381	.029	87	.271	.787	.001

Hypothesis 2

Hypothesis 2 stated that family communication about illness would predict decision time for hospice, or that families with more open family communication about

illness would likely make quicker decisions about enrollment to hospice care. Similarly to hypothesis 1, there was no statistically significant effect of family communication on decision time for hospice ($R^2 = .003$; $\beta = .029$, n.s.). This hypothesis was also not supported.

Table 4.13 Linear Regression Results for Decision Time and FCID

	B	S.E.	B	df	T	p	R²
FCID Average	.217	.445	.052	87	.489	.626	.003

Hypothesis 3

The third hypothesis was that referral source would be a predictive factor in hospice length of stay. I hypothesized that family referral sources would predict longer lengths of stay on hospice in comparison to medical professional referrals. Similar to the process used for the family communication hypotheses, I ran a linear regression with referral source and length of stay. Referral source was not a statistically significant predictor of length of stay ($R^2 = .008$; $\beta = .091$, n.s.); therefore this hypothesis was not supported. See table 4.14 for the results of this regression.

Table 4.14 Linear Regression Results for LOS and Referral Source

	B	S.E.	B	df	T	p	R²
Referral	.133	.155	.091	88	.858	.393	.008

Hypothesis 4

The fourth hypothesis was that referral source would be a predictive factor of decision time for hospice (or the length of time between referral and enrollment). More specifically, I hypothesized that family referral sources would predict shorter times between referral and admission in hospice care. In the first step, referral source was entered independently. 6% ($R^2 = .061$) of the variance in decision time was explained by the referral source. The presence of family involvement in a referral predicted greater

number of days between initial referral and hospice admission. This association was statistically significant (see Table 4.15, regression model 1; $\beta = .247$, $p < .05$). Though the hypothesis that referral source would be predictive in decision time for hospice is supported, the outcome is in the opposite direction than originally hypothesized. This is explored further in the discussion.

Since referral source was predictive, in the second step I added the control variables that were correlated with the decision time for hospice (age, diagnosis, functional status/PPS, and treatment; regression model 2). Nearly half of the variance in decision time ($R^2 = .486$) was explained by regression model 2 (referral, age, diagnosis, functional status, and use of treatment). The change from model 1 to model 2 was statistically significant ($p < .01$). Use of treatment was the most predictive variable ($\beta = .544$, $p < .01$) where the presence of treatment increased the number of days between referral and enrollment to hospice ($B = 1.007$). Functional status (PPS) was also predictive ($\beta = .544$, $p < .01$). Higher PPS scores predicted longer decision times between initial referral and hospice admission. When looking at these factors together, referral source was no longer predictive ($\beta = .139$, $p = .087$).

In a final step I added the remaining control variables (patient/family perception of the meaning of hospice, satisfaction with physician communication, spirituality, and race; model 3). There was not a significant change between model 2 and model 3 ($p = .507$). None of the additional control variables were significant predictors in the amount of time between initial referral and hospice admission.

Table 4.15 Regression Results for Decision Time and Referral Source

	B	S.E.	B	df	t	p	R²
Regression 1				88		.019	.061
Referral	.422	.177	.247		2.388	.019	.061
Regression 2				84		.000	.486
Referral	.238	.138	.139		1.732	.087	
Age	-.006	.004	-.130		-1.477	.143	
Diagnosis	.06	.145	.039		.417	.678	
Functional status	.009	.004	.184		2.127	.036	
Use of Treatment	1.007	.153	.544		6.590	.000	
Regression 3				80		.507	.507
Referral	.215	.144	.126		1.487	.141	
Age	-.008	.005	-.173		-1.854	.067	
Diagnosis	.078	.148	.050		.525	.601	
Functional status	.011	.005	.219		2.378	.020	
Use of Treatment	.941	.172	.508		5.481	.000	
Hospice Meaning Physician Communication	-.321	.409	-.072		-.787	.434	
Spirituality	-.232	.403	-.048		-.574	.567	
Race	.258	.281	.083		.918	.362	
	.142	.192	.064		.740	.461	

Hypothesis 5

The fifth hypothesis stated that family as a referral source would be a greater predictor of hospice length of stay than family communication. Since neither family communication nor referral source was predictive of length of stay, this hypothesis was also not supported.

Hypothesis 6

The final hypothesis was that family as a referral source would be a greater predictor of the length of time between referral and enrollment than family communication. This hypothesis was supported as referral source was predictive of decision time ($\beta = .247, p < .05$) and family communication was not ($\beta = .029, n.s.$).

Summary

Descriptive, bivariate, and multivariate analyses in this chapter examined the role of family in hospice utilization through the use of referral source and family communication about death and illness. Hospice length of stay and decision time (the amount of time between initial hospice referral and admission) were proxy variables for hospice utilization. Table 4.16 summarizes the hypotheses and whether each was supported. Family communication was not associated or predictive of either length of stay or decision time. Family referral sources, though, did predict decision time (but not LOS). However, once correlated control variables were added to the regression referral source was no longer predictive of decision time ($\beta = .139, p = .087$). The most predictive variables for decision time included functional status at the time of admission (measured using Palliative Performance Scale) and the use of further treatment. Other findings of interest included statistically significant differences in decision time by diagnosis, race, income, and prior hospice experience. There were also differences in length of stay based on patients' self-reported levels of spirituality.

Table 4.16 Summary of Hypotheses

Hypothesis	Supported	Not Supported
Family communication about illness and death (FCID) would predict hospice length-of-stay		X
Family communication about illness and death would predict decision time		X
Referral source would predict hospice length-of-stay		X
Referral source would predict decision time	X	
Referral source would be a greater predictor in hospice length-of-stay than FCID.		X
Referral source would be a greater predictor in decision time for hospice than FCID.	X	

Chapter 5

Discussion and Implications

Though studies have linked family as an important factor in decision making across the lifespan, few studies have considered the role of family in the decision for hospice care. This study looked at the role of family communication and family referrals on hospice length of stay and decision time between initial hospice referral and hospice enrollment. Though hypotheses were mostly unsupported, these findings still further our understanding of a family's involvement in the decision for hospice and provide a number of considerations in social work practice, policy, and in future research.

Discussion of Demographical Findings

Table 5.1 provides a comparison of participants in this sample with the most recent national hospice demographics from 2013 (NHPCO, 2014). This sample represented 14 diagnoses, but had a much larger cancer population (63%) compared to national demographics (36.9%). This sample was also somewhat younger than national demographics, as the sample in this study had more than double the number of patients under the age of 65 than compared to national demographics (34.4% versus 16.1%). For patients over 85, this sample had only 23.3% compared to 41.2% within national demographics. This sample is also skewed towards more female participants than what is seen at the national level within hospice (63.3% female versus 54.7% female). Patients' lack of ethnic diversity in this sample however, is much similar to national demographics, as both are about 82% Caucasian (80.9% national demographics and 82.2% in this study) and around 18% minority (19.1% national demographics and 17.7% in this study). These differences in sample population are likely due to having a non-randomized sample based on convenience and availability. One of the challenges I faced during data collection was dependence upon staff to make referrals. Though several staff

members were invested in this and provided referrals many others were not. I was most successful in getting referrals through the inpatient units where I showed up each week to ask if they had patients interested in participating. A second way I was successful in obtaining referrals was when I scheduled ride-a-longs with various staff members. I did not receive any referrals from assisted living or nursing facilities as it required a hospice marketer to first make contact with the facility administrator for permission (due to IRB restrictions). This is likely why this sample contained fewer patients above the age of 85.

Table 5.1 Sample Comparison with National Demographics

	Sample	National hospice demographics, 2013
Diagnosis		
Cancer	63.3%	36.5%
Non-cancer	36.7%	63.5%
Gender		
Male	36.7%	45.3%
Female	63.3%	54.7%
Age		
≤ 64	34.4%	16.1%
65 – 84	42.2%	42.7%
85+	23.3%	41.2%
Race		
White	82.2%	80.9%
Minority	17.8%	19.1%

This lack of diversity in my sampling attempts may have contributed to some of the null results related to length of stay. Surprisingly, hospice length of stay only correlated with two of the variables within this study, spirituality and functional status. Age (Sengupta, Park-lee, Valverde, Caffrey, & Jones, 2014), race (Chung et al., 2008; Johnson et al., 2011; Ngo-Metzger et al., 2008), physician communication (Ahrens et al., 2003; Lilly & DeMeo, 2000), and diagnosis (Sengupta et al., 2014) are other variables that prior literature has shown some relationship to hospice length-of-stay which this study did not. However, like this study, there are other recent studies that found no

significant differences in length of stay between minorities and Whites (Hardy, Chan, Liu, Cormier, Xia, Bruera, & Du, 2012; Park, Carrion, Lee, Dobbs, Shin & Becker, 2012). There is no dispute however, that minorities continue to access hospice at lower rates with no apparent growth (Bullock, 2011). Overall though, the discrepancy in significant relationships with length of stay in this study versus prior literature further support the suggestion that these relationships (including family communication) should be considered with a more representative sample.

Decision Time as a Key Variable in Hospice Utilization

Overpowering Role of Late Referrals and the Use of Treatment

Literature on hospice utilization characterizes late referrals to hospice care as a reflection of short lengths of stay due to advanced illness and imminent death at the time of admission (Rickerson et al., 2005; Quill, 2007) or based upon family perception of the referral timing (Teno et al., 2007). No studies in the literature reviewed for this dissertation looked at decision time based on the number of days between initial referral and hospice admission. Results of this study's analyses suggest that considering hospice utilization within the context of decision time is of great interest. In the multiple regression results for decision time, functional status and the use of treatment were the largest predictors. It is important to note how this supports widely held beliefs that late referrals to hospice continue to be a problem. For example, in this study patients' who were closer to death at the time of the hospice admission (based on functional status measured by lower PPS scores) had much shorter decision times from initial referral to hospice admission than those with higher levels of functioning at admission. This data demonstrates that high acuity patients are not learning about hospice until just prior to their admission (as initial referral in this study was defined as the first time a patient learns about hospice in regards to their illness).

The other highly predictive factor in decision time was the use of treatment. Even when hospice was introduced earlier in the process of illness, seeking treatment delayed the decision for hospice. Within our death-denying culture, where so many believe that hospice either equals death or means giving up (Andruccioli et al., 2007; Feeg & Elegiary, 2005; Freidman et al., 2002), the use of further treatment remains a beacon of hope in attempts to escape or postpone death. Even among a sample with high levels of family communication about health and illness, people choose to forego hospice for an illusion of longer life through treatment. However, research continues to suggest better outcomes for patients in hospice care when compared to those in active treatment (Connor et al, 2007; Teno et al., 2007; Higgins & Prigerson, 2013; Zhang et al., 2009; Gozalo et al., 2008; Kelley et al., 2013).

Though not all diagnoses have the luxury of a discussion about hospice in an earlier time frame (for example, strokes or accidental injuries) many other diagnoses provide long periods of chronic illness and decline where early discussion about hospice as an option for care would be appropriate. Decision time was correlated with diagnosis, functional status, and the use of further treatment ($p < .01$). Additionally, decision time was correlated with age ($p < .01$) and spirituality ($p < .05$). Consideration about how these variables interact is important for exploring these relationships further and in order to provide a greater understanding of the factors that impact the timing of the decision for hospice. In addition to regression and correlation results, this study also demonstrated differences in decision time across key demographic variables.

Ongoing Disparities in Access

Ongoing health disparities remain a problem of national interest (as highlighted in leading health indicator topics for Healthy People 2020; Office of Disease Prevention and Health Promotion, 2014). Results from this study show significant differences in decision

time for hospice by both race and income. Minority patients mean in decision time was 7.85 days compared to 60.36 days for whites. Though early hospice utilization is encouraged, short decision times likely reflect delays in learning about hospice as an option for care until periods of advanced illness or imminent decline (as discussed directly above). This difference suggests that minority patients may either seek services or receive information later during their illness process based on cultural barriers already noted within the literature, such as religious/spiritual value conflicts, distrust in the healthcare system (Bullock, 2011; Schmid et al., 2009; Shrank et al., 2005), or language differences, lack of insurance, and discrimination (Smith et al., 2009).

Similarly, patients with lower incomes (< \$50,000) had much shorter decision times (mean of 24.86 days) than those of higher incomes (mean of 113.68 days). Though there is no information suggesting exactly why this difference occurs, prior literature may provide possible insight. For example, due to systematic barriers lower income patients are less likely to be screened for cancer and may seek treatment later in their illness leading to later diagnoses (Katz & Hofer, 1994). Income may also be a factor in the decision for cutting edge treatment which may be too expensive for lower income patients. Further exploration of differences in decision time across both race and income is needed. Understanding how these interact with one another and other variables, such as diagnosis or the use of further treatment is an important area for future exploration.

Differences by Diagnoses

A final difference that was detected in decision time was related to diagnosis, cancer versus non-cancer. Waldrop and Meeker (2012) suggested that there were differences in the process of the decision for hospice enrollment prior to an initial encounter with a hospice representative, but that the process was the same after an initial encounter. This study supports a difference in that cancer patients had a slightly

longer decision time than those with non-cancer diagnoses (56.75 days compared to 45.91 days). Waldrop and Meeker's results suggest that the timing for cancer patients' decisions were tied more to a defined beginning and ending of treatment and to a steady decline in condition while non-cancer patients' decisions related to ongoing hospitalizations and prognostic eligibility. Future research considering diagnostic trajectories of the decision time for hospice care might need to consider interaction effects of diagnosis and treatment, or diagnosis and functional status in the decision time for hospice.

Exploring the Meaning of Hospice

Another finding from Waldrop and Meeker's study (2012) that is of interest here is that both cancer and non-cancer groups remained uninformed about the full scope of hospice care; non-cancer patients believed that hospice was just for cancer patients and cancer patients believed that hospice was only for the last few days of life. It is likely that belief of these misconceptions shaped individuals' understandings about the meaning of hospice, which in this study, emerged as an important variable for consideration. Though it was not correlated with either decision time or length of stay, the meaning of hospice was correlated with multiple other variables supported within the literature as factors in hospice utilization, such as age and diagnosis ($p < .01$) and the use of further treatment ($p < .05$). It was also correlated with family communication, race, and satisfaction in physician communication at a .10 level (these were not reported in the above results). Understanding the relationship between patients' perceptions about hospice care (aka what it means to them) and other variables identified as barriers or facilitators to hospice can improve our knowledge about how to help educate patients about hospice care prior to official referrals or hospice admission.

The Role of Family Communication in Hospice Utilization

Family communication about illness and death was not a predictive factor in either length of stay or decision time (hypotheses 1 and 2). The sample had a high overall mean for family communication (4.04 on a scale from 1 to 5) which due to a lack of variance may have impacted the ability to detect major changes in outcome variables. Though staff was trained to speak with all patients who met the criteria for the study it is likely that they referred patients with greater family support and communication, as staff perceived them as more willing to participate in a research study. While training staff I spoke about the importance of not screening for appropriateness and focusing more on eligibility based on the criteria I provided. However, along with referrals I often received commentary about how this patient or family member was “perfect” for providing insight about family communication and decision making at the end-of-life suggesting that this bias may have been present in the patients’ staff members chose to talk to and refer for the study.

Though family communication was not predictive or correlated with major variables, this study has achieved some progress in measuring family communication in this population. The FCID scale was modified from the Caregiver’s Communication with the Patient about Illness and Death (CCID) scale (Bachner & Carmel, 2009). The modified scale showed high internal consistency (Chronbach’s $\alpha = 0.79$) and provided an option for patients themselves to report on family communication instead of only gaining the perspective from caregivers after death. This also allowed for respondents to provide feedback about family communication during the period of illness instead of after the loss. The modified scale was also more inclusive of family as a whole rather than focusing only on a relationship between a caregiver and patient. No differences were noted in family communication based on respondent type (patient versus family member). Though

measuring family communication from the perspective of only one family member is a common method across family communication scales (Olson & Barnes, n.d.; McCubbin, Thompson, & McCubbin, 1996; Siminoff, Zyzanski, Rose, & Zhang, 2008; Arden-close et al., 2010; Bachner & Carmel, 2009), perhaps a more accurate method would be to take an average of family scores (Smith, 1997; Siminoff et al., 2008) or for the family to work together in providing answers to the scale. However, this would limit applicability among patients who are too ill to participate.

In addition to providing further insight into the measurement of family communication, this study offered a first attempt at testing the role of family communication in the decision for hospice care, or rather in overall hospice utilization. Much like the presence of hospice care in the end-of-life, literature suggests that positive family communication at the end-of-life is an indicator for lower distress, increased quality and satisfaction in care, and increased outcomes for caregivers (Abbey, 2009; Gotcher, 1993; Bachner & Carmel, 2009; Keeley, 2007). One of the limitations for this study was that it only considered the perspective of patients who chose hospice. In order to accurately reflect whether family communication impacts the decision for hospice, the perspective of those who never chose hospice must also be considered. Though this population had a high mean of family communication, it is unclear how this may differ among a population who never enrolled in hospice care at all.

The Role of Referral Source in Hospice Utilization

Pilot data for this study showed that patients referred by a family member or a friend in addition to or in lieu of a medical professional were on hospice nearly four times longer than those referred by a medical professional alone (Wallace & Adorno, forthcoming). However, this study did not support those findings as referral source was not a predictor for length-of-stay (hypothesis 3) and there was no statistically significant

difference in length-of-stay based on type of referral. Due to the discrepant findings from the pilot study data, further research should be done in this area. Data for official referral source is available within hospice charts so further inquiry in this area could be considered in a retroactive review of charts using a randomized sample (or inclusive of all patients who died within a particular window of time), which would overcome the challenges faced in this study regarding availability sampling.

Referral source was predictive in decision time between initial hospice referral and hospice admission (hypothesis 4). More specifically involvement of family predicted longer lengths of decision time leading up to the hospice referral. Though results were in the opposite direction than hypothesized, there is much information that can be gleaned from these results. Once correlated variables (age, diagnosis, use of treatment, and functional status) were added into the regression, referral source was no longer predictive ($\beta = .139, p = .087$). Use of treatment and functional status were the only variables that were predictive. The regression model explained 48.6% of the variance in decision time, demonstrating the overwhelming impact of these two factors. As discussed above, the closer someone was to death at the time of the hospice admission (lower PPS scores) the shorter the decision time was for hospice from initial referral to admission, suggesting that late referrals remain a key barrier to hospice. When hospice is discussed earlier in the process, hospice is often delayed due to the decision for further treatment.

The presence of family involvement predicted longer periods of decision time likely because conversation within these families about hospice as a possibility began so much earlier during the illness process. As demonstrated by the regression, the decision for treatment was a more prevalent factor than the referral source. Though current policy greatly restricts the use of concurrent care (hospice alongside curative care or treatment), current demonstrations are paving the way for concurrent care to be a possibility in the

future provision of hospice. If this barrier were overcome, the ability to detect the impact of family referrals and/or family communication on the timing of the decision for hospice might be more likely.

The Epigenetic Model of Family Processes, which was the main theory guiding this study, suggests that families with higher levels of attachment will have greater family communication abilities leading to more cohesive problem solving. However, due to the nature of late referrals and the overpowering influence of the decision for ongoing treatment, it is problematic for this theory to currently be tested among this group. The pressure to make a decision due to imminent death does not allow families the time to process or prepare to make any other decision. Even in the absence of a decision for hospice care the patient faces an imminent death. The overwhelming death-denying culture that leads patients to cling to further treatment also overshadows thoughtful discussion about end-of-life choices within the current structure of hospice as a separate entity of care from ongoing or active treatment. However, results of this study show a relationship between referral source and decision time for hospice care, suggesting that this needs further exploration in research, especially since this is the first study looking at referral source as a predictive variable in hospice utilization.

Limitations of Study

There are several limitations that must be considered in the findings of this study. First, due to the rate of turnover within the sampling frame, probability sampling was not practical. Due to the short period of time that many patients are on hospice services, it was important to access them (or their family members) when they were available and willing to participate. Since adequate sample size was also an important consideration, it was helpful to draw from the largest number of patients that were available to participate, rather than limiting numbers based upon a probability sampling method. One of the

additional challenges related to the sample was the lack of ethnic diversity. Though my sample was similar to the national demographics in hospice care, there is not enough minority representation to make comparisons across cultures or to make inferences about minority populations related to the impact of family in the decision for hospice care.

A second limitation was that data was collected about family processes (family communication) from only one member in the family. While perceptions may vary from one member in the family to another, this study targets the person who facilitates the decision for hospice based upon the signing of legal paperwork upon hospice enrollment. Though a large number of patients participated in the study (N = 32), when the patient was unable to contribute the legal decision maker completed the study instead. This allowed the data to be comparable across all cases.

An additional limitation was related to limitations in measurement. For example, several of the variables relied on self-report of the patient or family member and called for estimation rather than a precise or exact response. Due to the nature of the information being recorded, this was the best measure that was available due to restrictions in time and access to records. Also, for the length of stay variable, there were 12 patients that were still receiving ongoing hospice care at the end of the study. These patients were not dropped from the study as they represented patients with longer lengths of stay (since they had not died or discharged prior to analysis for this study).

Implications for Social Work Practice and Policy

Results from this study reinforce what hospice practitioners have known for years, which is that hospice referrals continue to be made very late into patients' diagnoses causing them to underutilize care. Based upon these late referrals and short stays on hospice, it becomes very difficult to test the theory in this study that successful decision making builds upon successful family communication. Since patients are often

not aware of hospice as an option until advanced stages of illness (measured in this study by functional status and scores on the PPS) decisions are made out of a feeling of necessity or feelings of having no other choice. Though many practitioners are often hesitant to discuss end-of-life choices with patients, knowledge about this as a continuing problem is important for social workers to advocate for earlier discussion on end-of-life options. From a perspective of policy, the reimbursement of such conversations may also be important in overcoming barriers to earlier conversations about end-of-life care and hospice.

Another implication for policy has to do with the recognition that treatment continues to display a strong influence in delaying the decision to enroll in hospice. This emphasizes the need to consider concurrent care within current policy. Though only 20% of the population in this study delayed hospice for treatment, there is likely a much larger number among those who delayed the decision for hospice and died prior to enrolling in services. The provision of concurrent care (allowing hospice to be provided alongside active treatment) would allow for earlier and increased utilization of hospice providing more positive outcomes for patients and family members at the end-of-life.

This study also provides a number of considerations for social workers' assessments when working with a family during a referral to hospice. For example, it is important to note prior hospice exposure in addition to taking the time to explore a patients' and families' understanding of what hospice means. Though the roles of family communication and family referrals on hospice utilization were not highly predictive (or predictive at all in some cases), there is still some clinical significance that should be acknowledged. After recognizing the overwhelming influence of treatment and functional status at the time of a referral, it is important for social workers to note that families may be talking about hospice well before any medical professional has suggested it.

Assessing for prior hospice exposure is one way to open the door to this conversation and to gauge patients' level of knowledge about hospice. The inclusion of family members in this discussion (as supported by the patient) is also important given that just over 1 in every 4 patients in this sample was referred by a family member or close friend. Talking with patients about their spirituality and the role this plays in regards to their illness is also important to assess, as differences were detected in length of stay based upon the role of spirituality in patients' daily lives.

Recommendations for Future Research

Suggestions for future research are provided throughout this discussion so a summary of recommendations is provided here. Likely due to the challenges faced in obtaining a representative sample, length of stay was not found to have a relationship with many of the expected variables (as supported by prior research). Due to this, this author recommends that these relationships (including family communication and referral source) should be considered using a more representative sample. Additionally, research in this area should include patients who were referred to hospice, but never enrolled in services. Inclusion of those patients will provide a more complete picture of the impact of a variable on the decision to pursue, or not pursue, hospice care.

Though hospice utilization has been well studied within the literature, decision time has not been included elsewhere. This study measured decision time based on the number of days between an initial referral to hospice, or the first time a patient or family member learned about hospice as an option for care, and the date of hospice enrollment. Though respondents often provided an estimate for the initial referral (as the exact date one learned about hospice was sometimes difficult to recall), an estimation allowed for decision time to be calculated as a continuous variable. Results from this study suggest that decision time is a pertinent variable within the discussion of hospice utilization and

that it should be included along with hospice length of stay in future studies within this area of inquiry.

Results highlighted a number of relationships between independent and control variables in this study. Further investigation into how these variables interact with one another needs to be explored further. For example, regression results demonstrated the important role of the use of treatment and functional status in predicting decision time while bivariate analysis showed a difference in decision time by diagnosis, race, and income. Due to high correlations between diagnosis and functional status, there may be a relationship between these variables that impact decision time for hospice. In other words, the impact of functional status on the decision for hospice may be further explained by diagnosis. Similarly, the impact of the use of further treatment on decision time may also be impacted by diagnosis, or perhaps income as another example. This study demonstrates a number of relationships among these variables suggesting that follow up studies should explore how they might be related and how these interactions may impact overall hospice utilization.

A final area of inquiry deserving further attention based on results from this study is the role of the meaning of hospice on overall hospice utilization. This study considered respondents' perceptions of hospice (positive, neutral, or negative) and whether or not these perceptions predicted decision times or lengths of stay. Though not predictive, the meaning of hospice was correlated with a number of other independent and control variables. Recognizing how hospice recipients qualitatively understand the meaning of hospice and how that understanding may change based upon hospice experience might provide further insight into these relationships, in addition to providing a more precise way of measuring the construct. Further quantitative exploration about how respondents'

perceptions of hospice relate to other key barriers or facilitators to hospice utilizations is also warranted.

Conclusion

Overall, this dissertation brings a new perspective to hospice utilization through the use of decision time as an outcome variable. Decision time was correlated with a number of barriers to hospice from within literature and prior research. Referral source was also predictive of decision time for hospice, suggesting that when a patient is referred by a family member or a close friend in addition to or in lieu of a medical professional, decision times for hospice were longer. This was likely due to these patients starting a conversation about hospice as an option earlier during the illness process. However, referral source was overshadowed by the impact of functional status at the time of hospice admission and use of treatment. These were the largest predictors of decision time for hospice reinforcing the role of late referrals and current policy restrictions (limiting patients' abilities to seek treatment while accessing hospice care) on hospice utilization.

This dissertation also provides a number of connections among barriers to hospice as a starting point for future research. Both the meaning of hospice and spirituality presented as impactful variables requiring more in-depth follow up about how patients and their families define and understand these constructs in relation to the decision to enroll in hospice. Differences in decision time across race and income support literature related to ongoing healthcare disparities. Differences related to diagnoses support the notion that there may be need for different approaches in talking about hospice with patients based upon their diagnosis. Though ongoing inquiry about hospice utilization remains important due to the continuing growth of our aging population who will likely need services in the near future, results of this study strongly imply that the time to revisit policy for concurrent care is now. Additionally, the ongoing battle of talking

about end-of-life matters within a death denying society must be at the forefront of cultural discourse.

Appendix A

Community Hospice of Texas Letters of Research Support

7/9/2014

Research

Cara,

I am very pleased to inform you that your research project has been approved by our Administrative team. I am so sorry that I was not able to give you a final answer until today. The only thing we would like to incorporate into the project is a clear communication to patients and families that states that the research is not being conducted by Community Hospice of Texas and that a decision as to whether or not to participate in the project will in no way impact the care provided by Community Hospice of Texas. I think that is more on our end, but it needs to be part of the training with our staff and documented in some way. I welcome your thoughts.

I look forward to moving forward with this project. Please let me know how I can be helpful

Thanks,

Pat Jackson | Chief Operating Officer | [817.870.2795](tel:817.870.2795) | pjackson@chot.org



6100 Western Place | Suite 500 | Fort Worth, TX 76107 | fax: 817.546.2173

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<https://pod51034.outlook.com/owa/#viewmodel=ReadMessageItem&ItemID=AAMkADJiMTViZTM2LTU4M2UINDhhZC04ZjVmlWY5NDE0ZWVjYzkwMgBGAA...> 1/1



November 20, 2012

To whom it may concern:

It is our privilege to join with Cara Wallace as she conducts her research project to discover potential factors influencing the time between referral to enrollment in hospice care. This is information that would be helpful for us to know as it might affect how we approach our introduction of hospice to patients who have been referred to us. The information might also be used to improve our communication with patients and families after hospice admission.

Cara will be collecting the information from patients, families, and caregivers who are located at their own homes and our two inpatient units (Hospice House Downtown and Hospice House at Huguley). Our psychosocial staff (social workers and chaplains) will refer potential subjects of the research to Cara, based upon their own initial conversation with the subjects about the research opportunity.

We are confident that this research project will be conducted with protocols in place that protect the confidentiality and privacy of our hospice patients, families and caregivers.

Sincerely,

Michael Downs
Director of Organizational Performance
6100 Western Place, Suite 105
Fort Worth, TX 76107

6100 Western Place, Suite 105 • Fort Worth, TX 76107
817-870-2795 • 800-226-0373 • Fax 817-878-3717 • www.chot.org

Appendix B

University of Texas at Arlington IRB Approval Letter



July 21, 2014

Cara Wallace
Dr. Debra Woody
The University of Texas at Arlington
School of Social Work
Box 19129

EXPEDITED APPROVAL OF HUMAN SUBJECT RESEARCH

IRB No.: 2014-0755
TITLE: *Predictors of Timing in Hospice Utilization: The Role of Family in the Decision for Hospice Care*
Effective Date: July 19, 2014
Expiration Date: July 19, 2015

Approved Number of Participants: 300 (Do not exceed without prior IRB approval).

The University of Texas Arlington Institutional Review Board (UTA IRB) has made the determination that this research protocol involving human subjects is eligible for expedited review in accordance with Title 45 CFR 46.110(a)-(b)(1), 63 FR 60364 and 63 FR 60353, categories (5)(7). The IRB Chairperson (or designee) approved this protocol effective July 19, 2014. IRB approval for the research shall continue until July 19, 2015.

APPROVED NUMBER OF PARTICIPANTS:

This protocol has been approved for enrollment of a maximum of 300 participants and is not to exceed this number. If additional data are needed, the researcher must submit a modification request to increase the number of approved participants **before** the additional data are collected. Exceeding the number of approved participants is considered an issue of non-compliance and will result in the destruction of the data collected beyond the approval number and will be subject to deliberation set forth by the IRB.

INFORMED CONSENT DOCUMENT:

The IRB approved and stamped informed consent document (ICD) showing the approval and expiration date must be used when prospectively enrolling volunteer participants into the study. The use of a copy of any consent form on which the IRB-stamped approval and expiration dates are not visible, or are replaced by typescript or handwriting, is prohibited. The signed consent forms must be securely maintained on the UT Arlington campus for the duration of the study plus a minimum of three years after the completion of all study procedures (including data analysis). The complete study record is subject to inspection and/or audit during this time period by entities including but not limited to the UT Arlington IRB, Regulatory Services staff, OHRP, and by study sponsors (if the study is funded).

Appendix C

Hospice Personnel Recruitment Script

- Hospice Personnel:* (speaking to **patient** or **legal decision-maker** of patient)
- As a hospice worker, I have the opportunity to learn so much from the experiences of my patients and their family members. There is so much that can be gained from studying experiences similar to yours. Community Hospice of Texas has partnered with a PhD student at the University of Texas at Arlington (UTA) School of Social Work in order to conduct research about decision making for hospice care. Would you be interested in learning about how you can spend 20-30 minutes sharing some of your story in order to help other patients who are faced with decisions about hospice care?
- [No] Okay, thank you for your time. (*Hospice visit will proceed as normal*)
- [Yes] Okay, first I will tell you that your hospice services are completely separate from this study and that this study has no bearing on the care you will continue to receive from us. Participation is voluntary.
- The primary investigator for the project is a prior social worker of ours, Cara Wallace, and her research is supported by a faculty committee at UTA. The study has also been approved by the Institutional Review Board at UTA. The main purpose of the study is to examine specific factors that may impact the decision for hospice care. If you decide to participate, Cara or her research assistant will meet with you and administer a research questionnaire and a short 6-question survey. In addition to your participation answering the questions on these two forms, Cara asks for your permission to access regularly obtained information from within your (the patient's) hospice chart. For example, she will record the diagnosis, admission date, referral date, along with other demographic information. Completion of the study should take no longer than 20-30 minutes. Your name will also be placed into a drawing for one of five \$20 donations that will be made in your honor to the agency or charity of your choice. This is an additional way for you to potentially make a difference through your participation within this study.
- Can I have Cara or her research assistant contact you to schedule a research visit?
- [No] Okay, thank you for your time. (*Hospice visit will proceed as normal*)
- [Yes] Okay, great. I will have them get in touch. (*Hospice personnel will make referral to Cara. In the referral, include whether or not it is the PATIENT or LEGAL DECISION MAKER who will be participating*)..

Appendix D
Informed Consent Form

UT Arlington Informed Consent Document

PRINCIPAL INVESTIGATOR

Cara L. Wallace, LMSW
PhD Candidate
School of Social Work
University of Texas at Arlington
Cara.wallace@mavs.uta.edu

FACULTY ADVISOR

Dr. Debra J. Woody, Associate Dean for Academic Affairs
School of Social Work
University of Texas at Arlington
Box 19129
211 So. Cooper Street
Arlington, TX 76019
debwoody@uta.edu

TITLE OF PROJECT

Predictors of Timing in Hospice Utilization: The Role of Family in the Decision for Hospice Care

INTRODUCTION

You are being asked to participate in a research study about how patients and their families make the decision to begin hospice care. Your participation in this study is voluntary. Refusal to participate or stopping your participation at any time will involve no penalty or loss of benefits to which you are otherwise entitled. For example, your participation in hospice care will not be influenced in any way by your decision to participate or not within this research study. Please ask questions if there is anything you do not understand.

PURPOSE

The purpose of this research is to examine the role of family, among other important things, in the decision for hospice care.

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DURATION

You will be asked to participate in 1 study visit lasting 30 minutes to 1 hour depending upon the nature of your responses.

NUMBER OF PARTICIPANTS

The number of anticipated participants in this research study is 300.

PROCEDURES

The procedures which will involve you as a research participant include:

1. Completing a questionnaire and survey about yourself, your experience with the illness relating to the hospice admission, and your relationship with your family and health providers.
2. Giving this investigator permission to access regularly obtained information from within your hospice chart (for example: age, diagnosis, referring physician, date of admission, etc). Upon admission to hospice you were given a copy of Community Hospice of Texas' HIPAA authorization form related to this permission.

POSSIBLE BENEFITS

Participation in this study may encourage open communication for you and your family members about the illness experience. Some patients and families find that talking about their experiences is helpful and results in less anxiety about their circumstances. In addition to this, results of this study will help researchers identify what things contribute to how and when patients and families decide to enroll in hospice services. This will help us identify how to help patients and families talk about their illness and options for care at the end-of-life.

POSSIBLE RISKS/DISCOMFORTS

You might experience discomfort due to the nature of questions relating to your relationship with your family and to your (the patient's) illness experience. If you become anxious or uncomfortable, the principal investigator is available to process those feelings with you in addition to make referrals to outside counseling support as requested. The principal investigator in this study is a licensed master's social worker and has five years of experience providing hospice care. The hospice social worker, chaplain, and other

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team members will also remain available to you for further support. You have the right to discontinue any study procedures at any time at no consequence. You may do so at any time by informing the principal investigator.

COMPENSATION

For your participation, your name will be placed in a drawing for one of five \$20 donations made to the agency or charity of the winner's choice. If chosen, you will be notified by mail that a donation was made in your honor. If chosen, what agency or charity would you like for the donation to be made?

(agency of choice for donation if chosen)

ALTERNATIVE PROCEDURES

There are no alternative procedures offered for this study. However, you can elect not to participate in the study or quit at any time at no consequence. Participation in this study will not have any effect on the services you receive as a part of your routine hospice care.

VOLUNTARY PARTICIPATION

Participation in this research study is voluntary. You have the right to decline participation in any or all study procedures at any time. You may also quit at any time at no consequence.

CONFIDENTIALITY

Every attempt will be made to see that your study results are kept confidential. A copy of this signed consent form and all data collected from this study will be encrypted and stored with password protection for at least three (3) years after the end of this research. If during the course of this study any information is disclosed regarding abuse, neglect, or harm to self or others, the investigator must report this information to appropriate authorities to the extent of the law.

The results of this study may be published and /or presented at meetings without naming you as a participant. Additional research studies could evolve from the information you have provided, but your information will not be linked to you in any way; it will be anonymous. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA Institutional Review Board (IRB), and personnel particular to this research have access to the study records. Your records will be kept completely confidential according to current legal requirements. They will

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not be revealed unless required by law, or as noted above. The IRB at UTA has reviewed and approved this study and the information within this consent form. If in the unlikely event it becomes necessary for the Institutional Review Board to review your research records, the University of Texas at Arlington will protect the confidentiality of those records to the extent permitted by law.

CONTACT FOR QUESTIONS

Questions about this research study may be directed to the Principal Investigator, Cara Wallace, through e-mail at cara.wallace@mavs.uta.edu or to faculty advisor, Dr. Debra Woody, at 817-272-0789. You may also contact any of the investigators or advisor at the e-mail addresses provided at the top of this form. Any questions you may have about your rights as a research participant or a research-related injury may be directed to the Office of Research Administration; Regulatory Services at 817-272-2105 or regulatoryservices@uta.edu.

As a representative of this study, I have explained the purpose, the procedures, the benefits, and the risks that are involved in this research study:

Signature and printed name of principal investigator or person obtaining consent Date

CONSENT

By signing below, you confirm that you are 18 years of age or older and have read or had this document read to you. You have been informed about this study's purpose, procedures, possible benefits and risks, and you have received a copy of this form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue participation at any time without penalty or loss of benefits, to which you are otherwise entitled.

SIGNATURE OF VOLUNTEER DATE

IRB Approval Date: JUL 19 2014

IRB Expiration Date: JUL 19 2015

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Informed Consent Document**

ASSENT

By signing below, you confirm that you have read or had this document read to you. You have been informed about this study's purpose, procedures, possible benefits and risks, and you have received a copy of this form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time. You understand that due to your medical condition that your power of attorney(s)/legal guardian(s)/next of kin have consented for your participation.

You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled, and you may discontinue participation at any time without penalty or loss of benefits, to which you are otherwise entitled.

SIGNATURE OF MEDICAL POA/LEGAL GUARDIAN/NEXT OF KIN DATE

SIGNATURE OF VOLUNTEER (if able) DATE

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IRB Expiration Date: JUL 19 2015

Appendix E
Research Questionnaire

Research Questionnaire

This form should be completed by the patient OR their medical Power of Attorney/decision maker.

Please complete the following questions or statements.

Who is the decision maker for patient's healthcare decisions?

- Sole decision maker _____
- Primary decision maker with some influence from other family/friends _____
- Shared decision making (2 or more individuals) _____

Other family members involved with care?

What is the process for decision making? (For example, conversation or collaboration, doing research, self-reflection, etc)

Who is participating in the responses of the following questions? (Check all that apply)

- Patient
- Patient- with assistance from _____
- Primary decision maker (POA or next of kin)
 - Decision maker lives within the same home
 - Decision maker lives in separate home from patient

Which group most closely describes your (the patient's) ethnicity? (Check all that apply).

- | | |
|--|---|
| <input type="checkbox"/> Hispanic, Latino, or Spanish origin | <input type="checkbox"/> Asian |
| <input type="checkbox"/> White | <input type="checkbox"/> American Indian or Alaska Native |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Native Hawaiian or Other Pacific Islander | |

What is your age and relationship to patient?

- Self _____
- Spouse/partner _____
- Parent _____
- Child _____
- Sibling _____
- Other relationship _____

What is your (the patient's) highest level of education?

- Some high school or less
- High school graduate
- Some college
- College degree
- Graduate degree _____

Patient's current yearly household income:

- Less than \$25,000
- \$25,000 - \$50,000
- \$50,000 - \$75,000
- \$75,000 - \$100,000
- \$100,000 - \$125,000
- \$125,000 - \$150,000
- \$150,000+

Since the diagnosis/illness, have you (patient) experienced a change in your income?

- Yes
- No

If yes, what was your yearly income prior to the illness? _____

Are you (the patient) a veteran?

- Yes
- No

Is patient's spouse a veteran?

- Yes
- No

If yes, prior to hospice care, what percentage of your care did you receive through the VA system? _____

Using a scale from 0 – 10, rate the level of importance that spirituality plays within your daily life. (0 = not important at all, 5 = somewhat important, and 10 = the most important thing) (Frame this question where the "your" is the decision makers stated in question 1).

0 1 2 3 4 5 6 7 8 9 10

How long before enrolling in hospice did you FIRST learn about hospice as a potential option for your (the patient's) care/current illness? (For example, days prior to the start of hospice care, 2 weeks prior to the start of hospice care, 6 months prior to the start of hospice care, etc).

Current Location of care:

- Hospice inpatient unit
- Home (includes retirement facility)
- Assisted living
- Nursing home
- Other _____

How did you learn about hospice as a potential option for your (the patient's) care/current illness?

- Family/friend/self _____
- Medical professional
 - Primary care physician
 - Specialty physician
 - Nurse
 - Social worker
 - Other Medical professional _____
- Other _____

After recognizing hospice as a potential option for your (the patient's) current illness, did seeking continuing or additional treatment delay your decision to start hospice care?

- Yes
- No

Do you feel that hospice care was started at the right time?

- Yes
- No, starting hospice care earlier would have been helpful.
- No, I should have started hospice care later.
- Other _____

Rate your level of satisfaction with how your (the patient's) physician communicated with you about your (the patient's) illness, diagnosis, and prognosis prior to hospice care.

- Greatly unsatisfied
- Unsatisfied
- Neither Satisfied nor Unsatisfied
- Satisfied
- Greatly Satisfied

Rate the level of trust you feel with the doctor(s) that referred you (the patient) to hospice.

- Great Trust
- Trust
- Undecided
- Distrust
- Great Distrust

Further description of your understanding of hospice at the time you FIRST learned about it as an option for your (the patient's) care/current illness: _____

Describe your understanding of hospice NOW: _____

Which of the following best describes the INITIAL perception of hospice as described by patient (or decision maker) in question above. (Researcher makes determination based upon nature of response in initial question above).

- Very Positive (supportive care and services to manage needs)
- Somewhat positive
- Neutral
- Somewhat negative
- Very negative (sure or sudden death; overuse of medications; etc)

Which of the following have you (the patient) completed? (Check all that apply)

- Medical Power of Attorney
- Financial Power of Attorney
- Healthcare Directive (or Living Will)
- Out of Hospital Do Not Resuscitate

Do you (does the patient) have a primary care physician (a family doctor)?

- Yes
- No

If yes, how long have you (the patient) been receiving care from this physician?

- 6 months or less
- 6 months to a year
- 1-3 years
- 4-5 years
- 6+ years

If yes, I (we) have great trust in my (the patient's) primary care physician.

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

Have you had previous experiences with hospice?

- Yes
- No

If yes, how long did your loved one receive hospice care? (For example, a few days, a week, 2 months, a year, etc). _____

If yes, how involved were you with the patient's hospice care?

- Daily involvement
- Greatly involved
- Somewhat Involved
- Distant, but made several trips in person during patient's care
- Distant, but connected by phone
- Distant or removed from care

Where were you just prior to your admission/transition to hospice care?

- Home
- Hospital _____
- Facility _____
- Other _____

How was the transition to hospice care from your (the patient's) previous level of care?

What advice do you have for others who are faced with making a decision about hospice care?

Appendix F

Information from Patient's Chart Form

Information from patient's chart

Please complete the following questions or statements.

Patient Name: _____

Patient's Age: _____

Patient's Gender: _____

Diagnosis: _____

Religious Affiliation: _____

Palliative Performance Scale upon admission: _____

Karnofsky Index upon admission: _____

Date of first official referral: _____

Patient's location during official referral to hospice:

- Hospital
- Non-hospital setting (for example, home, doctor's office, nursing facility, etc).

If referral was in the hospital setting, was a palliative care team involved?

- On Palliative Unit
- Referral from Palliative care consult
- No documentation of involvement of a palliative care team/physician.

Who FIRST contacted hospice about patient referral?

- Family/friend
- Medical professional
 - Primary care physician office
 - Specialty physician/hospital
- Other _____

Date of admission: _____

If the patient delayed admission, what were the cited reasons on the chart for this delay? _____

Date of death/discharge: _____

Death

Discharge (state reason for discharge): _____

Calculated Hospice Length of Stay: _____

(This is calculated by adding the number of days between the date of admission and the date of death/discharge, where both the start date and end date are included in the calculation).

Location at time of death:

Hospice inpatient unit

Home

Nursing home

Hospital

Other _____

Appendix G

Family Communication about Illness and Death (FCID)

Family Communication about Illness and Death (FCID)

Please complete the following questions using the scale shown below.

1	2	3	4	5
Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree

Patient version:

- _____ 1. I hardly talk with my family about my illness because I do not want to make them sad.
- _____ 2. Conversation with my family about my illness makes me uneasy.
- _____ 3. I am afraid to talk with my family about their lives continuing without me.
- _____ 4. I avoid talking with my family about my feelings and fears.
- _____ 5. My family doesn't know what to say or do when I am feeling down.
- _____ 6. I avoid talking with my family about my illness and future death.

Family version:

- _____ 1. I hardly talk with my loved one (or other family members) about his/her illness because I do not want to make him/her (or them) sad.
- _____ 2. Conversation with my loved one (or other family members) about his/her illness makes me uneasy.
- _____ 3. I am afraid to talk with my loved one (or other family members) about my life (our lives) continuing without him/her.
- _____ 4. I avoid talking with my loved one (or other family members) about his/her (their) feelings and fears.
- _____ 5. I don't know what to say or do when my loved one (or other family members) is (are) feeling down.
- _____ 6. I avoid talking with my loved one (or other family members) about his/her illness and future death.

Adapted from Bachner & Carmel's (2009) Caregivers Communication with the Patient about Illness and Death

Appendix H

Permission to Use and Modify Caregiver's Communication with the Patient about Illness
and Death (CCID) Scale



Yaakov Bachner <bachner@bgu.ac.il>

Mon 4/21/2014 3:44 PM

mark as unread

Dear Cara,

Permission is granted for you to use the "Caregiver's Communication with the Patient about Illness and Death (CCID)" scale in your research. Upon completion of your dissertation, I would appreciate receiving the Cronbach's alpha of the CCID scale.

Good luck with your research.

Yaacov

← REPLY ←← REPLY ALL → FORWARD ⋮



Wallace, Cara L

Mon 4/21/2014 2:37 PM

Sent Items

mark as unread

To: bachner@bgu.ac.il;

Dr. Bachner,

I am very interested in using the Caregiver's Communication with the Patient about Illness and Death (CCID) within my dissertation. I am e-mailing in hopes of receiving written permission to do so. My dissertation is on the role of family communication in end-of-life decision making about hospice care. I like that your scale is specific to illness communication, as in my pilot study I do not think that the family communication scale I used captured the necessary information. I do have some other potential options, but am hopeful that you and your colleagues might be willing for me to adapt the CCID for use with the family (family communication about illness and death) and from the perspective of the patient or the caregiver/family member.

I would be happy to send you further information if needed. Thank you for your consideration in my use of your measure.

Best,

Cara L. Wallace, LMSW

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Biographical Information

Cara Wallace, PhD, LMSW, is a May 2015 graduate of University of Texas at Arlington. Cara was a recipient of a Graduate Teaching Assistantship package, the Bob and Anne Utley Fellowship, and the Spring 2015 Dissertation Fellowship during her time at UTA. Additionally, Cara was named Outstanding PhD Student in 2012. A member of the third cohort of the Association of Gerontological Education in Social Work (AGE-SW) Pre-dissertation Initiative, Cara also served as a Student Representative for the AGE-SW national board from 2013 – 2015, receiving the prestigious Doctoral Student Leadership Award in 2014. During completion of her PhD Cara taught as an adjunct at both University of Texas at Arlington and at Texas Christian University. She received her BSW from TCU in 2005 and her MSW from UTA in 2006. Prior to returning to school for her PhD, Cara worked for five years as a hospice social worker for Community Hospice of Texas.

In 2015, Cara was appointed as a tenure-track Assistant Professor at Saint Louis University, School of Social Work in Saint Louis, Missouri. Overall, her research interests are related to improving end-of-life care and are informed by her background in practice along with a desire to improve access to programs through imparting knowledge about best practices to practitioners. Equally passionate about social work education, Cara has been able to find connections between her research interests and her teaching. Preparing students to face issues surrounding death, illness, grief, and loss is connected to the central concern, overcoming barriers to care, represented within her research agenda. Cara is also particularly interested in the roles of family within decision making processes at the end of life.