The Experience of Being Discharged from Hospice Alive as Perceived by Patients, Their Spouses, and Adult Children

by

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Dissertation
Presented to the Faculty of the Graduate School of The University of Texas Medical Branch in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

The University of Texas Medical Branch
March, 2011
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by

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2011
Dedication

I dedicate this dissertation first to my father, Ricky Watson (1948 - 2008). I am truly sorry you are not here to see me receive my doctorate, but I thank you for the inspiration to find my path.


To my mother, Retha Ann Watson, you always said I could do anything I set my mind to.

To my husband, Stewart Edward Campbell, you encouraged and supported me through this endeavor and never once complained.

For my children Chase and Danielle—you inspire me to be better than I am.

I LOVE YOU!
Acknowledgements

I would like to first thank the chair of my committee Diane Heliker, RN, PhD. She has been my mentor and guide on this journey. With patience and understanding she has modeled the profession of researcher.

I am also appreciative to each of the members of my dissertation committee: Carolyn Phillips, RN, PhD; Darlene “Cheyenne” Martin, RN, PhD; Kay Sandor, RN, PhD; Michele Carter, RN PhD; and Kenneth Unger, MD for all of their invaluable expertise, comments, and suggestions that allowed me to complete and refine my dissertation. I appreciate the time and energy that each of them invested in my education, training, and future. I will always “trust the process.”

To Alice Hill, RN, PhD and Vince Loffredo, PhD: when I lost my way I came to you for options and you opened the door and welcomed me into the program. I will never forget that you gave me my opportunity. My dear friends Paula Stangeland and Suzanne Lundeen encouraged and supported me along the way. I could not imagine doing this without them.

Ultimately, it was the willingness of the participants to share their stories that enabled me to be successful: I thank you.
The Experience of Being Discharged from Hospice Alive as Perceived by Patients, Their Spouses, and Adult Children

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The University of Texas Medical Branch, 2011

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Approximately 1.56 million patients received hospice care in 2009, and 243,000 individuals were discharged alive (NHPCO, 2010). There is a paucity of research describing the experiences of individuals discharged from hospice alive. The purpose of this transcendental phenomenological study was to explore the experiences of adult individuals with a life-limiting condition who were discharged from a hospice program due to decertification related to ineligibility or extended prognosis from the perspective of the individual and his or her adult family members. The study’s research questions were: (a) how do participants perceive and describe the experience of being discharged alive from hospice, and (b) how do participants perceive and describe their quality of life after a live hospice discharge?

A transcendental phenomenological design guided this study (Moustakas, 1994). Purposive, snowball sampling was used to recruit 12 volunteers, aged 35-92 years, who had experienced live hospice discharge due to decertification. Data collection included open-ended interviews and methodological, personal, and field journals. Interviews occurred at the participants’ residences and were recorded and transcribed verbatim. The initial interview question was: “Tell me about being discharged from hospice.” Data
analysis followed Moustakas’s (1994) approach utilizing Lincoln and Guba’s (1985) trustworthiness criteria for rigor.

Findings included two primary themes: suffering “as…” and the paradox of hospice discharge. These primary themes were supported by 12 subthemes: having support and needing support, mixed feelings, not dying fast enough, hospice equals life, abandonment, unanswered questions, loss of security, loneliness, uncertainty, anger and frustration, physical decline, and bearing exhaustive witness. Understanding this experience may create new possibilities for hospice care, including review of policies and guidelines limiting hospice enrollment to a temporal status.
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CHAPTER I: INTRODUCTION

You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die. – Dame Cicely Saunders

SIGNIFICANCE

Approximately 1.56 million patients received end-of-life care from hospice organizations in the United States during 2009 (National Hospice and Palliative Care Organization [NHPCO], 2010). Of that number, 243,000 hospice patients were discharged alive (NHPCO, 2010). Literature indicates that approximately 35% of discharged patients die within six months of discharge from hospice, suggesting that hospice benefits were in fact appropriate for this population (Kutner et al., 2004).

Hospice programs have seen dramatic growth in the number of patients enrolled over the last several years (NHPCO, 2007, 2008). The NHPCO estimates enrollment increased by 100,000 patients per year over the last seven years (NHPCO, 2008, 2010). Nearly 30% of older adults currently use hospice (NHPCO, 2010); as our population ages and incidences of chronic illness increase, the number of persons discharged alive from hospice will likely multiply (NHPCO, 2008).

The admission and discharge characteristics of hospice patients are well documented (Hospice Association of America [HAA] 2008; NHPCO, 2007, 2008, 2009). Hospice admission diagnoses have shifted over the years from malignant diseases to nonmalignant chronic illnesses. Moreover, patients with nonmalignant chronic illness tend to have higher live discharge rates than those with malignant diseases (Kutner et al., 2004). More than half (61.7%) of hospice patients have chronic terminal illnesses requiring symptom and pain management (NHPCO, 2009); however, predicting death often proves difficult because of the disease processes involved (Joshi et al., 2006). Indeed, Lynn and Forlini (2001) reported that many chronically ill patients have a 50% chance of surviving for six months the day prior to their death. The difficulty in accurately predicting a six-month demise for patients with non-malignant diagnoses
means that thousands of U.S. patients are discharged from hospice due to ineligibility or extended prognosis only to die shortly thereafter (Huskamp et al., 2001; Kutner et al., 2004; NHPCO, 2007). These patients are effectively denied the benefits of hospice and potentially suffer negative outcomes as a result (Kapo et al., 2005). Live discharge from hospice may have adverse affects on patients’ quality of life and health status, resulting in increased patient suffering (Kapo et al., 2005).

The Center for Medicare and Medicaid Services (CMS) pays 84% of all U.S. hospice claims and sets the standard for hospice enrollment and eligibility (HAA, 2008; NHPCO, 2010). Current Medicare policy places a temporal limit of two 90-day periods and an unlimited number of 60-day periods on hospice enrollment. Patients are eligible for this benefit only if a hospice physician certifies the patient has less than six months to live assuming admission diagnosis runs its natural course (i.e., no curative treatment) (U.S. Department of Health and Human Services [USDHHS], 1998). If this temporal estimate is inaccurate, the hospice agency may be required to repay all monies collected from Medicare, possibly lose Medicare certification, and ultimately face charges of Medicare fraud (Carlson et al., 2008). This financial and legal pressure may influence hospice enrollment, leading to excessively short lengths of service (Han et al., 2007).

**PURPOSE AND AIMS**

The purpose of this transcendental phenomenological study was to explore the experiences of life-limited adults who were discharged from a hospice program because of decertification related to ineligibility or extended prognosis; these experiences were examined from the perspective of the individual and his or her adult family members. It is believed that live discharge from hospice may adversely affect the patient’s quality of life and health status, resulting in increased patient suffering (Kapo et al., 2005). The meaning of being discharged from hospice alive and understanding the quality of living post-discharge for these individuals may lead to new possibilities for palliative and hospice care as well as revisions in current Medicare policy, guidelines, and procedures.
The long-term goals of the study were to: (a) inform guidelines and procedures specific to live hospice discharges, and (b) possibly modify current hospice eligibility criteria and temporal limitations. In the short term, understanding the perceptions of patients discharged alive from hospice and their family members will provide healthcare workers information that can be used to assist families and patients who transition from hospice and improve end-of-life care.

The specific aims of the study that will address these objectives were: (a) describe the experience of being discharged alive from a hospice program due to decertification related to ineligibility or extended prognosis as perceived by the adult (aged 18 and older), (b) explore adult’s view of their quality of life following hospice discharge, and (c) explore the family’s perceptions of this phenomenon.

Two research questions addressed these aims:

1. How do participants (adults and family members) perceive and describe the experience of being discharged alive from hospice?
2. How do participants (adults and family members) perceive and describe their quality of life after a live hospice discharge?

**OVERVIEW OF DESIGN**

A description of the experience of being discharged alive from hospice was developed through detailed first-hand descriptions shared by volunteer participants. Moustakas’s (1994) transcendental phenomenological approach was used to conduct the study. According to Moustakas (1994), transcendental “adheres to what can be discovered through reflection on subjective acts and their objective correlates” and phenomenology “utilizes only the data available to consciousness—the appearance of objects” (p. 45).

Researchers who use Moustakas’s (1994) philosophical approach to understanding a lived experience first seek to set aside prejudgments so that participants living the phenomenon can reveal the experience exactly as they perceive it. The commonalities of the experiences of all participants are then expressed as a composite
structural description of being discharged from hospice alive. Rigor is addressed using the criteria developed by Lincoln and Guba (1985).

CONNECTIONS

A Professional Connection to Live Hospice Discharge

Like many healthcare professionals, my experience with hospice was limited and somewhat remote. As a nurse working in an intensive care department, very few of the patients I cared for were enrolled in hospice services. To me, hospice was a place where patients went to die and simply wasn’t an option for many of the patients I cared for. Hospice referrals typically came only after there were no more treatment options and the patient, families, and staff were suffering.

My understanding of hospice changed when I entered graduate school. A colleague, who was a hospice nurse and who had practiced previously in an intensive care unit, helped me to understand the full potential of hospice: an environment where people were allowed to truly live until they died. Hospice is not a specific place; rather, it is an idea—a way of living and dying in peace and comfort. Hospice is also a family-centered approach that allows family members a place to share and accompany their loved ones on the journey. My colleague helped me to see that hospice was the right choice for my father.

A Personal Connection to Live Hospice Discharge

After a life-long struggle with neurofibromatosis (NF), my father was enrolled into hospice services in 2007 for congestive heart failure (CHF). Due to intricacies in Medicare requirements, his underlying disease process of NF became secondary and CHF became the primary hospice diagnosis. The years of suffering from NF and the resulting paralysis had taken a toll on my father and our entire family. His ability to perform activities of daily living (ADLs) was extremely limited and his independence almost nonexistent. Hospice was immensely beneficial to my father and our family as it relieved some of the burden, fatigue, and strain of caring for a chronically ill and disabled loved
one, allowing our family to prepare for the inevitable death of my father and giving him the opportunity to repair relationships that had been altered or lost.

Like many other hospice patients, my father suffered from chronic illness and multiple co-morbidities. His quality of life dramatically improved while on hospice; he became more independent and mobile, and the intractable pain he suffered from was finally under control. Our family attributed this improvement to the comprehensive, holistic care he received from hospice.

My personal experience with hospice discharge began in the summer of 2008 with my father’s live hospice discharge. He had thrived on hospice and his discharge shocked us all. My father suffered terribly from pain and paralysis; even his physician believed his illness was incurable and life-limiting. Nonetheless, my father was discharged from hospice. How could this happen? Simply put, he had reached a plateau in his condition and hospice could no longer demonstrate that his health was in terminal decline.

After my father’s hospice discharge, our family struggled with the traditional healthcare system and Medicare to procure the equipment, care, and medications required to control his symptoms and pain. My father died from his illness within one month of his discharge from hospice. To this day our family believes that his discharge from hospice and our inability to provide the same level of care caused him great suffering and ultimately hastened his death. Although not unusual, our family’s type of hospice experience may go unnoticed by policy-makers, healthcare systems, insurance companies, and Medicare. From this experience I began to wonder about the prevalence of this occurrence. Was it an anomaly, and if not, how do others manage the experience? My search for information led me to more questions and fewer answers. Therefore, I set off on the journey to learn and better understand the experience of being discharged from hospice alive.

SUMMARY

The purpose of this transcendental phenomenological study was to describe the phenomenon of being discharged from hospice alive from the perspective of the
individual who experienced the phenomenon and that individual’s adult family members. The individual’s quality of life following discharge will also be explored. Chapter I introduces the reader to the phenomenon of being discharged alive from hospice and the potential impact on both the patient and the family. The aims and research questions are delineated along with the long-term research goals. Chapter I also reveals my personal experience with live hospice discharge and my motivation for seeking a better understanding of the experience. Chapter II provides a comprehensive review of the extant literature specific to live hospice discharge as well as other literature pertinent to the topic. Moustakas’s (1994) approach to performing transcendental phenomenology also are introduced and described. Chapter III provides a detailed description of the methodology employed to explore the experience of being discharged from hospice alive. The study protocol, including recruitment of participants, data collection, analysis, human subjects’ protection, and rigor is described. Chapter IV provides the results of the study along with sample narratives and collective findings. Chapter V presents the conclusion and recommendations based on the findings presented in Chapter IV. The study findings may be used to inform future practice and policy regarding those patients who are discharged from hospice.
CHAPTER II: REVIEW OF THE LITERATURE

Chapter II provides the reader with an introduction to hospice, including relevant terminology and an overview of the Medicare hospice benefit and related legislation. An extensive review of the literature related to this study is presented, beginning with the history of the hospice movement and the government policies that support the program. The next section addresses the empirical and theoretical research related to hospice care and the remaining gaps in the literature. Finally, the reader is introduced to philosopher and psychologist Clark Moustakas, whose phenomenological notions provide one way to understand the lived experiences of the individuals at the very center of this study—the patient who is discharged from hospice alive and the experiences of the family.

BACKGROUND OF HOSPICE


Initially designed to care for terminally ill cancer patients, hospice aims to ease suffering and provide dignity to dying persons. From years 2000 – 2010, hospice enrollments have shifted from a majority of patients with malignant diseases to those with chronic illness. Currently, only 40% of hospice patients have cancer (NHPCO, 2010). Additionally, non-cancer diagnoses comprise 60% of hospice admissions, which include diagnoses such as unspecified debility (13.1%), heart disease (11.5%), and dementia (11.2%) (NHPCO, 2010).

Hospice Defined

Hospice services focus on caring for the individual patient and his or her family after foregoing curative treatments of a terminal illness or injury (HAA, 2008). Hospice teams are interprofessional, typically comprised of physicians, nurses, social workers,
therapists, spiritual counselors, home health aides and specially trained volunteers, among others (see Figure 2.1, below).

Hospice care is often provided in the patient’s home, although care may occur in hospitals, nursing homes, freestanding hospices, or other long-term care facilities. Central to the hospice model is the concept that everyone deserves to die free of pain, with dignity and support for their families. Hospice strives to provide care to patients regardless of age, ethnicity, race, religion, gender, or disease process (NHPCO, 2008).

**Family-Focused**

Hospice is a family-focused, holistic model of care. Hospice strives to help patients and families address physical, psychosocial, and spiritual issues while preparing for the patient’s death (Canadian Hospice Palliative Care Association [CHPCA], 2002). Patients typically are part of a larger family group and families commonly serve as primary care providers; thus hospice care and support are provided to the patient and family as a unit (NHPCO, 2008; CHPCA, 2002). This support is provided to patients’ families throughout enrollment and up to one year for bereavement follow-up (NHPCO, 2008).

**Related Terms**

The following definitions apply to the purposes of this study and are not intended to be inclusive of all terms applying to hospice research and care.

- *Live Hospice Discharge*—The removal of hospice benefits or services by the providing agency for reasons of extended prognosis or other criteria, which in turn renders the patient ineligible for Medicare Hospice Benefits. This definition excludes those persons who choose to withdraw from service and resume curative treatments or change providers.
Figure 2.1 Interprofessional Hospice Team (Adapted from NHPCO, 2008)

- **Extended Prognosis**—Occurs when a hospice patient’s disease process or admitting diagnosis can no longer be certified as likely terminal within six months.

- **Terminal Illness**—An irreversible illness for which there is no cure and the prognosis is fatal; a life expectancy of six months or less (Social Security Act, 2003).

**Medicare Hospice Benefit**

The Medicare hospice benefit (CMS-HB) was created through passage of the Tax Equity and Fiscal Responsibility Act (TERFA) in 1982. Provision of hospice benefits is funded directly by Medicare Part A at a current base per diem rate of approximately $145; exact rates vary by region (Center for Medicare and Medicaid Services [CMS], 2009). CMS-HB is the single largest hospice payer in the U.S., providing coverage to nearly 85% of hospice patients, with Medicare-certified hospices accounting for 95% of all hospices. Hospice is a growing health industry: in 1983 there were 45 CMS certified hospices; in 2011, there are 4,700 hospices nationwide.
Overall, more than 1.5 million Americans utilize hospice services every year. According to the NHPCO, approximately 42% of deaths in the U.S. occur while the patient is under hospice care (NHPCO, 2010). The Center for Medicare Services reports that 40% of Medicare beneficiary decedents utilized hospice prior to death in 2007 (MedPac, 2008). Researchers project the saving of as much as $2,309 per patient by using hospice services instead of traditional medical treatments (Taylor et al., 2007).

Nonetheless, there has been a call from providers to change the CMS-HB. Jon Keyserling, Vice President of Public Policy and General Counsel to the National Hospice Foundation, made the following statement regarding CMS-HB:

Since its inception a quarter century ago the Medicare Hospice Benefit has been an incredible success and an invaluable resource for millions of patients and their families. As the healthcare delivery system has evolved over those 25 years, the Medicare benefit has remained virtually unchanged. To better serve the needs of the nation’s dying, the benefit needs adjusting so that hospice can expand its reach and commitment to high quality care (NHF, 2009).

The CMS-HB is based on the cancer trajectory and does not account for the variance seen in non-malignant disease processes. Anecdotally, many hospice advocates feel that the CMS-HB should be updated to compensate for the changes in the population that hospice serves.

Hospice enrollment will continue to grow as the American population ages and the number of persons living with a chronic disease increases. However, the hospice funding payment reform implemented in 2008 may serve to limit enrollment through caps and other measures aimed at reducing costs (HAA, 2008).

The Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) Hospice Benefit is the only Federal program similar to the MHB. CHAMPUS-HB mirrors CMS-HB eligibility and reimbursement conditions. Many private insurance companies also use the CMS-HB as a guideline for eligibility and reimbursement criteria (NHF, 2008).
Federal Patient Self-Determination Act

The Federal Patient Self-Determination Act (PSDA) was enacted on November 5, 1990 as Section 4206 and 4751 of the Omnibus Budget Reconciliation Act of 1990, P.L. 101-508 (Summary of the Patient Self-Determination Act, n.d.). Although popularly referred to as an Act, the PSDA is an amendment to federal Medicare and Medicaid law. The PSDA focuses on patient rights and serves to strengthen the existing hospice benefit by reinforcing “individuals' constitutional right to determine their final health care” (P.L. 101-508 as cited by McCloskey, E., 1991).

Operation Restore Trust

In 1995, the Office of the Inspector General (OIG) announced the creation of the program Operation Restore Trust (ORT). ORT was intended to restore confidence, combat waste, and limit abuse in Medicare and Medicaid, including hospice programs in California, Florida, Illinois, New York, and Texas. The program was extended to all Medicare service areas in 1997. ORT findings included overpayment of approximately $23 for every $1 in services provided (USDHHS, 2000). ORT efforts over five years successfully recovered nearly $2 billion dollars and resulted in multiple indictments of providers (USDHHS, 2000). ORT’s effect was described as follows:

Operation Restore Trust and similar enforcement activities may be restoring confidence that inappropriate expenditures are being wrung out of the hospice system. But at the same time, they are also creating distrust, particularly among those with noncancerous conditions, about whether they will receive the benefits for which they are eligible and to which they are entitled. In part, this is a consequence of the chilling effect (real or perceived) that aggressive enforcement is having on physicians and hospice medical directors who certify eligibility to the program (Morris, 2003, p. 1).

The current regulatory environment may add to the dilemma of prognosis, and eligibility criteria providers must navigate to provide for patients at the end of life (Morris, 2003).
The Patient Protection and Affordable Care Act

The health care reform bill known as Patient Protection and Affordable Care Act (PPACA) was signed into law on March 3, 2010. As of December 7, 2010, only 18 of the 40 specific regulations implementing PPACA’s requirements have been published (Burgess, 2011). The PPACA impacts hospice in several ways, including quality, data collection, accountability, payment reform, and access to care.

According to Burgess (2010), the PPACA addresses the issue of hospice quality by requiring hospices to report quality data measures (to be determined no later than October 1, 2012) to the Secretary of the Department of Health and Human Services (DHHS) starting in 2014. The PEACE Project and AIM Project have been offered as likely sources of the quality measures. Additionally, as many as 15 hospice programs will participate in a concurrent care demonstration to determine whether providing beneficiaries hospice and other Medicare services improve patient care, quality-of-life, and cost-effectiveness.

Starting January 1, 2011, the DHHS Secretary began to collect data to revise hospice payments including cost and charge information, charitable contributions, patient visits, and other information as deemed appropriate. Also beginning January 1, 2011, prior to the 180th day of service, the hospice physician or nurse practitioner must have a face-to-face meeting with the patient to determine continued eligibility. The PPACA also requires medical review of hospice patients with lengths of stay over 180 days for programs exceeding the percentage of such cases specified by the DHHS Secretary. Beginning in 2013, the DHHS Secretary will implement revisions to the payment methodology, which determines the rates for home care and other services. These revisions may include adjustments of the per diem rates due to resource intensity. Finally, the PPACA allows for children to receive concurrent care for hospice services without waiving the right for coverage for the treatment of their illnesses (Burgess, 2010).

Currently, the PPACA is under review by the U.S. Justice Department and the Supreme Court because the PPACA was ruled unconstitutional by Justice Rodger Vinson on January 31, 2011 (Kaiser Health News, 2011). The future of the PPACA and its
potential impact on hospice care remains uncertain as legislative review unfolds in the U.S. legal system.

STATE OF THE SCIENCE

In alignment with transcendental phenomenology posited by philosopher Clark Moustakas (1994), the literature review frames the research problem and sets the stage for inquiry by defining the state of the science and indicating the direction of the proposed research. Therefore, a comprehensive review of extant literature, including theoretical and empirical works, was conducted to provide an overview of the state of the science related to hospice discharge. The goal of this integrative review was to examine the relevant literature and nurture a more complete understanding of hospice discharge and the outcomes of persons discharged alive from hospice care.

The following research questions guided the review of literature:

• What is known about live hospice discharge?
  o What are the outcomes of patients discharged from hospice?
  o What is the gap in the literature regarding hospice discharge?

Hospice has been a topic of serious discussion and research since the end of the 20th century. Prior to establishing the first hospice organization and before any legislation was enacted regarding hospice, research focused on the value and benefits of the hospice concept. The creation of the Medicare hospice benefit quantified and articulated the guidelines for hospice enrollment seen today. Consequently, the implementation of the Medicare hospice benefit and other legislation since 1980 sets the time frame for this review.

The search for relevant literature was limited to the EBSCO research database for citations published after 1980, using the keyword Hospice* (*truncated search including all alternate endings). The terms Discharge*, Alive/live, After/post, Decertif*, and Eligibil* were further utilized to delimit the sample. The EBSCO database includes access to CINAHL, MEDLINE, military, government, and PsycInfo publications. This search resulted in a pool of 8,261 references. Further restrictions regarding language
resulted in 174 articles. Abstracts were reviewed and selected for potential inclusion in the review based on each article’s inclusion of the topic hospice discharge. Forty-nine articles with some reference to the term “hospice discharge” were selected for critical review. Eventually, 12 articles were chosen for inclusion based on specific relevance to the topic; six articles were directly related to hospice discharge and six others addressed hospice survival rates. Articles excluded from the review were those that did not specifically address the phenomenon of live hospice discharge.

The majority of extant research is based on secondary analysis of data collected by the National Center for Health Statistics’ (NCHS) National Home and Hospice Care Survey (NHHCS) from 1996 – 1998. Collectively, these articles attempt to quantify and describe the outcomes and characteristics of hospice patients. Commonalities were identified and the literature was categorized into the following dimensions: predictors and characteristics, prognostication, ethnic disparities, and policy issues.

**Predictors and Characteristics**

Kutner et al. (2002) used data obtained from the National Center for Health Statistics’ National Home and Hospice Care Survey to identify rates and predictors of live hospice discharge. Records of over 800,000 discharged patients from 1996 – 1998 were used in the retrospective comparative design. The majority of patients were discharged deceased, while 45,875 patients were discharged alive. The researchers found that patients discharged alive from hospice had longer lengths of service, non-cancer diagnoses, and better functional status than those discharged deceased (Kutner et al., 2002). Although the use of a large, nationally representative sample lends strength to the study, it is based on a secondary database and thus limits the study’s scope.

In a more recent study by Kutner et al. (2004), researchers sought to describe the outcomes and characteristics of patients discharged alive from hospice. This longitudinal, prospective cohort study included 164 English-speaking adults recruited from 18 participating hospices. A telephone survey was used to follow participants for six months or until death. Descriptive demographic data were obtained from records of the
discharging hospice. The researchers found that 35% of participants died within six-months post-discharge from hospice. The strongest predictor of death was the family report of decline in the participant’s condition. Strengths of the Kutner et al. (2004) study include its heterogeneous sample and longitudinal design. The authors reported that potential selection bias and sample size were limitations of the study. The findings of this study indicate a need to follow-up with patients discharged from hospice alive so that the experience of being discharged from hospice can be examined in a more qualitative fashion. Table 2.1 (below) provides the reader additional information regarding patient outcomes following hospice discharge as presented by Kutner et al. (2004).

Cassarett and colleagues (2001), using a retrospective cohort study design, identified predictors of hospice withdrawal. Data from approximately 1,700 first-time hospice enrollees were collected from date of admission until death or discharge. Ninety-eight patients were discharged due to ineligibility and 260 eligible patients withdrew from hospice voluntarily. These researchers found that eligible patients were more likely to withdraw from hospice if they were male, less than 65 years old, did not have cancer, lacked a do not resuscitate (DNR) order, and did not have an intravenous access device or symptoms needing intervention. Cassarett et al. (2001) did not specifically study patients discharged for ineligibility, but they did describe similarities in the two populations. Furthermore, the authors stated that it was possible some patients might have been classified incorrectly as an eligible withdrawal when in fact they were ineligible. This limitation reinforces the need for more research to determine the outcomes of patients after hospice discharge and to establish or verify the reason for hospice discharge.
Table 2.1 Outcomes Six Months after Hospice Discharge (from Kutner et al., 2004)

<table>
<thead>
<tr>
<th>Discharged patients with follow-up available (n = 139)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dead within 6 months (n = 48; 35%)</td>
</tr>
<tr>
<td>Alive at 6 months (n = 91; 65%)</td>
</tr>
<tr>
<td>Hospice readmit</td>
</tr>
<tr>
<td>(n = 33; 69%)</td>
</tr>
<tr>
<td>No hospice readmit</td>
</tr>
<tr>
<td>(n = 15; 31%)</td>
</tr>
<tr>
<td>Hospice readmit</td>
</tr>
<tr>
<td>(n = 10; 11%)</td>
</tr>
<tr>
<td>No hospice readmit</td>
</tr>
<tr>
<td>(n = 81; 89%)</td>
</tr>
</tbody>
</table>

Prognostication

One of the factors that presents a challenge in decisions regarding the temporal constraints surrounding admission into a hospice program and live hospice discharge relates to prognostication and prediction of life expectancy. Murray et al. (2005) conducted a literature review to describe the current understanding of disease trajectories and how those related to clinical implications. Murray et al. (2005) described three current trajectories related to various disease processes: (a) Trajectory 1—steady progression clear terminal phase (e.g., cancer), (b) Trajectory 2—longterm limitations with intermittent serious episodes and sudden unexpected death (e.g., respiratory and heart failure), and (c) Trajectory 3—prolonged gradual decline (e.g., dementia). The authors encouraged the use of these trajectory models to open a dialogue with patients and their care providers with the intention of establishing a plan of care appropriate to the needs and desires of the patient and their disease process. Limitations to the paper included the absence of other trajectories related to psychosocial or spiritual dimensions in the discussion. Murray and colleagues (2005) suggested palliative care be provided not only in the last few weeks of life but alongside curative treatment over the course of the disease processes.

Mitchell et al. (2010) conducted a prospective cohort study of 606 residents with advanced dementia in 21 Boston area nursing homes. The purpose of the study was to validate the Advanced Dementia Prognostication Tool (ADEPT) and compare it to hospice guidelines. Limitations to the study included a report by the authors that the accuracy of the ADEPT could be improved with the addition of additional variables. Further, the study sample consisted of predominantly Caucasians from one geographical
area and the ADEPT was not validated with patients residing in the community. Findings of the study indicate the ADEPT tool score could be used as an indicator to predict death within six months. However, this was only modestly more accurate than the hospice eligibility guidelines. Mitchell and colleagues (2010) suggested that due to the difficulty in prognostication of the population, care should be provided to patients based on treatment goals instead of life expectancy.

**Ethnic Disparities**

Kapo et al. (2005) studied 358 patients discharged from hospice to determine if African American patients leaving hospice returned prior to death. This retrospective cohort study analyzed data derived from electronic medical records and chart reviews. Study findings indicated that African Americans discharged from hospice were less likely to return to hospice service prior to death when compared to other racial groups. The study was enhanced by its use of a large heterogeneous sample. The choice to use a secondary database of medical records from one facility was addressed and defended, although this could represent a threat to the study’s validity. Kapo et al.’s (2005) study, like other authors in this review, did not address experiential data regarding quality of life or the meaning of being discharged from hospice.

The NHPCO (2008) reported that hospice is chosen predominantly by non-Hispanic Caucasians. The reasons why persons of other races and ethnicities enroll in hospice less frequently remains unknown, but cultural beliefs have been suggested as a possible cause (Kapo et al., 2005). The findings of Kapo et al.’s (2005) study indicate live hospice discharges may exacerbate preexisting health disparities and access to care issues already prevalent in the African American population.

**Policy Issues**

Carlson et al. (2008) conducted a study examining implications of expanding the Medicare Hospice Benefit. Lynn and Forlini (2001) chose to focus on the terminology
used in hospice eligibility, encouraging providers to use language and services directly targeted to the population served by hospice.

Carlson and colleagues (2008) delineated the implications of expanding Medicare hospice benefit eligibility. These authors addressed the history of hospice and current policy issues. In addition, they discussed hospice target population, Medicare hospice benefit eligibility, and barriers to enrollment (Carlson et al., 2008). Specifically, “[t]he disadvantage of retaining the current eligibility criteria is that it may be increasingly difficult for individuals with uncertain diagnoses and more complex treatment options to access hospice in a timely manner...particularly for individuals with non-cancer diagnoses” (Carlson et al., 2008, p. 440).

Potential author biases toward a hospital-based palliative care team model versus hospice care do not diminish the value Carlson et al.’s (2008) contribution. In fact, the discussion of alternatives to hospice and the Medicare hospice benefits serve to strengthen and inform the debate. The authors clearly explicated the difficulties involved in expanding hospice benefit eligibility and associated funding increases in addition to providing support for the provision of palliative care. Carlson et al. (2008) provided valuable information regarding the implications of expanding the Medicare hospice benefit to persons currently considered ineligible as well as the consequences of maintaining status quo:

The decision to move hospice in a new direction and substantially alter eligibility for the MHB, although a popular policy solution, is a decision to restructure our entire system for palliative care delivery. The advantages and challenges of such a decision, and its effect on patients and families, must be carefully considered and compared with the consequences of retaining the existing benefit (p. 442).

Lynn and Forlini (2001) critiqued the Centers for Medicare and Medicaid Services requirement of “terminal status” as limiting access to the Medicare hospice benefit. These authors suggested using the term “serious and complex” rather than “terminal” (Lynn & Forlini, 2001). The term “serious and complex” “applies to patients with conditions that are already quite disabling, are expected to be fatal, and require
ongoing health care” (Lynn & Forlini, 2006, p. 316). This change in language could broaden hospice eligibility and possibly improve quality of life of patients who cannot be classified as terminal by allowing the reprioritization and repackaging of health care services provided to those with a “serious and complex illness,” which in turn would allow patient care to suit patient needs (Lynn & Forlini, 2001). Limitations to the paper included the authors’ failure to recognize the “downside” of expanding the current eligibility guidelines, particularly as it pertains to taxpayer cost; however, the authors successfully opened dialogue about the issue. Lynn and Forlini (2001) encouraged providers to utilize language and services directly targeted to the growing population of hospice patients with chronic noncancerous disease processes.

**Research Synthesis**

Kutner et al. (2002) studied the characteristics of hospice discharges in an attempt to determine predictors of live hospice discharge. Kutner et al.’s (2004) study suggested that investigations into patient experience of live hospice discharge would be useful in evaluating their impact on patients. Yet, to date, the lived experience of patients discharged alive from hospice remains an unexplored topic in the literature.

Findings reported in the Kutner et al. (2002) study suggested that a disproportionate percentage of patients discharged from hospice have chronic, noncancerous diagnoses. The authors posited that psychosocial implications such as emotional distress of both healthcare providers and family members might be attributed to live hospice discharges. Furthermore, the literature suggests that patients discharged from hospice alive are likely to die without receiving hospice care immediately prior to death, potentially increasing burdens on the patient, family, and the primary caregiver (Kapo et al., 2005).

The studies reviewed herein state that the prediction of a six-month life expectancy for persons with chronic illnesses is an unwise assumption due to the unpredictable trajectory commonly seen in these diseases (Carlson et al., 2008; Christakis & Escarce, 1996; Connor et al., 2007; Han et al., 2007; Kapo et al., 2005; Kutner et al.,
2002, 2004; Lynn & Forlini, 2001; Rickerson et al., 2005). These authors suggest expanding the temporal limitations of hospice enrollment and creating bridge programs that are intended to transition seriously ill patients into hospice or palliative care programs. It is hoped that these programs will accommodate the slow declines punctuated by exacerbations often seen in nonmalignant disease.

**Common Findings**

The literature overwhelmingly reports that patients who suffer from nonmalignant disease processes such as heart failure, dementia, and chronic obstructive pulmonary disease are more likely to be discharged alive from hospice than patients diagnosed with malignant diseases (Cassarett et al., 2001; Kapo et al., 2005; Kutner et al., 2002, 2004). Additionally, these patients are thought to be at an increased risk for reduced access to health services after hospice discharge due to the loss of continuity of care for their serious and complex conditions (Kapo et al., 2005; Lynn & Forlini, 2001).

**Operational Definitions and Instruments**

Few studies addressed herein discussed how the measurement variables related to hospice were defined or operationalized. Among these measurements were: (a) length of stay or service, (b) admission diagnosis, (c) discharge status, (d) co-morbidities, and (e) demographic information. Although these variables were noted consistently in the empirical studies, it was difficult to ascertain the reliability and validity of the measurement strategies due to the secondary data sources (e.g., medical records, chart review) used to collect the information (Christakis & Escarce, 1996; Connor et al., 2007; Han et al., 2007; Kapo et al., 2005; Kutner et al., 2002).

In addition to the data collected from secondary sources, Kutner et al. (2004) and Rickerson et al. (2005) also reported using investigator-developed surveys to collect data directly from participating hospice organizations and participants. Information retrieved by the researcher-developed surveys included perceptions of services provided, demographics, patient conditions, reasons for discharge, and length of enrollment. No information regarding reliability or validity testing is available for either instrument.
However, the Kutner et al. (2004) survey form is readily available at the following web address: www.uchsc.edu/popcrn.

These studies describe participant characteristics but do not predict behaviors. As such, it is appropriate to use secondary data collected by other sources. However, secondary data, and in particular medical records, may not be reliable or complete. This casts uncertainty on the accuracy of reported results, and caution should be used prior to generalizing these results with other populations.

**SUMMARY**

The literature presented describes the demographics and outcomes of patients discharged from hospice. The experience of being discharged from hospice and the effects of that discharge (if any) on the patient, families and providers remains unknown. Although the population hospice was developed to serve is changing, the CMS-HB has not followed suit. Hospice benefit guidelines need to be updated to compensate for the changes in the population that hospice serves. Hospice enrollment is projected to increase as the population ages and the number of persons living with a chronic disease multiplies. On the other hand, the hospice funding payment reform implemented in 2008 may limit enrollment through caps and other measures aimed at reducing costs (NHF, 2008). Although the 2008 payment model takes into account high beginning and end costs seen in hospice, the intent is to remove the incentive for hospice agencies to enroll patient groups who may survive longer than the current temporal limitation permits, thus recouping the loss from shorter stays. The ultimate result may be fewer chronically ill patients enrolled into hospice care.

The literature cited generally contains consistent operational definitions, similar methodologies, and often the same data set. Unsurprisingly, most of the authors arrived at similar conclusions regarding the results of their particular studies. This literature review exemplifies the need for further research in the area of hospice discharge, specifically the experience of being discharged from hospice alive.
GAPS IN THE LITERATURE

Live hospice discharge is an under-researched and often overlooked area in hospice research with great potential for improving patient outcomes. While the extant literature provides valuable information regarding the quantitative aspects of a live discharge from hospice such as patient characteristics and outcome data, there is paucity of research describing the impact or meaning of live hospice discharge on patients and their families. These gaps in the literature relate directly to the absence of patients’ voices and their ongoing experiences with the healthcare system after hospice discharge. What remains to be investigated are patients’ perceived quality of life after hospice discharge as well as the meaning they ascribe to the actual hospice discharge.

Kapo et al. (2005) hypothesized that live discharge from hospice might adversely affect patients’ quality of life and health status, resulting in increased patient suffering. Understanding the meaning of the live hospice discharge experience may lead to new possibilities for palliative and hospice care as well as revisions in current Medicare and Medicaid policy, guidelines, and discharge procedures. The perceptions of patients discharged alive from hospice and that of their families will provide health care workers with information that can be used to assist patients in transitioning from hospice and improve end-of-life care.

ADDRESSING THE GAPS

The transcendental phenomenological approach of philosopher and psychologist Clark Moustakas offers one approach to accessing and understanding the phenomenon of being discharged from hospice alive. In his work related to caring, Moustakas stresses that “intervening caring” means to: “…attend fully, to feel some responsibility for, to want to protect from further pain…to watch over in a protective and supportive way, to feel compassion for…. Caring means to enter [the other’s] world, to understand the views, feelings, and experiences” (1995, p. 146). Moustakas’ notion of “anticipatory caring as a concernful presence” (p. 147) speaks to the essence of being-with another during a period of breakdown or suffering. Further explained in Chapter III, Moustakas’
notions will guide understanding the essence of the phenomenon of being discharged alive and provide the philosophical underpinnings for this study.
CHAPTER III: METHODS

Chapter III details the philosophical framework and methodology used to describe the lived experience of being discharged alive from hospice; it also addresses the gaps in the literature relating to the absence of the voices of patients after hospice discharge as well as the voices of family members. Clark Moustakas’s (1994) transcendental phenomenological approach guided the exploration and explication of the meaning of the phenomenon. The philosophical underpinnings and methodology allows participants’ voices to be heard and illuminates participants’ views of health status and quality of life after hospice discharge. Additionally, the meaning ascribed to the actual hospice discharge can be better ascertained via phenomenology.

Thus, the following research questions guided the study:

1. How do participants (adults and family members) perceive and describe the experience of being discharged alive from hospice?
2. How do participants (adults and family members) perceive and describe their quality of life after a live hospice discharge?

DESIGN

Moustakas’s (1994) approach to transcendental phenomenology is based, in part, upon Edmond Husserl’s philosophy (1900/2008) of subjective openness and is considered psychological and descriptive in nature. Moustakas’s approach provides an organized, disciplined, and systematic method for conducting a scientific study in alignment with Husserl’s philosophy. The outcome of a transcendental phenomenological study is a structured-textural definition describing the universal meaning, or essence, of the phenomenon as shared by those experiencing it.

Methods and procedures for conducting research in accordance with Moustakas’s approach require that the researcher base the inquiry on a phenomenon that holds autobiographical meaning as well as social significance. The question should grow from an intense interest in the topic; thus, the researcher’s own excitement and curiosity should
inspire and drive the research. The current study was driven by the personal experience of my father’s live hospice discharge and a professional desire to improve the quality of care for dying patients and their families.

Moustakas’s (1994) research paradigm has several distinct characteristics: it seeks to reveal the essence of human experience, it seeks the qualitative factors of behavior and experience, it engages the total self of the participants sustaining personal and passionate involvement, it does not predict or determine causal relationships, and it illuminates the experience through comprehensive descriptions rather than measurements. This study describes the experience of being discharged from hospice alive from the perspective of the adults and their family members and has been designed specifically to meet each of the expectations addressed by Moustakas (1994).

Philosophical Notions

Four Husserlian philosophical notions are fundamental to understanding Moustakas’s (1994) transcendental phenomenology: epoche, transcendental phenomenological reduction, imaginative variation, and synthesis.

Epoche is the effort made by the researcher to prepare for the study, to derive new knowledge, to remain free of preconceptions or judgments, and to remain open and receptive to the experience related by the participants (Husserl, 1913/1983; Moustakas, 1994). True epoche is rarely achieved; however, it is important for researchers to recognize their own prejudices so that they may be open to emergent meanings of others’ experiences (Moustakas, 1994). My knowledge and personal experience of having a family member discharged alive from hospice was examined and recognized as part of the study to increase awareness of any influence my experiences may have had on the expressions of participants or my own interpretive analysis. Personal and methodological journals were used throughout the study to ensure the epoche process (Lincoln & Guba, 1985).

Transcendental phenomenological reduction is the process by which each participant’s experience is considered independently (Moustakas, 1994). Each experience
is reduced to its invariant or unchanging constituents. These unchanging components are described in textural or richly detailed language to establish the full context of the experience. This degree of texture allows us to understand participants’ experiences in new ways and to cluster emerging themes. Themes can then be organized into a coherent textural description of the phenomenon (Moustakas, 1994).

Imaginative variation seeks to identify all possible organizational meanings of an experience from multiple divergent perspectives (Moustakas, 1994). Facts and measurable entities allow for larger meanings and essences to be explored as one examines how individual parts of an experience are related. This intuitive process enables one to understand how the experience became what it is and to begin to derive common structural themes from the textural descriptions; in turn, one can determine if a common thread or essence is revealed (Moustakas, 1994).

Synthesis is the integration of all themes into an organized description of the shared commonalities of the experience (Moustakas, 1994). It is through the inter-subjective experience between participant and researcher that the phenomenon may truly become known.

Sample

A purposive sampling design was employed to identify individuals or family members of individuals who had experienced a live hospice discharge. Purposive sampling involves the selection of participants based on their characteristics or first-hand experience of a phenomenon (Creswell, 2008; Polit & Beck, 2004). Through purposive sampling of adults with direct experience of the phenomenon of interest, the study provided data allowing for in-depth understanding of the experience.

The objective of a transcendental phenomenological study is to understand a particular experience from the perspective of individuals who have direct experience with the phenomenon (Moustakas, 1994). Although there are no strict criteria to determine sample size in qualitative studies (Lincoln & Guba, 1985), Creswell (2007) recommends in-depth interviews with a minimum of 10 individuals. Therefore, recruitment for this
The study ended with the enrollment of 12 participants when no new themes emerged from the data collected rather than attempting to set a predetermined enrollment quota.

Enrollment in the study was limited to volunteers who met the following inclusionary criteria: (a) adults 18 years of age or older, (b) discharge from hospice alive due to decertification, (c) adult family members of individuals who have been discharged from hospice alive due to decertification, (d) ability to speak and understand English, and (e) willingness to participate in interviews. No participants were excluded based on race, ethnicity, gender, religion, or socioeconomic status.

**Recruitment and Setting**

This study was guided by, and adhered to, the ethical principles of research with human participants, including, but not limited to, maintaining clear participant agreements, recognizing privacy and confidentiality, and full disclosure of the research (Moustakas, 1994). Recruitment began after obtaining approval from The University of Texas Medical Branch (UTMB) Institutional Review Board (IRB). Two regional hospice organizations agreed to participate in the study as facilitators to recruitment (Appendix A). The participating hospice agencies distributed recruitment flyers (Appendix B) detailing the study and the principal investigator’s (PI) contact information to patients as they were discharged from hospice services. Recruitment flyers also invited family members of patients discharged alive from hospice to participate in the study. Persons who were interested in participating in the study individually contacted the researcher.

Network or snowball sampling also was employed to recruit volunteers whom the researcher knew or other participants who had the experience of being discharged alive from hospice either personally or through the experience of a family member. These volunteers were afforded the same protection as those recruited through the participating hospice agencies.

The study was explained and questions answered before obtaining a signed informed consent. Those volunteers who discharged from hospice alive were notified that there would be no alteration in their care should they choose not to participate. It was also
explained that participation was voluntary and that participants could withdraw from the study at any time. Participants were informed that all personal information would be held in strict confidence. Each participant was assigned a pseudonym and unique identification number in order to protect the privacy of the volunteers. The enrollment process included obtaining informed consent (Appendix C) and the completion of a demographic questionnaire (Appendix D). The demographic form aided the collection of information on race, age, gender, religion, and discharge date.

As a part of the enrollment process, all participants were asked to journal or reflect on the experience of being discharged alive from hospice in preparation for the first interview (Moustakas, 1994). These reflections and journals gave the participant an opportunity to collect and order their thoughts but were not reviewed by the researcher.

Individual participants determined the setting for data collection. All data collection, including the enrollment process and interviews, occurred at a time and place of the participants’ choosing. Allowing the participants to choose a place perceived as safe and comfortable is thought to facilitate open and honest communication (Richards & Morse, 2007).

**Data Collection**

Understanding the phenomenon from the perspective of those who have lived it was achieved through in-depth, face-to-face interviews with the intent to capture the meaning of the live hospice discharge experience in the participant’s own words (Moustakas, 1994). All interviews were conducted by the PI. Interview questions were unstructured, open-ended, and used probes as necessary to gather additional information (Appendix E). The phenomenological researcher acts as the instrument during these interviews (Munhall, 2007), modifying and adjusting the flow of the interview according to the needs and direction of the participant (Rubin & Rubin, 2005). The initial interview question was, “Tell me about being discharged from hospice.” This question was followed by probe questions determined by the interview’s progression such as, “Tell me more about that” (Moustakas, 1994; Rubin & Rubin, 2005). The initial interview question
asked of family members was, “Tell me about [name] being discharged from hospice.” An example of a probe question that followed this was, “What was that like for you?”

The length of each interview varied from 30 to 130 minutes depending on participant fatigue (Rubin & Rubin, 2005). Each participant was interviewed at least twice to develop rapport between the participant and researcher through prolonged engagement (Lincoln & Guba, 1985; Rubin & Rubin, 2005). Field notes were kept during and after interviews to note participant behavior, including expressions and mannerisms or other data pertinent to the context or setting of the interview. Methodological journals were maintained to establish a decision trail made by the researcher to inform future interviews or data analysis (Lincoln & Guba, 1985).

All interviews were audio recorded and transcribed verbatim by the PI. These audio files were identified with the participant’s unique identification number. All identifiable information was removed from the transcripts. The PI reviewed transcripts for accuracy. MAX QDA is a software program distributed by VERBI of Germany and used by qualitative researchers worldwide (Creswell, 2007). This study used MAX QDA for storing and managing the narrative data.

Data Analysis

Moustakas’s (1994) approach to data analysis begins with the verbatim transcription of each participant interview. The researcher reads each transcript several times to become familiar with the data. Statements relevant to the experience of live hospice discharge are identified in each transcript. Moustakas (1994) refers to these statements as the invariant meaning units. The meaning units are clustered into themes. The meaning units and themes lead to development of a textural description of the experience.

Textural descriptions are highly detailed, giving the experience context and depth, and describe what was experienced. After reflection on each description, the PI used Moustakas’s notion of imaginative variation to develop a structural description of the experience. Structural descriptions describe how the phenomenon was experienced. The
fundamental meaning or essence of each individual’s experience was revealed as textural and structural descriptions came together. Finally, the researcher synthesized a composite description by integrating all individual descriptions into a universal description. Moustakas’s approach enabled the PI to maintain the uniqueness of each participant's lived experience while allowing a description and understanding of the essence of the phenomenon (Moustakas, 1994).

Data analysis was conducted with the assistance of an interpretive research team, which included some members of the dissertation committee and two doctoral students familiar with phenomenology. Throughout the data analysis process, sections of coded transcripts related to significant statements or particular interpretations were reviewed by the research team to ensure accuracy and limit bias. In addition, the PI kept a personal (reflective) journal to record feelings or insights that could influence the interview progression or interpretations (Lincoln & Guba, 1985). This reflective journal enabled the PI’s own perceptions, feelings, and intuitions to be acknowledged and understood in order to recognize conflicts and challenges as well as harmony and balance (Moustakas, 1995).

**Rigor**

Moustakas’s (1994) method of human science research is open-ended and does not have one single definitive or exclusive requirement for rigor; each researcher is responsible for establishing methods and procedures for data collection and analysis. Therefore, rigor for this research study was achieved by following the methods for trustworthiness established by Lincoln and Guba (1985). These criteria are in alignment with the philosophies of both Husserl and Moustakas (Creswell, 2007).

Criteria of trustworthiness include: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability (Lincoln & Guba, 1985). Credibility refers to the likelihood that the findings and interpretations remain faithful to the text (Lincoln & Guba, 1985). In this study, credibility was achieved through maintaining prolonged engagement with the participants and the data through multiple interviews and
triangulation of data collection by utilizing interviews and journals. In addition, an interpretive team enhanced the credibility of the findings by meeting periodically with the PI to discuss interpretations (peer debriefing) (Lincoln & Guba, 1985). Member checks were performed throughout the data collection process. These were achieved at the time of the second interview, when initial interpretations were shared, giving the participant an opportunity to provide additional information or clarify previous statements (Lincoln & Guba, 1985).

Transferability speaks to the potential application of method or techniques to similar populations (Lincoln & Guba, 1985); it was achieved in this study by the development of a thick, rich description of the findings and their context. Dependability was maintained throughout the study and established the overall stability of the study’s findings (Lincoln & Guba, 1985). Dependability was demonstrated through the journaling process and a peer debriefing process. Confirmability of the entire process is demonstrated by keeping a verifiable audit trail (Lincoln & Guba, 1985). This study’s audit trail consisted of field notes, methodological journals, and reflective journals.

PROTECTION OF HUMAN SUBJECTS

The study did not involve the use of any new device, investigative drugs, or medical intervention; therefore, the risk of any serious adverse event was exceptionally low. No physical risks to the participant were anticipated, although participants may have felt sadness as they spoke of their experiences. Participation was completely voluntary. Participants were assured that they could describe only those experiences they wished to share during the interview and were given the opportunity to end the interview at any time. Nevertheless, in the event that a participant might have appeared to be in any physical or mental distress during the interview process, the interview would have been concluded by the researcher immediately. The population of interest included persons of potentially fragile health status; therefore, consideration was given to the health and well being of each participant during the interview process. In addition, referral sources for professional services were available if needed.
Privacy and confidentiality of all participants were maintained throughout the study. Each participant was assigned a unique numerical identifier and a pseudonym for use during the study. Participant information was removed from the audio files prior to the transcription of the interviews. Members of the interpretation team were provided transcribed interview text with all identifiers removed. A master code linking data and participant information was kept in a location separate from the interview data. Access to the raw data was restricted to the researcher only. Data pertinent to the study were stored in a secured area (locked cabinets) in the PI’s office. All data were kept in a locked file cabinet or encrypted file and only the PI had access to the key and code. Audio files containing raw interview data were destroyed at the conclusion of the study. Findings were reported in an aggregate format without identifying individuals. Study findings and interpretations will be explicated in Chapter IV.
CHAPTER IV: ANALYSIS AND FINDINGS

Chapter IV begins by presenting the reader with a description of the study sample demographics and continues with a brief summary of the data gathering and analysis process. Thematic analysis and findings include the emergent primary themes, subthemes, and significant statements derived from participant transcripts that support the themes. Following thematic analysis, textural (what was experienced) and structural (how it was experienced) descriptions of the phenomenon are presented. Finally, the textural and structural descriptions are synthesized into a composite description that reveals the fundamental meaning or essence of being discharged alive from hospice (Moustakas, 1994).

DESCRIPTION OF STUDY SAMPLE

The study included a total of 12 participants recruited with the assistance of two regional hospice organizations. Five participants received care from hospice agencies located in the Harris, Galveston, and Bexar Counties of Texas after 2008. Additionally, four spouses and three adult children of patients who had been discharged decertified from hospice also participated in the study. Table 4.1 (below) presents various demographic and social data to assist readers in determining whether findings were meaningful or applicable to other situations (Lincoln & Guba, 1985).
### Table 4.1 Demographic Data

<table>
<thead>
<tr>
<th>PARTICIPANT (PSEUDONYM)</th>
<th>AGE</th>
<th>RACE</th>
<th>GENDER</th>
<th>PATIENT RELATION</th>
<th>HOSPICE DIAGNOSIS</th>
<th>PATIENT STATUS</th>
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</thead>
<tbody>
<tr>
<td>Adam</td>
<td>78</td>
<td>C</td>
<td>M</td>
<td>Patient</td>
<td>Cancer</td>
<td>Alive</td>
</tr>
<tr>
<td>Alec</td>
<td>51</td>
<td>C</td>
<td>M</td>
<td>Patient</td>
<td>Cirrhosis</td>
<td>Alive</td>
</tr>
<tr>
<td>Andrew</td>
<td>70</td>
<td>C</td>
<td>M</td>
<td>Patient</td>
<td>Cirrhosis</td>
<td>Alive</td>
</tr>
<tr>
<td>Alfred</td>
<td>70</td>
<td>C</td>
<td>M</td>
<td>Patient</td>
<td>COPD</td>
<td>Alive</td>
</tr>
<tr>
<td>Ann</td>
<td>90</td>
<td>C</td>
<td>F</td>
<td>Patient</td>
<td>CHF</td>
<td>Alive</td>
</tr>
<tr>
<td>Billie</td>
<td>79</td>
<td>C</td>
<td>F</td>
<td>Spouse</td>
<td>Cirrhosis</td>
<td>Alive</td>
</tr>
<tr>
<td>Brooke</td>
<td>75</td>
<td>C</td>
<td>F</td>
<td>Spouse</td>
<td>Cancer</td>
<td>Alive</td>
</tr>
<tr>
<td>Blanca</td>
<td>80</td>
<td>C/H</td>
<td>F</td>
<td>Spouse</td>
<td>Alzheimer’s</td>
<td>Alive</td>
</tr>
<tr>
<td>Bobbie</td>
<td>60</td>
<td>C</td>
<td>F</td>
<td>Spouse</td>
<td>CHF</td>
<td>Deceased</td>
</tr>
<tr>
<td>Casey</td>
<td>35</td>
<td>AI</td>
<td>F</td>
<td>Daughter</td>
<td>CHF</td>
<td>Deceased</td>
</tr>
<tr>
<td>Chelsea</td>
<td>40</td>
<td>AI</td>
<td>F</td>
<td>Daughter</td>
<td>CHF</td>
<td>Deceased</td>
</tr>
<tr>
<td>Carmen</td>
<td>49</td>
<td>C</td>
<td>F</td>
<td>Daughter</td>
<td>Alzheimer’s</td>
<td>Deceased</td>
</tr>
</tbody>
</table>

At the time of data collection, all participants lived in suburban areas outside the Houston-Galveston (n=8) or San Antonio areas (n=4) and spoke English as their primary language. Participant ages ranged from 35 to 90 years of age (X: 65 years); education levels varied from high school graduate to doctor of philosophy; professions included engineering (n=1), registered nurse (n=3), licensed vocational nurse (n=1), teacher (n=2), hospice volunteer (n=1), insurance salesperson (n=1), contractor (n=1), accountant (n=1), and administrative assistant (n=1). The majority of participants were Caucasian (84%), two were American Indian (16%), and one identified herself as Hispanic of Caucasian decent (8%). The sample reflects the reported trend of hospice discharges as primarily Caucasian males with non-cancerous disease processes (Cassarett et al., 2001).
DATA GATHERING

Setting

The setting for collecting data was determined by the individual participants in an effort to facilitate open and honest communication (Richards & Morse, 2007). Participants were encouraged to choose a place perceived as safe and comfortable for all data collection, including the enrollment process and interviews. Most participants chose their own residences; however, one interview took place at the researcher’s home.

Interviews

Understanding the meaning of the live hospice discharge experience was achieved through in-depth, face-to-face interviews. All interviews were conducted by the PI using unstructured and open-ended questions and probes such as, “tell me about being discharged from hospice” or “tell me more about that” (Appendix E). Interviews lasted from 30 to 130 minutes with 10 to 15 minute follow-up interviews. A total of 24 interviews were conducted.

Data Analysis

Moustakas’s (1994) approach to data analysis begins with the verbatim transcription of each participant interview. The researcher read each transcript several times to become immersed in the data. Two hundred seventy-five statements relevant to the experience of live hospice discharge were identified from the participant transcripts and recorded separately. Moustakas (1994) refers to these statements as invariant meaning units. The meaning units were clustered into themes. Subsequently, a textural description of the experience was developed using the meaning units and themes.

Textural descriptions were highly detailed, giving the experience context and depth to illustrate “what” was experienced by the participant. After reflection on each textural description, a structural description of “how” the experience occurred was developed. As textural and structural descriptions came together, the fundamental meaning or essence of each individual’s experience was revealed. Finally, the researcher
synthesized a composite description by integrating all individual descriptions into a universal description. Moustakas’s approach enabled the PI to maintain the uniqueness of each participant's lived experience while allowing a description and understanding of the essence of the phenomenon (Moustakas, 1994).

Throughout the data analysis process, sections of coded transcripts, significant statements, or particular interpretations were reviewed by the research team to ensure accuracy and limit bias. A personal (reflective) journal was kept by the PI to record feelings or insights that may have influenced the interview progression or interpretations (Lincoln & Guba, 1985). The reflective journal enabled the researcher to acknowledge her own feelings and perceptions, thus limiting bias (Moustakas, 1995).

**Meaning Units/Themes**

The significant statements removed from the text were clustered into themes and meaning units. The statements and themes might have had overlapping meanings because lived experiences often do not fit in clear, mutually exclusive categories—a common, if unexpected, occurrence in phenomenological research. Moustakas (1994) suggests reducing or removing the overlapping statements. This process of reduction led to the selection of two primary themes: the paradox of hospice discharge and suffering “as...” The paradox of hospice discharge was supported by the following subthemes: having support and needing support, mixed feelings, not dying fast enough, and hospice equals life. Suffering “as...” was supported by the following subthemes: abandonment, unanswered questions, loss of security, loneliness, uncertainty, anger and frustration, physical decline, and bearing exhaustive witness.

The development of the essence of being discharged from hospice alive begins with an introduction of the participants and provides a brief narrative of the overarching theme of their individual experiences. Subthemes are presented along with selected supporting statements derived from the transcripts (Tables 4.2 – 4.13). Immediately following the theme table, a brief description of each subtheme as described by the
participants and interpreted by the researcher is presented. Finally the universal essence of the experience of being discharged from hospice alive is provided.

**INDIVIDUAL DESCRIPTIONS**

The individual textural-structural descriptions of the phenomenon, including quotes from the interviews and introduction of the participants, provide the reader with an understanding of what was experienced (textural description) by the participants and how they experienced the phenomenon (structural description). These individual descriptions illuminate the participant’s perceptions within the context in which they occurred.

**Adam**

A retired engineer, Adam is a 78-year-old Caucasian male who had been a hospice patient because of liver cancer. He was discharged from hospice in November, 2009. Now in remission, Adam lives with his wife, Brooke, who is also a participant of the study. The recurrent theme of Adam’s story was having support. He credited his improved health and his attitude to the available support of his friends and family, particularly Brooke and his children. “I definitely had the backing of the family, and I think the family is a very important thing when you're ill… I felt like I had a pretty good caregiver, and I had a pretty good organization looking out after me.”

**Alec**

A former insurance salesman, Alec is a 51-year-old male Caucasian participant. He was diagnosed with liver cirrhosis and eventually was discharged from hospice in May, 2010. Alec continues to live at home with his wife and children. Alec reported ambivalence regarding his hospice discharge, “...I guess I had a little mixed feelings; but I don’t want to be on Hospice…. That’s a pretty serious thing. I wasn’t too excited to be in Hospice. That’s kind of a finalistic kind of thing.” At the same time Alec recognized that his health was in fact better than it had been at his admission. “It was good and bad
getting off of hospice. The good part was when you’re on hospice, they’ll have a noble death knocking at your door. The bad part was it was easier to get my medicine.”

Andrew

An accountant, husband, and father, Andrew is a 70-year-old male Caucasian diagnosed with liver cirrhosis. Andrew was discharged from hospice in February, 2010. He lives at home with his wife, Billie, who is also a study participant. Andrew summed up his hospice discharge in a matter-of-fact way, “‘you’re not cooperating by dying when we thought you would, and you stabilized instead; so we’re going to have to discharge you.’ They were expecting to meet me, and then go downhill almost any day. Like I said, I wasn’t cooperating.” Andrew implied he was not dying fast enough for hospice and stated very plainly that he was dissatisfied with the care he was provided:

I was all in favor. They basically weren’t doing anything. They had a nurse that came in theoretically once a week. Sometimes they didn’t make it each week; so theoretically once a week. And my opinion is sort of colored because I looked at the financial statements about two or three weeks ago and saw what the company charged for all this.

Alfred

A former building contractor, Alfred is a 70-year-old Caucasian male with end stage chronic obstructive pulmonary disease. He was discharged in March, 2010. Alfred lives with his wife and adult son. He is currently on hospice service with another hospice agency following a hospitalization secondary to COPD exacerbation. Alfred equated hospice with life: “I think hospice is keeping me alive.” After multiple hospitalizations he became aware of the cyclical nature of his illness and in retrospect he credits hospice with his life:

No, like I say, I think [agency name] has kept me alive, and now [agency name]. I figure if it wasn't for them, I'd been dead a long time ago, because I was going to get to the point where I wasn't going back in the hospital anymore…. I mean, you
go in a week, come home a week, go back the next week - that gets old…. I think Hospice has kept me living—I gotta say that.”

Ann

Ann is a 90-year-old Caucasian female with a diagnosis of CHF. She was discharged from hospice in 2008. At the time of the interview Ann was living alone in an assisted living facility. She relied on outside contract providers to assist her with her daily needs. Her daughters visited occasionally and managed her affairs. Ann expressed feelings of abandonment (or desertion) with her previous hospice admission when she related, “they never told me they weren’t coming back, they told my daughter…. I wondered why she [the hospice nurse] didn’t come anymore, they didn’t say goodbye… they [hospice] just stopped coming.”

Billie

Billie is a 79-year-old Caucasian female and is the spouse of Andrew, a participant and former hospice patient. Billie was trained as an LVN and worked as a missionary for many years. Billie focused on the security or “peace of mind” that hospice provided; the discharge from hospice represented an unknown and potentially traumatic event for her and her husband. She said that Andrew’s health improved prior to his discharge allowing him to “do things not allowed on hospice,” as if they should be homebound to qualify for services. The discharge from hospice left Billie with many unanswered questions and fears regarding her husband’s care and impending death: “How can he die at home without going to the hospital? That should happen. We don’t have hospice right now. What would we do? What would I do? Who would I call? I could call my GP, but they don’t make house calls…” These unanswered questions added to the sense of fear and burden Billie already had regarding her husband’s impending death.
Brooke

Brooke, a 75-year-old Caucasian female, is the spouse of Adam. She worked closely as a volunteer with her local area hospice agency for many years. Brooke was also very active in her church and other activities. Brooke associated hospice with security. The comfort of “knowing help was just a phone call away” was a considerable loss when her husband was discharged from hospice. She did not discuss her fears or worries about Adam’s condition because she was afraid to upset him. However, she realized his health could decline at any moment and waited for “the other shoe to drop.”

Blanca

Blanca is an 80-year-old Caucasian Hispanic female, the wife of Alberto who had been discharged from hospice, but was unable to participate due to his dementia. Blanca worked for many years as an administrative assistant until she had to retire to provide Alberto constant care and supervision. Blanca struggled with finding support for herself and her husband. He had severe dementia and multiple co-morbidities; consequently, finding both short and long term care was impossible for her. She had no friends or family to rely on, “we don’t have anybody. It’s just him and me.” Facilities near her had refused to admit Alberto because he was labeled “difficult.” She stated, “they said, ‘oh we heard about your husband and we just don’t think we can handle him.’” Her quality of life was poor. Isolated, sleep deprived, and cut-off from support, she strived to “keep him home until the next time they take him away.” Then she will start the cycle again.

Bobbie

Bobbie is a 60-year-old Caucasian female, the widow of Aaron, a former hospice patient with congestive heart failure (CHF) who had been discharged from hospice and died several weeks afterward. Bobbie is a registered nurse and served as Aaron’s primary care provider. She lives alone and has two adult daughters, Casey and Chelsea, both of whom were participants in this study. Bobbie’s story was replete with references to feelings of uncertainty regarding her husband’s discharge. For Bobbie there was an “on
again, off again” aspect to the discharge process that left her feeling that it was possible the discharge was not going to be completed and her husband could stay on hospice services. The hospice eventually discharged Aaron on a day that Bobbie was at work; Bobbie was unable to participate in the process, leaving her with feelings of powerlessness and abandonment.

**Casey**

The 35-year-old daughter of Aaron and Bobbie, Casey is an American Indian female and registered nurse. She is married with one small child at home. Currently, Casey is an instructor at an area nursing school. Shortly after his discharge from hospice her father, Aaron, died of complications arising from CHF. Casey’s story focused on suffering, both before and after hospice. She discussed the fact that her father had suffered from his illness long before entering hospice service, “he suffered all his adult life. That’s why we chose hospice, to alleviate some of that.” While Aaron was on hospice, he finally had some control over his symptoms. With that control came a well-being the family had not known previously. Following the discharge, Casey’s father’s condition deteriorated quickly, “you can’t just pick up where you left off—it doesn’t work that way, he had to start over with his health care. Because of that he suffered, his independence was gone, he was back to being a burden on the family, he hurt all the time, and he was suffocating.” Despite the family’s efforts to acquire needed equipment and medication, Aaron died without the resources he needed within weeks of his discharge.

**Chelsea**

Chelsea is the 40-year-old daughter of Aaron and sister of Casey. An American Indian female, Chelsea is a wife, mother of 3 adult daughters, full time graduate student, and former middle school teacher. She lives in San Antonio with her husband and youngest daughter. Chelsea expressed anger and frustration with the hospice discharge, “I’m just angry and frustrated…. If they would have transitioned him out, as they transitioned him in and they made sure that he had the tools necessary.” However, it
seemed that much of the anger and frustration was related to the difficulty Chelsea and her family experienced during the period of time immediately after the discharge when they were initiating services with new providers. She remained angry because the care and services her father needed to survive were never reinstated after his discharge.

Carmen

Carmen is a 49-year-old Caucasian female and registered nurse. She is the daughter of Alice, who was discharged from hospice and reenrolled after several weeks. Alice died from complications of Alzheimer’s disease within days of her reenrollment to hospice. Carmen lived with her husband in Galveston County and her mother, Alice, lived in Bexar County until her death in 2008. Carmen reported that after Alice was discharged from hospice she could not remain in her home due to the safety issues related to Alice’s Alzheimer’s disease. Carmen stated that,

There was such a decline in her physical abilities from being discharged from hospice and having to make the transition of moving out of your home because you no longer have that extra help to going into a long term care facility…. Her Alzheimer’s immediately was very much more noticeable. You know three weeks after being there sometimes she didn’t know my name. Before that she always knew my name.

Alice’s condition rapidly deteriorated and three weeks later she died in an intensive care unit. Carmen related this rapid deterioration in her mother’s health directly to her hospice discharge and subsequent admission into a long-term care facility.

Thematic Findings

Findings are reported according to the primary themes: the paradox of hospice discharge and suffering “as...” The following thematic findings tables contain data derived from the participant narratives that support the particular subtheme. Supporting
statements are provided to allow the reader to decide the merit of the interpretive analysis (Lincoln & Guba, 1985). Each table is followed by a brief interpretation of the subtheme.

**The Paradox of Hospice Discharge**

Four subthemes shape the paradox of hospice discharge: having support and needing support, mixed feelings, not dying fast enough, and hospice equals life. A paradox is defined as “a tenet or proposition contrary to received opinion; an assertion or sentiment seemingly contradictory, or opposed to common sense; or that which in appearance or terms is absurd, but yet may be true in fact” (Define.com, n.d.).

The paradox of hospice discharge is exactly that—seemingly contradictory, opposed to common sense, yet true. Participants in this study described both the need for and the receipt of support, mixed feelings related to the discharge, the notion of not dying fast enough, and the belief that hospice equaled life.
Table 4.2 Thematic Findings: Having Support and Needing Support

<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Participant</th>
<th>Supporting Statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Paradox of Hospice Discharge</td>
<td>Having Support and Needing Support</td>
<td>Adam</td>
<td>I definitely had the backing of the family, and I think the family is a very important thing when you're ill. …I felt like I had a pretty good caregiver, and I had a pretty good organization looking out after me. So then they come along, and said, ‘Well, you know, it's in remission, so nothing we can do right now.’ So that made me feel a lot better.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Alec</td>
<td>People just need – when you think you’re going to die, [inaudible] no pill or surgery or shot that’s going to help. But the chaplain would sit down and listen, and she was very empathetic. She would listen, and was very entertaining…But she would just sit down and listen and we’d talk. I was sad to see my chaplain go. I really got attached to her. She was really nice. The nurse was nice, but she’s a nurse. She wasn’t a chaplain. The chaplain was your cry-on-your-shoulder kind of person, so we did a little of that.</td>
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</table>

Having support and needing support (Table 4.2) was a subtheme that encompassed the time before, during, and after hospice discharge. Participants attributed great value to the support they received from their family and hospice team members. For some, the support received gave them the confidence to move forward after their discharge. For others, discharge represented a loss of support they could not find outside of hospice.
<table>
<thead>
<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Participant</th>
<th>Supporting Statements</th>
</tr>
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</table>
| The Paradox of Hospice   | Mixed Feelings        | Alec        | ...I guess I had a little mixed feelings; but I don’t want to be on Hospice.  
Well, it was mixed feelings. [inaudible] – That’s a pretty serious thing. I wasn’t too excited to be in Hospice. That’s kind of a finalistic kind of thing.  
It was good and bad getting off of Hospice. The good part was when you’re on Hospice; they’ll have a noble death knocking at your door. The bad part was it was easy to get my medicine.  
I was making funeral plans. I was reading death books. The chaplain came out, and talked to the kids. You’re getting ready to die, which isn’t easy when you’re 51 years old. I’d rather just wake up dead than die slowly. I was talking to the nurse, [nurse’s name], about what’s going to happen. It didn’t sound too pretty; so I wasn’t looking forward to that. But I can go for a while now. So, now you’re stuck with me a long time. |
| Discharge                 |                        | Brooke      | It [hospice discharge] was great in the sense that we knew he was getting better and he was in remission, but the other side of the coin was it is kind of like waiting for the other shoe to drop, because he is in remission.  
[Tell me about waiting for the other shoe to drop] He’s doing fine, but we know it’s there [the cancer] and he never talks about it. I mean he’s going to be well and he just doesn’t, he has never really talked about it. |
|                           |                        | Chelsea     | No, I mean there was no relief that he wasn’t dying. Like I said, that disease didn’t just mysteriously disappear.  
Well, it was a pretty good feeling, but I also realized that this may not be the end of it, that they [cancer] could recur, and the next thing I know, you know, am I going to make it for Christmas. |
|                           |                        | Adam        | Well, you know you ain’t going to be around a while, no doubt. It kind of sticks on your |
Several participants reported mixed feelings or ambivalence (Table 4.3) regarding their hospice discharge. There was some relief at the notion of no longer being labeled as dying. However, the knowledge that the disease continued to exist dampened these feelings of relief. Most participants who had been enrolled into hospice primarily for chronic disease processes recognized the variable nature of the continual exacerbations and periods of improvement as well as realized the potential for relapse.
### Table 4.4 Thematic Findings: Not Dying Fast Enough

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<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Participant</th>
<th>Supporting Statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Paradox of Hospice</td>
<td>Not Dying</td>
<td>Andrew</td>
<td>[How did they broach the subject of your discharge?] You’re not cooperating by dying when we thought you would, and you stabilized instead; so we’re going to have to discharge you. They were expecting to meet me, and then go downhill almost any day. Like I said, I wasn’t cooperating.</td>
</tr>
<tr>
<td>Discharge</td>
<td>Fast</td>
<td>Chelsea</td>
<td>We are going to let you die on your own. That’s what it was. It wasn’t a, ‘Oh, you mean he’s not dying?? Oh, that’s great!’ No, it was a case of, ‘Yeah, you are still dying, you’re just not dying fast enough.’ Yes, we knew he was going to die, he was dying. He just wasn’t dying fast enough for them.</td>
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<td></td>
<td>Enough</td>
<td>Casey</td>
<td>It was ridiculous. It was ridiculous. I mean he had been on hospice, we know he is dying. You know, okay, you know he is not dying fast enough. Whatever, he is still dying. They have not come up with a cure for CHF; they haven’t come up with a cure for COPD. He is dying period any way you look at it, he’s going to die.</td>
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<td></td>
<td></td>
<td>Carmen</td>
<td>I felt…rushed. And they didn’t look at the big picture. The hospice we used at home was an outside agency paid by VA. But when they discharge you, it wasn’t good… I mean- you’re on hospice one day the next you’re not. They gave me 3 days to say were going to be discharging her in 3 days. Yeah, she was probably on hospice 8 weeks and like 3 days before they were going to discharge her, she no longer met criteria. She wasn’t sick enough… she was doing well. She could stand with her walker. She couldn’t make it to the bathroom by herself but she could with help.</td>
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47
but if they had looked at the big picture she would have meet it. When she was discharged the first time we had to go to long term care because of the situation with me living so far away I couldn’t just change everything that quickly. If they had sat down as a team and talked to us they wouldn’t have discharged her the first time. She was dead 3 months later and isn’t that the time frame 6 months?

Blanca

Because he was going to die in a couple days; then after 3 weeks they sent me a letter that he doesn’t meet the criteria. Because a person has to be that they are going to die or something…

Not dying fast enough to qualify for services (Table 4.4) was a theme seen throughout the transcripts. The participants of this study understood the eligibility requirements established by the Center for Medicare and Medicaid Services were created to protect the system from abuse. They also understood the disease processes that led to their enrollment into hospice in the first place (although terminal) were not producing a quick enough demise to remain on hospice. This knowledge caused frustration and anger at somehow being blamed for failing to die according to an arbitrary schedule that was not congruent with their disease process.
Table 4.5 Thematic Findings: Hospice Equals Life

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<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Participant</th>
<th>Supporting Statements</th>
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<tbody>
<tr>
<td>The Paradox of Hospice Discharge</td>
<td>Hospice Equals Life</td>
<td>Alfred</td>
<td>I think hospice is keeping me alive. Yeah, because like I said, if I wasn't on that stuff $[O_2]$, where would I be again - back in the hospital. And the last time they took me off Hospice, as soon as they took me off, I told them if you take me off this, I’m a goner - oh no, he's fine, he's fine. That same weekend, I was in the hospital. No, like I say, I think [agency name] has kept me alive, and now [agency name]. I figure if it wasn't for them, I'd been dead a long time ago, because I was going to get to the point where I wasn't going back in the hospital anymore. .... I mean, you go in a week, come home a week, go back the next week - that gets old. ....I think Hospice has kept me living - I gotta say...</td>
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<td></td>
<td></td>
<td>Bobbie</td>
<td>He was so physically dependent on the services they were providing and I knew that it was equivalent of someone being on life-support. What did it cause me during that particular period of time? It was like being in a nightmare; it was just like being in a nightmare. It seemed like nobody, we were screaming; Aaron and I were screaming and yelling and it’s like nobody could hear us. No one could believe that this was happening and everybody wanted to know, ‘Well, what did you do wrong?’ Everybody thought it was my fault or Aaron’s fault that we did something wrong to alienate the entire medical community against us. We felt alienated because it couldn’t possibly be the entire medical community. It couldn’t possibly be all of [facility]. The world is not conspiring against you. It’s not that bad! But yet he died, because he didn’t have what he needed to live...</td>
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<td></td>
<td></td>
<td>Casey</td>
<td>That’s why we turned to hospice in the first...</td>
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</table>
A paradox is a statement that is seemingly contradictory or opposed to common sense, yet one that may also be true (Merriam-Webster, n.d.). Seemingly contrary to our society’s understanding of hospice, the participants in this study equated hospice with life rather than death (Table 4.5). The support, care, and equipment provided by hospice allowed participants to remain out of the hospital and to stabilize their conditions. These participants had no intentions to seek a cure, only a desire to live to the potential allowed by their diseases. The loss of hospice represented a return to dying and suffering.

**Suffering “as...”**

Suffering is defined as the act of feeling or enduring pain or distress, or sustaining injury, disadvantage, or loss (Random House Dictionary of the English Language, 1970). The “as” in the theme suffering “as...” refers to how a phenomenon is interpreted, i.e., the meaning of that phenomenon to the individual. For example, Ann interpreted suffering as...abandonment, whereas Billie interpreted or experienced suffering as...unanswered questions. The phenomenon of the “as...” is a meaning-structure (Heidegger, 1927/1962). The primary theme and subthemes demonstrate the “how” of suffering in this phenomenon. Linking together the primary theme and subthemes demonstrated the relationship between them. The eight subthemes that supported the primary theme suffering “as...” were abandonment, unanswered questions, loss of security, loneliness, uncertainty, anger and frustration, physical decline, and bearing exhaustive witness.
### Table 4.6 Thematic Findings: Abandonment

<table>
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<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Participant</th>
<th>Supporting Statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffering</td>
<td>Abandonment</td>
<td>Ann</td>
<td>They never told me they weren’t coming back, they told my daughter.</td>
</tr>
<tr>
<td>“as…”</td>
<td></td>
<td></td>
<td>I wondered why she didn’t come anymore, they didn’t say goodbye… [long pause] … so they [hospice] just stopped coming.</td>
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<td></td>
<td>I felt angry and frustrated and abandoned. My husband cried. He thought nobody cared about him. He cried. It’s like you are not worthy, you are not worth our time.</td>
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<td>What happened was I was at work one day and I got a call from Aaron at about noon and Aaron said, ‘What do I do? The Hospice Company just came and picked up all of my equipment, including my CPAP.’ I said, ‘Well, tell them they cannot take it’ and he said, ‘Well, they’ve already gone.’ That’s how he was terminated from Hospice.</td>
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<td>But can you imagine what it would be like to find out that somebody came into your home while you were not there and took something that was so vital for somebody that was so vital that your disabled husband’s life depended on it and you knew he would die without it? And that somebody could come into your home and take advantage or because of a poor disabled man in a wheelchair that I’m supposed to come and pick up the CPAP, and so, he didn’t know anything. He’s loaded down with drugs anyway and he didn’t have the resources to say no. He didn’t have the ability to say, ‘Let me call my wife before you take that. What am I supposed to do about that?’</td>
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<td></td>
<td></td>
<td>Bobbie</td>
<td>Everything became evident. This is like, ‘Whoa, this is not only you’ve taken away all of the help that you provided, so you are dumping me out on the side of the road without any help at all, you cut my connection to any other resources by decertifying him, saying that he is not eligible, so that we have to go through the whole nine yards of getting every single test run in the world again.’</td>
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<tr>
<td>Chelsea</td>
<td>We were abandoned. It’s like driving down the road and stop at the truck stop and say, ‘Get out.’</td>
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<td>------------------------------------------------------------------------------------------------</td>
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<tr>
<td>Casey</td>
<td>We felt abandoned and lost struggling to survive.</td>
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</table>

Abandonment is a term used to imply the withdrawal of help or support, or the leaving behind of someone meant to be a personal responsibility. The participants in this study conveyed the feeling of abandonment (Table 4.6). Hospice simply stopped coming or left the families feeling lost or forsaken. This feeling of abandonment added to the anxiety and desperation some participants expressed as they described their experience.
Table 4.7 Thematic Findings: Unanswered Questions

<table>
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<tr>
<th>Theme</th>
<th>Subtheme</th>
<th>Participant</th>
<th>Supporting Statements</th>
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<tr>
<td>Suffering</td>
<td>Unanswered Questions</td>
<td>Billie</td>
<td>I guess my question is how can he die at home without going to the hospital? That should happen. We don’t have Hospice right now. What would we do? Who would I call? I could call my GP, but they don’t make house calls…</td>
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<td>Bobbie</td>
<td>Hospice was 100% responsible for providing all aspects of healthcare for my husband and it’s like, ‘Okay, who is going to take over this job? Who is going to take over that job? How do we coordinate all of this stuff together?’ That was one of those things that at the time I knew what had to be done and I knew the severity of it, I knew the intensity of it, and I knew that I was not able to get all of that stuff done by myself.</td>
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<td>Alfred</td>
<td>I mean, if I needed oxygen, why would they disqualify - you know, turn me loose. It didn't make sense to me</td>
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<td>Andrew</td>
<td>We signed up, so that she would have someone to call. I don’t make calls like that. The only call I would make would be to EMS if she was dying. Otherwise, she’s the one that makes the calls. So it didn’t matter to me one way or another.</td>
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<td>Chelsea</td>
<td>Oh, my God, who is going to help us with all of this? I think about it now and I’m like we should have acted more diligently at that point, but we did not realize the ramifications of that conversation. We did not understand what they were talking about when they were out there telling us that he was going to be discharged. It’s like do you ever have those conversations where you hear exactly what somebody says and you walk away from that and then you think about it maybe a year later and you realize the enormity of what you missed? That’s what that was. That was our opportunity to begin early, we should have started then.</td>
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So you are already grasping at straws of, ‘Please help us. Give us some help, some assistance’ and then you take that away and then, ‘Now what? What do we do? Where do we go for help?’

What do we do now? Where do we put him? ...What do you do afterwards? Where do you go?

I was real worried about ok, what’s going to happen next? So Even though I wanted her to come live with me she turned that offer down. So now it’s like what do we do now?

I don’t know- what do have to be to get diagnosed as dying? I’m not real sure. What does she have to have wrong with her to keep hospice and have help coming in for the 70 year old woman who’s taking care of her on a daily basis?

[Pause] it was basically that she… she didn’t meet the criteria for being on hospice because she didn’t have a DNR signed… Even though we went and we got all the paperwork done because we just went to the VA hospital and they have social workers that do all of this for us. So we go and we make the appointment and we get all the paperwork done it gets notarized and whatever it needs to be done. But then she doesn’t qualify because she doesn’t meet criteria physically. I don’t know what that means…

They say he doesn’t meet the criteria, I don’t know what that means.

Do we need to start all over with doing renal function tests? Do we need to get the full body MRI? Do we need to do all the CT scans? We had to do a new sleep study and I told you the story about the sleep study doctor going on vacation, so another two weeks. I mean that was just ridiculous, but nobody would do anything for him. Nobody would write him a prescription for anything until we had all this. ‘Well, we need to know where he is.’ B-S. ‘We need to know what his status is.’ His status is a dying man. All he wants is to have
some relief from his pain, some control over his heart rate, and to die in peace, but we had to start over.

The participants reported having unanswered questions regarding their experience (Table 4.7). Many of these questions were standard discharge planning topics. Others were more fundamental and related to the reason for discharge. These participants were unsure why they were discharged and reported having a great deal of difficulty immediately following the discharge in securing the services and care required.
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<th>Theme</th>
<th>Subtheme</th>
<th>Participant</th>
<th>Supporting Statements</th>
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<tr>
<td>Suffering</td>
<td>Loss of Security</td>
<td>Brooke</td>
<td>…there was such a secure feeling knowing that if anything happened, you know from the time we left [facility name] and we got on Hospice there was just a few days that we called and once we got on Hospice there was that secure feeling knowing that if anything happened that I had someone to go to, I had someone to call 24/7, and that is a wonderful feeling. You know like we don’t have that now. I think that was probably the worst thing coming off Hospice was not having that security blanket and even though we can get a hold of Dr. ___ any time, it’s not like if you call you don’t know when you might get a call back.</td>
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<td>Andrew</td>
<td>Well, to me it was like losing the security blanket, you know having to switch doctors, I mean health services again.</td>
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<td>Bobbie</td>
<td>I really don’t think it [hospice] was a good idea, because it produced a false sense of security. It was like going to an old religious revival and as long as you are there with everybody else and you’re singing the hymns and everybody is praying in unison and you are just, ‘YES, I believe, I’m going to be saved,’ and then you realize that there wasn’t anything, there wasn’t any truth to it. Yeah, because I thought I had somebody helping me. I really thought I had somebody helping. And then it was over. It’s like, ‘We’re not going to help you anymore.’ It’s like somebody, you know, maybe another way to look at it is, another thing that pops into mind is like the little boy scout helps out the little old lady to cross the stress, but he gets her over into the median and then he turns around and goes back, and she is stuck in the middle of the road.</td>
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<td>Andrew</td>
<td>We had them primarily so that Billie had someone to call in case I had a problem, which I didn’t.</td>
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I guess for me, having a doctor that you can call and get help right away and not go to the emergency room—if he could die in peace at home that would be the best.

Being on hospice was wonderful. It was peace of mind.

Sorry [crying] I’m very sensitive. I cry very easily. Having a doctor so that if something happened, he could stay home.

No, but hospice was a peace of mind for me.

Adam

I know that there'd be somebody there to check on me

Security is the state or feeling of being safe and protected; freedom from worry or loss. The loss of security after the hospice discharge was a major concern for the participants of this study (Table 4.8). Hospice service made patients feel confident that everything would be taken care of in the event of an emergency. Once they no longer received hospice services, patients were acutely aware of how alone they truly were. Surprisingly, this feeling was more pronounced in the transcripts of family members than in patients themselves.
### Table 4.9 Thematic Findings: Loneliness

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<th>Theme</th>
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<tr>
<td>Suffering</td>
<td>Loneliness</td>
<td>Blanca</td>
<td>We never had a wild life and lots of friends. We used to have some friends many years ago and we had bbq outside sometimes, but they all died so we don’t have anybody. They died little by little and we’re all that’s left… I belong to seniors group that has a meal every month. If he is behaving good then I take him with me and I go to the dinner. The other place I wanted, they don’t want him. [facility name] don’t want him. I wanted to take him there because I was going to a support group when he was in the nursing home. Then I stopped going so they sent me an invitation. So I called to tell them I wasn’t coming because I had no place to leave my husband. She said it is no problem to bring your husband as long as you make the reservation 2 days before. So when I made the reservation they said’ oh we heard about your husband and we just don’t think we can handle him.’ So there goes my support group. I really wanted to go because I like to see other people and talk. ...Even if it’s one day or only a few hours so I can be by myself for a little bit and do other things. Since the hurricane there is no other place for seniors and if they won’t take him I can’t go… If he is a bad, miserable patient then nobody wants him. It was nice to have someone to talk to…We don’t have anybody. It’s just him and me. I can’t make him believe that. He thinks this is a nursing home and there are more patients in this house. He’s always asking where the other ones eat. He’s always asking about them. I say no this is your house. You have to trust me, this is your house, and it’s only the two of us here. He just keeps his mouth shut but he doesn’t believe it.</td>
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<td>Alec</td>
<td>People just need – when you think you’re going to die, [inaudible] no pill or surgery or shot that’s going to help. Of course, in my situation, everybody’s busy. I have a wife that works and three kids, and our house is a circus most of the time.</td>
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time. It’s always hustle and bustle, and my wife’s real busy. And she’s not really the type to sit down and really listen anyway. But the chaplain would sit down and listen, and she was very empathetic. She would listen, and was very entertaining. [inaudible], which is the hardest part. Physically I wasn’t hurting. Of course, other people in Hospice, they go through a great deal of pain and agony and all that sort of thing. But she would just sit down and listen and we’d talk.

I was sad to see my chaplain go. I really got attached to her. She was really nice. The nurse was nice, but she’s a nurse. She wasn’t a chaplain. The chaplain was your cry-on-your-shoulder kind of person, so we did a little of that.

I really enjoyed my visit with the chaplain probably more than anything because my wife’s busy. We have three kids, twin girls and a teenager. Nobody has time to listen, and the chaplain would listen; and you could voice your feelings, I guess. That really is better medicine than anything really

Bobbie

I was trying to do it all on my own.

So when hospice went away and we had to go back into that arranging schedules to make sure that somebody could be sure to be there to feed daddy, making sure that his needs were being met, and it’s just my sister and I and my mom.

Casey

I was supposed to find help or do it myself. And that’s basically what we did. Her friend did the most part because I was 250 miles away. I helped by phone trying to screen and tell her who would be calling or coming by.

So someone had to be there. And with me not living close, she only had a sister who was in her 80s and a best friend who was in her 70s to help take care of her and home health was not an option.

Carmen

For me it was definitely a weekend trip by the time I drove the 250 miles to San Antonio and the 75 miles to the hill country added into it that was a whole day. I’d get there that night and be able to visit. So I’d leave on Friday evening to go up there. I’d be able to stay on Saturday and then
come back and visit her early Sunday morning and then by noon I had to be on the road in order to go to school and work on Monday. She had lots of friends that would come to visit her but only 2 people would help take care of her on a regular basis. And that wasn’t even her sister it was her best friend.

If you have a 2-member family you can’t do it, it takes every single person around you to help take care of you. I mean mom and dad started relying on the next-door neighbors. They had to, because there’s no other way to make it through.

On hospice you knew that you were never, never alone.

Similar to loss of security was the feeling of loneliness. This feeling of loneliness was different than being physically alone (Table 4.9). These participants were bearing the burden of their own demise, or their loved one’s death, in such a way that they felt alone in the journey. For some, it was the close companionship of others that eased their burden. Others, even in the presence of family and friends, felt solely responsible to care for their loved ones. Hospice provided a respite from this loneliness through the presence of staff, the reduction of responsibility, or simply time away to tend to one’s self. Discharge from hospice represented a return to bearing the burden alone.
Table 4.10 Thematic Findings: Uncertainty

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<th>Theme</th>
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<tr>
<td>Suffering</td>
<td>Uncertainty</td>
<td>I remember the off and on. I remember the uncertainty, it was a very strange feeling at first, because maybe it was just because of my awareness of the situation and at first it was like, ‘This is happening. This is not happening. We’re going to do this.’ The conflict of information, there was a lot of that in the very beginning, because the nurse said, ‘We cannot continue to see you’ and the social worker could not explain the reasoning behind the discharge at first. It seemed like she was trying in many ways to get the situation remedied so that he did not have to be discharged from Hospice; this went on for a couple of months. They were going to give us a week in the beginning. It was like, ‘Well, this is the end; we are not going to be seeing you after one week.’ Well, no, that’s just not satisfactory, you know, that is just not appropriate. At first it was, ‘You’ve got a week’ and we said, ‘No,’ and the social worker was able to convince the hospice company to extend services to allow her to assist us in arranging for the care. As you know just simply having an appointment with a doctor does not necessarily mean that doctor is going to be able to function as your particular healthcare provider, primary care provider and that was what our problem was. The hospice company stated that their only requirement was to make sure that we had an appointment with another healthcare provider and that ended their responsibility. If they would have explained things to us, ‘Okay, we don’t see any further need,’ so if they had said, ‘We’re going to decertify Aaron and therefore he will be discharged,’ I could have said, ‘What do you mean, ‘Decertify’?’ I did not know that they were decertifying him until after the fact and we had called and had arrangements for another Hospice company to come in and take over his care, is when we found out he had</td>
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Uncertainty was a theme that ultimately related to the presence or absence of communication (Table 4.10). These participants related their understanding of the discharge as nebulous, i.e., more abstract than reality. As merely a potential, the discharge process did not take on the urgency or importance that participants could understand until it was too late, leaving the patient and family without access to necessary equipment or care. This uncertainty toward understanding the pending hospice discharge lent itself to fear of the unknown and ultimately to the next theme, anger and frustration.
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<th>Theme</th>
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<tr>
<td>Suffering</td>
<td>Anger and “as…” Frustration</td>
<td>Chelsea</td>
<td>It made me feel angry and upset for myself, because it’s like, ‘Oh, crap, now I have to go through this again…’ It also made me feel mad and upset for his sake that they are taking this away from him again… Yes, we were afraid and angry because we knew where we were going and we didn’t want to go. We knew what was going to happen. We knew. I’m just angry and frustrated….If they would have transitioned him out, as they transitioned him in and they made sure that he had the tools necessary. Yeah, it would have been hard on us. Yeah, it would have been difficult. Yeah, we would have gone through all that pain all over again for years, but at least he wouldn’t have died six weeks after being discharged. In a sense it’s kind of, in a selfish sense, it’s kind of a blessing that Hospice discharged him the way they did, because it didn’t drag out another five years!</td>
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<td>Casey</td>
<td>When he was on hospice, it was the best our family ever had. That’s why we are so angry, because we had the best and they took it from us and they took it away. He was more independent, he was happier, he was better than he had ever been and they took it from us. That’s what we are angry about.</td>
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<td>Carmen</td>
<td>In order for her to be on hospice they told us they had to stop her tube feedings. It was more like a threat- we either stop her tube feedings or she can’t be on hospice again… I thought I was being given an ultimatum. You know, you either feed her and not put her on hospice or not feed her and put her on hospice. Now this woman is a diabetic, you know I’m pretty damn angry about that. So we wound up putting her in a long-term care facility, nursing home, whatever you want to call it, what’s politically appropriate. And then she gets sick, she has her DNR but they</td>
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Blanca

send her to the hospital. When she gets to the hospital, you know we want hospice. And so they say the only way she can have hospice is if we don’t feed her. And that’s pretty damn cold don’t you think?

Our old doctor dropped him without telling us. I’m real mad about that. The way I found out was that the people who send me the supplies called and said Dr ___ doesn’t want to sign for the supplies because he says he’s not your doctor anymore.

Participants clearly articulated their feelings of anger and frustration regarding hospice discharge (Table 4.11). This anger and frustration came largely from a lack of effective communication between hospice staff and family members. These participants were angered not only by the loss of services that they had come to rely upon and the value of those services, but also the manner in which the services were removed.
Table 4.12 Thematic Findings: Physical Decline

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<tr>
<td>Suffering</td>
<td>Physical</td>
<td>Carmen</td>
<td>Maybe it was her improvement while they [hospice] were coming, but as soon as they weren’t coming anymore it was a continuous downhill decline. There was such a decline in her physical abilities from being discharged from hospice and having to make the transition of moving out of your home because you no longer have that extra help to going into a long term care facility. There was such a physical decline because of that move, and I’m going to say it’s because of that move. It may not have been, it could have just happened normally but I think when you take someone out of their normal surroundings that they really go downhill. Her Alzheimer’s immediately was very much more noticeable. You know 3 weeks after being there sometimes she didn’t know my name. Before that she always knew my name. A big change in her quality of life from the time- within three weeks it was very noticeable. She could no longer stand on her own. She couldn’t walk in a walker. She was in a wheelchair. I would say five weeks, maybe six weeks, I noticed drop foot. I noticed that she had a significant decrease in muscle tone in her legs. I mean just her physical abilities were she couldn’t hardly feed herself without shaking. Even though that’s part of the disease process for Alzheimer’s it seemed more accelerated. I don’t think it should have progressed that quickly, but maybe- I don’t know. After the discharge from hospice it took me a month and a half to find another facility and she was there for less than six weeks and she qualified to be back on hospice because of her medical condition. …It got really bad just before she was readmitted to the hospital. When I showed up on a weekend she didn’t know who I was and she was screaming ‘get this person away from me’ when I was trying to take her outside. That was hard.</td>
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It was hell, [crying] he was in DT’s, and he was shaking and he was miserable, and he was hurting… He died the following Friday. It was just too much for him. He was so exhausted and I don’t know what; he was just totally worn out, just totally worn out from that, going through that weekend.

So that was less than two weeks... Less than three weeks. His last few days… He said, ‘I’m trying to keep it together,’ because he was having times where he said, ‘I can’t remember, sometimes I cannot even remember what I’m doing.’ And he said, ‘I get confused’ and I knew that was because of the hypoxia. …He never did get over that last weekend, he never did. He never did.

You know besides having Alzheimer’s and dementia my husband was always a difficult man, personality wise. So that personality hasn’t gone away. He has that problem plus the problem of the dementia. Because the dementia causes him to forget things and get upset, that part he has, but then he is also has the other part that he is mean. You have to watch him that you don’t get too close, leave it alone, and don’t let him get his hands on you.

Hospice had taken away his feelings of inadequacy to a certain degree. It had enabled him to relieve the pressure off the family and by doing that, by taking him off Hospice, it was like disabling him all over again, because he didn’t have the use of his hands and he couldn’t walk very well, later he couldn’t walk at all.

You don’t have quality of life. He doesn’t have what he needs, he’s not getting the medications that he needs, he’s not breathing like he is supposed to, so he’s not resting like he’s supposed to. He’s not eating like he’s supposed to and because of all of that his mind is going. There’s nobody that’s coming in and giving him a bath like he needs it anymore, so he doesn’t have any interaction with anybody. His quality of life disintegrates rapidly past that point.
Alfred It wasn't much life, just like a zombie sitting here. I'd go for days at a time without oxygen, because I'm trying to learn not to use oxygen, because I'm not going to have it; and I told my wife, ‘Hey, the doctor ain’t gonna write for oxygen,’ and if she does, I can't afford it, because I had oxygen once before, before I ever got with [agency name], and I kept it two months, and I let it go, I says honey I gotta do without this - I can't afford that bill anymore.

In the theme physical decline (Table 4.12), the participants discussed the deterioration of health after hospice discharge. Although not all participants experienced this aspect of the phenomenon, for those that did, it was extreme, powerful, and often quickly led to the patient’s death.
Table 4.13 Thematic Findings: Bearing Exhaustive Witness

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<th>Theme</th>
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<tr>
<td>Suffering</td>
<td>Exhaustive</td>
<td>Casey</td>
<td>He suffered all his adult life. That’s why we chose hospice, to alleviate some of that. But you can’t just pick up where you left off- it doesn’t work that way, he had to start over with his health care. Because of that he suffered, his independence was gone, he was back to being a burden on the family, he hurt all the time, and he was suffocating. He went from too healthy to be on hospice to dead within a month. The problem was that he didn’t have to die like that- Slowly suffocating and in pain. If he had been on hospice he may have lived a few more months or died anytime, but he would have had a better quality of life at the end. The family wouldn’t have had to go through the trauma of trying to reintegrate back into the medical system. He would have had the support and care he needed, and we wouldn’t feel so guilty for failing him. <strong>He immediately began to deteriorate.</strong> He was having episodes during the day where he would de-SAT and his mental status would just; combine the lack of oxygen with the morphine and all the other narcotics. He had been having these episodes where he would de-SAT and he would get confused and bothered grandma a lot; she really worried. She was like, ‘I don’t know what to do. I want to take him to the hospital, I don’t know what to do’ and that tortured her, because she was for ten days watching him everyday go through this, where she is watching him die. Then when he died it was just horrible for her. Oh and it gets worse. Her husband was on Hospice at the same time and daddy was sleeping in her bed, so not only did her son die at her house, in her bed, but she was on watch for her husband to die at the same time. I just couldn’t do anymore and my mom, the same way. It was just too much too quickly, all</td>
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<tr>
<td>“as…”</td>
<td>Witness</td>
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at once and the dread of going back to that, what was before Hospice, was overpowering. I remember my grandma waking me up at 2 o’clock in the morning and I want to say it was either the day before or the day after daddy’s funeral, crying that granddaddy is dying. What happened was, he had a supra pubic catheter that had clotted off, because he was dying of bladder and renal cancer, so he was bleeding profusely from his bladder and from his catheter site, and it was clogging off the catheter. So we had to go down there and here my mom and I are with my granddad irrigating his bladder. I mean it was like a blood bath, you know there was just blood everywhere and it was because we were stripping catheters and he was literally spraying out of his catheter site. This was like within hours of my dad’s funeral. I can’t remember if was before or after and we are thinking, ‘If they discharge him grandma can’t do this.’

Oh, yeah. He suffered a lot with the detoxing and its like, why?

The whole experience just wore me out. It’s been almost a year now, two years? Almost two years and I’m just now getting to where I’m beginning to look for things to do. I spent a lot of time and effort trying to get things done, trying to get somebody to listen, but nobody wanted to listen. I think it just increased the agony, knowing what I know, yeah. Oh, absolutely, it just totally increased the agony. On my part, because my husband depended on me to help him get through the healthcare system; he depended on me.

I’m having a great deal of difficulty getting over it, because I feel so guilty because I am a healthcare professional and I wasn’t able to do anything and I was there and I feel like I was screaming and yelling, and I was pleading and pleading and pleading, ‘Please, help us! Please help us!’ and nobody seemed concerned. ‘It’s not my job. I’m sorry, it’s not my problem. I
have other things, I have my own life to deal with, I can’t deal with yours.’ And it’s not important to me if your husband dies. And so much stupid and it’s like the people that; I just feel like I was just a failure, I was supposed to be taking care of him and I allowed them to just terminate him [crying]. I didn’t want that, I didn’t want him to be terminated. He didn’t want to, he said, ‘I want to live.’ He was so looking forward to going to our daughter’s wedding; he was so excited about that; he wanted to go...

These are supposed to be the golden years. It didn’t look too golden to me.

After she was put back on hospice it was only a couple of weeks that she was on hospice the second time around before she died because she’s diabetic, not being feed. Now I know it was not because they didn’t want to feed her it was because her stomach wasn’t working anymore. Her body was shutting down- even her eyesight, she could hardly see anymore.

She used to be able to see wearing her contacts and glasses but it seemed that after her discharge...

She was a DNR, I don’t know why they sent her back to the hospital but she had an infection and she had a severe urinary tract infection. You know how that affects diabetes- her blood sugars were very unstable. So they sent her to the hospital. By that time her Alzheimer’s had advanced and she didn’t even remember who I was.

The guilt because I was happy. Because we didn’t have to go through it anymore. I could get off the rollercoaster, so you feel lots of guilt for feeling that. I mean I was happy in the fact that he was no longer in pain, but I was also happy for myself, in the fact that I didn’t have to go through that anymore. And, of course, because you feel happy someone is dead you feel guilty, because you feel happy that someone is dead. So you are feeling guilty because someone is dead and welcome to the
circle.

[Did he suffer?] He was in pain, I know it was advanced pain, it was terrible pain, but I think he was comfortable in the fact that he was home…. He’s at peace, he’s at rest.

I want him to be like he is now, at least that- able to walk and see the birds and look around. I’m trying to get him to watch television. He used to watch it and he knew all the actors and politicians. He could say ‘oh that’s so and so.’ He’s a library in his head. He knew all that. Now once in a while he will look at the television, but he doesn’t like it much. I am making him watch so he can tell me what’s going on, for him to pay attention.

If there is a place I can’t bring him then we just don’t go. If he’s upset then I don’t take him anywhere, if I realize he’s going to behave then we go.

He seems so normal sometimes. Then he might get upset that he doesn’t have any money in his pocket, or the clothes he’s wearing are not the ones he remembers. So he gets upset saying that someone stole all is stuff. It’s all there put away. I go and show him all of his things; I’m not going to get rid of his things. That’s not right, it belongs to him.

He’s got much more than that. He’s going to live another seven years, but I won’t live that long and that’s why I’m always looking around and asking questions because I have to find a place for him. It has to be suitable for him and me and they are going to take care of him.

It’s been two years now. I can’t do anything- its 24/7. I learned not to sleep- I sleep as I can, maybe 10-20 minutes here and there. Last night I didn’t sleep all night because he was up walking all night. He sleeps some during the day. I don’t mind that he sleeps because I have a lot to take care of; just me. Yesterday I mowed the grass, take care of the inside and washed clothes. I take care of all these things when he sleeps and at night I catch what sleep I can. My body doesn’t take much sleep anyway.
Suffering is defined as the bearing or enduring of pain, inconvenience, or loss; distress, loss, or injury incurred; such as suffering by pain or sorrow or by want or by wrong (Define.com, n.d.). These participants clearly suffered following their hospice discharge. Bearing exhaustive witness (Table 4.13) referred to the pain and helplessness endured by participants’ family members. These participants help us to understand that suffering was not only the physical pain experienced with disease but also the anguish of watching those we love helplessly wrestle with illness and disability.

**COMPOSITE DESCRIPTION**

The individual textural and structural descriptions of the experience were combined into a composite description of the phenomenon as a whole (Moustakas, 1994), revealing what Husserl describes as the “essence” of the experience (Husserl, 1913/1983). Both Husserl (1913/1983) and Moustakas (1994) noted that the essence of an experience is never exhaustive, rather it is reflective of the point of view of the participants at a particular time and place. Therefore, the essence of live hospice discharge provided in this study related to the experience of individuals as they perceived it at the time of their interviews.

Being discharged from hospice alive involved multiple factors. The participants in this study shared their stories, which included the good and bad aspects of a hospice discharge. The universal essence of being discharged from hospice alive included paradoxical and suffering dimensions, and was informed by the initial transition into a hospice program.

**Patient Entering Hospice**

The experience of hospice discharge began prior to the patient’s enrollment into hospice services. The decision to enter hospice was predicated not only by the diagnosis
of a terminal disease, but also by the patient’s understanding of the finality of the disease process. For some study participants, the hospice decision followed years of illness and struggle. For others, the choice of hospice was thrust upon them quickly when they were diagnosed with a new fatal disease.

Hospice is so effective in caring for patients that many improve, or at least stabilize, while on service (NHPCO, 2010). Stabilization or improvement led participants to equate hospice with life rather than death. Many of the study participants had struggled for years trying to manage multiple co-morbidities and frequent hospitalizations. Upon entering hospice, the “rollercoaster” stabilized, which led participants to believe that “hospice is keeping [them] alive.”

The seemingly simple act of enrolling into hospice was far from easy. The participants shared stories of how they made the transition from curative treatment to palliative care. On the other hand, the change in focus from curative to palliative care was deemed confusing. Hospice patients experienced “being toward death” as they began to understand and realize the terminal nature of their disease. They existed “in-between” actively living and actively dying.

Family Experience of Patient in Hospice

The family members of hospice patients journeyed alongside patients. “Burdened” with the responsibility of providing financial, emotional, and physical care for their loved one, family members often were forgotten or ignored until the patient was enrolled into hospice. Being on hospice is described by family member participants as, “wonderful…the best we’d ever known…. We got to have a real family relationship, one that didn’t involve the physical care of a chronically ill person.” Perhaps it was this acknowledgment and understanding of the difference between hospice and traditional healthcare that families valued most.
Patient vs. Family Perspectives of Discharge

Upon being discharged from hospice, the experiences of patients and families took on varied and paradoxical meanings. This new experience of hospice discharge blended a cautious reprieve from the expected patient death within six-months with the ongoing experience of living with a chronic, terminal illness. Patients in this study viewed their discharge and their disease with resolve and acceptance: “Basically, the good Lord decided that it wasn’t my time to go home yet. So I’m here. When it’s my time to go, I’m going home.” Patients initially chose hospice to gain assistance for their spouse as caregiver and somehow ease the burden of care.

Family members were most fearful of the discharge and the potential outcomes. As primary care providers, many expressed the need to be strong for their loved ones: “you do a lot of grieving…but I just try to keep it hidden and go on. I don’t want to upset him.” The priority for family participants was quality of life; for patients, discharge simply meant a return to “the way things were before hospice.”

The paradox of hospice discharge reflected the incongruence of the hospice experience that participants described. Participants credited the improvement of health with the support hospice provided. Yet, that same improvement led to discharge and the ultimate loss of that very support that brought about the improvement in the first place, which in turn initiated a decline in patients’ health. Further, mixed feelings accompanied the discharge. There was some relief in the knowledge that death was not imminent. However, the awareness that the disease remained uncured, only slowed, dampened the joy of the reprieve. This awareness of the continuation of the disease shrouded the lives of participants as they waited “for the other shoe to drop.” While participants were happy to be deemed “too healthy for hospice,” participants were also acutely aware that they “[were] still dying.” Bizarrely, these patients were discharged for what participants described as “not dying fast enough.”

The paradox of being discharged from hospice, i.e., the essence of the phenomenon, informed the experience of suffering. Suffering “as...” abandonment was described as the removal of support and care that patients and families had grown to rely
upon. Participants described feeling “abandoned, left behind, and wondering why.” Suffering “as…” uncertainty about the pending discharge until after the fact was a significant dimension of the essence of being discharged from hospice alive. Participants were not only unsure whether the discharge would actually occur, they were also unprepared and left questioning when the discharge did occur. Distressed participants experienced suffering “as…” unanswered questions, such as “oh, my God, who is going to help us…what do we do?” Suffering “as…” loss of security left the responsibility of care squarely with the family yet without the resources needed to adequately provide such care. Suffering “as…” loneliness in the struggle to provide care to a loved one was amplified by the loss of hospice: “on hospice you knew you were never, never alone.” Without hospice caregivers struggled, “trying to do it all on [their] own.” Suffering “as…” anger and frustration was demonstrated in the emotional angst of trying to secure needed supplies and equipment. Left to witness their loved one’s suffering “as…” physical decline and re-hospitalization, readmission to hospice, or even death, families explicitly depicted the physical suffering endured by themselves and their loved ones. Suffering “as…” bearing exhaustive witness illuminated the emotional pain that lasted years afterwards:

I’m having a great deal of difficulty getting over it…I feel so guilty because I am a healthcare professional and I wasn’t able to do anything and I was there and I feel like I was screaming and yelling, and I was pleading and pleading and pleading, ‘Please, help us! Please help us!’ and nobody seemed concerned…I just feel like I was just a failure, I was supposed to be taking care of him and I allowed them to just terminate him [crying]. I didn’t want that, I didn’t want him to be terminated. He didn’t want to, he said, ‘I want to live.’

**Universal Essence**

The universal essence of being discharged from hospice alive was beginning a new reality filled with paradoxes and suffering for patients and their family members. Hospice decertification as a result of extended prognosis left the patient and family
vacillating between a renewed hope for life and waiting for the intensification or reappearance of the disease process. In addition, the patient and family existed somewhere between relying solely on each other and experiencing the loneliness of being separated from professional caregivers who had been ever-present providers of special help and understanding. The experience of being discharged from hospice alive meant starting over, searching for a new physician, obtaining appropriate medication and equipment while simultaneously resuming the slow and steady, often painful, physical decline of disease. This experience encompassed being with family members who were exhausted, overwhelmed, tired, guilty, and who alone bore witness to a dying loved one. The universal essence of this new reality was living in-between the purgatory of living and dying.

**SUMMARY**

Chapter IV described the phenomenon of being discharged alive from hospice as perceived by those who have experienced it. Individual participant descriptions were provided along with supporting statements derived from the data collected during the interviews with 12 participants. Themes relevant to the phenomenon of live hospice discharge were discussed. Finally, the universal essence was presented.

Chapter V provides the study conclusion and recommendations based on the findings presented in Chapter IV along with a comparison of study findings with the extant literature. Study limitations are addressed as well as the significance of the findings to nursing and hospice. Finally, implications for future research are explored.
CHAPTER V: DISCUSSION AND CONCLUSIONS

We have done all we can to help ourselves, and shall ever struggle on, but it drives me almost insane to face the future. It is not the end that affrights anyone, but the road to be traveled to reach that goal. To die is easy; very easy; it is only hard to strive, to endure, to live. – Adolphus Greely, 1884

Chapter V begins with a summary of the current study followed by a discussion of the interpretive findings. The findings of this study will be compared to extant literature and related philosophical texts. Limitations of the study will be addressed. Discussion of the implications to nursing, hospice, policy, and future research is followed by the conclusion.

STUDY SUMMARY

There is a dearth of knowledge concerning people’s experiences following live hospice discharge. This study recognized the experience of not only the patient but also family members who support, care for, and suffer alongside patients in the journey toward death. The purpose of this transcendental phenomenological study was to explore adult individuals’ experiences with life-limiting conditions who were discharged from a hospice program due to decertification related to ineligibility or extended prognosis from the individuals’ perspectives and that of their adult family members. The research questions were:

1. How do participants (adults and family members) perceive and describe the experience of being discharged alive from hospice?

2. How do participants (adults and family members) perceive and describe their quality of life after a live hospice discharge?

Moustakas’s (1994) approach to transcendental phenomenology was used to capture the meaning of live hospice discharge. Twelve individuals who experienced live hospice discharge either as patients (n=5), spouses (n=4), or adult child (n=3) participated in non-structured open-ended interviews. The initial interview question was, “Tell me
about being discharged from hospice.” Following the initial question, probe questions such as, “Tell me more about that” were asked to further clarify or elaborate upon participants’ responses. Participants were encouraged to discuss aspects of the experience they felt most meaningful and invited to share anything they deemed important. All interviews were tape-recorded and transcribed verbatim.

Significant statements were derived from participant transcripts. Primary themes and subthemes were developed using textural (what was experienced) and structural (how it was experienced) descriptions of the phenomenon supported by narrative data. Finally, the textural and structural descriptions were synthesized into a composite description revealing the fundamental meaning or essence of being discharged alive from hospice (Moustakas, 1994). Rigor of the study followed the criteria for trustworthiness established by Lincoln and Guba (1985). Thematic findings of this study may inform educational programs, nursing practice, and hospice policy regarding live discharge. Interdisciplinary hospice teams that work closely with patients and families will derive a better understanding of the discharge experience, thus becoming more prepared to anticipate patient and family fears, needs, and concerns as they transition out of hospice care.

**DISCUSSION OF FINDINGS**

Participants in this study described the experience of being discharged alive from hospice and the meaning ascribed to the experience. Two primary themes emerged from the data: the paradox of hospice discharge and suffering “as....” The paradox of hospice discharge was supported by the following subthemes: having support and needing support, mixed feelings, not dying fast enough, and hospice equals life. Suffering “as...” was supported by the following subthemes: abandonment, unanswered questions, loss of security, loneliness, uncertainty, anger and frustration, physical decline, and bearing exhaustive witness.

The literature reviewed in Chapter II encompassed the most relevant and up-to-date information available on the subject of live hospice discharge. While the admission
and discharge characteristics are well documented, it was noted that there remains a
dearth of knowledge regarding the experience of being discharged from hospice alive
from the perspective of the patient and family. This study adds to the extant literature by
revealing the voices of the patients and families themselves. The following text compares
the findings of this study with the literature evaluated in Chapter II. The following
section addresses participant characteristics both in this study and in comparable studies.

Discharge and Characteristics

A retrospective comparative study by Kutner et al. (2002) used data obtained
from the records of over 800,000 patients discharged from hospice between 1996 and
1998 to identify rates and predictors of live hospice discharge. Kutner et al. (2002) found
that 45,875 patients were discharged alive and had longer lengths of service, non-
cancerous diagnoses, and, unsurprisingly, better functional status prior to discharge than
those patients who were discharged as deceased. Similar to the findings of the Kutner et
al. (2002) study, the majority of patients discussed in our study were chronically ill with
non-cancerous diagnoses. However, only two participants reported similar longer lengths
of stay (>180 days) as those described by Kutner et al. (2002). Responses in our study
varied based on the participants’ perceptions of the severity of illness and co-morbidities
of the patient as well as the length of time from initial admission to discharge. Further,
reports of decreased functional status following discharge were present in many of the
participant narratives in the present study.

A 2004 study by Kutner et al. sought to describe the outcomes and characteristics
of 164 adult patients discharged alive from 18 participating hospices. Their longitudinal
prospective cohort study used descriptive demographic data obtained from patient records
and followed participants for six months or until death. Findings revealed that 35% of
participants died within six months post-discharge. Kutner et al. (2004) also reported a
need for further research to examine the experience of being discharged from hospice in a
qualitative way.
Comparable to the findings reported by Kutner and colleagues’ study (2004), 37.5% of the patients discussed in our study were deceased within six months of discharge. Similarly, the thematic finding of physical decline in our study also denoted how participants described the deterioration of health following hospice discharge. Of specific concern is the fact that participants in the current study may have been dying without the hospice care they desired. These data suggest that more research addressing the role of comprehensive discharge planning is needed to identify the desires of the patient and family to better prepare them and to facilitate the transfer of services.

Cassarett and colleagues (2001) used a retrospective cohort study to identify predictors of hospice withdrawal using data collected from approximately 1,700 first-time hospice enrollees, 98 of whom were discharged for ineligibility and 260 of whom withdrew from hospice voluntarily. Findings from the Cassarett et al. (2001) study indicated that eligible patients who were male, less than 65 years old, did not have cancer, lacked a DNR order, and did not have an intravenous access device or symptoms needing intervention were more likely to withdraw from hospice. Cassarett et al. (2001) did not evaluate the patient condition following discharge, so it is impossible to draw any parallels with the current research study other than a coincidental similarity in population. Cassarett et al. (2001) do, however, recommend further research in this area to determine if discharge has a negative impact on patient outcome. The current study’s findings describe the potential for a negative impact on patient and family quality-of-life post discharge and indicate the need for further study.

**Prognostication**

Murray et al. (2005) conducted a literature review to describe three current trajectories disease trajectories to determine clinical implications. Murray et al. (2005) described each trajectory related to its most commonly associated disease process: (a) Trajectory 1—steady progression clear terminal phase (e.g., cancer), (b) Trajectory 2—longterm limitations with intermittent serious episodes and sudden unexpected death (e.g., respiratory failure, heart failure), and (c) Trajectory 3—prolonged gradual decline
(e.g., dementia). Limitations to the paper included the acknowledgement that other trajectories related to psychosocial or spiritual dimensions were not included in the discussion. Murray and colleagues (2005) encouraged the use of these trajectory models to establish a plan of care appropriate to the needs and desires of the patient and their disease process, including the provision of palliative care alongside curative treatment over the full course of the disease processes. The current study’s findings support the idea that patients might benefit from the concurrent receipt of palliative care and traditional healthcare benefits as they navigate the transition out of hospice services.

Mitchell et al. (2010) conducted a prospective cohort study of 606 residents with advanced dementia in 21 Boston-area nursing homes to validate the Advanced Dementia Prognostication Tool (ADEPT) and compare it to hospice guidelines. Study limitations were that the accuracy of the ADEPT could have been increased with the addition of additional variables, that the study sample consisted of predominantly Caucasians from one geographical area, and that the ADEPT had not been validated with patients in the community. Findings of the study indicated the ADEPT tool score was modestly more accurate than the hospice eligibility guidelines as a predictor of death within six months. Mitchell and colleagues (2010) suggested that due to the difficulty in prognostication of persons with dementia, care should be provided to patients based on treatment goals instead of life expectancy. Only two of the participants in the present study were family members of a patient with dementia. However, their stories support Mitchell et al.’s (2010) findings that prognostication for patients with dementia is difficult. Had care for these participants’ family members been provided based on goals of care as opposed to life expectancy, the outcomes might have been drastically different.

**Ethnic Disparities**

In a retrospective cohort study, Kapo et al. (2005) sought to determine whether African American patients leaving hospice return to hospice prior to death. The researchers analyzed data derived from electronic medical records of 358 patients who had been discharged from hospice. Findings indicated that African Americans were in
fact less likely to return to hospice service prior to death than other racial groups when they had been discharged from hospice. Findings of the Kapo et al. (2005) study indicated that live hospice discharges might exacerbate health disparities and access to care issues prevalent in African American populations.

The purpose of the current study was not to specifically address separate experiences of minority groups discharged alive from hospice from other ethnic groups, although 3 of the 12 participants identified themselves as either Hispanic or American Indian. The participants of this study described experiences of inaccessible care issues such as providing medications and equipment, daycare or respite care, and, most importantly, adequate management of symptoms. These findings support the results of the Kapo et al. (2005) study, indicating access to care issues seen in minority populations. However, as there were no African American participants in the current study it would be inappropriate to assume any other similarities in results.

**Policy Issues**

Carlson et al. (2008) reported on implications of expanding the Medicare Hospice Benefit. The authors addressed the history of hospice and current policy issues regarding treatment restrictions and potential barriers to hospice enrollment as well as discuss the target hospice population and the Medicare hospice benefit eligibility. The authors noted that it might be particularly difficult for individuals with uncertain or non-cancer diagnoses to access hospice. Difficulties involved in expanding hospice benefit eligibility and funding issues were explicated and support for the provision of palliative care encouraged. The current study findings support Carlson et al.'s (2008) argument that the advantages and challenges of hospice eligibility reform, including its effect on patients and families, must be considered carefully and compared with the consequences of retaining the status quo. Many of the participants of the present study were adversely affected by discharge from hospice. Participants associated hospice with life (e.g., hospice equals life); therefore, from their perspective removal of hospice services was equivalent to terminating life support.
Lynn and Forlini (2001) discussed the terminology used in determining hospice eligibility and encouraged providers to use language that directly addresses the population currently served by hospice. The authors critiqued the CMS requirement of “terminal status,” arguing that it limited access to benefits; rather, they suggested the term “serious and complex.” Serious and complex refers to patients with conditions that require ongoing health care, are disabling, and are likely fatal. The term potentially broadens hospice eligibility and may improve the quality of life of patients unable to be classified as terminally ill.

Several patient participants in the current study could be described using Lynn and Forlini’s (2001) term “serious and complex” because they were “patients with conditions that are already quite disabling, are expected to be fatal, and require ongoing health care” (p. 316). The inability to predict imminent death prevents such patients from being considered “terminal,” in turn rendering them ineligible for hospice. The participants of the present study continued to have unmet healthcare needs, which might have exacerbated their underlying disease processes and added to their suffering. Although it would be imprudent to revise the CMS hospice benefit eligibility criteria based on the findings of a single study, our study strongly suggests that the care hospice patients and families receive post-discharge should be carefully reviewed and monitored.

Relevance of Findings across the Literature

The true paradox of hospice discharge is that we are surprised by its complexity. Thompson et al. (2006) conducted a grounded theory study that examined the processes nurses use to facilitate the transition from curative to palliative care. Thompson et al. (2006) found that nurses created a “haven for safe passage,” which in turn facilitates and maintains the “lane change” from curative to palliative care through “being there” and “manipulating the care environment” (p. 92). The findings of the present study supported the assumption that similar difficulties met during one’s transition into hospice might be encountered during the transition out of hospice.
The experience of hospice discharge encompasses mixed feelings regarding the discharge as well as having support and needing support. Thompson et al. (2006) found that nurses facilitate the transition on hospice through advocacy, presence, and manipulation of the environment. It would be interesting to know if such nursing actions might facilitate the transition out of hospice.

Suffering is the feeling of being alone, alienated, or estranged from the community one feels part of; this can be particularly distressing for the chronically ill (Diekelmann, 2002). Whether it is the understanding of the terminal status of the underlying disease process that precedes the hospice enrollment or the attachment developed while part of the hospice community, participants in the present study reported being distressed by the discharge. Discharge from hospice leaves patients and families in a place that might be described as the in-between of living and dying. No longer are these individuals part of the hospice community, labeled as dying and eligible for the care and support they have become accustomed to; yet the yoke of a terminal disease means they no longer were part of living. Diekelmann (2002) noted that patients burdened with physical, medical, emotional, and financial needs must struggle to make sense of the new reality of “otherness” (p. 100). This combination of burden and loss of community was described by patients with their stories of anger and frustration.

Loneliness is an inevitable reality in death and dying experienced both by patients and their loved ones. Loneliness is experienced in periods of transition and in between endings and new beginnings (Moustakas & Moustakas, 2004). Further, Moustakas (1972) noted that the loneliness of a broken life is a form of existential loneliness where life is suddenly shattered by betrayal, deceit, rejection, misunderstanding, pain, separation, death, illness, tragedy and crisis that severely alters one’s sense of self, relationships, work, and world. The loneliness described by participants in the present study resonate with those aforementioned qualities.

In On Death and Dying, Kugler-Ross (1969) emphasized the importance of family in caring for the terminally ill. Although families’ needs change, they often continue to need assistance long after the death of the patient. This continued need after
hospice discharge was reflected by families who were bearing exhaustive witness—exerting themselves to point of collapse and unable to “maintain a sound balance and respecting their own needs” (Kubler-Ross, 1969, p. 167).

A transfer of services requires adequate “hand-off” communication (Speck, 2006). Communication among providers, facilities, staff, patients and families during transitional periods ensures continuity of care and benefits all of those involved (Speck, 2006). Communication, or lack thereof, played a vital role in our participants’ feelings of uncertainty and abandonment. Their questions were left unanswered, services lost, and support withdrawn. Patients and families experienced loss of security as they started over again—locating a physician, pain medication, and equipment. The in-between (hospice and post-hospice discharge) was unbearable: there was no bridge, no guide. The experience could have been alleviated had there been improved communication among the discharging hospice, the new provider, and the patient and family. What was needed was a plan of care that included the patient and family, a bridge to support, care, and supplies. Such a bridge would have eliminated unanswered questions that haunted the family participants after discharge. The lack of a defined plan left participants with a loss of security. Had there been a viable bridge to support the participants, no question would have existed about what to do and whom to call in case of an emergency.

Diekelmann’s (2002) concernful practices study described ways of being in-the-world and the common meanings and shared experiences of schooling, learning, and teaching among students, nurses, and faculty that recur over time. These concernful practices, which were identified by a 14 year study, may offer an avenue for developing possibilities for understanding how healthcare professionals care for and connect with patients and families discharged from hospice alive. These patterns demonstrate ways of understanding what is most meaningful and of concern, not only in the world of academe but in the world of suffering, in the in-between sacred space where nurse meets patient. Heidegger referred to a similar state of being called “break-down,” wherein the taken-for-granted of everyday life shifts (1927/1962). Healthcare professionals often meet patients and families in “break-down.” Transitioning from the safe world of a hospice program,
with its trusted relationships and practices, to another reality can be considered suffering and “break-down.” Concernful practices offer a guide to nurses as they meet patients and family and help them understand or assign meanings during this time; cultivate a safe space for those discharged from hospice alive, engender a community of support post discharge; create places that incorporate the in-between of uncertainty post-discharge; listen attentively and interpret needs and concerns of patients and families; be present; attend and be open to the world of the patient during transition and post discharge; make visible this very uncertain time; and stay with families as they continue their vigil. Patients and families have voiced their concerns; healthcare professionals must listen and, together, new possibilities of care and new meanings can be co-created.

**Implications for Nursing Practice**

It is clear that patients and family members alike continue to require information and support both during and after hospice discharge. Nurses, who advocate for family-centered care, are in a unique position to provide the type of anticipatory guidance necessary to transition out of hospice service and avoid the unmet needs and difficulties experienced by study participants.

Euphemisms such as “moving on” or “passing away” have been used in end-of-life care discussions, often proving to be detrimental to all involved. Discomfort with the topic of death spurs the use of these terms. Realistic dialogue regarding illness trajectories and expectations of care could facilitate the provision of high quality end-of-life care (Murray et al., 2005). The findings of this study emphasize that direct communication and information provided in advance of hospice discharge can assist patients in the transition from hospice. By removing uncertainty and providing factual information, we can inform and thereby empower the patient and family in the new reality of hospice discharge.

A discharge program that provides the patient and caregivers with specific information regarding the role of discharge planners, social workers, nurse, and physicians involved in the hospice discharge could prevent a lapse in care, in turn
facilitating transition. Such a program could provide a predetermined number of nurse visits or perhaps the continued services of a case worker who could facilitate the acquisition of supplies, medications, or services that patients require to transition to another provider as well as prevent deterioration and suffering.

**Implications for Nursing Education**

Nurse educators prepare future nurses to care for chronically ill patients and their families. This study shows that in addition to current preparations, a new aspect must be considered: care of the chronically terminal patient. The reality of patients being discharged from hospice alive must be included in the education of our future providers to prepare them in areas of anticipatory guidance, live hospice discharge planning, and family-centered care planning.

**Implications for Hospice**

The founder of hospice, Dame Cicely Saunders, stated in 1998 that, “Hospice didn't set out to look after everyone in the world who was dying of everything.” Yet over the past 23 years hospice has changed its focus to include “everyone” dying of “everything.” Meanwhile, not every patient enrolled in hospice services takes the expected course of enrollment, decline, and death. Some patients, such as those who participated in this study, reach a plateau or even improve, which renders them ineligible to receive hospice benefits.

The findings of this study show that patients discharged alive from hospice continue to have unmet needs and suffer due to withdrawal of hospice services; this pain and suffering is inconsistent with the mission of hospice even though the act may be unintentional. To assuage the suffering reported by study participants, hospice must recognize the potential for abandonment, unanswered questions, loss of security, loneliness, uncertainty, anger and frustration, physical decline. Moreover, families themselves may be bearing exhaustive witness, so hospice services should provide aid to the patient and family via clear communication and anticipatory guidance. Families must
understand that this is not their fault. Yet patients and their families in this study left hospice with the perception that patients were not dying fast enough, and thus ineligible for continued care. Although not part of this study, hospice staff members were very concerned about their patients and the family members but they often felt as helpless as the patients.

**Ethical Considerations**

The American Nurses Association (ANA) has established a code of ethics to guide nursing practice and provide nurses with a standard for practice. According to the ANA Code of Ethics Provision 1.3:

The nurse respects the worth, dignity and rights of all human beings irrespective of the nature of the health problem. The worth of the person is not affected by disease, disability, functional status, or proximity to death. This respect extends to all who require the services of the nurse for the promotion of health, the prevention of illness, the restoration of health, the alleviation of suffering, and the provision of supportive care to those who are dying.

The measures nurses take to care for the patient enable the patient to live with as much physical, emotional, social, and spiritual well-being as possible. Nursing care aims to maximize the values that the patient has treasured in life and extends supportive care to the family and supportive others. Nursing care is directed toward meeting the comprehensive needs of patients and their families across the continuum of care. This is particularly vital in the care of patients and their families at the end of life to prevent and relieve the cascade of symptoms and suffering that are commonly associated with dying (ANA, 2001, pp. 3-4).

The duty to provide care as delineated in Provision 1.3 clearly applies to the patients and families discharged from hospice. No patient should be discharged from hospice until a plan of care and all healthcare providers are in place, including any equipment and supplies the patient requires. Nurses have a moral and ethical duty to
stand alongside their hospice patients and families while they are in the in-between. In the case of a live hospice discharge, the ethics of the profession are not supported by the guidelines and laws governing nursing actions, which potentially places the nurse and other hospice staff at-risk for moral and ethical distress (Murray, 2010).

The Centers for Medicare and Medicaid services have specific guidelines regarding discharge from hospice:

The hospice notifies its Medicare administrative contractor (MAC) and SA of the circumstances surrounding the impending discharge. The hospice should also consider referrals to other appropriate and/or relevant state/community agencies (i.e., Adult Protective Services) or health care facilities before discharge (State Operation Manual, 2010).

This provision does not give specific instructions as to how a hospice agency might provide such services or even to what extent the services are required. Moustakas (1967) states:

We must not live by instructions, by rules, by social, administrative or therapeutic directives but by moral strength, individual and universal value, spiritual strength that can be exercised in the moments of life with other persons when freedom and choice and responsibility are not enough where there are no instructions but where moral and ethical value provides the directive which gives essence to the existence and brings an internal sense which carries its own instructions in the regions of the spirit and the heart and mind of man (p. 103).

A dilemma exists in the situation of live hospice discharge—must we wait for instructions from a regulating body, or should we instead rely on our own ethical stance as healthcare professionals to do the right thing? Somehow we must provide support to patients and families in need; in so doing, we can reduce suffering and improve care. However, we must also provide funding and resources for these services; without a
mandate from a payer source, hospice organizations will be unable, and in some cases even barred, from providing such services.

**LIMITATIONS**

There are several potential limitations in the present study: sample size, self-report, potential for researcher bias, and homogenous sample. Each aspect is addressed as it pertains to the study and phenomenological research. The scope of the study is also evaluated.

Although the small sample size (n=12) was not suitable for generalization, this is not regarded as a limitation for a phenomenological study as generalization is not the goal (Lincoln & Guba, 1985). This study was intended to understand the unique experience of being discharged live from hospice from the perspective of 12 individuals, both patients and family, and to inform future research in the field of hospice and palliative care through a rich thick description of the findings.

Participants are considered truth tellers in phenomenological research. The accuracy of their stories is not an issue. Participants share their experiences within their level of comfort, although those recollections and meanings of an event or phenomenon may change over time. This study allowed each participant to select the interview setting, thus enhancing rapport through prolonged engagement (multiple interviews). Participants were encouraged to share recollections, meanings, and feelings related to their experiences of live hospice discharge and their post discharge quality-of-life (Lincoln & Guba, 1985; Richards & Morse, 2007).

The investigator is the study instrument in qualitative research. Moreover, as an adult child, the PI personally experienced the phenomenon of a discharged hospice patient. Therefore, it is possible the researcher’s familiarity may have unwittingly introduced bias into the data collection and interpretive analysis of interview text. Steps taken to reduce potential bias included peer debriefing and reflexive journaling. Throughout the study process, sections of coded transcripts related to significant statements or particular interpretations were reviewed by a research team to ensure
faithfulness to the text and to limit bias. A personal (reflective) journal was kept by the PI to record feelings, biases, assumptions, and insights that might have influenced the interview progression or interpretations (Lincoln & Guba, 1985). This reflective journal enabled the researcher’s perceptions, feelings, and intuitions to be acknowledged and understood so that conflicts and challenges as well as harmony and balance could be recognized (Moustakas, 1995).

Additionally, the breadth of the sample was limited due to the self-selective recruitment process. The sample was mostly non-Hispanic Caucasian with no African-American participants. Also, the hospice patient parent of all adult children participants was deceased. This could have influenced their experience and therefore the findings of this study in a way that was unanticipated by the researcher.

The experience of being discharged alive from hospice is a topic potentially too expansive for one study to address completely. Further, research needs to be conducted with family members and care providers alike in order to fully appreciate the phenomenon and to plan a course of action that will alleviate the sense of suffering these participants described.

Despite the potential limitations, the current study does open dialogue concerning the experiences of these 12 participants, bringing to light the struggles they endured following their own live discharge or that of a family member from hospice.

**Recommendations for Future Research**

The findings of this study illuminate the perceptions of persons discharged alive from hospice and those of the family members. The emergent themes provide a more in-depth understanding of the experience and a foundation that can inform the design of an instrument to measure patient and family perceptions of the discharge experience; such an instrument could quantify the experience in a way that allows for evaluation of an intervention to improve outcomes post hospice discharge. A quantitative or mixed-method study design using instruments developed for this population could build on the current knowledge and provide a more detailed description of the phenomenon of being
discharged from hospice alive. Longitudinal mixed-method studies documenting the long-term effects of live hospice discharge also could expand knowledge related to this phenomenon. Specifically, pilot programs developed to bridge the transition from hospice could be evaluated for effectiveness and feasibility. Outcome measures may include reduced rates of patient demise within six months of discharge or even reduction in participant-identified levels of suffering. A descriptive comparison study comparing the viewpoints of patients and families with the perspectives of hospice staff could also add a new dimension to the subject area.

To our knowledge, no other published research exists that explores the qualitative experience of a live hospice discharge. A grounded theory approach could provide specific data needed to generate concepts for a theoretical framework that better addresses this phenomenon. Thematic findings of this study can inform the development of an initial conceptual framework that would explain the actions of patients, families, and healthcare providers during hospice discharge. Furthermore, exploring the psychosocial processes and social interactions among all stakeholders might provide a theoretical framework that could serve as the basis of an intervention to improve the outcomes of patients and families discharged from hospice.

An ethnographic approach would allow for an in-depth look at the experiences of minority groups when discharged from hospice and help determine if there is there a link between culture, language, and suffering after hospice discharge. If so, what tools do some cultures have that others do not? Moreover, can other cultures implement these tools effectively?

Further phenomenological research is recommended to explore the perceptions of hospice workers who experience live hospice discharges and the meaning they assign to this phenomenon. Related phenomena such as moral distress and ethical concerns must be addressed in these conversations. Once this phenomenon is understood from hospice workers’ perspectives, subsequent support of these workers would then be more effective.
PERSONAL REFLECTION

Throughout the conduct of the study, I reflected often on my own experience and struggles and those of my family after my father was discharged alive from hospice. I was continually reminded of both the fragility of flesh and strength of the human spirit. My father did not survive his discharge from hospice but his struggle inspired me to look more closely at the system that failed him. By hearing the voices of the individuals in this study, my own understanding of their experiences and that of my father grew in breadth and depth. These patients and family members continued to search for new meanings in life and to fight every day to live to the fullest degree possible despite the burden of living with a chronically terminal disease. Although there seemed little one could do to alleviate the suffering experienced by these individuals, I learned that by asking about and carefully listening to their stories, we co-created new meanings in the context of their suffering, even if these meanings were primarily lending their voices to the world to make others aware that transitioning out of hospice can become a step into a world of utter desolation. I learned that as family members must bear exhaustive witness during and post-hospice discharge, so too do the nurses, physicians, nurse aides and all hospice workers—individuals who were ever present, ever caring, and ever concerned. The complexity of prognostication of the time of one’s death, national economics, policy constraints, and myriad other factors inherent in our healthcare system actually appear to prevent hospice agencies from helping individuals die with dignity unless that death can be predicted within a six-month period.

This study illuminates the anguish of being discharged from hospice alive; it also arguably points to the finest example of quality holistic care in the United States: a model of care in which patients and family members receive the most comprehensive level of support and experience caring relationships; a model of care in which dying patients often get better: hospice. This study points toward a place for palliative care, based on the tenets of hospice, and available to every person for as long as they live. The stories in this study will carry the legacy of these participants in my practice, my classroom, and at my conferences; they will always be in my heart.
CONCLUSION

The essence or meaning of being discharged from hospice alive was revealed through the voices and stories of patients and families who experienced it. The study findings were consistent with extant literature. Further, the findings expounded upon the limited knowledge in the field regarding the experiential aspect of the phenomenon, thus providing a more in-depth, descriptive meaning. This study revealed a need to attend more closely to the voices of patients and families to learn from their experiences—to illuminate that which may be hidden, thereby improving patient outcomes.
November 6, 2009

Rebeca Watson Campbell
Doctoral Student
School of Nursing
University of Texas Medical Branch
Galveston, Texas 77555-1029

Ms Watson Campbell:

As Executive Director of Hospice Care Team Inc., I am happy to confirm our commitment to your proposed research study: *The Experience of Being Discharged from Hospice as Perceived by Adult Patients*. This is an exciting study and we are glad to participate.

In support of your project, Hospice Care Team will distribute recruitment flyers to patients being discharged from services due to extended prognosis or decertification for the purpose of recruitment by you.

Your study is a promising approach to learning more about the patient’s experience during and after discharge. We are happy to participate and look forward to your results.

Sincerely,

Deborah Perryman, LMSW
Administrator/Executive Director
November 7, 2009

Rebecca Watson Campbell, RN
Doctoral Student
School of Nursing
University of Texas Medical Branch
Galveston, Texas 77555-1029

Ms Watson Campbell:

As Medical Director of Vitas Hospice of Houston, I am happy to confirm our commitment to your proposed research study: The Experience of Being Discharged from Hospice as Perceived by Adult Patients. Your protocol has been approved by our corporate IRB. This is an exciting study and we are glad to participate.

In support of your project, Vitas Hospice will distribute recruitment flyers to patients being discharged from services due to extended prognosis for the purpose of recruitment by you.

Your study is a promising approach to learning more about the patient’s experience during and after discharge. We are happy to participate and look forward to your results.

Sincerely,

Kenneth M. Ungar, MD, FACP, FCCP, FAASM
Medical Director, Houston Program
APPENDIX B: RECRUITMENT FLYER

HAVE YOU OR A FAMILY MEMBER BEEN DISCHARGED FROM HOSPICE?

To help provide quality care after hospice, a study is being conducted to better understand the experience of being discharged from hospice by patients and family members. Volunteers over the age of 18 are asked to share their experiences of live discharge from hospice in 1-2 private interviews.

If you are interested in sharing your story, please contact Rebeka Campbell, RN at:

Phone: [redacted]
Cell: [redacted]
E-mail: [redacted]
APPENDIX C: IRB APPROVAL AND INFORMED CONSENT

March 12, 2010

MEMORANDUM

TO: Diane Heliker, RN, PhD/Rebecca Watson Campbell, RN, BSN

FROM: Interim Director
          Institutional Review Board 0158

Subject: IRB #09-064 – Administrative Approval of a Change in Study Title, Revised Protocol, Revised Research Consent Form and Revised Recruitment Flyer.

New Title: The Experience of Being Discharged from Hospice as Perceived by Adult Patients, their Spouses, and Adult Children

The Institutional Review Board acknowledges receipt of your Request for Protocol/Consent Modifications dated 3/3/10, requesting approval of a change in study title, revised protocol, revised research consent form and revised recruitment flyer. The study title has been changed to The Experience of Being Discharged from Hospice as Perceived by Adult Patients, their Spouses, and Adult Children. The protocol was revised to reflect the expansion of the study population to include the family members (spouses and adult children) of the discharged hospice patient. This change reflects the philosophy of hospice care as being patient and family focused, allowing the inclusion of the family unit experiencing the phenomenon of the study. The consent form was revised to reflect the study title change and the expansion of the study population. The recruitment flyer was revised to address the new study population. The change in study title, revised protocol, revised research consent form and revised recruitment flyer were reviewed and approved through an expedited review process by the IRB on 3/12/10.

This project will require annual review by the IRB and will be due by January 31, 2011. Research that has not received approval for continuation by this date may not continue past midnight of the expiration date.

Attached is the subject consent form with the date of the IRB approval. Please use this consent form with the IRB approval date and make additional copies as they are needed, in accordance with amendments to 21 CFR Parts 50, 312 and 812 effective 12/5/96, consent forms must be dated when consent is obtained.

NOTE TO THE INVESTIGATOR: The sample advertisement that you submitted is approved for publication on the Internet, television, mass electronic mailings, campus, local and regional newspapers and magazines, and bulletin board postings. If you desire to advertise via radio, please submit the script to be used. In addition, these items must be submitted to the Office of University Relations (x20156) for review and approval of format prior to being published on or off campus.

CRB/cc

Attachment: Research Consent Form
RESEARCH CONSENT FORM

You are being asked to participate as a subject in the research project entitled, *The Experience of Being Discharged from Hospice as Perceived by Adult Patients, their Spouses, and Adult Children* under the direction of Rebeka Watson Campbell, RN.

PURPOSE OF THE STUDY

The purpose of this study is to better understand what it is like to be discharged alive from hospice, and if that discharge changes the way you live your life. You are being asked to participate because you or a family member has been discharged from hospice.

PROCEDURES RELATED TO THE RESEARCH

Procedures include two (2) interview sessions with the researcher to discuss being discharged from hospice and the one time completion of a demographic form. Prior to the first interview, it is requested that you prepare by reflecting or journaling your thoughts and feelings regarding your (family member’s) hospice discharge and current quality of life.

RISKS OF PARTICIPATION

No physical risks of participation are anticipated. However, you may feel sad as you relate your experiences. You may share only what you choose. You will be given the opportunity to end the interview at any time.

NUMBER OF SUBJECTS PARTICIPATING AND THE DURATION OF YOUR PARTICIPATION

The maximum number of subjects anticipated to be involved in the study is fifteen (15), with none participating at the University of Texas Medical Branch. The length of time for your participation is about 90 minutes over two (2) visits. The second visit will occur within two (2) weeks of the first interview.

BENEFITS TO THE SUBJECT

The only benefit you may gain may be that your story may help care providers understand the perspective of an individual discharged from hospice.

REIMBURSEMENT FOR EXPENSES

There will be no reimbursement for participation in this study.

COMPENSATION FOR RESEARCH RELATED INJURY

If you are physically injured because of any procedure performed on you under the plan for this study, UTMB will provide you with the appropriate medical treatment. Your insurance company will be billed and any charges not covered by your own insurance or health care program will be provided at no cost to you. You will be responsible for paying any costs related to illnesses and medical events not associated with being in this study. There are no plans to provide other forms of compensation. However, you are not waiving any of your legal rights by participating in this study. Questions about compensation may be directed to the study doctor.
USE AND DISCLOSURE OF YOUR HEALTH INFORMATION

Study records that identify you will be kept confidential as required by law. Federal privacy regulations provided under the Health Insurance Portability and Accountability Act (HIPAA) provides safeguards for privacy, security, and authorized access of your records. These regulations require UTMB to obtain an authorization from you for the use and disclosure of your health information. By signing this consent form, you are authorizing the use and disclosure of your health information related to the research study. Except when required by law, you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier in study records disclosed outside of the University of Texas Medical Branch (UTMB). For records disclosed outside of UTMB, you will be assigned a unique code number. The key to the code will be kept in a locked file in Ms. Campbell's office.

If you sign this form, you are giving us permission to collect, use and share your health information. You do not need to sign this form. If you decide not to sign this form, you cannot be in the research study. We cannot do the research if we cannot collect, use and share your health information. Whether or not you agree to the research project or give us permission to collect, use or share your health information will not affect the care you will be given at UTMB.

Your records may be reviewed in order to meet federal or state regulations. Reviewers may include, for example, the Food and Drug Administration, UTMB, UTMB IRB. This authorization for the use and disclosure of your health information as described above expires upon the conclusion of the research study except for FDA regulated studies. For FDA regulated studies, the study sponsor and government agencies, such as the FDA may review your records after the study ends.

If you change your mind later and do not want us to collect or share your health information, you need to contact the researcher listed on the attached consent form by telephone or by letter. You need to say that you have changed your mind and do not want the researcher to collect and share your health information. You may also need to leave the research study if we cannot collect any more health information. We may still use the information we have already collected. We need to know what happens to everyone who starts a research study, not just those people who stay in it. The results of this study may be published in scientific journals without identifying you by name.

ADDITIONAL INFORMATION

1. If you have any questions, concerns or complaints before, during or after the research study, or if you need to report a research related injury or adverse reaction (bad side effect), you should immediately contact Ms Campbell at [redacted], if after normal office hours, at [redacted].

2. Your participation in this study is completely voluntary and you have been told that you may refuse to participate or stop your participation in this project at any time without penalty or loss of benefits and without jeopardizing your medical care at UTMB. If you decide to stop your participation in this project and revoke your authorization for the use and disclosure of your health information, UTMB may continue to use and disclose your health information in some instances. This would include any health information that was used or disclosed prior to your decision to stop participation and needed in order to maintain the integrity of the research study. If there are significant new findings or we get any information that might change your mind about participating, we will give you the information and allow you to reconsider whether or not to continue.

3. If you have any complaints, concerns, input or questions regarding your rights as a subject participating in this research study or you would like more information, you may contact the Institutional Review Board Office, at [redacted]
The purpose of this research study, procedures to be followed, risks and benefits have been explained to you. You have been allowed to ask questions and your questions have been answered to your satisfaction. You have been told who to contact if you have additional questions. You have read this consent form and voluntarily agree to participate as a subject in this study. You are free to withdraw your consent, including your authorization for the use and disclosure of your health information, at any time. You may withdraw your consent by notifying Ms. Campbell at [redacted]. You will be given a copy of the consent form you have signed.

Informed consent is required of all persons in this project. Whether or not you provide a signed informed consent for this research study will have no effect on your current or future relationship with UTMB.

<table>
<thead>
<tr>
<th>Signature of Subject</th>
<th>Date</th>
</tr>
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</table>

Using language that is understandable and appropriate, I have discussed this project and the items listed above with the subject.

<table>
<thead>
<tr>
<th>Signature of Person Obtaining Consent</th>
<th>Date</th>
</tr>
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</table>
APPENDIX D: DEMOGRAPHIC INFORMATION

ID#___________

1. Age: _______
2. Gender: ☐ Male   ☑ Female
3. Race:
   ☐ White
   ☑ Black or African American
   ◐ Asian
   ◐ Native Hawaiian or other Pacific Islander
   ◐ American Indian or Alaska Native
4. Ethnicity:   ☐ Latino or Hispanic   ☑ Not Latino or Hispanic
5. Language preference:   ☐ English   ☑ Spanish   ◐ Other
6. Education (last grade completed): __________________
7. Marital Status:
   ☐ Single, never married
   ☑ Married/ living with partner
   ◐ Separated/ divorced
   ◐ Widowed
8. Relationship to Patient:
   ☐ Self
   ☑ Spouse/Significant Other
   ◐ Adult Child
9. Insurance Coverage:
   ☐ Private Insurance   ☑ Medicaid/Medicare
   ◐ Self Pay   ◐ Other: __________
10. Date of Hospice Discharge: ___/___/_____
11. Date of Initial Interview: ___/___/_____
12. Date of Follow-up Interview: ___/___/_____

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APPENDIX E: INTERVIEW GUIDE

Patients:
1. Tell me about being discharged from hospice.
   a. What does it mean for you to be discharged from hospice?
   b. What thoughts did you have when you learned about your discharge?
2. Tell me about your quality of life since discharge.
   a. Talk to me about how things are now, since you have been discharged from hospice.
   b. How do you feel discharge from hospice has affected you? i. Your sense of self/self worth, health, and relationships?

Family members:
1. Tell me about [name family member] being discharged from hospice?
   a. What was it like for you?
2. Tell me about your quality of life since [name family member] discharge.
   b. Talk to me about how things are now, since [name family member] has been discharged from hospice.
   c. How do you feel [name family member] discharge from hospice has affected you? i. Your sense of self/self worth, health, and relationships
BIBLIOGRAPHY


VITA

Rebeka Bianca Watson was born on August 16,  in Lubbock to Ricky (1948-2008) and Retha Ann Watson. She has an older sister, Kristina Leigh Harville. Rebeka attended The University of Texas Medical Branch at Galveston, where she obtained a Baccalaureate Degree in Nursing in April 2005.

Rebeka married Stewart Edward Campbell on in Hobart, New York. She has two children, Chase Anthony and Danielle Rae. Rebeka and Stewart reside in League City, Texas with her youngest child Danielle.

Rebeka worked as a Registered Nurse in the Surgical Intensive Care for the University of Texas Medical Branch at Galveston, Texas from April 2005 to April 2006. She also worked for the Clear Lake Regional, Intensive Care Unit in Webster Texas until she was accepted into The University of Texas Medical Branch Graduate School of Biomedical Science in Nursing PhD program.

Honors awarded include: Membership into Sigma Theta Tau International Honor Society of Nursing Alpha Delta chapter along with an elected position on the Leadership Committee. She was awarded Best Student Poster for *Minorities Aging and Health Disparities Research* at the 12th Annual Forum on Aging with a competitive, monetary award. She is also a member of the American Nurses Association, Texas Nurses Association (District-6 Vice President), and the Southern Nurses Research Society.

Permanent Address

Education

B.S.N., April 2005, the University of Texas Medical Branch at Galveston, Texas

Publications

SUMMARY OF DISSERTATION

Approximately 1.56 million patients received hospice care in 2009, and 243,000 were discharged alive (NHPCO, 2010). There is a paucity of research describing the experiences of individuals who are discharged from hospice alive. The purpose of this transcendental phenomenological study was to explore the experiences of adult individuals with a life-limiting condition who were discharged from a hospice program due to decertification related to ineligibility or extended prognosis from the perspective of the individual and his or her adult family members. Research questions were: a) how do patients discharged alive from hospice perceive and describe their experience, and b) how do participants perceive and describe their quality of life after a live hospice discharge?

A transcendental phenomenological design guided this study (Moustakas, 1994). Purposive, snowball sampling was used to recruit 12 volunteers, aged 35-92 years, who had experienced live hospice discharge due to decertification. Data collection included open-ended interviews, methodological, personal, and field journals. Interviews occurred at the participant’s residences and were recorded and transcribed verbatim. The initial interview question was, “tell me about being discharged from hospice.” Data analysis followed Moustakas’s (1994) approach utilizing Lincoln and Guba’s (1985) trustworthiness criteria for rigor.

Findings include two primary themes: suffering “as…” and the paradox of hospice discharge. These major themes are supported by 12 subthemes: having support, mixed feelings, not dying fast enough, hospice equals life, abandonment, unanswered questions, loss of security, loneliness, uncertainty, suffering, anger and frustration, and physical decline. Understanding this experience may create new possibilities for hospice care including review of policies and guidelines limiting hospice enrollment to a temporal status.