Communicating spirituality, dying and a "good death" at the end-of-life: The role of hospice interdisciplinary team members

Jillian A. Tullis Owen

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Communicating Spirituality, Dying and a “Good Death” at the End-of-Life: The Role of Hospice Interdisciplinary Team Members

by

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A dissertation submitted in partial fulfillment of the requirements for the degree of Doctorate of Philosophy
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Dedication

“Life in its passing is a sacred thing, never to be repeated.”

~Author Unknown

The Chaplain of the Sunflower team offered the inspirational quote above during one of the team meetings I observed. The quote rightly captures one of the lessons I learned while completing this project. Coastal Hospice’s patients, their families, and the Sunflower team members helped me see that each day is a gift. My hope is that from their wisdom and kindness I will allow the sacredness of life to guide my choices and my communication.

I dedicate this dissertation to all of the hospice patients I encountered. Thank you for granting me the high honor of being present with you as you traversed the final journey of life. I also dedicate this dissertation to the members of the Sunflower hospice team who shared their knowledge and experiences of providing compassionate end of life care. Finally, I dedicate my pursuit of knowledge about spirituality, dying and death to my aunt Genie, my grandpa George, my friend Leah, my grandma Evelyn, and my granddad Dan, whose lives and deaths serve as inspirations for improving the ways we communicate about living and dying well.

The finite quality of life and the permanence of death makes taking the time to listen and share (Kübler-Ross, 1969) essential throughout a life, but certainly at the end of life. And it is my wish that this project captures the sacred moments when people come along side those in need with the goal of sitting, listening and sharing.
Acknowledgements

It takes a village to raise a Ph.D. and during the last year of my doctoral program, I found myself being thankful for the support of my family, friends, colleagues, and the faculty at USF. I owe a tremendous debt of gratitude to all of the people who encouraged me, offered their advice, wisdom, and ideas, listened to me bitch, and entertained my incessant interest in a topic I know most of you would prefer to avoid. I appreciate your compassion and care.

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To my mom, Jill, I cannot put into words how wonderful a mother and friend you are. Thank you for always answering the phone with a smile in your voice and offering words of encouragement and smart ideas. Thank you to my father, Dan, Jr., for instilling in me the love of conversation and the penchant for entertaining, both come in handy in the classroom. Many thanks to my friend and peer mentor Mary Poole; my friends Liz Edgecomb, Emily Ryalls, Sandra Wheeler-Abeyta, Tony Adams, and Steve Schoen; my brother Dan and my sister-in-law Maggie. Thank you for surrounding me with your love when times were good and hanging in there when times got tough. Finally, I would like to thank the University of South Florida Center for Hospice, Palliative Care and End-of-Life Studies for their financial and professional support of this project.
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Communicating Spirituality, Dying and a “Good Death” at the End-of-Life: The Role of Hospice Interdisciplinary Team Members

Jillian A. Tullis Owen

ABSTRACT

Hospices use interdisciplinary teams to aid patients and families as they cope with the imminence of death while helping them achieve a death free of physical and spiritual pain, also known as a good death. This study investigated the communication between hospice team members and their patients regarding spirituality, dying, death and a good death. Through 300 hours of participant observation and interviews with hospice staff at one large not-for-profit hospice in the Southeastern United States this project shows that team members understand patient’s spirituality through a religious frame potentially compromising spiritual care. Talk between patients and their care team rarely focuses on what constitutes a good death and team members eventually come to narrate all hospice deaths as good.
Prologue

“Dolphins,” someone shouts from a banquet table in the front of the room.

“A sunset overlooking the ocean,” two people yell from another table at the opposite end of the meeting room.

“Umbrella drinks. Your favorite Hawaiian shirt,” a few more people offer. There is a pause as the orientation facilitator, Dr. Paul, waits for the hospice employees to rewind their mental digital video recorders back to the first day of new employee orientation training in an effort to recall his personal imagine of a perfect death. “Uhh, Jimmy Buffett music,” someone contributes.

“Who’s Jimmy Buffett?” Jamal, a Certified Nursing Assistant, asks in a genuinely inquisitive tone. I glance across the table at Julie, a counselor, and Barbara, a Registered Nurse, and we start laughing. Since the first day of new employee orientation at Coastal Hospice five days ago, Jamal has served as my primary source of amusement. I am not sure if it is his voice, which is a mixture of Southern hip-hop star and flamboyant gay man, or his perfectly timed candor, or both. Either way, I am happy to share a table with him and not with the woman who is going to work in the finance department or the durable medical equipment truck driver. I can tell, even from across the room that, they are not nearly as much fun as Jamal and my other tablemates. “He sings that song, Margaritaville,” says Esther, a Licensed Practical Nurse.

1 All names, including the name of the hospice organization, teams, employees, patients, and families are pseudonyms.
“Oh, I think I know that song,” Jamal says unconvincingly. The rest of the new employees continue to recount the features of Dr. Paul’s ideal death. I hear someone say, “You also want to have lobster, if you can eat.”

“That’s right,” Dr. Paul says. “But there is one more thing you still haven’t mentioned.”

“A hammock!” Everyone shouts.

“You got it! You’re going to make great hospice employees. And if you’re around, God forbid, and I have a terminal illness, I am counting on you to remember what I want. And you know what? We can do most of these things, even the dolphins, for our patients. We’ve given patients rides on Harleys and even took one guy fishing with his oxygen and all."

I make a note on a Coastal Hospice Post-It that reads, “GOOD DEATH= fulfilling last wishes?”

At the end of the fifth day of orientation, I feel good about Coastal Hospice. I share a few “Hospice Hugs” and well wishes with my tablemates and tell them I hope to see them at the organization’s Revitalize and Reconnect event in three months. I drive home and think more about what events and experiences might comprise my own good death, but as I try to conjure up an image of my own illness and dying, I realize that my youth and clean bill of health makes such a scenario too difficult to contemplate in any realistic way. I shift my focus from my wishes to those of current hospice patients and wonder if they are as articulate about their dying wishes as Dr. Paul. The image Dr. Paul
creates stands in sharp contrast to the feelings I had during one of the orientation activities intended to recreate the dying experience.

Two veteran counselors asked us to create a list of people, objects, values, beliefs, interests, and hobbies we hold dear. I carefully selected four items for each category and wrote them on my activity worksheet. Next, the facilitators read a scenario intended to emulate the illness experience from a thyroid cancer diagnosis to death. At each phase of the experience, as the illness worsens, the counselors prompted us to cross items off the list. The activity forced me to “give up” going to the movies and eating my favorite foods. I let go of my patience, but I hung onto my dogs for as long as I could, but when it was time to choose between them and my mother, I had to let my dogs go too. By the end of the activity, she was all I had left. As the facilitators instructed us to cross the final item off our list, I fought back tears. My heart ached at the thought of my own eventual death. I realized, however, that my feelings had more to do with a distinct sense that this activity accurately reflected what my own dead loved ones must have experienced as their lives slowly ended. My aunt Genie, my mentor Leah, and my grandmother Evelyn, all died of cancer. I could hear other people sniffling, and a few people blew their noses. The counselors helped us debrief the activity and process the emotions that came up, encouraging us to use our reactions to inform patients’ experiences and their subsequent care.

I think back to the last time I did this exercise, during hospice volunteer training in California, and realize my response was almost identical. The sadness I felt was unbearable and it lingered for a couple of days. As I draw my attention away from my
thoughts and back to the road, I glance in the rearview mirror and notice the sun is beginning to set. I am convinced that Dr. Paul’s beautiful deathbed scene is more idyllic fantasy than reality, but then I remind myself that my role as a researcher affords me the opportunity to see the dying process at Coastal Hospice for myself. Rather than discount hospice’s ability to achieve a deathbed scenario like Dr. Paul’s, I will allow my forthcoming fieldwork to serve as the source for a more realistic image of life’s end. Hospice employees surely know and are likely to articulate their wishes at the end of life, but would patients? I consider my curiosity a positive sign and I begin to look forward to observing how Coastal Hospice’s interdisciplinary teams would use communication to deliver holistic care, and help patients and their families achieve good deaths.

* * * * *
Chapter 1 – Introduction

In her book *On Death and Dying*, psychiatrist Elisabeth Kübler-Ross (1969) said, “I am convinced that we do more harm by avoiding the issue [of terminal illness] than by using time and timing to sit, listen, and share” (p. 142). Forty years ago, Kübler-Ross first attempted to raise awareness about the communication needs of the dying, hoping to diminish the agony and suffering the terminally ill and their loved ones may experience in the final stages of life. Since Kübler-Ross’s appeal for more explicit and open communication about dying and death, scholars responded by researching the historical (Ariès, 1974; Stephenson, 1985), psychological (Marrone, 1997), and sociological (Mellor & Shilling, 1993; Walter, 1991; Willmott, 2000) reasons people fail to communicate about dying and death. Few people, however, have studied communication about dying and death as it occurs.

Thanatology (the study of dying, death, and grief) scholars from various disciplines argue that the proscription on death is recent (Ariès, 1974). Industrialization, geographic distribution of family members, the decline of religious and community dying and mourning rituals, and medical and technological advances are frequently cited as catalysts (Ariès, 1974; Marrone, 1997; Mellor & Shilling, 1993; Stephenson, 1985). Drawing on the work of ethicist Daniel Callahan, authors Ragan, Wittenberg-Lyles, Goldsmith, and Sanchez-Reilly (2008) argue that medical technologies “have lead to the eradication of diseases once considered death sentences [and] permit us the belief that we
have conquered death” (p. 5). Some scholars (Doss, 2002; Walter, 1991), however, question the presumed taboo surrounding communicating about death and contend that certain attitudes and behaviors instead signal a shift in modern-day society’s willingness to make death and dying more visible. Doss (2002) argues that

Contemporary debate surrounding abortion, AIDS, euthanasia and gun control…as well as increased popular interest in ‘good death,’ the afterlife and bereavement therapy, suggest the questioning and perhaps the lifting of certain death-related taboos. (p. 63)

Medical technologies and some increased interests in death related topics mark a transformation of dying and death, but not necessarily one that indicates the removal of related taboos. Connor (1998), for instance, contends that the ability to prolong life encourages an obsession with unnatural death and an avoidance of natural death. Walter (1991) also argues that death’s taboo includes more nuances than many scholars describe. According to Walter, the proscription surrounding death exists for certain groups (medical personnel and the media), and individuals (the dying and bereaved), but not for society as a whole. Walter fails to acknowledge, however, that people with terminal illnesses, medical personnel, and the media permeate society in ways that make it nearly impossible to deny their broad reaching influence on death’s proscription.

Doss’s (2002) and Walter’s (1991) critiques may challenge contemporary thinking about death’s taboo, but it does not resolve the proscription on death and death-talk because, as Connor (1998) points out, “the United States is both a death-denying and death-obsessed culture” (p. 122). The denial/obsession dichotomy creates communication
challenges for individuals and society. Walter’s (1991) speculative claims regarding death’s categorical proscription highlights how little we know about how people communicate about death in light of the cultural and social transformations described by Doss (2002). While there exists little consensus about the cause of death’s taboo – I believe the prohibition flows from a combination of factors rooted in communication – terminal illness and death gives rise to several social and existential paradoxes (Mellor & Shilling, 1993) that enable or constrain communication.

Death impels people to reconsider and reshape their roles and responsibilities within familial and social groups. Mellor and Shilling (1993), however, state that “in so far as people talk about and ‘confront’ death in modern society, they tend to do so indirectly, rather than face up to the ontological reality of death directly” (p. 423, emphasis theirs). In addition to a lack of direct or explicit communication about death, scholars (see e.g., Mellor & Shilling, 1993; Steeves & Kahn, 2005) observe the limits and inadequacies of the language for talking about death and grief. Scholars agree that many still find dying, death, and grief an isolating experience (Foster, 2006; Mellor & Shilling, 1993; Seale, 1998; Steeves & Kahn, 2005; Stein, 2007; Stephenson, 1985; Willmott, 2000). Attempts by individuals to “reflexively construct [language about dying and death] is inherently fragile since…the construction of meaning around death is an essentially social, [and] communal phenomenon” (Mellor & Shilling, 1993). Redressing the lack of language and attending to communication problems requires collaboration among people who are terminally ill and their professional and non-professional caregivers with the explicit goal of understanding and making sense of death while
simultaneously reducing suffering. Hospice exists to reduce this stress and diminish the feelings of isolation that accompany the dying process. The goals of hospice include reducing suffering at the end of life by creating an environment supportive of open communication about patients’ wishes and concerns about dying and death.

Answering Kübler-Ross’s (1969) call to sit, listen, and share, this dissertation captures and describes communication among hospice interdisciplinary team members and their patients and families focusing its analysis on dying and spirituality. Through narratives, I describe the content and form of these conversations, and who (e.g., patient, family, team member) initiates conversations about dying, death, and spirituality. I also discuss the ways in which various institutions (e.g., Medicare, the hospice) and institutional roles and expectations enable or constrain these conversations. Finally, I consider the role communication plays in achieving a death free of physical and spiritual pain also known as a good death, one of hospice’s principal goals for their patients and families.

In the following pages, I discuss the existing literature about end-of-life communication and spirituality. In addition, I describe the research methods that I used to investigate these topics, and I discuss the ethical dilemmas I negotiated while conducting research with terminally ill people and their family members. In an effort to understand the setting where my study occurred, I first summarize the development of hospice in the United States.
History of Hospice in the United States

Everyone must die. Most people, however, do not embrace this reality with ease. Due to advances in technology, which have improved diagnostic tools and treatment options, many people do not experience the death of a loved one until later in life (Marrone, 1997; Stephenson, 1985). Moreover, these same technological advances mean that people can live several years with life-threatening illnesses (Puchalski, 2006). As such, the first intimate exposure a person may have to death not when someone dies, but when someone receives a terminal diagnosis. The futility of curative health measures marks the moment when a physician declares a person terminally ill and turns her or his attention to making a patient comfortable. A physician may choose to refer a patient to hospice to receive comfort care.

Hospice is a philosophy of care and not necessarily a place where a person goes to die, although some hospices have in-patient facilities. Contemporary notions of hospice evoke an image of a highly structured and regulated organization that manages the needs of people at the end of their lives. The concept of hospice, however, dates back to medieval times when travelers sought respite on their way to the Holy Land (Hayslip & Leon, 1992; Leming, 2003; Marrone, 1997). Hospice care, as it exists in the United States, derives from the St. Christopher’s hospice in London, founded by Dr. Cecily Saunders in 1967 (Hayslip & Leon, 1992). When hospice migrated to the United States, it began as a grassroots movement in communities dissatisfied with the current medical model around end-of-life care (Egan & Labyak, 2006). The first hospice in the United States began in Connecticut after Dr. Saunders lectured about her work at Yale
University and in 1982, Congress created the hospice Medicare benefit (*Hospice facts & statistics*, 2008). Subsequent legislation divided the Medicare hospice benefit into three benefits periods (two 90-day periods and an unlimited number of 60 day periods) at which time beneficiaries must be recertified as terminally ill (*Hospice facts & statistics*, 2008). As of March 2008, there are 3,257 Medicare-certified hospices across the country and approximately 200 volunteer hospices that do not participate in Medicare or Medicaid (*Hospice facts & statistics*, 2008).

Hospice care has evolved since its inception, yet its mission remains the same – “ministering to the spiritual and physical needs of dying patients” (Leming, 2003). According to Leming (2003), more than 90% of hospice care takes place in a patient’s home. The patient and her family members (or other close loved-ones, and/or a non-professional caregiver) make up the unit of care; together, the patient and family directly influence the types of support needed during the dying process. In addition to providing care outside of a traditional health care setting, hospices use palliative care (also sometimes called comfort care), which seeks to help people with a terminal illness manage symptoms and control pain caused by disease progression (Ragan, et al., 2008). According to Egan and Labyak (2006), in offering palliative care “a hospice supports the patient through the dying process and the family through the experience of caregiving, the patient’s illness, dying and their own bereavement” (p. 1; see also, Figure 1.1 for a list of Medicare reimbursed hospice services).
Interdisciplinary Hospice Teams

An individual or single discipline cannot adequately meet all of a patient’s physical and emotional needs; therefore hospices use an interdisciplinary team approach (Connor, Egan, Kwilosz, Larson, & Reese, 2002; Marrone, 1997). According to Wittenberg-Lyles, Oliver, Demiris and Courtney (2007), in 1983 federal guidelines required hospices to provide patient care using an interdisciplinary approach. The team approach to healthcare provides patients and families with comprehensive assessment and treatment (Ellingson, 2005; Ragan, et al., 2008). The expected outcomes of interdisciplinary teams in healthcare include better patient experiences and health outcomes than one-on-one or uni-disciplinary teams (Connor, et al., 2002; Ellingson, 2005; Faulkner Schofield & Amodeo, 1999; Hearn & Higginson, 1998; Ragan, et al., 2008).

Figure 1.1
Medicare Reimbursed Hospice Services
(from Hospice facts & statistics, 2008)

- Nursing care
- Medical social worker services
- Physician services
- Counseling (including dietary, pastoral, and other)
- Inpatient care (including respite care and short term inpatient care for procedures necessary for pain control and acute chronic symptom management)
- Home care aide and homemaker services
- Medical appliances and supplies (including drugs and biologicals)
- Physical and occupational therapies
- Speech-language pathology services
- Bereavement services are also available for families (up to 13 months following a patient’s death)
Each member of the hospice interdisciplinary team maintains professional expertise in one of five dimensions of quality of life (see Figure 1.2): physical, functional, interpersonal, well-being, and transcendent (Byock & Merriman, 1998). Nurses, for example, provide the bulk of the physical (medical dimension) care creating, maintaining, and adjusting a patient’s care plan, while social workers and mental health professionals’ (e.g., Licensed Clinical Social Workers) primary responsibilities involve maintaining a person’s mental health and well-being. Home Health Aids and Certified Nursing Assistants who help patients with their Activities of Daily Living (e.g., eating, bathing, and grooming) strive to meet a person’s functional needs. Chaplains and other religious leaders help patients and families with spiritual and existential issues (transcendence dimension). In addition to requiring the use of interdisciplinary teams to deliver hospice care, Medicare requires hospices receiving reimbursement under the Hospice Medicare benefit to have 5% of its workforce consist of volunteers. Hospice volunteers who choose to provide patient care, as opposed to administrative support, receive training to assist patients and families with social support and respite (interpersonal dimension). As Foster (2006) notes, volunteers serve an invaluable role in carrying out hospice’s mission by providing patients and family members with social support to combat the isolation that usually follows a terminal prognosis (see also, Wittenberg-Lyles, 2006).
Although each member of the team holds expertise in one of the dimensions above (e.g., physicians and nurses primarily care for the physical dimension), team members should respond, to some degree, to each of the dimensions as needed (Connor, et al., 2002). However, legal regulations limit the types of assistance certain members of the team can provide. For example, only licensed mental health professionals can do therapy and only nurses and physicians can administer medication. Nevertheless, the spirit of the hospice model of care grants all members of the team, including volunteers, equal influence in dictating patient care. In the next section, I outline some of the ways in which an egalitarian interdisciplinary team approach to hospice care enables and constrains care as well as communication.

According to Hayslip and Leon (1992), the blurring of professional roles and responsibilities inherent in effective interdisciplinary teamwork generates constraints,
including the pressure to extend knowledge and skills beyond professional boundaries (see also, Ellingson, 2005). Some team members may feel a lack of autonomy because they remain accountable to the hospice patient and their team. Others may find that expectations to work outside of professional boundaries allow for more creativity and flexibility in carrying out the group’s goals for assisting hospice patients and their families with achieving a death free of physical, spiritual, mental and social pain.

Although the interdisciplinary team model implies equality across team members, certain members of the team, especially physicians and nurses, hold the most power because their responsibilities dictate such authority. While volunteers or Home Health Aids can offer their opinion about what types of care patients should receive, physicians are responsible for certifying (for Medicare reimbursement purposes) services as necessary for the treatment of a patient’s terminal illness. In practice, which team members speak and whether or not their voices can influence care inherently constrain the type of services patients will receive.

Dying Well, Achieving a Good Death

There is widespread agreement that the role of hospice is to help the dying and their families achieve a good death, yet little consensus exists about the characteristics of such a death (Kehl, 2006; McNamara, Waddell, & Colvin, 1994). In its most basic form, a good death is a death free of physical and spiritual pain. The ambiguity of the concept allows patients, family members, and hospice teams a great deal of flexibility to work towards this end. Translating the characteristics that define a good death into practical guidance for clinicians proves more difficult (Emanuel & Emanuel, 1998). Smith (2000) outlines 12 principles of a good death (see Figure 1.3), but does not address how to
achieve these ideals. Generally, the characteristics of a good death involve freedom from physical and spiritual pain through various medical and psychosocial interventions including medication, psychological counseling, spiritual consultations, prayer, physical therapy, massage, and music and art therapy. However, lack of economic, caregiving, and social support may require attention in order to help alleviate a patient’s pain. For example, dying people may become preoccupied with the financial well-being of the loved ones they will leave behind, which in turn causes the dying person psychological pain. Kellehear (as cited in McNamara et al., 1994) described the five features of a good death differently by focusing on the internal (or personal) and external (or social) work of dying well, which include such factors as “[t]he social life of the dying person, identifying awareness of dying, social adjustments and personal preparations, public preparations, arrangements relating to work and farewells” (McNamara, et al., 1994, p. 1502). Although categorized differently, the characteristics of a good death described by Kellehear correspond to the five dimensions of the quality of life (Byock & Merriman, 1998). Scholars, however, recognize the importance of defining a good death as a series of interactions that should begin months before a person dies (Emanuel & Emanuel, 1998), rather than a single event (McNamara, et al., 1994).

The amount of time a patient receives hospice care may complicate a hospice team’s ability to help patients and families realize a good death. In 2006, the average length of a hospice stay was 71 days (Hospice facts & statistics, 2008), with some patients receiving hospice care for as little as a few hours or in some cases as long as several years. We can only speculate about the relationship between the quantity of time
a patient receives hospice care and a good death; however, it seems the length of time it takes to process a terminal diagnosis and to develop trusting relationships with professional caregivers influences the ability to achieve a good death.

The structure of reimbursement for hospice services under the Medicare hospice benefit is another factor with the potential to constrain communication about spirituality, dying and a good death. According to the Hospice Association of America (Hospice facts & statistics, 2008), reimbursement rates vary by the level of care an individual receives. The basic level of care, known as Routine Home Care, reimburses hospices at the rate of $135.11 per day no matter the “volume or intensity of services” (p. 2). If a patient, for example, requires a daily visit from a Home Health Aid, weekly visits from a nurse, counselor, and a chaplain, the daily rate for Routine Home Care will not cover what it costs a hospice to provide that level of service. Hospices, then, must maintain a large enough census with patients who require minimal services in order to cover operating expenses. Increased numbers of volunteers (over the 5% required by Medicare) and donations also help defray hospice care costs. Hospice employees may attempt to keep costs low by hoarding services and supplies (e.g., adult diapers, hand sanitizers, Universal Precautions, etc.) or prioritizing public contributions over care.
Finally, family dynamics and an emphasis on patient autonomy can further complicate hospice team members’ ability to accomplish a good death. Hospice focuses on the needs of patients and families to mitigate health care’s tendency to focus almost exclusively on patient autonomy. Incorporating family members in hospice care brings its own set of ethical dilemmas (Hardwig, 2001). Despite efforts to prepare for a patient’s decline and the possibility of an eventual inability to express wishes for healthcare, ethical dilemmas can arise when families and caregivers attempt (intentionally or unintentionally) to undermine a patient’s ideas about a good death. Family members may disagree about which care decisions best meet the needs of a dying loved one. Alternatively, families in denial about a family member’s dying may demand avoiding any talk about dying (Mamo, 1999) or insist on particular types of care, including artificial nutrition or hospitalization. The capacity to help patients die well, in the face of

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<tr>
<th>Figure 1.3 – Principles of a good death (Smith, 2000)</th>
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<td>• To know when death is coming, and to understand what can be expected</td>
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<tr>
<td>• To be able to retain control of what happens</td>
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<td>• To be afforded dignity and privacy</td>
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<td>• To have control over pain relief and other symptom control</td>
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<td>• To have choice and control over where death occurs (at home or elsewhere)</td>
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<td>• To have access to information and expertise of whatever kind is necessary</td>
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<td>• To have access to spiritual or emotional support required</td>
</tr>
<tr>
<td>• To have access to hospice care in any location, not only in the hospital</td>
</tr>
<tr>
<td>• To have control over who ever is present and who share the end</td>
</tr>
<tr>
<td>• To be able to issue advance directives which ensure wishes are respected</td>
</tr>
<tr>
<td>• To have time to say goodbye, and control over other aspects of timing</td>
</tr>
<tr>
<td>• To be able to leave when it is time to go, and not have life prolonged pointlessly</td>
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17
such familial and ethical dilemmas, presents communication challenges to the hospice team’s goal of a good death.

Research on bio-medical ethical dilemmas at the end of life tend to focus on the delivery and withdraw of treatment (Baergen, 2001). However, because the hospice philosophy prescribes a holistic approach, spiritual issues make up an important component of the hospice approach to health care ethics. Research (Phelps, et al., 2009) suggests that “religious factors affect medical decisions as the end of life” including a desire for more aggressive care (p. 1141). Phelps and colleagues (2009) go on to say that failure to address patients’ spiritual needs could lead to spiritual crises at the end of life. According to Emanuel and Emanuel (1998), we know a great deal about how hospice intervenes when a patient has physical symptoms, but we know little about how staff meet psychological, social, spiritual needs and resolve ethical or spiritual dilemmas. Furthermore, our knowledge about the role of providing spiritual care as it relates to a good death is limited.

*Spirituality in Hospice*

Research suggests that spirituality and spiritual issues comprise a particularly important element of a person’s life when the ill and their caregivers struggle to make sense of dying and death (Kaut, 2002; Puchalski, 2006). The health care literature widely documents the benefits of spiritual care, and the relationship between a person’s spiritual well-being and health (Balducci, 2008; McClain, Rosenfeld, & Breitbart, 2003; Puchalski, 2006; Schenck & Roscoe, 2008). Dame Cicely Saunders, founder of contemporary hospice, recognized the universality of dying people’s spiritual needs,
believing that the best type of care combined medical treatment (for pain and symptom control) with pastoral care (Bradshaw, 1996). According to Bradshaw (1996), Saunders believed “quite clear[ly] that the work of caring for the incurable and dying called for a Christian foundation” (p. 411). Yet, hospice encourages people from all belief systems, not just Christianity, to serve and receive care from hospice. Therefore, hospice emerged as one system of health care that integrates spiritual care (Puchalski, 2006).

Many scholars draw clear distinctions between spirituality and religion, associating spirituality with a search for meaning (Egbert, Mickley, & Coeling, 2004; Hall, 1997; Hermsen & ten Have, 2004; Keeley, 2004), whereas organized structures and practices constitute religion and religiosity. Willis (2007) contends that spirituality is a private matter, while people enact religion collectively and in public settings. The concepts inform each other rather than subsisting apart from each other. In other words, according to Hermsen and ten Have (2004), “Religion usually expresses spirituality, but spirituality does not necessarily relate to religion” (pp. 354-355). The distinctions between spirituality and religion acknowledge that while not everyone embraces a religion, all people are spiritual and can benefit from spiritual care. It is important to note, however, that scholarly definitions between spirituality and religion may reflect contemporary American discourse and not necessarily mirror cultural or social practices that take place in health care settings.

Meeting individuals’ spiritual needs presents several challenges. First, hospice and palliative care experts note the relative ease of diagnosing and treating physical pain over other types of pain people experience at the end of life (Callanan & Kelley, 1992;
Puchalski, 2006). Second, despite the difficulties hospice professionals experience trying to determine a person’s spiritual beliefs and struggles, Kaut (2002) states that “the evidence of spirituality is likely to be expressed in observable attitudes, beliefs, and behaviors” (p. 226). However, some patients may not know, easily identify, or understand their spiritual needs, while others may know and articulate them to their team. In other instances, chaplains and other hospice team members may have to draw them out by offering prayer, suggesting guided meditation, or asking patients about their beliefs related to the meaning of life, the purpose of illness or disease, or exploring what matters most to a patient on that day.

Since hospice in the United States developed to satisfy patients’ and families’ needs for better quality health care at the end of life, these organizations use interdisciplinary teams to improve patients’ experiences. While the use of teams enables its members the opportunity to provide high quality holistic health care, it can also create certain constraints on a team’s ability to help hospice patients and their loved ones achieve a good death. The ambiguity about what constitutes a good death and the ability to translate those concepts into clinical practices remains one of the quandaries explored in hospice scholarship. Similarly, the health care literature acknowledges the relationship between spirituality and a person’s health and well-being, but the ability to recognize and respond to spiritual needs remains elusive.

I argue that additional research that seeks to study and, in turn, improve communication at the end of life will further aid hospice teams in their goal of achieving a good death, which includes spiritual care. The multifaceted nature of communication
about spirituality, dying, death and achieving a good death combined with various institutional structures, requires more research. Next, I will discuss the existing literature from the discipline of communication to illustrate the need for additional communication research regarding how hospice interdisciplinary teams communicate about spirituality, dying, death, and a good death.

*Health Communication*

In the introduction to the *Handbook of Health Communication*, editors Thompson, Dorsey, Miller and Parrot (2003) claim that a handbook signals the history and geography of a field of study and assert health communication’s decisive place on the disciplinary map. Alternatively, in a brief article in the *American Journal of Hospice and Palliative Medicine*, Yingling and Keeley (2007) take medical researchers to task for failing to turn to communication scholarship when research findings reveal that improving communication would enhance patient care and health outcomes. A review of the handbook reveals the marked absence of end-of-life (including hospice and palliative care) communication and its importance to health communication’s disciplinary topography. Though one section in the text describes research about breaking bad news, this discussion focuses on communication skills training. However, communication scholars have studied death and dying and do find the area of study relevant to a person’s health and well-being (Foster, 2006; Geist-Martin, Ray, & Sharf, 2003; Keeley & Yingling, 2007; Toller, 2005; Wittenberg-Lyles, 2006).

Due to the limited amount of research from the field of communication about dying, my review centers on research from other disciplines that focuses on
communication about dying and death. Then I turn to the contributions communication scholars made to our knowledge of these topics to establish the need for undertaking the current research project.

Researchers (Mamo, 1999; Marrone, 1997) outside of the hospice setting observe that talk about death frequently does not occur until necessary, such as following the passing of a friend or family member. When talk about death might be considered appropriate, strong emotional responses, such as sadness, anger or fear, “no longer inspire piety but rather, repugnance – a sign of emotional instability, or bad manners. Within the family, one is restrained from letting go of these deep feelings for fear of unsettling others” (Marrone, 1997, pp. 8-9). Book (1996), and Portfield, Cain and Salidinger (2003), observe that when families do communicate about death, many of the interactions lack substance, often failing to address personal concerns and answer questions.

In her study about family communication about death, Book (1996) found through the analysis of participants’ narratives that “communication regarding death occurred through impressions and silence expressed by families through implicit and explicit rules” (p. 323). For example, one participant, named Linda, learned that her best friend died when her mother opened her bedroom door and said, “Guess what? Oh, Rachel’s [participant’s best friend] dead,” and then walked out. Linda was forbidden from attending her best friend’s funeral and prohibited from talking about her friend’s death and suffered from nightmares. Book’s (1996) research reveals that communication in families about the subject of death can have negative consequences for adolescences, including high levels of anxiety and fear. In addition, Mamo’s (1999) ethnographic
research found that family members’ failure to communicate openly about a family member’s dying created stress and anguish for an entire family.

Not all family communication about death yields negative reactions. In another ethnographic study about a dying man and his family, FitzSimmons (1994-1995) found that the family member with the most frequent and open communication with the dying individual reported a positive experience and less fear about death. Whereas, the family member with the least amount of communication and knowledge about the gravity of the situation reported a less positive experience. In sum, FitzSimmons (1994-1995) found that open communication about death helped family members cope with impending loss.

Communication is also important after death. Toller (2005), for example, investigated parental grief, discovering that many bereaved parents feel isolated, and as such, long for opportunities to talk about their deceased children.

Despite research that supports the benefits of freely communicating about issues at the end of life and after death, people neglect talking about dying and death (FitzSimmons, 1994-1995; Zhang & Siminoff, 2003). According to Zhang and Siminoff (2003), families avoid talk about illness and dying, hoping to maintain positive attitudes and to sustain the health of the ill family member. Miller and Knapp (1986) further observe that many people feel unprepared to communicate with people who have a terminal illness (see also, Ellis, 1995). Most do not know what to say and avoid conversations with the dying for fear of saying the wrong thing.

Miller and Knapp (1986) outlined three strategies used by caregivers when communicating with the dying: avoidance, confrontation, and reacting. In the first
strategy, avoidance, people tend to evade talking about dying or death by trying to bolster a dying person’s spirits. Being upbeat, talking about current events, and recounting memories from the past were all examples of avoidance strategies. The confrontation strategy involved offering platitudes, such as “It’s all part of God’s plan,” or definitive statements such as “everyone must die,” or more demonstrative displays, such as openly crying in front of a dying family member or friend. Finally, the reacting strategy involves being more reflexive than the other two approaches and includes such practices as asking open-ended questions and mirroring emotions.

In addition to outlining these strategies, Miller and Knapp (1986) interviewed professional caregivers, specifically chaplains and hospice volunteers, about their experiences communicating with terminally ill people. Through retrospective self-reports, these caregivers offered examples of what Miller and Knapp call wrong behaviors as well as advice for effective communication with the dying. Poor timing, offering false hope, platitudes and withholding feelings were some of the examples of wrong behavior. Advice included such suggestions as listening more and talking less, showing emotional commitment, and not worrying about saying the wrong thing.

Miller and Knapp (1986) and others (Foster, 2006; Keeley, 2004; Keeley & Yingling, 2007; Toller, 2005; Zhang & Siminoff, 2003) draw attention to the need to move past our fears of saying the wrong thing to a person who is dying. Not only does avoiding such conversations harm people who are dying, but it also hurts the people who love them. Zhang and Siminoff (2003) found that people who fail to talk reported higher levels of stress, while those family members (about 15%) who spoke openly about illness
reported less tension. The health benefits of candidly communicating about terminal illness, dying, and death may explain why health communication scholars are beginning to take up the charge to study end-of-life issues.


With the exception of Foster (2006), each of these studies (Keeley, 2004; Keeley & Yingling, 2007; Wittenberg-Lyles, 2006) involves retrospective reports with survivors and does not necessarily capture actual interactions with people who are dying. Nevertheless, these studies are first steps to understanding communication with people who are dying, as well as talk about dying, spirituality and death. In hospice, a person who receives their services can expect representatives to communicate openly about dying and death as one means to achieve the hospice mission. In the book *Communication at the End of Life* (Foster, 2006), however, hospice volunteer and communication scholar, Elissa Foster, found that hospice volunteers rarely talked about death with their hospice patients. Furthermore, the lack of conversation about dying and death was inconsistent with volunteers’ expectations for communication with patients.
The volunteers in Foster’s research expected to talk with patients about dying and death. While others were motivated to become volunteers to assist hospice patients’ progress towards a *good death*. Volunteers are only one member of the hospice care team; therefore, it is possible that another member of the interdisciplinary team communicates with patients about spiritual issues, the dying process and death. Given the essential role teams play in delivering hospice services, I turn to the literature on communication in healthcare teams.

*Team Communication in Healthcare Settings*

Interdisciplinary healthcare teams, such as those used in hospice “are characterized by team members who work from different orientations while at the same time engaging in joint work (Ragan, et al., 2008, p. 108). According to Ellingson (2005), the use of interdisciplinary and multidisciplinary in health care continues to grow because this approach provides patients and families with comprehensive assessment and treatment of the whole person (see also Eisenberg, 2008; Ragan, et al., 2008). With improved assessment and treatment comes the expectation that the team approach will produce better patient experiences and improved health outcomes (Connor, et al., 2002; Ellingson, 2005; Faulkner Schofield & Amodeo, 1999; Hearn & Higginson, 1998). Furthermore, the assumption is that increased collaboration and communication among people from different disciplines will decrease fragmentation of care and lead to effective teamwork (Eisenberg, 2008; Ellingson, 2005). The reality is that with the diversity of healthcare professionals expected to work together as a team comes additional communication challenges, not fewer. Some healthcare professionals, for example, have
little education working with a team or, lack education in interpersonal skills, while mental health professionals, for instance, receive more training in this area (Connor, et al., 2002). Moreover, research (Ellingson, 2003) shows variations in information collection and sharing across disciplines that challenge effective teamwork. And while the team concept encourages egalitarianism, research reveals this is not the case (Eisenberg, 2008; Ellingson, 2005; Street & Blackford, 2001). Several communication issues related power and role ambiguity (Ellingson, 2005); and challenges centering on role conflict, decision-making processes, management of conflict, consensus building and cultural diversity (Street & Blackford, 2001) emerge on healthcare teams.²

Despite the benefits of the team approach to health care, little is known about how teams communicate to deliver holistic care (Connor, et al., 2002; Ellingson, 2005). Ellingson (2005) points out that the vast majority of research regarding healthcare teams measures patient outcomes and does not necessarily focus on how team members communicate to achieve those ends. Eisenberg (2008) further asserts that an emphasis on defining communication as message transmission discourages an appreciation for how communication is constitutive of effective teamwork. In light of these gaps in our knowledge, “documentation and explication of existing communication practices on teams will help generate strategies for improving communication” within and outside of teams (Ellingson, 2005, p.7).

Recognizing the need for more research that focuses on health care teams in action, communication scholar Laura Ellingson (2005) conducted an ethnographic study

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² These communication issues are synonymous with the five communicative dimensions of teamwork (Eisenberg, Goodall, & Trethewey, 2007).
of the communication practices of a geriatric oncology team’s clinic. By focusing on the team’s communication in the front and backstage, Ellingson (2005) articulated three important findings about team communication. First, team communication is “constrained and shaped by persistent gender, racial, class, and disciplinary hierarchies in the medical establishment” (p. 8). Second, the boundaries between frontstage and backstage (Goffman, 1959) team communication are more fluid than previously theorized. Third, teamwork occurred outside of structured or formal communication channels (e.g., meeting and memos). Ellingson (2005) refers to this phenomena as embedded teamwork, which acknowledges

The discourse between dyads and triads of team members in which disciplinary (or professional) lines are blurred and redrawn; significant variation in teamwork practices occurs; team members’ beliefs and attitudes are expressed and change over time: and contextual constraints are reproduced, resisted, and negotiated through communication. (p. 70)

Embedded teamwork, then, encourages scholars to examine the formal and informal interactions between team members and the site where health care delivery occurs to understand what teams “are making together when they communicate” (Eisenberg, 2008, p. 11).

Few communication scholars, however, have studied how health teams communicate about spirituality, dying, and death in hospice or elsewhere. Furthermore, as a whole, spirituality and religious faith are noticeably absent from the health communication research (Parrott, 2004) despite agreement that health communication
scholarship can contribute greatly to our knowledge and understanding (Wills, 2007). Communication scholars are uniquely positioned to contribute to this body of knowledge because, as Yingling and Keeley (2007) observe, communication researchers understand relational processes, their research focuses on tangible behaviors, and they are adept at analyzing communicative interactions in depth.

Recognizing the importance of communication to the delivery of hospice care, my dissertation research project ponders Foster’s (2006) findings about hospice volunteers’ limited communication about dying and death and poses the questions: To whom, if anyone, do hospice patients talk to about death, and what is the nature of these conversations? In addition, what role does this communication play in a good death? In the remainder of this manuscript, I discuss the research methods I used to answer these questions and the data collection process. First, I will describe in more detail the proposed study’s goals.
Chapter 2 – Methods

Over the years, thanatology researchers employed both quantitative and qualitative methods to examine questions about death and dying with the bulk of our knowledge coming from quantitative measures. Qualitative methods have gained popularity among thanatology researchers for their ability to capture the details of lived experiences (Caverhill, 2002; Gilbert, 2002; Wright, 2003; Wright & Flemons, 2002). Qualitative data collection methods, such as interviews, allow informants to look back upon their experiences. While retrospection allows informants to make sense of their experiences (Lindloff & Taylor, 2002; Weick, 1995), such methods have limitations. This project, therefore, used participant observation and interviews, allowing me to examine the lived experience of dying as it happened and as told by patients, family members, and hospice staff members. Such research methods also compliment studies about communication and interdisciplinary teams in action (Ellingson, 2005). Observing team meetings and shadowing team members as they interacted with hospice patients positioned me to observe communication about dying and spirituality from several angles and answer the following research question:

RQ 1: How do hospice interdisciplinary team members communicate with hospice patients and their families about spirituality, dying, and death?
The research question emphasizes the types and topics of communication essential for achieving hospice’s goal of a good death. Yet no studies have directly investigated the function of communication in achieving a good death. Therefore, I offer the second research question for investigation:

RQ 2: In what ways do hospice interdisciplinary team members use communication to achieve a good death for their patients and families?

To help answer this research question I used participant observations, as well as in-depth interviews with hospice interdisciplinary team members from each of the five quality of life dimensions, to collect narratives about experiences with hospice patients. In addition to understanding an individual’s experience and perspective retrospectively, interviews usually elicit experiential knowledge in three forms of discourse: stories, accounts (excuses or justification for behavior), and explanations (of behavior) (Lindlof & Taylor, 2002). Interviews, therefore, supplemented and enhanced observations in the field. Next, I describe the data collection process in more detail.

Data Collection Process

In April of 2007, I received a competitive research assistantship from the University of South Florida’s Center for Hospice, Palliative Care and End-of-Life Studies to undertake this project. In the original project, I requested to work with two community-based non-profit hospices, but only collected data from one organization due to time and institutional constraints. In addition, I originally intended to observe only with chaplains, but was encouraged to modify my research design to observe all members of the interdisciplinary hospice team. As a caveat for conducting this research project and
gaining entry into the organizations, I attended new employee orientation for each hospice (in August 2007 and in January 2008 respectively), and secured Institutional Review Board (IRB) approval from the University of South Florida in November 2007. In addition, I completed 72 hours of work as designated by each hospice for a total of 144 hours of unpaid labor.

Attending orientation training helped orient me to each organization including the Interdisciplinary Team’s (IDT) role in the larger hospice structure. Completing training also provided me access to observe team meetings and attend training sessions relevant to my research offered by Coastal Hospice. I did not collect any data, however, while I awaited IRB approval.

Informed Consent Process for IDT Members. Immediately after receiving approval from the University of South Florida’s Institutional Review Board, I began the process of recruiting IDT member participants from one home based team. The director of research at Coastal Hospice recommended the Sunflower team, which worked in a community close to the hospice’s main campus (Coastal Hospice has three campuses). I gave a presentation to the Sunflower team about my research and requested volunteers for participation. In addition to explaining the goals of the project, I informed team members that there were four elements of involvement, each voluntary. First, some participants might wish to give consent only for participation in the component of my research that took place at team meetings. Second, others might only want to volunteer for the interview portion of the study. Third, team members could volunteer for job

3 The office support staff does not have in-home patient contact and only attend team meetings occasionally, therefore, I did not recruit them for participation in the study.
shadowing allowing me to observation their interactions with patients. Fourth, team members could agree to all of the above levels of participation. And finally, staff could choose to not participant in any element of the study. I explained that I would take no notes about individuals who did not consent to participate in the study. Fourteen of 29 team members agreed to participate during the initial recruitment and a fifteenth person, who was not in attendance during my presentation, subsequently enrolled after the start of data collection.

After the research presentation and informed consent process, I continued to attend interdisciplinary team meetings each week, collecting data by openly taking fieldnotes. I increased my understanding of team members’ roles and although I did not expect others to perceive me as a full-fledged member of the team, I hoped my presence at meetings would illustrate my commitment to the project and my interest in understanding the hospice approach to care, while simultaneously normalizing my presence during meetings and in the field. In addition to my learning about patients, observations of team meetings afforded me the opportunity to become educated about the Medicare re-certification process, which determines whether patients are “hospice appropriate,” and the maintenance of patient care plans, which I will discuss in more detail in chapter three. I also used the team meetings to schedule observations and interviews with team members. Job shadowing with team members as they completed their regular day-to day activities allowed me to directly observe and interact with hospice patients.
Patient Informed Consent Process. My completion of new employee orientation and training allowed me to accompany IDT members to patient visits without receiving patient informed consent prior to the initial visit. Participation in my study and subsequent data collection, however, required securing informed consent from hospice patients. Though I observed during several patient visits, those patients did not become participants until consenting. I encouraged team members to use their discretion about informing patients in advance about my shadowing. In certain instances, some IDT members contacted patients prior to my visits and secured verbal permission for me to shadow while others explained my role at the time of the visit. In both instances, I explained my research and secured informed consent for participation in my study at the time of a visit.

In an attempt at ethical and mindful informed consent, I gauged the appropriateness of soliciting patient and family (or caregiver) participation in my research and subsequent informed consent based upon the needs of the patient at the time of observations. I did not request participation in my research during a new admission or if the patient’s emotional or physical state appeared fragile. For example, while shadowing the chaplain, we arrived at a home to find the hospice patient was having difficulty following the course of conversation. While the chaplain and I explained my student-researcher status, I opted to wait to obtain the patient’s consent to participate in the study. Instead, we chatted and ended the visit with prayer. I frequently relied on the expertise of the team member as well as my own impressions to determine the appropriateness of discussing and recruiting participants for my research. I also instructed
team members to focus first on their duties and only initiate conversations about my research if it did not compromise the patient’s needs. Within weeks of presenting my study to the Sunflower team, I scheduled several appointments to observe team members interacting with patients.

Fieldwork – Observing Team Members Communicate with Patients. My initial goal for data collection was to observe as many team members as possible interacting with as many patients as possible. However, I soon realized that this might not be the best approach for several reasons. First, the progression of disease and the severity of a patient’s illness meant that I might only visit a patient once because she might die the following week. I knew that the length of time patients spent in hospice and their eventual deaths would challenge my ability to observe interactions over time. The pace at which patients died surprised me. I recall telling the team leader, Dani, short for Danielle, about this revelation and she just laughed at my naiveté. Furthermore, my commitment to obtaining informed consent under what I considered the contextually appropriate time meant that I might see six patients in a week, but only recruit one participant. In addition, if I successfully recruited a participant who died the following week, there was no guarantee that my observations would yield any relevant data.

A second problem involved the team members themselves and their roles as gatekeepers. Team members consistently talked about patients in terms of those who might be “good” for my study, which I discuss in more detail in chapter 4. As a result, team members who initially volunteered to have me shadow them never scheduled any observations because it seemed to them that they did not have any good patients.
Similarly, the volunteer coordinator claimed it was too difficult for me to observe with a volunteer because of scheduling and timing. When I suggested that she could give my contact information to any willing volunteer, she implied that relational dynamics between the patient and volunteer further complicated my ability to observe. I sensed reluctance on her part to allow me access to the team’s volunteers and so I let the matter go. Although I do not know the exact reason for the volunteer coordinator’s hesitation, I suspect her inexperience with research contributed to her lack of assistance. I did, however, attempt to contact the one volunteer whose telephone number she provided me, but his personal travel schedule was prohibitive to shadowing him during my data collection timeframe.

The ethical and organizational barriers to recruiting participants led me to modify my approach to data collection. I opted to observe with the team members most open to my shadowing them and selecting patient/participants based upon those observations. Once I established regular visits with a team member, I shadowed them weekly. This approach allowed me the opportunity to observe team members and their patients interacting over time as their relationships developed and as their disease progressed.

Another challenge to my ability to observe patients over time and with a variety of team members involved the plan of care and scheduling of visits. Not all patients receive care from representatives from all five disciplines. In other words, a patient who sees a chaplain may not receive many visits from a counselor. Some patients may never receive a visit from a Home Health Aid because their illness does not warrant it or they have sufficient assistance from another caregiver (e.g., family member). Additionally,
some team members, such as nurses and counselors, schedule regular weekly or bi-
monthly visits whereas chaplains schedule their visits as requested. The team physician
only visits patients under extreme or unique circumstances and while I did have the
opportunity to observe one such visit, the patient was severely cognitively impaired due
to mental illness, and unable to consent to participate in a research study. Home Health
Aids have their visits scheduled for them by an administrative staff person and frequently
do not know who they are going to see until the day of a visit. The ability to dictate which
patients I could see, and with which team members, and when, was frequently outside of
my control.

The barriers described above and the subsequent modifications I made to my data
collection process created some inconsistencies in my data reflecting my inability to
collect data equally among team members from each of the five IDT disciplines.
However, I was able to collect rich data about a small number of patients and team
members. One social worker in particular, Allison, appears repeatedly in the narrative
accounts of my observations. As such, I introduce observations with other team members
in the form of vignettes from fieldwork and interviews alongside more detailed stories
where Allison is a central character.

Documenting observations. I captured detailed observations during team meetings
and in-home visits in written and audio-recorded fieldnotes. Although I openly took notes
during team meetings, I did not take notes during patient visits. I captured observations
after leaving a visit because I did not want my note taking to distract team members or
patients. Team members, however, took notes, referred to as “bed-side charting” during
visits. Taking notes was synonymous with the role of a hospice team member, yet I did not want patients or team members to feel scrutinized by the “researcher.” Of course, not taking notes caused some patients to question my role. “So what exactly are you doing?” one patient inquired, adding, “You just come here to watch us?” I used such questions as opportunities to explain my data collection methods again. These questions allowed me the occasion to treat informed consent as a continuous process (Ellis, 2007).

Interviewing Hospice Team Members. In addition to conducting fieldwork, I interviewed six team members (three counselors, a chaplain, a Home Health Aid, and a registered nurse) at the conclusion of fieldwork. These semi-structured interviews (see Appendix A for interview schedule) focused on perceptions of their work at hospice, the role of communication in hospice and in facilitating a good death. I also used interviews as an opportunity to probe about some aspects of the patient visits I observed. Responses to interview questions were audio recorded, transcribed, and used to inform interpretations of narrative themes described in the following section.

Analysis of Data

The use of narrative as a method of inquiry is gaining in popularity among scholars interested in capturing the human experience for the social sciences (see, Denzin, 1997; Lieblich, Tuval-Mashiach, & Zilber, 1998; Mumby, 1993; Polkinghorne, 1988). In this project, my use of narrative as a method of inquiry includes the analysis of narratives and narrative analysis (Denzin, 1997; Ellis, 2004; Polkinghorne, 1995). According to Ellis (2004), analysis of narrative involves using narratives as data and identifying themes across and within stories. Narrative analysis involves the collection of
events and happenings (Polkinghorne, 1995) and “assumes that a good story itself is theoretical” (Ellis, 2004, p. 195). Each narrative presented here represents one or more major themes reflected in communication among hospice team members and their patients. I then add a subsequent “layer of analysis by stepping back from the text and theorizing about the stor[ies]” from a communication perspective (Ellis, 2004, p. 195). Ultimately, what I sought to do in my analysis was borrow from multiple genres and multiple methods of analysis in an approach known as crystallization (Ellingson, 2005, 2009; Richardson, 2000). Richardson’s (2000) introduction of the concept of crystallization sought to go beyond the use of triangulation in research studies in an effort to acknowledge that there are “far more than ‘three sides’ from which to approach the world” (p. 934). Richardson goes on to say that “crystallization provides us with a deepened, complex, thoroughly partial, understanding of the topic” (p. 934). According to Ellingson (2009), however, Richardson’s (2000) original conception of crystallization did not explicate a methodological or research process. Therefore, Ellingson’s (2005, 2009) version of crystallization combines multiple forms of analysis and multiple genres of representation into a coherent text or series of related texts building a rich and openly partial account of a phenomenon that problematizes its own construction, highlights researchers’ vulnerability and positionality, makes claims about socially constructed meanings, and reveals the indeterminacy of knowledge claims even as it makes them. (p. 4)

While there are limitations to crystallization (see, Ellingson, 2005, Appendix C), this practice afforded me the opportunity to move back and forth in 1.) the creation and
analysis of narratives; 2.) the interpretation of those narratives using various communication theories and concepts; and 3.) work along the art and science continuum of social science research (Ellis, 2004). This mosaic like analytic approach allowed me space to tell a story of hospice informed by multiple voices. For example, in chapter four I break away from the narrative of one patient to delve into the theoretical implications of politeness related to talk about death. I use observations, interview data and existing literature to capture the many facets of end of life communication.

To begin the process of analyzing the data I collected during fieldwork, I converted observations into fieldnotes. This process allowed me additional opportunities for reflection and to engage in additional inquiry and a deeper level of analysis (see Richardson, 2000). Throughout my time in the field, I consistently asked myself, “What is going on here?” and compared experiences with various patients and team members across observations to hone in on the types and topics of communication. I also made in-text notes while writing and reviewing fieldnotes and developed lists of topics to explore and potential literatures to review for aiding additional analysis.

With the goal of identifying specific examples of communication about spirituality, dying, and death, I initiated a closer analysis of the data after completing observations. I searched fieldnotes for instances when verbal or nonverbal communication evoked emotions (among participants or the researcher), long silences, or avoidance of topics such as funeral planning or advance directives. I also scanned the fieldnotes for conversations about topics related to dying, death, and spirituality, such as pain or loss of autonomy, prayer, talk of God, and so on. My goal for analyzing data was
not to thematize or categorize all of my experiences, but to describe richly communication related to spirituality and dying. To answer the research questions, I found it important to focus in on these conversations rather than the breadth of communication that takes place in hospice. Absent the emphasis on creating exhaustive categories, this approach to data analysis is similar to the constant comparative method described by Frey, Botan, and Kreps (2000).

Mining the data, I selected experiences with four participants to serve as exemplars of team member and patient communication about spirituality, dying, and death. I then took the fieldnotes of my observations with these four patients and developed narratives of each. The process of creating the narratives produced additional insights about field observations, which sometimes led me back to other stories in my notes. These patients’ narratives became the focal points for additional in-depth analysis and interpretation of communication. The first narrative focuses on talk about dying and death, the second describes spirituality and spiritual pain, the third discusses communication about denial of death, and the fourth section concerns missed opportunities. Where appropriate for explaining or enhancing research findings, I incorporated interview data into the narratives. Finally, to analyze the communication illustrated in these stories, I applied various theoretical orientations such as Petronio’s (2001) Communication Boundary Management to understand self-disclosure in interpersonal relationships. Politeness Theory (Fraser, 1990), and the Stages of Dying (Kübler-Ross, 1969) aid interpretations of communication about taboo and mysterious topics such as death and spirituality.
Now that I have established the need for research about communication regarding spirituality, dying and death, made an argument for studying these topics in a hospice setting, and described the research methods I used in this study, I will describe my initial introduction to Coastal Hospice.
Chapter 3 – Entering the Field

My first introduction to hospice occurred prior to beginning the present research project. I was a hospice volunteer for a few months before relocating to Florida to begin my doctoral studies. I found my brief stint as a volunteer less than invigorating. The hospice patient I was teamed with probably was not the best fit because we had little in common and therefore not much to talk about, but I continued to sit with him because I recognized his 20-something year old grandson, his primary caregiver, needed a break. Although my introduction to hospice was not what I hoped for (see e.g., Foster for an excellent narrative ethnographic account of the hospice volunteer experience), I intended to return to hospice volunteer work once my life settled. Almost three years after volunteering at a hospice, I found myself back, but this time sitting with patients had a much different objective because I was conducting research and not an altruistic volunteer. At least this is what I thought when I began conducting research for this dissertation. This time, as a researcher, I would have more access to the behind the scenes workings of hospice.

Orienting and Acclimating to the Hospice Culture

After attending new employee orientation in August, I found myself energized by the thought of working with Coastal Hospice, one of the largest not-for-profit hospices in the United States. I had the sense that my fellow orienters and I were equally enthusiastic to start working with patients. I attributed this atmosphere to all of the speakers we heard
during orientation who appeared genuinely passionate about their work. Most of the staff we met during our five day orientation worked for Coastal for at least a decade. I interpreted the staffs’ tenure a positive sign about the quality of the organization.

Following orientation, I met with the director of research for Coastal Hospice’s research institute who made several recommendations for middle managers I should meet and interview for background purposes. He also recommended a home-based hospice team to recruit for my study. Everything was falling into place and my research was getting underway. Then he provided me with five, three ring binders of various sizes containing materials about hospice training and education. Within weeks of my meeting with the research director, I was attending team meetings and learning about patients from nurses, counselors, chaplains, and Home Health Aids. After these first few meetings, I recognized that I had a lot to learn about hospice not talked about in books and journal articles. In the following section, I discuss those insights by describing the structure of Interdisciplinary Teams (IDT) at Coastal Hospice and recounting what takes place during a typical Interdisciplinary Team Meeting.

The Structure of Interdisciplinary Teams

Coastal Hospice serves people who reside in Palm County. Where a patient lives within the county determines hospice patient assignments. For example, the patients assigned to Sunflower, the team I studied for this dissertation, reside in the northeastern most portion of Palm County. Other teams, all designated by a type of flower, provide care to patients in the remainder of the county. The Violet team for instance, is a facility-based team, where as the Poppy team serves a southern portion of the county and so on. There are 17 home and facility-based teams and Costal Hospice’s daily census, which
describes the number of patients enrolled in hospice, usually runs over 2000 patients. The Sunflower team’s average daily consensus is generally 100 patients, not including patient’s family members or patient’s caregivers, which also comprise hospice’s unit of care.

The Sunflower team further divides its geographical patient care zone into Sunflower-South and Sunflower-North. The regional distinctions within the Sunflower team, however, are not rigid and have more influence on IDT meetings than anything else. Sunflower-South meets for IDT during the 1st and 3rd weeks and Sunflower-North meets the 2nd and 4th weeks of the month. In addition to team meetings, all members of the Sunflower team meet twice a month for Team Supports, which serve as an opportunity for the team to get additional education on the topic of choice (e.g., pain management, employee engagement). Sometimes Team Supports involve doing something fun and not necessarily directly related to patient care, such as watch a movie or learning how to decorate for the holidays like a professional. No matter the content of the Team Support, the goal of these meetings includes giving team members opportunities to bond, as well as social or educational support. The distinct disciplines (except volunteers who meet monthly with other volunteers) dictate the topic of Team Supports in an effort to ensure that no one discipline controls the subject or types of activity.

*Backstage – Team Meetings in Action*

The structure of teams and their respective meetings function to support patient care so that team members with patients in common meet as a group. Team meetings,
however, do not involve the creation or development of patient care plans, and, much to my surprise, discussion of patient care does not constitute the majority of IDT meeting talk. At Coastal Hospice and on the Sunflower team (although I observed similar interactions within another facility-based team), a meeting’s primary objectives include introducing new or incoming patients to the team and determining if existing patients remain hospice appropriate based upon Medicare criteria. The interdisciplinary nature of team meetings resides in the presence of the different disciplines as opposed to the quality or type of interaction. The team meetings are multidisciplinary, with multiple disciplines represented, but without much, if any, collaborative interaction among team members. The room set up and seating arrangement contributes to lack of interaction across disciplines as well. Some of the rooms are set up using a horseshoe seating arrangement, but the set up for the majority of meetings frequently uses a t-shape and prohibits team members’ ability to see each. No matter the room set up, the team physician always sits at the head of the room near the team leader and the other members segregate themselves by discipline. Nurses frequently sit near each other, working from their laptops, while Home Health Aids, for instance, sit together at another table.

While team meetings were fragmented, patient care, however, is interdisciplinary, meaning that if necessary, patients can receive care from several disciplines who work jointly to accomplish a mutual goal (Ragan, et al., 2008). As was the case in Ellingson’s (2005) study, embedded teamwork, in the form of telephone conversations, text messages, and e-mails comprised the bulk of patient care at Coastal Hospice. Observing
Team meetings, therefore, offers few opportunities to study the development of, or adjustments to, a patient’s care plan.

Team meetings serve a secondary purpose, however. By bringing the team together, hospice staff can offer each other emotional support in response to the challenges that arise when providing care to the dying and their caregivers. A typical team meeting begins with the chaplain who uses various activities to promote reflexivity and encourage social support that serve complementary roles. The team meeting is where we first see spirituality’s role in hospice.

Incorporating Spirituality in the Organization

Robin, the Sunflower chaplain, calls the meeting to order, “Okay, are we ready to start everybody,” she says trying to get people to turn their attention from side conversations, signing-in, reading the roster, and eating lunch (this team meets at noon). “Someone sent me this story by e-mail,” she begins, “and I thought I would share it with you,

We were driving in the right lane when suddenly a black car jumped out of a parking space right in front of us. My taxi driver slammed on his brakes, skidded, and missed the other car by just inches! The driver of the other car whipped his head around and started yelling at us. My taxi driver just smiled and waved at the guy, and I mean, he was really friendly. So I asked, 'Why did you just do that? This guy almost ruined your car and sent us to the hospital!' This is when my taxi driver taught me what I now call, The Law of the Garbage Truck. He explained that many people are like garbage trucks. They run around full of garbage, full of
frustration, full of anger, and full of disappointment. As their garbage piles up, they need a place to dump it and sometimes they’ll dump it on you. Don’t take it personally. Just smile, wave, wish them well, and move on. Don’t take their garbage and spread it to other people at work, at home, or on the streets. The bottom line is that successful people do not let garbage trucks take over their day. Life’s too short to wake up in the morning with regrets, so... Love the people who treat you right. Pray for the ones who don’t. Life is ten percent what you make it and ninety percent how you take it...

“Oh, that’s good,” some of the team members say when the chaplain finishes.

“Can I get a copy of that?” One of the counselors asks.

“Sure,” I’ll make you a copy, the chaplain replies with the hint of a Southern accent.

The messages the chaplain brings to the group usually relate to the ways team members can reduce stress or make sense of their field experiences, and offers suggestions for how team members can live a more spiritual life both at work and at home. After the motivational reading, the chaplain will give the team what she calls an ashtray affirmation, which is a quote on a colored strip of card stock people can take with them and refer to while they are out in the field to calm their nerves or regain focus. It is not clear, however, whether team members use the ashtray affirmation in this way or if the quotes have a more ephemeral quality. In the time that I spent with team members traveling in their vehicles going to and from patients’ homes, I did not see many of the quotes in ashtrays. This segment of the IDT, however, is an opportunity, once each week,
for team members to focus inward while communally acknowledging the challenges and constraints of hospice work among understanding colleagues (Ragan, et al., 2008). The same is true for prayer.

Following the readings, Robin asks the team if anyone has a prayer request. One by one, team members make their prayer requests for their patients or patients’ family members or caregivers. Team members also make personal prayer requests. Usually team members call out the names of patients who are imminent (within days of death) or for surviving family members who just experienced the death of their loved one. Other requests are for hospice team members themselves. If a nurse is sick or if a counselor’s family is traveling long distances, they will receive prayer from the team. I found the seamless incorporation of religious and spiritual practices, such as prayer and inspirational readings and quotes, astonishing because most organizations oppose the presence of religion or spirituality in the workplace. Yet I did not witness anyone protest the use of the words, “God” or “Amen,” that began and ended the requests for prayer.

The chaplain frequently used silence and deep breathing techniques, tools used in meditation and other spiritual traditions, to focus inward and concentrate on the here and now.

Incorporating such alternatives to traditional religious practices offers those who may not find any particular value or benefit in prayer another option for engaging their own conceptions of spirituality. The inspirational readings, as well as the time for prayer, afford team members the opportunity to tune out the challenges of working in the field. As Ragan and colleagues (2008) note, such self-care is an important component for team
members working in end-of-life care where “team members are able to get energy from each team member, creating a synergy among the group” (p. 129). This opportunity can benefit all team members, and is particularly advantageous for staff members who may not make time during their workweek to take a conscious break from the emotion-laden environment. However, this portion of the team meeting is not voluntary and unless an employee arrives late, she or he must participate (even if only passively). The first ten to 15 minutes of a team meeting stand in sharp contrast to the remainder of the IDT meetings, which concentrates almost exclusively on the business side of hospice – Medicare reimbursement.

*From Spirituality to Hospice Appropriate*

Following prayer, the meeting facilitator, usually the team leader, calls the team’s attention to any announcements and then moves on to new patient admissions. The counselor and nurse assigned to a new patient (and their caregiver if they have one) introduce them to the team in one of two ways. If the nurse and counselor have met with the patient prior to IDT, usually during a joint visit, they share what they know about the patient based upon that visit. The patient’s description includes her current medical status (e.g., what brought the patient to hospice), a brief synopsis of her medical history, if relevant to hospice diagnosis, and any potential or existing psychosocial issues. If the nurse and counselor have not met with the patient prior to the team meeting, they will disclose the facts of the patient’s case from admission notes.

The counselor first presents new patients, referred to by team members as *new admits* (short for new admission), followed by a report from the nurse. Interestingly,
counselors’ reports do not often match the professional role of counselors. Frequently, team counselors (of which there are four on Sunflower team) provide team members with the medical, and not psychosocial information about a new admit. For example, the counselor offers the patients name, sex, age, relationship status, and diagnosis, but does not mention mental health issues or resource needs. Counselors also indicate if a patient has a “Do Not Resuscitate” order, living will, advance directives, funeral arrangements, and an evacuation plan in place. On the face, these documents appear only legal in nature to protect hospices, but team members perceive patients with such documents in place as more ready to accept their fate than patients who, for example, refuse to have a do not resuscitate order. The team leader and psychosocial team leader inquire about these documents during team meetings and encourage staff, especially counselors, to work towards getting the patient to complete them as soon as possible.

Following the report by the counselor, the nurse then repeats much of the same information about a patient’s medical history, elaborating on physiological concerns, including status of pain and symptoms, and will include in her (there is only one male nurse on the team) report psychosocial matters such as anxiety or caregiver issues. The way team members give report about New admits offers a clue into how counselors and nurses assess patients’ psychological and spiritual issues and the amount of import these issues receive during IDT. The information given about a patient’s psychosocial status is generally incomplete and often superficial; for example, “The patient suffers from generalized anxiety,” or, “The patient does not want to talk about death and dying.”
There are two possible explanations for these types of reports. First, it generally takes more than one visit to completely assess a person’s mental health status; therefore, initial and superficial impressions, such as those above, become the best description of a patient’s status. Second, a patient’s mental health history or status does not dictate eligibility for the Hospice Medicare benefit. Therefore, such issues receive less attention than whether the admitting diagnosis meets Medicare criteria or the types of medication a patient takes to control, for example, pedal edema (collection of fluids in the feet) is reimbursable under these criteria.

Spiritual needs receive even less attention during initial new admission reports than psychosocial issues. Counselors, and sometimes nurses, will state, “The patient does not request a chaplain at this time.” The report suggests that team members do not complete a spiritual assessment per se, but instead ask a new patient if they would like to see a chaplain (A more thorough discussion of the team’s approach to assessing patient’s spiritual needs appears in chapter 7).

In addition to limited information provided during IDT about new admits’ psychosocial and spiritual needs, there is almost no mention of a patient’s potential need for a volunteer, which fulfils the interpersonal dimension of care. The team’s Volunteer Coordinator may pick up certain clues that a patient is lonely or isolated during a report and ask if a visit from a volunteer, pet therapy, or message therapy might benefit that patient, but like the statement about a patient’s desire for a chaplain, the need for a volunteer is generally absent from initial reports.
It is no coincidence that bio-medical concerns receive substantially more focus than the other needs of patients despite the use of interdisciplinary teams because biomedical care determines whether a patient is hospice appropriate; therefore the psychosocial, spiritual, or interpersonal needs of a patient or their family members are secondary. Once the nurse establishes a patient’s hospice appropriateness, the question of how team members assess her other needs, as described by the dimensions of hospice care, remains unclear. What is evident is that team meetings are not the site for creating or adjusting care plans. New admission reports emphasize bio-medical needs and de-emphasize or gloss over psychosocial or spiritual needs.

Striking a balance between the five disciplines on the team is an issue that arises not just during new admissions, but also throughout a patient’s hospice experience. Some patients do not need lots of care from their nurse. A visit every 14 days, the minimum required by Medicare, may suffice to manage a patient’s symptoms and medication. This same patient, however, may need mental health counseling from a Licensed Clinical Social Worker, assistance from Home Health Aids to manage Activities of Daily Living (ADLs), or frequent visits from a volunteer to combat social isolation and loneliness. By focusing primarily on bio-medical needs during team meetings, a patient's other needs receive less attention, sending an implicit message to other non-biomedical staff about hospice care values. Team meetings then reinforce a biomedical model of care and situate the other disciplines on the fringe. Furthermore, this places additional burden on nursing staff to assess and sometimes even offer care outside the boundaries of their professional training and expertise.
Patients and their caregivers do not have full knowledge or appreciation of the types of care they could receive from hospice when only two members of the IDT visit at the time of admission. This places additional burden on team members (usually nurses) to identify and recommend the ways in which a patient and a patient’s loved-ones could benefit from the full range of hospice services. Despite the fact that hospice uses an interdisciplinary team approach to care, the organizational and institutional structures that shape hospice give nurses the primary responsibility for creating and managing patient care plans. As such, nurses have a great deal of power in determining whether patients receive non-biomedical services, including mental health counseling, social support, or Home Health Aids. In fact, nurses establish the need for a Home Health Aid and the frequency of their visits during their initial assessment. The volunteer coordinator assigns volunteers to patients and chaplains get patients by referral, which offers home health aids, volunteers and chaplains no opportunity to conduct an assessment themselves, much less dictate care plans. These team members, then, become resources, as opposed to equals, for nurses and counselors to call upon as needed.

Once the nurse-counselor dyads present all of the new admissions, the nurses quickly state whether their existing patients, whose hospice re-certifications are due, are complete. Next, in the presence of the team physician, nurses discuss existing patients whose hospice re-certification periods are approaching, to determine if these patients remain eligible for Medicare reimbursed hospice care. I emphasize Medicare eligible or hospice appropriate because there are times when a patient may, in the opinions of the team members, need hospice, but do not meet Medicare’s criteria. Generally, the question
of whether or not a patient is still appropriate for hospice involves asking, “Would you be surprised if this person died within the next six months?” If the answer is “yes,” meaning the patient is expected to live beyond six months, then the team should move to discharge the patient from hospice. However, if the answer is, “no,” then the patient should be recertified. Expectations about the timing of patients’ death do not sufficiently justify their eligibility for hospice care. To establish a patient’s appropriateness, nurses’ tasks include identifying whether or not a patient has disease specific symptoms related to their hospice diagnosis. Hospice care and its subsequent reimbursement through Medicare illustrate how the bio-medical side of dying drives care and financing.

Discussions about psychosocial and spiritual issues, however, receive more focus if these factors interfere with medical care. In other words, if a patient has a mental illness, or perceived as mentally ill, then team members bring these challenges to the team. Other talk about management of care arises when a team member finds a patient’s case too complicated or outside the reach of the team member’s skill set. For example, if a nurse is unable to control a patient’s symptoms, such as pain or shortness of breath, the nurse will ask the team physician for recommendations about how to proceed. If a patient is non-compliant, has mental health problems, or lacks certain resources that influence her or his quality of life, a team member might mention this challenge at a team meeting. What is interesting about difficult patients or patient challenges presented to the team relates to how feedback about helping the patient evolves and who team members call upon to offer opinions. Rather than ask the advice of the mental health professionals on the team, nurses will usually defer to the team physician or even the team leader (another
nurse) for counsel. The lack of collaboration across disciplinary boundaries is problematic for effective teamwork and promotion of an horizontal hierarchy (Eisenberg, 2008).

Hospice scholars (Connor, et al., 2002) claim that their site is the place where interdisciplinary teamwork fully developed. Team meetings, however, do not represent all of the work that comprises hospice care (Ellingson, 2005). On the other hand, these meetings offer staff members’ opportunities to reconnect with their colleagues in addition to creating occasions for professional and social support. In the next chapter, I will discuss how team members work with hospice patients during in-home visits.
Chapter 4 – Friendship & Dying

“I have someone for your study,” Allison, a counselor on the Sunflower team, tells me enthusiastically at IDT.

“Okay,” I say not sure how to read the counselor’s excitement.

“Who is that?” Judy, a nurse on the team, asks as she crunches on her salad of field greens, dried fruit, and various seeds, and low-fat raspberry vinaigrette.

“Sonny,” Allison says. “Don’t you think he’ll be good?” she continues, looking for Judy to match her eagerness.

Judy agrees nonverbally, but scarcely mirrors Allison’s vibe. I find Judy’s lack of verve amusing because of the first conversation we ever had when I asked my standard introductory questions about what brought her to hospice. Called by God to work for hospice, Judy quit her long time job as a surgical nurse. At the time, I was not really prepared to probe about the religious nature of Judy’s pilgrimage to hospice, but I noted the significant difference between working in surgery and working for hospice. “I liked my job. That’s not why I left. I was making better money too,” she noted. What she liked most about working in the operating room was the unconscious state of her patients. “They’re out when I get them and out when they leave,” she said. Communication or lack of communication with patients appealed most to Judy about working in surgery. Given the reputation surgeons have for being arrogant, I asked Judy what the work environment was like, and she said that it was not at all problematic. How odd, I thought, but I
accepted Judy’s story as illustrative of the true power of a spiritual message from God. In her forties, Judy is similar to the other nurses on the Sunflower team. She has short blonde hair, practices yoga, and attends church regularly. What sets her apart from the other nurses is her dry wit and first-rate sense of humor, yet she is rarely the most animated, at least not without good reason. Judy and Allison, who share most of the same patients, are a Ying-Yang tag team, which works most of the time, but as I learned over the next few months these differences sometimes created friction related to management of patient care.

*Good Patients Equals Good Participants*

During the IDT meeting, I wondered what made Sonny a suitable participant. One reason Allison suggested him related to his emotions – he cried during their visits. I am not sure why this qualified Sonny over others, but I met him willingly. Other team members similarly thought of their patients as *good* fits for my study. Immediately after introducing my study to the team, I had a list of at least 10 *good* patients. I never asked anyone directly what made a patient *good*, but one team member, a Family Resource Specialist (FRS), a non-licensed social work position, recommended a patient to me because she told interesting stories about playing the fiddle in popular country music venues. Even though I dislike country music and its requisite fiddle playing, I was in no position to discriminate. I met this patient once (without the FRS) and I did not find her *good*, at least not for the reasons cited by the FRS. To begin with, the patient was depressed and had no interest in playing the fiddle or offering any anecdotes from her past. I did not resent her depression, but expected it – the woman was frail and in pain,
which she attempted to control exclusively with dollar store brand topical analgesic.

What I did begrudge was her ordering the chaplain and me around. She insisted that we
clean out her refrigerator and take out the subsequent garbage.

Often times, good patients were those whom the team members liked, were
agreeable, but not necessarily overtly spiritual or open to talking about dying. I wanted
team members to allow me to observe with them and see what happened. Instead, many
became gatekeepers who sought to shelter me from problem patients. Each time a team
member told me they had a good patient I tried to reiterate the value of seeing any patient
willing to let me observe. Looking back, I suspect that some team members, the FRS in
particular, used the contrived good patient criteria to avoid hosting me in the field.
Thankfully, such barriers did not exist with all team members and I arranged to shadow
Allison when she and Judy planned to visit Sonny during the upcoming week.

Not a Hospice Death

Before Allison could introduce me to Sonny, however, tragedy struck the
Sunflower team just days three days into my observations. I was in the field with Carrie,
a nurse, when she received a page saying there was “an emergency with one of our own”
and she should return to the hospice’s main campus as soon as possible. I could not
fathom what type of emergency the page referenced. At first, I thought aloud that maybe
someone fell and broke a bone or, at worse, had a heart attack in the field. I then
speculated that maybe the page was one way to get all of the employees back to the office
for a holiday party – it was December after all. The nurse noted such a page was a terrible
way to invite someone to a party. I concurred and kept any further musings to myself
realizing the uselessness of my predictive powers. Instead, we opted to change the subject and I asked a few questions about Carrie and her experience at hospice. Carrie jogged every day, was a vegetarian, taught yoga, and had a Guru. She snacked on raw almonds and other healthy snacks between patient visits throughout the day to keep up her energy. We had several interests in common from yoga to raw almonds, yet despite learning a great deal about Carrie in just half a day, I felt as though she was inaccessible in some unidentifiable way.

As we drove east towards the office, stopping and starting for the traffic lights along Bay Shore Road, I asked Carrie about her work as a psychiatric nurse. I then asked her about the transition from the drama and dangers of psychiatry to the mellow world of hospice when the topic of her most memorable patient came up. She proceeded to tell me a mesmerizing story that gave me goosebumps. “We were really close,” Carrie stated. “We just had a connection,” she says. Carrie is focusing on the road in front of her, but her gaze communicates that she is reflecting back on an image of her patient in her mind.

“How long was he in hospice?” I ask. The question dissipates the image in Carrie’s mind and she says, “About three months.”

“Wow that’s not very long to feel that kind of a connection,” I note aloud.

“Yeah, well I guess not. So, it was becoming clear he was imminent – within 72 hours of dying,” Carrie says, taking her eyes off the road to sneak a glance at me in an effort to determine if I understand the concept.

“Umm, hmm,” I reply to keep from breaking the flow of the story again. Carrie continues, “I was tossing and turning all night. I just couldn’t get to sleep, you know?”
respond with another filler. After a fitful night sleep, she rose to find that the patient with whom she had grown so close to had died. The connection the two had transcended their waking life and continued into the patient’s death and it required a letting go. Carrie’s Guru instructed her to do a chant. Little did I know I would do the same chant just a few hours later.

Carrie and I pull into the tree-lined parking lot of the hospice’s main campus to find many employees milling about. I always find the property’s pine trees, walking paths and ponds serene, reminding me of Lake Tahoe. As we walk up the sidewalk to the entrance of the designated meeting room, I notice the faces of several managers (whom I interviewed just a few weeks earlier) through the tinted windows. I feel surprisingly composed despite having no idea what we are walking into, yet out of place because of my insider/outsider status as a student-researcher. I open the door and allow Carrie to enter first and guide the way. I see a police officer talking with people in another room when Bobbie, the Sunflower Team’s Senior Staff Nurse, greets us.

“What’s going on?” Carrie asks, surveying the scene in search of clues.

“Lisa and Sharon were murdered,” Bobbie tells us.

I have no idea who Bobbie is talking about and the gravity of the deaths slides off me. Carrie turns around and repeats the message to me again as if I have not heard a word.

“I don’t think I know who they are,” I say, apologizing for my ignorance. Carrie explains that Lisa worked in the office for the Sunflower team and that Sharon worked on another team. Lisa and Sharon had recently started dating after Lisa divorced her
husband. Bobbie tells us that Lisa’s ex-husband is the lead suspect in shooting the couple as they slept and killing their two small children before shooting himself on the side of the road.

I could sense the shock and devastation among Lisa’s and Sharon’s colleagues who were crying and hugging each other in futile attempts at finding comfort. People from all levels of the organization wandered about aimlessly. I could hear employees talking about the circumstances of the deaths in an effort to process their meanings. Sudden death brought about by violence did not constitute a good hospice death.

I watched as the Sunflower team leader, Dani, tell everyone who came to console her about how close she came to having to identify her subordinate’s body. Dani’s ability to describe Lisa’s fresh ink – one tattoo covered her ex-husband’s name with the names of their two children, and the other a religious symbol of peace – protected her from the misfortune of having to identify Lisa’s body. The significance of this tragedy for the Sunflower team and Coastal hospice is beginning to sink in. Several people offered to take me back to my car, which I left at Carrie’s house earlier that morning, but I insisted on staying. I thought maybe it would prove helpful to the team to have someone not so close to the victims present. I was not sure what, if anything, I could or would do if I stayed. I also did not know how I would get home, but I decided to deal with that issue later.

A half hour passed and I started to think it might be time for me to leave because I spent the majority of my time not comforting others, but listening and watching Bobbie gently tell team member after team member about the deaths. I am not a full-fledged
member of this family, hardly a distant relative, and I am beginning to feel more and more out of place. I decide to step out and call my friend, Mary, who lives in the area for a ride to my car. I regret making the call almost immediately when Mary begins questioning me about the identities of the people involved in the violence. “Oh no. I know some people who work at hospice,” she says. “Who is it?” I try to feign any knowledge about the victims’ identities, but when that does not work I try to use my ethical obligation as a researcher to avoid breaching any issues of confidentiality. She begs me to tell her, or confirm rather, what she already suspects, that her friends, Lisa and Sharon, are dead. I relent and confirm her fears. “What about the babies?” she asks with fear in her voice. I tell her I think two of the children are dead, but that Sharon’s daughter survived. My uncertainty stems from speculation that the toddler witnessed the shooting of her mother and her mother’s girlfriend. I reluctantly give Mary a few more details and tell her the little girl’s screaming combined with the sounds of gunfire prompted a neighbor to call the police. I can hear Mary weeping and crying, pleadingly asking, “How could he?” and saying, “Oh no, not the children.” I can hear Mary relaying the news to her daughter who also knows the victims. What have I done? I thought. I tell Mary I will find someone else to come pick me up, but she insists. I try to reason with her, arguing that she is clearly in no condition to drive, but between sobs, she continues to insist. I really do not want to bring another grieving person into this situation, but Mary persists and I give in.

While I await Mary’s arrival, I decide to walk down to the research institute to speak with my primary hospice contact, Joe, the director of research. He searches the web
for additional details while I tell him what I know. Joe offers to give me a ride to my car in his new convertible, but I tell him that my friend, who lives in the area – and coincidently knows all of the victims – insists she will pick me up. I tell him about my reservations over having Mary come get me. I am looking for reassurance about my actions. Joe notes the serendipitous nature of the events and concludes without reservation, and to my relief, that my call to Mary was destiny. I feel better about having called Mary and I leave Joe’s office to return to the meeting area when I run into Allison who is wearing what looks like pajamas. Her eyes are puffy from crying. “Is this going in your study?” she asks. I do not know what to say and before I can respond Allison says, “It should. Your project is about death, right?”

Allison had a point, but I did not want this trauma to become the focal point for my research. I also had numerous concerns about how I would incorporate such an event into a project about a much different type of death – one protracted while the other abrupt – both garnering sadness, but for dissimilar reasons. The story of Lisa and Sharon holds a place in the larger narrative of this project because their deaths became the basis of conversations between hospice team members and patients during visits. This violence also prompted talk among team members about loss, grief and domestic violence, topics frequently met with silence. Whether I liked it or not, the event bonded me to the team.

I shared in some formal and informal healing rituals as seemed appropriate and necessary. A week after the murders, for example, I participated in a Team Support focusing on the deaths, which consisted of a roundtable moderated by a counselor. After the roundtable, I talked for two hours with Bobbie, the Senior Staff Nurse who broke the
news about the murders to team members as they arrived. We talked about domestic violence, death caused by violence, spirituality, and forgiveness. I specifically talked with Bobbie because I thought she could use some support after carrying the additional burden of repeatedly telling her co-workers about this tragedy. On the day of the murders, I also took part in an impromptu chanting session with Carrie and two of the team’s nurses in the parking lot shortly after Mary arrived to pick me up. Although I felt some relief about having my friend come get me, I was concerned about having Mary join us because the deaths were just as much the team members’ losses as they were Mary’s. Not to mention the nurses’ calm nature, especially when compared to Mary who had mascara running down her face and foundation smeared by her tears. She was practically keening, doubling over with grief. When she arrived, she again asked me about the children and when I repeated their fate she cried harder, questioning the reason for such evil acts, especially those committed against children. Despite my concerns, the nurses encouraged Mary to join us and offered her comfort. Together we chanted to release the souls of those murdered – just as Carrie had for her unforgettable patient. Bobbie offered words of peace for the man who perpetrated the crimes and then took his own life. At the conclusion of the chant, Mary let out a deep sigh and said, “I feel better. Thank you.” We hugged each other and then Mary and I left.

With Mary in the passenger’s seat of her blue Toyota, I drove to Carrie’s house to get my car, kissed and hugged Mary good-bye and then drove home. During the 45-minute drive, I called my mom and recounted the day’s events. I could not believe the

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4 Mary reviewed this story for her approval and commented that she did not recall me telling her on the phone that the children had died. She recalls learning of their deaths after arriving to pick me up.
coincidence of my placement on this team. I also called my friend Nick because it was his birthday, but I did not say anything about the murders because his birthday falls on the day after the anniversary of his wife’s death. No one should have so many traumas linked, even loosely, to the date of their birth. When I got home, I told my husband who saw some of the coverage on the local news about the particulars. That evening I learned that Sharon and I completed orientation training together. Now, the sorrow of the murders hit closer to home because of the bond I had developed with my fellow orienters. Sharon’s wisdom made her memorable. I also remember her talking about how much she loved her daughter and the joy of singing in an a cappella group. The chanting ritual only provided temporarily relief because from that night forward the news would print and broadcast the details of the events leading to the bloodshed, forcing each of us to edit and amend the narrative we constructed in an effort to make sense of the senseless.

The murders happened on a Friday and I spent the weekend wondering what to do about my field observations. I agonized over whether or not to keep my appointments or cancel my observations for the week following the murder-suicide. I was concerned that team members would perceive my interest in continuing my nascent data collection as self-serving and insensitive. Alternately, I did not want to assume these events put my observations on hold. I worried about coming across as presumptive because after all these people were death professionals. I considered myself a death professional too, so rather than assuming anything about the status of my research with the team, I forced myself to push through the feelings of uncertainty about violating any implicit or non-existent etiquette and ask for guidance directly from the team.
I e-mailed the team leader, Dani (the person I thought most traumatized by the deaths) and inquired about the status of team meetings. In my message, I also offered to help in the office by answering phones, but she did not take me up on the offer. Dani did tell me the meetings would go on as planned. I then contacted Allison to discuss the observations we had scheduled for later in the week. During our call, she told me she planned to work as usual, but when the day approached, Allison canceled. It would take two weeks before I was back in the field observing patients.

*Returning to the Field*

Allison and I returned to the field together and our first visit was to see Sonny. Pulling up to a small house with a single car garage, Allison tells me that Judy is already here. The counselor/nurse team is making co-visits with this patient because Judy suspected some sexual impropriety, after Sonny made borderline lewd comments. Allison explained that Sonny attributed Judy’s hot flashes to sexual attraction. Allison and I found this hilarious and harmless, but Judy did not. With this information in hand, I prepared myself for the possibility of similar commentary from Sonny upon our first meeting.

I follow Allison as we walk toward the house’s side gate leading directly to the converted single-car garage where Sonny lives. Sonny moved into the garage of his daughter’s house after his Chronic Obstructive Pulmonary Disease (also known as emphysema) became terminal. I always feel awkward visiting someone’s home when I am not necessarily an invited guest. Sonny knows I am coming today, but I am not sure I am genuinely welcome.
Allison knocks on the door and we hear a voice inviting us to come in. The door opens into the laundry room where an oxygen concentrator is running and a shower chair hangs on the wall. To the right is the doorway to the kitchen in the main part of the house and to the left is Sonny’s studio apartment. I notice there are no windows in the room, not even in the garage door, but there is a bed, desk with a computer, television, chest of drawers, and nightstand. Sonny sits in a black office chair directly across from his 25-inch television, tuned to CNN’s morning news.

Sonny wears a navy blue flannel shirt over a navy sweatshirt. He also has on navy blue sweat pants, white athletic socks, and black faux leather slippers. Sonny’s hair is white and worn close to his head, although he combs the top over in an attempt to cover his balding. His round cheeks accentuate the close proximity of his blue eyes. The smoothness of Sonny’s chin suggests he shaved before our visit. Nasal canula tubing sits across Sonny’s upper lip and over his ears. I note that he does not look particularly sick as much as he looks old, like a grandpa.

Allison introduces me to Sonny by briefly explaining that I am a student doing research with hospice. We shake hands and I look around for a place to sit. The room is small and the seating limited. I notice a space on Sonny’s twin-sized bed next to Judy, but I wonder if sitting on a stranger’s bed violates a norm about personal space. I point towards the bed and ask Sonny if it is okay to sit there. “Yeah. Of course. Sure,” I hear everyone say in unison. The group’s reaction disappoints me because I really hoped to have Sonny’s autonomous permission without the influence of his care team. “Are you sure?” I ask. “Yeah, you can sit anywhere you like,” Sonny, responds, not wanting to
make a fuss. I take a seat next to Judy and try to avoid rumpling the bedspread. The
counselor wheels the chair over from the computer desk and takes a seat. The space is
small for the four of us and I worry that my presence is even more of an intrusion than I
first thought. Judy sits with her laptop computer open and her blood pressure cuff next to
her. Allison opens her laptop soon after we arrive. The organization requires team
members to complete their charting at the bedside, but the device creates a physical
barrier between patient and hospice team member. Furthermore, the computer holds
questions that dictate the course of conversation and draw additional eye contact away
from patients and their families.

“How are you feeling today?” Allison asks.

“I’m doing okay,” Sonny says, glancing away from the television.

“He doesn’t have any pain today,” Judy offers, cueing Allison to make note in her
computerized chart. “And he brought a fan for me too,” Judy adds, referring to the small
oscillating fan set to blow directly on her as needed.

“Good. That’s nice. That should help her with those hot flashes,” Allison says,
smiling and looking at Sonny. Allison recaps the story about Sonny mistaking Judy’s hot-
flashes for sexual attraction to let me in on the joke. I suspect Allison is repeating these
backstage facts in the frontstage (Goffman, 1959) for the benefit of the patient to create
the illusion that we do not talk about them outside of their presence. “Sonny thought that
Judy was hot for him,” Allison says. I feel embarrassed for Sonny and I am a little
surprised that Allison mentions the blunder now.
“Well I didn’t know,” Sonny says, cheeks flushed. “What do I know about women?” he poses, pleading ignorance. Allison watches closely, attuned to Sonny’s nonverbal reactions from the time we walk in the door. Her level of attentiveness draws my eye and I wonder if she is looking for some additional clues about Sonny’s welfare. Allison focuses as much on his body as Sonny’s words and I am worried that he will catch her looking at him, but his focus remains on the television headline news. Sonny reaches for the remote and changes the channel to a local station that I never watch. The local paper rests on a TV tray to Sonny’s right. Next to the TV tray is a plastic chest of drawers. Atop the drawers sits a small plastic cup perspiring condensation onto a neatly quarter-folded paper towel. Among the items on the chest of drawers is An I Can’t Believe It’s Not Butter container, an inhaler and a box of Kleenex. Prescription bottles line the edge of the drawers like soldiers waiting for roll call. Judy takes Sonny’s blood pressure, listens to his lung sounds, counts his respirations and pulse and records them in the electronic chart while verbalizing the information to Allison. Judy then asks Sonny if he needs any prescriptions and Sonny passes the six amber colored bottles to Judy who places a call to the hospice’s pharmacy requesting refills. The medications will arrive by volunteer courier within 24-hours.

Once Judy completes the call, she and Allison record Sonny’s responses to a series of standardized questions intended to gauge his level of suffering and quality of life. Not only do they want to know if he has pain and at what level, they ask Sonny if he is suffering, and the level on a scale of one to ten. They also ask, “What is most important to you today?” In response to the last question, Sonny tells us he would like to take his
scooter out to get a steak sandwich from a little shop not far from the house. I look to my left from my position on the edge of Sonny’s bed and see a large motorized wheelchair against the wall closest to the door we entered just 15 minutes ago.

“That sounds good,” Judy says. “It’s a nice day outside.”

“Yeah, but you better be careful,” Allison says. “You heard about that guy in a chair that was killed right around the corner from here.”

“I read about that, but I can usually go the back way, through an alley, and avoid that intersection,” Sonny says, trying to settle Allison’s concerns.

“Oh, I don’t want to get up in the morning and hear about you on Coastal 9 News,” Allison says referring to the local morning news program they both enjoy watching. Sonny reaches for the newspaper and Allison asks if she can see the section with the horoscopes so she can read hers. Allison and Sonny are both Cancers. I take this as a good sign since I have many Cancers in my life and we get along beautifully. Allison reads their horoscope first which says that today is going to be a happy day, and as if it is prophecy, she declares the day a happy one. She asks Judy for her sign, which is Aries, and then reads from the paper. “Okay. Aries, you will have problems with communication at work, today. Be sure to be nice to your co-workers, especially Cancers.” We all realize Allison fabricated the contents of Judy’s astrological chart, yet she continues to try to play it cool. “What? That’s what is says.” We just look at her and I start to laugh. “What’s your horoscope?” she asks me. I hesitate to answer because I do not want to reveal that my birthday is less than a month away. I also do not want any of
the attention on me. I feel like everyone is looking at me and waiting so I acquiesce, “I’m a Capricorn.”

“Ahh, Capricorn. Let’s see. You are attractive and persuasive. Today is an excellent day for making new friends. Hmm,” she says approvingly looking up at me and then at Sonny. “Your lucky number is 3.”

“That’s cool,” I say.

“So, you’re a student at USF,” Sonny asks me.

“Yes, I am getting my Ph.D. in communication.

“She’s going to be a doctor,” Allison offers.

“Yes. And I have to do a research project to get my degree. Should I talk about it now?” I ask, looking to Allison and Judy for approval to interrupt their visit. They agree and I explain the project to Sonny in very basic terms, recognizing that graduate school and its hurdles are foreign to almost anyone without first-hand experience. As I explain the purpose of the study, I debate using the D words or their euphemistic substitute end-of-life. I decide to use both death and dying and follow with their softer understudy.

“I am asking hospice patients like yourself,” I say, reading from the informed consent form, “to participate in a research project about how hospice team members communicate with their patients and families about spirituality, dying, and death. I’m interested in how people communicate at the end-of-life,” I add the last sentence quickly and I realize I am sweating. Not only am I worried about Sonny’s reaction, but I also realize that Judy and Allison might find fault in my approach. I continue covering the rest of the form, going over the mundane details of how I will collect data and protect
confidentiality. “I’ll give you a fake name like Clark Gable,” I say, attempting to make a joke to counteract the bore factor. When I finish what feels like a stammering mess, Sonny says, “So you just watch us?”

“Yeah, pretty much,” I say, partially relieved and surprised that the topic does not draw more scrutiny or more emotion.

“Okay,” Sonny replies. I cannot tell if he is confused or just disinterested in a non-judgmental way. My research after all is of little consequence to his life.

“Maybe you could be a participant?” I suggest.

“Sure. I’d be happy to help you with your schooling.”

“Great! Thanks,” I say. I show Sonny where to sign and I hand him his own copy of the informed consent form. I close by suggesting, “If you can’t sleep tonight, you can just read this. It will put you right out.” Everyone humors me by chuckling.

“Well,” Judy says as she begins to pack up her laptop and stethoscope back into her wheeled travel bag. “I better get going.”

“Okay then,” Sonny says, as Judy walks over to give him a hug.

Once Judy leaves, Sonny asks Allison about the murder-suicide.

“I read about it in the paper and heard about it in the news. Did you know those people?”

Sonny’s line of questioning is reasonable, but I am worried about how Allison is going to respond because I know how upset she is still about Sharon’s and Lisa’s deaths. To add insult to injury, Allison felt the organization’s response to the crisis was poor and did little to support the teams closest to the victims.
“Yes, I did know them. One of the women was on the Sunflower team. She worked in the office.”

“Oh I didn’t know that. Did you know her too?” Sonny asks, looking at me.

“Not really. I went through orientation training with one of the women and met the other because of my work with the Sunflower team. It’s still very sad and shocking.”

“It sounds like the guy couldn’t handle his wife being with the other woman and that he just went crazy,” Sonny offers.

“Maybe so; he was an abuser,” Allison says calmly. I know Allison would like to say more given her background in domestic violence and trauma, but she refrains.

We allow for some silence as we process the proximity of this domestic violence to our lives.

“I’m sorry about your co-workers,” Sonny offers. “I wondered if you knew them.”

I am impressed with the way that Sonny and Allison handle the conversation – Sonny delicately and Allison honestly. Throughout the day all of the patients would ask about the deaths and the counselor and I would do our own additional debrief at lunch.

“We probably better get going,” Allison says, packing her laptop into her blue and green Vera Bradley bag. I cannot believe an hour has passed already. “Same time next week?” She asks. Sonny nods.

“Is it okay if I come back with Allison?” I ask.

“Sure! You can come anytime,” Sonny says.
Sonny nods and we each give him a hug. I tell Sonny it was nice meeting him and I look forward to seeing him next week. We walk back through the laundry room, and out the door to the side yard.

“Don’t forget to close the gate,” Sonny calls out.

“Okay,” Allison says, carefully latching the gate. In the car, Allison tells me that Sonny is usually more emotional and I suggest that maybe he kept his emotions in check because of me, a new person, a researcher. Sonny would not shed a tear during our subsequent visits. Maybe the lack of emotional response comes from the topics we discuss. I learn during our next visit about Sonny’s past including his military service.

“So you were in the Korean War?” I ask, pointing to a Korean War Veterans baseball cap.

“Yes. I was just a kid then,” he replies.

“What branch? What did you do?”

“The Army. When I first got in I was in the infantry, but then I became a cook.”

“Why?” Allison asks.

“Because I got to eat better,” Sonny says laughing. We laugh too.

“So were you over there?” Allison asks wanting to know if Sonny served in Korea.

“Yes. And you know what I remember? We were on one hill and they were on the other – we used to call them Gooks back then – ” Sonny observes apologetically.

“Well yeah,” Allison interjects to balance the pause. I nod in acknowledgement.
“And I just remember at one point it was all over and they walked down the mountain and we walked down the mountain and met in the middle. And you know what I remember? Their shirts were so white.”

“How. And that was it, it was just over? The whole war ended just like that?” I ask.

“Yeah that was it. And I always wondered about their shirts. I still think about that.”

“So what happened when you got home? I know they say it was the ‘Forgotten War,’” I inquire, wanting to learn about history directly from someone who lived it.

“Yeah, that’s right. I remember coming home and walking down the street in my uniform with my duffle bag and no one even seemed to notice. I mean we just got back and some people didn’t get to come back. It was strange, as if no one knew we were gone.”

“That must have been really difficult,” Allison says.

“Yeah, it was hard,” Sonny observes, noting the differences between and the return of Korean War soldiers and sailors and those who served during World War II. “Back then we supported our boys when they got back. There were parades and stuff. But when the Korean War ended there was nothing.”

Following a tour in Korea and receiving an honorable discharge from the Army, Sonny opened a diner, called Sonny’s Place. Sonny loved to shoot pool; he also loved gambling and playing cards so much that he had a pool table in his diner and turned the small restaurant into a card room after regular business hours. He partially attributed the
demise of one of his two marriages to rumors about infidelity when in fact he was just out
playing cards with the boys. The diner closed after a run in with The Mob over a jukebox
and fears that his business partner’s criminal ways became too risky. Allison and I tried
to encourage a juicier story about the Mob, but could not draw one out.

The only thing Sonny loved more than horses and cards were his seven children:
five girls and two boys. “That was the happiest time of my life, when I was raising my
kids. I used to come home from work and make dinner for the kids and then do it the next
day all over again,” Sonny told us a few weeks after we first met.

“That’s pretty unique for that time,” I say, observing that few men had primary
custody of their children in the 60s and 70s.

“Yeah, but I didn’t mind. I liked it.”

When Sonny mentioned raising his children again at our visit the following week,
I decide to broach the topic gently with Allison as we drive towards our next visit near
the inter-coastal. “Do you think there is something going on with Sonny and his family?”
I worry she might interpret my inquiry differently than I intend. I hope she will take my
suggestion as a topic to probe further rather than an affront to her professional expertise.

“I don’t know. Why?”

“Well Sonny’s mentioned his family a couple of times now and I just wonder if
he’s worried that he didn’t do a good job or something,” I say treading lightly with a tone
that I hope conveys conjecture rather than certainty, although I feel confident about my
interpretation. “I don’t know, that’s a good question. I’ll have to ask him,” Allison
replies. The following week, Allison pursued the topic of Sonny’s family further. By
now, my co-visits with the counselor and the nurse dwindle to overlapping visits. The nurse arrives at nine and then Allison and I arrive about 30 minutes later. At first, I thought this was purely for convenience, but as Allison observed, Sonny felt more comfortable talking about a wide range of topics, from politics to relationships, with Allison and me when Judy was not around. We became, “You girls,” to Sonny. I no longer sat on the edge of his bed because Sonny would take his gray shower chair from the wall outside his room and place a folded faded burgundy towel down for me to sit on.

*My Time, My Way*

Now, when we arrive at Sonny’s we make chitchat while Judy finishes her assessment of Sonny’s condition. Today, the two team members talk about the previous day’s meeting concerning the organization’s new policy about text messages – the new preferred mode of communication on teams. Nurses, for example, must now submit prescription refills by text message instead of voicemail and a numerical coding system replaces descriptive messages. A text message with the number one, for instance, is urgent and a five means no response is necessary. I think the procedures will constrain communication in a myriad of ways, even fire departments who once used 10-Codes have returned to plain language, but I keep my opinions to myself because I notice Sonny looks uncomfortable. “When will someone listen to me?” he says with an inflection that attempts to combine anger with jest, but I suspect he is more upset than he is letting on.

“We’re sorry, Sonny,” Judy says with some sarcasm. “What do you want to talk about?”

“I don’t know, but not that work stuff. I thought this was my time,” he replies.
“Okay, okay, you’re right,” Allison says. “How are you doing today?”

“Well, I’m just fine,” Sonny says, content that the focus is on him again. There is no clear explanation for Judy and Allison’s lapse in giving Sonny their undivided attention, but I recognize that Sonny’s overall health and easy-going personality makes it easy to forget that he is dying and thus his time is precious. Sonny uses oxygen regularly to increase his comfort, but I notice these days that he rarely wears his nasal canula when we visit. Upon our arrival, he takes the tubing off and hangs it on the armrest of his chair. It bothers me that Sonny’s not wearing his oxygen, especially because I suspect he does this to demonstrate his prowess when Allison and I visit. I make a mental note to bring this up to Allison later.

Judy completes her visit and now we can talk about more interesting things than the topics broadcast on local news or CNN’s crawl. Allison wastes no time and dives right into asking Sonny about his family. “So last week,” she begins, “you talked about your family and raising your children. Are you worried about them?”

“Well, you always worry about your kids. It never matters how old they are.” Sonny goes on to talk about each of his children. Most of them have done well for themselves with their own families and careers, but two of his children have problems, one with money and the other with substance abuse. Although Sonny does not sound extremely concerned about how his children will fare after he dies, he spends many visits talking about them and the era Sonny called, “The best time of my life.” Listening to Sonny talk about his children and this important time in his life makes me think that he is more proud than worried about his children. I also suspect that talking about them is an
attempt to receive some recognition for his parenting from his children. Sonny’s daughter divulged that her father could be critical and harsh, doing such things as commenting on one daughter’s weight gain whenever he saw her or criticizing another daughter’s choice in partners. The combination of the daughter’s insights and Sonny’s reflections suggests to me that Sonny wanted recognition, but also needed Allison and me to help him reframe his parenting as good.

*Attending a Funeral and Talking about Death*

Two weeks ago we talked with Sonny about his family and the week before that his military service. I realize that I am beginning to look forward to my visits and as I get ready on Thursday mornings, I catch myself making choices about how I am going to wear my hair and what I am going wear with Sonny in mind. I know if he does not like something, he will not hold back his assessment because he has already commented that he prefers my hair when I wear it pulled back. For his part, I have noticed that Sonny seems to have a plan for the conversational topics he would like to discuss. Today, however, our attire diverts from any pre-planned subject matter Sonny might have in mind.

“You two look like you’re going to a funeral,” Sonny says, after we walk in the door and take our seats. I freeze like a deer in the headlights (or at least I think I appear frozen) and I wait for Allison’s response. I am grateful my research focuses on watching her work and not the other way around. “We are. Going to a funeral,” Allison says. I feel a bit caught off guard by her bluntness and her wisecracking tone. I suspect my reaction to Allison’s frankness is the byproduct of our culture’s over reliance on politeness when
communicating with people who are terminally ill. I understand that, for some, Sonny’s question invites an opportunity to tell a white lie or at least a lie by omission under the guise of protecting him. But then again, maybe I am really thinking of protecting myself from awkward feelings. I am shocked that I might actually be trying to guard against my own feelings of discomfort and nearly succumbing to wrongheaded beliefs about freely talking about death or death related subjects around a dying person. To tell Sonny a lie holds multiple and compounding consequences since one of the premises of hospice includes openly discussing topics such as funerals.

The truth for me is this; today, I will attend my first hospice related funeral and I am dressed for the occasion (from head to toe in black). Attending funerals and memorial services is not necessarily a responsibility or a team member’s job because there are no organizational obligations or expectations. Instead, the organization encourages team members to participate if they choose or feel the need. In many cultures, attending a funeral shows respect for the deceased and supports the family, and can help bring about feelings of closure. Allison developed a close relationship with the person whose funeral we will attend later today. In fact, Allison described Betty as a person who reminded her of own grandmother and, therefore, it makes sense for Allison to feel a special obligation to appear at the service. I, on the other hand, met Betty, a woman in her 80s, only once. What I should say is that I did not actually meet Betty in any traditional sense, but I was in her presence in the hospital about a week before she died. Betty was unconscious and surrounded by her family when we shared the mutual space of her hospital room.

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5 I omit other biographical information about Betty to protect her and her family’s anonymity.
I feel a bit apprehensive about attending Betty’s funeral today. I feel as though there are rules – all of them arbitrary – for how long you should know someone before you attend her funeral. Yet, I also recognize that such implicit and frequently unquestioned norms motivate my research. I did not know Betty or her family at all, and the time we did spend together in Betty’s hospital room, about 15 minutes, was hardly an opportunity to develop a relationship. I met Betty and a few of her family members during an extremely emotional and confusing time further complicated by denial.

Betty’s children refused to accept their matriarch’s health status in part because she kept secret the details about the severity of her cancer.⁶ Betty’s disease, however, progressed, prompting her family to hospitalize her. While there, the oncologist sedated her for comfort, which decreased her level of consciousness. Her children were naturally distraught about her condition, especially her lack of alertness, and demanded the reversal of those medications. Seasoned hospice staff members told me that the medication reversal process is similar to someone abruptly waking you from a deep sleep and leads to terminal restlessness (also sometimes called terminal agitation). Terminal restlessness, which usually occurs in the last 48 hours of life, can include such symptoms as thrashing, agitation, anxiety or muscle twitching which are difficult to control without sedation (Head & Faul, 2005). Betty’s family did not know the symptoms of terminal restlessness were more traumatic than the effects of sedation and again changed her treatment plan to include sedation.

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⁶ I learned at her funeral that Betty had cancer throughout her body, which she did not tell her family. This lack of knowledge contributed to the family’s expectations that Betty would recover and likely prompted the family to insist that she not receive sedation.
I also do not know what to expect at this funeral and I do not like feelings of uncertainty. I worry that I will express emotions for a person I did not even know, and I wonder if Betty’s casket will be open. All of the funerals I have attended involved cremated remains. I have never seen a dead body up close despite working as a Certified Nursing Assistant and taking a tour of a funeral home for a course on the psychology of death and dying when I was a Master’s student. It does not help that most of the narratives I have heard about bodies prepared for open casket viewing were negative. Sonny’s question this morning adds to my feelings of nervousness.

“Attending funerals is one of the things that we do at hospice. We’ll be at yours too,” Allison says. I nod to affirm Allison’s statement. “Oh, that’s good to know,” Sonny replies. I cannot tell how this new knowledge plays with Sonny, though his response suggests neutrality. He makes little eye contact, keeping his attention mostly on the television. I wonder if the thought of us talking about attending his funeral makes him feel sad or happy. I recognize the dichotomous nature of my internal inquiry and realize that no one feels either happy or sad when contemplating her or his funeral, but a mixture of both. The tenor of the conversation makes me feel more relaxed. I appreciate and am impressed by the way Allison handles Sonny’s question. The conversation does not feel too heavy or morose and Allison uses this discussion about Betty’s funeral to focus the talk back on Sonny. “I promise to wear my hair back too,” I tell Sonny referencing previous discussions about his preference for a sleeker look over my wilder (and more ethnic) curly coif. Sonny gives a strained chuckle and is forced to catch his breath from

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7 I only saw one dead person over the course of one year of observations with the hospice and that was at Betty’s funeral.
the laughter we share. I wonder, almost immediately after I speak, if I should have kept with a more serious tone rather than injecting some humor, but I think the moment of brevity fit relationally, but also worked to resist the notion that talk about death must always remain somber.

**Politeness and Talking about Death**

This very brief exchange between Sonny, Allison, and me illustrates how a conversation about death can emerge. In addition, Allison’s candid response to Sonny’s query and my reflexive cringe at the rejoinder illustrate how a tendency to err on the side of perceived politeness holds the potential to squelch communication about dying, death, and mourning. Reflecting back on our exchange, I wonder how I might have responded if I was in Allison’s place and responsible for the direction and tone of the conversation. I suspect I would have attempted to evade the conversation.

I understand that the rules of politeness dictate that we engage in communication that makes the hearer feel good and does not impose on the listener (Fraser, 1990, p. 224) (Fraser 1990, p. 224). The conventions of politeness, however, involve more than the quality of a person’s listening skills. Leech (as cited in Fraser, 1990) articulates six interpersonal maxims of politeness, all of which put the interests of the listener before those of the speaker. These principles require a speaker to employ an ethic of “do no harm” when communicating, but telling a white lie to Sonny could do more than evoke strong emotions; they could also damage our relationship. However, I also realize that talking about funerals with a person whose awareness of their own dying is acute carries a different weight than talking hypothetically about a healthy person’s funeral.
According to Fraser (1990), politeness dictates that the speaker should minimize listeners’ costs while maximizing their benefits (tact maxim), avoid putting listeners in positions where they have to break the tact maxim (meta maxim), maximize listeners’ benefits (generosity maxim), and maximize sympathy between the speaker and the message receivers (sympathy maxim). These maxims overwhelmingly support Allison’s choice to tell Sonny the truth. In addition, Allison’s approach simultaneously communicates that talk about death is not taboo. Under the guise of politeness, speakers sometimes communicate in vague or indirect ways or evade certain death related subjects all together. Thus forcing hospice staff to find the right balance between the goals of politeness, which usually involves honoring a person’s wishes for information or approach to care, and maintaining the honesty necessary for establishing, and in some cases developing, trust. An example will help illustrate this point.

During one particularly memorable visit to the home of a newly admitted hospice patient, I watched the nurse and counselor work to remain polite, yet honest, while navigating a family’s anticipatory loss and simultaneous attempts at denial. The patient’s eldest daughter asked the counselor in a whisper, “What should we tell Mother? Is it okay to tell her that she will get better?” The counselor responded quietly by saying, “It’s been my experience that most people are aware of what’s happening. No one knows their body better than they do.” I thought this answer was honest yet vague. Rather than directly answering the daughter’s question, the counselor offered a strategically ambiguous (Eisenberg, 2007) response that allowed the daughter to decide the most appropriate way to communicate with her mother. Collusion between the patient’s daughter and the
hospice staff is necessary for the patient’s daughter to maintain any denial therefore; the counselor must offer a message prohibitive of such denial.

The counselor’s reply serves another function not necessarily possible with more direct or explicit guidance about how to proceed. The implicit message in the daughter’s request for guidance about what to say is, “I am not ready to talk with my mother about her dying. I am not ready to face her imminent death.” Hence, if the counselor told the patient’s daughter, “No, it’s probably not okay to tell your mother she is going to get better,” the greater the likelihood of violating the daughter’s expectations for politeness and damaging face (Fraser, 1990).

Research suggests that people want honest information about their health and the health of their loved ones, yet health care practitioners frequently grapple with the tensions that exist when offering an honest assessment that protects face, maintaining politeness, and preventing emotional pain. The concept of hope, attempting to maintain hope when no hope for recovery remains (see, Roscoe, 1998), creates communication challenges for hospice team members. Some consider it impolite to take away a person’s hope, but in this context, it is unrealistic to perpetuate hope for recovery and so hospice team members must focus their communication goals elsewhere.

This does not mean, however, that hospice should perpetuate the alternative, but instead focus their communication on the quality of care and processing emotions. I contend that for health care providers to navigate these tensions they must avoid sanctioning illusions about recovery. In fact, I suspect that early in a hospice admission,

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8 In fact, the daughter said later in the visit that she “just keeps hoping someone will say [her mother] is going to get better,” despite the gravity of her mother’s health.
patients and families make comments about getting better in an effort to have someone confirm what they already suspect so they can let go and enter into anticipatory grieving (Ragan, et al., 2008; see also, Glaser and Strauss, 1965). Hospice team members can take questions about the possibilities for recovery as opportunities to communicate about spirituality, dying and death. In addition, communication about these emotional laden topics should focus less on preventing appropriate emotional reactions (such as anger or sadness) and attend to delivering difficult information in a way that is truthful and compassionate while leaving an opening for further communication about the topic.

*Patients as Conversational Guides*

Communication in hospice, however, tends to avoid talk about dying, spirituality and a *good death* by allowing the patient to dictate topics of conversation. In interviews with team members, they frequently describe scenarios where they allow patients to decide what topics to discuss until a patient’s health dictates more explicit talk. This approach is synonymous with the patient-center approach to care “that elicits and privileges the patient’s voice as the most important one in the health care interactions surrounding palliative [and hospice] care” (Ragan, et al., 2008, p. 2). If the bulk of research in thanatology is correct and death and related topics are taboo, failing to guide a patient through the dying process by failing to broach the subject is problematic.

The conversation among Allison, Sonny, and me demonstrates that honesty and directness relate to politeness. In fact, the conversation indicates caring, honesty, and the maintenance and promotion of positive face while remaining polite. Telling Sonny that we will attend his funeral shows respect and liking while demonstrating our commitment
to him. Moreover, the conversation with Sonny helps maintain rapport and trust, both of which the team members work to establish. The quality of Sonny’s relationship differs from that of a newly admitted hospice patient because early in an admission team members actively work to establish rapport and build trust if the circumstances allow. However, as one team member told me, there is not always time to build rapport. “I think that if I walk into a crisis, they're in a crisis [mode]. They're, a lot of times, or most times, when they are receptive to anything and that's when you can start hitting them real hard [with talk about dying and death], or what I call hard hitting, on things and bringing out the Gone from My Site book (this small publication describes the physical signs of dying). Things like that. You almost, you turn into a crisis team.”

However, if a patient’s health is less severe the communication will emphasize getting to know the patient and family and allowing them to guide topics of discussion and approaches to care. Team members respond in ways that mirror these expectations, but simultaneously avoid offering false hope. In the example of the newly admitted patient and her daughter mentioned above, the daughter resisted the presence of the counselor. The daughter repeatedly stated that she did not need a counselor because she would handle her “feelings the way she always did” by pushing them aside. The counselor’s appearance likely symbolized the gravity of the situation and implied that the daughter should experience particular emotions requiring the help of a professional. The counselor’s visit during the first few days of an admission, however, is standard protocol and not usually dictated by the severity of a patient’s illness or assumptions about a family’s coping skills. The daughter’s communication set the stage for members of the
hospice team to communicate less candidly in order to maintain the contract of politeness and face-saving. The night nurse, we learned during the visit, failed at mirroring the daughter’s denial and subsequently asked not to return. Politeness in this example is contextual and with Sonny relational. The context requires team members to avoid communicating in a way that patients and families might perceive as offensive while relational politeness obligates communicators to continue to build rapport while maintaining bonds of trust.

The need for politeness in both examples establishes a foundation for future communication among team members and patients or patients’ family members. As death related topics arise or the dying process brings up emotions and new physical changes, taking steps to normalize such talk early is crucial. Talking about advance directives, living wills, and funeral plans upon admission can serve a similar purpose. Some patients and families, however, resist having these conversations because “they are not ready,” emotionally or physically, believing that death is not close enough to justify such discussions. Allison’s forthright talk about attending another patient’s funeral helped set the stage for talking with Sonny and his daughter about what type of services Sonny wanted when it became clear that death was near.

*Capturing Sonny’s Story – An Eternal Legacy*

The time we spend with Sonny listening to his stories combined with his love for his family prompts Allison to suggest that he make an Eternal Legacy video for them. The content of the video is at the discretion of the patient, but Coastal Hospice provides prompts to aid the process. High school and Community College students come to the
house, record the patient’s message to his family, and then edit the film with music and scanned photographs. Sonny agrees to do the video.

“I don’t know what I’ll say, but I’ll do it,” he tells Allison and me.

“You have great stories,” I say.

“Yeah,” Allison agrees. “Talk about being in the military and owning Sonny’s Place, and how the women at Stouffers teased you,” Allison says, referring to Sonny’s time working for Stouffers when it was a restaurant and not just entrees that you buy in the freezer section of the grocery store.

“Just tell the stories you’ve told us,” I suggest.

“Alright. You know, I remember how when I was a kid, we made a glove out of a paper bag, so we could play baseball in the street,” Sonny says laughing. Allison and I find the paper bag glove less humorous than Sonny, but we indulge his amusement at the memory and encourage him to include that story too. Sonny sounds enthusiastic about making the video and over the next few weeks, he elicits the help of his granddaughter to develop a script. The day arrives for Sonny to make the video and The Eternal Legacy coordinator arrives unexpectedly with two students instead of one and Allison and I are worried about all six of us fitting comfortably into Sonny’s single-car garage apartment. We manage to make room for all of us and begin.

The coordinator gives Sonny some instructions about what is going to happen during the recording, and reminds him they can stop anytime he needs to take a break. They wire Sonny for sound and the Eternal Legacy recording session begins. Allison and I are very excited about getting Sonny’s wonderful stories on tape for his family. Not
long after pressing the little red button on the recorder, Sonny stuns us. The narrative begins as we expected with the story about the paper bag glove, which Sonny again finds hysterically funny. The Eternal Legacy coordinator tries to work from the script by asking questions about the topics he put on paper, but to no avail.

Sonny’s narrative takes a turn for the worst when he begins talking openly and negatively about his ex-wife and her selfish parenting style, and then he begins lamenting the flaws of some of his children. At first, Allison and I look at each other appalled, but as the stories continue, our shock turns to resignation. The goal for creating the Eternal Legacy video was to capture a few of Sonny’s experiences for prosperity, not to leave his family with a reminder of their missteps. We held out hope that the students and their program coordinator could salvage the video with a few strategic edits, but I feared there would not be enough positive, funny or interesting stories to make a video that he could feel proud of or his family would appreciate. What concerned me more was Sonny’s labored breathing. The coordinator noticed too and tried to encourage him to wear the oxygen. She informed him at the start of the session that such equipment was hardly visible on tape, but Sonny refused and continued without the O₂. After an hour, signs of fatigue surfaced. Sonny’s breathing worsened during the course of the taping, forcing him to pause between sentences and his eyes were sagging and watery. By the end of the tapping session, I thought Sonny desperately needed a nap. The coordinator must have noticed his waning energy too and suggested they end. “So,” the coordinator said, “Is there any message or advice maybe, that you would like to tell your children?” Sonny
does not give the interviewer’s question much thought and begins to speak. I hope that he will say that he loves them, but he ends saying, “You’re all good kids.”

The Eternal Legacy video came out well and was much more positive than I expected in light of Sonny’s diversions and negative remarks. Sonny had given the Eternal Legacy creators some photos of him with his children to scan and include in the DVD. They ended the video with one of our personal favorites, a picture we called *Dapper Dad* that showed Sonny from his younger, more robust days dressed in a black turtleneck and a black blazer. The integration of the images helped fill out the video and created the feeling of seamless transitions between Sonny’s stories and commentary. Sonny’s daughter agreed, noting that the stories captured her father’s personality well.

*Sonny’s Steady Decline*

The video session was a success after all, but it marked a turning point in Sonny’s decline. Sonny first began removing his nasal canula during our visits months earlier and the act upset me then. I suspected that he compromised his own comfort for us girls. I told Allison at the time that it upset me, but she told me to let it go because it was what he wanted. I never said anything to Sonny and I tried to not notice, but it still pained me even though I knew that taking off the tubing was one way he could maintain some control while attempting to minimize the severity of his illness and his decline. What I really wanted was for Sonny to feel comfortable enough to allow this one image of his vulnerability, but I understood this step would require a level of intimacy we had not yet reached. Taking off the nasal canula during the hour-long visits, however, became increasingly problematic when they started to hinder Sonny’s ability to think clearly.
prompting him to do things like make derogatory comments about people, usually women, on the television. The offenses were minor and never directed at any of Sonny’s team, but it was clear that Sonny’s filters were down and Allison and I wondered if this behavior was indicative of the ‘real’ Sonny or if the lack of oxygen caused some delirium. There were times when Sonny had difficulty recalling conversational topics and staying on track and I attributed those moments to decreased oxygen in his blood, but more than anything, like the effects of alcohol, the lack of oxygen freed Sonny to speak his mind. He could wonder aloud about the meaning of particular events in his life.

Listening to Sonny I was left with the impression that he did not have unfinished business with his second ex-wife as his Eternal Legacy session hinted because he never expressed any interest in confronting her. He accepted that marriage did not suit him, but he did ask, rhetorically, if he was ever destined to know true love. His failed marriages then were reminders of a lost opportunity at true love rather than occasions to wrap up unfinished business with his former spouses. I think Sonny felt good about the time he spent with his children, but I also think he frequently contemplated whether he had done enough for them. Furthermore, bad-mouthing the mother of his children and questioning why he had to make so much effort raising them when she made none was one way to draw clear distinctions between his efforts at parenting and her apparent lack of concern. Sonny had grievances as well as questions, but speaking them aloud unburdened him even if he would never fully understand why and gave him the opportunity to restory his life.
Sonny offered to show us the CD, forcing Allison and me to confess that we watched it before turning it over to him. Watching the video was a preemptive move on our part to prevent any unwanted public display of emotions. I did not want to cry in front of Sonny, nor did Allison. From this moment on, I began watching Sonny very closely for signs of his decline. My fieldnotes from March always begin with a description of Sonny’s physical appearance and breathing: puffy cheeks and labored breathing. This may sound ridiculous, since I knew from the moment we met that Sonny would die, but now we were friends, I was his big girlfriend (I learned this from one of the male Home Health Aids) and his death would surely cause me pain. My sense of our friendship, sadly, still did not prevent Sonny from taking off his oxygen each time we arrived and it did not make watching him struggle to breathe through pursed lips any easy either. Instead, he would puff on his inhaler to give him some relief during our visits. We continued talking about the race for the White House and other topics in the news, but Sonny participation in our conversations declined with his health.

One day I noticed Sonny referencing a piece of paper when initiating stories about things he wanted to tell us. He was having a difficult time remembering things and took notes throughout the week in anticipation of our visits. He was also checking another piece of paper he kept concealed under a towel. I could see what looked like hash marks on the small sheet of paper and I surmised that he was tracking his inhaler treatments, and checking the time to pace them to get the most from each dose. I learned that by using the inhaler too frequently the medication will eventually fail to offer relief. Sonny may have
thought taking off the nasal canula covered for his illness, but he was giving away his decline in other ways.

**Searching for Clues**

I have been visiting Sonny for almost four months now and before each visit I wonder what Sonny might want to discuss. In the past we have talked about everything from the Democratic candidates for President, to wars (past and present), women, lost love, and horseracing. Now I focus less on what we might talk about and move on to searching for clues that might tell me how many more Thursday mornings we will share. I realize that I have no idea what to expect because I have never experienced a death caused by emphysema. I do not know what the signs are and I am beginning to wonder and worry if suffocation and all of the fear of oxygen deprivation will constitute Sonny’s death. Allison and I walk through the gate and into his small studio-garage. Sonny smiles when we arrive, but today he is not beaming the way that I have come to expect. His blue eyes still sparkle, but they look heavy. “Is there anything else you need?” Judy inquires, packing up her blood pressure cuff.

“There’s nothing more you can do for me. Except for this thing,” Sonny says as he points to the nasal canula he took off a few minutes after Allison and I arrive. Sonny exhales slowly through his pursed lips. *His difficulty breathing is getting worse, I think to myself.*

I am simultaneously sad and taken aback by Sonny’s statement. My initial reaction is to think he is talking about us, the members of his hospice team, but then I realize that is not what he means. Allison’s nonverbal response, the way she shifts
forward in her chair, tells me we share the same train of thought. Sonny’s nurse, Judy, is not. “What, you don’t like us anymore, Sonny?” Judy says, making light of Sonny’s frustration. Her comment halts Sonny’s thinking and leaves little space for him to share his concerns with us.

“No, no, that’s not what I mean,” Sonny says, with little expression in his voice. He tries to pick up where he left off before Judy’s comment. “Going to the bathroom is a pain,” he says drawing out the word pain for emphasis. He points towards the door that leads to the main part of the house reminding us of the walk he must take to get to the toilet. Judy jumps into problem solving mode and interrupts, “Well do you have a urinal?”

“Yeah.”

“Do you use it?”

“Yes, I use it at night.”

“What about your port-a-potty? Do you use that?” Judy asks, pointing to the crude device.

“I don’t want to have to clean that thing out,” Sonny says, with some aggravation in his voice.

“Maybe you could have your daughter do it for you?”

“I’m not going to have her do that,” Sonny says, looking disgusted by the thought. “She works full time. I’m not going to ask her to do something like that.” Now Sonny sounds irritated by the suggestions.
I feel like a spectator watching Judy and Sonny interact. Judy’s persistence is beginning to make me feel uncomfortable. Sonny does not want solutions to his problems; in fact, Sonny’s demise is impossible to solve.

“Okay, okay,” Allison says trying to end the back and forth between Judy and Sonny. The subject shifts to something more light hearted and Judy takes the opportunity to leave for her next patient, which means Allison will have a chance to check on Sonny’s mental well-being. I am wondering if Allison will return to Sonny’s comment about his long oxygen tubing.

“Sonny,” Allison says, “I’ve never heard you say anything like, ‘there is nothing more we can do for you.’” I am relieved that Allison has returned to Sonny’s comment despite Judy’s earlier diversion. We are sharing the same wavelength. I look to Sonny, eagerly awaiting his response.

“I’m sorry I said that. I didn’t mean to suggest that I didn’t appreciate you girls visiting. What I meant was that I just can’t do much anymore. I have to drag this thing around,” Sonny says as his shakes his oxygen tube like a dog’s leash. “No, you’re an inspiration to me. I look forward to when you come around.”

“I didn’t take what you said as a slight,” Allison says. I silently nod in agreement, as I realize Sonny is coming to terms with the progression of his disease, his growing dependence on oxygen to maintain his quality of life, and the approaching end of his life. At this moment, I realize the importance of hospice’s presence in helping Sonny make sense of this experience.
More than a Threshold, a Vestibule

I walk into the conference room where IDT is this week and look for a seat that will not get me into too much trouble. Allison and I have been spending so much time together that we have our inside jokes and she likes to write me notes during meetings and although they are usually work related, I have the feeling she is under scrutiny during IDT and the last thing she needs is for my presence to draw attention to her. I decide to sit next to Grace, one of the Home Health Aids. Grace is a tall, full-sized, platinum blonde whose Italian neighborhood still reverberates in her voice. During one of our first visits together, we visited a woman in her forties with Huntington’s disease and I found Grace gentle and agile. The latter is not always the case for someone with Grace’s build. Yet, every time I see Grace, I think back to a different patient, Mr. Franklin, who started a family owned jewelry business with his wife.

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Arriving at the door of Mr. Franklin’s ranch-style cinder block constructed house on a corner lot, we find the woman of the home looking agitated and maybe a little distraught. Grace notices the woman’s distress right away.

“What’s going on?” she says with her strong Jersey accent. Grace does not bother with the standard introductions just yet.

“Something’s changed,” Mrs. Franklin says.

“I could tell something was up when you opened the door,” Grace replies.

As the woman reports on her husband’s status, Grace just nods as we stand at the threshold of the house. Still standing in the doorway because Mrs. Franklin has yet to
invite us in, Grace and I tower over the patient’s wife, and I wonder if we come across as strong, competent, and there to help, or just intimidating. I am impressed with Grace’s swift and astute observation of the scene with such little information to work with. The only information Grace had was a facesheet with the patient’s address, demographics, and diagnosis. The administrative staff who give Grace her patient list have instructed her to give Mr. Franklin a shower today. Other times Grace does not know which Activities of Daily Living (ADL) she will assist her patients with until she arrives at their homes. Today, we know very little about the status of Mr. Franklin’s illness contributing to the level of uncertainty about what we can expect when we arrive.

Mrs. Franklin’s story does not offer any clues about what happened to Mr. Franklin and Grace takes advantage of a break in the story to move the visit forward, “Well, why don’t we come in and see what’s going on.”

“Oh, yes please come in.”

Standing in the foyer, I look around and feel confused by the layout of the home. Usually a caregiver’s stance will give away where the patient might be in the house, but Mrs. Franklin’s worry, maybe even her feelings of fear, hinders my ability to pick up any indication of where to go. She begins to direct us to the kitchen and not the master bedroom where her husband lies dying.

“Why don’t we see what is going on with Mr. Franklin. Why don’t you take me to where he is,” Grace says, trying to guide Mrs. Franklin.

“Oh okay. He’s in here,” she says, pointing over our shoulders. We all do an about face to follow the patient’s wife to the master bedroom.
Almost as soon as we reach the threshold for the room, Mrs. Franklin switches on the light. A small bulb set behind a square opaque white glass fixture in the ceiling comes on, yet the room remains dimly lit. “You don’t need to do that. We don’t want to disturb Mr. Franklin,” Grace says.

“Oh okay,” Mrs. Franklin says, switching the light to the off position. Stepping into the room, I expect to see Mr. Franklin in a hospital bed, but instead he lies in a king-sized bed, which is far too large for his frail frame. His beard looks rough like salt and pepper colored bristles on a broom. I notice the bed is very low to the ground, too low for caregivers who might need to change diapers and give bed baths safely. I know this is a concern for Home Health Aids whose responsibilities are the most physical of all the team members. They spend the majority of their time standing, stooping and bending over patients. Sparsely furnished, the master bedroom houses a dark wood bureau and two nightstands flank the bed. With help from a rare overcast and drizzly day, the room is awash in gray and the scene is quiet and peaceful.

As Grace maneuvers around to the side of the bed the patient faces, the wife offers to draw the curtains to let in some natural light, but as she reaches for the cord Grace stops her and says, “That won’t be necessary. He’s grinding down and we don’t want to bother him.”

Grace’s assessment of Mr. Franklin captures my attention. I get the impression Mrs. Franklin noticed this change in her husband as well, but did not have the vocabulary to describe what she observed.
“Are you sure?” the wife offers again almost disappointed she cannot offer some help.

“No, that won’t be necessary,” Grace says, her accent more pronounced with words like necessary.

Grace introduces herself to Mr. Franklin and asks if he would like a shave. She explains to Mrs. Franklin that sometimes men do not want a bath, but do prefer a shave. Mr. Franklin’s responses are barely audible; he is grumbling and I cannot make out what he is saying. Grace translates for us, claiming that he refused the bath, but agreed to the shave. Grace asks Mrs. Franklin if she has the supplies necessary for a shave and she replies by eagerly moving to the bathroom. The bathroom is pink and tiny. Grace picks up the washbasin, a washcloth, a razor, and the hospice issued soap and turns on the water. I feel a bit helpless and I think Mrs. Franklin does too. Grace turns and looks at me over her right shoulder and tells Mrs. Franklin that she has everything she needs. I take this as a cue and offer to talk with Mrs. Franklin in the other room while Grace works.

I follow Mrs. Franklin to her kitchen table. She offers me coffee, which I decline out of politeness and fear of being served instant coffee. As she drinks her coffee, we talk about her family. She and her husband are in the jewelry business and her sons work there now. I learn that Mr. and Mrs. Franklin have been married almost twice as long as I have been alive, that one of her sons died last year of a massive coronary following a fishing trip, and she has a beloved great-granddaughter. Not surprisingly, she is distraught over the imminent death of her long time partner. She tells me about the fond memories of their time together as we sit. Her talk is part life review, but also a type of
anticipatory grief work. I can hear in her voice an attempt to project optimism about her future without her husband. She shows me her jewelry, her custom-made wedding ring is a source of great pride and then retrieves a thin string of delicate pearls she is repairing.

I listen and only ask questions when I need some clarification or if I think my question might bring about a happy memory or take us down a path lined with pride or joy. The death of Mr. and Mrs. Franklin’s son is a sad and unexpected revelation only exacerbated by the thought of the pain Mrs. Franklin must feel as she contemplates her husband’s pending death. In just an hour, Mrs. Franklin reveals some of the highlights from her life. We look at photos of her family and she talks about her children, their spouses, and her grandchildren as if I have known them for years. Interspersed among the photos of her family are a few pictures of Mrs. Franklin and her husband before he got sick. I realize that had I not identified her in the snapshots, I probably would not have recognized Mr. Franklin because the internal ravages of cancer are not yet visible. She shows me a photo, probably taken at Sears or Wal-Mart’s portrait studio of her great-granddaughter wearing a Christmas dress. “Look at her blue eyes,” I say.

After Grace finishes Mr. Franklin’s shave and comes to the kitchen table to sit with us, she gets an abbreviated version of Mrs. Franklin life story and skims through the photos. I know that Grace has a tight schedule to keep, and so I do not interject any questions or prompts that might elicit any more stories. Grace explains that she will discuss with the nurse what she saw today. Mrs. Franklin tells us that the nurse was there yesterday and all of her family visited last night. Grace encourages her to have the family
around as much as possible, but never explicitly tells Mrs. Franklin that she thinks her husband is very close to death.

To close out visits, Home Health Aids chart their care, but not electronically like the other team members. Instead they use hardcopy triplicate forms, which Grace completes and asks Mrs. Franklin to sign. “This form just says that I have been here and that I gave your husband a shave,” Grace says, turning her clipboard towards Mrs. Franklin to sign. We get up from the kitchen table and walk towards the front door. As we say goodbye I lean over to give Mrs. Franklin a hug. “It was nice talking to you,” I say.

“You too, and good luck with your studies,” she replies.

I feel bad about swooping in and leaving so quickly. The house suddenly seems bigger now than when we first arrived, which makes me think about how lonesome the dying experience is for caregivers too, especially when death nears. I imagine that in the past, Mr. and Mrs. Franklin could work in different parts of the house and not feel alone. The couple probably spent many hours of their marriage making and fixing jewelry together content even in silence, but now I wonder if those feelings of security exist for Mrs. Franklin anymore as her husband of 60 years transitions from this world to the next.

Grace and I get into her car and I sit in silence as I wait for Grace to settle. She shuffles some papers around on her clipboard and places a call to Mr. Franklin’s nurse as we sit in the driveway with the car running and the windshield wipers flapping. Grace tells the nurse about the chain of events and then hang-ups. The nurse, she tells me, will see the Franklin family later today and determine if Continuous Care (24 hours nursing
care) is necessary. As we drive away, I tell Grace how impressed I am with how she quickly assessed the situation and took action and in a matter of fact tone she tells me such skills comes with experience. I ask her to elaborate on the concept of “grinding down” because I have never heard the expression before. She explains that dying is work and elaborates on this idea during our subsequent interview.

There is something very different, spiritually, in the air. Depending upon how sensitive you are, you can feel it. And, there is some truth to getting quiet, to darkening the lights, you know, bringing them down. Taking away familiar things. Like familiar music. A song like, Amazing Grace, for example, is so familiar and I won’t sing it (she says referring to her work with Coastal Hospice’s bedside music program) if they are close, I don’t want to yank them back, so to speak. I wouldn’t say it like that to everyone. You don’t go in when someone is trying to transition and bring familiar things. These things will ground a person. A person can become very restless. It must take a heck of a lot of physical power too, to transition in death. And…they need all of that energy. Um, I have seen people die with the Italian family yelling over the body. I mean, I have. That’s the dynamics of that family. But, um, usually, when they start seeing us coming in and saying to them like, ‘No, you don’t have to turn that light on,’ or, ‘No you don’t need to turn that blind,’ or, ‘I can do this in the dark,’ you know, or they start hearing us bring our voices down and they start seeing us moving a little slower it almost sets a tone.”

Graces pauses to think and continues relating the dying process.

“I don’t know how to describe it, but I think it’s more than a threshold. I think there is like a vestibule and then after that vestibule there is a whatever to pass on to
because I have seen people pass into that vestibule and pull back. Go deeper into that vestibule and pull back. And then get into that vestibule and then you start to recognize, physically recognize, the heart slowing down, the breathing slowing down, the pulse going lower and then they step in, and hopefully [there] can be a fluidity to it and not a yank. At The Hospice that’s what we do try to do. Does that make sense?

“Yes, it does. It’s actually a really beautiful explanation, one of the best I’ve heard,” I respond, understanding fully why she encouraged Mrs. Franklin to keep the lighting in the room muted. A week after we visited the Franklin residence, I read in the local paper that Mr. Franklin died peacefully at home the next day.

Back to the Business of Hospice

As Grace and I chat about her daughter who lives up north, I hear Allison calling my name as she enters the conference room. “I’m going to New York!” she says in a voice reminiscent of kids teasing each other on the playground. “You are,” Grace says, enthusiastically. “Where ya goin’?” she asks increasing the New Jersey in her accent.

“The City. Manhattan.”

“Are you going to go shopping?”

“Yeah,” Allison says as if the answer to Grace’s question is obvious. “We’ll also go to the Museum of Modern Art and stuff like that too. So, we’ll have to figure out what to do with your shadowing. Judy already knows, so maybe you can talk with her about going to see Sonny,” Allison says to me.

“Oh, Sounds good,” I say. I have not clicked with Judy quite the way I have with Allison, so I hope she will allow me to shadow her on Thursdays while Allison is
gone or at least meet her at Sonny’s house for our regular weekly visit. Robin, the team chaplain, is ready to begin the meeting and so I take a seat next to Grace and turn my attention to her inspirational reading.

Today, Robin reads from a pastoral care publication a brief narrative about dying patients’ ability to know caregivers’ feelings and thoughts. She encourages us to make sure we have good thoughts before entering a patient’s home, not just during a visit, because they may perceive any negative thoughts or feelings we may have towards them. The Senior Staff Nurse, Bobbie, tells a story supporting Robin’s message. Bobbie tells us a tale of a person who had a near death experience caused by an auto accident who reported that she could hear all of the negative thoughts of the people who were stuck in traffic. Listening to Bobbie tell this story, I feel guilty thinking back the times when struck in traffic I have said to passengers (or myself), “Someone better be dead up there.” I silently vow to hold a positive thought and pray that no one is hurt the next time I am stuck in a traffic jam. We move from the message to the ashtray affirmation which reads, “To let go is to fear less and love more.” Robin then asks for names for the prayer list. Once everyone makes their requests, Robin says a prayer for patients, families, and the team. Together we say “Amen” and begin the business of hospice.

I notice that Sonny is up for discussion because his hospice re-certification period is approaching. As is standard procedure, the nurses and counselors share information about the New admits. The nurses affirm the completion of the re-certifications currently due and then begin discussing the upcoming re-certifications. Sonny is fifth down on the list. Judy’s assessment is brief. She reads Sonny’s demographic information from her
computerized chart, then looks up in the direction of the team physician, and says, “He’s on \( O_2 \) at 2 [liters per minute], lung sounds are tight and he’s using his inhaler more with less relief. He’s definitely declining. He’s hospice appropriate.”

“Okay,” the doctor says, and we move onto the next patient. I realize once they move on to the next patient on the list that I am relieved my name did not come up this time. I am sure I blushed when Allison announced to the team that Sonny was in my study and then turned a darker shade of red when she told everyone he calls me his, “Big Girlfriend.” The facts of Sonny’s medical status, although accurate, seem separate from the reality of his life. Judy left out that Sonny does not get to go the horse track or the sandwich shop anymore. In fact, he does not leave his room to go outside now and a trip to the refrigerator no more than 15 feet from his chair is too taxing to do more than once a day. If Sonny wants fresh air, a look at the blue sky, or the trees, his only option involves taking in the view from where he sits in his black office chair.

*Pre-Imminent*

I am on my way to the Sunflower team meeting when my phone rings. I look at the small screen on my red cell phone and see that Allison is calling. “Hello,” I say.

“Hi, it’s me, Allison,” she says.

“Hey, what’s up?” I say in an effort to maintain the pre-caller I.D. tradition of surprise that used to come with taking a phone call.

“I just talked to Sonny.”

“Yeah, how’s he doing?”

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“He’s not doing too good. We didn’t talk for long. I just wanted to call and say goodbye before I leave for New York. I’m worried that he might die while I’m gone,” Allison says. My eyes start to well up.

“Uh-huh,” I utter, in an attempt to disguise the quivering in my voice. I clear my throat and continue, “What did you say?”

“I just told him that I was getting ready for my trip and was calling to say ‘goodbye’. I also told him that you were coming with Judy while I was gone,” Allison explains.

“And what did Sonny say?”

“He just said, ‘Alright then. Have fun.’ I think he was tired, but I just didn’t want to leave without saying good-bye, you know?”

“No, totally,” I say.

“I don’t like not having closure,” Allison offers, apologetically.

“Yeah, I’m sure,” I say. “I’ve not done this before – he’s my first patient – so I am not sure what to expect, but I think it’s good that you called him.”

“I tried to ask Judy if she thought he was pre-imminent, but she said she didn’t know,” Allison says, further explaining why she is erring on the side of caution. If a patient is imminent, the nursing staff suspects that the patient will die within 72 hours. Alternatively, pre-imminent is not a technical term and staff are discouraged from using the phrase, but it suggests a marked transition between living with a terminal prognosis, and actively dying.
“Well, I think it’s good that you called him and that you talked with Sonny and his daughter during our last visit about what type of service he wants. Well have fun on your trip and I’ll talk to you when you get back.”

“Okay. Have fun at IDT.”

“Oh, I will,” I say sarcastically. “Bye.”

“Bye,” Allison says. As soon as I close my phone and end the call, I let a few tears fall. I am feeling sorry for myself for the first time since beginning this research project six months ago. Last week, I felt sorry for Sonny and his eldest daughter when they talked openly about Sonny’s final days and funeral services with a type of awareness I had never witnessed before. The poignancy of the moment encompassed a range of emotions from tenderness to sorrow. Their conversation made clear Sonny’s wishes and solidified his daughter’s commitment to help Sonny carry out those desires. I fought back tears then too, but I knew those feelings came out of empathy for Sonny and his daughter. Today, however, I feel sorry for myself as if this is first moment I fully comprehend that Sonny is going to die.

I manage to pull myself together before IDT and I arrange with Judy to meet her at Sonny’s house the next morning. When I turn onto Sonny’s street, I am surprised to see that Judy, who is usually very prompt, is not here yet. I decide to sit in my car listening to the news on National Public Radio to burn time as I wait for Judy. I feel a little anxious today because Allison is not here to act as my guide, but also because I have some trepidation about Sonny’s appearance. I speculate, as Sonny gets closer to death, if he will begin to look like a drowning man without the water – conscious and aware that the
desire to breath overwhelms his ability. In my rearview mirror, I see Judy’s mini-van pull around the corner and my anxiety begins to subside.

We enter Sonny’s garage apartment together and his labored breathing immediately catches my attention. Sonny’s shoulders curl forward and he must use his belly to move air in and out of his lungs. He smiles at us and says hello, but turns his attention back to breathing.

“How ya’ doin’ today, Sonny?” Judy asks.

“Oh, I’m okay,” Sonny says. He is really not okay, I think to myself, but what other words could he possibly evoke. I suppose he could report that he cannot breath and it sucks, but this is the course of terminal emphysema and there is little medical intervention available to alleviate his discomfort. What hospice can offer medically – oxygen, inhalers, narcotics, and anti-anxiety drugs – only provide short-term relief, if any at all.

“Are you in any pain?” Judy inquires.

“Not really. My back is hurting a little bit, though,” Sonny says. This is as close to a complaint as I have ever heard from Sonny.

“How would you rate your pain on a scale from one to 10, with 10 being the worst?” Judy asks.

“Oh, I don’t know, maybe a five or six,” Sonny offers.

“When was the last time you took a pain pill?” Judy asks in an attempt to gauge how effective the narcotics are at relieving Sonny’s pain.

“Just before you girls got here,” he replies.
“Okay, good. So it should be kicking in pretty soon,” Judy says. “You know, you’d probably feel more comfortable if you laid down,” referring to the hospice issued twin sized hospital bed.

“I’m fine here,” Sonny says, turning down Judy’s suggestion.

“You could adjust it so you could still see the television,” Judy adds.

“No, I’m okay here. I like my chair.”

“Are you sure? Because I think you would be more comfortable in the bed; it would give your back some rest,” Judy reasons, hoping to persuade Sonny.

“I’m okay here. Besides, I just got out of bed. Why would I need to get back in it?” Sonny says, in one last attempt to fend off the suggestion.

“Okay, then. Let me listen to your lungs,” Judy says, not pursing the topic any further.

Sonny’s resistance to getting in the bed makes sense in light of its connotation. According to hospice staff, it is common for patients, especially men, to resist getting into a hospital bed. As one team member explained, “I always call them electric beds. They equate hospital beds to being very sick. Once you get to that bed, you're to the bed. You're in the bed and you're never going to get out.” Although Judy was aware of this sentiment among patients, she nevertheless attempted to appeal to Sonny’s physical well-being. However, consistent with Sonny’s resistance to using his nasal canula, he refused to get in the bed as a show of his strength.

Judy finishes taking Sonny’s vital signs and checking his medications when Sonny’s daughter, Katie, comes into the room. Katie is a grade school teacher and is
home from work for Spring Break. She asks her dad if he needs anything, and when he declines, she asks Judy how he is doing.

“He’s doing okay, except his back is bothering him. I told him getting in the bed would probably be more comfortable, but he won’t do it.”

“I know, I know, but he doesn’t want to do it. He’s always been stubborn. Haven’t ya’ dad?”

Sonny looks up at his daughter and just smiles. We keep the visit under an hour today since Sonny’s breathing makes it difficult for him to reciprocate. In a three-person conversation, Judy and I did most of the talking. The extent of our discussion centered mostly on Allison’s absence. Judy and I made a few jokes at Allison’s expense allowing him to communicate nonverbally. We close our visit with our standard Hospice Hugs. I move in to embrace Sonny, and I can see him trying to lift himself out of his chair and I tell him he does not need to do that because I can bend over. I give him a hug around his shoulders and he puts his arms around my waist. “I’ll see you next week, okay?” Saying those words aloud, I wonder if I have any reason to believe their veracity.

I follow Judy to the local grocery store where I will leave my car while we visit her next patient. We stop into the store and get a few things for lunch. I follow Judy to the produce section and ask her what Sonny’s death might be like.

“What’s going to happen to Sonny? I mean, I’ve seen people die of cancer, but I have no idea what to expect with someone who has COPD,” I ask, not sure I want to know the answer. I have conjured up such a terrible image of what might happen to
Sonny in the moments before he dies that I am surprisingly nervous about Judy’s response.

“He’ll lose consciousness and his breathing will slow down and then eventually stop,” Judy tells me in a matter of fact tone. We reach the section of the store with pre-made salads, fruit bowls, and veggie trays. Judy searches through the salads for one she likes. I feign looking as well. I glance up from the refrigerator case and say,

“Oh, good because I was worried he would suffocate to death, which sounds awful. What you’ve described sounds better.”

“Yeah, I’ve not seen a COPD death either, but that’s what I’ve been told happens,” Judy adds. “Do you have any of the salads with strawberries,” she asks the produce man. As they negotiate the type of salad Judy wants, so he can make one to her specifications, I continue searching through the case for a salad with the right combination of lettuce and vegetables and I feel foolish for worrying about Sonny’s death, especially since Judy is so matter of fact. I realize this is in her nature, she was a surgical nurse, and Allison has always said that nurses are very black and white, but for me Sonny’s death is a big deal. He is not one of a 100 patients, or in my case research participants, he is my first long-term study participant and one of the closet hospice bonds I have. For everyone else, Sonny’s death is not unique. Judy’s reaction forces me to reevaluate my feelings and I question if I am unnecessarily worried about how he will die. On the other hand, I find having facts comforting and I can see how helpful information is for patients and families as well. As a result, I am less worried about Sonny suffering during his final moments.
Judy has the salad she wants and after a stop at the salad dressing aisle, we are ready to check out. Judy offers to pay for my salad, but I refuse by handing her a five-dollar bill. Walking to Judy’s vehicle, we talk about the next patient whose name reminds me of a candy bar or snack cake. Sonny is still on my mind, but it is time for me to shift my thinking from him to the next patient and I want to get the update before we arrive since I have not seen this patient for many months.

_How to Say Goodbye_

It is a new week and I am going to meet Judy at Sonny’s house. As I pull around the corner, I do not see Judy’s vehicle, instead, I see a fire engine and note that Sonny’s garage door is up. My heart begins to pound forcefully in my chest. Inching closer to the house, I see the fire engine pull away and round the corner. I take a deep breath to calm my nerves and tell myself the fire department did not visit Sonny’s house, but a neighbor’s. The garage door remains open and I decide to hang back to avoid drawing any attention to myself. I do not want Sonny or his daughter to see me for fear they will invite me in (I am not supposed to visits patients without a hospice representative). Judy pulls up a few minutes later and Katie, Sonny’s daughter, meets us outside. Katie wants to talk with Judy about her father’s decline. She tells us that most of her siblings are coming to town this weekend. I glance over Katie’s shoulder and I can see Sonny looking at us. He waves to me and so I excuse myself, telling the two of them, “I am going to talk with Sonny so the two of you can keep chatting.”

I enter through the garage door, instead of the side door. “Hi Sonny,” I say, as I walk into the other room where my shower chair hangs. I watch him as I walk by and
notice that his breathing is even worse than last time. I did not think it could get worse, yet is has and I am surprised that he is able to sit upright at all. He purses his lips together like a woman in labor, but the intensity of each breath is much different than the quick Lamaze breaths. I take a seat on my chair across from Sonny so I am easier for him to see and make eye contact. “There was a fire engine outside when I got here,” I say. I notice that I can see Sonny’s bare knees. He always wears sweat pants, but today, I can see that he has a towel across his lap.

“Yeah, I guess one of the older women in the neighborhood fell or something.” Sonny says.

“I thought maybe they were here when I saw your door open,” I say, offering a little confession.

“No, I just wanted to get some fresh air. The trees are so green,” Sonny says haltingly.

I look outside and take in the lush green of the trees’ leaves. I wonder how I missed the explosion of greens that marks the transition from winter to spring.

“They are green, aren’t they,” I say. “And look at how blue the sky is.” I add. “I have always thought the sky is bluer here than anywhere I’ve ever been. I’ve heard, from my grandmother, who used to live there, that New Jersey is really gray,” I say, referring to Sonny’s native state. We sit in silence for a few moments and gaze outside. Sonny is becoming restless as the conversation between his daughter and nurse continues on the sidewalk.

“Are they still talking out there?” Sonny asks.
“Yes,” I say. “I heard your family is coming to visit,” I add, hoping to distract Sonny for a few moments longer.

“Yeah, I think everyone except my daughter who lives in California is coming to visit. I don’t know where they’re going to stay.”

“Oh, I’m sure they have it all worked out,” I say. “Do you want me to go get them?” I offer, realizing I did not successfully placate Sonny.

“Yeah, tell Katie I need her,” Sonny says.

“Okay,” I say, hopping up and walking down the driveway to where Judy and Katie stand. The two come back and Katie says, “What cha need, Dad?”

“I need some more water,” he says pointing to his green plastic water cup.

“Anything else? Do you want something to eat? Are you hungry?”

“No, just some water.” Katie takes the cup and walks from the room to the kitchen looking at Judy and me out of her peripheral vision as she passes. I take Katie’s look as a silent message that communicates an awareness that the request for water was nothing more than an attempt to get her to come inside.

Judy begins with her standard assessment and medication check and ends the visit by asking Sonny if he needs anything else before we go. Sonny asks us to help him get on the scale so he can weigh himself. I think this is an odd request, but Judy and I try to help him on the scale. We each take an arm and as his pushes up with his legs, and we pull up on his arms, the towel he had spread across his lap begins to fall. Seeing Sonny’s white briefs makes me a little uncomfortable, but not mortified because I consider this as a byproduct of illness – people become more dependent and less concerned about any
previous inhibitions. What is more disconcerting about Sonny’s exposure is that the garage door is still open and any passerby could see him partially clothed. Placing his feet on the scale for a few seconds, Sonny steps back down on the ground and returns to his desk chair. I do not catch a glimpse of the reading on the scale, but Sonny grumbles his disappointment with the number, yet I am not sure why. He carefully smooths the towel back down across his lap and focuses straight ahead.

“Okay, well I guess we’re going to get goin’ then,” Judy announces. “You have the hospice number if you need anything over the weekend.” Sonny nods in response to Judy’s comment about reaching hospice.

“Have a nice visit with your family,” I tell Sonny. “See you later, okay. Take care,” I say reaching over to give Sonny a hug. What an idiot I am, I think. Since talking with Allison before her trip and in light of last week’s visit, I did not want to miss an opportunity to say a final goodbye. I also wanted to say something much more profound because I am acutely aware that Sonny is closer now to death than ever, except I could not conjure up a message that would not sound too sappy or absolute. “Bye,” I say, waving to Sonny as I walk out the garage door.

Tears for my Hospice Guy

My cell phone rings as I walk across campus back to my office following a meeting Monday afternoon. I can see Judy is calling. Judy told me on Thursday before we left Sonny’s house that she might visit him again – earlier in the week than usual – since he is declining, so I am not surprised to see her name appear on the screen. In the
split-second it takes me to flip open my phone to receive her call I know she is not calling
to confirm our visit time. Judy is going to tell me that Sonny died.

“Hello?” I say trying to sound cheerful even though I know bad news is coming.

“So, I guess you already heard that Sonny died on Sunday?” Tears immediately
come to my eyes. I slow down my pace to avoid stepping into the on-coming traffic from
the parking garage. I find it is odd that she would assume that I already knew, but I do not
bother to question her about this. Instead I just say, “No. I didn’t know that. Oh, poor
Sonny. Did he get to see his family?”

“Yes, they were all there and had a chance to visit him. Katie said he died
peacefully on Sunday with everyone there.”

“Is there going to be a service?”

“No service is planned yet. They are thinking of waiting until the summer, closer
to his birthday, when everyone is out of school to do a service. Also, Katie wanted to
know who she should contact to send them a letter about you. She wanted to know if you
had a supervisor or something at the school she could contact to tell them how well you
were doing.”

“Really, okay. I can bring the information to the team meeting. I’m glad he had a
chance to see his family. Thanks for calling, Judy. I’ll see you on Wednesday,” I say
referring to the weekly IDT meeting.

“Okay. See you then.”

“Bye.” I hang up my phone and immediately begin to cry. By the time I make it
back to the office I have managed to turn off the water works, but I know that I could
burst into tears again at any moment. I walk down the hall towards my office and hope I do not run into anyone who will try to comfort me with platitudes. I see that my friend Tony, who only comes to campus to teach now that he is working on his dissertation, has his office door open. He is talking with a new Ph.D. student, Emily. Uninvited, I come in and plop down in one of the empty chairs. “Is everything okay?” he asks. Unable to speak, I shake my head no. Emily stands up and closes the door. “Oh no. What happened?” he asks, the tone of his voice changing from concern to sympathy.

“My hospice guy Sonny died,” I blurt out. The tears begin to flow heavily and freely.

“Oh no. I’m sorry,” Tony says reaching out to hug me. He steps away and the deluge of tears lifts long enough for me to speak again.

“I feel like an idiot for crying. It’s not as if I didn’t know how it was going to end, you know? It’s just so sad,” I add trailing off at the end of the sentence because I have started to cry again. I sniff loudly trying to keep the snot that has suddenly formed from sliding out of my nose. “He was just my first death, at least the first person in my study who I was kind of close to, you know.”

“Oh Jillian, I hate to see you so upset. Wouldn’t it be easier if you just study something like reality TV?” Emily says, referring to her own research interests.

“No! Probably. I don’t know,” I say I laughing at the thought. “Sorry to come into your office and just start crying. Here you were talking and I just barge in with my crap.”

“You don’t have to apologize,” Emily says. “We were just chatting anyway.”

“I’m sorry,” Tony adds, as I get ready to stand up.
“Thanks,” I say. He gives me another hug and I leave.

On Wednesday at the end of the team meeting, I know Sonny’s death will appear on the roster and Judy will share the details with the team. I am worried I will start crying again, but I do not learn anything more than what she told me on the phone earlier in the week. In the weeks that follow, I suggest to some of the team members who knew Sonny that we should all go to the horse track and place a bet in his honor, and although people thought the ritual was a good idea, no one followed through on the suggestion. Four months after his death, Allison and I were able to carry out our pledge to attend Sonny’s memorial service at the Veteran’s cemetery.

After the uniformed Veteran’s Administration staff folds the American flag and once the sounds of *Taps* no longer lingers in the air, we walk over to the spot where Sonny’s cremains will rest. Family members place flowers on top of the red, white, and blue box holding Sonny’s ashes. Allison, Judy and I stand back silently watching the scene. I look up from the small hole in the ground and visually absorb the cemetery grounds. The grass looks freshly mowed, and although I cannot see the blue sky because of a light drizzle, I notice that huge trees with deep green leaves serve as the backdrop for Sonny’s burial plot. And just as I promise, I have my hair back in a ponytail, the way Sonny liked it.
The relationship I developed with Sonny over five months left an impression on me and I noticed that it framed how I felt about my interactions with new hospice patients. Upon meeting new admits, or during a first meeting with an existing patient, I looked for the same qualities that Sonny had. So when I met Helen, I thought I might have found another hospice friend.

Allison and I arrive late for our first visit with Helen. Our being late, I am sad to say, is common. Sometimes I am late; other times the delay rests on Allison, other times we blame the Starbucks drive-through, it depends. Patients eventually come to expect our tardiness, but I notice that most often the patients attribute our chronological challenges to Allison and never me. I am not sure why this is the case, but I suspect my student status mitigates any responsibility. New patients, however, do not know what to expect and this is probably why I am worried about being late today.

I previously visited the Lexington, an adults-only apartment complex, with the team chaplain and a Home Health Aid. I thought then, and still think now, that living at the Lexington would not be too bad. The apartment complex for seniors is equipped with a pool, a community coffee room, a library, and a mini-market. I have not visited the Lexington in months and in the interim (according to a team member’s report at an IDT meeting) someone burglarized the little market on the first floor. The Home Health Aid concluded that homeless people, not the residents, committed the act of theft. I never
considered the Lexington’s neighborhood good or bad, but the Home Health Aid’s report forces me to reconsider my initial thinking and it occurs to me that the Lexington is an oasis from the drug dealers and gunfire a few blocks away.

Pulling into the long driveway leading to the complex, I look to the right at another familiar apartment complex and my thoughts drift back to a patient I met once days before the start of the new year. Mr. Johnson, who was in his 80s, was dying of cancer. I remember Mr. Johnson and his meek black lab mix. The dog, I learned, was spending more and more time at the foot of his sick bed. I also remember that during this visit the counselor discovered that the woman she thought was Mrs. Johnson was not the patient’s wife, but a long-time companion. More interestingly, the woman used to be the wife of Mr. Johnson’s best friend. These factors, however, did not make Mr. Johnson memorable; the stories he told about his work as a chauffeur made him unforgettable. He drove some of the most famous “colored” people of the times including Esther Rolle, Miles Davis, and Cicely Tyson who he described “as black as the ace of spades.” I tried to not let the words irk me, but as a bi-racial woman with a café au lait complexion, hearing the phrase “colored people” and its other antiquated variations, involuntarily maked my skin crawl from the inside out. I hoped my visceral reaction remained invisible. I tried to rationalize his use of the phrase as not only generational, but possibly a misreading of my mixed ethnic identity and thus somehow less offensive.

Following the visit, Allison apologized. I told her not to worry about it because I expected something like this would happen at some point during my observations, I just did not expect it so soon. (I had only started my observations two-weeks earlier.) We
agreed the use of the term “colored” was generational and not intended to offend me.

Allison further surmised that Mr. Johnson needed to share those stories as part of his dying process. What surprised her was that in all of the time she worked with Mr. Johnson, he never mentioned any of his time as a chauffeur or his encounters with the rich and famous. The disclosures were mysterious and timely.

During the visit, Mr. Johnson told us that he wanted to live to see his next birthday in mid-January, but recognized he would have to settle for living long enough to see the New Year. Mr. Johnson told us he was ready, that he had it all figured out, “up here,” he said, tapping his temple. He had worries about how his daughter might cope after his death, he wanted to make sure she would be okay, but otherwise Mr. Johnson described his affairs as being in order. I wondered then and still question now, six months and many patients later, why Mr. Johnson told the stories of chauffeuring Florida Evans, the Prince of Darkness, and Miss Jane Pittman. I cannot help but think that my presence somehow motivated Mr. Johnson to share those stories, especially since his counselor never heard any of them.

Throughout my fieldwork, I frequently contemplated whether my role as a researcher evoked such disclosures and encouraged people to offer the most interesting events from their lives. Mr. Johnson’s occupation did put him in contact with some prolific and influential people and I suspect this was part of his motive for sharing. He probably thought a young black woman (he did not know that I am also white) would find his experiences impressive, not to mention that the stories created a connection we might otherwise not have. I can only speculate, but whatever the motive, I did not
begrudge Mr. Johnson for sharing or even using archaic language; instead I felt honored to have learned about his experiences and his brushes with such historical figures. At the team meeting, the following week, I learned that Mr. Johnson died after hearing celebratory fireworks, just a few minutes after midnight on January 1st, four days after our meeting.

I pull my thoughts away from Mr. Johnson and back to the new patient visit. Allison briefs me on the patient we are about to see. “Helen Holyfield is 73, I think, with COPD,” Allison says, trying to recall the patient’s demographic information. “She just moved here from the east coast to be closer to her daughter.” “Okay,” I say and take one final sip of my grande iced-coffee knowing it will taste terrible by the time we return to the car. (I want to get my money’s worth.) Reaching for the car door handle, I see a woman with a tan that resembles orange nagahide dragging a small poodle like dog with mated white hair. For a moment, I think that I am in a scene from Ben Stiller’s film, *There’s Something About Mary*.

“Oh, my,” I say. “Look at that. I think she was walking that dog the last time I was here.” I feel bad for the commentary, but this woman is an amazing sight and Allison obliges my mockery.

“She’s probably been walking the dog the whole time since your last visit. Someone has a little sun problem and needs to go to a Meeting,” Allison says referring to Alcoholics Anonymous.
Changing the subject, Allison reaches into the backseat for her laptop and says, “We’re going to 217. There should be a hospice wheelchair, a dog statue, and some flowers out front.”

“Okay, 217,” I parrot back in an effort to commit our destination to memory. We walk through the entry to the elevator. Every time I visit an apartment complex like this I am left wondering how all of these old folks would get out in the event of an emergency. A single slow moving elevator will surely impede evacuation.

Fake potted flowers with a gel substance meant to mimic water adorn a table in the center of the lobby; they are for sale and I threaten to buy one for Allison. I notice the mini-market is closed, but there are a few folks mingling in the coffee room. The door to the elevator opens and a woman with a three-pronged walker steps out. She looks up and says hello. “Hello,” Allison says. “How are you today?”

“Good, thank you.”

“Have a nice day,” I say, closing the loop on our interaction. We are like a regular Coastal Hospice greeting party. Allison and I get off the elevator and I repeat the apartment number. We assuredly walk down the hall, passed the library and a piano, but as we pass a major corridor I begin to wonder if we are already lost. “You did say 217, right?” I ask.

“Yeah, it should be right up here. See there’s 210 and 212. The numbers are getting bigger.”

“I think I see a wheelchair.” We walk up to an apartment with a bird clock on the wall. “Are you sure this is it?”
“Yeah 217.” Allison knocks and I am nervous, but not because it is a new visit. I am worried we are at the wrong apartment – none of the identifying markers sits out front, but the number matches. Allison and I have joked about showing up at the wrong house like a couple of Grim Reapers. Over the past eight months, we have never accidently arrived on the wrong doorstep. There is no answer and I suggest we leave.

“Didn’t you say earlier that there would be a hospice wheelchair out front? And flowers and a dog statue? There’s only a clock. Let’s go before someone comes to the door,” I say anxiously.

We start to walk back down the hall and Allison checks the facesheet one more time. “Yeah, there should be a hospice wheelchair out front and she said flowers and a dog statue when I called to schedule the visit. It’s 207, not 217,” Allison states, after double-checking the information provided by hospice.

Retracing our steps, we finally find the correct apartment with all of the identifying markers in place. The dog statue holds a sign that says, “Welcome.” We were behind before, but our little stroll around the 2nd floor of the Lexington makes us even later, which means we will have to delay lunch, maybe even cut it short so we can make our afternoon appointment on time. I can feel my body is nearly finished metabolizing the FiberOne bar I ate on the way to Allison’s place this morning.

Allison raps a little tune on the door and we wait. We hear the quick pattering of footsteps on the other side of the door and then silence. The door flies open and a thin woman wearing white bobby socks, a pair of white capris with an elastic-drawstring waist, and a striped jersey knit shirt greets us with a smile.
“Hi, I’m Allison with Hospice and this is Jillian.”

“Oh yeah, I thought you weren’t coming,” Helen says referring to our tardiness.

“Well come on in. I don’t want the cat to get out. I’ve already chased her once. I’m not even supposed to have her. Well, I can have one, but not two and they don’t know about Baby.” We squeeze through the front door both looking down to ensure the cat’s confinement.

I am fond of Helen almost immediately. Her petite size and hospitality (translated: her insistence on feeding us) reminds me of my mother-in-law. Helen’s apartment includes all of the basic accoutrements necessary for living, but it is the second refrigerator that speaks to Helen’s personality type.

“Have a seat wherever you like,” Helen instructs as we walk towards the living area.

“Where do you normally sit,” Allison asks, recognizing that the layout of the room and the limitations of her illness connote that Helen probably has a designated seat. Helen’s breathing reminds me of an out-of-shape person winded after walking up a small flight of steps. The strain is indicative of her illness, but she is not helping the situation by scurrying around her apartment.

“I normally sit there,” Helen says, pointing to the recliner that sits opposite the television. Allison and I take a seat on the deep red sofa to the right of the recliner. I look around Helen’s apartment and notice books stacked and stashed everywhere. There are Dove chocolates and peppermint candies on the coffee table in crystal dishes. A smiling doll sits in the corner on a little wooden rocking chair. Later when we take the tour of
Helen’s apartment to look at family photos, we see another doll facing the wall as if he is counting alligators for a game of hide-n-seek.

“Would you like something to eat?” Helen offers just as my mother-in-law would do immediately after greeting you.

“What cha got?” Allison asks. I would love to eat something, because I feel hunger approaching, but it is not really the time or place to eat and I assume Allison’s reply is really rapport building banter.

“Well I have some left over Sheppard’s Pie.”

“Hmm, I love Sheppard’s Pie,” Allison says.

“So do I,” I say, playing along.

“But, I think we’ll pass. We’ll have lunch later.”

“What about something to drink?” Allison and I look at each other in an attempt to communicate using mental telepathy.

“I’ll have some water,” I say, realizing that a complete refusal will only lead to continuous insistence that we consume something. Not taking anything will probably come across as impolite as well.

“Are you sure that’s all? I’m going to make some tea. It’s only the instant stuff, but I like it,” Helen says, as if embarrassed by her own tastes.

“No thanks, water would be fabulous,” I say. I detect a Southern twang in Helen’s voice that I cannot place. I do not get the impression that she is from Florida but rather some place like Tennessee. I find out later that Helen is actually from the Midwest.
After buzzing around, Helen finally sits down half cross-legged in her recliner. She tells us that she really cannot eat much so she avoids going out to eat and when she cooks, it is mostly for her family. As Helen talks about cooking and her children and grandchildren, her free leg bobs ups and down to add dramatic effect. Bobbing her leg and pulling at the small ponytail of thin gray hair at the back of her head, Helen says, “My hair is a mess.

“I like your hair. It looks cute,” I say.

“Oh pffft. I used to have thick hair. Not as thick as yours,” she says talking about my curly hair, which I have pulled back at the nape of my neck. “Or even yours,” she says to Allison, who has thick straight brown hair cut shorter than a traditional bob.

Helen spends a few more minutes fussing with her hair and bobbing her leg. “I used to have great legs too and these,” she says, lifting her breasts. “They weren’t much, but they were perky. I used to Tom Cat around. What’s good for the goose…”

Allison and I both smile at Helen’s chest grabbing demonstration. This discussion is where the similarities between my mother-in-law and Helen begin to diverge.

“Men aren’t good for nothing,” Helen says. Allison and I are not in a position to disagree. Allison is divorced and although I am married, I am the first to acknowledge that married life is more difficult than I would like to admit. “You’re married.” Helen says, noticing my wedding ring. “And you?”

“I’m divorced,” Allison says.

“Yeah, so you know what I’m talking about then,” Helen says. “I’ve been married twice. I divorced my first husband, and my second husband, Jimmy, died in hospice two
years ago. That’s why I love animals. They love you unconditionally. See, look at my picture of my baby, Jimmy. I named him after my boy,” Helen says, referring to one of her sons, but I am confused because I am sure she just told us that Jimmy was her second husband. “I know you’re not supposed to have favorites, but I can’t help it. I love my boys.” Helen has five kids, three boys, one of whom died, and two daughters. Helen reaches in a basket next to her recliner to find a picture of her beloved Jimmy, the dog who looks like a cross between a collie and a corgi.

“Oh he’s cute,” I say when Allison passes the photo to me. Not really my type of dog – I have big dogs with short hair and I am partial to them – but I support anyone’s love of their dog. “But you have cats, or a cat,” I inquire playing along with Helen’s efforts to undermine the apartment complex’s one pet policy.

“He’s with my son because he really needs a yard and I can’t take him up and down to go outside. Maybe if I was on the first floor I could do it,” Helen explains.

“I understand,” I say, recognizing the limitations of Helen’s illness.

I decide Helen’s talk about the decline of her physical appearance is an unnecessary apology for aging. What I find more perplexing is Helen’s statement about Tom Catting considering that we have just met, but I do not think much more about it because Helen does not stick to one topic long enough to allow any deep contemplation. Helen tells us all about her family and her relationships with them. We already know that her relationships with men were tenuous, but she loves her sons deeply. She loves her daughters as well, but for different reasons. “Girls will take care of you because they’re responsible. They get it,” she tells us. One of her sons is an addict currently in recovery.
Another is dead. She has a daughter who lives an isolated life in the country. And her daughter who lives in the area has a child who Helen refers to, affectionately, as “a blonde headed hussy.” Helen also tells us that she went to jail for beating up a woman named Shelly for trying to take her baby.

“So you have stories then?” Allison asks.

“Oh I got stories, but nothing you want to hear.”

“Nu-huh. We do want to hear them. Tell us,” Allison pleads.

Helen glares at us through her peripheral vision and moves on to talk about her work as a housekeeper.

“Oh, I love to clean houses. I wish I could clean houses now. I cleaned those vases up there the other day. She says pointing to several cobalt blue vases atop the kitchen cabinets. Helen must have used a ladder to clean them or, worse yet, stood on the counter. My daughter about beat me up for it she was so mad.”

“Well yeah! You could fall. Jillian can tell you all about that,” Allison teases. She knows that I am working on a research project with another hospice about preventing falls. Although it is an important issue, Allison also knows that I pretty much dread the work I have to do on the project. I just nod and laugh at the reference, but do not say anything.

“Can I come clean your house?” Helen says to Allison.

“You can come clean my house anytime,” I offer.

“Can I?” Helen says. “I loved working and I have a hard time keeping my ass sitting still for long, as you can probably tell, and a person can only read so many books
and watch so much television.” I feel trapped in a web of my own making, not realizing how seriously Helen would like to work again.

Understanding Life Review in Hospice

Over the course of an hour, we learn that Helen’s social life is not what it once was, thanks to a perfect storm of life changes. Her husband died just a few years ago under another hospice’s care. Helen relocated to the Lexington after receiving a terminal diagnosis forcing her to sever ties with many friends who included some of her former employers. Helen’s work (which she talked about repeatedly during subsequent visits) gave her life purpose and comprised a significant element of her social life. The move also meant that Helen could no longer have the type of animal companionship she craved. Her menagerie once included a monkey. Her illness limited her activities as well. Any physical activity created shortness of breath and fatigue while an abdominal procedure made eating out impossible because Helen could not trust her bowels (a condition not related to her Emphysema). The numerous life changes required her to amend her spiritual narrative.

In hindsight, I realize Helen humorously previewed some of the turning points in her life setting the stage for revealing more intimate details, but such disclosures also comprised a strategy for managing uncertainty communicatively (Brashers, 2001). Helen’s communication is intriguing and enticing to Allison and me. I can only speculate about why Helen (reminiscent of Mr. Johnson) was so willing to disclose so much of her life, so quickly, to complete strangers. Allison’s role as a professional counselor suggests

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9 The team offered Helen Pet Therapy, but it was not the same as having her own dog and in fact exacerbated her feelings of loss.
that some disclosure, maybe even personal disclosure, is logical and likely to occur quickly, but the setting confounds me. We are in her home, not a therapist’s office, and Helen did not come to Allison for counseling. Most people probably never consider therapeutic counseling among the services available from hospice. Furthermore, patients and families frequently assume that hospice social workers serve as advocates only and gatekeepers for initiating social services. During our initial visit, Allison only stated her position, did not describe her work as therapy nor did she establish parameters or goals for visits. The frame for understanding visits with the hospice counselor (and chaplains) is ambiguous at best. Of course, what patients like Helen understand about the roles and responsibilities of Licensed Clinical Social Workers or a Doctor of Psychology remains unknown.

The standard therapeutic frame, however, may not explain Helen’s communication style. The knowledge of her dying creates an existential crisis that influences her talk, while reframing how and what she communicates, and why (Mellor & Shilling, 1993). Petronio (2001) asserts that “revealing private information is risky because there is a potential vulnerability when revealing aspects of the self” (p. 311). This prevailing theory about self-disclosure and its risks, however, does not necessarily hold up in the face of terminal illness. People who are dying may not need to maintain the communicative boundaries of their past because they may feel as though they have less to lose. The typical risks associated with self-disclosing personal or stigmatizing information may also change because a life-limiting prognosis creates *terminal time* (Yingling & Keeley, 2007), which fosters a sense of urgency. I argue that terminal time
frees up the psychic space necessary to engage in communication behaviors perceived as risky.  

Although listening for the purposes of supporting or facilitating life review (Baugher, 2008) occurs in hospice, my observations suggest that patients do not actively seek out hospice care with the goal of engaging in life review, achieving therapeutic breakthroughs, or even making new friends. In fact, I have heard patients, including Sonny, say that they were surprised that hospice offered much more than a place to go and die. Members of the care team do not stipulate life review as a goal of hospice care either, but recognize that some patients may wish to talk about their pasts. It also appears, based upon observations and interviews that team members understand storytelling as life review and, therefore, part of the dying process. An excerpt from an interview with a team member illustrates this perception about life review.

Jillian: So what do you do when a patient or family member doesn’t agree about what would make somebody comfortable, or what will make for a good death?

Allison (counselor): Well, I have to do more rapport building and work on accepting the patient where they’re at and then give them the (medical) information as it’s available. And usually they do come around and usually, like the one patient whose daughter said they didn’t want to talk about death or dying and they initially didn’t even want hospice. So we had to discharge them and then re-admit. And um, now that we’ve been in there about a month, they’re doing life review.

A participant’s age likely plays a role in her willingness to communicate more freely. It is also possible that older people are more likely to reflect back upon their lives rather than project themselves into the future.
They might not realize that they’re doing life review, but they’re talking about their seven children, and I don’t think that they would do that if we didn’t actually kind of prompt them. I don’t know how much good it’s doing because we still can’t really tell her, you know, “Hey, you’re dying.”

An alternative way to understand life review is that it is frequently a spontaneous result of having a captive audience of strangers. In order for patients to get to know the members of their team and vice versa they will engage in communication techniques such as open-ended questions and small talk to build trust and rapport that result in life review. Learning about a person’s past holds clues for the type of care they might like to receive as well as offer insights into their spiritual needs.

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I am feeling disoriented – a combination of low blood sugar and Helen’s dizzying pace. Helen takes a soft peppermint candy from the plastic tub next to her recliner and encourages us to take as many as we want from the dish on the coffee table. I take one. I can hardly peel the cellophane fast enough. I thoroughly enjoy the pillowy texture of the peppermint, but the candy is gone so fast it does little to dull my hunger pains.

We have been listening to Helen talk about the details of her life for an hour and we have not glimpsed her escape artist cat once. My water is almost gone and I am ready for Allison to start wrapping things up so we can eat. I have learned a few things about listening after many months of field work. One, listening is hard work. Two, the ability to listen for longer than an hour is the reason therapists give you 50 minutes, not 60. Three, my body knows, without the assistance of a clock, when a visit reaches an hour. And
fourth, being hungry (or extremely hot) does not make for an environment conducive to listening. In fact, my need for food prompts me to fantasize about where we might go for lunch.

“Well,” Allison says, “We’d better get going. We’ll see you next week; at the same time? We’ll be on time.”  Ouch. I really wish Allison wouldn’t make promises that we probably won’t keep. Helen agrees to the next meeting. We leave with our standard hospice hugs and my standard closing remarks, “Helen, it was nice meeting you. I look forward to seeing you next week.”

Walking to the car, I cannot help but think about Helen’s resemblance to Sonny. The two look alike with white hair and wrinkles that indicate a similar age. Both are quick witted, but Helen is much more energetic. (I do not know how much the stages of their illness at the time of our introductions account for this difference.) Spunky or feisty are both good words to describe Helen whose devotion to using foul language I admire. Sonny and Helen both love their families and like Sonny, Helen’s living environment is the result of a lovingly demanding daughter. Helen’s likeness to Sonny makes me nervous. I like her so much and so fast. I wonder if I can stand getting close to another hospice patient only to lose her. On the other hand, I am not sure it is even possible to replicate the same type of intimacy I had with Sonny again or why I feel compelled to emulate our relationship. Allison makes a similar observation when I tell her that I really like Helen. We talk about all of Helen’s qualities that make her a good, or at least fun, hospice patient and we attempt to piece together all of the fragments of her life into a coherent narrative.
“The only thing I didn’t like were those creepy dolls that look like little kids. Eww,” I say, shuddering at the thought.

“Did you notice how they were all positioned as if they were being punished?” Allison asks.

“Yeah, now that you mention it.”

“I bet there is some history of trauma or sexual abuse there.”

“Hmm,” I say thinking about the apparent limits of my powers of observation. I recognize that Allison’s interpretation of the dolls’ positionings directly relates to her training, but it makes me wonder what else I might miss.

“Yeah, that makes sense, I suppose, when you think about what she said about Tom Catting around and what’s good for the goose. She’s a hoot though,” I say applying my best *Loveline* psycho-analysis skills.\(^{11}\)

“Exactly. I don’t know if I can handle another Sonny though.”

“I know,” I say, feeling pouty. “Do you know if they are still going to do his service next month?”

“I haven’t heard anything about it. It kind of sucks because first, we don’t get any closure and then we’ll open up old feelings again,” Allison says, referring to the family’s decision to delay Sonny’s memorial service until the summer, near Sonny’s birthday in July, so more family members can attend.

\(^{11}\) *Loveline*, a late night radio talk show hosted by a disc jockey and a physician. The hosts frequently detect a history of sexual abuse among callers, usually female, who engage in promiscuous, unhealthy behavior.
“I know, but we can’t not go,” I contend. I also think back to the missed opportunity to honor Sonny by going to the track and betting on the horses. I guess I value such symbolic rituals more than I realize.

“Of course we’ll go. I’m just sayin’…”

“I hear ya. So, where are we going to eat?” Danny Boys across the street is out because Allison was just there Sunday and so I suggest the Thai place next door to the Lexington. Thai it is and I am not disappointed.

At lunch, we talk more about Helen and her frantic communication style and complicated family. Allison and I cannot agree on who-is-who or even how many kids Helen has, but we definitely know the blond headed hussy is her granddaughter. It will take at least three more sessions before we can finally piece together and track the Holyfield family tree.

*Storytelling and Spiritual Suffering*

Although the first visit with Helen was a solo visit, the next two observations are joint visits with the nurse and counselor. I had not seen Carrie, Helen’s hospice nurse, in action much since the murder-suicide in December. Having a chance to see Carrie interact with patients offered me a few new insights. Carrie is very thorough, meticulous actually. I recall the first time I saw her work (not with Helen) and I noticed that she cleaned the bell of her stethoscope with hand sanitizer before using it on a patient. No other nurse took such minute steps. Impressive and considerate, I thought. Allison coined a term to describe Carrie’s care for her patients, *The Carrie Variable*. She used the term because none of Carrie’s patients ever died. This is a bit of an exaggeration, of course,
because Carrie’s patients did die, but some of them had received hospice care for years, not months, before dying. Helen interpreted Carrie’s performance differently, adding a layer to my assessment.

“She’s a sweetheart, Carrie, but she’s slow as molasses,” Helen tells Allison and me during our first visit without Carrie since Helen’s admission to hospice.

“I know,” Allison agrees. “But she’s good. So, are you going to tell us some stories? I want to hear some stories, today?” Allison says, cutting to the chase and cleverly avoiding any criticism of Carrie.

“What stories?” Helen says, playing coy.

“I don’t know. I’m hoping there’s some murder and intrigue involved,” Allison replies.

“Yeah, did you witness a crime? Are you in the witness protection program or something?” I chime in.

“Tell us about when you went to jail,” Allison says, hoping to egg Helen on a bit. Helen does not immediately oblige, but opts for another topic of discussion. Instead, she tells us a bit about her son’s struggle with addiction. Helen feels guilty about contributing to his dependency. “I shouldn’t have let him stay with me, but I didn’t know what to do. He would’ve had no place to go.” I do not want my personal experiences with another’s addiction to take the attention away from Helen’s story, so I offer a generic observation and say, “It’s really difficult because we don’t always recognize our own behaviors and habits as encouraging co-dependency.” Helen seems to accept my comment as a possible explanation, but then she jumps to a new topic. She tells us about the challenges she had
fostering a stronger relationship with her youngest daughter, Lucy, and this revelation is

enough of a lead in for Helen to tell us about her criminal record.

“I blame Shelly for the stuff with Lucy,” Helen begins.

“Shelly is your step-mom, right?” I say, in an attempt to verify my understanding

of all of the characters in Helen’s life.

“Yes,” she says.

“And she was close to your age?” I ask rhetorically.

“Yeah, that’s right. And after I had Lucy, Shelly took her,” Helen adds. I want to

ask another question about why Shelly would do that, but I decide to hold off, allowing

the story to unfold.

“So I went over to the house to get my baby and she made me mad so I beat her

up. I wasn’t going to let her keep my baby. I walked around the corner to where Jimmy

worked – because he worked down the street from the house – and told him about it and

that was that. The lawyer told me I better just pack up and leave town so that’s what I

did. I packed up and left.”

“Wait a minute. Jimmy’s your husband, right? Was Shelly sleeping with your

husband?”

“Yeah, why do you think I kicked her ass? I mean she did have my baby too and I

wasn’t going for that shit. It was like that little bitch was trying to take my life from me.”

As Helen talks, I am still trying to put the pieces of this fascinating puzzle

together so I ask another question knowing that if I do not ask now I may not have a

chance to return to the topic later, “Wait a minute. Let me make sure I have this right.

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Shelly, who was your age and married to your dad, took your daughter, Lucy, and was having an affair with your husband?”

Helen nods, raising her eyebrows. “Now you know why I went to jail. I really don’t think I knew what I was doing. It was like, you know, how they say someone goes into a blind rage? (We nod.) It was like that. I did know all of the cops,” Helen says, diverting from the topic. Helen’s leg is bobbing and it catches my attention. “They’re good people to know and I used to have them over and I gave them coffee when they were in my neighborhood. This was back when cops used to walk a beat.” We nod again, but I wonder silently if Helen’s leg is a liar’s tell revealing to us that some of her paramours were police officers. “They knew me,” she continues, “because I didn’t take any crap.” Helen goes on to describe a few of the times when the cops came to her house. I can tell she is bragging; illustrating her power and toughness.

Helen’s stories frequently leave out important details and rarely unfold linearly, but I have learned to limit my probes because questions can sidetrack the larger narrative. We do not know Lucy’s age and we also do not know the whereabouts of Helen’s other children when this fight with Shelly ensued. Listening to Helen, however, I get the sense that her daughter, Lucy, was old enough to recognize the drama, but not so mature that she could fully comprehend the motivations that contribute to such discord among adults. Allison brings the conversation back from the stories of police officers walking the beat to Helen and her daughter. Allison asks, “And so you think your daughter sided with your step-mom after the fight?”
“Yeah, I don’t really think she ever forgave me for taking her back,” Helen says. The expression on Helen’s face, one of deep contemplation, suggests she is conjuring up an image in her mind from her past.

“Do you want to talk to your daughter about this?” Allison asks, to gauge what level of work Helen might want to do before she dies.

“I don’t think it would matter much. Lucy is stubborn like me. I’m not really good talking about this kind of stuff.”

“But maybe now is a good time to talk with her. If it’s still on your mind then it’s probably bothering you. But I also understand that it’s hard to do after all these years,” Allison suggests.

“I think you’re pretty good at talking about this kind of stuff,” I say thinking that my knowledge of communication might carry some weight. “You know, it’s also hard when you’re a kid and being an adult might make it easier for your daughter to understand or see your perspective. She probably doesn’t know all of the facts,” I add.

There is silence among the three of us.

“I love my kids,” Helen says, transitioning to a less painful subject, “but I should have never married.”

“So, why did you marry? I mean you said before that men are a waste,” I ask figuring there is another story here. My boldness surprises me.

Helen pauses for a moment before she answers. “I just got tired of Tom-Catting around and thought it was time to settle down. I wanted to have kids too.”

“And so you needed a husband to have children,” I state.
“Pretty much. My first husband was nothing to look at. I wasn’t really attracted to him in that way, but he was a good man – a good provider.” I used to think that Helen’s proclamation about dating and sleeping with many men during her youth implied that she was unfaithful to her spouse, but now I am reconsidering my earlier conclusion.

The pieces of Helen’s life are beginning to come together for me during this visit. I cannot believe the Jerry Springer like drama this woman endured in her life and then at other times I am not surprised. I am in awe of her resilience and upbeat attitude.

A week later, I arrive at Allison’s condominium for our weekly visit when she says, “Helen is definitely moving. We’ll probably have one final visit with her after this.”

“Damn. That’s too bad. I really like Helen. I can’t believe her daughter is making her move again and to that place,” I say, referring to the more upscale condominiums where Helen is relocating.

“People have to do what they have to do,” Allison says, sidelifing my attempt to whine about the premature dissolution of our budding relationship. Our arrival at the Starbucks drive-through derails the conversation from Helen to soy lattes and iced coffees.

Allison and I spend the 15-minutes it takes to get in Helen’s apartment chatting about another patient in my study, Doug, who I have not seen in some time. Allison tells me we are going to see him later today. She also tells me he is declining. This news is not a surprise, but it remains sad because Doug is young.
We pull into the driveway of the Lexington and my attention turns back to Helen. I wonder what she is going to say about having to move again. The last time we visited, the possibility of moving was in the discussion phase. In past visits, Helen has alluded to her inability to relate to her children in emotionally sensitive ways, but she can easily engage in bickering and antagonism with them (I witnessed this first hand when one of Helen’s daughters came to visit). It is also common for Helen to push her feelings aside in response to pain and sadness. Although moving is in no way synonymous with Helen’s other losses, I suspect the demise of another set of relationships, this time with her hospice team, will sit at the forefront of her mind.

We settle into our normal positions on the sofa and I can see signs of Helen’s move in the adjoining room. “So you’re moving, huh?” Allison begins.

“Yes, I’ve already starting packing. My daughter thinks it will be better for me to be closer to her,” Helen says. I do not get the impression that Helen agrees with her daughter’s assessment, but she also sounds resigned to the idea and knows she cannot put up a fight this time.

“Well, we’ll miss you,” I say.

“Can you still visit?”

“Yeah, we can. You’ll be assigned to the Daisy team though,” Allison says.

“I don’t think I’ll like them as much as you two.”

“You never know,” I add.

Allison reaches into her bag and hands Helen three books that Helen loaned her. The two spend a couple of minutes talking about the narratives while I listen. Helen
offered me some books too, but I had to turn them down and blamed my lack of reading for enjoyment on graduate school. The two finish chatting about Jodi Picoult and then move on to talking about Helen’s family, again. The topic of her son’s death comes up.

“I don’t like to think about it because it makes me upset all over again, so I just stuff it down. That’s what I’ve always done. I didn’t feel the same way when my husband Jimmy died. I knew it was going to happen and he had a long life. That’s what I think I did when my mom died. And then a few years later that’s what I did when I was raped by a group of men. I never told anyone because I was afraid no one would believe me. I was afraid my dad would be mad.”

“And that he would blame you,” Allison says, completing Helen’s unspoken thought.

“Probably,” Helen says. “I never told anyone – not until now – I don’t even know why I just told you two.”

This topic is Allison’s area of expertise so I sit back and watch her work.

“It’s hard to carry that around and not be able to tell anyone, especially if you were afraid they would not believe you or blame you,” Allison adds.

Helen unpacks her trauma and its costs on her life. Helen suspected that she was an inconvenience for her parents. Her mother was sick most of Helen’s life with a heart ailment and her father could not or did not express any loving emotions toward her. Following her mother’s death when Helen was twelve, she looked to her father to express his love in material ways – she always had what she needed when it came to clothes or toys – but she never felt as though she had her parents’, especially her father’s love. The
rape just a few years after her mother’s death prompted Helen to seek relationships with men that lacked genuine intimacy.

As Helen talks, she stares at the wall and the look on her face combined with a certain feeling in the room makes me think she might start crying. I do not notice any signs of emotion, yet I can tell Helen is sad, sadder than I have ever seen her. We let the silence communicate for us. After about a minute Allison tells Helen that she has experience doing counseling with survivors of sexual abuse and trauma and they could do some therapy. Helen does not dismiss the idea out of hand, but she does not leap at the chance either. The moment of silence among the three of us gives me pause. I often wonder about Allison’s training and how it influences her communication choices. In the moments before someone speaks, I try to anticipate how long the silence will last, who is going to break the silence, and how. If Allison breaks the silence first, she usually offers an empathetic response and rarely a solution and for some reason I expect the latter each time. If patients take the initiative to speak first they usually downplay the moment that triggered the silence as if the weight of the moment cannot exist without interference. I do not, however, interpret such hedging as a form of disconfirmation (Cissna & Sieburg, 2002), but as a communication behavior marking the ends of the depths of a patient’s emotional reservoir. Most people return to these emotional places – sometimes in the same or subsequent visit – as a type of communicative toe testing of the water. Gradual self-disclosure illustrates the importance of viewing patient visits as a small part of a larger whole. A process over a task oriented approach allows team members to pick back up on narrative threads or at least create opportunities to return to certain themes. Failure
to create these spaces prohibits communication about dying or spirituality, which is important at the end of life. These topics, however, are not explicit goals for team members; rather they emerge as byproducts of other seemingly incidental talk.

Our time with Helen for the week ends and as we conclude with our hug I say to Helen, “I can’t speak for Allison…” I pause because Allison looks up at me with a curious expression. I begin to question my decision to talk, but continue anyway, “…But I am honored that you would trust us enough to share your story. It means a lot to me.” As soon as the words leave my mouth, I question why my genuine attempt at sharing an authentic sentiment sounds, or maybe feels, trite. Helen smiles, “I like you – even this one,” she says, smacking Allison on the rear-end.

“Oh-huh,” I exclaim and start laughing. Helen’s behavior does not surprise me because smacking someone on the rear is a form of affection consistent with her personality. Allison looks up at me stunned. She does not say a word, but her face conveys a what was that? kind of look. “Well on that note,” Allison says, “we’ll see you later.”

Assessing Spiritual Needs

According to Long (2001), spirituality and communication are interdependent and the two concepts are so enmeshed that it is difficult to know where one ends and the other begins. Helen’s story and storytelling illuminate this point. Cleaning house, a topic Helen mentioned several times during our visits, on the surface seems a superficial act easily given up when illness becomes prohibitive, particularly for someone like me who rarely makes her bed and is lucky to vacuum once a week. Cleaning houses, however, gave
Helen’s life purpose, meaning, and a sense of order and control; thus cleaning was a spiritual act. Kellehear (2000) calls this type of spirituality, situational transcendence, which can arise out of such issues as the physical side-effect of symptoms, foreign environments, and the loss of familiar work and home surroundings. Although Helen recognized the limits the illness placed on her ability to carry out a central element of her life, her inability to do such meaningful work allowed the traumatic psychological dust to settle. Kübler-Ross (1969) argued that those of us not actively dying need to take the time to sit listen and share, but this process is a two-way street. By taking advantage of a captive audience, Helen supervised the cleaning of her spiritual house.12

Writing about spirituality in hospice care, Kellehear (2000) notes that people who are not religious have concerns about forgiveness and closure that are more synonymous with religious discourse than we might expect. The tendency is to assume that religious approaches are sufficient for resolving a patient’s moral and ethical dilemmas as well as spiritual suffering. A excerpt from my interview will Judy, a nurse, is one example.

Jillian: How do you assess a patient’s spiritual needs?

Judy: Um, sometimes I just come out and ask them, “Do you believe in God? What’s your belief? What’s your faith?” Sometimes they say no, and sometimes they say oh, absolutely there is a Heaven, there is a God.

Jillian: And what do you do if someone says, for example, “Well, no, I don’t. No, there’s no God.” What do you do if their belief is completely different from your own?

Judy: Well, if they say, for example, “No there isn’t a God,” I just say, “Why do you think so?”

12 Thanks to Steve Schoen for his contribution to this analysis and house cleaning metaphor.
Jillian: What kind of reception do you normally get?

Judy: Um, some of them say, “Well, no, I’ve never really thought about it. And that’s just a – that’s just a fairy tale, or something like that.” Um, and then sometimes depending on the person and how long I’ve known them, I’ll just say, “Well, I know that there’s a God and I know there’s a Heaven and a Hell, and I know that I’m going to Heaven.” And then I usually leave it and see if they bring it up again.

Jillian: Right. Okay. So have you ever had any conflicts around the issues of spirituality or religion with patients?

Judy: Well, I had one patient that um, he just politely said, “I don’t want to talk about it.” And I said, “Well, that’s okay, but I’ll still pray for you.”

Jillian: And was he okay with that?

Judy: Uh-huh. He just didn’t want to talk about it.

Jillian: And how do you define uh, spiritual suffering? Because you know, it’s a term that’s ...(we are interrupted by the server.)

Judy: Say – say it again?

Jillian: So how do you define spiritual suffering? Because that’s something that’s talked about quite a bit in hospice. How would you explain it to somebody like, like me maybe. [Laughs]

Judy: Well, I think . . . spiritual suffering to me would be someone who wants to believe that there is a God and a better place to go, but maybe they’ve never been introduced to the Bible or never been told how to be Born Again and to repent of their
sins. And so they don’t know what’s going to happen to them when they die. That to me would be a big suffering, that would. Not knowing that, yeah.

Patients, however, may resist team members’ use of religious interventions to solve their spiritual crises (See chapter 7 for more detailed discussion about pastoral care.). Therefore, it is important to recognize that “[c]oncerns about right and wrong and the problem of forgiveness are not necessarily directed towards one’s relationship with God nor are these issues seen as particularly relevant to the welfare of one’s soul” (Kellehear, 2000, p. 151). While some patients may look to traditionally religious outlets, such as prayer, for achieving this type of spiritual transcendence, other patients may need forgiveness (self or family), or self-reflexive analysis, or therapy to move on psychologically (Kellehear, 2000). Helen created an opportunity to engage in moral and biographical transcendence through storytelling by revealing the sexual trauma that she experienced as a young girl, describing her attempts at sexual retribution against men, and acknowledging her flaws as a parent.

*Ambiguous Ending*

During our final visit together, Helen said, “I’m probably never going to see you again.” The statement was equal parts declaration and query. Although Allison told Helen we would visit again, we never did. Helen’s move to another team’s jurisdiction protected me from the experience of losing her to emphysema, but it did not diminish my interest in Helen or her story. I check the obituaries almost daily hoping to gain some closure. I once asked Allison about her after I left the field, but she had not followed up on Helen’s status.
I liked Helen so much and was disappointed that I would never have the opportunity to find out if we would become closer friends or if I would mourn her death the same way I mourned Sonny’s. On the one hand, I am thankful to avoid the pain that accompanies such a loss; on the other hand, the lack of pain also means less joy. I would never discover the extent of my contribution to her quality of life and hers to mine.

Helen’s declaration during our first visit about the limited value of men left me with the impression that I could benefit from her hard-earned wisdom. I thought Helen could teach me something about how to live and die. And in return I could listen without prejudice and witness the end of her journey. I hesitate to claim such an altruistic role as that of a liberator – I only knew Helen for just over a month – but I had the distinct feeling that she needed someone to help unload, if only temporarily, her burden. A month of visits did not seem like enough time. This is not to say that Helen was completely unencumbered, cleansed, or made whole again by sharing a few closely guarded secrets, but the timing suggests that Helen needed someone to come alongside her and share the weight of her worries. Listening allowed Helen a few moments of weightlessness.

Illness and dying are lonely experiences\textsuperscript{13} exacerbated by having to carry the yoke of past mistakes and regrets or the frustration of unfulfilled ambitions (see also, Puchalski, 2002). I have focused on the way Helen communicates about her past with one member of her hospice care team and me to illustrate that spiritual pain can include a wide range of subject matters. And while a few of Helen’s spiritual concerns appear religious (the need to confess and receive forgiveness), they are in fact only cloaked in traditionally Christian religious discourse. What gave Helen’s life meaning included her

\textsuperscript{13}I thank Leah, a friend and mentor (who died of ovarian cancer) for teaching me this lesson.
family, her animals, and her work (cleaning homes). Such inclusive understandings of spiritual communication are necessary to identify and meet patients’ complex spiritual needs. While some (Kirkwood, 1994) argue that broad spiritual conceptions are problematic because they are too inclusive, I disagree and ask, who does a narrow conception of spirituality serve and who is uninvited? I concur with scholars, such as Kellehear (2000), who appreciate the multiple dimensions of a person’s spiritual experience and its relationship to ‘good spiritual care’. A broad understanding of spirituality and spiritual communication helps us recognize that the stories we tell, whether they are about traumas, regrets, pleasures or accomplishments, may indeed constitute the essence of being human (Long, 2001).

The ability to look back upon a life and restory it is only possible for people who feel as though their lives constitute certain accomplishments. For some, having and raising children equals a full life, for others personal and professional accomplishments constitute a life well lived. Some individuals are fortunate “to identify their unique missions, their own sacredness, before they die” (Balducci, 2008, p. 102). Others however, do not attain the quality or achieve the quantity of life necessary to bring a sense of completion to their lives. The next chapter focuses on how dying young – before fulfilling goals and dreams – and denial create communication opportunities for hospice care.

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14 I want to draw attention to the notion that spiritual communication may come from one’s past, but also stems from ruptures in the narrative a person hoped to create, but now must abandon because of a life-limiting illness.
Chapter 6 – Dying Young, Denying Death, and Searching for Answers

Previous research has focused on the failure of health care professionals to communicate about dying or death with patients and their caregivers (Ragan, et al., 2008). By placing the focus on health care providers, such studies frame communication too simplistically, employing a transmission model of communication. However, more recent medical research (Larson & Tobin, 2000) is beginning to acknowledge that communication is more dynamic than a transmission model allows. Recognizing that communication involves a transaction and dialogue between at least two people, the burden and expectations about who is responsible for end-of-life conversations then becomes the responsibility of the speaker and the listener or the carer and her patient. The question about who is responsible for initiating talk challenges communication scholars to look beyond the skills of speakers and focus on the institutions that influence communication. Sometimes patients rather than their health care providers create opportunities or barriers to talking about dying and death. Doug and Mr. Greenberg illustrate this challenge.

Stages of Dying and an Unfinished Life

I felt a twinge of nerves as we pulled up to Doug’s and Tom’s bungalow nestled less than 10 miles from the Gulf of Mexico. I always feel nervous when I meet a new admission. I have come to view my paranoid thoughts as reflecting my concerns about acceptance as opposed to fear about meeting a person who is terminally ill. Newly
admitted hospice patients have many new people coming in and out of their homes during the first week or so following admission. After an admitting nurse visits, patients have appointments in their home with a nurse and a counselor from the team they were assigned. Depending on the severity of the patient’s illness and caregiving needs, a new admission sometimes necessitates the delivery of equipment, such as oxygen concentrators, a hospital bed, and even medicine. In a matter of days, hospice can convert a person’s home into a mini-hospital and the space between the world of health and the world of terminal illness begins to narrow for some. I am confident that my presence, another new person, a person irrelevant to a patient’s care, may contribute to feelings of turmoil. Not wanting to add more stress, I get nervous and I prepare myself for the possibility that my presence will be unwelcomed.

The circumstances of Doug’s case likely contributed to the anxiety I felt as we walked the path to the bungalow’s front porch. I learned at the Interdisciplinary Team (IDT) meeting the day prior, that Doug had been living with AIDS for over 20 years. At the age of 42, after managing AIDS with pharmaceutical cocktails, Doug however, was not dying from the autoimmune disease, but from cancer. Although I did not know much else about Doug’s life beyond his health status, those facts alone made me feel sad because I, only eleven years Doug’s junior, could appreciate how much life he had yet to live. Our first meeting confirmed my preconceived ideas about Doug’s unfinished life.

Standing on the porch, we could see three figures towards the back of the house. Allison knocked, called out and then unlatched the screen door allowing us enter. As we crossed the threshold of the Kent-Frey residence, I was surprised to see its interior did not
at all match my expectations. The neighborhood was close to a major thoroughfare and the other houses on the block were rundown with untidy yards. The garnet red walls, shiny cherry-wood floors, and simply decorated spaces appeared straight out of a home decorating magazine. Judy, Doug’s nurse, was already sitting at their Amish style table. The feeling of light chatter suggested to me that Judy and Doug were becoming fast friends. Tom, Doug’s life partner, hovered around the kitchen, operating somewhere between quiet observer and concerned participant. Doug’s frame was long and slim, covered in a casual pair of cargo shorts and a t-shirt. He wears his dark hair cropped closed to his head, a remnant from his time in the service, I suspect. Doug’s distended abdomen was the only tip-off that he was sick.

All of the action takes place at the kitchen table and as we approach, Allison introduces herself, “Hi, I’m Allison, a counselor with the Sunflower team. Jillian is a communication student shadowing me doing a project about hospice.” I extend my hand to Doug and to Tom, who has finally taken a seat at the table, and say hello. “Oh, she can tell you more about it than I can,” Allison says, waving her hand in a way to defer her knowledge of my project to me. “Yeah,” I reply. “I can tell you about it later, after you’ve had a chance to talk,” I say, referring to the purpose for Judy and Allison’s visit. I take a seat at the table next to Allison and watch the discussion unfold.

Judy begins to ask the standard hospice questions about bowel movements and pain. As Judy asks and Doug answers, both Judy and Allison document the responses into Coastal’s computerized bedside charting program. The screen displays a series of questions that, when selected, produces a drop down menu of possible responses. “Are
you suffering?” Judy asks. “No, but if I was, I would take some of that liquid morphine they gave me at the VA,” Doug replies. “But I’m hoping I won’t have to do that. I just got off of it. I was taking way too much of that stuff, drinking it straight out of the bottle. I was sleeping all day until Tom told me I had to get off of it. I’m glad I did, because I would’ve just been knocked out for the rest of my life.”

“Can I see what you have?” Judy asks.

“Yeah. Tom, can you get those bottles. I was addicted to that stuff, but I haven’t touched it. I just stopped taking it and I’m glad I did.” As Tom pulls the square white bottles from the kitchen cabinet, I worry that Tom is being too punitive by insisting Doug “get off” his morphine. I am also concerned that Doug might refrain from using the morphine even when he needs it for fear of developing an addiction, which is a common, but often unnecessary concern for people at the end of life. Doug’s proclamation that he quit cold-turkey makes me suspicious about the authenticity of his story since combating a dependency to opiates is difficult. I also get the sense that Doug’s claim is for Tom’s benefit, given his apparent opposition to Doug’s use of the substance. Tom brings the bottles over and hands them to Judy.

“Oh yeah, that’s some good stuff,” Allison says.

“When Tom and I moved back down here from Wisconsin after I got this cancer, I was taking that stuff a lot,” Doug says, in a matter-of-fact tone. “I just can’t believe I got this cancer.”

“That must have been difficult,” Allison says, with a genuine tone of empathy. Judy silently enters information from the prescription bottle into the computer.
“Yeah, I just can’t believe that after all this that I’m dying,” Doug says. *Whoa, I think. Most of the patients and their caregivers that I have observed, until now, do not make any explicit or even overt mention of dying. Doug is so matter of fact.*

Judy has already taken Doug’s vital signs, including lung sounds, blood pressure and heart rate, which all check out fine, and she begins packing up. “Okay, so ahh, it was nice meeting you. I’ll see you the same time next week?” she says in an accent from the heart of the Midwest.

“Sounds good,” Doug replies. “Will you put that on the calendar?” Doug says to Tom.

“Sure,” he replies walking over to the calendar on the refrigerator. Tom’s compliant, but not eager.

“I just can’t believe it,” Doug repeats. “Everything was going along fine and then this. We’re going to need to try to sell our house up north so I’ll have to go up there at some point to get it ready to sell.” Tom scrunches his face as Doug talks about getting the house ready to sell. “And then I’m going to have to tell my mother.”

“What are your concerns about giving this news to your mom?” Allison asks as if she is reading my mind. *How could he not tell his mother is what I’m wondering. She would be the first person I would call if I was diagnosed with cancer.*

“That she’ll freak out and get all emotional. That she’ll want to come down here and help,” Doug says, annoyed by the thought. *Doug not calling his mother scares me more than the thought of him having to make a very difficult phone call. My mind races*
as I try to explain to myself why Doug would delay having this very important conversation. “I don’t want her coming down here and I don’t want her trying to help.”

“I can understand that,” Allison says, supporting Doug’s wishes without any additional background knowledge. “And you don’t have to call her if you don’t want to. You might want to later and if you do, I can help you.”

“That’s good to know,” Doug says. “So, what else can you do?”

“Well, I’m Licensed Clinical Social Worker, which means that I’m licensed to do therapy. I am here to help you through the dying process.” Allison’s explanation is direct, yet ambiguous enough to leave room for interpretation, but I wonder what it means to help someone through the dying process.

“Oh we see a counselor over at the Mission to deal with some relationship issues. Her name’s Mary Jardin. Do you know her?” Doug inquires.

“The name doesn’t sound familiar, but I know about the Mission.” Allison explains to me later that the Mission is a not-for-profit organization that provides mental health and substance abuse counseling generally for low-income people and not people who own two homes in two different states. It is not clear why Doug uses all of these social services (including Meals on Wheels), but the sense of entitlement and the willingness to take advantage of these programs when they might not be needed disturbs me.

“I have some anger issues from my past. I was abused by a family member and it affects my relationship with Tom. I get angry about things when I shouldn’t and I take my anger out on him and I don’t want to do that anymore. Especially because of this
cancer. But we’re going to keep on living. We want to travel and enjoy the time I have left. The doctor says I could have up to three years and I want to enjoy it.”

*I feel like a tennis ball traversing the court at Wimbeldon. I think that Doug, in one breath, is accepting his terminal diagnosis, but in the very next breathe, he is talking about overcoming past traumas, repairing and perfecting his 20-year relationship with Tom, and jet setting during the next three years of his life. The reality is that if Doug is in hospice he has been diagnosed to have 6-12 months to live at best, and given the fact that he has untreatable liver cancer complicated by AIDS, it is more likely that he has less than six months to live.*

“Well, I can certainly work with you on the past trauma, I used to work with trauma and abuse survivors and we can definitely talk about your anger because that does come up a lot with people when they are sick,” says Allison.

“Okay good. So where do we go for that?”

“Right here. I come to you.”

“Oh that’s great,” Doug says, looking at Tom. “Do we just schedule an appointment for that?”

“Yes. Sure, we can take care of that,” Allison replies enthusiastically.

“That would really be great because I don’t want to be mad at Tom all of the time.”

Doug’s eagerness and persistence about receiving counseling from Allison seems unusual. I have this strange feeling that Doug has spent a lot of time in therapy. He talks too succinctly and with such clarity about his past trauma, and the very fact that he calls
his experiences trauma sounds as though he is diagnosing himself. Doug already seems
to know the source of his anger, but like many people facing relationship issues he
continues to have difficulty making positive changes.

During the course of the discussion about Allison doing counseling with Doug
and Tom, I agree to not come to their next appointment so they can communicate openly
about their pasts. I try not to appear disappointed when they schedule their next non-
therapy related appointment for another day that I cannot observe.

“I just can’t believe it. I mean here I am dying. I mean, when I was first diagnosed
with HIV I never would have thought,” Doug says.

“I can imagine. It must be very strange. I bet being in hospice makes you angry
too and you probably take it out on Tom and you don’t even know it.”

“Yeah. Exactly. I still have things I want to do. I’ve always wanted to go to Italy,
so we’re planning a trip to Italy. I mean I’ve always wanted to go to Italy so why not go
now before I’m too sick to go.”

“Oh,” I say, not wanting to discourage Doug, “have you read the book, Eat, Pray,
Love? It’s all about this author who goes on a spiritual journey and the first place she
visits is Italy because she always wanted to learn to speak the language. While she’s there
she just eats and eats. She makes the food sound so good. It’s a really good book. I would
recommend it, even if you just wanted something good to read.” I immediately regret
opening my mouth. I have a feeling that I have said too much and what I have said is not
particularly helpful, only contributing to his denial.

“Oh yeah, the food. We love Italian.”
“What’s your favorite place?” Allison inquires.

“Oh you know Amici’s in Native Rock? We used to love to go there,” Doug replies.

“Yeah, yeah,” Allison cheers bouncing on her seat, “That place is good.” Allison draws out the oood in good.

“We haven’t been there in a while because I’m not feeling up to it, but sometimes we’ll get take-out and just have it here.”

“Yeah,” Allison says, encouraging Doug and Tom to enjoy their love of food any way they can. “What other kinds of things do you like to do? Do you cook or do you just eat out?”

“Oh no, we love to cook.”

“I thought so,” Allison says admiring the kitchen behind her.

“Cook and drink wine,” Doug adds. “Remember that time we went up to Susan and Joe’s and drank all of those Martinis?” Doug asks directing his attention to Tom who nods affirmatively. “That was so much fun. Susan is Tom’s sister and Joe’s her husband.”

“Maybe you should go visit them again,” Allison adds.

“Yeah, maybe. That would be fun. But we’re going to go to Italy. What’s the name of that book again? I’ll have to write that down. Can you get me a pen, Tom?” I am probably just paranoid, but I wonder about the authenticity of Doug’s interest in reading the book. I’m worried he is just humoring me since I was so enthusiastic about the memoir. After Tom hands Doug a pen I watch as he carefully prints the name of my latest favorite book at the top of some VA papers. The papers look too important for this use.
“Well, we’re going to get out of here. I’ll see you next week,” Allison says, referring to their upcoming counseling appointment. As we stand to show ourselves out, Allison reaches to give Doug a hug. “We hug in hospice,” Allison declares. “Oh that’s wonderful,” Doug replies. Tom doesn’t seem too keen on the idea, his posture appearing rigid. He makes me feel awkward, as though I should just shake hands with him to honor his comfort level, but instead I give both of them hugs and we leave.

Allison and I walk out to her car in silence. As we don our sunglasses and seatbelts, Allison says, without moving her mouth, “They’re probably watching us, to see if we’re talking about them.”

“I know,” I reply through my own gritted teeth. As soon as we believe we are safely out of sight, we begin processing the visit.

“Wow that’s sad. He’s so young and that sucks that he’s got cancer after living all of these years with AIDS. Is he in denial or what?” I say, trying to check my perception of the encounter against Allison’s perception.

“He’s doing a lot of bargaining,” Allison offers. *Bargaining, was that what that was, I think to myself. Bargaining had dropped off my mental list of the responses dying people have as they move closer to the end of their lives.*

“Yeah, I suppose,” I say reflecting on Doug’s constant fluctuations between disbelief and acceptance. “I mean, does he really think he’s going to Italy?”

“Yes.” I can’t tell if Allison is being sarcastic or serious so I wait for her to elaborate. “That’s what he needs to tell himself right now.”
“I guess, but then in the very next breath he’s saying he can’t believe he’s dying; as though he’s accepted it. It never occurred to me that you could go back and forth that fast. I couldn’t keep up. It was making my head hurt.”

The conversation Allison and I have about Doug and Tom moves from Doug’s illness to his relationship with Tom. “There is something going on there,” Allison observes.

“What do you think it is?” I ask. “I did think all of that stuff about the morphine was kind of strange. I sure hope Doug doesn’t avoid taking drugs if he has pain, if he needs them.”

“I thought that was interesting and so was the stuff about anger and going to therapy at the Mission. I bet they are institutionalized,” she says, referring to the ways that Doug and Tom had absorbed aspects of mental health and social services. “No one should be in therapy for that long. It means they are not getting any tools. I bet there is some history of domestic violence,” Allison asserts putting an emphasis on the first syllable in *domestic*.

“You’ll have to let me know how the visit goes next week,” I say, still disappointed that I am going to miss next week’s session.

*Rethinking Denial as a Barrier to Communication*

Doug’s first visit is an interesting case because of his willingness to openly talk about the inevitability of his impending death. The majority, if not all, of newly admitted patients that I have observed do not acknowledge that a hospice admission means they have six months or less to live. When asked, “Why are you in hospice?” many people
state that they were referred to hospice to “get a break” or to “get some extra help.” Although these statements are factual, the reason for patients’ hospice admission is always a life-limiting diagnosis. Given Doug’s embrace of talk therapy and his history of AIDS, suggest his willingness to openly talk about death is not surprising. What is curious is how despite recognizing that his death is imminent, Doug’s communication remains future-oriented. He reacts to his cancer diagnosis and hospice admission by talking about future travel plans to Italy and working on improving and finally getting right his relationship with his partner of 20 years.

On their face, such proclamations would suggest a high level of denial which hospice staff must help Doug overcome to eventually accept his dying and death. The first visit, however, is an opportunity to build rapport, assess Doug’s goals for living the rest of his life, and begin to understand what might constitute a good death. For example, Doug does not want to be “out of it,” so the members of the team can use this information to develop a course of treatment or care that keeps Doug pain free, but not sedated. Also, Doug makes explicit his wish to have some healing related to past trauma and improve certain aspects of his relationship with Tom. The progression of Doug’s disease may make traveling to Italy impossible, but it nonetheless tells the team about some of Doug’s goals and provides another opportunity to make specific care plans. One problem is that not all patients are as reflexive, self-aware, or communicative.

*Denial as a Social and Relational Phenomenon*

This encounter also shows how denial is not only a psychological state but also a relational and socially constructed phenomenon among Doug, his partner Tom, the
hospice staff, and a researcher. None of us questioned, for example, the travel plans Doug discussed and thus we were complicit in his denial. According to Zimmerman’s (2004) review of palliative care literature, denial is overwhelming portrayed “as an internal psychological state that is residing within the psychology of the individual” (p. 1771). In order for denial to exist it is understood as an unconscious response to impending death. Patients’ talk about their illness and reason for their hospice admission reveal that denial is a communicative act. Hospice staff’s communication about patient and caregiver denial indicates that denial is not always a natural psychological reaction to impending death, but is in some cases a choice.\textsuperscript{15} In the hospice model, patient autonomy is supposed to take precedence over the will of the team and sometimes caregivers. Thus if denial is a choice it should not be pathologized, but accepted as a patient’s desired reality. Whether or not team members understand denial as a psychological phenomenon or a choice, denial creates a particular type of communication problem hospice teams must negotiate. Hospice staff label patients or their caregivers who deny impending death for too long or at the wrong times as difficult. Denial requires hospice staff to tip-toe around the inevitable, to use more caution when choosing their words or delay helping patients make plans for after death care. Viewing denial as a patient’s right increases the likelihood of communicating in ways that accommodate denial. In some instances, denial is a problem because caregivers act as if their loved one is going to live forever or be cured (for a discussion about misunderstanding remission, see Ragan, et al., 2008). As a result of denial, family members and other non-professional caregivers will force patients to eat

\textsuperscript{15} This portion of analysis stems from Zimmermann’s (2004) review of palliative care literature about denial as a patient’s choice rather than solely a patient’s unconscious response to death.
when they are not hungry, make them take showers when they are too weak, or encourage them to remain hopeful in light of a hopeless situation.

A patient’s or family’s denial of dying is a source of frustration for team members. Some team members express shock when patients deny they are dying and veteran team members, usually nurses, remind the team that denial and its accompanying non-compliance is the patient’s right even if this denial might lead to what most would define as a bad death.

One patient’s story presented at a team meeting illustrates this point. A woman in her 50s with end-stage ovarian cancer was receiving tube feedings at the insistence of her family. As predicted, the patient was unable to process the artificial nutrition and began experiencing complications including severe pain and vomiting feces. The patient’s team, especially the nurse, chose to use the argument that good medicine should prevail rather than attempting to get the patient or her family to accept the inevitability of her death. Deferring exclusively to sound medicine is an interesting rhetorical choice and seems to encourage the denial of dying rather than help a patient and her family begin preparing for a loss. This emphasis on medicine as the primary solution is a problem given hospice’s interdisciplinary approach. A nurse, under similar circumstances, could ask a patient about the motivation (or hopes) for pursuing such treatment. A chaplain or counselor could assist a patient and her family with making sense of the illness and the meaning of treatment on a spiritual or psychological level.

Viewing denial as an autonomous choice to avoid talking about death fails to acknowledge the myriad of ways to help a patient and her family to prepare for, if not
fully accept, a death. Denial of death then is appropriate during the early stages of a terminal diagnosis until such time that the imminence of death cannot be denied or the denial of death prohibits care or is otherwise detrimental to the patient or her family (Zimmermann, 2004). The belief that denial is appropriate at certain stages because it is a normal reaction to dying, as well as a choice, allows a patient to proceed at her own pace down a path to acceptance. Such an orientation to denial of dying, however, is not always realistic because there are times when patients and their families need to accept death sooner rather than later, to put affairs in order, resolve past conflicts, make treatment choices, or just create opportunities to live life as fully as possible until death. The progression of an illness can provoke team members to broach end-of-life topics, but there are times when team members will avoid such discussions because the patient never mentions them. Doug’s story is an example of how information about a patient’s level of denial can set the stage for future communication about the dying process.

*The Dialectic of Denial*

Elisabeth Kübler-Ross (1969) branded the stages of dying and noted that denial is but one stage and that patients can move back and forth between all of the stages (e.g., bargaining, depression, acceptance, anger). What is often missing from the discussion about denial of a terminal diagnosis, and its counterpart acceptance, is that patients and their families may simultaneously accept a diagnosis yet deny the inevitability of death, which exacerbates the ability to move down a straight and narrow path towards a good death. If patients never acknowledge their inevitable death, then they risk missing the opportunity to make related choices. I think this is particularly true of the patient who has cancer. Since cancer is frequently invisible to the naked eye, I have seen patients who
struggle to see how the disease will result in their demise. In some instances, patients hold onto hope for a cure or that one more round of treatments will prolong their life. Doug’s talk about living for three years, yet expressing his disbelief about having cancer, illustrates this point. Doug does not explicitly deny he has cancer or the reality that it will kill him, but his discussion about making travel plans and living far beyond the diagnostic parameters that make him eligible for hospice suggest that he also maintains some level of denial. A patient’s hopes and dreams and subsequent denial is problematic for hospice only insofar that it interrupts or interferes with care.

Another one of my participants is also an excellent example of the dialectical tension that exists between acceptance and denial. Mr. Greenberg, a 91 year old man with cancer of the liver, was told by his physician that he had less than six months to live. Nine months later, he was still alive and cantankerous as ever. “How come I’m not dead yet?” Mr. Greenberg asked his nurse, Peggy, the first time we met. “I don’t understand. I was in such terrible pain before I got into hospice, and Dr. Sloan told me I wouldn’t live for more than six months. But I’m still here and I feel great! I have some pain in my back sometimes, but otherwise I feel fine.” Mr. Greenberg accepted his diagnosis, but could not fully envision the inevitability of its outcome. Moreover, Mr. Greenberg felt confused and defeated by his doctor’s estimate. The disconnect between the doctor’s prognosis and Mr. Greenberg’s health captures the essences of why some physicians remain reluctant to give prognostic information. Peggy reminded Mr. Greenberg that he did have cancer, but the disease was likely slow moving, and took this as an opportunity to tell Mr. Greenberg what he could expect as the disease progressed. “You’ll probably get tired and sleep more
and eat less,” Peggy explained. “But you’re not dying yet. So keep doing what you always do and enjoy the time you have.” Mr. Greenberg and his wife both nodded and thanked Peggy for the information. This level of openness allows team members to communicate frankly with Mr. Greenberg whose communication style is open and accepting.

Other patients approach conversations about dying differently as Grace, a Home Health Aid describes during an interview.

Jillian: So, you just let them really guide the topic of conversation?

Grace: Yes, and you see how it goes along. And, sometimes, talking about death will start out funny. Um, it’s never one of these, uh, cut and dry things. Like, “boy, I’m glad you’re here, because I want to talk to you about my death!” No. But maybe through conversation. Like, for instance, let’s go back to April (a patient Grace discussed earlier in the interview), where she said to me, “After I’m dead, please call Christopher (April’s son) every now and again.” So, I said okay. Um, it comes in bits and pieces. It doesn’t usually come in one large sitting.

In fact, I don’t think I’ve really…It’s not coming to mind. I don’t think I ever really had one full sitting where we talked about death. It comes in bits and pieces.

The bits and pieces that Grace describes above may explain why patients do not talk frequently about dying or death, and move back and forth between accepting and dying a terminal diagnosis, as Mr. Greenberg’s and Doug’s stories reveal. The fluidity of boundaries between stages creates a dilemma for hospice not easily overcome or even acknowledged. Denial, whether or not hospice team members address it explicitly,
remains a co-constructed phenomenon. A patient’s refusal to accept the inevitability of their dying and eventual death would appear to mark a failure of hospice to prepare someone for the reality of death, yet team members make sense of this tension as the patient’s choice rather than the failure of the care plan or the skills or abilities of the various practioners. The hospice model always prevails; and as we will see in the next chapter, the same is true of team members’ understanding of what constitutes a good death.
Chapter 7 – Creating Opportunities to Communicate about Death

Hospice care and its mission are unique when compared to other health care organizations. The founding principles that guide hospice care, for example, developed in response to dissatisfaction with health care practices and social attitudes detrimental to people with terminal illness. Yet hospices and the conversations that occur there are not immune from the influence of other institutions. Traditional medical models of care, the concept of stewardship, and Medicare requirements enable and constrain communication about spirituality, dying, death, and a good death in hospice. In the section that follows, I will discuss how such institutions shape communication in hospice. I begin by first discussing some of the communication barriers that constrain spiritual care in hospice by returning to observations from the field.

Missed Opportunities and the Hospice Chaplain’s Perception Problem

“Would you like to see the chaplain?” Allison asks Sonny.

“No. I don’t think so. She’s a nice gal and all. I did talk to her a couple of times, but the last time she called I told her she didn’t need to come out here. There is no reason for her to waste her time coming to see me. I got it all figured out up here,” Sonny says tapping his pointer finger on his temple. This gesture makes me think of Mr. Johnson. I wonder if he feels the same way in his heart.

“But you do know it’s no trouble for her to see you, right?” I ask just to be sure Sonny knows it is not an inconvenience.
“Yeah, I understand, but I know what I believe. I don’t want anyone trying to convert me,” Sonny replies.

“Well, she’s not going to try to convert you,” Allison clarifies.

“I still don’t want her to come out,” Sonny says.


* * * * *

Sonny’s response to Allison’s inquiry about having the team chaplain come for a visit reflects a common response particularly for people who do not practice a religion or adopt one of the faith traditions. Many people, however, consider themselves spiritual, but not religious, yet do not call on the chaplain. In fact, all of the individuals I observed while shadowing the chaplain exercised their beliefs through such religious practices as prayer and/or taking communion. In addition, I did not observe any hospice patients who sought the care of the chaplain to work on spiritual matters independent of organized religion or religious rituals.¹⁶ I contend that one reason the chaplain is underutilized and when called, only employs religious rituals, relates to how patients perceive and understand the roles and responsibilities of chaplains. Sonny and others had concerns that the chaplain might seek to convert them. Sonny once mentioned, when talking about his parents, that his father was a devoutly religious man who forced the family to attend church every Sunday. The distain in Sonny voice while talking about this time in his life made me think there might be more to the story, yet I felt it inappropriate to probe further. While Sonny never explicitly linked his disinterest in seeing the chaplain with his

¹⁶ The chaplain did discuss conducting guided meditations with a patient.
Catholic upbringing, I suspect he was reluctant to pursue visits for this reason. I could sense that his father’s insistence that he attend Mass left a permanent bitter taste.

Second, I believe team members do not adequately assess patients’ needs for a chaplain. Team members’ definitions of spirituality frequently focus on the conception of a supreme being and patients’ relationships with their God, which significantly limits the scope of what constitutes spirituality and thus spiritual pain. The spiritual issues people described when narrating their lives to team members were vast, including such topics as giving up a child for adoption, drug use, addiction, and sexual abuse. One patient described renting an apartment for a woman so she could be a prostitute under his management. The woman eventually ran off with her first customer sparing the patient any additional regrets regarding this venture. Three of the five team members I interviewed defined spirituality using monotheistic terms including God or Higher Power. If team members define spirituality more broadly, the greater the likelihood they would recommend spiritual care. Helen’s story in chapter five exemplifies this dilemma. Rather than recognizing Helen’s inability to pursue her passion for cleaning houses and caring for her animals as elements of what gave her life meaning, and therefore a component of her spiritual self, hospice staff treat these dilemmas exclusively with non-spiritual interventions such as counseling and pet therapy. Therapy may benefit similar patients and reduce spiritual pain, but this does not preclude patients from also receiving spiritual care from a chaplain. Alternatively, team members who tend to focus on the body or a patient’s psychological state, rather than what patients’ stories say about the meaning or purpose of their lives, staff will miss opportunities to recommend a chaplain.
Team members’ lack of recognition of the connection between the progression of illness and a spiritual crisis means that many patients may not receive the holistic care foundational to the hospice philosophy. By using narrow definitions of spirituality, team members’ discourse emphasizes religion and not spirituality. Most team members will talk about spirituality, employing religious terms, prohibiting talk about spirituality among patients. Such discourse also exists in team meetings where talk centers on medicine and related interventions. The organization’s use of the word chaplain, with a definition firmly rooted in religion, is one such example. Another barrier to the use of chaplains in hospice includes how team members present the idea of spiritual care to patients and families.

*Introducing Spiritual Care to Patients*

The first time hospice inquires about a patient’s religious or spiritual beliefs occurs during initial admission and then again when members of the patient’s care team make their first home visits. At these visits, as well as throughout the patient’s time in hospice, nurses and counselors ask, “Would you like to see a chaplain?” Offering spiritual care in this way tells patients very little about the chaplain, such as whether she or he espouses exclusively to one religion or is non-denominational. No matter a patient’s beliefs, an organization the size of Coastal Hospice can accommodate a patient’s needs. Lack of such details and insights leaves patients to come to their own conclusions about what a chaplain does. For some patients, especially those raised Catholic, the image of a chaplain likely brings to mind Last Rites (now known as the Sacrament of the Sick).
Furthermore, people who are Jewish, Muslim, Buddhist, Atheist, and even Wiccan\textsuperscript{17} may not immediately identify their beliefs or concerns as synonymous with a chaplain’s purpose.

The work of chaplains acknowledges and holds sacred the knowledge that there is much more “to human life than the state of the body” (Callahan, p. s7-s8). A team lacking a shared understanding of what constitutes spirituality prohibits the ability to offer spiritual care. The loss of autonomy or physical pain are no less important than the state of a person’s essence or soul, but an exclusive focus on a person’s body as the problem neglects a person’s spiritual well-being, creates a gap in delivery of holistic hospice care, and potentially hinders a patient’s opportunity for a good death. This is especially true in light of the emphasis on teamwork to accomplish such care. I now return to Doug’s story to illustrate the concept of a good death.

\textit{Communication and a Good Death}

The last time I saw Doug two weeks ago, the 42-year old military retiree dying of cancer, we played charades in an attempt to distract him from walking around his house and injuring himself. (He had already fallen the day prior and had a huge bruise on his head). During the visit, his abdomen was so large and distended that I silently feared a wrong move might result in a torrent of fluids spewing from his belly. Doug hoped he could have another drain and the procedure would gain him a few more days of comfort, but to Allison and me, combating the ascites appeared futile. Doug’s cancer had advanced to the point that he would have to receive a drain every other day. Since the round of charades, Doug moved out of the team’s jurisdiction to the local Veteran’s

\textsuperscript{17}One patient in my study identified as Wiccan.
Administration hospice. Today, Allison and I are going to see Doug for what we suspect will be the final time.

The Veteran’s grounds are expansive with services including a hospital (with a hospice ward), a nursing home, rehabilitation center, and a cemetery. The landscape is beautiful with trees, colorful flower beds, and ponds. We have trouble finding the floor where the hospice is located because of recent remodeling, but after several misdirections, caused by the staff at the information desk, we manage to find the hospice floor. It reminds me of an empty library – subtly lit and eerily quiet. A volunteer greets us and provides Doug’s room number, but before we can make it to his room, a staff member stops us and introduces herself. Unlike the staff downstairs at the information desk, this woman is very helpful and welcoming. Getting closer to Doug’s room, I see a man wearing a leather motorcycle vest with patches indicating his military service. I silently hope he does not come by Doug’s room because although they share a common bond of military service, they could not be more different. Doug seems more refined than this man who looks as though his primary mode of transportation is a Harley Davidson Road King and the bulk of his income stems from selling POW-MIA patches and bumper stickers on the Washington Mall.

We enter the room to see Tom standing over Doug’s bed. The nurse tells us they are planning to transfer Doug to a chair so he can go outside for lunch. I look towards the bed and notice that Doug’s head looks smaller than I remember and he has bed-head with his short hair going in different directions. His stomach, however, remains substantial. Although his eyes are open, unlike last time when he used one eye to avoid seeing
double, his pupils have a wild quality that combines deer in the headlights with calm recognition. I take this as a sign that he is transitioning, maybe even imminent.

The nurse manages to transfer Doug and his morphine drip to the chair, which is part wheelchair and part recliner. The nurse gives Tom some tips about how to maneuver this SUV of wheelchairs and the four of us take off for some lunch and a cigarette on the patio. Like an entourage, Tom, Allison, and I surround Doug, creating a physical and social barrier between him and the staff, patients, and visitors who pass us in the hallway. Allison complains to Doug about how all of the service staff – mostly janitors and maintenance workers – all stare and say hello to me, but not to her. I try to explain that this is what black folks do – speak to each other as if we are kin – but she is unsatisfied and looking for some sympathy. Doug does not offer much and claims that if he were straight he would probably say ‘hi’ to me too. He laughs infectiously and we join him.

Anxious for a cigarette, Doug puts one in his mouth almost as soon as we cross the threshold from his room to the hallway. We remind him at the elevator, in the elevator, and once more downstairs that he cannot smoke inside, but he keeps putting the lighter to the cigarette he cradles between his lips. Each time we hear the wheel of the lighter strike the flint we look over the chair and tell Doug he needs to wait until we get outside before he smokes. Each time we remind Doug and he acquiesces. None of us hears Doug light his Marlboro Light, but a woman in a lab coat immediately notices he is smoking.

“You can’t smoke that in here!” she says, as we pass by. We start laughing because we are less than five feet from the automatic doors leading outside. Moreover,
the absurdity of chiding a dying man for failing to follow the rules is comical. Doug says, okay, as if he did not know he was violating a rule and does not take another puff until we find the designated smoking area under a gazebo far from anyone in a white lab coat. Allison bums a cigarette, revealing to her clients that she smokes, and together the two enjoy the soothing effects of inhaling nicotine. Doug’s morphine pump hums, indicating a dose of the pain reliever is forthcoming. Taking a drag from the cigarette, Doug speaks, the words sliding out of his mouth, “I realize you can only help so much. That you don’t know anything about this. You’ve never done it before.”

Allison and I glance at each other over the top of Doug’s chair. Doug’s observation illuminates our weaknesses – we are not the guides who chart a specific course for people who dying. While we have knowledge about others’ dying experiences, that type of information is not helpful at this moment when death is so close. The mysterious nature of the imminent phase of dying appears too unique to articulate much less project onto another’s experience.

“You’re right,” I say, resigned to the truth of Doug’s observation and disappointed that hospice, an organization I felt a part of, had not contributed more to his ability to make sense of his dying. I also realize, however, that Doug’s expectations for what hospice could do for him were too high. He wanted precise answers from us about his death that we could not give because of the individual and experiential nature of dying. “But we’re hoping you can teach us,” I add.

“Yeah, I guess,” Doug replies, as he stubs out his half smoked cigarette.
I was hoping for some great insights about dying to flow from Doug, but his lucidness wanes.

“Maybe we can have your sister come down,” Tom suggests in recognition of Doug’s acknowledgment of his approaching death.

“That would be nice,” Doug replies listlessly. Allison nods approvingly. “As long as my mother doesn’t come,” he adds.

I have worried about Doug’s relationship with his mother since we first met. In fact, each time Doug’s name came up I would ask Allison if he had talked with his mom yet. The answers was the same every time I asked and it pained me to think that he was still trying to protect her from the pain of losing her son.

“You don’t have to worry about that,” Tom says.

“That’s good because I don’t want her trying to get my stuff. She’s a bitch,” he says simply, but slurring his words.

“No, all the paperwork is in place for your niece and nephew to get everything,” Tom adds.

“Good,” Doug states.

Listening to Tom and Doug talk, I suddenly feel a sense of relief wash over me. I now understand why Doug never made contact with his mother after learning he had terminal liver cancer. While I recognized at the time that I was projecting my own positive relationship with my mother onto Doug’s relationship with his, I could not see the benefit of withholding such information. For some reason, hearing that Doug’s relationship with his mother is tarnished and his interest in avoiding communication was
about something other than protecting her, I can let go of the image of a loving mother-
son deathbed scene.

Hospice work frequently involves acknowledging the boundary between your story and a patient’s story and discovering what you might want for your own dying. I never pressed Doug about contacting his mother, although I found it distressing to think that Doug would avoid calling, I had to accept that making the call would be my journey and not his. Furthermore, I realized that my image of a heartfelt deathbed scene between family members perpetuates a very specific narrative of a good death that involves forgiveness, repairing damaged relationships and making amends. Doug’s assertion reminds me that not all people need forgiveness or even find these things necessary to achieve a good death. A good death for Doug included having the last word in an ongoing dispute with his mother and bequeathing his material possessions to his niece and nephew.

Tom offers Doug something to eat and gives him the choices of lunch or dessert from Armand’s. Doug picks dessert. Opening a small box sealed with a satin peach ribbon, Tom reveals a smorgasbord of pastries: a lemon tart, a meringue, two turnovers (one cherry, one blueberry), a small pecan pie, and a piece of chocolate mousse cake. Doug decides to have the tart. Good choice, I think.

Given the severity of Doug’s illness, his appetite astonishes me. Each bite looks like a heavenly experience with dribbles of lemon curd sliding down Doug’s chin and dripping from his fingers. Tom takes a small carton of milk and a straw out of a white paper bag and offers some to Doug. He takes several gulping sips, releases the straw from
his lips, and says, “Hmm, real milk.” After finishing the tart, Doug takes a couple of bites of the light and crunchy meringue that Tom started, but decides he would rather dig into the cherry turnover. Flakes of paper thin dough drift onto his t-shirt. *The nursing assistant responsible for bathing and dressing Doug is going to be pissed when she sees this mess, I think.* I tell Doug that I have never seen someone enjoy anything so much. He unleashes his trademark big belly laugh and offers to share, but Allison and I both decline declaring that it is much more fun to watch him. After eating the second turnover, Doug appears satiated. Sugary goo from his afternoon snack covers his face and his shirt, which he tops off by smoking another half of a cigarette. We enjoy the sunshine and the company, but the time has come for us to leave. Allison and I hug Tom who seems to have taken to the Coastal Hospice tradition, and then we embrace Doug and say goodbye for the final time. Doug died the next week following a visit from his sister and just days after his dessert extravaganza.

* * * * *

According to the principles of a good death described by Smith (2000), the final chapter of Doug’s life exhibited each of the 12 principles, including, 1.) knowledge that death is approaching; 2.) the ability to maintain control over when and where his death would occur; 3.) the ability to have control over who is present; 4.) management of pain, and 5.) the availability of a myriad of services including hospice. Not all patients or their families can maintain such tight control over all 12 principles of a good death (Roscoe, 1998). Doug’s ability to communicate his desires for his end of life care contributed to his ability to die well. I believe Doug’s long history with HIV and proclivity for therapy
made him more likely than some to have considered dying and death as an everyday element in his life. Doug wanted, for instance, to remain as lucid as his ability to tolerate pain would allow, and he communicated such desires to his partner who in turn advocated for and ensured health care providers attended to his needs throughout the dying process. The ability to self-advocate is not always the case for patients because some cannot vocalize their wishes as a result of the progression of an illness, and others have no surrogate (Baergen, 2001), which is one reason Coastal Hospice encourages patients to have a living will, advance directives, or a designated health care surrogate.

Patients such as Betty, whose family demanded the reversal of sedating medications (discussed in chapter 4), do not have the opportunity to directly participate in their pain and symptom control because they are unconscious, leaving them at the mercy of other caregivers. Allowing next of kin to make health care choices is potentially problematic given research which shows that many family members are often wrong about their loved one’s wishes (Leichtentritt & Rettig, 2002). Further compounded by pervasive fears of dying and death, some families may choose life prolonging treatment, painful procedures or the withholding of palliative medications or procedures (the latter was the case for Betty). The concept of patient autonomy is foundational to the hospice philosophy; therefore, any behavior that prohibits the ability to carry out personal choice contradicts accomplishing a good death. Inaction or allowing another to make choices on your behalf, however, is also a form of autonomy, but only if such passivity is executed intentionally and with knowledge of the outcome of a failure to act.
Patient Choice and a Good Death

The debate over passive versus active health care decision-making and dying well came up frequently during team meetings. Most team members adopted the perspective that patients should do exactly as they choose if capable of engaging in the desired behavior. Team members regularly joked about encouraging their patients to consume things like beer and chocolate during their final days. Smoking cigarettes, for example, is acceptable as long as the patient does not smoke while using oxygen.\(^\text{18}\) Autonomy also extended to decisions about health care choices. During one memorable team meeting a nurse shared a story about his patient who after a hospital admission left the hospital against medical advice and bled to death – alone – in his home. The nurse said, “I thought I had seen lots of blood – working in dialysis – but this was more than I imagined. There was blood everywhere; in the hall, in the bathroom. I don’t think this patient had a good death at all.” The nurse’s story prompted a dialogue among veteran team members about the quality of this patient’s death, ultimately reframing the patient’s death as a good, no matter how traumatic the circumstances.

“He decided to leave the hospital AMA [against medical advice],” one nurse asserted in defense of defining this patient’s death as good.

“But he couldn’t have known what that meant…,” another nurse says in the patient’s defense.

“He decided to leave the hospital though, and he could have called 9-1-1 for help,” one nurse interrupts.

\(^{18}\) Using oxygen near an open flame can explode. One patient died this way and hospice team members frequently tell this story when the topic of patients who smoke comes up.
“He couldn’t have known what was happening to him and once it started it’s too late to do anything,” a nurse says, referring to the process of bleeding out.

One of the team leader’s boiled this patient’s death down to choice: he chose to leave the hospital, and he chose to stay home rather than returning to the hospital when he started to bleed from his mouth. The patient made a series of choices, and thus had a good death. “No one should die that way,” the nurse countered. Some team members posited that he had no idea the consequences of his choices, but overall no team members vocalized that the patient had a bad death.

Another patient discussed during a team meeting who opted to have his pacemaker turned off was said to have experienced a good death as well. The nurse, however, described a deathbed scene wrought with pain and fear, but because the patient had knowledge of the full range of options the nurse reconciled herself to having helped the patient die the way he wanted. On the other hand, patients who made health care choices that team members interpreted as indicative of denial, fall short of dying well. One woman who was dying of cancer (mentioned in chapter 6) insisted on, with the vehement support of her family, receiving artificial nutrition. Team members adamantly argued this would result in a difficult, if not bad death, despite the fact that receiving such care likely fulfilled a psychological, spiritual, or communicative function for the patient and her family.

The woman’s resistance proved problematic for the team for nonmedical reasons as well. The desire to pursue futile treatment conflicts with the hospice philosophy and thus the patient fails to write her own story in a way that is consistent with the larger
hospice narrative. According to Mak and Clinton (1999), a good death is predicated “on how effectively staff can competently promote what patients regard as a good death” (p. 99). Interestingly, the team did not view their communication as enabling or constraining the patient’s ability to narrate her story in a way that would substantiate hospice’s claim of supporting patients’ wishes, which would ultimately reflect the hospice mission. The team did not fully accept the patient’s wishes as synonymous with a good death whereas the other patients made autonomous choices that were then storied to match the hospice narrative. Once the patient discontinued the tube feeding, team members interpreted this as a sign she accepted her fate and put herself back on track towards a good death and achieving hospice’s goals.

Talking about a Good Death

Researchers encourage health care providers to engage in more dialogue with patients about their health care goals. Ragan et al. (2008) argue that palliative care teams successfully accomplish this goal, but my observations of hospice team meetings indicate that the objective of such talk is primarily persuasive (Mak & Clinton, 1999) rather than dialogic. Team members specifically spoke about patients in terms of persuading them of the right or hospice way. In none of the hospice visits I observed did team members ask patients to describe what a good death might look like for them and very few conversations focused on related topics. Findings from interviews suggest that team members do not think of how their work strives to help patients achieve a good death outside of controlling physical pain. The following interview excerpt highlights this issue.
Jillian: So can you tell me about one of your patients that you would describe as having had a good death?

Judy (Nurse): Oh. You want me to name names? Oh, geeze.

Jillian: Well, no, not names but can you tell me what the circumstances were. Like their diagnosis, and then how did the illness progress, and then what happened that made you say, “Oh, this would be my – my best example of a good death”.

Judy: Oh, brother. [Laughs.] Uh, uh, uh, uh. Gosh. Well I can think of one patient, I can’t really remember the name of his diagnosis. It had something to do with his eyesight. It was some – some weird disease. And uh, he had worked as a CEO for a big company. And he had the means for private hire [health care], and all that. And so, I guess his death – even though he lingered for a while. I thought he was going to die quickly and since I was going to have time off I prepared the continuous care folder so he could have 24 hour care. And it took eight weeks before he finally died.

Jillian: Wow.

Judy: Yeah. But he died peacefully at home, in bed with his family around him.

Jillian: So can you tell me about a time when you asked, or if you ever have asked a patient what a good death means to them?

Judy: Well, we have some new questions in our computer base. (I never saw these questions while I was observing because they were added after I completed my fieldwork and I was disappointed when I learned the particulars of each question because they probably would have influenced the outcome of my research findings.)

Jillian: Okay.

19 Occupation changed to protect confidentiality.
Judy: Has she [Allison] showed them to you?

Jillian: No. Uh-uh (no).

Judy: And we ask – matter of fact we asked Molly (a patient Judy referred to earlier in the interview). I’m trying to think how they word it because they’re new and she’s the only one we have asked them on. “What – what – what important things would you want to have around you when you die, what or who would you want to have around you when you die?” Um, and one of her answer was lavender. Soft music. Of course, her family.

Jillian: Right.

Judy: And then we said, ‘Does that include us?’ At first she said, ‘No.’ And then she laughed.

[Laughs]

Judy: Um, I’m trying to think what the four questions are. Basically, I think that’s about it. What would be your wishes for your final days?

Jillian: Right, right. I guess I’m wondering how you know what to do for somebody to give them a good death. Or what are some things that nurses do for instance, that help make sure . . .

Judy: Well, no pain.

Jillian: . . . No pain.

Judy: No pain. No pain. And you know, sometimes they die sooner than we think they’re going to, and then other times they linger. So I mean, it’s just trying to make sure that they’re – they’re comfortable, no pain, um, try to be able to ask those questions
previously if there’s anything that they want to talk about, or anything they need to – closure on anything.

This excerpt shows that until Judy received specific questions to ask about what people might want as death nears (e.g., thoughts about final days, surroundings including people or things, and services such as prayer, music, aroma therapy), she never inquired with patients about what constitutes a good death beyond pain control and the place of death (at home or in a facility). Her brief story about the CEO conjures up images of a canonical deathbed scene. When I probed for more information about the right time to introduce the concept of a good death or dying in general, Judy said the following:

Judy: Well, sometimes you don’t really have the conversation with the patient, sometimes it’s with the family. Um, depending on whether the patient is coherent or not, that’s something to take into consideration. Um, sometimes you know, after we’ve had them, if it’s the patient we’ve had for six or eight months and you can see the decline, we will ask, “How – How is your relationship with your children?” If we haven’t heard much about the family. We ask questions like that if we haven’t heard anything mentioned. And sometimes we get conversation, sometimes we don’t.

Jillian: Uh-huh (yes). Uh-huh (yes). So really when you start seeing the physical signs of decline, that’s usually a time when you’re gonna introduce either the topic with the family or maybe talk to the patient about some other – some – some stuff that might help with closure, something . . .

Judy: Uh-huh. Yes.
Waiting until signs of decline appear limits a patient’s ability to engage physically, emotionally, and spiritually in the type of interactions and psychic work necessary to work through family matters. I would add that such a conversation at the moment of decline is probably frightening for patients who could interpret such talk as a sign that the end of life is near especially if this is the first time team members have had such a conversation. Further complicating talk about what comprises a good death are patients who do not know or fully acknowledge their terminal diagnosis.

Framing Hospice and a Good Death

For some patients, the first time they learn that hospice is for people with less than six months to live is when they have their first visit from a member of their care team. Only one team member I observed made an effort to get a sense of patients’ understanding of their illness. This means that a patient’s referring physician and the hospice admissions nurse neglect to frame appropriately the purpose of hospice. This lack of talk creates additional constraints for team members ultimately responsible for caring for uninformed patients and their family members.

This dilemma became clear when I visited the home of a couple married for 60 years. The husband had Mesothelioma, a type of lung cancer caused by exposure to asbestos. The man did not look sickly, but small hints of his illness appeared around their mobile home. For example, durable medical equipment sat in the bathroom and yards of oxygen tubing stretched along the brown shag carpet. The counselor tried to ask the patient if he knew why he was in hospice, but the man’s wife interjected and said, “The doctor said it was to give us some extra help.” She never once mentioned that they
recognized the husband’s illness as life limiting. During another visit, when a patient with emphysema was asked if she had her advance directives, a living will, or had made funeral arrangements, both she and her caregiver-daughter said, “We’re not ready for that yet.”

If we accept Smith’s (2000) principles of a good death, the ability to die well is limited without first properly framing the purposes and goals of hospice. In addition, it is important for hospice caregivers to introduce the medical and non-medical issues related to dying in an effort to solicit information about patients’ wishes. A good death, then, necessitates effective communication. I contend that although hospice claims patients and their family members guide their own ships with hospice’s assistance, most patients need some direction about hospice’s services, goals, and approaches to achieving those objectives to get the most out of the available end of life care.

Narrating a Good Death

Communication about good deaths also arises in team meetings. From my observations, it appears that talk in team meetings reveals that hospice team members eventually come to narrate all deaths as good because there is no room for bad deaths in a hospice organization’s narrative or its founding philosophy. In fact, after a patient’s death, the team’s task includes identifying how all of the events that transpired prior to death contributed to dying well and a good death. Recognizing a death as good involves team members narrating the actions of patients and families in such a way that reframes and reflects the principles of dying well. Through retrospective sensemaking, team members come to view all deaths as good by describing the outcome as a patient’s
choice, an inability to accept their fate, or destiny. Each step along the journey towards a patient’s death always culminates in having died well.

Narratives of good deaths unwittingly imply that with or without hospice interventions, the outcome does not change. Dying well and achieving a good death, however, includes more than a single narrative told by the hospice team members at team meetings after someone dies. Many events and many conversations that lead up to a death make up a good death. A narrative from an interview with a veteran hospice employee will illustrate this point.

Jillian: So, I know this is going to be hard, because you’ve been here for years, but can you tell me about your most memorable hospice patient?

Terry (Counselor): My most memorable. That would have had to have been probably one of the first patients I ever had, not with this hospice. She was a lady of, I believe she was like 36 years old. She had four children. The oldest one was 18 and he was in Montana, in like a boot camp, and then she had three other little boys. They were like 8, 9, and 11. They were little stair steps. She was a drug user. She and her oldest son would sniff paint together and she had had a hard, hard life. The state was involved. There were a lot of agencies involved with her. She was Hispanic, and in that area there were a lot of Hispanic people with a lot of family members, so the family members really helped raise these little boys, because she was so into drugs. She became terminal and she had no plans for these kids, for where they were going to go. Her sister really couldn’t take them. Her mother really didn’t want to raise three little boys, because they were a handful.
She woke up one day and told her mom, “I have an appointment with God at 8:30.” The interesting thing was that her husband had died at 8:30 years earlier. Well, she didn’t want to die at home. She wanted to die at the hospital. So, when her mom called we said get her to the hospital. That’s a red flag. We got her to the hospital and we stayed all day. Me and another social worker went around town and got, it was a small little town, a couple thousand dollars, got all of this food to be donated, because we didn’t know how long she was going to be there and these people were very, very poor. We got all these different restaurants to donate food at different times, so the family could stay there (at the hospital), and it was really cool. I was so young. The kids were there and we tried to get her to sign. We had an attorney in there and we tried to get her to sign paperwork for the kids to go with their grandmother, and she was too ill. We couldn’t do this.

In the meantime, the morticians that were going to take care of her, they had become involved with her, because she started going to their church and they were discussing whether or not they would adopt these children because they didn’t have any children of their own and couldn’t have. So, all this was going on the whole entire day. There were many, many family members in and out, in and out, and I worked with the kids and the kids were right there with her and everything.

I finally went home about 5:30 and everybody kind of just left. We were exhausted emotionally. I got a call at 9:30. She had just died. The grandmother told me that the youngest little boy wanted to go home. Grandma took him home to get him, I don’t know. Whatever. Something. And all the sudden, he’s like, “I’ve got to get back to the hospital.
Get me back to the hospital.” She took him back. The boys were there with their aunt. All the family members and their friends had left. The only people in that room were her sister and those three little boys. The patient’s mom had stepped out to go to the bathroom. And the boys told me she sat up in bed, she looked around, and she smiled and laid down and died. I thought, “Gosh, she missed the 8:30. What’s the deal with the 8:30?” Well, we were in Mountain time. Her husband had been killed in a drug interaction and he was buried in California.

Jillian: So, it really was 8:30.

Terry: It really was 8:30. Just before she died, the funeral people, the funeral directors, had said, “Yes, we’re going to adopt these boys.” It was like about the same time that they had decided we will adopt these three little boys. It was just, “Woo hoo!” So they stayed with the funeral directors. They would go back and forth from grandma’s to the funeral director. They had this beautiful home and everything.

After the patient died, the family asked me to take the boys to the funeral home to see their mom, and I thought, “This is not my position. The family should be doing it.” but nobody had a car. So, I took them and you just kind of let things go. That’s when I learned you just let things happen the way they should be, because I thought, “I don’t want to do this. This is going to – and it was so cool. They came up and it was just her laying in the coffin, and they tied friendship bracelets on her and they touched her and they talked about her and then they would take off and they'd go do something and then they'd come back and they would say, “Did she have a beautiful smile?,” and then they would take off, and then they would say, “Why is she so cold?” I just let them talk and

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then the oldest son, he was on his way from Montana on a bus. That was the only way they could get him here. He got into town. He called and he said, “Would you take me to see my mom?” I'm like, I shouldn't be doing this.

Jillian: I don't want to interrupt you, but I have to ask. You said, this is when you learned you just had to let things go and you also said that you didn't want to do it. Can you explain “letting go” meaning you had to just let things happen the way they were going to happen? You couldn't intervene?

Terry: Yeah. It was just kind of like the family should be doing this instead of me just taking these little kids, because they would always have the family and they wouldn't have me after this. And now also, it's like how do you explain to kids and how would they react, and even though I was a teacher, it was different and that's when I just thought, ‘You know what? Let's just let them go and whatever questions, I'll answer the best I can and we'll try to get answers for them if need be,’ and it worked out. I didn't tell them, “Don't touch the body!” I just let them.

Jillian: Right. I see.

Terry: They tied things on her and they touched her and everything. The oldest boy, I just left him alone. I just sat in the back and I just, and then they didn't have a car, so I ended up being like a taxi. I took a lot of people to the funeral.

Jillian: So, it sounds like you were incredibly involved.

Terry: I was very involved. Probably, in all honesty, I wouldn't say too involved, but at that given time and it was a small town. Here there are more resources and I probably wouldn't have been a taxi cab and had to drive loads of people back and forth,
but it was a good learning experience. It was something that I will always remember.

Laura.

Jillian: So, what was she dying from? She was 36, you said?

Terry: I think it was breast cancer and had just metastasized everywhere.

Jillian: She was so young.

Terry: Yeah.

Jillian: So, would you say, you said her name was Laura. Would you say she had a good death?

Terry: Yes.

Jillian: And what made it good?

Terry: I think it was good that we did finally get her comfortable. She didn’t want to die at home and we were able to get her to the hospital. Just the fact that when she died, she died with a smile on her face. She looked so peaceful and because she had had a really hard, hard life. She had spent time in prison. She was a heroine addict. She had a hard life and she just looked finally at peace for her. I don’t know how the kids are doing.

Jillian: It would be interesting to see how they turned out in spite of all that.

Terry: I should Google that funeral home.

Jillian: Yeah.

Terry: I’d recognize the name and see if they still have the boys or see what happened.

Anecdotally, some people argue that how people live will dictate how they die, which would surely influence the possibility of dying well. Some scholars (Balducci,
2008; Schenck & Roscoe, 2008) contend that dying well includes using narrative and other spiritual tools. Although Laura, the patient in the narrative above, did not appear to narrate her death, she certainly put in place her wishes. Helen and Sonny, on the other hand, used some of these tools, narrating their joys, achievements, disappointments, losses and traumas. Although all patients have access to such tools, not all patients use the spiritual tools hospice avails them. There are two primary reasons patients do not employ these tools: one relates to patients’ and families’ perceptions of the role of the chaplain, and the other to professional and disciplinary roles and boundaries.

Previous research about nurses’ perceptions of a good death (McNamara, et al., 1994) support some of these observations, indicating that stories of good deaths shape the event rather than the events shaping the stories. This is logical given that research about good deaths usually occurs after the fact, which allows professional caregivers the opportunity to engage in subsequent sensemaking. Hart, Sainsbury, and Short (1998) argue that ascribing “patients’ behaviors to ‘good’ outcomes may well be a source of work satisfaction to professional caregivers” (p. 72). McNamara and her colleagues (1994) assert that ideologically a good death serves two purposes:

Firstly, the occurrence affirms the socially responsible individual who quietly slips away once all that could be done is seen to have been done. Secondly, it benefits hospice in-patient and community administrative structures by supporting their philosophies and goals and by facilitating the smooth running of the organizations. The Good Death, therefore, establishes a degree of stability within
the growing institutions of hospice care by providing precedents relating to
normative behaviours. (p. 1504)

McNamara et al. (1994) adds that these goals of a good death may constrain creativity
and the development of the hospice movement as a whole. The authors, however, neglect
to elaborate on the consequences of these constraints, so it is unclear which aspects of
hospice care or its social movement remain undeveloped. Hart, Sainsbury, and Short
(1998), however, argue that the ideology of a good death “legitimizes a new form of
social control over dying people; their choices are powerfully shaped and controlled to
this end” (p. 75). I believe this claim is true to some extent, but is shortsighted because it
fails to consider the ways patients exercise autonomy discussed earlier. Moreover, Hart’s
and his colleagues’ (1998) assertion denies the aspects of hospice care negotiated by
patients and team members. I step back from the arguments of McNamara et al. (1994)
and Hart et al. (1998) to contemplate how communication shapes conceptions of a good
death in hospice between team members and their patients. I argue that by focusing on
how the idea of a good death benefits hospice as an institution, we fail to acknowledge
the ways in which an emphasis on a good death prohibits communication about bad
deaths. It is natural for an individual, team or organization to want to downplay mistakes,
but failing to talk about bad deaths means missed opportunities to improve the
communication constitutive of care at the end of life. One team member shared a
narrative of her most memorable hospice whose indelible mark comes not from his good
death, but his bad death.
Robin (Chaplain): Well, it – it (her most memorable patient) would probably be the patient that died, I probably already told you this story, the patient that died – I had been seeing him about once a week for probably eight months. I’d been seeing him ever since I’d started with Hospice. And he was in his early 60s and he had lung cancer. And he was doing quite well. He lived in an apartment that was reduced income for seniors. He had a little Chihuahua that was really cute. And he had a history of alcohol, and drug abuse, and prison, and motorcycle gangs. And he had reformed.

And he and I just really formed a bond. He liked for me to come and I spoke very bluntly with him at times, especially, when he was feeling down. But he had started going to church with a neighbor and he had had a spiritual experience and he had gotten baptized. He felt like he was Saved, everything was wonderful, he was so happy and he liked to talk about his new life and how great it was. He didn’t have any connection with any family. He had a small connection with his sister that lived someplace else but she refused to come see him toward the – as his illness progressed and he was too ill to go see her. He felt bad about that but he had no connection with anybody else. So Hospice really became his family. I think he was our patient maybe two or three years.

And one time I went to see him and he told me he wasn’t feeling well and he was feeling really kind of down. And I was a little bit abrupt with him telling him – he was afraid he was going to hell. He got depressed and he’d been thinking about his past and he just decided that maybe he was too bad to get Saved. And he’d been listening to a CD from his minister. And there was something on this CD that led him to believe he couldn’t be Forgiven for what all he had done. And so I tried to help him but he – I didn’t feel like
I was very helpful to him and I kind of just said, “Snap out of it Charlie. You know you don’t have to have these negative thoughts. You need to replace these with something else.”

And so that was like on a Friday and when the nurse went Monday, he was incoherent and very ill and was taken to Baybridge (the facility based hospice under The Coastal Hospice umbrella). And I went to see him the next morning in Baybridge and they thought perhaps he was imminent. So I went to see him in Baybridge and he was sitting up, completely dressed on the side of the bed, and his nurse and physician came in and nurse practitioner and his physician. And they talked to him and I followed them out and I told them he was one of our favorites, that we all really liked him a lot and what was his condition. Was he imminent? And the doctor said they thought so the night before but now he was up and dressed and they weren’t really sure what his condition was. And so I thought about him all day and I had been listening. He had given me the CD that his minister – the one that had bothered him. And I had listened to it all weekend so I could hopefully find the right words to help him to feel better about where he was.

And so I went in the next – I decided I was going to do an anointing ceremony and anoint his head with oil to see if he could get the same kind of feeling he had when he was baptized ‘cause he felt so good about that. And when I went in to Baybridge, he was in the process of a bleed out which I did not realize and the room was covered in vomit and there were pads on the floor. I had to just walk through it and nobody was in there with him and I asked him, “What’s going on” and he said, “I’m really, really sick.” And I said, “Are you in pain?” And he said, “Yes.” So I went down to the nurse’s station and I
said, you know, “what’s going on down there?” And they said something about an internal hemorrhage with a large emesis. And I didn’t know what – and I said, “But he’s vomiting.” I didn’t know emesis was vomit.

So I said, “He’s really in pain” and they said, “Well, it’s shift change and we’ll get something down there as soon as we can.” And so when I went back down, I told him, you know, that I had an anointing ritual that I wanted to do with him, a little service and that he was gonna feel the same as he did when he was baptized, that all of his sins were going to be forgiven. And so I did it for him and at the end of it I said, “Charlie, when your time comes, I want you to reach out and take the hand of Jesus and just grab it ‘cause you’re never going to be alone. Jesus is going to walk with you to the other side.”

And he reached up and took my hand and died.

Jillian: Wow.

Robin: And so I, you know, and I just couldn’t believe he had died. And I couldn’t believe that I represented the presence of Jesus to him in that moment. So it was a very sacred moment for me, and a sad moment, and a scary moment because there was vomit all over everything and he had vomited his last vomit and then he died. So it was kind of messy besides the sacred significance of it. And I was really angry at the nurses for leaving him in there alone and leaving him in this mess because it was shift change.

And then when I went and told the nurse that I thought he had died, and I kept watching him to see if he was going to breathe again I really wasn’t sure if he was dead, and they came and checked him and they put on all sterile gown, gloves, mask, put a glove around their stethoscope. And of course, I’m standing there holding his hand with
nothing on. And she just walked out of the room. The nurse didn’t even speak to me. And so I had to follow her down the hall and I said, “Well, is he dead?” And she said, “There’s no heart activity,” and she just walked away.

Jillian: This is a Hospice nurse?

Robin: This is a Hospice nurse at shift change.

Jillian: Oh, my goodness. Do you have any good feelings left about Baybridge?

Robin: I – I was very, very angry about it and I realized the conflict for me, my badge said that I worked for Coastal Hospice. And I was reacting like a personal friend or family in thinking they had not treated him well and I wanted to raise cane with them. I mean I just really wanted to throw a fit about it. And yet it was such a sacred moment and it was a perfect death for him as far as death’s go because he wasn’t alone. And that was his fear was being alone. He was really afraid he would die alone and he didn’t. So I was really conflicted and it took me really weeks I think to sort out all the feelings I had about it, you know, the horror of him vomiting and me not knowing what emesis was and nurses only using the word emesis and not realizing it was a bleed out, which is what it was. And then feeling it was absolutely perfect the way it occurred for him and yet being angry at the way they had treated both me and him, both me and him.

And I think the nurse could tell I was upset. I didn’t address them. I went down to the chaplain’s office. I felt like I needed a chaplain but I had gone in about seven in the morning and the chaplains weren’t in yet. So nobody had come in yet so there was nobody there. And I called the team area and I said, you know, I said, his name and I
said, “He just died” and I’m crying. And they said, in the team area, they said, “What was the time of death” and I go, “I don’t know what the time of death was.”

Jillian: Don’t you get it?

Robin: Yeah. So that was my most memorable one and probably, you know, I have others actually but that will probably always be and I was relatively new. You know, I think it was – it – I think it may have been the first time I was actually present when a patient died at Hospice.

Jillian: I wonder if the first patient becomes, I don’t know, as solidified as sometimes the most memorable because it was the first. I don’t...know...But the circumstances around his death certainly make it memorable in and of itself.

Robin: Right. Yeah. I think it would have been memorable any time and that seems to be true because were you there when I did the good death bad death support? I don’t think you were there. It was interesting because I wanted to talk about it from a chaplain’s perspective because we reflect on what our feelings are in that moment and nurses seem to just do their job and clean everything up and go on.

And so I was wanting to talk about, there had been a big article in a chaplain publication about what’s a bad death, what’s a good death. And it was an interesting, a lot of chaplains have written in and there was a lot of information on it. And so I wanted to talk about it for [Team] Support and I was cautioned that the nurses were going to have a hard time because they don’t process the feelings.

Jillian: Right. Right.
Robin: And that good death and bad death was only to talk about your feelings that you experienced at this time. And the nurses did have a hard time with it and it was the newer nurses that spoke.

Jillian: That spoke up in a way more in line with what you were trying to...

Robin: Uh huh (yes).

Jillian...trying to...

Robin: And the older nurses...and one of them said that, you know, “I think we’ve had so many we just – it’s not that it’s routine but we’ve had a lot of them.” But the newer nurses all had one that they wanted to talk about and...

Jillian: Yeah, I’m sorry I missed that one. And in fact, some of my questions are going to be related to this concept of the – that the good death.

Robin: I can give you those printouts. It’s really – they’re really – some of them are quite theological. Some of them are a little bit judgmental because we all have those judgments going on but it was – and I loved reading them because it’s just what I do. But the nurses weren’t so interested.

Jillian: Interesting.

Robin: And it wasn’t – it was in their case support and we ended up talking about good ones and we ended up with some laughter so it was okay. But it didn’t exactly go the way I envisioned it.

Jillian: Right. So you would say in the case of Charlie’s death, it was a good death.

Robin: It was a good death.
Jillian: He did not want to be alone and he didn’t have to be alone.

Robin: And he was reaching for Jesus and I was that presence for him.

Jillian: And were there any other things about his death that made it good?

Robin: It was – you know, he did not suffer a long time. I mean he had had the illness for a long time but he was up and dressed the day before, not feeling great. And he had given his dog the – his nurse had agreed to take his dog, turned out to be temporarily. He knew his dog was going to be okay. He knew somebody had his dog.

Jillian: Were there any things about it that made it a bad death?

Robin: It felt bad to me because I felt inexperienced. I had never gone through anything like this where there were no nurses present, where there was vomit all over everything. I mean, it was eight feet away from his bed. I mean it covered the room and apparently, when that process starts, you just duck or there’s nothing they can do to stop it. And he was done really but by the time I got there, by the time I walked in except for a little bit more that came out when he died. So for me it was hard to see that and it was hard not to have anybody to comfort me or to talk to.

Jillian: Yeah. I’m trying to think of his, this is not one of the questions on my pre-formed list. I want to ask just generally what defines a good death. And I think more, more specifically how do you know – how do you know what’s a good death for a patient?

Robin: Oh I don’t think we can know. I don’t think we can know. The good death bad death is for each individual person involved in it. And they would label it according to their feelings and emotions. I don’t think we know for the patients. We can guess. We
can guess whether it seems peaceful, whether it seems quick, but I think part of that is it’s
totally a judgment call ‘cause they’re not there to say. And I had one lady that had hung
on forever and her family was really tired of it. She had a 15-year-old son. And her
family was tired of this. I mean we could not believe she had lived so long. And we had
called – the Hospice nurse had called her family in from out of state like three times and
she would come back from the brink.

And finally, the time, you know, she couldn’t come back anymore. And she and I
had spent a lot of time together. She went to Baybridge. I went down there and she said,
“I can’t do this anymore.” And she told the physician, and the physician talked to her
about sedation to keep her free from pain and it was going to be very soon. I mean she
just could not breathe any longer. And her family, at that point, wanted to all come in
from out of state and they were begging her to hang on for a few more days so they could
all get there.

And to me, I thought, oh no. They can’t ask her to hang on any more. She is ready
to go, let her go. And when they started coming in, each one was begging her to wait a
little bit longer and it seemed absolutely cruel to me, but I finally got that from her
viewpoint, she probably was thrilled with them asking her to hang on until everybody got
there. And she was thrilled that they all wanted to be there for her. And she was thrilled
that they were all telling her they loved her even though she was just hanging on by a
fraction of a breath, struggling every moment. It probably was a good death for her. And
I was thinking, just let it be. Get it over with, you know, it’s been years.
So I think you can’t – and she was way too sick to ask her how she felt but I’m guessing that she felt very complete with the way, even though they were going you’ve got to live another day mom and...

Jillian: So has there ever been a time when you’ve asked somebody what it would mean for them to die well? Either, it doesn’t have to be like that direct question like, “What would be a good death for you?” But have you ever asked something that even was indirect or...

Robin: Well, we ask them where they want to die. Whether they want to be at home or whether they want to be at Baybridge. I think the biggest fear most people have is that they’ll be in pain and they’re not – most people say, “I’m not afraid to die but I am afraid to be in pain.”

Jillian: So are there other – other clues about – I guess what I – I guess what I’m hearing, well let me put it this way. I guess what I’m hearing you say is there are sometimes when you’re going to have to guess because based on what you know about a person, based on all the conversations that you have had, that’s the best way to kind of get a sense about whether or not the death is good or bad. But of course we don’t know because there’s no real concrete way of knowing but you can have a sense based on – would that be true based on what you know about a person?

Robin: I think so but realizing it’s totally a judgment call.

Jillian: Right.

Robin: And what one person might call a good death, somebody else standing there might call it a bad death. You know, I’m thinking about the lady where – where I
had never seen her before, never been involved with her and she was imminent. We had Continuous Care in there. I think it had been about 10 days and she was moaning and carrying on and they could not get her to die. They just could not believe why she was still living. And they had given her lots of pain medication just way, a whole lot. And she was still moaning and carrying on.

And when I went in and did a meditation for her, she calmed down and calmed down and calmed down and calmed down and died. And her son-in-law was there and he thought it was perfect and peaceful. But she had been in conflict for over, almost two weeks, trying to die but something was not right for her. So what would she call that? Good or bad? I don’t know.

Right. And maybe it is sometimes left for the people who are surviving to make the choice. Like the son thought it was good...

Jillian: Yeah....and maybe that’s what counts sometimes.

Robin: And I’m sure she did – she wanted somebody who – she was younger and really wasn’t ready to die. She didn’t want to. And whether that was what was keeping her in that conflict. There was a lot of activity in the home. The bed was out in the middle [of the room] and it just felt hectic when I walked in there. It didn’t feel – the energy didn’t feel good in the room. And whether she needed peacefulness and yet the other lady I was talking about that was at Baybridge, she just had all this activity in her room and I’m suspecting that’s what she wanted.

Robin’s narratives reveal several important issues for hospice and team’s conversations about dying well and good versus bad deaths. First, she notes that team
members, especially nurses, do not want to discuss good or bad deaths because of the emotions they bring up. She also highlights the challenges of helping patients achieve a good death, one of which involves a lack of communication. Robin indicates, as do the other interviewees, that team members ask patient about their desire for their place of death, but nothing else. All other actions related to patients’ deaths are judgments calls or intuitive choices on the part of team members. Team members appear to perceive good deaths as events of chance rather than a series of deliberate actions. It is unclear why hospice team members do not directly ask patients and family members what a good death would mean for them. The absence of explicit communication related to dying well could serve to improve communication among patients and on interdisciplinary teams.

_Improving Communication on Hospice Teams_

Communication during team meetings focuses primarily on determining whether a patient is appropriate for hospice based upon Medicare criteria. Nurses hold the bulk of the responsibility for making the case to a team physician that a patient is appropriate. The other four members of a patient’s care team have little voice in this process. These other team members might vocalize concerns about the consequences of a patient not receiving hospice care, but these concerns rarely contribute to substantiating Medicare appropriateness. Nurses are also the primary force for dictating a patient’s care plan. The combination of these responsibilities place nurses at the top of the team’s hierarchy and in turn affords them more authority and status. A structure of this sort, however, contradicts the purpose for providing interdisciplinary care (Eisenberg, 2008; Ellingson, 2005). Even if hospice teams, out of medical necessity, must keep nurses at the topic of
the team hierarchy, they can improve communication by creating opportunities for all members to participate in developing patient care.

Twice during my observations, the team physician asked for those presenting new admissions to offer the information as a patient narrative, not just their health status. I support this suggestion, but stress that the team should discuss these narratives throughout patients’ time on the team in an effort to enrich discussions about their care. There are three times when the team members from each of the five disciplines should contribute to the development of a patient’s narrative and care plan. The first is upon admission, the second is at the initial 90-day recertification period (and if appropriate subsequent recertification periods), and the third is after a patient’s death. These Patient Narrative Talkbacks (PNT) would provide team members a structured opportunity to communicate their perceptions of a patient’s progress towards a good death. Patient Narrative Talkbacks would allow all team members to offer suggestions from their professional expertise and through these narratives realize opportunities to provide care from the non-biomedical dimensions of patients’ quality of life. Furthermore, team members should physically integrate during team meetings rather than sitting in groups that perpetuate a visual reminder of professional roles. Segregating by area of expertise contributes to a sense of hierarchy among team members.

In addition to PNTs, I have three recommendations to increase the use of chaplains on the team. First, Coastal Hospice should consider renaming their chaplains to reflect the comprehensive spiritual care they are capable of providing. A title such as Spiritual Care Specialist is less likely to carry the baggage of a term such as chaplain. In
addition to renaming the chaplain role, nurses and social workers should introduce the idea of receiving spiritual care in a way that echoes the identified needs of the patient. Chaplains should conduct their own spiritual assessments upon new patient admissions or conduct joint visits with other team members as a way to introduce themselves to patients. Finally, I would also recommend team members ask patients directly about the people and events that would make a good death and limit the need for judgment calls and narrating all deaths as good.

Many people live full, meaningful lives while suffering through physical pain; therefore the notion that a good death or dying with dignity only focuses on the state of body is problematic. The goal of the hospice chaplain is much more about the purpose of life and supporting and guiding a person towards their personal journey than it is about securing a place in heaven for a person’s soul. With a few changes in communication practices, team members can improve patients’ perceptions of chaplains and in turn improve end-of-life care overall. Improving spiritual care and communication about dying and death also involves improving communication among team members, particularly as it relates to managing patient care. In order to achieve a good death for patients, team member should focus less on narrating the quality of patients’ deaths and begin to make connections between how those narratives can influence care.

Observing and listening to patients with life-limiting diseases carries numerous ethical and emotional dilemmas. In the next chapter, I will discuss some of the ethical issues that influenced the methodological and personal challenges I faced conducting a research project with Coastal Hospice.
Chapter 8 – Methodological & Ethical Issues

In 2004, I first started thinking about the ethics of conducting research with people who are dying as I sat in the hospital room of my mentor, Leah, who was dying of ovarian cancer. Nick,20 her husband who was familiar with my interests in studying death and dying, turned to me and said something akin to, “You know you can write about this if you want.” At the time, I thought the suggestion was incredibly obscene. I was not about to sit there taking fieldnotes in between Leah’s slowing and labored breaths. I politely declined the invitation, telling Nick and others, who mentioned the prospect of including this experience in my research, that I needed some critical distance before I could even think about writing about Leah’s dying and death.

In retrospect, I realize my refusal to accept Nick’s invitation had more to do with my desire to be present during Leah’s dying than any reluctance to make use of Leah and Nick’s experience to explore my research interests. Conducting research with and about people who are dying continues to give me pause. Through this experience, however, I recognize that I can be present with people who are dying and their loved ones while simultaneously conducting research. The lines between empathy and objectivity are blurry, yet the fluidity of those boundaries makes research of this kind possible. With that said, I will address the ways in which I managed the methodological and ethical challenges of conducting research with people who are dying. What I will discuss here

20 Nick is an ethnographer and both Leah and Nick were communication scholars.
are those ethical issues and dilemmas not addressed by Institutional Review Boards or Health Insurance Portability and Accountability Act (HIPPA) regulations, such as terminal time (Keeley & Yingling, 2007), member checking, and anticipatory grief among participants and researchers. I will also address the ways in which I believe qualitative methods are the more ethical choice for conducting research in hospice (e.g., the interpersonal qualities) and close with recommendations for improving hospice communication.

For some people, a terminal diagnosis or entering a hospice program makes the finite nature of life real for the first time in their lives. Recognizing that life is limited, people may feel a sense of urgency, and time becomes more precious. Keeley and Yingling (2007) refer to this phenomenon as terminal time. For a researcher, the concept of terminal time means asking participants to give their valuable and limited time to participate in a study. Although participating in an ethnographic study appears a passive activity, patients must give their physical and mental energies. Furthermore, most research projects that focus on the end of life will most likely yield no benefits to participants who will not live long enough to see the results.

With this in mind, I never asked individuals who were imminent – within 72 hours of dying – to participate. When I considered my ethical responsibilities to hospice patients, their families and loved ones, I could hear the words of my advisor, Carolyn, “Try not to ask too much of participants who may get little out of being part of your study” (Ellis, 2007, p. 24). I took this recommendation to heart and put it into practice. For example, while visiting the home of a newly admitted hospice patient, I opted to
pursue informed consent at a later visit because the patient and his caregiver were very emotional about the patient’s terminal cancer diagnosis. I explained the project and they verbally agreed to participate in my study, but I told them they could complete the necessary paperwork at our next visit. This newly admitted hospice patient was capable of giving informed consent at the time of our initial meeting, but I did not think it appropriate to ask for participation given the patient and the caregiver’s emotional susceptibility to psychological harm.

Most often, hospice patients happily agreed to “help me with my project” when I told them about the study and asked for their participation. In fact, I never had a hospice patient or family member refuse to participate or ask to withdraw even though I anticipated such challenges. I expected the demands placed on me by the Institutional Review Board to disclose the purpose of my research would turn many people off and possibly cause more trauma than if I withheld the rationale of my study. I found people’s responses surprisingly neutral when I told them that my goal was to understand “the ways in which IDT members communicate about spirituality, dying, and death with hospice patients and families.” However, the explanation of my study did prompt some unexpected emotions from one participant.

Seven months into my fieldwork, while I was observing with the team’s chaplain, I made a patient I call Billie cry. I met Billie, a woman in her 50s, several months earlier while shadowing a Home Health Aid, but I had not seen her since. I found Billie memorable for two reasons. First, her 32-year-old son died less than a year earlier after succumbing to cancer – the same disease now hastening her life. Billie’s six cats also left
an impression on me. The house smelled like a combination of ammonia and kitty litter. I remembered thinking during my initial visit that despite my love of animals, I could not wait to wash my hands.

The familiar smell of the cats assaulted my senses when I visit Billie for a second time. The difference today is that it is the peak of summer and the air is thick with humidity. I make every effort to turn off the receptors hindering my ability to give Billie my undivided attention. Normally, a few deep breaths effectively hone my attention, but deep breathing is not advisable under the current circumstances, so I develop an impromptu mantra. “Focus, Jillian. Focus.” In an effort to keep the distraction to a minimum, I also offer to help Billie unwind and sort a tangled mound of yarn sitting delicately on her blanket-covered lap.

Robin, the chaplain, starts the conversation slowly by asking Billie how she feels, but Billie’s response seems lackluster, yet not tired. Robin continues to ask questions at a pace in keeping with Billie’s disposition to which Billie reacts slowly with confusion. Robin asks, “The anniversary of Steven’s death is next week, right?”

“No, it was last week,” Billie replies.

“Weren’t you in the hospital last week?” Robin asks, certain about the date of her son’s death and the timing of Billie’s hospital stay.

“Yes,” Billie responds. Despite the confusion Robin continues,

“Are you going to do something? Have a memorial for Steven?”

“I don’t know. I was thinking I would leave carrots,” Billie says.

“Did your son like carrots?” I ask, looking up from my baby blue strand of yarn.
“No, he hated them,” Billie says emphatically.

“Oh, I see,” I say, smiling in recognition of the inside joke. I am a surprised that Billie and her husband do not have more planned, yet I understand that Billie’s physical and mental limitations hinder her ability to do more. Furthermore, I have heard many of the team members discuss Billie’s difficulties moving through the grieving process and manage her own illness. For example, Billie frequently refuses to take a shower when Home Health Aids visit and cannot stay focused during meetings. Today’s visit is no different.

As I stand at the foot of Billie’s extended recliner, she asks, pointing to a statue over my left shoulder, “Is that an angel or a fairy?”

“That’s an angel,” the chaplain says with a tone of certainty.

“It’s definitely an angel. Fairies have pointed ears,” I add realizing as the words come out that Robin does not need my reinforcement.

“I’ve been thinking about getting rid of it,” she tells us, “because of a dream I had while I was in the hospital. An angel came to visit me and it scared me. I told her to go away.”

“Because you’re not ready to go?” Robin asks. Billie nods, emotionless.

“She thinks the angel was coming to take her away,” her husband offers as Billie’s eyes revert in the direction of his matching recliner. I cannot tell if the interruption irritates her or not. “But you’re not going to die,” he adds. I want to tell Billie’s husband his assertion is false. Billie is going to die. I want to tell him to just keep quiet and let his wife process her dying, but I just watch and listen.
“It’s a really difficult time right now, isn’t it Billie?” Robin asks, referring to Steven’s death, Billie’s illness, and her husband’s own health issues. Robin’s affirmation only prompts a nod. Billie diverts from the topic of the angel and tells us that someone put several hundred dollars in their mailbox to which her husband replies with a look of confusion. Billie’s husband spends the next several minutes talking about innocuous things in minute detail and since the conversation between Billie and Robin is now a monologue featuring Billie’s husband David, the time has come for the visit to end until Billie returns to the conversation.

“And what are you studying?” Billie asks in a moment of lucidity. I take this opportunity to bring my yarn duties to a close. I give my normal spiel – something I have probably said a hundred times by now – with little fanfare. I repeat the study’s description and Billie does not say anything; she just nods. Robin takes over and asks Billie, “Would you like prayer today?”

“Yes,” Billie replies.

“What would you like prayer for today, Billie?”

Billie asks for good health for her and her husband and the four of us join hands. Robin has one of Billie’s hands and I hold the other. I close my eyes and bow my head and the chaplain begins, “Dear God, Jillian and I come here today with Billie and David to ask that You look over them as the anniversary of their son Steven’s death approaches. Jillian and I ask that you give Billie and David the strength they need as they await David’s medical test and results. God you know what is in Billie’s interests and you know what is in their hearts…In Your name we pray, Amen.”

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I open my eyes and we stand in silence with our attention on Billie who is the first to speak. “She said something that made me mad.” Billie’s not looking at anyone in particular, but my intuition immediately tells me that she is talking about me. My heart begins to pound and my hands start to get moist. Tears well up in Billie’s eyes and Robin and I immediately kneel down to flank her. We both react in the same way and I think how this is not the first time we have knelt down to console an emotional patient. “She said, ‘communication at the end-of-life,’” Billie says. I can see the tears spilling down from behind Billie’s glasses. I initially feel bad for making Billie cry, but shock quickly supplants my sympathy. I am stunned that my well-rehearsed and unmoving description of my study prompted such a reaction.

As Robin and I surround Billie in her recliner, Robin acknowledges Billie’s pain with a simple response that acknowledges the gravity of Billie’s feelings, “It’s scary isn’t it?”

“I don’t want to die,” Billie says.

“You’re not going to die,” David says again, in an attempt to comfort his wife. This statement is unhelpful and dishonest and I feel frustrated when family members say such things. I wonder how Robin will respond because such attempts by family members to dismiss the reality of a person’s terminal prognosis creates constant battles for hospice team members. Robin says nothing and her quiet reminds me that there are times when silence is the best and only response. Rather than try to convince Billie or her husband that Billie’s life is limited, Robin tries to console Billie by acknowledging that knowing we are dying is painful. “I’m sorry Billie,” I say. “That was not my intention. I didn’t
mean to upset you.” Billie nods in recognition of my apology and eventually her body relaxes. Readying ourselves to leave again, I thank my hosts and apologize, “I hope you’ll have me back again.”

“Oh of course, you’re welcome anytime,” Billie says, as I let go of her warm doughy hand.

Having completed our goodbyes with hugs and handshakes, Robin and I walk through the screen door and free ourselves (and Billie’s gray cat) into the stagnant, yet fresh air reminiscent of a summer in Florida. I take a deep breath, one that cleanses my sinuses and brings a feeling of relief. We are half way across the lawn en route to the chaplain’s silver coupe when she whispers, “Are you okay?”

“Oh yeah, I’m fine,” I say. I am not sure my answer is honest because I really do not know how I feel about what happened. “I feel bad. I didn’t mean to make her cry.”

“Don’t feel bad,” Robin says, emphatically. “That was the first time Billie was real during the entire visit. I was glad when she started to cry,” Robin says laughing at how absurd it is to feel satisfaction about someone’s tears. “Didn’t you notice?”

“Oh yeah,” I say. I understand exactly what Robin is saying and I know why she is glad Billie expressed some genuine emotion. “I guess I’m just surprised because of all the times I’ve told patients what my research is about. Until today, no one has ever batted an eye. I just feel bad.” Again, I say I feel bad, but I really do not and I cannot say why. I struggle to come up with any better explanation. “Actually,” I say, as we round the corner to the house of the next two patients – a husband and wife both in hospice – “I don’t feel bad. I can’t feel bad about talking about death and dying or the feelings that come along
with it because that’s exactly what my research is about.” We continue to process the
visit, recounting the various highpoints and the frustrations. I make a point to tell Robin
that I noticed how hard she was working to get Billie to go deeper into exploring her
feelings.

The visit with Robin and Billie is a perfect example of the constraints terminal
time has on patients and their difficulty communicating about spiritual issues and death.
The visit also reminds me that my work, despite the lack of emotional response I have
received from patients in the past, does or at least can have an emotional effect on
patients. Billie reminds me that the words *end-of-life* and *death and dying*, do hold
weight, especially for people who have a terminal illness. Yet, Billie’s reaction and
Robin’s goals for her visit with Billie do not mean that hospice staff or patients’ family
should avoid the topics related to the end-of-life. As the Sunflower team leader told me
during a meeting, “If we don’t bring it up, who will?”

Hospice staff and people who research hospice are not only obligated to broach
the subject of dying and death, but must also feel prepared to discuss and cope with the
emotions that arise. There are few guidelines, however, for researchers. Institutional
Review Boards (IRB) want researchers to ensure that safeguards are in place, but those
guidelines do not make explicit how researchers can or if they should protect against the
emotions associated with dying and loss. The feelings people experience when they or
someone they love is dying or dead are impossible to avoid, but the better question to ask
is why a researcher should want to avoid them in the first place. What I am suggesting is
that it is impossible and unrealistic for an IRB to expect a researcher to prevent fear or
anxiety among her participants who are facing loss. But this is indeed the impression IRBs leave with researchers.

While I have hospice counseling resources at my disposal should I cause emotional pain to a participant by introducing my research topic, I wonder if counseling is only a temporary or pseudo stopgap measure. This is not to say that hospice counselors are anything but competent, because the truth is that the psychosocial staff I observed were excellent. What I am suggesting is that emotions, for example, tears, sadness, anxiety, and fear, are very likely and expected during the dying process. What Billie illustrates to me is that researchers should not try or be expected to prevent feelings if they emerge during the regular course of a visit. These feelings can serve as a basis for generating knowledge and create opportunities for hospice staff to provide care.

Billie’s story also illuminates how few patients expressed any concerns about fears regarding my topic. After the encounter with Billie, I wondered if the description of my study evoked emotions that never surfaced during visits. If so, assisting a patient, detecting harm, or preventing emotional trauma could prove impossible for researchers or hospice staff. It worries me to think that after a session with a participant, she or he might burst into tears. At the same time, the visit with Billie makes me wonder if or how the informed consent process made hospice work easier by creating an opening for talking about topics relevant at the end of life. I question if there were times when my mention of communicating about dying, death and spirituality made people more willing to openly talk about their feelings or concerns. I have no way of knowing and this question was not among the goals of this research project, but these questions do challenge some of our
assumptions regarding talk about death and the role of Institutional Review Boards in ensuring participants’ emotional and physical safety.

According to Institutional Review Board criteria, my research methods were sound and my informed consent includes all of the required components, yet I must make choices in the moment about whether or not it is appropriate to recruit patients for my research project in ways not mentioned by IRBs (Ellis, 2007). At times, I find it is necessary to develop relationships with patients prior to asking them to become research participants. For example, I visited the home of a hospice patient with an eighth grade education. In addition to having a terminal diagnosis himself, his wife recently completed chemotherapy to treat breast cancer, a disease that took their daughter’s life just five years earlier. I spoke with the patient and his wife about my project in very general terms and asked if I could return next week with their nurse. My aim was to give the patient and his wife the opportunity to feel comfortable with my presence in their home, and to work on developing a relationship first, then request their consent. Obtaining informed consent is a process (Ellis, 2007) that does not necessarily begin or end once a patient has signed a consent form. I believe ethical research is relational (Ellis, 2007) and therefore it is necessary that I establish and maintain relationships with my participants to the greatest extents possible.

I could not predict if or how relationships would develop with the patients and the family members who agree to participate in my study. Billie could have turned down participating in my research in an effort to suppress emotions that arise because of what I symbolize. Attempts to avoid certain emotions may also explain why patients delay or
avoid receiving hospice care all together. Each visit from hospice is, after all, a reminder that death is near. Moreover, I wonder if there is an additional emotional strain placed on my participants when I develop a close relationship with them. My relationship with Sonny illustrates my concern.

*Reflections about Friendships with the Dying*

Sonny looked forward to the days when Allison and I visited; and I looked forward to talking with Sonny every Thursday. During our visits, we talked about Sonny’s service in the Korean War, horseracing, politics, and lost loves. In just over a month, I learned that Sonny went from an infantryman to a cook while serving in the Army. I also found out that Sonny did not place his bets at the track based on the horse, but the jockey. Sonny, a democrat, was not shy about sharing his political opinions. He believed anyone could do a better job than George W. Bush, but he was not sure the country was ready for Barack Obama. When Barack Obama won the election in November, I wished I could talk with Sonny. I also knew that Sonny was unlucky in love, married and divorced twice, and the best time in his life was when he raised his seven children, alone, for 12 years.

Sonny’s willingness to disclose the intimate details of his life made me think that we were friends. Just as Sonny, Allison, and I started to get close, we had to begin saying goodbye. I expressed my sadness over the thought one day to Allison after leaving his house and she said, “You know, this has got be hard for Sonny.” I paused for a moment.

“What do you mean?” I said.

“Well, we’re two more people he’s got to say good bye to.”

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Damn, I thought; this is risky work, but not for the reasons I carefully anticipated or even the reasons described by the IRB. Allison’s observation stopped me in my tracks and I realized I had to make a decision about how to manage my emotions, my attachment to Sonny, and his attachment to me. This accelerated trajectory of our relationship and simultaneous anticipatory grieving made me wonder if I have avoided spending time talking about the politics or horseracing or asking questions about Sonny’s youth. Maybe I was enjoying myself too much, at the expense of Sonny’s well-being. My presence in Sonny’s life (and his in mine) was ephemeral and it altered his dying experience. In other words, Allison helped me realize that although I am a researcher, the closer my bond with Sonny, the greater the likelihood that I would became another person Sonny must face losing. This is not to say that I was as important to Sonny as his children or his many grandchildren, but that the benefits and risks of my research to Sonny are more than the benefits or risks an IRB application inquires about. Despite the number of hours I have spent in the field and the number of hospice patients I met, I have yet to reconcile how to negotiate this ethical dilemma, except to say that I never take for granted any of my participants, especially those who allow me into their lives and hearts.

*Member Checking in End-of-Life Research*

The inevitable death of my participants presents another ethical predicament not often discussed in the literature on researcher ethics. Many qualitative researchers recommend member checking, or what Lindlof and Taylor (2002) call member validation, which involves giving participants the opportunity to preview and comment on a researcher’s findings. The majority of my patients, however, will not live long
enough to correct or respond to my textual representations of their words and behaviors. The inability to return to the field and validate many of my observations does not give me free reign. In fact, according to Ellis (2007), my ethical responsibilities are more poignant. For these reasons, I worry about invading participants’ privacy by recounting the intimate, sometimes even embarrassing, stories or experiences about a person’s life. I believe such experiences make a person, but I wonder if I should disclose traumas such as sexual abuse, domestic violence, or a stigmatized illness such as liver disease or AIDS (see also, Foster, 2006). I question my role as a researcher because I am not simply reporting the facts of a life, but offering interpretations of those lives. As a result of such a dilemma, I am often conflicted about the boundaries between my position as a researcher and a confidant. I have erred on the side of caution and likely make my participants appear more virtuous than they might be. The halo affect is a tendency I apply to hospice team members as well because informed consent does not mean that I own my participants’ stories. Informed consent means that my participants bestow their trust in me to represent them as truthfully and respectfully as possible.

The potential risks to participants when conducting end-of-life research may be greater than among other populations. Dying is an emotion-laden experience and, as such, dying and grieving people are most vulnerable during this time. Despite the lack of emotions I observed in the field, terminal time (Keeley & Yingling, 2007) compelled me to protect the ethical integrity of each interaction I had with people I worked with.

I feel driven to conduct research about communicating about dying, but I am simultaneously reluctant to engage in such works because of the ethical minefield I must
navigate. Each time I meet a potential participant, I wonder if it is ethical to ask a person whose life is near its end to participate in a research study whose benefits they will never know. I struggle to notice nonverbal cues that might indicate a person’s reluctance to get involved in my work. I worry about my ability to portray my research subjects who have trusted me with their stories. And while I may never know the effects of my brief appearance in the lives of patients and their families, I never forget that the opportunity to be present at the end of a person’s life is a privilege. Moreover, qualitative research, unlike other methods, allows me to share a person’s story with others, which is an honor.

**Concluding Thoughts**

According to Roscoe, Egan, and Schonwetter (2004), “Improving care in the final phase of life has been an important medical and societal goal during the last two decades” (p. 1). Improving communication about dying and providing spiritual care (Puchalski, 2006; Rousseau, 2003) is essential to improving health services at the end of life. This type of care takes place in numerous settings including hospitals and nursing homes. One of the beliefs that propelled my focus on hospice, however, was the notion that this setting and its philosophy created a unique space for dying people and their loved ones to communicate openly about spirituality, dying, and death. Previous research (Foster, 2006) found that volunteers, in their roles as members of the interdisciplinary care team, had almost no conversations with their hospice patients about dying and death. The goals of this project consisted of identifying whether other members of the team engaged in conversations about these topics. My aim included richly describing those conversations while considering communication regarding spirituality and a good death.
The ethnographic and interview data suggest that hospice staff talk with patients about death and dying infrequently and employ narrow conceptions of spirituality that focus on Judeo-Christian conceptions of religion. In addition, team members do not explicitly discuss what constitutes a good death for patients and assume that it always involves a death free of physical pain and the location of a person’s final days (e.g., where the patient wants to die). The lack of talk about dying and death in general and a good death more specifically, combined with monotheistic understandings of a patients’ spirituality is problematic in light of hospice’s philosophy of providing patients with deaths that are free of physical and spiritual pain. Research (Steinhauser, et al., 2000) suggests that pain and symptom management are extremely important to patients, but patients have “a strong preference for having an opportunity to gain a sense of completion in their lives. Life review, saying good-bye, and resolving unfinished business provide both patients and their families with an opportunity for human development at the end of life” (p. 2481). Moreover, lack of more explicit communication that concentrates on what constitutes a good death enables and constrains a team’s ability to provide a patient with all the tools needed to die well.

Although team members likely engage in embedded teamwork (Ellingson, 2005) to accomplish patient care, the lack of talk related to patient’s experiences during team meetings and the emphasis on electronic forms of communication such as mobile phones, e-mail, computerized bedside charting with pre-selected responses, and text messaging is troubling. Not only do these methods of communication, especially when used alone, compromise care, but they perpetuate the hierarchical structures that the use of
interdisciplinary teams are supposed to resist (Eisenberg, 2008; Ellingson, 2005). Rather than replicate the medical model, hospice teams should “take seriously the social construction of [their] healthcare teams…[and] look more closely at what these teams are making together when they communicate” (Eisenberg, 2008, p. 11). Hospice teams should focus on how they communicate to help patients and their families achieve good deaths. By making clear the team’s goal, which I believe centers on a good death, and then concentrating on a patient’s story rather than their list of symptoms (Browning, 1992; Eisenberg, 2008), teams could simultaneously improve patient care and team collaboration.
Epilogue

I have not seen Dr. Paul or thought of his image of a perfect death in months. In the interim, I have seen many sunsets, a few dolphins, and I look forward to sipping on an umbrella drink or two this summer. More than a year after meeting Dr. Paul and contemplating my own vision for the end of my life, I am more knowledgeable about the dying experience, having witnessed the lives and deaths of many people. Through their journeys, my life is fuller, but I sense that I have more to learn and I continue to conjure up and revise an image of my own good death.

Many people ask what prompted my interests in studying how people communicate about death and so I end this project by returning to the beginning. I always try to boil the tale of my journey down to a few sentences in an effort to avoid recounting my entire life story. I usually start in the middle and claim that the HBO television series Six Feet Under deserves the credit for spurring conversations between my mother and me about a myriad of topics related to illness, dying, death, and even spirituality. Back when Six Feet Under was still on the air, I realized that my mother and I were talking about death with relative ease – this was a new development. As an eager M.A. student in need of a literature review topic, the conversations with my mother about Six Feet Under prompted me to search the communication literature for research about how people talk about death, but I found little. In the intervening years, more scholars have researched the topic, but my own questions, curiosities, and interests in the subject persisted. Early in
my graduate career, the studies I found did little to satiate me because they were uninspired reports of survey results. I have studied the topic ever since hoping to fill those gaps.

If I were to start at the beginning and not in the middle, the truth is that all of the deaths I experienced before graduate school – a total of three – planted the seeds for my interests. The death of my former professor and mentor, Leah, solidified my commitment to this topic. I see Leah as central to my story because her illness marks the moment I had to put into practice all of the theory and research I had read. I could no longer just read, talk or write about the necessity of studying this type of communication: I had to begin enacting the principles I espoused. This was simultaneously a blessing and a curse.

From the time Leah received a Stage-IV ovarian cancer diagnosis, I walked a tightrope between apprentice and master. I often felt as though my graduate school colleagues looked to me for guidance because I was, after all, the girl who studied death. I performed the role as best I could, but the reality was that most of what I said about the importance of communicating about death came not from research, but was conjecture from my personal opinion. I consulted with my mom a lot during this time. “People get scared and avoid the sick person,” she reminded me. “You could be the person that’s not afraid.” My thesis advisor, who shared my interests in the topic of serious illness and dying and death, told me, “Now’s the time to put all of that you’ve been studying into practice.” I used the collective wisdom from my moms (one biological, the other academic) to do what many others avoid. I asserted and inserted myself into Leah’s and her husband Nick’s lives by calling and offering my time and emotional support.
I had taken classes with Nick when I was an undergraduate student and Leah was my teaching supervisor in graduate school. I also spent time with them at academic conferences and Leah eventually became a de facto mentor to me when I started researching doctoral programs. I would not have considered myself, however, a member of their inner circle. In fact, because Leah and Nick were two fiercely independent and private people, I was taking a risk by offering to help them during what most people consider a personal time or a private matter. This isolationist attitude is problematic and troubling in many facets of life from domestic violence, to addiction, to dying. In an attempt to give people their privacy, we send them the message that says, “You’re on your own.” This stance is the opposite of what most people actually need in times of crisis. Illness and dying is just as much a social phenomenon as a private one. So rather than giving them their space and private time, I figured the best course of action was to regularly offer my support and let Leah and Nick turn me down.

The process of observing people who are dying has taught me that receiving someone’s support presents a greater challenge than we might expect. A society that encourages independence produces people who do not know how to receive aid, much less how to ask for what they need. Eventually, Leah and Nick did take me and another graduate student colleague up on our offers of help. I sat with Leah on nights when Nick taught classes, and picked up groceries when Leah awoke from several days of sleep and asked for organic chicken (Vande Berg & Trujillo, 2008). I sat with Leah again and watched Nick cry at the hospital in the days before she died. I think my presence in their lives helped, but I failed to help Leah in one way. In my attempt to help her, I did not
allow her the opportunity to help me. I deprived her of the chance to carry out her role as my graduate school mentor when I neglected to ask her for letters of recommendation for my doctoral program applications. I thought such a request too burdensome and selfish and it was, but not in the ways I anticipated. Just as I allowed space for Leah and Nick to turn down my offers of assistance, I should have done the same thing with opportunities for them to assist me.

Despite my best intentions, I did Leah no favors with my feeble attempt at protecting her. A life-limiting illness does not mean that a person no longer has something to offer because “a dying person is [still] a living person” (Reisz Jr., 1992, p. 185). I failed then, but here is the thing about bearing witness to a person’s dying: you have the opportunity to do it better each time. I know I can better serve people who are sick and dying thanks to my experience with Leah. I use the word better deliberately, but not because I or anyone else can perfect such communication, but because I believe that each time we are with a person who is sick, we are more at ease. The comfort means authenticity, more openness, and less stress.

My development, however, is also the outcome of letting go of past fears. The death of my cousin (when he was seven and I was five) in a car accident remains a mystery to me, but the memories I have conjure up images of fright. A few years later, when I could better understand the gravity of illness and death, I was afraid to see my aunt when she lay in a hospital dying of cancer, so I avoided her. I was scared and had nightmares after my maternal grandfather died unexpectedly, but when my friend Leah was dying, I made a much greater effort to push through feelings of uncertainty and fear.
I took some personal risks and I feel honored and proud to have been invited to participate in Leah’s and Nick’s journeys.

Observing hospice patients interact with the members of their care team added new layers of understanding to my experience with Leah, but my time with her also informed how I communicated with others. Despite, or maybe because of, my time with hospice I still have some fears, but I recognize that those worries stem from uncertainties about what I might see, and not what I might say, when I enter the space of a person who is very ill or dying. After many months shadowing team members and visiting dying people in their homes, I noticed that once I laid eyes on the patient my anxiety dissipated and my interactions with patients and caregivers felt comfortable rather than stressful. My concerns about what a person might look like as their bodies deteriorated are minor and my interests to learn about living and dying always overshadows my worries.

My paternal grandfather’s diagnosis of renal failure in January caused by multiple myeloma (a type of bone marrow cancer) prompted me to reflect on how this project has changed me not just as a researcher, but also as a person. That is not to say that I see the two as unrelated. In fact, I believe my personal and professional lives are so enmeshed it is difficult at times to distinguish where one begins and the other ends. Moreover, I want my research to influence others as well as me in positive ways. But after hearing that my granddaddy was gravely ill and his prognosis poor, I wondered if I had lost my ability to feel compassion for a dying person and for the people who love them because when my father called to give me the news, I spoke to him with a cool detachment that made me feel sad and scared.
In my own defense, I can say that it was late when I got the call about my grandfather and I was exhausted. My attempts to derive a deeper layer of meaning from what my dad was telling me about my granddad’s condition prompted a more analytical and less emotional approach. I was listening and asking questions to help me assess the urgency of the situation. Based on the conversation I had with my dad and grandmommy, the tones in their voices, in particular, prompted me to go visit my granddad without hesitation, which was something I did not do when he was in the Intensive Care Unit eight years ago for 60 days.

Contemplating visiting my grandfather and saying good-bye for the last time pained me. The sting of the tears pooling in my eyes, however, was a relief because it meant I still had feelings. Until that moment, I seriously questioned whether I had damaged my emotional thermostat through over exposure to dying and death. Once I arrived as his bedside, I knew that I was not broken. The image of my grandfather, a man whose booming baritone voice terrified me until I was an adult, lying in a hospital bed with a tube down his throat made me want to weep. I held his hand, still enormous despite the ravages of multiple illnesses, and stroked his forehead. I silently prayed his suffering would end before I had to return home to Florida, but it did not. He lingered in the hospital for a month after my visit before dying on his way to receive another futile dialysis treatment.

My grandfather’s death helped me see that living out my final days in a hospital, with tubes and dialysis procedures, is not what I would want for anyone, but certainly not for myself. What I do hope for in my final days is to feel the love of my family, which is
something my grandfather did have. I did not say anything special to my granddad the last time I saw him in the hospital, I just kissed him on the forehead and said goodbye. I realized that my presence said more than the words that I could conjure.

All of the deaths I have witnessed help me act much more confidently than ever before. I would not go so far as to say that I know the right things to do, but I do not have any hesitation when it comes to making decisions to act. I think doing nothing is far worse and much less helpful than showing up, stepping in, assessing the situation, and just figuring out the next best step. I have only come to this way of being – which is a way of acting and a frame of mind – through experience. I am better at dying or I should say, at experiencing another person’s illness or dying, than I was when I started this project. Not only do I think I am more comfortable with dying and death, but I do try to live my life more fully. I have not created a well-developed list of people or things I want around me when I am dying like Dr. Paul. Dolphins and umbrella drinks are probably not at the top of my list and none of those things were important to the hospice patients I met either. The dying people I met, no matter how debilitating or painful their illness was, wanted just one more day of life. “Dying people are not listened to – their wishes, their dreams, their fears go unheeded. They want to share those with us” (Puchalski, 2002, p. 289). The gravity of this type of awareness, the keen knowledge that life is finite and that too few people are listening is the most important lesson I have learned. I hope this wisdom will allow me to embrace an illness with grace and honesty and ultimately conquer death by accepting it as part of life (Balducci, 2008).
References


Appendices
Appendix A: Interview Schedule

(Questions adapted from Charmaz, 2002)

1. Can you tell me our position/title and how long you have been working for hospice?

2. What type of work did you do before coming to hospice? What prompted the change?

3. Tell me about your most memorable hospice patient.

4. Would you say she/he had a good death?
   a. If yes, what made her/his death good?
   b. If no, what could have happened differently to provide that person with a good death?
      i. Can you tell me about a good death that you have been a part of while working for hospice?

5. Can you tell me about a time when you asked a patient or family about what it means to die well?
   a. What made you decide it was time to talk about dying or a good death?
   b. Has there been a time when you were reluctant to mention dying with a patient or family member? Can you tell me more about that?
   c. What do you do when a patient and family do not agree about what makes a good death?

6. What about spirituality? Would you mind telling me your definition of spirituality?
a. Is there a difference between your personal definition and how you define spirituality in your work?

b. Thinking back on your work at hospice, in what ways, generally, have you incorporated spirituality in your work?

c. How do you assess a patient’s spiritual needs?

d. What do you do if your patients’ spiritual beliefs are different from yours?

e. How do you respond to patient and family conflicts related to spirituality?

f. How do you define spiritual suffering?

   i. How do you help patients who are suffering spiritual or are experiencing spiritual pain?

   g. How often do hospice patients specifically want to talk with you about death and dying? Spirituality? Can you give me an example?

h. Can you tell me about a time when you initiated a conversation about spirituality with a patient or his or her family member?

7. Are there any challenges/issues that make it difficult for you to talk about dying or spirituality with a patient? Or talk with the patient’s family?

8. What metaphor would you use to describe your work as a hospice staff member?

9. In what ways has working with hospice patients changed you, if at all?

10. Can you tell me how your hospice training prepared you to work with patients and their families?

11. Is there anything that you might not have thought about before that occurred to you during this interview?
About the Author

Jillian is a Native Californian and it was in the Golden State where she developed her love of Communication Studies earning both her Bachelor’s of Arts and Master’s of Arts in the subject at California State University, Sacramento. When not conducting research about the end-of-life or teaching Health Communication, Jillian enjoys walking her dogs, practicing yoga, going to the movies, watching sports, and drinking red wine.