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# NARRATIVES OF HOSPICE VOLUNTEERS: PERSPECTIVES ON DEATH AND DYING

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By

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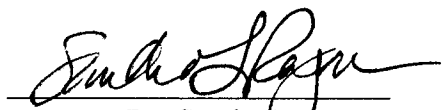
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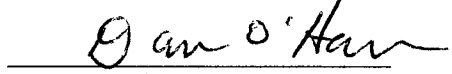
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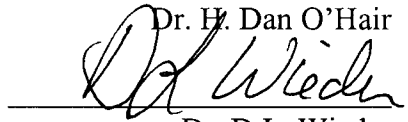
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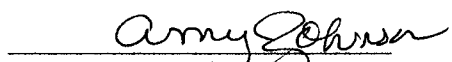
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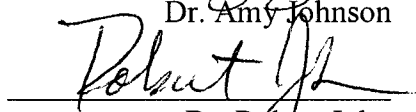
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Roses are red

You all are absurd!

Now get on your knees

And bow to Dr. Wittenberg!!

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ABSTRACT

Advances in medical technology have prolonged life and consequently death. As a result, Americans are taking longer to die, thus necessitating the need to talk to dying persons as well as the need to talk about death. A narrative functional analysis was used to determine how hospice volunteers negotiate communication with dying persons and to further understand how their experiences with the dying impacts their lives. Additionally, a dialectical theoretical approach was used to investigate psychosocial information sharing by case managers during hospice interdisciplinary team (IDT) meetings.

This study found that hospice volunteers' narratives function to make sense of death, warrant decisions for advanced preparation of their own death, illustrated an attempt to control their own death, transformed their identity into hospice representatives, and build community by establishing standard narrative formats. Moreover, ethnographic analysis revealed that additional psychosocial information provided by case managers during IDT meetings creates dialectical tensions for the care team. Future research is needed to understand communication apprehension with dying persons and to learn more about psychosocial information sharing in IDT meetings.

# NARRATIVES OF HOSPICE VOLUNTEERS: PERSPECTIVES ON DEATH AND DYING

## Chapter I

## Introduction

Advances in medicine and medical technology have changed the way Americans are dying. Quick and intense deaths caused by infectious disease, accident, or injury are no longer the norm (Callahan, 2000). The ability to receive medical treatment and advanced testing has caused illness to become a permanent condition rather than a temporary state, further obscuring the medical community's ability to determine when death is imminent (Callahan, 2000). This prolongation of life has shifted the cause of death from infectious to chronic diseases. In essence, the act of death has been replaced by the medical process of dying. Callahan summarizes that this has resulted in "longer lives and worse health, longer illnesses and slower deaths, and longer aging and increased dementia." (p. 47).

As a result of this change, Americans are experiencing death differently. For example, 50 percent of children in 1900 experienced a death in their nuclear family before the age of 15 compared to 10 percent of children born in 1976 (Bern-Klug & Chapin, 1999). According to Bern-Klug and Chapin (1999), of the 2.3 million deaths that occurred in 1995, over two-thirds were people 70 years or older. Opportunities for learning about death and how to communicate with dying persons are limited by this older population of dying (Bern-Klug & Chapin, 1999). As more causes of death result from chronic conditions, people are living in a dying role longer, thus making it more frequently necessary to communicate with dying persons (Bern-Klug & Chapin, 1999).

In addition to the need to talk to dying persons, there is also a need to talk explicitly about death. Buckman (1998) posits that there is a 'social denial of death' due to a lack of experience of death in the family, society's high expectations of health and life, a materialistic culture, and the change from community-based religion to individualized religion. Moreover, realistic views of death from practical experience have been replaced by "a voyeuristic, adolescent preoccupation" with death as the dying have been unrealistically portrayed (Littlewood, 1993, p.70). This misrepresentation has contributed to the trepidation associated with communicating with dying persons who are seen "as living reminders of the unavoidable reality of death.. [and] may be avoided rather than supported." (Littlewood, 1993, p. 70). As a result many people are dying alone and individuals are missing the opportunity to say good-bye to loved ones.

The medicalization of grief and bereavement which occurred during the 1950s prompted a transition in the place of death from home to hospital, and the medical community believed it was their responsibility to keep death away from the community (Littlewood, 1993). It was only recently that healthcare professionals began to focus on end-of-life care, namely hospice and palliative care. Both hospice and palliative care are aimed at maintaining a decent quality of life for the patient. The focus is on the patient's comfort and practical needs, as well as psychological, social, and spiritual needs. This healthcare approach is patient-centered as the patient is able to dictate what he/she wants in their last days/weeks.

Hospice and palliative care are provided by a team of healthcare professionals and volunteers. There are over 3,600 palliative and hospice care teams in North America (Finlay, Higginson, Goodwin, Cook, Edwards, Hood, Douglas, & Norman, 2002). These

teams are responsible for coordinating care and improving communication among health care professionals, patients, and families (Finlay et al., 2002). A palliative care team is called in by a physician when a disease is not responsive to treatment, whereas a physician refers a patient to hospice when a patient has been diagnosed with a terminal condition and has a life expectancy of less than six months. "Hospices coordinate the care of the terminally ill acting as a gatekeeper to manage treatment of the terminal condition." (Gage, Miller, Coppola, Harvell, Laliberte, Mor, & Teno, 2000b, p. 5). In hospice the focus is on care not cure, and patients no longer focus on curative treatment. On the other hand, palliative care patients may receive treatment for their terminal condition. Thus, although the two both provide care for dying patients, palliative care goes one step further to involve patient attitudes and includes expert pain management, expert psychosocial support, and forms of treatment (Robbins, 1998; Aranda, 1999; Fordham et al., 1998; Carney & Meier, 2000).

According to Schumacher (2003) there were over 885,000 patients in hospice care in 2002, all of whom experienced the compassion of some 2 – 3 million volunteers. Overall, volunteers provide an average of 15 percent of all hours worked for hospice (Sendor & O'Connor, 1997). However, the impact of volunteerism in general is still not known as measurement instruments have not been established (Littman, 1998) and volunteer effectiveness is difficult to measure (Gerson, Glastris, Chetwynd, Fox, Randsell, & Cohen, 1997). Moreover, there is limited research aimed at ascertaining the knowledge, skill, and understanding that is acquired by hospice volunteers in their role in end-of-life care. As such, this dissertation is a preliminary examination of the experiences

of hospice volunteers with the purpose of examining volunteers' communication with dying persons.

This study investigates the practices of hospice volunteers as they negotiate their role in caring for dying persons and their families. According to Naomi Naierman, President and CEO of the American Hospice Foundation, volunteers are available to assist the family, do household chores, provide companionship for the patient, and "generally respond to the family's need for support" (Naierman, 2003). Furthermore, the Department of Health and Human Services brochure on Medicare hospice benefits states that volunteers are able to assist with everyday tasks "such as shopping and personal care services, like bathing and dressing."

When compared to family members and primary care givers, the role of a hospice volunteer in end-of-life care is unique for several reasons. First, the volunteer does not have an emotional history with the patient and therefore is more apt to more objectively determine the needs of the family and patient. Second, the volunteer goes into the care situation with prior experience and training on how to communicate with dying patients. Third, the volunteer does not have a specific duty in his/her role as a hospice team member. Fourth, the volunteer is not getting paid to be there and thus feels that he/she has something to gain from their participation. Given their unique role, volunteer experiences become a meaningful data source that has the potential to contribute to knowledge about end-of-life care.

At the root of hospice and palliative care practice and philosophy is communication: communication between physicians and patients, between patients and relatives, and between healthcare professionals, all of whom contribute to the dying

experience (Doyle, Hanks, & MacDonald, 1998). De Montigny (1993) characterizes the palliative care unit as 'strengthened by the sharing of tasks, helping one another, and reciprocity." (p. 13). These communicative processes are all affected by contact with dying persons (Servaty & Hayslip, 1999).

The fear of death and how and whether to talk about death affects how people communicate with a person with a terminal illness as well as with each other. The experiences of hospice volunteers also provide a unique context for studying communication with dying persons. The presence of someone who is dying is perceived to be highly threatening on both an individual and social level (Littlewood, 1993). As a result many people experience communication apprehension when communicating with a dying person. This apprehension stems from a fear of one's own death and/or death of loved ones, a fear of the new and untried, a fear of inadequacy, a fear of not being accepted, and/or a fear for one's health (e.g. in AIDS cases). Volunteer training and experience force volunteers to confront these and other fears in ways that perhaps the rest of the population does not. For example, Hayslip (1986-87) examined communication apprehension of hospice volunteers regarding dying persons (CA-Dying) and found that adequate training decreased their communication apprehension.

*Statement of the Problem*

Little is known about the apprehension associated with communicating with dying persons. Learning more about how hospice volunteers face these fears can provide insight on how to communicate with dying persons. Moreover, their experiences are a rich and meaningful data source as they illustrate the effect that the experience of a death can have

on a person's life. Lastly, their experiences could possibly illustrate specific junctures that demonstrate America's cultural manifestation of death denial.

*Theoretical Approach*

Theorizing about health communication can best be explained in terms of dialectical tensions (Babrow & Mattson, 2003). For example, Babrow and Mattson (2003) posit that there is tension between the values and assumptions associated with scientific and humanistic study, more specifically the "power and potentialities of science and the desire to recognize and actualize our humanity." (p. 42). This tension is best summarized in the health field as the difference between the biomedical model, which emphasizes the disease of the patient, and the biopsychosocial model (Engel, 1977) which is a patient-centered model that includes the biological, psychological, and social aspects of healthcare.

Babrow and Mattson (2003) posit that attitudes and practices related to death and dying demonstrate the dialectical tension between science and humanism. A scientific perspective illustrates medical advancement as research on disease and treatment have prolonged life for many Americans. However, a humanistic approach reveals that these advances have ironically increased the time it takes to die as well as the suffering associated with the dying process. Overall, death has become less definitive as advances in technology have generated life support systems that allow individuals to go on "living." However, what hasn't been taken into consideration is the quality of life associated with this type of "living." From a humanistic perspective, these individuals may be dead (or at least their quality of life is severely compromised) but scientifically they are being kept alive.

Consequently, this blur between life and death, argue Babrow and Mattson (2003), contributes greatly to the cultural denial of death that has resulted in our inability to discuss death explicitly. Overall, Babrow and Mattson (2003) conclude that this attempt to control death has resulted in the loss of understanding of the meaning behind death. "We must, in short, face and refashion our understandings of nature and death and ultimately of what it means to live a human life" (p. 42-43).

Examining narratives in health communication is one approach that forces scholars to challenge the assumptions of scientific knowledge (Geist & Gates, 1996). Narrative examination allows scholars to move from a biomedical model to a biopsychosocial model that includes a sociocultural, political, and historical understanding of health care (Geist & Gates, 1996). Geist and Gates (1996) conclude: "the 'science-ing' (of our research, our medicine, our lives) is a silencing in the sense that it marginalizes aspects of our identities that we attempt to incorporate in our interactions with others" (p. 219-220).

Narratives of the hospice volunteer are particularly heuristic for two reasons. First, because volunteers do not have a specified duty they are in a position to really listen to their patients. The volunteer is thus able to apply the patient's story to his/her own life, thereby incorporating the patient's story into their own stories. In contrast, narratives gathered by health care providers may be limited to scientific knowledge concerning the biological condition of the patient, thereby further limiting information about the patient (Geist-Martin, Ray, & Sharf, 2003). Moreover, Geist and Dreyer (1993) posit that providers often are not able to listen to their patient's stories as they are preoccupied with their professional responsibilities.

Second, narratives provided by volunteers about their experience with hospice patients should afford valuable information on how the experience of death affects an individual's life. Their unique position allows them to hear the stories of a dying patient as he/she recounts the experiences and emotions of dealing with impending death (Geist-Martin, Ray, & Sharf, 2003). These narratives have the potential to become a source of knowledge for volunteers to be used in their own lives or to share with future patients and families (Geist-Martin, Ray, & Sharf, 2003). Additionally, Geist-Martin, Ray, and Sharf (2003) posit that narratives provided by others are constructed in the process of providing support and thus providers struggle "with their own identities in relation to those who are ill or diseased." (p. 38).

The Narrative Paradigm Theory (NPT; Fisher, 1987) will be utilized as a guide for this analysis. According to NPT, human beings are *homo-narrans*, that is storytellers. The theory posits that narratives, or stories, develop as language is learned and the story is thus a natural form of communication used to account for human action. As multiple narratives are shared, individuals begin to assess narratives by comparing them with previous narratives. Individuals thus have the ability to accept or reject the stories they hear based on the congruency of past narratives.

A narrative approach to health communication "highlights the meaning of the phenomenon of the illness experience primarily to the individual or groups of people with a particular health problem, and secondarily to others who witness or read those personal renditions." (Sharf & Vanderford, 2003, p. 16). Overall such an examination views health communication as a social construction of reality, defined by Sharf and Vanderford (2003) as "a dialectic between social reality and individual existence." (p. 10).

This dialectic is exemplified by a social construction approach to health communication which emerged as a humanistic response to scientific medicine (Sharf & Vanderford, 2003; Babrow & Mattson, 2003). Communication about health occurs in two distinct discourses (Sharf & Vanderford, 2003). One discourse is objective language, which represents the scientific approach to medicine. This language type is restricted to biological jargon associated with information that can be observed, verified, or tested. On the other hand, subjective language is utilized to discuss the non-verifiable experience of illness, reminiscent of the humanistic side of disease/illness meanings. Mishler (1981) identifies these two languages, objective and subjective, as the "voice of medicine" and the "voice of the lifeworld," respectively.

While much health communication research has focused on the voice of the patient, more than one account of reality needs to be explored in order to ascertain key points of divergence and commonality in the illness experience (Sharf & Vanderford, 2003). For example, an examination of the narratives of hospice volunteers will yield insight on illness narratives, those stories that involve the patient's experience of the disease or ill health (Sharf & Vanderford, 2003). These types of narratives incorporate the humanistic perspective of disease and illness as they extend beyond the biological suffering associated with illness and include the patient's experience with illness as related to changing roles, relationships, and identities (Sharf & Vanderford, 2003). Volunteer accounts may elaborate on these types of stories as well as illustrate the manifestation of death denial.

Additionally, health narratives facilitate the transformation of identity and provide the opportunity for individuals to re-shape their identity (Sharf & Vanderford, 2003).

This re-shaping can include the identification of life changing incidents, revelation of character, and integration of personal expertise (Sharf & Vanderford, 2003). Moreover, this narrative function illustrates how illness alters relationships. Sharf and Vanderford (2003) conclude that illness narratives demonstrate changes in patterns, actions, and choices which typify struggle, surrender, and accommodation to one's capacities (p. 30). More importantly, illness narratives also have the ability to awaken listeners and readers to issues they may have in their own lives (Sharf & Vanderford, 2003). Accounts of hospice volunteers should provide insight on the effect that listening to and experiencing illness narratives can have on an individual's life.

> "From a social construction perspective, the work of health communication scholarship is to unpack the sociocultural sources of symbolic usage that is often accepted as natural and inevitable without consideration of how such meanings emerge from contextual and political sources, in ways that mold health beliefs and behaviors, clinical judgments, and organizational routines." (Sharf & Vanderford, 2003, p. 12).

This study analyzed narratives of hospice volunteers' experiences in an attempt to learn more about how individuals communicate with dying persons as well as to ascertain how the experience of death can impact an individual's life. I advanced the following questions to guide my research:

RQ: What do hospice volunteers' stories reveal about how they experience the dying and death of their patients?

RQ: What are the themes/issues/topics, etc. of hospice volunteers' stories?

RQ: What do hospice volunteers' stories reveal about communication apprehension regarding dying persons?

RQ: What do these stories illustrate about the social denial of death?

These questions will be explored throughout the next several chapters. Chapter two will provide a general review of current literature on volunteerism in healthcare, with a focus on the hospice volunteer and communication apprehension. Then, chapter three will outline the methodology utilized to ascertain the research questions. Next, chapter four will provide an analysis of the narrative functions of the findings. Lastly, chapter five will provide an ethnographic account of fieldwork and chapter six will highlight the conclusions and implications of the study.

# Chapter II

## Literature Review

The focus of this study is the experiences of hospice/palliative care volunteers. Few researchers have examined the impact of death on communication processes, namely the impact of experiencing a death or communication apprehension with dying persons. Hospice/palliative care volunteers provide a unique context for studying such phenomena as they willingly situate themselves in the context associated with death. Therefore, this analysis begins with a review of the literature on volunteerism; focuses on volunteerism in healthcare; summarizes the history and role of the hospice volunteer; summarizes communication apprehension as a concept; and provides an overview of narrative research.

## Volunteerism

According to Rojak, Fredrickson, Fitpold, and Uhlken (2001) "volunteerism is based on helping persons in need." (p. 117). In lieu of the American ideology that places importance on individualism, volunteerism symbolizes America's history of free spirit and small town camaraderie (Wuthnow, 1991). It represents goodness, decency, and compassion. "Compassion becomes a symbol of the society we would like to have for ourselves and our children." (Wuthnow, 1991, p. 266). Overall, volunteerism is a way of envisioning a better society (Wuthnow, 1991).

Over the past decade America has experienced a growth in volunteerism. Ladd (1999) reported that a 1997 survey showed a 44 percent increase in the number of people volunteering. Moreover, four in ten who volunteered reported doing so because of a personal invitation to get involved. Overall, the number of volunteers totaled 93 million

individuals in 1995 (Ladd, 1999). A November, 2000 survey found that 111 million Americans (54%) volunteered in the past year, with 60 million of them volunteering on a regular basis (Pew Partnership). Current reports estimate that almost 110 million Americans volunteer an average of 3.5 hours per week (Eberly & Streeter, 2002).

Traditionally, volunteers have been seen as "natural helpers" who volunteer their time as a part of their religious beliefs. Historically these natural helpers have been women, typically stay-at-home mothers. However, the volunteer pool has shifted to retired persons as Americans are continuing to live longer in retirement. Nonetheless, women continue to volunteer more than men (Littman, 1998), and volunteerism is highest among persons who are middle-aged (35-55), have college degrees, earn an above-average income, and have children (Ladd, 1999; Littman, 1998).

The decision to volunteer is still linked to religious beliefs, and research indicates that there is a strong correlation between volunteering and church attendance (Ladd, 1999). Rojak, Fredrickson, Fitpold, and Uhlken (2001) report that the reasons for volunteering include: making a difference, improving social conditions, experiencing a sense of satisfaction, helping others, achieving fulfillment, seeing change, and experiencing professional enhancement. Furthermore, research shows that volunteers participate because they were asked to, they heard about the opportunity from the organization they belong to, or a family member or friend would benefit (Gerson et al., 1997).

Despite the notion of "giving back to the community," Adams, Schlueter, and Barge (1988) conclude that volunteers are intrinsically motivated. Ashley, Steel, and Bartlett (2001) propose that individuals are motivated to volunteer out of self-interest;

volunteering provides a way to gain new skills and experience as well as the opportunity to socialize. Additionally, some individuals who volunteer do so to raise their self-esteem. According to Snyder and Omoto ("Volunteers give," 1994) there are five benefits that individuals get from volunteering: improved self-esteem; new understanding; solidified community ties; affirmation of personal values, and personal development.

Ladd (1999) concludes that voluntarism is shaped by three factors: (1) moral commitment; (2) socioeconomic development; and (3) short-term forces that influence the population. Rojak et al. (2001) posit that the success of volunteer programs rely on the five "Cs": commitment, collaboration, creativity, coordination, and communication. Positive reinforcement plays a pivotal role in bolstering morale and ensuring volunteer programs. "Without a good infrastructure behind them, many volunteers become frustrated and quit or cannot find appropriate volunteer work" (McGrory, 1997, p. 39).

Although the use of volunteers is common in many organizations, there has been limited research on volunteers. Research that has been conducted has examined volunteers as part of an organization's structure and has focused on volunteer management (Ashcraft & Kedrowicz, 2002; Adams & Shepard, 1996; Cantrill, 1991; Adams, Schlueter, & Barge, 1988). Researchers conclude the following: that compliance-gaining strategies of volunteer supervisors focus on the worth of the individual and decision-making strategies are participative (Adams, Schlueter, & Barge, 1988); that volunteer staff relations are problematic for two reasons: (1) ambiguity regarding the role of the volunteer in the organization; and (2) uncertainty about how to supervise and motivate volunteers (Adams & Shepard, 1996); and that volunteers prioritize the role of social support in accomplishing empowerment (Ashcraft & Kedrowicz, 2002).

Furthermore, Cantrill (1991) found that voluntarism is successfully induced through the Foot-In-The-Door technique (i.e., getting the individual to comply with a small request results in further compliance with a second, larger request).

## Volunteerism in Healthcare

Volunteerism grew mainly out of Judeo-Christian ethics. Early forms of volunteering were the result of numerous women's associations that had gathered for religious efforts. The emergence of print media, specifically newspapers, also contributed to the rise of volunteerism as articles often highlighted social movements which emphasized volunteering. Moreover, Wuthnow (1991) notes that the idea of volunteerism was passed down in narrative form as children heard the story of "Generous George" and Aesop's fable of the dog in the manger.

One of the main areas that had a demand for volunteers was healthcare. Health was a pertinent topic to society as a whole, and social service programs were evolving. Volunteer lay people and physicians joined associations, such as the Hygiological Society in 1854, which focused on welfare services (Ellis & Noyes, 1990). Overall the health care arena was advanced through the efforts of many doctors and women who volunteered their time to serve in dispensaries and clinics (Ellis & Noyes, 1990).

Periods of war in America's history contributed greatly to the rise of volunteerism in the health care industry. Prior to the Civil War many volunteer organizations emerged, such as the Cooper Shop Volunteer Hospital in 1861. The hospital was operated by a doctor who volunteered without pay and a staff of volunteer women. According to Ellis and Noyes (1990) it was the medical needs of the northern army in the Civil War that accelerated healthcare volunteerism. The pinnacle of such efforts resulted in the creation

of the United States Sanitary Commission in 1861 and was entirely dependent on voluntary contributions (Ellis & Noyes, 1990). Overall, it was the largest private relief organization of the war (Ellis & Noyes, 1990). Mainly it was a supply house for donated materials such as food and clothing. Later, nursing became a valuable component to the commission's services. Dorothea Dix, a volunteer herself, was responsible for recruiting and supervising volunteer females who served as nurses (Ellis & Noyes, 1990). Other activities promoted by the commission included evangelical work and general care taking of soldiers. The Civil War proved to be a pivotal point in the emergence of volunteerism in America as many civilians volunteered to fight or take care of those who had fought (Ellis & Noyes, 1990).

Following the Civil War, America experienced a surge in the creation of voluntary health care agencies and organizations. During the 1900's thousands of charitable institutions were founded (Wuthnow, 1991). Church attendance was high, and children learned to be good Samaritans. The proliferation of these organizations spearheaded the country's move towards research in healthcare, with the main focus on cancer. The formation of the American Cancer Society in 1913 was established through a strong relationship with the General Federation of Women's Clubs (Ellis & Noyes, 1990). Later, the National Cancer Foundation was created to assist cancer patients and their families with specialized help. The Red Cross was another major volunteer organization that was established during this time. As voluntary health and social welfare agencies continued to grow in the 1920's, so too did volunteerism in healthcare (Ellis & Noyes, 1990).

The role of the healthcare volunteer transitioned from the role of the caretaker to include being a fundraiser, a speaker, and an organizer. For example, the largest health care effort during the 1950's was the promotion of the Salk vaccine (Ellis & Noyes, 1990). "In the years 1953 to 1955, more than 200,000 lay volunteers enabled the vaccine tests to proceed smoothly and accurately" (Ellis & Noyes, 1990, p. 245).

In the 1970's and 80's volunteerism in healthcare turned to specialized needs (Ellis & Noyes, 1990). For example, volunteers were welcomed into neonatal care units as "cuddlers" and "godmothers" and volunteers developed after school programs for latch key children (Ellis & Noyes, 1990). Other volunteer efforts focused on the plight of missing children which resulted in the printing of photographs on milk cartons (Ellis & Noyes, 1990).

In 1987 the U. S. Surgeon General endorsed self-help as a strategy for dealing with health issues (Ellis & Noyes, 1990). The endorsement resulted in a proliferation of self help groups that had already began to develop in this era. Among the organizations that sprang up were Heart-to-Heart, Overeaters Anonymous, Mensa, and Mother's Against Drunk Driving. Also, voluntary emergency service for rural areas formed. Although many continue today, the fear of lawsuits and rising insurance has added to the cost of these volunteer programs (Ellis & Noyes, 1990).

Another area that emerged in the 1970's as a result of volunteer leadership and organization was the hospice movement. Although the first hospice was found in 1967 by Dr. Cicely Saunders in England, the first hospice program in America was established in 1974 in New Haven, Connecticut. By 1983 there were over 600 programs established

(Ellis & Noyes, 1990). In December 1983 the Medicare system accepted hospice programs as a legitimate form of healthcare.

Overall, there are many areas to which a volunteer can contribute in the healthcare field. According to Ellis and Noyes (1990) these include: professional associations (such as the American Medical Association), national voluntary health organizations, hospices, hospitals and clinics, family planning and related services, services to those with special needs, services to people with AIDS, patient rights and self-help, thanatological issues, childbirth services, public health, and anti-addiction projects.

Healthcare continues to be a popular choice for volunteers. Tuckman and Chang (1994) reported that in 1989 over 21 million healthcare volunteers contributed 2,463 million hours. Healthcare volunteers report that their reason for volunteering was "the desire to help others" and "a desire to feel needed" (Tuckman & Chang, 1994). Additionally, 31 percent were motivated to volunteer because their child, relative, or friend would benefit from the activity in which they volunteered (Tuckman & Chang, 1994). Additionally, 55 percent of healthcare volunteers also worked with a religious institution and four out of every ten are professional workers.

In 1993 the Robert Wood Johnson Foundation (RWJF) started a program entitled "Reach out: Physicians' initiative to expand care to underserved Americans" aimed at promoting community service among physicians. Over the next four years the program provided medical and surgical services to 200,000 patients though free clinics and by collaborating with numerous healthcare entities (Scott, 2001). In 1997 the RWJF founded Volunteers in Healthcare (VIH) as an information resource center for local health care initiatives that rely on volunteers (Scott, 2001). The VIH provides information

and assistance on fundraising, recruitment, organizing, tracking patients, and liability (Scott, 2001).

There are many benefits of utilizing volunteers in the healthcare industry. Aside from the mere fact that they are substitutes for paid workers, volunteers facilitate much needed care, and their efforts "increase the quality of healthcare delivery relative to what would be available in their absence" (Tuckman & Chang, 1994, p. 2). Healthcare volunteers also contribute to the overall working environment (Tuckman & Chang, 1994). They add new ideas on processes and services as well as share their skills from other areas. Moreover, they have the ability to help raise funds and establish relationships between organizations.

More relevant to this project, volunteers can provide an outside assessment of healthcare delivery since they are more apt to see the patient's point of view. Gelb (1994) proposes that healthcare volunteers are needed to evaluate service delivery. In this manner the hospital is provided with useful feedback and the volunteer is able to consider him/herself a patient. Gelb (1994) argues that this approach could possibly bolster volunteer attitudes and help retention efforts.

Today volunteerism is in demand by many organizations and hospitals. Consequently, health organizations are now faced with having to stimulate and promote the job of healthcare volunteer (Pforzheimer & Miller, 1996). Retention and recruitment now rely heavily on meeting the needs of volunteers in order for them to be satisfied with their volunteer job/community (Pforzheimer & Miller, 1996). Consequently, hospitals must change their recruitment efforts to meet the changing demands of volunteership. More specifically, Pforzheimer and Miller posit that hospitals must recruit more widely

by promoting volunteerism among all people regardless of age, race, or ethnicity. They propose that volunteers should have flexibility and variety and be afforded the opportunity to develop new skills. Moreover, it is necessary for hospitals to show their appreciation and inoculate loyalty into the institution. Volunteers who are trained correctly not only provide a valuable service to healthcare organizations but also are advocates in the community (Pforzheimer & Miller, 1996).

## History of the Hospice Volunteer

Ten years after hospice emerged as a service, the Medicare Hospice Benefit was introduced as a cost saving measure under the Tax Equity and Fiscal Responsibility Act of 1982. This was preceded by the establishment of the Palliative Care Unit at Montreal's Royal Victoria Hospital in 1976 and the creation of the National Hospice Organization (NHO) in 1977. The NHO later became the National Hospice and Palliative Care Organization (NHPCO).

In 1983 the Medicare Hospice Benefit became available to all Medicare recipients. In order to be eligible for hospice care the patient must meet three criteria: (1) the patient's doctor must certify that the patient has a terminal illness with a life expectancy of six months or less; (2) the patient must choose hospice care rather than curative care; and (3) the patient must enroll in a Medicare-approved hospice program. By enrolling in a hospice program, the patient waives the standard Medicare benefits for treatment of a terminal illness. Patients can receive hospice care as long as their illness is certified by a physician as terminal. The enrollment period is two 90 day periods that are followed by an unlimited number of 60 day periods.

Medicare's hospice program pays almost four-fifths of all hospices in the United States and in 1997 spent $2.7 billion on hospice care (Gage et al., 2000a; Gage et al., 2000b). In 1995 there were 390,000 patients in hospice and 96% were receiving routine home care at about $114 a day (Gage et al., 2000a; NHPCO, 1995). The National Center for Health Statistics reported in 1998 that almost 80 percent of all hospice users are age 65 and older, many of them dying from some form of cancer (Gage et al., 2000a). Although five percent of the elderly population dies each year, only 18 percent of these individuals enroll in Medicare hospice (Gage et al., 2000a). Furthermore, from 1987 – 1990 more than 40% of patients in all healthcare settings were enrolled in the hospice benefit program for less than 15 days.

The 1982 legislation established four levels of hospice care: routine home care, continuous home care, inpatient respite care, and general inpatient care (Gage et al., 2000b). According to the National Hospice and Palliative Care Organization (NHPCO) the Medicare Hospice Benefit provides for: physician services, nursing care, medical appliances and supplies, drugs for symptom management and pain relief, short-term inpatient and respite care, homemaker and home health aide services, counseling, social work service, spiritual care, volunteer participation, and bereavement services. Thus, hospice uses a team approach wherein everyone has equal input on all issues pertaining to the patient. The hospice team is available 24 hours a day, 7 days a week.

The federal law also required the use of volunteers and mandated records on their use and cost savings. Volunteers were pivotal in getting the hospice movement off the ground and thus "proponents thought that their continuous involvement was important to

preserving the hospice philosophy." (Gage et al., 2000b, p. 10). Consequently, that law requires that volunteer efforts should account for five percent of total hospice efforts.

> Since living with dignity in the midst of serious illness, dying itself, and bereavement are all essentially natural processes, normal and natural friendship, openness, and listening are critically important support services to dying patients and their families. For this reason, a volunteer component is a federal requirement for all Medicare certified hospice programs. (Sendor & O'Connor, 1997, p. 170).

The NHPCO reported that there were over 96,000 hospice volunteers, 75, 000 female and 21, 000 male, who contributed 5.25 million hours of service in 1992.

All hospice volunteers must meet the same pre-employment health requirements as the paid staff and must provide professional certification if necessary (Sendor & O'Connor, 1997). They are also required to submit a background resume and at least three references. Sendor and O'Connor (1997) report that volunteers must document their hours by providing their volunteer coordinator with a log of hours as well as completing other forms. Volunteers are usually asked to make a commitment of four hours a week for one year and are reviewed every three months (Sendor & O'Connor, 1997).

Originally structured into hospice care to provide bereavement counseling to the patient's family, volunteer services have grown to include many aspects of support (Hoyer, 1998). Leete (1994) provides a summary of the hospice volunteer role: "We may listen, and talk judiciously, help with meals, run errands, help with seasonal chores, read aloud, help with correspondence, answer the phone, play music, play with children, pick up prescriptions at the pharmacy. We may hold the hands of patients, hug them, put our

hand on their forehead." (p. 28). Qualities of a good hospice volunteer include acceptance of self, acceptance of others, flexibility, and patience (Wilson, 2000).

Overall there are five main areas that hospice volunteers serve: (1) office assistant; (2) as a "Good neighbor" wherein they work directly with the family and the patient; (3) as bereavement volunteers; (4) as professionals providing expertise without pay; and (5) as members of the Board of Directors/Trustees (Sendor & O'Connor, 1997). Hospice volunteers that act as 'Good Neighbors' provide support to the patient and family. Such support is described as performing chores as well as compassionate listening (Sendor & O'Connor, 1997).

Volunteers who serve as "Good neighbors" are expected to participate in the design of planned care which includes attending team meetings, providing updates, and maintaining regular communication with the volunteer coordinator (Sendor & O'Connor, 1997). The role of the volunteer is to strengthen and support the services provided by the care team (McKinnon, 2002). This role is unique to the other members on the care team as the volunteer typically has more contact with the patient and the family (Stolick, 2002; Hall & Marshall, 1996; Craig, 1994). Consequently, it is the volunteer's duty to report any changes in the patient's condition. These reports help ensure the patient's physical and psychological comfort which aides in the family's coping process (Sendor & O'Connor, 1997).

All volunteers are required to undergo training, which typically ranges from 15 to 36 hours (Sendor & O'Connor, 1997). Core topics in a hospice education curriculum include hospice and palliative care philosophy, the roles of the interdisciplinary team members, the responsibilities of the volunteer, physical aspects of terminal illness,

psychology of death and dying and its impact on families, dynamics of grief and bereavement, psychosocial and spiritual dynamics, and communication skills (Stolick, 2002; Wilson, 2000; Cummings, 1998).

Training includes seminars led by medical and mental health experts, social workers, and clergy who share their knowledge and insight on how to support the needs of the patient and the family (Sendor & O'Connor, 1997). Volunteers are also taught the practical and physical concerns of impending death including whom to call and what to expect. During training, volunteers are introduced to possible family situations, living arrangements, and family dysfunctions (Hall & Marshall, 1996). An effective pedagogical tool in hospice training is the inclusion of stories and anecdotes shared by staff members (Wilson, 2000). Additionally, Finlay, Stott, & Kinnersley (1995) found that simulated patient interviews were also successful.

According to Larson (1997) a good volunteer program includes creative recruiting and upgraded training, encouraging volunteers to focus on talents they can use to enhance the hospice experience (referred to as gift-based services), strengthened accountability which can be accomplished with volunteer paperwork/forms, planning and task groups, and advanced training in spirituality. Spirituality training includes a personal spiritual formation as well as the skill to be a spiritual companion (Larson, 1997). In fact, many volunteer training programs prepare individuals for their own death or the death of a person they love (Stolick, 2002; Leete, 1994). Leete (1994) explains further that this experience allows volunteers to "free themselves of self-centered concerns and be a 'host' for the concerns of others, to listen rather than advise, to touch rather than talk at the wrong time, to open their arms rather than keep them crossed." (Leete, 1994, p. 28).

One of the most important qualities of volunteers is their ability to listen (Stolick, 2002; Leete, 1994) which allows them to "just be" with a patient (Stolick, 2002). Volunteers are to share feelings only when appropriate and their primary role is to be a "sounding board" for the patient and the family (Hall & Marshall, 1996). Sendor and O'Connor (1997) posit that after six months hospice volunteers have developed compassionate listening skills. Foster (2002) conducted an ethnographic account of hospice volunteers and found that good listening meant focusing on the life of the patient and not impending death. In this manner, volunteers learned new ways to accomplish meaningful communication. Foster (2002) concluded "by allowing our patients to share their daily lives, histories, wisdom, and ideas with us, we send the message that they are valued as human beings" (p. 250). Additionally, her study revealed "just being" with a patient involved being comfortable without conversation.

Aside from content areas, volunteer training emphasizes effective communication skills (McKinnon, 2002; Wares & Stileman, 1987). These skills include the awareness of having non-threatening nonverbal communication (open armed body stance, relaxed shoulders, eye contact) and facial expressions that demonstrate active listening (Craig, 1994). Hospice volunteers are also taught to encourage communication by using validating statements and active listening skills (Hall & Marshall, 1996). Typically, these are taught through role-playing exercises. There are three core conditions to be communicated by the volunteer to the patient: (1) to provide genuinely honest communication about how you feel; (2) unconditional positive regard; and lastly (3) empathic understanding (Hall & Marshall, 1996).

Hospice volunteers are described as being the "backbone" or "heart" of hospice care (Caldwell & Scott, 1994; NHPCO, 2003). Without volunteers hospices would not perform their intended range of healthcare (Field & Johnson, 1993).

> As in families, hospice organizations depend upon the fusion of physical labor and emotional caring in much of the work of their volunteers. In this respect volunteers can be important agents in the maintenance not only of the physical but also of the psychosocial and spiritual bases of hospice care – although their contributions to the latter may not always be fully appreciated by either the volunteers themselves or by paid hospice staff. As with emotional labor in general, much of the work of volunteers may remain invisible, or be taken for granted as just part of the 'natural' coping repertoire of the volunteers. (Field & Johnson, 1993, p. 203).

Ethically, Rothstein (1994) points out that volunteers must make tough communication choices. First, volunteers must recognize that truth telling is important, however, not always their job to tell it (Rothstein, 1994). Second, volunteers act as a channel of information from the patient and family to the rest of the hospice/palliative care team (Rothstein, 1994). These interpersonal relationships develop in a short period of time between volunteers and the patient and family (Rothstein, 1994). As a result volunteers are faced with decisions over what information to keep confidential and what information should be shared with the hospice/palliative team.

Still another problem is role ambiguity when providing care. The primary concern among volunteers is to what extent they may physically help a patient. Volunteers are not able to provide hands-on care to patients, such as administering medication, unless they

are certified to do so. However, it is not uncommon for volunteers to be in a situation where the patient is in pain and they are the only person available to provide such services. Another area that has been problematic for volunteers is respite care, the temporary relief of a patient's primary caretaker. Volunteers can never leave a patient home alone, and, unfortunately, it is not uncommon for a primary caretaker to return late or not at all (Schumacher, 2003). Other potential problems include inadequate training, becoming too involved with a patient, and conflicts with paid staff (Field & Johnson, 1993).

Poor communication can exacerbate these problems. Moreover, volunteers must learn how to communicate in situations of death and dying in a culture that denies the end of life. This social denial of death produces fears of one's own death, the dying process, and losing loved ones. Together these fears contribute to the apprehension associated with communicating about death and with dying persons. This type of phenomena is related to a general communication concept called communication apprehension.

## Communication Apprehension

When first introduced as a concept by McCroskey (1970), communication apprehension was defined as "a broadly based anxiety related to oral communication." (p. 270). Since then the concept has been expanded to involve an individual's anxiety over real or anticipated communication which hinders their ability to interact (McCroskey, 1977). This anxiety occurs in varying levels and can occur chronically or situationally. Overall, there are four types of communication-apprehension: (1) trait apprehension wherein anxiety occurs across all contexts; (2) context-based apprehension which is dependent on the context of the communication setting such as crowd size; (3) audience-

based apprehension which develops as a result of communicating to specific people; and finally (4) situational apprehension which occurs because of a given person or persons in a particular situation. McCroskey (1977) posits that communication apprehension occurs as a result of low self-esteem, lack of parental reinforcement, and/or inherited trait. His work in this area has also led to further research on receiver apprehension (Wheeless, 1975) and writing apprehension (Daly & Miller, 1975), all of which have resulted in the construction of assessment scales.

Communication scholars have utilized communication apprehension as a concept in researching child-parent communication (Lucchetti, Powers, & Love, 2002), instructor-student communication (Myers, & Rocca, 2002), learning styles (Messman & Jones-Corley, 2002), and classroom communication (Dwyer, 2000). However, Hayslip (1986-87), a psychologist, was the first to apply the concept to communication with terminally ill persons. Hayslip (1986-87) argues that individuals who have fears about communicating with those who are dying exhibit characteristics of communication apprehension. These characteristics include physical symptoms of nervousness that indicate that the individual is psychologically uncomfortable. The result is an unwillingness or reluctance to communicate.

Research about communication apprehension with the dying (CA-Dying) is limited to the work of Hayslip and colleagues who primarily focus on assessing death anxiety as a key component that triggers apprehension. Originally Hayslip (1986-87) found that CA-Dying was positively related to death anxiety, negatively related to chronological age, and independent of general communication apprehension (see also Servaty, Krejci, & Hayslip, 1996; Servaty & Hayslip, 1997). Hayslip (1986-87) posits

that individuals who are not psychologically comfortable communicating with dying persons have a fear of their own death. Additionally, he suggests that individuals who fear another person's death avoid communicating with dying persons. This communicative avoidance thereby triggers an increase of fear of his/her own death. Servaty, Krejci, and Hayslip (1996) further found that individuals with less anxiety about death-related events have low CA-Dying.

It is assumed that death education is a primary component to reducing death anxiety associated with CA-Dying. Servaty and Hayslip (1997) compared death attitudes of students enrolled in a death and dying course to students in a general psychology course. They found that death education reduced death fears. Additionally, Servaty, Krejci, and Hayslip (1996) found that senior level medical students (both physicians and nurses) had lower CA-Dying scores than freshmen students. However, Hayslip, Galt, and Pinder (1993-94) conclude that general death education does not reduce death fears. Rather, the authors suggest that death education reduces denial which thereby allows the expression of unconscious death anxiety. Moreover, they conclude that this is most successful when addressing the fear of one's own death. Servaty and Hayslip (1997) posit that "increased knowledge, values clarification, and preparation for future loss may promote more death accepting attitudes." (p. 145).

The loss of public rituals and practices surrounding death and dying (both cultural and religious) has contributed to communication apprehension in these contexts (Callahan, 2000). Callahan (2000) argues that it is these practices that teach us "the comfort of knowing how to behave publicly in the presence of death – what to say, how to composes one's face, to whom to speak and when to speak." (p. 33). Without them,

individuals do not know how to behave. Moreover, Mooney (2003) notes that the dying process is a very intimate time for families of a dying person. It is a time when "they are the most defenseless, dealing with circumstances that they have no control over" and they are "frightened or confused." (p. 16).

Specific discourse used to talk about death and dying also contributes to death anxiety and consequently CA-Dying. According to Corr (1997) as cited in Golubow (2002, p. 154):

> Prominent illustrations of ways in which death is forbidden in much of modern society include language of ordinary discourse, professional speech and communication about dying. It is important to pay attention to these linguistic practices because naming helps to define and to determine reality. How we speak says a good deal about who we are and the attitudes we hold...(p.36).

The use of euphemisms such as "passed away" and "no longer with us" are examples of how our thoughts about mortality and the dying process are denied (Golubow, 2002). Particularly in end-of-life care, healthcare professionals and dying patients often experience miscommunication as a result of "undisclosed fears and anxieties over an end stage diagnosis and feeling of mortality" (Golubow, 2002, p 151).

One approach to learning more communication apprehension associated with dying persons is to examine narrative accounts of death and dying experiences. Narrative form is one way that individuals construct meaning of a phenomenon, especially illness (Mishler, 1986). "It is through the sharing of stories about everyday experiences, such as about illness, that a community creates a mutually intelligible world. As such, investigation of narratives informs us of the cultural assumptions that permeate our

society and our very identity." (Murray, 2000, p. 343). For example, the Hospice of the Florida Suncoast conducted a language project that entailed focus groups with survivors. When survivors were asked what the term *dying process* meant to them they told personal stories as a way of giving meaning to the term (Jacobs, 2003). The next section will review the connection between narratives and illness.

## Narrative Analysis

Many interpretivist researchers ascribe to the ideology that all social interaction is a form of communication that has incorporated meaning. Communication carries with it layers of meaning and often times these layers are multiple and interconnected. Thus in order to fully understand and gain knowledge of certain communication phenomena and occurrences, researchers must shed light on as many layers as possible; to recognize communication as well as the impetus for communication and what that communication means.

Hermeneutic Empiricism is a philosophy of interpretation which functions on the primary ideology that human behavior is a symbolic expression requiring observation. The argument incorporates the idea of voluntarism, that human beings have free will and thus calls for a resuscitation of agency. Along the lines of studying human behavior, this argument sets precedence for a subjective analysis that includes the use of narratives. Narrative refers to the "process of making a story" and narrative expression resembles and often times accounts for human expression (Polkinghorne, 1988, p. 13). "Narrative is a primary scheme by means of which hermeneutical meaningfulness is manifested." (Polkinghorne, 1988, p. 125).

According to Narrative Paradigm Theory, all human communication takes place in the form of narratives (Fisher, 1987; Riessman, 1993). Such narratives are considered to be "interpretations of aspects of the world occurring in time and shaped by history, culture, and character." (Fisher, 1989, p. 57). The five basic assumptions of Narrative Paradigm Theory, according to Cragan and Shields (1995) include:

1. Human beings are storytellers (Fisher, 1987, xi).
2. All forms of human communication are best viewed as stories.
3. Through discourse humans use "good reasons"-values or value-laden warrants-for believing or acting in certain ways (Fisher, 1987, xi)
4. All human beings naturally possess a narrative logic that they use to assess human communication (Fisher, 1987, xi)
5. Humans create reality through sets of stories (accounting and recounting) that must be chosen among to live life in a process of continual recreation (Fisher, 1987, p. 5).

Narratives are one way that individuals are able to redefine themselves and make sense of what is happening to them. Frank (1995) argues that the experience of illness encourages a narrative form of communication as illness impacts the story of life. Illness forces us to examine our own identity, our relationships with others, and our self worth (Frank, 1995). Frank (1995) posits that there are three types of narrative forms that emerge from the illness experience. One narrative form is the restitution narrative wherein the focus is on the process of illness (i.e. treatments and possible outcomes). Another narrative form is the chaos narrative wherein the focus of the story is on blame. These stories are not sequentially organized. Lastly, Frank (1995) identifies the quest

narrative wherein the narrator shares his/her story hoping to gain something from the experience. The communication discipline recognizes this emerging communicative form as instrumental in health communication and Harter, Japp, and Beck (in press) explore this in their upcoming book *Constructing our health: The implications of narrative for enacting illness and wellness.*

Particularly important in illness experiences, narrative accounts allow for the expression of uncertainty. Babrow and Mattson (2003) conclude that the pervasiveness of uncertainty in illness permeates illness experiences and communication about health and illness. Thus, the meaning of uncertainty is determined by the context of the illness, wherein health communication forces a "rearticulation of (un)certainty and (un)certainty compel(s) the rearticulation of values." (p. 45).

Moreover, illness narratives are unique because they make use of familiar elements that are used to shape our perceptions of the world (Sharf & Vanderford, 2003). Such elements of analysis include characters, scenes, motives, plots, narrator's voice, and the telling of the story. They are also unique because they provide insight to the storyteller's psychosocial experience of disease/illness. Sharf and Vanderford (2003) propose that there are five functions of health narratives: sense-making, asserting control, transforming identity, warranting decisions, and building community.

First, narratives function as a way of making sense of reality (Sharf & Vanderford, 2003). For an individual that is ill, narratives allow him/her to create meaning from their experiences. In this manner, storytellers are able to make sense of their illness experience. A large part of making sense of the illness experience includes being able to recall events and assign responsibility or blame. Sharf and Vanderford

(2003) conclude that "the very act of generating a story allows the narrator certain degrees of agency." (p. 19).

Second, narratives allow individuals to assert control over their illness experience (Sharf & Vanderford, 2003). As a storyteller, an individual assumes agency in not only sharing their internal thought processes about their illness, but they are also able to explain their suffering and loss of autonomy. Thus, narrating allows the narrator to exercise some control at a time when control over reality is limited. Another form of control exhibited through narrative form is the opportunity to emphasize certain aspects of the illness experience.

Third, narratives provide the opportunity to transform an individual's identity (Sharf & Vanderford, 2003). As stated previously, these narratives illustrate changes in patterns, actions, and choices which typify struggle, surrender, and accommodation to one's capacities. Fourth, narratives function as a means for warranting decisions (Sharf & Vanderford, 2003). The narrative form reveals the narrator's values and reasons for action. These types of stories indicate the way the patient thinks the world ought to operate (Sharf & Vanderford, 2003). Finally, narratives facilitate building community as stories have the ability to influence others. These stories are dominated by support groups, both on-line and face-to-face, that form their own vocabulary, rituals, etc. Additionally, community building occurs as a result of media/film dramatizations which have the ability to provoke advocacy, fund raising, and policy change.

To summarize, the goal of volunteers in healthcare is to make a change in the quality of care and services. Hospice and palliative care volunteers in particular are concerned with the psychosocial aspects of end-of-life care. Their experience with death

and dying persons provides a context for learning more about communicating in death contexts, especially in a culture that denies death experience. Narrative research of such experiences is beneficial to learning more about hospice and palliative care. Narratives function to help patients and their families accept the reality of their prognosis, to garner further understanding about the care of the dying, and to serve as a means of evaluating hospice and palliative care practices (Wittenberg & Ragan, in press). Research for this study was a narrative analysis of volunteers' experiences as well as ethnographic fieldwork. The goal of this type of descriptive research is to describe narrative accounts, as interpreted and told by the narrator and will be detailed in the next chapter (Polkinghorne, 1988).

# Chapter III

## Methods

In order to investigate communication with dying persons and learn more about how the experience of death can impact an individual's life, unstructured interviewing was utilized to elicit narrative accounts of hospice volunteers. Additionally, fieldwork was conducted to complement interview data. This chapter outlines the epistemological assumptions that guide narrative analysis, the unstructured interviewing method, ethnographic fieldwork, the recruitment of participants and fieldwork conducted, and the procedure utilized to analyze the data.

### *Epistemological Approach*

Qualitative research entails an open-ended, inductive analysis of a particular social setting (Lofland & Lofland, 1995). It is a grounded theoretical approach that begins with data. The analysis of qualitative data entails breaking down a whole phenomenon to research its components. By breaking down data, categorizing and coding, the researcher is able to establish a pattern for the whole by relating codes/categories to one another (Schwandt, 2001). This process is known as analytic induction, as meaning is inferred from the data collected. In general, the methodology consists of "induction, deduction, and verification" to develop theory and is also known as a grounded theory approach (Schwandt, 2001; Price, 1999).

A qualitative approach is particularly insightful when examining communicative phenomena embedded in issues concerning health. The predominant concern over communicating with ill persons involves the interplay of the body and communication (Babrow & Mattson, 2003). As the body changes as a result of illness and/or disease, so

does our communication with others. Cultural and social influences behind the conceptualization and labeling of illness and disease cause changes in individuals' behaviors (Babrow & Mattson, 2003). Moreover, these influences are further redefined by social attitudes which can be discovered through a qualitative analysis (Babrow & Mattson, 2003).

Additionally, a qualitative approach allows for the examination of a holistic model of disease and illness, rather than an ontological approach (Aronowitz, 1998). In an ontological view, disease is seen as outside the person. On the other hand, a holistic approach views the disease as a part of an individual, changing his/her psychological and physical state of mind. A qualitative examination allows the researcher to examine the values associated with personal meanings of illness which is consonant with a holistic model (Babrow & Mattson, 2003).

*Unstructured Interviewing*

One approach to data gathering from a qualitative perspective includes unstructured interviewing. According to Lofland and Lofland (1995) unstructured interviews "seek to *discover* the informant's *experience* of a particular topic or situation." (p. 18). Unstructured interviews are open-ended and informal, thus allowing the researcher flexibility and responsiveness to emerging issues. The format also provides individuals with the opportunity to control the flow of conversation, including the introduction of new topics (Mishler, 1986). Lofland and Lofland (1995) conclude that structured interviews assess the frequency of things (events) while unstructured interviews assess what exists.

Thus unstructured interviews are one way in which researchers can elicit narrative accounts. Considered "guided conversations", the interview protocol consists of a list of things to cover, and the interviewee is allowed to speak freely on the topics introduced (Lofland & Lofland, 1995). Mishler (1986) argues that this format allows the individual to share a wide variety of information that may otherwise be limited by a highly structured schedule of questions.

It is important to note, however, that both structured and unstructured interview formats can elicit narrative accounts (Riesman, 1993; Mishler, 1986). "Precisely because it is a form of discourse that is known and used in everyday interaction, the story is an obvious way for social actors, in talking to strangers (e.g., the researcher) to retell key experiences and events" (Coffey & Atkinson, 1996, p. 56). Moreover, important stories/life events are often told as narrative accounts as they are memorable. Additionally, the reasons why they are memorable also provide some meaning to the story (Coffey & Atkinson, 1996).

The investigation of communication with dying persons and the impact that death can have on a person's life was conducted through an unstructured interviewing format with the goal of collecting data in the form of narratives. More specifically, to assess general volunteer issues surrounding recruitment, I asked the following questions: (1) What lead you to get involved with hospice?; (2) What is your current level of involvement with hospice? To answer $\mathbf{RQ_1}$ (what do hospice volunteers' stories reveal about how they experience dying and death of their patients?), I asked the following questions: (1) Tell me about a time one of your patients died (alternative: tell me about the first time one of your patients died); (2) Tell me about your most memorable

experience as a hospice volunteer. (possible follow-up questions: what was it like the first time you met this patient? how did this impact you personally?); (3) What are your thoughts on your own death? To answer **$RQ_2$** (what are the themes/issues/topics, etc. of hospice volunteers' stories?), I asked: (1) Have you ever turned a patient down?; (2) What recommendations/advice would you share with a new volunteer?; (3) What does volunteering do for you personally? Why do you continue to volunteer?

To answer **$RQ_3$** (what do hospice volunteers' stories reveal about communication apprehension regarding dying persons?) and **$RQ_4$** (what do these stories illustrate about the social denial of death?), I asked: (1) Tell me about your first assignment. Were you nervous?; (2) Tell me about a bad experience as a hospice volunteer; (3) What are your thoughts about meeting a new patient for the first time? Have they changed from the first patient?; and (4) How do people react to you when you identify yourself as a hospice volunteer? Please see Appendix A for an overview of the interview protocol.

*Ethnographic Field work*

To complement the interview data I also conducted fieldwork, known as ethnography. In ethnographic fieldwork the whole communicative phenomenon is investigated in its natural environment through participant observation. By becoming a participant-observer the researcher "becomes an instrumentality or medium of the research" (Lofland & Lofland, 1995, p. 3). That is, the researcher is able to get direct experience as to what the participants experience firsthand. This experience as well as observations are then recorded as field notes and ultimately provide a thicker, richer description and deeper understanding of the cultural phenomena. "A culture is expressed (or constituted) only by the actions and words of its members and must be interpreted by,

not given to, a fieldworker." (Van Maanen, 1988, p. 3). The end result, an ethnography, is the interpretation of these field notes. Schwandt (2001) defines ethnography as "the process and product of describing and interpreting cultural behavior." (p.80). According to Van Maanen (1988), "the fieldworker must display culture in a narrative, a written report of the fieldwork experience in self-consciously selected words." (p. 4).

*Recruitment of Participants*

The sample of volunteers was taken from three different locations, two hospices in Oklahoma and one hospice in Texas. Volunteer coordinators at each site were contacted regarding the interviewing of volunteers. For both Oklahoma locations, it was agreed that the researcher would attend the monthly volunteer meeting and solicit volunteers for the study. Volunteers interested in being interviewed provided the researcher with their names and telephone numbers. After telephoning 10 volunteers in Oklahoma, the researcher was able to secure nine interviews. Additionally, the volunteer coordinator at the hospice in Texas arranged for the researcher to interview one volunteer. Prior to interviewing volunteers for the study, the researcher interviewed two hospice volunteers over the telephone to test the interview questions and format and to receive feedback. These interviews were not audio-taped and were not included in the actual analysis.

Three men and seven women volunteers from the three different hospices participated in the study. Only volunteers who interact with patients were interviewed; six volunteers participated in home care services and four volunteers worked with patients in nursing home environments. An unstructured interview format was used to prompt volunteers to share their experiences about hospice. The researcher used a

question format that was the same for each interviewee (see Appendix A for interview questions); however, some deviations did occur depending on the volunteer's response and also to ensure a conversational flow in the interview. The questions were asked in the same order for each interview.

Five of the interviews were conducted in the volunteer's home and five of the interviews took place in a private office setting. Interviews lasted anywhere from 35 minutes to an hour and 45 minutes, with an overall average of one hour and 5 minutes. All interviews were recorded to ensure that reliable data was gathered. The interviews were then transcribed by the researcher. In total, the data yielded ninety-two pages of transcription (see Appendix D for interview transcription).

Additionally, the researcher logged 30.5 hours of field work. The researcher participated in two volunteer training programs (at two different hospice locations), three monthly volunteer meetings, a funeral home tour, and attended five interdisciplinary team meetings at one hospice. In total, this data set consisted of 23 pages of typed field notes. To protect interview respondents as well as other participants, all identifying information was taken out and pseudonyms used when needed.

*Narrative Analysis*

Unstructured interviewing is ideal in gathering narrative data as it allows the researcher and participant to share in dialogue, thus fostering an environment conducive to storytelling. Researchers who relinquish control over the interview process are thus able to generate narratives from almost any type of question (Riessman, 1993). According to Riessman (1993) a narrative analysis consists of three steps: (1) eliciting stories from an interview format, (2) transcribing those stories and (3) analyzing them.

Narrative data or stories are typically diachronic, that is the data changes over time (Schwandt, 2001). "It contains surprises, coincidences, embellishments, and other rhetorical devices that draw the reader." (Schwandt, 2001, p. 169). Polkinghorne (1995) posits that narrative analysis requires diachronic data. "Diachronic data contain temporal information about the sequential relationship of events." (Polkinghorne, 1995, p. 12). Therefore, multiple narratives about the same event are different for different persons. The sequence, focus, and things emphasized are different depending on the narrator's background. Additionally, when a person tells a story it becomes different from the next time he/she tells the story. This is partially due to the role of the interviewer in the construction of the story (Riesmann, 1993; Mishler, 1986). The interviewer is the respondent who provides feedback for the continuation of the story, and the narrator frames the story for the interviewer as the audience (Mishler, 1986). Therefore, narratives are not completely consistent. Riessman (1993) argues that "narratives are laced with social discourses and power relations, which do not remain constant over time." (p. 65).

A review of literature on narrative analytic schemes yields several ways to analyze narrative data. Some of the most prolific analysis directives stem from Reissman (1993), Mishler (1986;1995), and Polkinghorne (1995; 1988). Riessman (1993) advocates that narrative analysis involves examining poetic structures. She suggests that transcripts should first be on numbered lines and parsed using Labov's (1972, 1982) framework for organizing narratives. This involves noting the organization of the narrative by identifying the following components: an abstract for what follows; orientation to the listener; the carrying out of the complicating action; an evaluation of its meaning; and resolution of the action. Because the focus of this study is on learning more about

communication apprehension with dying persons, the importance is on what is being said rather than how it is said. Thus, this analytic scheme was not utilized. Rather, analysis for this study focused on the function of narratives.

A narrative functional analysis was adopted for several reasons. First, the study aims to examine *how* hospice volunteers negotiate communication with a dying person and/or in a death context. Second, the research is intended to examine the *role* of hospice volunteers' experiences in their own lives. Third, the project explores the *meaning* associated with death and the dying process, which ultimately contributes to the social denial of death in American culture. Thus, the focal point of the narrative analysis is the function of the narrative and not so much on how the narrative is constructed.

Moreover, the exploration of narrative functions in health communication research illustrates how patients' stories are constructed as well as reflect their social realities. As Riessman (1993) points out "individuals' narratives are situated in particular interactions but also in social, cultural, and institutional discourses, which must be brought to bear to interpret them." (Riessman, 1993, p. 61). Consequently, the functions of narratives are just as important as the narrative itself as they illustrate "the social action implied in the text" (Coffey & Atkinson, 1996). For example, the act of telling narratives reiterates a hospice volunteer's belief in the hospice system as well as functions to reduce death anxiety. Thus, a functional narrative analysis provides insight about communication apprehension associated with dying persons as experienced by hospice volunteers as well as how their lives have been impacted by death experiences.

This study employed the functional analysis of narratives as detailed by Mishler (1995). According to Mishler (1995) narrative functional analysis focuses on what stories

do, the setting in which they are told, and the effects they have. A narrative function analysis attempts to answer the question: "what purposes do they (narratives) fulfill, and what functions do they serve – for storytellers themselves, their audiences, their larger communities?" (Mishler, 1995, p. 107-108). According to Mishler (1995) "*function* is defined in a variety of ways both within and across different disciplinary traditions. These differences tend to reflect their primary units of theoretical analysis: persons, cultures, social processes, institutions" (p. 108).

By examining the functionality of narratives, the researcher takes into consideration the "narrativization of experience," identified by Mishler (1995) as a combination of cognition, memory, and self (p. 112). That is, stories function as a means to construct identity and create a collective identity through shared storytelling. Additionally, a narrative analysis that focuses on function provides insight into the "interactional and institutional functions of storytelling." (Mishler, 1995, p. 112).

More importantly to this project, narrative functional analysis illustrates three main functions of storytelling for hospice volunteers. First, the ability to re-story an experience provides individuals with the opportunity to re-examine feelings. For instance, the reflective process of storytelling allows the volunteer to seriously consider her own thoughts on death and dying. Second, "stories or narratives that persons have lived through determine their interaction and organization" and thus illustrate that narrative influences learning and memory (White & Epston, 1990, p. 12). For example, hospice volunteers are able to learn from their experiences and apply their knowledge to future situations. Third, transformation of identity is part of the telling of personal stories. For

hospice volunteers, part of their acceptance of death as a part of life is the ability to tell death stories.

*Procedure*

After interviews were concluded the researcher proceeded to transcribe the interview data. Each participant was assigned a code number and was thereafter referenced by an assigned number. Next, the participant's answer to each interview question was coded (Lofland & Lofland, 1995). A code is a word or short set of words that identify a "distinction, a concept, or an idea" gleaned from the data obtained (Lofland & Lofland, 1995, p. 88). Additionally, the researcher identified key stories or quotes that elaborated or highlighted the participant's answer to the question. For example, for the question "what are your thoughts on your own death?," participant number one was coded "quick death/only treated once/on hospice at home." The identifying quote from the interview transcript read: "Well I would rather die quickly in an accident quickly than linger. But if I had a lingering illness and especially if I had a cancer and it was treated once and it reoccurred I would never go for any more treatment because when it metastasizes it's bad. So you're better off having a quality of life than length of days."

Quotes selected from the interview transcripts and used as part of the coding process were left in their entirety. That is, the literal transcript of the interview is presented, as conversation analytic methodology was used as a guide during interview transcription. Congruent with many discourse studies in the field of communication, the transcription notation system devised by Gail Jefferson (Sacks, Schegloff, & Jefferson, 1978) was employed in interview transcription. Thus, quotes appear in their 'raw' form,

including the presence of vocal fillers such as "uh" and "um" and punctuation was used to indicate explicit pauses in speech patterns, as detailed in Jefferson's (1978) notation system.

Overall, each interview question was coded for each participant's response with no attention to narrative form. A narrative functional analysis pays "less attention to narrative form and structure." Thus, for each response narrative format was not necessarily determined (Mishler, 1995, p. 108). Rather, in analyzing narrative functions, the researcher "alludes to the functional qualities...[and] the idea of function can be brought to the fore and used as a principal analytical unit." (Coffey & Atkinson, 1996, p. 62). Coffey and Atkinson (1996) describe the process this way:

> "This can involve taking a slightly less systematic and structured approach to narrative analysis, deriving more context-dependent infrastructure and focus to explain the effect (intended or unintended, implicit, or explicit) of the story or tale. This emphasizes the idea that individual narratives are situated within particular interactions and within specific social, cultural, and institutional discourses." (p. 62).

Moreover, "the narratives we call data are illustrative, linguistically, of perceived human experience" and do not always consist of narrative form (Mello, 2002, p. 234). Franzosi (1998) posits that a narrative is not always determined by the literal connection of sentences. Rather, stories are often portrayed through the logical conclusions drawn between two or three sentences. "The events in the sequence must be bound together by some principle of logical coherence" (Franzosi, 1998, p. 521). Thus, Franzosi (1998)

concludes that "a narrative text will comprise a mixture of both narrative and non-narrative clauses" (p. 524).

Given that narrative texts often require logical inferences it seems possible that the entire interview data can be seen as one large narrative text from which conclusions can be drawn. Therefore, in this study, a narrative functional analysis was conducted by examining the entire interview as one large narrative. Taken together, unstructured interviewing responses represented the narrative of hospice volunteers' experiences. Within this narrative, smaller, nested narratives appeared which highlighted and bolstered their overall experiences. By approaching narratives holistically the researcher was able to explore multiple meanings and emergent findings (Mello, 2002).

Following the coding of each interview question, coded responses for each participant were grouped together based on the corresponding research question. That is, each interview question contributed to learning more about a specific research question posed. Thus, coded notes were lumped together based on the research questions. For example, in order to investigate $RQ_1$ (what do hospice volunteers' stories reveal about how they experience dying and the death of their patients?), the following questions were asked: (1) Tell me about a time one of your patients died (alternative: tell me about the first time one of your patients died); (2) Tell me about your most memorable experience as a hospice volunteer (follow-up: how did it impact you personally?); and (3) What are your thoughts on your own death? In many interviews these questions were numbered 4, 5, and 12.

The next step in analyzing data consisted of organizing the coded material into research question categories, more specifically, recruitment, experiencing patient deaths

($RQ_1$), themes/issues/topics ($RQ_2$), communication apprehension with dying persons ($RQ_3$), and the social denial of death ($RQ_4$). Then, coded interview responses for each interview question were further sorted and organized. According to Schwandt (2001), sorting involves examining frequency counts of data, developing categories, selecting concepts that define relationships between categories, and formulating assertions that explain data. Thus sorting involves organizing data wherein the researcher compares, contrasts, and labels the data. Ultimately codes were organized into a category or concept. For instance, coded notes on the question "What are your thoughts on your own death?" were further coded into categories such as "wants quick death/wants hospice/not afraid/planned for it."

Then, in order to answer the overall research question, all coded categories were memoed. "Memos are the written-out counterparts or explanations and elaborations of the coding categories." (Lofland & Lofland, 1995, p. 193). Memos tell us more about the code and can vary in length. (This same process of coding and memoing was used to analyze the ethnographic field notes). For example, coded notes for research question one were memoed into the following format:

(1) Make death positive instead of negative

a. Good deaths are memorable

i. Characteristics of good death; ideal for their own death

b. Experiences teach them

i. What to appreciate in life

ii. To love and embrace hospice

(2) Experiences become a pedagogical tool in life (teachers of death)

a. With friends, family, others (patients?)

b. As a way to learn more about their own death

These concepts were compared to find uniformities or patterns across experiences in an effort to further define the concepts and its properties (functionality) (Schwandt, 2001). I examined memoed findings by employing the five typologies of narrative functions as detailed by Sharf and Vanderford (2003) in formulating my own narrative functional analysis. The five typologies included examining narrative function in terms of sense-making, warranting decisions, asserting control, transforming identity, and building community. The typology was used as a means for organizing data; some of the functions do not apply to the individual but rather to the group for which the story is told. Overall the interview data consisted of (1) transcripts; (2) ideas in the form of codes and memos; and (3) summaries and notes (Lofland & Lofland, 1995).

To summarize, a qualitative approach was used to investigate how communication is affected by death and dying and how death experience in turn impacts lives. This approach entailed unstructured interviewing to gather narratives of hospice and volunteers and ethnographic fieldwork. Volunteers were recruited through hospice volunteer coordinators. Narratives were analyzed using the five typologies of narrative functions as detailed by Sharf and Vanderford (2003). Additionally, ethnographic observation of one hospice's interdisciplinary team meetings was used to complement the findings in the narrative analysis. The narrative analysis is detailed in the next chapter.

# Chapter IV

## Narrative Analysis

This chapter details the findings of stories elicited from hospice volunteers about their experiences working with dying patients and in a death context. First, narratives reveal that volunteers' experiences facilitate a positive perspective of death as well as serve as a means to teaching others about death. Second, narratives illustrate that education about death and dying function to reduce uncertainty by emphasizing listening skills. Next, volunteers' narratives suggest that communication apprehension with the dying is due in large part to nervousness experienced in terms of communication expectations. Lastly, narratives reveal that the social denial of death is associated with fear of one's own death as well as a fear of the death event. This chapter also explores the narrative function of sense-making, warranting decisions, asserting control, transforming identity, and community building.

### *Recruitment*

In order to ascertain some general information about volunteering, I began each interview by asking volunteers about their participation with hospice. First, in an effort to add to or complement the literature on recruitment of hospice volunteers, I was interested in finding out how these volunteers got involved with hospice. Thus, I asked "What lead you to get involved with hospice?" Respondents reported that work experience in a healthcare setting, personal death experience, and/or learning more about hospice lead them to volunteer.

Work experience in a similar health care environment appeared to be one way that volunteers were lead into the hospice arena. Several volunteers mentioned that they had

previously volunteered in a nursing or assisted living home as well as an oncology unit. The experience of working with the elderly and/or seriously ill individuals paved the way for working with the terminally ill. In some way, the volunteers rationalized that because they felt at ease with these patients that they would just naturally feel at ease with a dying person. One volunteer who worked in a radiation and later a chemotherapy department described it this way: "I was comfortable talking with them [patients] about different things certainly not about their disease but you know just passing the time of day till they waited for their treatment" (#1). Many of the patients she interacted with were in hospice and since she felt comfortable with them, she believed that she would feel comfortable in a hospice setting. Additionally, two of the volunteers were also paid employees of the hospice. One volunteer was a young student who was interested in working with the elderly and had previously worked in a nursing home. The other, also a student, claimed that she wanted to get to know the patients.

In combination with work experience, it became apparent that experience with death was also a factor that lead to volunteer work in hospice. The prevalent idea was that death experience was the equivalent to hospice work. After explaining how she became involved with hospice, one volunteer concluded, "and I have a lot of experience with death in my personal life" (#6). Death experience was equated with having knowledge, knowledge that appeared to dismiss any apprehension about communicating with a dying person. This idea was echoed in a volunteer who was a 25 year cancer survivor:

> "So hospice over the years has kinda been on my mind but is been over 25 years since my illness and it took me a long time to be able to confront ever talking about it, it took me years, two decades before I could even do that." (#5)

The fact that he was able to talk about death and his own life-threatening illness gave him the knowledge to volunteer in a hospice setting. Additionally, two volunteers had experienced hospice services through the death of family members and had felt it important "to do something to give back and to return." (#4)

Lastly, finding out about hospice and learning more about hospice was integral in recruiting volunteers. Many people are not familiar with hospice care and philosophy and are not familiar with volunteer programs. One volunteer was at a church discussion group when he learned about hospice: "And so that tipped me over. I knew more about it and I was ready." (#5)

But just knowing about hospice isn't enough. One volunteer I interviewed had experienced hospice when his father passed away. However, he didn't immediately volunteer because he didn't know much about the volunteer program. Later, he met a co-worker who was a hospice volunteer: "he told me all about what he does, how much time he has to give. And I was like well it sounds like something I want to do." (#10) Learning about the time commitments and the different functions of a hospice volunteer contributed to their decision to volunteer. A 20 year old student who had been volunteering as part of a class requirement summed it up this way: "I know a lot of places you go and volunteer and basically you file papers...but in hospice you really get hands on training with people and you really get a lot of experience dealing with all types of people." (#8)

In addition to finding out how they got involved with hospice I was interested in learning more about what they did. I asked, "What is your current level of involvement with hospice?" Overall volunteers reported that they were assigned to one or two patients

and also participated in bereavement and respite care services. However, the environment in which their volunteering took place, a nursing home or the patient's home, mattered a great deal to the volunteer. When identifying their patient care services, all of the volunteers specified the location of their patients. The location of their patients seemed to be the most pertinent information about the services they provided.

It appears that even in an environment in which there is perceived to be no control because death is imminent, many volunteers still strive for control by preferring to visit patients in nursing homes. One volunteer summed it up: "I like structure and so therefore I go to the nursing homes." (#5) This structure allows volunteers to have some control over their visits: "I prefer to have them in nursing homes because I can visit them at my time and at a time that I think they may be awake." (#1) Control over time commitments was an issue that resonated with another volunteer: "because she is in an assisted living environment I usually don't spend more then an hour with her." (#4)

However, control over time is not the only issue. By visiting a patient in a nursing home, volunteers are exercising some control over the situation. This structured environment not only allows access to the patient at a time when the volunteer feels comfortable, but it also allows the volunteer to control his/her level of involvement in regards to the family. In a nursing home environment volunteers are less likely to get involved with a patient's family. The volunteer is inadvertently avoiding any undue stress that can be caused by the family. A ten-year volunteer explained it this way:

> You see there's a lot of patients that are just not uh volunteer appropriate.... There are situations where you feel like this is a real need and you can go in and visit and not only with the patient but with caregivers or caregiver and family and

whatever the case may be but the family dynamics with some of these cases is the biggest problem (#2).

By visiting patients in a nursing home, volunteers are able to forgo family dynamics and focus on the patient.

In contrast, volunteers who visit patients in their homes are typically more vested. Visiting a patient at home typically requires more services of the volunteer as trained health care professionals are not readily available if the patient needs health-related caregiving. Additionally, volunteers typically have more of a relationship with the patient and the patient's family. Consequently, experiencing the stress of a death is threefold when the volunteer is involved with the family. One volunteer shared with me that she had developed such a bond with one of her patients that she was able to change her diaper. When asked about her involvement with hospice, she explained "I lost one of my ladies that I really loved. She was just a real sweetheart and I kinda backed off for a while." (#3)

*Experiencing Patient Deaths*

In order to answer **$RQ_1$** (what do hospice volunteers' stories reveal about how they experience dying and death of their patients?) I asked the following combination of questions: (1) Tell me about a time one of your patients died (deviation: tell me about the first time one of your patients died); (2) Tell me about your most memorable experience as a hospice volunteer (follow-up: how did it impact you personally?); and (3) What are your thoughts on your own death? Overall the narratives illustrate that volunteers' experiences turn death into a positive experience instead of a negative event and that these experiences become a pedagogical tool in their lives.

Typically, death is viewed as a negative event in one's life. It is the end of the self and future manifestation of the self (Callahan, 2000). In other words, death is definitive. Callahan (2000) proposes that death is viewed as premature when death occurs before "biologically necessary" and tragic "in circumstances that are terrible" (p. 180). Callahan (2000) summarizes that death acceptance is a misnomer:

> More generally, we fail to realize how profoundly ambivalent most of us are about accepting death, not just because of the threat of death itself, but because we are heirs of the same tradition of technological optimism that has dominated modern medicine. Even if we *say* we can accept death, we believe in our hearts that the sting of death can be medically delayed, that fatalism is itself a source of fatality, that death is a kind of human artifact (p. 51).

However, for many hospice volunteers their experiences of death and dying facilitate a transformation of their view of death. For them, death is a positive experience as they are able to witness "good deaths." Such deaths, loosely defined in accordance with hospice philosophy, include dying with someone by your side, free of pain, and in a peaceful environment (typically the patient's home). It is through these experiences that volunteers begin to associate good feelings about death as they play a part in facilitating a good death for the patient and the patient's family:

> I think if you interview the volunteers they would all say the same thing – that uh we get more out of it then the patients. And you have to experience that to really understand us ... But uh anyway it's just you walk away feeling better then you did when you walked in (#6).

Thus, good experiences turn into good feelings about death. For example, one volunteer had developed a special bond with her patient which made her feel special:

> It was probably about the last three weeks that she was alive that she uh she didn't know where she was and she always recognized me. And she would tell me.... If anybody is going to watch after me you're my favorite (#3).

After the patient died, the family made a special effort to show their appreciation for her involvement with the care of the patient. At the viewing, the daughter came over and put a coin in her hand,

> And she said... I think I'm going to start crying here in a minute....Anyway she said take this home with you and it was one of those appreciation gold plated coins that you are suppose to pass on to anybody you appreciate a great deal. So I thought that was real sweet (#3).

The volunteer summarized her experience as meaningful because she was involved with such a peaceful death and she was appreciated. Being appreciated is an important aspect in making these experiences positive:

> And the patient's husband wrote hospice and thanked them about and named each one of us that worked over there and he sent me personal thank you notes about how appreciative he was of the care that I gave him and his wife. And that's also highly unusual. Hospice also always sends a thank you note when the patient dies but for the family too that was a first for me. And that made me feel special (#7).

Consequently, good deaths are memorable for hospice volunteers. In fact, many volunteers are able to recall very specific details about their experiences of such events. One of the most poignant examples of this is the story of a volunteer who was assigned a

33 year old prisoner who had AIDS. The volunteer was able to recall a detailed account of the event:

> So they had just taken his blood pressure and it was 40 over zero and of course he was comatose and he was laying on his side facing the wall and he was covered up and so I sat down there and carrying on and reach over and rub his blanket and say "[patient's name], you can let go you're not dying in prison." And I'll bet there was at least five of the workers there who came in and told him they loved him. You know they say hearing is the last thing that goes. Of course his breathing was labored and I sit there for about an hour and all of a sudden I noticed a drop off in his frequency and how deep he breathed. And uh I thought well should I tell somebody? What the heck are they gonna do? He's gonna die. And so in about another twenty minutes he quit breathing. And you know I felt like it was a blessing you can go ahead and get it over with. And it didn't bother me so much that he died but it bothered me to go out into the hall and tell them he was dead (#2).

The volunteer's remarks that it was a "blessing" illustrate that the death was a positive experience. The idea that this volunteer was "praying" for death is radically different from the cultural denial of death. Callahan (2000) posits that death becomes acceptable when we "see death in some situations as a lesser evil than continued life" (p. 180). The volunteer echoes this idea in his summary of the experience:

> Death ... to most people death is a spooky thing. And uh so when I sat with him there this was his only alternative. There was no way he was going to survive. And I sat there and prayed that he would go ahead and die. And so you know how

could I be very upset about it? (laugh). There was no way I would rather have it (#2).

The volunteer was at peace with the death and felt like he had made a difference in this person's life.

These "good death" experiences also serve as models for volunteers' own deaths. Not only are they experiencing good deaths wherein the patient dies at home, but they are also able to identify characteristics of a good death. Such characteristics identified in the narratives include care of the patient, the physical process of dying, and the family dynamics of the situation.

When asked to identify her most memorable death experience, one volunteer shared two stories. First, she recalled the death of her sister describing it as "heart-wrenching.... but a very natural thing" as her sister required much pain medication and oxygen. She juxtaposed this experience with the story of a patient she had that was also a friend of hers through church. In identifying the friends' death she characterized it as easy because the dying process was distinctive and apparent:

> That was much more memorable because it was an easy death and its just his breathing just got slower and slower and uh he would you know he couldn't retain his saliva. So I would I would mop you know the side of his mouth cause he's at an odd angle you know and would drip occasionally. So I would mop that and just talk to him and pray but mostly pray silently (#1).

This death was also considered "easy" because it was not a member of the volunteer's family.

Another characteristic of a good death was the family dynamics and level of care that the patient received. One woman served as the patient's volunteer as well as a paid sitter. She saw the patient three times a week and enjoyed her experience: "She was in a healthy situation and had a wonderful daughter and son-in law" (#3) This loving environment made the experience enjoyable for the volunteer. Another volunteer had a similar experience, commenting that the husband of the patient was very actively involved in the care of the patient and always asked questions. She was impressed by the care the patient was given:

> I mean that woman always had a dry diaper when I came. And I have been to many many patients where it looked like they've been sitting in that wet diaper for hours and there was a caretaker in the house (#7).

Lastly, the patient also served as a reminder of what a good death experience can be like. A patient who is aware of his/her fate and is able to capitalize on the time that is left because of good pain management is a reminder of a good death. One volunteer described such a patient as "like an angel" and "every time I came she had a big smile on her face" (#7). Such warmth and happiness at a time that is normally typified as sad and depressing was refreshing to the volunteer:

> Well she's memorable because she was such a sweet, sweet, angelic lady who appeared to me to be at peace with what life dealt her. I mean she could deal. I mean she knew what was happening (#7).

In contrast, an experience with a patient who is not at peace with their situation can be a reminder of the importance of their work. A memorable event for one volunteer was her exposure to a patient who was in terrible pain:

> I felt like it was very disturbing to hear her because she was in so much pain. I think she was pretty aware of what was going on and that was the frightening thing. Because she knew where she was, what was going on, and she knew that she was dying and she was in still so much pain (#8).

The volunteer said it was most memorable in terms of experiencing the sheer reality of dying. Another volunteer summarized this discrepancy in patient care:

> The other two that I talked about that died were so emaciated, and so sickly looking, and bones sticking out. This woman, her skin looked healthy, and she just she looked... I mean you couldn't tell... she looked healthy. And I said to her you just look so healthy. And she looked healthy when she died ... I mean you could see how the other ones [were] when you see how emaciated they become and all their changes and that kind of stuff (#3).

As a result, these experiences also teach volunteers about what to appreciate in life as well as reinforcing the importance of hospice work. A four-month volunteer concluded that her hospice experiences have taught her "how precious life is, how precious time is. How thankful we should be to know one another and not to be afraid. We take it for granted the time we have left." (#4) She illustrated these points by sharing a story about a man who was angry about dying:

> I just said okay let me have it. You're angry, let me have it. I won't take it personally. And he did. And you know later he thanked me for just allowing him to unload. And you know in my work and in my maturity in the past, I recognize that when people are angry and spout off at you it's not to you it's at you. And it's

not personal.....So I've learned not to be real sensitive about the anger stuff but I am sensitive to their needs (#4).

In conjunction with hospice philosophy she provided this gentleman with the opportunity to take advantage of the time he had.

An exemplar of the importance of hospice work was the story of one volunteer's involvement with a patient whose medicine was not taking care of her needs. As a result the patient became irate, irritable, and agitated. Later, when the medicine was corrected the patient was able to rest peacefully and enjoy quality of life. The volunteer recalls the situation:

> Um, it really made me believe more in hospice because I know that it's because, I mean besides my belief in God, that hospice was such a blessing in her life and got her medicine straightened out and able to get her I guess help get in a nursing home so her family could have a break because they were .... Um I talked to her daughter, the caregiver, and she was in tears talking to me and she doesn't even know me. I can't imagine what she was really feeling and she loved her mom and her mom is calling her the devil and killer and just saying hateful ugly things to her. It just... it definitely made me love hospice (#9).

Thus, in facilitating a change in their perception of death, these experiences also function as a pedagogical tool in life. More specifically, hospice volunteers become teachers of death which also consequently teaches them about their own mortality.

Hospice volunteers' experiences are used in their lives as a way of teaching friends, family, and others about death and the dying process. They are able to help others capitalize on the time involved in the dying process as well as educate others about the

physical elements associated with the dying process. Recalling the death of a friend, one volunteer explains how she was able to help the family through the process:

> At the time her family had told me that the last few days she had been talking to loved ones that were already dead. And what was interesting, this was probably more interesting than my patients have been so far because I was able to tell them what to look for in those final days and hours...I was able to explain some of that (dying process) to them and sort of help one of her sons who was not accepting what was going on with that and it really, and they told me later, how much the information did help them (#4).

The same volunteer went on to explain how she hopes to ease her family into understanding the importance of hospice ideology and practices:

> You know I have some in my family who don't wanna care about it or want to talk about it either. And I hope to be able in time, at the appropriate time and places, be able to share some of my experiences with them, in terms of patients as well as my own thoughts and feelings about it (#4).

As "teachers of death" hospice volunteers also learn more about their own mortality. In fact, many of them think about death on a regular basis and have planned for their own death. Many volunteers have written advanced directives, selected burial plots, penned their obituaries, and chosen songs to be sung at their funerals. When asked about her thoughts on her own death, one volunteer remarked: "My own death.... I have my own plot. I have my own tombstone with my name on it and uh some days I wonder when it's coming (laugh). But other than that I don't really think about it. It's just part of life." (#6)

While many of them still considered death a mystery, several volunteers said that they were not afraid:

> Well I am looking forward to it and I am not a suicidal sort of person. But um I'm just I know that this is gonna happen and I want it to be special for my family. I want them to understand and appreciate the process. I am not fearful of it at all (#4).

Ironically, despite their involvement in hospice, the overwhelming majority expressed a desire to die quickly. One volunteer explained it this way:

> Well I would rather die in an accident quickly then linger. But if I had a lingering illness and especially if I had a cancer and it was treated once and it reoccurred I would never go for any more treatment because when it metastasizes it's bad. So you're better off having a quality of life then length of days (#1).

Another volunteer, a breast cancer survivor, explained that her experiences with dying patients has taught her that illness is often times prolonged and given the opportunity she would specify "just give me a heartache....I hope it's going to be an easy one." Despite bearing witness to good deaths through hospice, the preference for a quick death is probably a result of interacting with dying patients. A 20 year old volunteer explained: "I would rather just die quickly and not have to experience humility and all sorts of really kind of almost dehumanizing aspects of becoming older, like incontinence and not being able to dress and feed yourself." (#8)

However, it became apparent that volunteers' experiences with hospice facilitated an understanding of death as an unavoidable part of life. That is, their experiences helped them to accept death. A 75 year old volunteer recalled a time when he was in the hospital

for surgery and was sharing a room with another patient. The other patient was an elderly gentleman who had difficulty swallowing and he began to choke on his own saliva:

> And I was in the second bed, and here they come in with a flash cart and at least half a dozen doctors and nurses. And the head nurse of the floor came over and said, 'Do you want us to get you out of here?' Well what chance did they have of getting me out of there? I said no I've been a volunteer at hospice long enough that uh I know that this is uh just part of life. And uh so I think through the hospice training and the experience that I've had with hospice kept that from really de-railing me. But um they worked on him for 2 or 3 minutes and the doctor said there is nothing to save here and they stopped (#2).

Their hospice experiences thus also function as a way of coping with death and dying. In fact, he concluded this discussion of thoughts of his own death by sharing a story of a patient who had 24 bed sores, with three or four of them close to the bone: "So I say there are things worse then death" (#2).

Additionally, their experiences often include a spiritual interpretation of death and as such functions as a means to accepting their own mortality. Likewise, the telling of their experiences provides volunteers a venue for sharing as well as reinforcing their spiritual beliefs. For example, one volunteer concluded a discussion of her own death by commenting, "I think I will be going to an absolutely beautiful place" (#4).

The reinforcement of their spiritual beliefs through storytelling could also promote coping as well as alleviate fears associated with death. One volunteer explained his spiritual perspective this way:

> I realized that it was God testing us, shaping us, these trials strengthen our character and all of this stuff is for... our character. And uh so I look at it that way as preparation.... So I am just going to take care of myself so when the judgment day happens I go the right way. And heaven is what it's all about. I don't even want to think about the other place. So life is ... is preparation for the afterlife. So that's the way I feel about it. I am just preparing myself and hospice is one of the best things I do. It's got all of these pluses on the ledger to offset some of these debits I've got there (#5).

Lastly, their experiences also help them to accept the death of their own loved ones. As volunteers shared their experiences, many of them summarized their accounts by relating them to elements of their own life. For example, one volunteer remarked how similar her patient was to her mother:

> Well I think that it impacted me personally because I could picture someone in my own family being in the same predicament and I think the members of my family would be more like this patient then they would some other patients that I've had in that my mother is very calm, very ... never been very excitable and that's the way this patient appeared to me (#7).

To summarize, hospice volunteers' stories reveal several aspects about how they experience dying and death of their patients. First, their experiences facilitate a change in the way that death is viewed, moving from a negative to a more positive perspective. This is primarily occurring because volunteers feel good about the work that they contribute to hospice care. For example, narratives illustrate that good deaths are memorable and provide volunteers with ideal characteristics for their own deaths. Second, their

experiences provide them with the knowledge and skills to teach others about death and dying as well as advance thoughts about their own mortality.

*Themes/Issues/Topics*

In addition to utilizing their experiences in their own lives, volunteers' experiences also illustrate important aspects of their volunteer work. In order to assess **$RQ_2$** (what are the themes/issues/topics, etc. of hospice volunteers' stories?) I asked the following combination of questions: (1) Have you ever turned a patient down?; (2) What recommendations/advice would you share with a new volunteer?; and (3) What does volunteering do for you personally? (follow up: why do you continue to volunteer?). The narratives collected exhibit three main issues: education, patient-centered care, and the benefits of volunteering for hospice.

The most prolific theme to emerge from volunteer experiences was education. Their first education about death and dying comes from their volunteer training. Many volunteers found their training to be helpful and especially appreciated the opportunity to visit patients for the first time with a volunteer coordinator or seasoned volunteer. In addition to their volunteer training, many volunteers have read and recommend reading books on hospice/palliative care work. Books that provide detailed accounts of real-life experiences as well as those that centered on the spirituality of death were encouraged. Regardless of how much time they had invested in participating in hospice services, many volunteers continue to educate themselves by reading books on death and dying. These educational tools assist the volunteer in preparing for their role as a hospice volunteer. By educating themselves, volunteers are able to reduce uncertainty about the situation and prepare themselves. Ultimately, education complemented by experience

facilitates preparedness. For example, one volunteer described how she prepares for visits:

> Well I always carry a little satchel with me, a little canvas bag. And in it I have scriptures, I have poems, I keep a set of rubber gloves in there. I keep a couple of extra little straws in there so that if I get to someone's house and they can't drink out of a cup and there's no little straws I have it....and I always bring a paperback book because a lot of times the patients will nap and I'll just sit there and read my paperback book (#7).

This type of preparation ensures her that she will be able to handle any situation that arises and functions as a means of reducing uncertainty about the situation. By preparing for anything she is able to take control of the situation, whatever it may be.

Being knowledgeable about what happens when a patient goes through the dying process also teaches the volunteer how to respond appropriately, thereby further reducing uncertainty. One volunteer explained it this way:

> Oh well uh this lady I just had a respite with a couple of weeks ago. Uh I went in to visit her and the niece said you probably won't have to talk to her at all and I said well I always go in and introduce myself... and um... the lady asked me after I went in after one hour, "Have you seen my mother around here. I saw her just recently." Now see her mother had been dead but lots of times people who are dying really do see these people that have died before. And those are the experiences that really give you chills. I mean sometimes they have been people that have just passed away recently that nobody has told this dying person about. And they say, "Well I saw so and so. She came to visit me." She might have, you

know. It gives me goose bumps. And see the family and volunteers too have to be aware of that because they know that the time is coming closer, that the person is gonna pass away. And also they should know not to say, 'Oh you couldn't have seen them.' You know, it's like a person with Alzheimer's, you just go with the flow (#1).

Thus, her education and experience helped her handle this situation. She knew how to respond in this context which made the conversational interaction easier to handle. The prevalent idea is that learning about death and the dying process arms you with the tools necessary to facilitate interaction. According to Maxwell and Klein (2000) hospice volunteers "are expected to think ahead and to be well prepared to adjust their communication styles as patients decline." (p.35). A young woman who had been volunteering for only four months provides some insight on this way of thinking:

> So you have to be the one who kind of takes charge, and you've been trained and should have a good idea of what is acceptable to do and what is not as far as helping them or you know explaining things to them. You know you only do what you can or what you feel is right (#8).

In addition to the emphasis on education, another prevalent theme among volunteers was the main premise of hospice philosophy: "it's not about you!" A ten-year volunteer described it this way: "the patient is the boss. If the patient doesn't feel like you being there, if they don't feel like visiting, or having to be attentive to you, you excuse yourself and come back later" (#2). Volunteers stressed the importance of understanding the patient's needs and desires. By putting their own feelings aside, volunteers are able to accomplish this. Maxwell and Klein (2000) describe volunteers as having the gift "to

enter into all feelings openly, spontaneously, and non-judgmentally" (p. 29). One volunteer described it this way:

> So you just check your ego at the door, check your life at the door, become a hollow, empty vessel when you walk through that door. It's not about you at all. You just ...you just have to put yourself aside and say 'what can I do to make a difference with this patient today?' (#5).

However, one volunteer also pointed out that in this process it is equally important for the volunteer to be perceptive of his/her own feelings:

> Realize that it's not at all about you or your feelings and if they say things that are unpleasant to you or if they do unpleasant things it's definitely not because of you or as a result of anything you've done. So if they get hateful or if they get upset in any way it's probably about not you so don't be so self-conscious about it (#8).

One way that volunteers are able to accomplish such a task is to practice active listening skills. An overwhelming majority of them highlighted listening skills as a key component to the services they provide. For example, a volunteer who is also a cancer survivor originally thought that he would become involved with hospice so that he could share his own experience with cancer. However, he quickly found out that his role is "to get them to open up – not you opening up to the patient." (#5).

Aside from just being a good listener, volunteers also recognized the importance of their visits. They understand the value of hospice philosophy and services and recognize the importance of what they do:

> Never underestimate how important it is that you're there. Cause when I would go in and I would sit with that lady ...sometimes I go out there and all that

> woman does is sleep. The whole time... like I went yesterday and she was up for like five minutes for the two hours I was there, she slept the rest of the time. That, just to make sure that that woman is safe you know, her daughter can know just... it's so important to that family. It might not seem like a big deal to me at all because I'll just go and bring a book and I'll just read and I would have done that anyways. So it's not that big of a deal to me ... but it makes such a big difference to that family (#9).

While volunteers aren't expected to do anything except provide companionship to the patient and the family, many volunteers do housekeeping chores. One volunteer shared with me that she felt compelled to clean:

> One house I went to her husband was not a housekeeper and the refrigerator was so bad that one day when she was sleeping I just took everything out of it and cleaned the whole thing. I put everything back in but I cleaned the interior because there were spills and drips and sticky and gooey you know. He didn't have time and some men don't think of things like that (#7).

Finally, one of the main themes from the narratives elicited center around the benefits of volunteering for hospice. The most prominent reason was because it makes them feel good:

> It makes me feel worth while. You become the closest thing to an angel on earth. It's the closest you'll ever get. Because you are doing something special, you know you are, every time. Because these people are incredibly lonely. They are incredibly lonely and you are their angel...Plus there's something about getting to play an angel for awhile. I think we all got a little of it in us. I think that every

hospice volunteer, if you really scratch'em hard, they would admit that they feel like that uh God's touched them a little bit, given them a little bit of an edge (#5).

For many volunteers, their involvement with hospice is their way of giving back to society with the hope that the world will be a better place. This idea was associated with religious beliefs: "I believe that in giving to others you also are serving God...It's important that we do appreciate the gift that we have and to share them with others" (#4).

Despite the idea that volunteering is selfless, many volunteers shared that their involvement was one way that they hoped to pave the road for their own end-of-life care. There was strong desire to be involved in a hospice program should the circumstances deem that necessary. One volunteer concluded:

> In the long run I would hope that there would be people that would come and visit me, if I were sick, and um you know give my husband a rest, or come and visit him and give me a rest (#1).

The emphasis of such desires was on visiting and having visitors. Other volunteers also explained how much they enjoy being a part of the group of volunteers and being able to talk to them about the many issues involved in providing care in such a context.

To summarize, volunteers emphasize continuing education about the dying process and death, are steadfast in recognizing that hospice work is all about the patient and not the volunteer, and recognize the many benefits to volunteering in such an environment. Taking all of this into consideration I now turn to examining communication apprehension with dying persons and the social denial of death.

*Communication Apprehension with Dying Persons*

A large part of this study also focuses on communication apprehension associated with talking to dying persons. Thus, **$RQ_3$** (what do hospice volunteers' stories reveal about communication apprehension regarding dying persons?) and **$RQ_4$** (what do these stories illustrate about the social denial of death?) were assessed by asking the following questions: (1) Tell me about your first assignment. (follow up: Tell me about the first time you met the patient. Were you nervous?); (2) Tell me about a bad experience as a hospice volunteer; (3) What are your thoughts about meeting a patient for the first time? Have they changed from the first patient?; and (4) How do people react to you when you identify yourself as a hospice volunteer? (follow up: do they ask you about your experiences?). Generally, the narratives suggest that apprehension about communicating with dying persons is not culturally linked to a fear of death, but rather that nervousness is experienced in terms of communication expectations. Additionally, experience and the relational connection between volunteer and patient play a large part in reducing apprehension. Lastly, hospice volunteers' narratives illustrate that the social denial of death is associated with relational depth as well as a fear of the actual death event.

Research suggests that individuals experience anxiety when communicating with a dying person (Hayslip, 1986-87). However, several hospice volunteers reported that they were not nervous at all, mainly because they had done similar work in similar environments. Some had additional training from other job experiences and others just felt comfortable around older people. When asked if she was nervous about her first assignment, one volunteer commented, "I wasn't too scared because I've done stuff like that before." (#9). Still, some volunteers reduced anxiety by engaging in uncertainty

reduction techniques to find out more about the patient beforehand. For example, one volunteer commented that she really checks out a patient's chart. Another volunteer goes even further: "I like to find out a little bit about them as far as... I like to talk to the staff. You want to know if there is anything you should be watching for, like don't bring them sweets because they're diabetic, something like that." (#3).

While only a handful of volunteers expressed that they were indeed nervous about their first assignment, this nervous energy was experienced positively. Nervousness was described in terms of "anxiousness", "exciting", "enthusiastic", and volunteers "looked forward" to their work. One volunteer explained her excitement this way:

> So then you get your information sheet usually in the mail or the telephone and then I always feel anxious at that point. Not anxious *anxious* but excited about going to meet somebody new.... I am always interested and my curiosity is piqued about who they are, what they are gonna have to say, what kind of needs they have, how I can fulfill their expectations (#4).

Overall, volunteers viewed their experiences as an adventure. However, one volunteer did stress that he was nervous about being too emotional. He had first experienced hospice through his father's death and was worried that the situation might bring up old memories.

Despite their positive feelings about entering into a death and dying context, some volunteers experienced anxiety over their role. As noted earlier, role ambiguity can be problematic for volunteers (see pages 26-27). In describing his first visit with his first patient, one volunteer described this ambiguity as a complication: "The one complication was that he needed to get up to use the port-a-potty and he needed help so I helped him

but we're really not suppose to do that. We are suppose to call nurses but it wasn't practical to do so." (#5) While this incident did not seem to upset this volunteer, it made another volunteer very cautious:

> Anyway he left it [medication] and he told me you know now I have just given this to her but if she needs another dose she can have it. And I said okay. Well I hoped and prayed I wouldn't have to give it to her because you know I can't do that. They can measure it out and I can give it to the patient and the patient can take it. But I'm not to administer medication so I was a little concerned about that. I told the volunteer coordinator about it and the next time I told the husband that I could not physically give her medicine. Now if it was pre-measured I could hand it to her and she could take it but I was not to administer medication so we got that worked out and that was the only thing I was concerned about there (#4).

Role ambiguity in this context made the volunteer very nervous. While she wanted to help the patient she struggled with what she was allowed to do. Thus, a fear of breaking the rules created anxiety.

On the whole, apprehension was primarily experienced in terms of eliciting and regulating the flow of communication. Although there is much emphasis on the importance of good listening skills in hospice volunteer training, volunteers still felt that it was their role to regulate the flow of conversation. One volunteer described how this made her feel nervous: "And um I was nervous because it was my very first patient and I didn't want to have big lulls in the conversation but I didn't want to prattle either." (#7) Consequently, she felt a tremendous amount of pressure to keep the conversation going. This feeling also resonated with another volunteer's experience with a patient:

> I found out that his war experiences were numerous and he loved to talk about it so whenever there was a lull in the conversation because I felt like I needed to... we needed to talk and I just didn't want to sit there because he was okay except being in a hospital bed and paralyzed (#1).

The pressure to continually converse with patients created anxiety. Likewise, patients who were not able to communicate reduced the volunteers' apprehension. For example, one volunteer described meeting her second patient:

> I wasn't nervous at all. Because [name of patient] I never saw [name of patient] except her back. Her bed her hospital bed faced the wall, she was facing the wall, she was asleep the whole time I was there and all I did was give the caregiver, her daughter, some time to go to her own home and prepare dinner and do things like that. I just went so that there would be a body there. She was on... she had a catheter in, she was on oxygen, she was breathing very heavily and so I never even talked to her (#7).

The patient's inability to communicate reduced her fear of having to communicate, thereby reducing her anxiety about the situation. Moreover, communication difficulties leave volunteers feeling inept, which also creates anxiety. One volunteer recalls her first patient experience as being awkward:

> Well the first time I went and saw her she was not doing very good....she was real loud and kind of disoriented so it was a little... I guess that made it a little awkward.... I went in and I tried to talk to her about the things that she liked to do and she just said fishing and that was it. And I tried to get her to elaborate on it

> some more and she just said that she liked to do it and I just I don't know it was kind of hard to get her to … talk (#9).

The struggle over communication made the volunteer feel uneasy about the situation. Another volunteer experienced the same feelings when initiating a relationship with a patient who spoke English and Spanish fluently and additionally had some hearing problems:

> So that first time I was just like basically yelling and trying to make my words as clear as possible. She would… she talked …even in English she's a little garbled. I think mostly from being elderly and also from her having an accent. Both of those make her a little difficult to understand and so I was hopelessly confused by what she told me. And I was like please can you say it again with you know some sort of hope that I might have some sort of a response. Cause I didn't want to give the wrong response or I don't know, but um. That was really really unnerving because I thought she was angry at me (#8).

Taken together, these experiences suggest that facilitating communication can create apprehension when communicating in a death and dying context. One volunteer summed up the struggle this way:

> And you don't want to come over too strong and ask lots of questions you know you don't want them to think that you're nosey or something like that. But then again you don't want to be telling them all of your experiences and not hear any of theirs. Because many times these people are anxious to talk and so you just listen. You know it's just hard (#1).

Nevertheless, it appears that experience and relational development are two factors that reduce apprehension in this context. First, experience allows the volunteer to further understand the death process and provides him/her with a better understanding of how to respond appropriately. One volunteer attributes this to her interaction with staff: "After being around the hospice staff as long as I have you learn a lot more things to say, comforting things and things that don't just come to your mind but then having heard them for ... you can use those same phrases you know when you're talking to people." (#7) She goes on to describe this as a growth process: "I am maturing in hospice. Like you do with any other situation that you get into for the first time ... I just feel more at ease going into people's homes now and I ask more pertinent questions." (#7) This growth process takes place by learning what is appropriate and not appropriate. However, it also entails understanding the role of the volunteer and how complicated and emotional these contexts can be. For example, a gentleman who had been volunteering for a few months recalled his initial visit to his second patient who told him he did not want a volunteer. The volunteer concluded that this experience signified his own growth:

> And I think more, now especially after being turned away too, like I feel better like... it's not reflective of who I am... the first time I see them if they don't want to talk or do... like it's like regardless it's not reflective of who I am. So I think that... if that would have been my first patient I would have been like 'oh I am a terrible volunteer' (#10).

In addition to maturing in/through hospice, the data also suggests that the deeper the level of the relationship, the less apprehensive a person is about communicating in a death and dying context. Despite the context of death being imminent, the fact that the

person is a total stranger is a factor. A volunteer described meeting a patient for the first time as "a little touchy....because you don't know the person" (#1). The idea that the volunteer is going into a stranger's home was echoed by another volunteer who concludes: "you're just kind of unprepared I guess is the best way to describe it. And if you get kind of get antsy about being unprepared you worry about things" (#8).

Being with a stranger is especially problematic in a death setting. Hospice philosophy entails the ideology that no one should die alone. Encapsulated in that ideology, however, is an underlying assumption that the patient will die surrounded by loved ones. Anxiety is thus created when a volunteer has little or no relationship with the patient and death is imminent. For example, one volunteer recalled being asked to provide respite care for a woman who died before the time was scheduled. She recalls: "And I thought wow if she was that bad I didn't need to be with her. Although I have been with dying people ... I'd rather know them then just be a stranger in the home and maybe the only person in the home. You know that's kind of frightening." She went on to conclude: "As long as I know what the situation is but you know like when I heard that the patient that died before I even went over there I thought oh thank god because you just don't want to be with somebody who is a stranger to you and not have any of their family there." (#1) Thus, it wasn't the idea of being with the woman when she died that made this volunteer uncomfortable. Rather, the volunteer wanted to know this woman in some way so as to make the experience better for herself as well as for the patient.

In fact several volunteers spoke to me about their preference for serving as a volunteer to someone that they know personally. However the decision to take on a

patient who is also a personal acquaintance can make the experience more emotionally intense. One volunteer described it this way:

> Some of them [volunteers] do not want to or they would rather not take a patient that they know and I feel the opposite. I feel like if it is somebody I know that I can be more to them then I can to a stranger....but I feel it a privilege to do what I can for those people that I know ... [on the other hand,] other people can't take it if it's somebody they know that's dying (#2).

The other dilemma that arises is whether or not the patient and his/her family would like the volunteer to be involved in the patient's care. This was evident in another volunteer's decision:

> And so I went to the volunteer coordinator, this was after my training, and I said I have a friend and they called hospice and I really, if there is not a problem with that, I really would like to be her volunteer. And I said I would prefer that you call and visit with {name of patient's husband} to make sure its okay because I know, I knew, they were very private people. And I did not want to invade the privacy, if that was the case. And if that was the case it was fine with me. I understood perfectly. So I said to the volunteer coordinator will you please make that call because I think that ...I think it would be better if you called rather than me. And so she did and now that was fine with them. And so that worked out very well (#4).

While the decision to take on an acquaintance as a patient enhances the volunteer's emotional investment, the level of anxiety appears to be lessened when caring for someone in which there is a relational connection.

Consequently, having a relational connection to the patient really made a difference for how volunteers viewed their work and how they felt about their work. More specifically, volunteers who felt that they could make a connection with their patient felt more comfortable. Volunteers who described satisfactory experiences remarked how they "hit it off" with the patient, that the patient was "easy to get to know." One volunteer recalls his initial meeting with one of his favorite patients: "we got to talking and right off we found out that we have a lot things in common... And so we just kind of connected." (#2).

In contrast, volunteer experiences in which no relational connection was made were considered unpleasant. In describing her first patient one volunteer concluded that the patient "was just harder to get to know" (#1), and as a consequence the situation was uncomfortable for her. An even more poignant example of the importance of relational connection between volunteer and patient is the story of one volunteer's experience with a difficult patient:

> She wanted to use her dying as a weapon against people I think. And she would [say] 'This is not the way you would treat a terminal person' and blah blah blah. ...And that was some of the things that pushed me away. I could see that she was cantankerous with the [staff]... and bossy with her other people there. In fact I was asked to be a private sitter for her and I said no. I could see that that would not work (#3).

The lack of connection between the volunteer and the patient created a difficult environment.

Given that the relational connection between volunteer and patient play a large part in creating a comfortable communication environment, it may be that the closer a person is to the dying person, the less apprehension and anxiety are experienced. According to Keeley (2004) it is most often a family member or loved one who is in the role of communicating with someone who is dying. Presumably this heightened relational connection could actually lessen apprehension in this context. In fact, Keeley (2004) posits that despite being unprepared for conversations with a dying person, religious and spiritual beliefs facilitate such interactions. But what about interactions in which the two people are not close? Perhaps an examination of the social denial of death can shed some light on these dyadic interactions.

*Social Denial of Death*

According to Kübler-Ross (1969) dying persons go through fives stages of death acceptance. These five stages also highlight the means for coping with death and include denial, anger, bargaining, depression, and acceptance (Kübler-Ross, 1969). However, Callahan (2000) posits that the fear of death is multi-layered and consists of : (1) fear of pain; (2) fear of the loss of identity; (3) fear of the loss of relationships; (4) fear of losing the social world (understanding what our loss will mean to others); and (5) fear of not knowing what death entails. The narratives collected in this study represent an amalgamation of these fears.

The most prolific representation of the social denial of death in my data set was the family's denial of the patient's impending death. In many cases the fear of a loved one's death resulted in inadequate care for the patient. The most telling example of this came from a volunteer who recalled her experience with a family who could not accept

the fact that their loved one was dying. During the volunteer's visits the home health aide would come in and give the woman a bath and the patient would scream in pain. The volunteer explains:

> Well what the aide told me was that he [patient's husband] did not want to give her the pain medication because the pain medication made her dopey. And see when he came home from work he wanted to sit and talk with her and he didn't want her dopey. So but then we started giving her the pain medication before we gave her a bath because she was like huge bruises all over her body and just to turn her was so painful for her (#7).

The volunteer was appalled at what was happening and went on to explain the seriousness of the situation: "He [patient's husband] was leaving her alone in the day and going off to work and clumping her down in this chair and putting some food beside her and there she'd sit in that wet diaper all day." (#7) In this example it was obvious to the volunteer that the husband did not want to accept his wife's declining health. She summarized her experience in this way: "So uh that was a case where I mean the husband in my opinion should have been thinking of her pain more then his needs as far as talking with her" (#7).

In addition to compromising the care of their loved one, death denial is also illustrated in the way that the patient's condition is viewed. Many families do not want to give up hope and thus fail to accept the true condition of the patient. One volunteer experienced this discrepancy which made her feel very uncomfortable:

> [Wife of patient] didn't understand very well about the difference between coma and someone with real extreme dementia. And she wanted me to read to him. And

> I went up there and I probably didn't go to see him a half dozen times before I just told the volunteer coordinator I said he doesn't know if there's anybody there. Because he would jabber all the time that I was reading and I couldn't really get anything... I didn't think that he was aware that I was there and I felt like it was an effort ... And uh so that to me was the most unpleasant situation (#3).

The volunteer recognized that the patient was not benefiting from her visitations, however the wife insisted on them. Other volunteers remarked that families typically push for advanced treatment options even in the patient's last days.

Home care situations are not the only place that death denial is prevalent. Volunteers who visit patients in nursing homes remarked over and over again how few visitors these patients had. One volunteer provided a vivid description of the situation: "the only human outside contact they have from aside the staff is the volunteer. I mean they are warehoused. People warehouse these people. And they never, they have relatives but their relatives never come to see them ..." (#5). Another volunteer recalled her first patient who was in a nursing home:

> With her, um I just sat and held her hand and just talked to her. And she would always say just hold my hand, just hold my hand, and she was just she was constantly moving and she was so nervous. I would come in, on the days she was awake, she would just be yelling for somebody to come and sit with her and hold her hand. Yelling out the door for somebody to sit with her (#9).

This narrative in particular illustrates the loneliness experienced by many nursing home patients and suggests that many families do not want to deal with those who are elderly

and ill. Tragically, many of the volunteers shared horrific nursing home experiences. For example, one volunteer describes one of her visits to a nursing home patient:

> It was like a gathering room of sorts. And um she was spitting up, she had this handful of vomit that she was holding and I was trying to get somebody to come and help her... It took me probably about... I'd say 15-20 minutes to get somebody to help her with that...I would say that was the worst [experience] I've had only because I was disappointed that it took me so long to get her help (#6).

The difference between home care and nursing home care also typified a fear of the actual death event. Families who have family members in a nursing home do not have to worry about where the patient will die. In fact, they are so removed from the situation that the actual death event may be inconsequential. However, families who provide home care are faced with the reality that the patient will die in the home. The fear of death for some families makes this problematic. This was exemplified in one volunteer's experience:

> And they had their daughter and two little grandchildren living with them, at best I remember they were maybe 5 and 6 years old. And she [the wife of patient] was worried about the effect it would have on the children if he were to die at home. And uh I talked with them and I said you know that is one of the main thrusts of hospice is to allow people to die at home (#2).

The volunteer concluded this narrative with his own comments of how perplexed he was at the notion that the patient might not be given the right to die at home. In fact, he called in the chaplain and social worker to help the family understand the importance of a "good death."

Sadly, this lack of understanding death as an unavoidable part of life manifests death fears. Consequently, many people do not know what hospice is and what types of services are provided for dying persons. One volunteer concluded that there is a "lack of public knowledge of hospice." He recalls a friend's first introduction to hospice:

> The biggest surprise I have ever gotten was when a family that I know of a good friend requested me as a volunteer, terminal from esophageal cancer, and an educated person, a very educated career kind of guy. When I showed up he said well I guess this means no more water and food and I just my jaw just dropped. Here was a guy, an educated guy, didn't know what hospice is, that we were there to give palliative care and support and not kill him. That, I will never forget that as long as I live. I knew then that we've got to educate the public (#5).

Thus, the lack of knowledge of hospice plays a large part in death denial. The volunteer concluded: "When you have educated professional people at that level misunderstanding [hospice] then we just... we are in a world of hurt." (#5) Moreover, volunteers voiced concern about the low wages paid to nursing home and hospice services staff. This illustrates the low value we place on something we want to avoid.

Lastly, general responses to volunteer involvement in hospice revealed death denial. Many volunteers mentioned that they don't bring up their volunteer role unless someone specifically asks them about it. And when they do, some of the more common reactions include: "I could never do that", "oh how can you do that?", "how can you stand that?". However, most of the time people ignore the topic, as one volunteer describes what it is like:

> They usually ignore it, frankly. They might think, oh uh I don't know if I could do that. And there again you get that shadow, death and dying, hospice equals death. That's the way... that's the equation in the lay public. Hospice equals death and it makes them uncomfortable and it makes them change the subject. So I accept that. You don't want to cram it down their throats (#5).

Furthermore, the overwhelming majority of volunteers reported that they are not asked to share their experiences. For example, one volunteer commented on wearing her name badge in public.

> The other day I came from the office, the training, and I still had my badge on and I went to the grocery store to pick up some groceries. The young man checking my groceries said 'oh, you work for hospice...do you get paid for that?' I said no I am a volunteer. On other occasions I've worn it in the store no one has said anything (#7).

She was surprised that she was asked about hospice but not surprised that she wasn't asked about her experiences. The same holds true for another volunteer: "I mean they ask me what I do but they don't ask me specifically about the patients that I see." (#9)

Coffey and Atkinson (1996) recognize narratives as a "form of discourse used in everyday interaction" which thus serve a variety of functions (p. 56). With specific reference to health narratives, Sharf and Vanderford (2003) propose that there are five typologies of the functionality of health narratives; sense-making, asserting control, transforming identity, warranting decisions, and building community. In this study, the narrative function of sense-making, warranting decisions, asserting control, transforming identity, and community building are applicable to the interview data.

*Sense-making*

Narrative form allows individuals the opportunity to recall experiences, and consequently re-examine feelings. It is the reflective process of storytelling that allows individuals to create meaning and make sense of reality. By recalling their experiences an individual is able to make sense of what they experienced. Sharf and Vanderford (2003) identify this narrative function as sense-making. The findings from the interview data demonstrate that this reflective process allows hospice volunteers to consider their own thoughts on death as well as contemplate religious/spiritual interpretations of death.

When volunteers share their stories with others they are making sense of death. Their narrative of a death event or the experiences of interacting with a dying person facilitate their own sense making. Their recalled experiences detail and provide accounts for an emotionally charged and mysterious event, and consequently issues such as humility, interpretations of disease, family impact, and grief all play a part in their account. The way that they choose to recall events and experiences demonstrates their acceptance of death as a part of life. This was evidenced in one interview wherein the volunteer concluded that he was "happy" that his patient died. This conclusion exemplifies his acceptance of death as a natural event in one's life.

Making sense of death also entails understanding and interpreting the dying process. In addition to the biological process that the body goes through when dying, there are also spiritual elements to the death process that need to be understood and explained. The reflective process of telling others about a witnessed death event necessitates an interpretation of these phenomena. For example, many volunteers shared with me that dying persons see and talk to people who have already died. Volunteers

have to make sense of these experiences. For instance, in disclosing this information one volunteer commented "and you know I believe in that." Although she did not share with me what she believed in, the comment alluded to her spiritual beliefs which in turn facilitated her own deeper understanding of the death process.

With this deeper understanding of the death process, hospice volunteers also contemplate their own deaths. By recalling good, memorable deaths, volunteers are able to reflect on how they would like to die. In other words, their experiences provide them with exemplar deaths and bad deaths – and their narratives thus function as a means to understanding the benefits of good deaths and how death can be good or bad. Thus, they consider how they feel about death as well as reflect on spiritual aspects of life after death.

Likewise, in their effort to make sense of death, hospice volunteers ultimately have to contemplate and attribute meaning to life in general. Therefore, hospice volunteers' narratives also facilitate reflection of their own lives and choices they have made. In essence, a spiritual/religious evaluation of their life is triggered by the attempt to analyze death. As a result, many volunteers continually educate themselves about death and dying as a way of helping to make sense of the reality of death.

*Warranting Decisions*

By recalling past experiences, individuals are also able to recognize their own communicative choices and consequently evaluate their own role in the story. Additionally, this particular type of narrative function reveals the narrator's values and reasons for action. Sharf and Vanderford (2003) identify this narrative function as warranting decisions. Interview data suggests that hospice volunteers use narratives in

this manner to explain their involvement with hospice as well as justify their advanced preparations for death.

Hospice volunteers place value on helping others and believe that their participation in hospice helps make the world a better place. However, their participation in hospice can be warranted in two distinct ways. That is, their role in hospice is to help others, but it also helps them as well. First, hospice volunteers believe that their volunteer work contributes to the community. In this manner they rationalize that their participation is strictly selfless. On the other hand, many volunteers that I interviewed explained that they hoped that their volunteer work will "pay off" in the long run, in terms of their spiritual beliefs as well as with their own deaths.

Hospice volunteers believe whole-heartedly in hospice ideology and thus they are very cognizant of the choices they make regarding death and dying. One such choice that stems directly from their experiences with hospice is the importance of preparing for their own deaths. Volunteers use their experiences as a way of rationalizing preparations for their own deaths. Based on their experiences of witnessing family quarrels and intense grieving, hospice volunteers believe it is important and necessary to make concrete plans for death, including writing advanced directives, purchasing burial plots, writing their own obituary, and choosing songs for their funeral. This type of advanced planning is deemed a necessary component for attaining a 'good death'.

*Asserting Control*

The reflective process of telling narratives also functions as a means to explaining and expressing suffering. Sharf and Vanderford (2003) identify this process as the narrative function of asserting control. In this manner, the narrator is able to exert control

by explaining the loss of autonomy. For someone who is ill, the loss of autonomy can take several forms. Most obvious is the loss of physical ability as the body begins to enter the dying process. The person becomes dependent on caregivers and is no longer in control of his/her own life. Additionally, the psychological aspects of illness such as shame and embarrassment may be experienced (Sharf & Vanderford, 2003). Although hospice volunteers are not suffering from illness, this narrative function is still applicable as their narratives function to put off fear of illness and death. More specifically, hospice volunteers' narratives illustrate an attempt to control their own deaths.

According to Sharf and Vanderford (2003) the act of narrativizing an experience affords the narrator a degree of control. "Narrativizing one's experiences includes the creation of order, placing previously unexplainable events into relationships" (p. 24). By re-creating the experience through storytelling, the narrator is able to attribute causes for actions, thus exercising some form of control. In this context, narratives provide hospice volunteers the opportunity to explain their involvement as volunteers. That is, their participation in hospice is one way that they are taking steps in their life to ensure a 'good death.' Many volunteers felt that their involvement with hospice would benefit them in their last stage of life; that they would experience a 'good death' through hospice or that they would spiritually be given a 'good death' by going to heaven.

Additionally, Sharf and Vanderford (2003) point out that the narrative process affords the narrator the opportunity to exercise control in the future. In this manner, narrators are able to express their wishes before they are no longer able to do so. For hospice volunteers, the act of re-telling death experiences allows them to highlight certain aspects of what they want in their own deaths. In this process, they are able to assert

control over their own deaths by voicing their desires regarding the dying process as well as making advanced plans for their deaths.

*Transformation of Identity*

Narratives can also facilitate the re-development of an identity as well. Sharf and Vanderford (2003) refer to this narrative function as the transformation of identity. Narratives illustrate changes in the way individuals see themselves by demonstrating changes in thoughts and actions. Thus, narratives function as a means to learn from past experiences. As such, hospice volunteers are able to accept death through storytelling as well as develop their identity as a hospice volunteer.

For many hospice volunteers, the act of telling a story about their experiences facilitates the acceptance of death. In turn, this 'death acceptance' separates them from other individuals who are apprehensive about death and dying. By being in an environment in which death talk is acceptable, volunteers learn how to talk about death. The ability to talk about death in a comforting way is an important skill that is acquired through experience as well as by learning from others what to say. Several volunteers referred to this process as 'maturing in hospice'. Moreover, when sharing experiences with others, volunteers are exposed to various interpretations of death and dying, which possibly contribute to and influence their own interpretations of their experiences. Overall this type of environment facilitates a transformation of the volunteer's identity, wherein death becomes a natural aspect of one's life.

The opportunity to re-tell their experiences also creates a different persona for the hospice volunteer. Hospice volunteers are really proud of their work and they are eager to share their experiences with others. When interviewing hospice volunteers for the study,

it was not uncommon for the volunteer to bring a notebook that contained a complete history of each of their patients. In some cases, the volunteer clipped the obituary of the patients to include in their files. This ownership of their role in end-of-life care was important to them. In fact, among other volunteers it is prestigious to be a 'senior' volunteer as they are considered resident experts by other junior volunteers. Thus, through their work with hospice, their maturation is recognized not only personally but by others as well.

In addition, their role in end-of-life care establishes them as hospice representatives. This recognition results in two different identities for hospice volunteers. First, hospice volunteers assume the role of 'teachers of death.' That is, through the sharing of narratives, they actively take on the role of educating others about the dying process. Second, their unassigned role as part of the hospice team allows them to transform their identity to become an 'angel on earth.' As you recall, hospice volunteers do not have a designated duty in hospice care. Rather, they are there to provide companionship to the patient and his/her family. Thus, in recalling hospice experiences their role is insignificant to the other people in the story. Many hospice volunteers described this identity as servant-like because the hospice volunteer enters the care situation with no real identity of their own.

Lastly, a volunteer's identity is transformed when they are associated with hospice and share information with others about hospice. Although interview data depicts that the typical reactions to hospice volunteers are comments such as "I could never do that" or "how could you do that," individuals' reactions change once they have experienced a hospice situation with a loved one. In these situations, the role of a hospice

volunteer actually shifts, and people feel compelled to share their stories with them. For instance, several volunteers commented that once somebody knew they were involved with hospice they immediately shared their hospice story.

*Building Community*

Mishler (1995) notes that the re-development of identity is also intensified in a group format, wherein narratives can lead to a collective group identity. According to Sharf and Vanderford (2003) this narrative function builds community as stories have the ability to influence others. These stories are associated with distinct groups with their own vocabulary and rituals. Interview data illustrate that narratives are used to build community among hospice volunteers as well as health care staff.

One way a collective group identity can emerge is through the development of a standard story format (Mishler, 1995). This standard story format emerged during my interviews with hospice volunteers. Congruent with the biomedical mode of thinking, initial information about patients was shared through medical information. Thus, the standard story format actually served as a means for beginning to tell a story. For example, the standard story format included the patient's name, diagnosis, age, when they met them, where they received care, and over what period of time they had visited the patient.

This learned story style indoctrinates hospice volunteers into the hospice way of thinking, with the focus on biomedical information. Thus, hospice volunteers learn to interpret information about individuals in this manner. This learned story style also helps volunteers learn how to interpret patient information as it is the same format used by hospice case managers when providing details about a patient. Still, by focusing on death

and dying from a biomedical perspective, volunteers garner another way of looking at death and dying.

It is interesting to note here that the hospice system is premised on the biopsychosocial model of healthcare. To recall, this model of healthcare incorporates biological, psychological, and social aspects of disease into one approach to healthcare (Engel, 1977). This approach is the basis for hospices' interdisciplinary team approach. Thus, one would assume that the standard story format for sharing experiences would consist of elements of the biopsychosocial model. However, this study concludes that although narratives function to build community, they also function to reinforce the medical emphasis of the biomedical model.

To summarize, interview data from this study exemplifies four narrative functions of health narratives as explicated by Sharf and Vanderford (2003). Namely, narratives function as sense-making, warranting decisions, asserting control, transforming identity, and building community for hospice volunteers. This study suggests that hospice volunteers utilize narratives to make sense of death, warrant their decision for advanced preparation of their own death, attempt to control their own death, indicate a transformation of accepting death as a part of life, and build community through shared story formats. The next chapter will detail the ethnographic observation of one hospice's interdisciplinary team meetings as well as the findings of the observation.

# Chapter V

## Analysis of ethnography

The interdisciplinary team (IDT) meetings of Town Hospice were observed in order to examine how the company goal of providing "psychosocial needs of the patient and their loved ones" is addressed. More specifically, a dialectic theoretical approach was used to explore how case managers negotiate the addition of psychosocial information about patients during IDT meetings. From my observations I found that psychosocial information on patients was primarily limited to three types of information sharing; (1) information related to care goals; (2) family issues related to bereavement and caretaking; and (3) the request of additional help from team members. Additionally I understood that the addition of psychosocial information creates a dialectical tension for the team.

### *Introduction*

The interdisciplinary team (IDT) model utilized in hospice and palliative care services stems from a biopsychosocial approach to healthcare (Engel, 1977; Larson, 1993). This approach makes healthcare a collaborative effort by incorporating all aspects of care into one unified team effort. Hospice has embraced this ideology and has expanded it further to include the spiritual aspects of healthcare (Larson, 1993). However, the IDT approach has rarely been assessed and there is currently no research that has examined the IDT approach to ascertain the psychological, social, and spiritual elements of hospice care and philosophy.

Given the role of the biopsychosocial model in the development of the hospice interdisciplinary team approach, we would expect IDT meetings to involve all team members in a patient's plan of care. Dale Larson, recognized by the National Council of

Hospice and Palliative Professionals (NCHPP) as a pioneer in understanding the dynamics of IDT meetings, explains the IDT approach:

> Interdisciplinary clinical teams draw upon the expertise of specialists in each of these separate domains – biological/medical, psychological, and social – to diagnosis and treat the whole person and the context of illness (Larson, 2003, p.6).

Gibbons and Bouton (2003), nurse section leaders for the NCHPP, further explain that "in an interdisciplinary team model, the decision making/care planning process is conducted in a collaborative manner based on stated patient and family needs and goals." (p. 41). Gibbons and Bouton continue by adding that the "NHPCO's *Standards of Practice for Hospice Programs* (2000) specifically states that all team members must meet, review, revise, and document the plan of care." (p.41). Larson (2003) surmises that the biopsychosocial approach within IDT meetings constitutes shared leadership responsibilities and thus "independent collaboration" (p.6).

However, independent collaboration is often the barrier to incorporating a biopsychosocial approach in IDT meetings. For example, leadership in a team meeting is most often from a doctor or nurse rather than a social worker or spiritual care advisor and thus clinical information is primarily shared when reviewing cases (DeFord, 2003). Consequently, psychosocial information is often considered 'extra' information shared with the team. Larson (2003) concludes that the IDT approach is "often undermined by the failure of team members to understand the unique contributions and expertise of their colleagues from other disciplines" (p.6).

One way to learn more about psychosocial information sharing in IDT meetings is through ethnographic observation. Ethnographic observation of these meetings is best for two reasons. First, communication at IDT meetings is always emotional, due to the nature of the context (DeFord, 2003). DeFord, in describing an average IDT meeting, states: "The conversation of the team, at IDT meetings and among themselves, and with patients and families, is primarily about feelings" (DeFord, 2003, p. 14). Thus, ethnographic observation of these meetings should provide insight to communication about psychological, social, and spiritual elements of end-of-life care. A second reason to conduct ethnographic observation of IDT meetings is to obtain a complete portrait of the patient's situation. Briggs, allied therapist section leader for NCHPP, describes the challenges of comprehensive patient care: "A patient may be having good symptom control, be spiritually at peace, but struggling with the inability to walk alone without falling. These varieties of perspectives often challenge the communication and understanding within the IDT of what is really going on and the pertinent issues to address" (Briggs, 2003, p. 38). IDT meetings provide a venue for discussing psychosocial issues that are often left out of medical discussions. For example, IDT meetings can tell us how much discussion centers around psychosocial issues and how hospice staff address and negotiate these care issues.

*Background*

Town Hospice, which was launched as part of a health service company in 1997, serves families and patients across a large metroplex area. The hospice is for-profit and is Medicare certified, state licensed, and joint commission accredited to provide home care, hospice, and sitter-companion services. Medicare hospice benefits provide for services

such as nursing care, medical appliances and supplies, drugs for pain management, short-term respite care, and home health aides (for a complete list please see page 21). Congruent with the philosophy of hospice, all services are interdisciplinary team directed. That is, the scope of services provided by Town Hospice include intermittent visits performed by skilled nurses, physical, occupational, and speech therapists, home health aides, medical social workers, chaplain, volunteers, and bereavement counselors. The team is supervised by the hospice director and medical director. A registered nurse, known as a case manager, coordinates and implements the plan of care. At Town Hospice, these interdisciplinary teams meet twice a week for an hour to discuss new admissions, changes in care, deaths, and to review current patients on a rotating basis. These meetings, known as IDT meetings, are lead by the hospice director.

In their new patient orientation packet Town Hospice describes hospice as a concept of care "with the goal being to affirm a person's right to be in control of their life, to be free from pain, and to die with dignity. With the support of the Hospice interdisciplinary team the psychosocial needs of the patient and their loved ones are addressed." The orientation packet also details the five themes to hospice philosophy, as outlined by Town Hospice:

1. Recognizes dying as part of the normal process of living
2. Focuses on maintaining the quality of remaining life
3. Affirms life and neither hastens nor postpones death
4. Recognizes the patient and family as the unit of care and that they are in control of care decisions

5. Supports patients and families so that they may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them

Overall, the company's mission statement in the orientation packet reads: "Town Hospice believes in the importance of caring for each patient with honesty, respect, and dignity by adapting to the needs of each patient and providing individualized care." This study investigated Town Hospice to ascertain how these goals are met. A dialectical approach was utilized to guide the investigation.

*Theoretical Approach*

As mentioned previously, theorizing about health communication can best be explained in terms of dialectical tensions (Babrow & Mattson, 2003). Baxter (1988) was the first to propose that dialectical theory could be used to analyze communication within interpersonal relationships. Previously, relationships had been examined in terms of behavior and communication strategies aimed at maintaining a relationship once it had been established. However, Baxter (1988) proposed that relationships are not static but rather are in a constant state of change. She proposed a dialectical approach to relationships which consists of four major components: contradiction, change, praxis, and totality (for an example of a dialectic approach see Johnson, Wittenberg, Villagran, Mazur, & Villagran, 2003).

Dialectical theory is derived from Bakhtin's (1981, 1984, 1986) dialogism, which premises that dialogue is characterized by the opposition of centripetal (unifying) and centrifugal (diversifying) forces (Baxter, 1992). Thus "meaning [is] constructed in the ongoing negotiated interaction between persons." (Baxter, 1992, p. 331). This social approach to studying communication juxtaposes the intention of communication between

encoder and decoder, wherein intention is viewed in the interactive practices of the two partners. Thus, according to Baxter (1988), "a contradiction is formed whenever two tendencies or forces are interdependent (the dialectical principle of unity) yet mutually negate one another (the dialectical principle of negation)" (p.258).

Such contradiction exists in the context of end-of-life care. Babrow and Mattson (2003) argue that this contradiction is best illustrated through the values and assumptions between the scientific and humanistic study of medicine. On one hand, the scientific perspective, also known as the biomedical model, focuses on prolonging life through medical technology and pain management. On the other hand, the humanistic perspective, which is characterized more by the biopsychosocial model (Engel, 1977), concentrates on psychological and social aspects of care. While the goal of providing health care is the same, the contradiction can best be summarized as the dialectical tension between length of life versus quality of life.

According to dialectical theory, contradiction triggers change in the relationship and therefore relationships never sustain a stable state (Baxter, 1988; Baxter, 1994). The centripetal pole typically symbolizes normative social conventions while the centrifugal pole represents non-conventionalized behavior (Baxter, 1994). In terms of end-of-life care, the scientific perspective would be considered the normative social convention and would be characterized by advanced testing and treatment options. On the other hand, the humanistic perspective would be considered the non-conventionalized behavior and would consist of refusing potential treatment options and focusing on advanced planning arrangements. Brown, Altman, and Werner (1992) note that both poles of contradiction are necessary for the existence of either. Each contradiction takes place in an interactive

moment and is thus fluid (Baxter, 1994). Therefore, in the context of end-of-life care, the tension between the biomedical and psychosocial models is reflected by discussions of medical treatment options as well as psychosocial treatment options. Moreover, based on the interdisciplinary team approach to care, hospice IDT meetings should demonstrate a balance between the two discourses.

The third component of dialectical theory, praxis, characterizes the reactions to dialectical tensions. As change is inherent, according to Baxter (1994), one pole may dominate only temporarily. Therefore, in hospice IDT meetings, change should be evidenced by shifts between biomedical and psychosocial information sharing by IDT members. For example, a medical staff member would be likely to experience the tension between scientific information sharing and psychosocial information sharing. On the one hand the team member is cognizant of her own role (e.g., registered nurse, dietician) in the meeting which involves sharing biological/medically necessary information. On the other hand, the desire to share humanistic information about the patient is a large part of hospice philosophy.

Finally, the fourth component of dialectical theory, totality, must be taken into consideration. That is, a dialectical approach focuses on the relational situation (Baxter, 1988). Montgomery (1992) notes that interpersonal relationships take place within the context of the larger culture. Furthermore, dialectical tensions can be unconsciously felt or expressed within relationships because tensions occur between individuals (Montgomery, 1993). For example, these tensions occur when a medical staff member of the IDT (such as a nurse, doctor) decides to share psychosocial information. Each person in the IDT meeting has a unique education and background and thus focuses on his/her

specific job responsibility. Most often these people are medically trained and thus value biological information whereas professionals from the humanities value religious, cultural, and spiritual information (DeFord, 2003). Given the basis of a dialectical approach, case managers are the focus of this study as their primary role is to share biomedical information about patients and as such experience the dialectic nature of sharing psychosocial information with the team. Additionally, case managers lead the patient reviews in IDT meetings.

Furthermore, ethnographic fieldwork that focuses on examining dialectical tensions yields both a focus and a way of doing things for the ethnographer. Because dialectical tensions are socially constructed through interaction, ethnographic observation is one methodological approach to studying this phenomenon. As such, the focus of observation for this study was primarily the discourse between participants. More specifically, I was interested in what case managers shared about patients when providing their reports. Therefore, this impacted the way I conducted my ethnography. While noting the information sharing patterns of case managers, I also took into consideration how the tone of the meeting was impacted by the sharing of humanistic information. Over the course of the ethnography this meant that my field notes detailed instances when psychosocial information was shared by case managers as well as the staff's reactions to the information.

*Ethnographic Observation*

My initial introduction to Town Hospice was at the National Hospice and Palliative Care Organization's conference on Volunteerism in August, 2003. It was there that I met the Hospice Director of Town Hospice. After sharing several emails I was

invited to attend their annual fundraiser. During the fundraiser I was introduced to the owner of the company as well as several registered nurses and other hospice staff. It was agreed that I would be allowed to observe IDT meetings.

The IDT meetings are held twice a week, one in the morning and one conducted in conjunction with lunch. To better facilitate everyone's demanding schedules, Town Hospice provides lunch for team members for the afternoon meeting. During my visits on those dates I arrived early and ate lunch with the team. The meetings take place in a large room that has one large table and one small table. The hospice director sits at the head of the table and to her right sits the medical director and to her left an assistant. Other team members sit wherever they want to; however, the chaplains typically all sit together at the smaller table.

IDT meetings at Town Hospice are succinct. The hospice director leads each meeting. Upon my initial visit I was introduced to the team as a student who was studying hospice. At every meeting team members receive a detailed agenda, a list of new updates (new admissions, continue care patients, in-patients, deaths, and revoked patients). Additionally, an on-call list is provided for updates. The hospice director reviews the agenda, which primarily consists of organizational announcements and business, goes through the update list, and case managers provide information about patient changes. Following the update list, case managers report on patient cases that are scheduled for review. Finally, all team members participate in signing numerous amounts of paperwork, such as re-certifications, plan of care, as well as bereavement plans and sympathy cards (for another description of IDT meetings see also Winton, 1998).

I participated as a team member at five IDT meetings. I received copies of the agenda and update list. When it came time to process paperwork I simply passed it around to the member sitting beside me. As mentioned earlier, I often ate lunch with team members and chatted with them before the meetings. Since this study focused on the psychosocial information shared by registered nurses who serve as case managers, I stopped collecting data when patterns and themes emerged and I felt assured that the criteria of predictability and generalizability were met.

*Findings Regarding the Biopsychosocial Model*

When reporting on new admissions and providing updates on case reviews, I observed that there is a standard format for sharing information. A set of shared standardized practices makes this IDT meeting like others. For example, when updating the team about a new admission, I observed case managers consistently providing the date the patient was admitted, a complete diagnosis, medical history of the patient, current medication, whether there is a do not resuscitate order (DNR) and/or a power of attorney (POA) for the patient, and an assessment of pain management. Likewise, when reporting on case reviews, I observed case managers using the same format and pain management was reported as "no change" or a change in medicine was reported. Thus, a case manager's primary role is to inform the team about the medical condition of the patient; however, the opportunity to share additional psychosocial information is an option. From my observations I found that psychosocial information is provided in one of three ways: (1) as part of care goals/issues; (2) family issues; and (3) when making a request for additional help. Additionally, since psychosocial information is not

considered part of the standardized sharing process, such information sharing can create a dialectical tension for the team.

I initially observed case managers sharing psychosocial information about patients by relating it to care goals. More specifically, case managers felt compelled to share information about the patient especially if they witnessed inadequate care. For example, I heard a case manager report that a newly admitted nursing home patient was not "safe as the level of care was not adequate or appropriate for his condition." The tone of her voice emphasized how upset she was by the patient's environment. She requested that the hospice doctor see the patient as soon as possible. I observed that the rest of the team was not as bothered by the information.

At a later meeting, the same case manager reported on a similar situation with a different nursing home patient who also was not receiving adequate care. This time, however, she provided more details about the care of the patient, perhaps in an effort to elicit a response by other members of the team. She went on to explain that the patient could not reach the call button in his room. As a consequence, the patient was getting up and falling. Again, the tone of her voice demonstrated her frustration in finding such poor patient care. She continued her report by explaining that she had the staff move the room around so that he could reach the button. She went on to add that the patient was using a pitcher to urinate in as the care facility had not provided him with a urinal. Her first line of business for this patient was to bring him a urinal and her initial care goal was to have him moved immediately.

Taken together both examples represent a clear demonstration of the use of psychosocial information sharing (in the later case, the vivid description of patient care)

as a means to meeting care goals. In order to facilitate moving the patient to a new care facility, the case manager needed to have permission from one of the patient's family members. Obviously aware of this, I observed the bereavement coordinator asking the case manager if the patient had any family. The bereavement coordinator was informed that the patient had a daughter. I observed the bereavement coordinator tell the hospice director that she would contact the daughter as soon as possible. Thus, the case manager was able to expedite meeting care goals by including psychosocial information in her report.

I also observed psychosocial information being shared as a way of validating the work of the team. In these instances, I heard case managers provide information about the reputation of Town Hospice. For example, while providing information on a new patient, a case manager added that the husband of the patient was previously cared for by Town Hospice and the daughter called and requested Town Hospice because she was happy with the services. At a later meeting, I observed this type of information being offered again; this time the family of a patient was referred by the family of a current patient under Town Hospice's care. Since this information is not medically necessary for the team to know about the patient, it is considered psychosocial information about the patient. However, because it bolsters the work ethic of the team its contribution is warranted.

Case managers were also observed providing psychosocial information about the patient to justify care/treatment being received. For example, when a case manager provided an overview of one patient's medicine, the dietician questioned the medication prescription and steroid use of the patient. The case manager replied that the man was

still very active and worked out doors all day. The addition of this psychosocial information legitimized the plan of care. In another patient report, I observed a case manager commenting that a patient "is a lot more pleasant." I heard the case manager add, "she used to get mad about getting her hair washed. Now she's got a big smile." The case manager continued to explain that the plan of care had been changed to reduce the number of times the patient's hair was washed because the patient would scream when water was poured onto her head. The psychosocial information in this report is the elaboration of the reasoning behind the change in the plan of care. It was almost as if she had to justify why she felt the patient was more pleasant; thus she explained that it was not bio-medically related to this patient's care.

In addition to information that pertained to care goals, case managers were also observed providing psychosocial information as a way of evidencing good care. The types of comments I heard that were psychosocial in nature were related to quality of life, such as the description of one patient as "sitting at the table, all smiles, more alert than ever!" I heard another case manager conclude a patient report by adding, "I just love her. She's darling." Additionally, a case manager mentioned that a patient got her haircut and I heard her comment, "she looks gorgeous – a totally different woman" and then she went on to report no change in condition. Other quality of life comments that I observed included reaching milestones, such as a patient being able to go home for Thanksgiving.

However, when reviewing their update sheet, I observed case managers simply reporting "no change." In these instances, the patients were nothing more than a name on the review list. However, during my observations I understood that these patient's names *were* important to the case managers. For example, on two separate occasions I observed

the staff noticing that a patient's name was listed incorrectly on the update sheet. On the first occasion, when the patient's name was called I heard the corresponding case manager comment, "Who is that?.... That's not my patient." I understood that the case manager made it very clear that the patient's first name needed to be changed. At a later meeting, I observed another case manager commenting that her patient's name was incorrect and she requested that the name be changed.

I also observed family issues as a topic area that warranted the addition of psychosocial information, particularly because bereavement care is included in hospice services. As part of the standardized sharing process, case managers report a high, low, or moderate bereavement level. However, when family bereavement is high, I observed case managers providing psychosocial information to explain the situation. For example, I heard a case manager describe a 2 -3 hour fight among family members when a patient died. She explained that the son of the patient was drunk and could not accept the death of his mother. I heard her comment that it was the worst death she had ever witnessed. These last two comments taken together are considered psychosocial information, and thus function to justify the bereavement level as determined by the case manager.

In another patient review, I heard a case manager report that a patient had been hospitalized. This is congruent with the standardized sharing process. However, I then heard him add that the wife of the patient was "cracking" as she was overwhelmed and didn't want the patient to return home. This additional psychosocial comment evidenced his projected bereavement level. I heard additional psychosocial comments regarding bereavement levels such as "the husband of the patient is hyper and agitated" and one

case manager also reported that "the patient is still [sleeping] in his room with his wife" which was his way of alluding to a bereavement care issue.

In conjunction with additional information about family dynamics, I also observed case managers providing details about caretaker problems. For many home hospice patients their primary caretaker is a family member. Thus, when there are problems with a caretaker this also means that there potentially may be problems with the level of care provided to the patient. Thus, these types of problems warrant additional psychosocial information. For instance, I observed a case manager discussing a patient who was taken care of by her husband. The case manager explained that the husband required surgery and was going to be out of the home for several weeks. I heard her lead a lengthy discussion of how to handle care for this patient in her home while the husband was in the hospital. Additionally, I observed similar psychosocial information sharing with the team, such as a caretaker who was having financial difficulty and needed assistance from their non-profit fund as well as reports of caretaker depression.[i]

In some instances, caretaker problems were very serious and justified a lengthy discussion. For example, I observed a case manager reporting that a caregiver was not to be trusted to care for the patient's open wound. She further explained that the caretaker stopped giving the patient one of the prescribed medications as the caregiver determined it was not necessary. However, upon further examination, the case manager found that medicine was missing and suggested that the medicine was stolen from the patient's home.

Finally, I observed that the request for additional help is used as an occasion for inserting psychosocial information and it often bolsters the case. Although information

shared was primarily biomedically focused, case managers utilized this information in a persuasive manner to encourage other team members to see the patient. For example, I heard a case manager comment "unfortunately we are seeing the down side of this patient" as he reported that a patient's cancer had metastasized. He was then quick to provide psychosocial information about the patient by commenting that she is "amazing" because, despite her terminal illness, she continues to volunteer where she used to work. Immediately following this information, he requested that the dietician see the patient immediately.

In another report, I observed a case manager discussing a 93 year old patient who lived alone. The main concern for the team was caretaking, however finances were also an issue. I heard the chaplain interject, "At what point do we talk about alternative placement?" The case manager was quick to provide additional psychosocial information about this patient – she explained that the patient would 'kick hospice out' as she wanted to die in her home. She further explained that the patient had a son who lived down the street and looked in on her every morning and afternoon. I heard the case manager add that the patient is currently able to care for herself. The case manager insisted that a social worker be assigned and discuss with the son the possibility of an alert system. (Note: An alert system consists of a call button which automatically contacts emergency personnel.).

While case managers provided standard diagnostic information for all patients, I observed that the addition of psychosocial information signified a dialectical tension amongst the care team. From my observations, the most poignant example of such a tension occurred during a case manager's report of a patient who was dying of head and

neck cancer. Congruent with the standardized sharing process in IDT meetings, the case manager provided a summary of the medical status of the patient. This would be considered normative social behavior in the IDT meeting as it is the standardized sharing process. However, I observed him deviate from this standard format when he began to describe the patient's physical condition -- the patient had large visible holes all over her neck. In terms of the standardized sharing process of the IDT, this vivid description of the patient's condition is considered 'extra' information as it is not typical for case managers to describe the physical condition of their patients. Thus, it is considered non-conventionalized behavior and represents the dialectical tension between the biomedical and psychosocial approach to care.

It was obvious that the case manager was struggling with decisions regarding medical treatment options and the importance of psychosocial care. Accordingly, the contradiction between the two approaches was evidenced by a change in the demeanor of the team. I noted that this additional information triggered an uncomfortable environment. It seemed apparent that the additional description of the patient was too much information for the team as it deviated from the standardized sharing format. As the team continued to talk about the patient, I observed several team members shaking their head and struggling with the additional information. The room became extremely quiet and I heard another case manager comment that that this was the worst type of cancer.[ii] Overall, it seemed apparent that the expression of emotion by the care team signified a dialectical tension.

At one point in the report, the case manager asked the dietician to see the patient to help with food intake. The dietician replied, "You want me to see her? Why do you do

this to me?" Initially I thought that this comment would be viewed negatively by the team because they all work in a death and dying context. On the contrary, it appeared that the dietician echoed what other team members were thinking (i.e., I hope I don't have to see this patient). This is an example of how information sharing represents the dialectical tension between the biomedical and psychosocial model of end-of-life care. Apparently the medical diagnosis of a patient with head and neck cancer was alright for the dietician, as it was part of the standardized sharing practices in IDT. However, the inclusion of psychosocial information in the form of a description of the patient's condition caused her to feel uncomfortable about providing her services.

As the case manager continued, he began talking about the patient's medicine and the difficulties involved in feeding the patient through a tube. Thus, the case manager tried to negotiate the dialectical tension between the biomedical and psychosocial approach to caring for this patient. That is, the description of the patient is considered psychosocial or 'extra' information sharing for the team as the case manager's role is primarily to provide medically-oriented information. Probably as a result of recognizing that he deviated from the standardized sharing format, he quickly went back into the role of case manager and his discussion of the problem of feeding the patient, which is bio-medically focused.

Baxter and Montgomery (1996) identify this shift in conversation topic as relational praxis. Relational praxis occurs as a result of dialectical tension and signifies the negotiation of the contradiction. The relational praxis of *spiraling inversion* is taking place in this context (Baxter & Montgomery, 1996). That is, one pole is dominant at different points of time and the dialogue goes back and forth between the two poles.

Thus, the case manager shifted from biomedical to psychosocial and then back to biomedical as a way of handling the dialectical tension.

Finally, I heard the case manager continue to report that the husband of the patient is aware that the patient's death will ultimately occur from bleeding out one of the holes. The case manager reported that he told the husband that he had the right to revoke hospice and put the patient in the hospital at any time. At this point, I observed the team come together, and I heard many of them comment that if the patient began to bleed she would surely die before anyone got there to help. I observed the somberness of the entire team as they concluded this. I understood that physical descriptions of patients were too much information for the team. Thus, one way that they avoided such dialectical expressions was to stick with their standardized sharing process, which does not account for patient descriptions.

On a separate occasion I also observed that the addition of psychosocial information signified a dialectical tension for a case manager. As part of the standardized sharing process case managers provide additional information about the family when determining bereavement levels. Therefore, additional information about family issues is particularly warranted when the family bereavement level is high. However, the discussion of the new admission of a recent immigrant provides a clear example of how psychosocial information about family dynamics can illustrate a dialectical tension for the case manager.

After providing the standard information, I observed the case manager elaborate on the patient's case by describing family dynamics. The case manager explained that the patient did not speak English and was new to America. [iii] Primarily because of the

cultural differences, the case manager explained that the family did not understand hospice philosophy and care and insisted that everything be done. I heard the case manager comment, "The family keeps saying 'we can't just let her die'." She continued to explain that the family ordered x-rays of the patient's chest and "to please the family the hospital did the x-rays."

The elaboration of the family dynamics for this case is considered psychosocial information because it was unrelated to bereavement level determination and thus deviated from the standardized sharing practices in IDT. Moreover, it demonstrates the case manager's own dialectical tension between providing a primarily bio-medical plan of care as well as understanding the needs of this family in proving them a 'good death' for their loved one. I understood this as I heard the case manager report that she encouraged the family to take the patient home to die. She went on to share with the team that the daughter of the patient was spending every waking hour at the hospital. The case manager reported that she explained to the daughter that if the patient were at home it would be easier as she would not have to be up at the hospital all the time. I then observed the case manager refer to the medical director for advice on whether or not it was okay to bring the patient home. The medical director agreed that the patient could be taken home. This shift from psychosocial information sharing back to medically-focused information represents the dialectical tension experienced by this case manager. However, I heard this shift again as the case manager finished her report on this patient by emphasizing that the decision needed to be made quickly or the patient would die in transport.

Both of these examples taken together exemplify a third dialectical tension that I observed during IDT meetings. As you recall, all team members at IDT meetings receive an agenda, an update sheet and an on-call sheet. The update sheet lists new admissions, patients that are receiving 24 hour care, patients who have had changes in pain medication, deaths, and patients who revoke hospice services. However, I noticed that the standardized sharing practice did not include discussions of patient deaths. Rather, patient names were listed and bereavement level was reported by the bereavement coordinator.

Despite the fact that I observed case managers negotiating the tension between scientific and psychosocial information sharing, discussions of patient deaths hardly took place. For example, in cases where the patient's family struggled over where the patient's death would take place (for reasons such as fear of death event in the home or biological aspects of the death), I did not observe case managers providing follow up psychosocial information. For instance, on my last observation day, I noticed that the newly admitted immigrant was listed under recent deaths. During the meeting her death was reported and no one commented on it. After the meeting, I approached the case manager and asked her if this woman was able to die at home. The case manager informed me that she died in the hospital before she could convince the family to have her moved home.

This is a clear context that represents a dialectical tension – that is, the standardized sharing process does not allow for the discussion of patients' deaths and thus, the dialectical tension triggered by trying to meet psychosocial care goals is dismissed. Rather, this dialectical tension is internalized by team members and functions to keep information medically-focused. This might be one way that team members are able to deal with the continuous cycle of patients' deaths. I observed this happening in the

case of the patient dying from head and neck cancer. One week after the initial discussion of the patient, the dietician reported that the patient weighed 119 pounds and was eating 5-6 small servings a day. However, congruent with the standardized sharing process, she did not provide any comment on the physical description of the patient. One week later I noticed the patient's name on the in-patient list (hospitalized) and no one commented. Thus, the struggle between providing medical care and psychosocial care creates dialectical tensions, and deviations from the standardized sharing practices of Town Hospice's IDT meetings illustrate these tensions.

To summarize, one of the goals of Town Hospice is to provide psychosocial care to all patients. These observations suggest that this goal is being met as case managers actively negotiate the dialectical tension between biomedical and psychosocial information sharing during IDT meetings. More specifically, case managers include psychosocial information about patients by discussing care goals/issues, addressing family dynamics related to bereavement and caretaking, and as a way of requesting additional help from team members. The addition of psychosocial information often triggers a dialectical tension for the team and its members. The conclusions and pragmatic and theoretical implications for the entire study will be discussed in the next chapter.

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[i] In IDT meetings, comments such as "caretaker depression" did not trigger additional discussion. Rather, I observed that these cases were referred to the chaplain. Thus, as part of the standardized sharing process, this was treated as part of the plan of care and the designated responsibility was given to a chaplain. (Note: There were four chaplains that worked for Town Hospice).

[ii] It is worth noting here that during IDT meetings I observed that staff members were not always completely attentive during case reports. In fact, many of them would also do paperwork during these reports. However, in this case, the entire room was focused on the case manager's report of this particular patient.

[iii] The patient was Mexican and only spoke Spanish. The case manager assigned to the case also spoke Spanish.

# Chapter VI

## Conclusions and Implications

A qualitative methodological approach was used to learn more about how communication is impacted by the context of death and the dying process. Namely, unstructured interviewing was used to elicit narratives from ten hospice volunteers and a functional narrative analysis was used to analyze the data. Research questions for this study focused on hospice volunteers' experiences with dying and death, the themes of their narratives, insight on communication apprehension regarding dying persons, and evidence of the social denial of death. Additionally, ethnographic fieldwork of five interdisciplinary team (IDT) meetings was conducted in an effort to investigate psychosocial information sharing by hospice case managers. This chapter provides an overview of the findings, addresses pragmatic and theoretical implications, and suggests imitations and directions for future research.

### *Findings*

#### *Recruitment.*

The initial interview began with questions relating to recruitment. Overall, volunteers reported that they became involved with hospice through one of three ways: (1) work experience in a healthcare setting; (2) personal death experience; and (3) learning more about hospice. Additionally, it was determined that the environment mattered a great deal to volunteers, with many of them preferring to volunteer in a nursing home environment.

*Research Question One – Experiencing patient deaths.*

The investigation of how volunteers' experience their patients' deaths yielded two narrative functions: (1) volunteers use their experiences as a means to viewing death from a positive perspective; and (2) volunteers use their experiences to facilitate the role of "teachers of death," that is, they are able to help others learn more about the dying process.

*Research Question Two – Themes/Issues/Topics.*

Volunteers' narratives were also examined to find prevalent themes/issues/topics. From the narratives collected, three themes were apparent. First, volunteers emphasized on-going education about death and dying, and they particularly emphasized reading books on the subject matter. Second, volunteers highlighted that hospice care is all about the patient. Third, the narratives illustrated the many benefits of volunteering for hospice.

*Research Question Three – Communication apprehension with dying persons.*

Volunteers' narratives revealed that communication apprehension with dying persons is not related to a fear of death but rather is associated with communication expectations. Moreover, it seems apparent that relational level plays a large part in reducing anxiety, wherein the deeper the relational level, the less anxiety experienced.

*Research Question Four – Social denial of death.*

Narratives collected in this study suggest that the social denial of death is linked to a fear of one's own death as well as a fear of the death event. Death anxiety was characterized by a lack of understanding of hospice, nursing home patients receiving few if any visitors, and family denial about their loved one's impending death.

*Narrative function.*

Sharf and Vanderford's (2003) typology of health narrative functions was used as a basis for the narrative functional analysis. It was found that hospice volunteers' narratives function to make sense of death, warrant decisions for advanced preparation for end-of-life, illustrate an attempt to control their own death, transform their identity into hospice leaders, and build community by establishing standard narrative formats.

*Ethnographic fieldwork.*

The researcher observed five interdisciplinary team meetings at Town Hospice. The main objective of the study was to examine psychosocial information sharing in IDT meetings. The study focused on the role of the case manager and found that psychosocial information was shared as it related to care goals, family issues relating to bereavement and caretaking, and when requesting additional information from other team members. From the observations it was further concluded that the addition of psychosocial information created dialectical tensions for the care team.

*Pragmatic Implications*

This study has several implications for hospice staff. First, hospice staff should capitalize on hospice volunteers' experiences by promoting storytelling. Unfortunately, volunteers do not get the opportunity to tell their stories very often. In my research I found that volunteers were very willing to share their experiences with me. In fact, I believe that many of them truly enjoyed being able to talk about how they have made a difference in the life of a patient and/or the patient's family. The sense of ownership in their stories was hard to believe. Volunteer Coordinators should incorporate storytelling as a main component of the volunteer monthly meeting. Perhaps one volunteer could be

chosen each month to share an experience. This exercise should bolster retention as it provides volunteers the opportunity to either work through a difficult experience or share the joy of their volunteer work. It will also function to further build a community of support.

Moreover, stories shared by hospice volunteers could actually function as an effective recruitment tool as well. This study suggests that hospice volunteers who are involved in patient care could be the best recruiters. For many volunteers, their experiences help them accept death as well as teach others about death (see findings from RQ One). Volunteer stories of "good deaths" might serve as the best means of influencing an individual to get involved with hospice. According to Sunwolf (1999) narrative formats provide for persuasion through self-generated formats, active participation, modeling, and conscious deliberation.

Given that narratives can be used to develop a new way of understanding as well as provide a new way of acquiring knowledge, hospice organizations would likely benefit from training volunteers on how to tell narratives (Sunwolf, 1999). Narrative training teaches individuals to use story formats to provide instruction, prompt dialogue, enhance listening skills, and aid individuals "in crossing the barrier from collecting the known to approaching the unknown" (Sunwolf, 1999, p. 63). According to Sunwolf (1999) individuals can be trained in the use of stories. For example, Sunwolf explains: "One such technique was the repetition of things three times, in three different ways, once for each ear and once for the heart" (p. 55).

Overall, the benefits of volunteer storytelling would be twofold: (1) their stories could possibly promote recruitment by educating individuals about 'good deaths', and (2)

the act of telling their stories would reinforce hospice philosophy and beliefs, thus facilitating coping and possibly reducing burnout. While storytelling is utilized pedagogically in hospice volunteer training programs, it also can be beneficial as a tool in monthly volunteer meetings as well as in the recruitment of potential volunteers.

In addition to recruitment and retention, hospice directors should consider integrating storytelling into IDT meetings. There are two ways that this could be done. First, volunteers who attend IDT meetings could share an experience with the patient which thus contributes to assessing the psychosocial needs of the patient. Ideally this should be taking place in IDT meetings; however, volunteers rarely attend these meetings. Perhaps, then, volunteers could diary important experiences which could then be included in the patient's file.

Second, hospice directors can incorporate storytelling as a means to evaluating patients' deaths. As you recall, one finding from the ethnographic observation of IDT meetings was that deaths are never discussed in detail. One way to evaluate hospice services is to ascertain whether or not the company is providing patients with "good deaths." Thus, death reports should include psychosocial information, such as where the patient died and the spiritual needs of the family. Storytelling as a means to facilitating such discussions should provide hospice staff with a means of evaluating their own services.

Finally, this study recommends that hospice recruitment efforts should focus on individuals who have experience working in a healthcare setting. More importantly, however, recruitment efforts should be broadened to involve educating the public not only about hospice but about its volunteer program as well. Within this type of

recruitment program it would behoove hospice programs to highlight the volunteer advantages of caring for a patient in a nursing home. It is possible that this type of care may be viewed as less anxiety provoking then visiting patients in a home care situation.

*Theoretical Implications*

Theoretically, this study bolsters the idea that dialectical tensions are caused by contradiction and thus characterize relationships as being in a constant state of change. The ethnographic work in particular demonstrated this change in terms of dialogue patterns. Observation of hospice IDT meetings manifested that the normative social practice is the standardized sharing of biomedical information about the patient. Likewise, the non-conventionalized behavior of IDT meetings consisted of contributing psychosocial information. Interestingly, this pattern of information sharing contradicts the purpose and goals of hospice philosophy. As you recall, the goal of the interdisciplinary team model is to provide comprehensive end-of-life care that includes medical as well as psychosocial assessment and treatment. As such, hospice goals can be distorted by heavy emphasis on medical information sharing in IDT meetings. This is especially alarming given that observation of these meetings revealed that case managers typically engage in the standardized sharing process, deviate, and then return to the standardized format. More importantly, this relational praxis further impacts the way that dialectical tensions are handled in the future and consequently reinforces the standardized sharing format of biomedical information (Baxter & Montgomery, 1997).

Additionally, the standardized sharing practice could also represent the negotiation of the dialectical tension involving the interplay of the body and communication (Babrow & Mattson, 2003). Cultural and social influences behind the

conceptualization and labeling of illness and disease cause changes in individuals' behaviors. Moreover, these influences are further redefined by social attitudes, diagnostic tests, and treatments (Babrow & Mattson, 2003). Perhaps the standardized sharing of biomedical information about patients allows hospice IDT members to mentally disassociate patient names from their physical condition/description. Therefore, it is possible that the standardized sharing of biomedical information about patients is one way that case managers as well as other hospice IDT members cope with the emotional stress of working with dying persons.

Finally, this study advances a dialectical approach by demonstrating that a group can experience dialectical tensions and therefore dialectical tensions are not just experienced in a dyadic environment. Additionally, this study illustrates that ethnography is effective methodological tool in discovering and uncovering dialectical tensions. An ethnographic approach to dialectical tensions allows researchers to view this constant change as it is naturally occurring.

This study also illustrates that communication apprehension with dying persons (CA-Dying) is **not** always related to a fear of death, at least for the ten volunteers interviewed. This finding contradicts earlier studies on CA-Dying by Hayslip (1986-87) and others (see Servaty, Krejci, & Hayslip, 1996; Servaty & Hayslip, 1997) who argue that individuals who are not psychologically comfortable communicating with dying persons have a fear of their own death. Rather, findings from this study suggest that CA-Dying is associated with communication expectations for these individuals. That is, volunteers feel pressure to regulate the flow of conversation and that triggers communication anxiety. Ironically, Hayslip's (1986-87) original study found that

adequate training decreased hospice volunteers' communication apprehension, which supports this study's findings.

Anxiety is further produced in this context when individuals do not know each other. Thus, this study posits that relational level plays a key part in communication apprehension with the dying. This is particularly important when considering doctor-patient communication concerning end-of-life care, such as a prognosis of imminent death, treatment options, DNR's, and advanced directives. Not only are these content areas sensitive topics, but the communication transaction between the two participants can be confounded by relational dynamics, particularly in healthcare settings in which the doctor and patient have no relational history. Such contexts occur, for example, in emergency rooms wherein the physician and patient/family are likely to meet for the first time.

Overall, this study suggests that volunteers are not struggling with communication apprehension associated with dying persons, but rather the predominant factor in communicating in this environment involves getting to know the patient. Particularly because the end-of-life is such a private matter, many volunteers experience trepidation when initiating patient visits. Theoretical explanations such as Uncertainty Reduction Theory and Social Penetration Theory could be applicable in further defining the development of the volunteer-patient relationship. However, because this context is so personal and private, a more fitting theoretical lens might be communication boundary management, which provides one way of explaining private self-disclosures (Petronio, Ellemers, Giles, & Gallois, 1998).

By assuming that individuals own the information they wish to disclose, the theory posits that individuals thus develop rules for disclosing private information. Thus, an individual is able to control the boundaries for the types of information he/she discloses by imposing rules for disclosure. Overall, the "tension between opening and closing a boundary around private information is managed" (Petronio, et. al., 1998, p. 578). Thus, the boundary conditions surrounding private self-disclosure by hospice patients could provide some insight on how best to manage communication with a dying person. Moreover, communication boundary management theory posits that once information is disclosed it is now associated with dyadic boundaries, as both parties "are responsible for the management of this information" (Petronio, et. al., 1998, p.578). Thus, it is possible that anxiety is lowered when the two parties begin practicing shared boundary management.

Finally, this study evidences Sharf and Vanderford's (2003) typologies by providing concrete analysis with examples. The typologies proved to be useful in organizing data and developing themes. By using the typologies of health narrative functions, this study contributes more knowledge to the functionality of health narratives. Namely, it advances two things. First, this study adds to the literature by providing more information about why people volunteer for hospice. The functionality of health narratives explain some of the reasons why people enjoy volunteering for hospice and how their experiences make their lives better. Second, the use of these typologies also demonstrates how disease and illness affect people on many levels. Thus, individuals with a loved one who is ill or who know of someone who is ill are all impacted by the diagnosis of a terminal illness. The simple act of interacting with a terminally ill person

or in the context of death impacts a person, and the functionality of health narratives illustrates this through this study.

*Limitations*

This study was designed to learn more about hospice volunteers' experiences with death and dying. However, several study limitations exist. The primary limitation to the study of hospice volunteers is that the researcher has never been a hospice volunteer. Project development as well as experience as a hospice volunteer would have further focused the study. Particularly in terms of the ethnographic portion of the project, hospice experience would have been helpful. For example, interviews with hospice staff, especially case managers, would have shed some light on their participation in IDT meetings.

Another limitation to the study is that the participants did not represent the experiences of all hospice volunteers. The geographic location of the study could have biased the responses, as regional norms and customs vary according to different parts of the country. For example, people in the Mid-West are known to be friendlier than people in Los Angeles. Thus, the impetus for individuals to get involved with hospice is inherent in the way people feel about their community. Additionally, the number of participants in the study is a limitation as well. The conclusions of this study are based on interviews with 10 volunteers and 5 hours of ethnographic observation.

However, even more important than geographic location for the results of this study is the type of hospice. There are for-profit and non-profit hospices. Due to the location of the study, a majority of the hospice volunteers interviewed represented a for-profit hospice. Thus, narratives may have been different if the majority of hospice

volunteers represented non-profit hospices. Perhaps hospice volunteers experience different care situations depending on the type of hospice and the services provided by that hospice. Moreover, the ethnographic observation was conducted at a non-profit hospice and thus differences may be present there as well.

Lastly, while unstructured interviews are good at exploring complex and emotional topics, one limitation is that these interviews might not have elicited typical stories of all hospice volunteers. Mishler (1995) notes that "the teller of the tale is also engaged in a retelling. The version we hear or read is shaped both by the context of its telling and the history of earlier retellings." (p. 118). For example, during two separate interviews with a female volunteer, the spouse of the volunteer came into the room mid-way through the interview. In both instances, the female volunteer being interviewed lowered her voice so that the spouse could not hear her responses. It is possible that subjects not only lowered their voices but perhaps altered their responses as well.

*Future Research*

Results from this study suggest two separate paths of future research; studying communication apprehension associated with death talk and negotiating psychosocial information sharing in IDT meetings. First, future research is needed to explore the relational dynamics of communication apprehension with dying persons and in death talk. In order to learn more about how relational level correlates with apprehension in this context, dyadic conversations between spouses, friends, loved ones, and the like should be investigated. For example, an interesting dynamic to explore would be discussions about death and dying and discussions with a dying person between co-worker relationships as well as a comparison of casual, close, and best friends.

Second, future research should further examine IDT meetings. An interesting way to examine these would be to compare IDT meetings led by medical staff versus humanistic staff. DeFord (2003) proposes that IDT meetings would be drastically different if lead by a professional from the humanities. In fact DeFord (2003) advocates that IDT meetings led by professionals from the humanities "would tend toward a better balance with, shall we say, the more usual information from the natural disciplines. It may be that simply having a social worker or chaplain conduct the IDT meeting would elicit a more four-dimensional picture of the patient/family—precisely what hospice practice strives for." (p. 11). DeFord (2003) also points out that a strictly biomedical focus, as produced by IDT meetings that are lead by doctors and nurses, further inhibits the medical staff's opportunity to learn diagnostic skills of professionals in the humanities.

*Concluding Remark*

Similarities between the interview data and ethnographic fieldwork emerged in findings about the social denial of death. For instance, both data sets illustrated poor care of the elderly, particularly in nursing home facilities. There were also many cases reviewed in which families were in denial about their loved one's impending death and cases in which there was no family. Wuthnow (1991) reported that despite the fact that two-thirds of Americans visited someone in the hospital in 1990 and a quarter reported taking care of someone seriously ill, thousands of Americans still do not have someone to care for them.

This social denial of death exemplifies the tension between life and death. According to Callahan (2000) this life-death tension is characterized by the view of life

within life and the view of death as outside of life. As long as the medical community continues to situate death as outside of life (Callahan, 2000), the social denial of death will prevail. Callahan (2000) concludes that "the tension between our status as biological creatures – captives against our will of the generic death-dealing laws of biology common to all organisms – and our idiosyncratic, unrepeatable self-consciousness and will to live, makes death a terrible problem for us." (p. 164). Although end-of-life care is now an option, many Americans are never informed of that option and/or they decide it is not an option they want to take. Until the medical community decides to embrace end-of-life care whole-heartedly, Americans will continue to deny death and dying.

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Appendix A

Interview Protocol

1. What lead you to get involved with hospice?
2. What is your current level of involvement with hospice? *
3. What was it like when you got your first assignment? Tell me about your first assignment. * (were you nervous?)
4. Tell me about the first time one of your patients died.
5. Tell me about your most memorable experience as a hospice volunteer.
    - What was it like the first time you met this patient?
    - How did this impact you personally?
6. Tell me about a bad experience as a hospice volunteer.
7. Have you ever turned a patient down? Why?
8. What would you share with a new volunteer?
9. What does volunteering for hospice do for you personally? Why do you continue to volunteer? Can you be more specific?
10. What are your thoughts about meeting a new patient for the first time? Have they changed from the first patient?
11. How do people react to you when you identify yourself as a hospice volunteer?
12. What are your thoughts on your own death?

* denotes that questions were taken verbatim from the following study:

Sadler, C., & Marty, F. (1998). Socialization of hospice volunteers: Members of the family. *The Hospice Journal, 13(3),* 49-68.

# Appendix B

INFORMED CONSENT FORM FOR RESEARCH BEING CONDUCTED UNDER THE AUSPICES OF THE UNIVERSITY OF OKLAHOMA-NORMAN CAMPUS

INTRODUCTION: This study is entitled *Stories of the hospice/palliative care volunteer.* The person directing this project is Elaine M. Wittenberg, doctoral student, under the direction of Dr. Sandra L. Ragan, professor, Department of Communication. This document defines the terms and conditions for consenting to participate in this study.

DESCRIPTION OF THE STUDY: The goal of this study is to learn more about how individuals communicate with dying persons as well as to understand how the experience of death can impact an individual's life. This study will involve an interview lasting approximately one and a half hours. During the interview the researcher will ask questions about the experiences of hospice/palliative care volunteers.

RISKS AND BENEFITS: Risks should be minimal and would largely focus on the participants' feelings of discomfort associated with reliving some difficult moments. Participants will benefit from their participation in the study in two ways. First, the act of telling their stories can be therapeutic to what they have experienced and thus can function as a coping mechanism. Such an activity may also make them aware of their own communicative strategies in their work. Second, participants will benefit from the knowledge that they will be helping future volunteers work with dying persons.

CONDITIONS OF PARTICIPATION: Participation is voluntary. Refusal to participate will involve no penalty or loss of benefits to which the subject is otherwise entitled. Furthermore, the participant may discontinue participation at any time without penalty or loss of benefits to which the participant is otherwise entitled.

AUDIO TAPING OF STUDY ACTIVITIES: To assist with accurate recording of participant responses, interviews will be recorded on an audio recording device. Participants have the right to refuse to allow such taping without penalty. Please select one of the following options.

[ ] I consent to the use of audio recording.

[ ] I do not consent to the use of audio recording.

Audio tapes will be kept for a period of five years and could possibly be utilized in further studies.

CONFIDENTIALITY: Findings will be presented in aggregate form with no identifying information to ensure confidentiality. All participants and their responses will remain anonymous as audiotapes will not include the participant's name. Rather, all participants will be assigned a code number. Data will only be analyzed by the researcher who will use the code numbers for identification purposes. All data will be stored in confidential files in the PI's office in a locked filing cabinet. Non-project personnel will not have access to the data. The researcher will retain the tapes beyond transcription (five years) to allow a later analysis of the verbal communication used to talk about death.

CONTACTS FOR QUESTIONS ABOUT THE STUDY: Participants may contact Elaine M. Wittenberg at 405-325-0809 or witt@ou.edu or Dr. Sandra L. Ragan at 405-325-3111 or sragan@ou.edu with questions about the study. For inquires about rights as a research participant, contact the University of Oklahoma-Norman Campus Institutional Review Board (OU-NC IRB) at 405/325-8110 or irb@ou.edu.

PARTICIPANT ASSURANCE: I have read and understand the terms and conditions of this study and I hereby agree to participate in the above-described research study. I understand my participation is voluntary and that I may withdraw at any time without penalty.

| | |
|---|---|
| Signature of Participant | Date |
| Printed Name of Participant | Researcher Signature |

Appendix C

*The University of Oklahoma*

OFFICE OF HUMAN RESEARCH PARTICIPANT PROTECTION

November 17, 2003

Ms. Elaine M. Wittenberg
Communication
BURT 101
CAMPUS MAIL

Dear Ms. Wittenberg:

The Institutional Review Board-Norman Campus has reviewed your proposal, "Stories of the hospice/palliative care volunteer," under the University's expedited review procedures. The Board found that this research would not constitute a risk to participants beyond those of normal, everyday life, except in the area of privacy, which is adequately protected by the confidentiality procedures. Therefore, the Board has approved the use of human subjects in this research.

This approval is for a period of twelve months from November 17, 2003, provided that the research procedures are not changed from those described in your approved protocol and attachments. Should you wish to deviate from the described subject protocol, you must notify this office, in writing, noting any changes or revisions in the protocol and/or informed consent document and obtain prior approval from the Board for the changes. A copy of the approved informed consent document(s) is attached for your use.

At the end of the research, you must submit a short report describing your use of human subjects in the research and the results obtained. Should the research extend beyond 12 months, a progress report must be submitted with the request for continuation, and a final report must be submitted at the end of the research.

If data are still being collected after five years, resubmission of the protocol is required.

Should you have any questions, please contact me at 325-8110 or irb@ou.edu.

Sincerely,

Steven O'Geary

Steven O'Geary, Ph.D.
Director, Human Research Participant Protection
Administrative Officer
Institutional Review Board-Norman Campus (FWA #00003191)

JSO
FY2004-124

Cc: Dr. E. Laurette Taylor, Chair, Institutional Review Board
Dr. Sandra L. Ragan, Communication

Appendix D

Interview Transcripts

Transcripts~Participant Number One

Female
65 years old
10 year volunteer

E: How did you come to get involved with hospice?

Well that's a long one. Umm before I retired from the hospital I was working in the radiation therapy department and I was a secretary although I had plenty of time to meet the patients and the patient's families and I was comfortable with talking with them about different things certainly not about their disease but you know just passing the time of day till they waited for their treatment. And uh so after after I finished at the hospital uh I worked for the radiation oncologist no no no chemotherapy gal, Dr. X, in town and uh just did typed histories and things like that for her and so uh the more I thought about it the more I thought you know hospice is a good thing and she would refer people to hospice and so that just kinda rubbed me and so I have always followed Dr. X wherever at whatever hospice she is affiliated with I was gonna go... I have gone. And there have been I mean its changed hands or so 3 or 4 times so now its (Name of Hospice) but first of all it was just (Name of Town) Hospice.

E: What is your current level of involvement?

Oh yes, I have one patient now. Sometimes I've had two. I prefer to have them in nursing homes because I can visit them at my time and at a time that I think they will be awake. Sometimes its harder at nursing homes um but I 'd rather go on a weekly basis and as it is now I go on Sunday morning, after I finish with uh church and stuff like that while (Name of Husband) is still at his church so that I have the rest of Sunday morning. And uh I visit one there but there are also two more that have dropped off the rolls that I see there and I have two friends there at the same building so when she said last night I'm working on one for you I was thinking ya know I'll take a second one but uh I have five people that I see there already.

E: On a weekly basis?

Yes and I also do filing on Monday. (Name of Husband) and I split the filing that has accumulated over the weekend uh or since Wednesday sometimes if its not done on Friday. We try to get it done Monday, Wednesday, Friday and he and I do it on Monday and (Name of Another Volunteer) does it on Wednesday and then she tries to find someone to do it on Friday. It takes me about two and a half hours just to file the papers that he has put in the patient's names umm and then I have to get them in order and then

put them in the notebook. Two and half hours for my part and lots of times it takes him that long.

E: Tell me about your first assignment.

(Respondent cannot recall). I don't know whether it was the first but it was back there in the beginning and it was uh a long term thing. My patient was a gentleman who had been in the war and he was paralyzed from the waist down and he was about my age so it wasn't WWII . He might have been in the next war, Korean War maybe. He was a harder person to get to know.

E: Can you remember the first time you met him.

Well, it was ten years ago. I don't recall the specifics. Well usually the first time you go to see somebody especially when you're brand new you will go with a nurse or social worker or chaplain.

E: Did that happen to you?

I can't remember. It was over ten years ago and I really can't remember. But I um our um of course I of course I don't know how (Name of Volunteer Coordinator) handles it bow but we they were very strict with volunteers then. We had a weekend for seminar type classes, things like that. We didn't have to take tests similar to what we do now but we were interviewed and we got a chance to hear from every person on the team like what it was like to a volunteer or what it was like to work in hospice and what their specific job was like she said last night about (Name of Bereavement Coordinator) coming next time well we had a talk from an admissions person so that was like an in-service right there and then we had our talks from the chaplain and the social workers and the nurses and even the aides and then we talked about the volunteers involvement and not to get too involved and things like that. And they also told us we had required reading. We had to read two or three books uh and we were given a list of quire a few and we could choose them so we could get them from the library and uh we had to make two visits with a nurse or a social worker or a chaplain.

E: You don't recall if you were nervous?

I went down to Purcell with someone and I think I know it was a nurse because I remember her using a stethoscope and talking to a patient. Her husband was there but the lady was the patient. And she just introduced me as a volunteer in training because a lot of people want volunteers so that the staff....

E: Was it a natural thing for you that you just felt comfortable?

Yes and especially with the nurse. It's a little touchy the first time you go to visit a patient on your own but now I don't ask (Name of Volunteer Coordinator) to go with me or anybody else.

E: Why is it a little touchy?

Because you don't know the person. We have this form that shows that she gives us that says what the patients likes and dislikes are and things like that. And if you're gonna be a long term patient she fills that whole thing out but many times she'll call just for respite for the patient and so you have to find it. You have to ask a lot of questions you know. Does this patient know I can't get them out of bed and are they responsive.

Like one time just recently she asked us (her and husband, also a volunteer) one of us to go and stay with a patient and luckily we were talking about it in front of a nurse and the nurse said, oh [Husband's name] going to go... oh that patient wouldn't accept a man. And see [volunteer coordinator] didn't even know that. You know and then I was going to go and [volunteer coordinator] called me two times before I went in the next couple days and finally she called and said the lady passed away.

And I thought wow if she was that bad I didn't need to be with her. Although I have been with dying people but uh I'd rather know them then just to be a stranger in the home and maybe the only person in the home. You know that's kind of frightening.

E: Sure. Tell me about your most memorable experience.

I guess the one I remember most is when I was with my friend who was dying and I was the only one there with him but that sticks in your mind because it was just such a drastic thing. You know my sister had had hospice, my kid sister who had ovarian cancer. She had hospice two different times during her illness and she passed away about three years ago going on four I think. And uh I was there with her when she died but so was the hospice nurse and so was my other sister and that was really heart wrenching but I found that it was very a very natural thing. I had asked you know make sure we have oxygen because what I worry about is a patient not being able to breath. You know but my sister just sunk lower and lower and lower in her consciousness and so in the last 24 hours she wasn't even you know she was breathing but um wasn't struggling with it or anything like that and when she passed away and the nurse recognized the symptoms right away and everything and she said come on back in here she sent me for more pain medication and I was just had just stepped into the kitchen and she said come on back here she said I don't think she's going to need it and um within 20 minutes she was gone and it was that was really hear wrenching for me because it was my sister you know but um then my friend who had been a friend um through church and I had known for many years I was visiting with him and um he was pretty awf... pretty bad off that one day that last day and uh I guess people had recognized at the nursing home where he was how bad he was cause they moved him into a special hospice room you know where he had a sofa and a chair and the hospital bed and the curtains were all chinsy and things like that and us so I said to them one day I'll be glad to go up there and sit with [patient's name] but uh I'd rather no go when his wife is there because she's so hyper and and very talkative and I know that when you go to visit a patients you sh... you know you have to let them do the talking if they want to do the talking and let them lead the conversation but he was very good at doing things like that umm well you know through out the time that I was seeing him and um so I went up there that afternoon and he was sinking lower and lower and

lower and I was afraid to leave the bed and I don't carry a cell phone or anything so I didn't even go out to the nurses station but I kept praying well I was holding his hand and praying anyhow that just umm that somebody would come up you know the chaplain said he was gonna come up an the wife said she was gonna come back after she after she made some phone calls but nobody came and so I was the one that was with him and uh that was much more memorable because it was an easy death and its just his breathing just got slower and slower and uh he would you know he couldn't retain his saliva so I would I would mop you know the side of his mouth cause he's at odd angle you know and would drip occasionally so I would mop that and just talk to him and pray but mostly pray silently um he was a Catholic like I am and and I did pray aloud but many times it was just you know silent you know you kinda get lapse into thinking things and then you forget what you're saying because after all they're not responding to you.

E: Impact you personally?

I don't think so. I mean I really believe in this hospice thing that their in – it reinforced actually my feelings about us how good it is to have friends and family around you know uh and I had considered myself his friend well before I started seeing him but when he came on our hospice – I was the one who suggested to the wife you know there are you can have hospice and many people think it just for old people and [friend] was younger then that, but sick and uh I said talk to the doctor and see what the doctor says about it because I said that would really help you would have people stopping in to see him, because she was still working, and uh she was worried about him being alone and things like that and most people cannot afford a sitter you know so

E: yes.

I was glad to visit him. I would have visited him but not as certainly not as frequently because I try to see my patients on a weekly basis and he was up in [town] and so that was a little bit of a hike but you know so was [name]. My patient I had for well over a year so uh that was a ????

E: Tell me about a bad experience.

Not off hand. Uh other than feeling ill at ease sometimes.

E: Tell me more about feeling ill at ease --- about what?

Uh well I think it was from the person the family was very welcoming uh that that lady worked too and he had a son that was around – this was my first man, the long term one. I can't tell you if I had short terms before that, I don't even know where my first notebooks are but I keep a list of the patient's name and when I first saw them and their number because we always have to have their number and how many miles it is to and from the place. He was just harder to get to know but and I didn't know him and its harder to get to know a man of course for a woman as it is for another man I think. So I talked to him. I found out that his war experiences were were numerous and he loved to talk about it so

whenever there was a lull in the conversation because I felt like I needed to.... We needed to talk and I just didn't want to sit there because he was okay except being in a hospital bed and being paralyzed umm he could talk and he loved to talk and he would say shut off the oxygen I need a cigarette (laugh) and at that time I would stay in the room with him but now I prefer to leave because I don't even smoke you know because I don't like the smoke and I don't think its good for anybody but um you know sometimes a lot of people are smoking. I have a couple of kids who well I their clothes and their hair just smell like it whenever you hug them so you know its not that I don't hug them anymore but you could you always pick up on that.

E: Bad experience – because you couldn't get close to him?

Well yeah and I don't feel that you have to get close to people uh

E: You mean connection?

Well the connection was made. I mean we were connected alright but when he passed away it was when we were out on vacation um you know I didn't feel I uh I mean I would say poor [patient's name] but I didn't feel like I wanted to go to the funeral or anything like that and maybe I couldn't have gone because we were gone, usually its just long weekends for us or maybe a week but I know he died when I was away so it was probably a two week thing. Um of course I always write to the spouse or somebody almost always – sometimes they know me and sometimes they don't you know especially if you're just visiting in a nursing home uh you don't meet people. You hear a lot about them, you know my daughter this and my son that or son-in law or something like that you hear that all the time but many times you don't even meet them.

E: Really.

Because that's not their visiting time. You know everybody has... I mean and and you don't need to have two sets of visitors for the patient... I mean it's just superfluous. Uh

E: Have you ever turned a patient down?

No I don't think so uh I would never say that unless you know there was a lot of smokers in the house uhhh and once I've started seeing people I've kept on with them even though it's been a little bit of a chore sometimes uhh but many of them aren't as long term if you could see my list umm they just aren't as long term but some are you know that first man was over a year. Not a year but he was maybe six months or seven months or so – I would have to look back on it.

E: That's a long time for hospice. The average stay is 21 days.

I know but we loose so many just as were doing the intake. Because people wait so long.

E: That's the problem.

Yeah. Well that's because physicians are there to heal and they just don't want to admit that that uh the patient is gonna die. I mean there are two schools of thought that I found out when I was working in radiation therapy. One is that they'll just keep giving up everything until you're dying day. And my daughter just lost her father-in-law and he had received chemo the day before and I want to say okay did the doctor train at MD Anderson because they're really the ones but did he Dr. X will tell you. And some patients, I know one in particular, have gone to another doctor just because the family says we have got to try everything and that poor lady died.... You know within a very short time and what people don't understand is is that if you have hospice you have a group of support around you that is going to help you in so many different ways. I mean you don't have to bath the patient unless there is an accident or something in between because the aides will come, you don't have to worry about vital signs and things like that, you've got you know social services helping you and then you've got you know volunteers and the chaplain and it's just .....

E: Mind boggling.

Yes!

E: It is.

A lot of people just don't want to see it, especially you know like daughters will say "oh no, not my mother, my mother has to have everything" you know and that's not right. And I think that families when they go with their loved one to the doctor, an oncologist patient say, you know we want you to tell us, whether you tell my father or not, let us decide. But we want you to tell us and keep us apprised of all these things. But see most people do not. They don't know the thinking, they're afraid of it.

E: Yes, they are afraid of it.

It's such a shame because then people lose out.

E: What advice do you have for a new volunteer?

I would read the books. Um there is an excellent one that was required. But we read Elisabeth Kubler-Ross *On death and dying* and we've read at least one more of course. (Husband) won't remember the name of that book it's about... paperback size and its thin and its got fall leaves around it and it's name is right there... but its experiences about dying people so that there are things you can look for and uh and see and feel comfortable about because you know they've happened before to other people.

E: Like what? Give me an example.

Oh well uh this lady I just had a respite with a couple of weeks ago. Uh I went in to visit her and the niece said you probably won't have to talk to her at all and I said well I

always go in and introduce myself... and um... the lady asked me after I went in after one hour, "Have you seen my mother around here. I saw her just recently." Now see her mother had been dead but lots of times people who are dying really do see these people that have died before. And those are the experiences that really give you chills. I mean sometimes they have been people that have just passed away recently that nobody has told this dying person about. And they say, "Well I saw so and so. She came to visit me." She might have you know. It gives me goose bumps.

And see the family and volunteers too have to be aware of that because they know that the time is coming closer, that the person is gonna pass away. And also they should know not to say, "Oh you couldn't have seen them." You know, it's like a person with Alzheimer's you just go with the flow.

E: So it's how to respond?

Yeah yeah and not be negative about it but "Did that person say anything to you?" you know and I think we are there to reassure the family as much as the patient.

E: What advice do you have for new volunteers?

No. Just be yourself and if you try to put on a different face it won't work because when you go to visit the people time after time uh they will know that you are changing and also it's up to them to say if they don't want you specifically there. I can't think of one, that they have said, "You don't need to come back anymore."

E: story shared about volunteer.....

I have never taken them to doctors. Now we had Cancer Society people taking people to radiation therapy day after day and I also thought that that was a lot of responsibility. In fact I am surprised that volunteers can really do that I mean we are even allowed to feed a patient...unless you have special training from the health department. And before we use to be able to because I would go over and feed a lady.

I guess they have to think about lawsuits.

E: What does volunteering for hospice do for you personally?

You know what.... I love the group of volunteers. You could tell by the way we got around the table last night. Although [name of another volunteer] drives me crazy. I said to [husband] on the way home last night said if she only comes to one meeting a year that's enough for me! (laugh)

E: She's outspoken.

Yes, but [volunteer coordinator] keeps us focused. And you have to do that and we warned her when she started uh and each volunteer director that we have had – just stay

focused – because I mean [husband] likes to put in his two bits, I'll put in my two bits, of course I leaned over and talked to another volunteer a couple of times. It's the group of those people and knowing that your doing good in the community, that you're helping people and I don't know I never think about it but in the long run I would hope that there would be people that would come and visit me, if I were sick and um you know give him [referring to husband] a rest. Or come and visit him and give me a rest (laugh).

E: Sure. What are your thoughts about meeting a patient for the first time?

It doesn't really bother me too much… uhh

E: Do you think that is experience?

Yes I think it is –

E: Has that changed from your first patient?

Well of course the first time you're very apprehensive, especially the first time you go on your own. In fact you can always ask….

E: Why?

Just because you are going into a stranger's home. Or the nursing home to visit this person and you have to establish what their likes are and what you have in common. And you don't want to come over too strong and ask lots of questions you know you don't want them to think that you're nosey or something like that.

But then again you don't want to be telling them all of your experiences and not hear any of theirs. Because many times these people are anxious to talk and so you just listen. You know it's just hard. (laugh) You know if you're nervous you can always ask to go with somebody the first time. And they'll let you know what their schedule is and you can go with them.

E: Here it is ten years later – do you get nervous now going to meet patients?

I don't think so. No. I haven't with these old gals in the nursing home or young gals you know. And I wasn't nervous when I did that respite a couple of weeks ago. As long as I know what the situation is but you know like when I heard that the patient that died before I even went over there I thought oh thank god because you just don't want to be with somebody who is a stranger to you and not have any of their family there. Of course they could be just unconscious and the family thinks that they are just sleeping. It's not for me to go in there and determine if the patient, what kind of shape the patient is in…um… so you know it's just kind of worrisome in that respect. But I haven't had…..

E: worrisome in terms of being alone with the patient and not knowing what their condition is?

Yes.

E: How do people react to you when you identify yourself as a hospice volunteer?

Well they like get...for the most part. See I am associated with people who have worked at the hospital so they know about hospice. I am associated with Health for Friends where I just do a little bit of typing there in the pharmacy but they know I am a hospice volunteer. See it's all kind of a medical thing. The only other thing is the uh...

E: If you met somebody outside of the...

Well usually you don't tell them everything about yourself. But I have. At the library I worked and now I volunteer at the library and those people know that I am a hospice volunteer and they know that they can talk to me about it. You know if they wanted to.

E: What would you say would be a general response? Do they ask you questions about it?

No. They just say oh I could never do that. But I attribute a lot of this to my background but however [husband's name] didn't have this kind of background and he's a good volunteer. Uh so , uh I don't know.

E: One last question, what are your thoughts on your own death?

Well I would rather die in an accident quickly then linger (laugh) But if I had a lingering illness and especially if I had a cancer and it was treated once and it reoccurred I would never go for any more treatment because when it metastasizes its bad so you're better off having a quality of life then length of days. And I hope that I would be able to stick with that too. But you see so many or hear of so many people that are going back time and time again and I saw that in radiation therapy. They would come because they had bone mass from breast cancer or prostate or something like that...

E: Where it metastasizes?

Yes. When it gets so bad and you have to do this part of a leg and this part of a shoulder and get radiation on that and get that for two..... it's too much and I don't think there's a lot of hope in after that. And although I don't like the idea of the pain of bone mass um when you're with hospice they can make sure that you have enough pain medication. But then there's repercussions from pain medications (laugh) and that's not good either.

I would want to be in the hospice program and I would rather stay in my own home. I don't know if I could. We don't have any hospice hospitals around here, buildings. It would be nice but I think we would have an awful lot of people going to them.

Transcripts~Participant Number Two

Male
75 years old
10 year volunteer

E: How did you come to get involved with hospice?

My wife. She noticed they were having a training program and she asked me what I thought and I said sure let's try it.

E: What's your current level of involvement with hospice now? How many patients? Your wife [participant no. one] mentioned that you all do the filing.

Well, um yes we do the filing on Mondays. I have a patient that I see once in a while. Since we do the filing I notice the notes on him every once and awhile. He doesn't return calls to the nurse and I figure if he doesn't return calls to them I'm not going to be bothering him because uh he's got a lot of problems and he needs a liver transplant and he's going through the VA on that and so and he's just down the road.

E: Was he a patient of your previously?

No. I visited with him several times and was interested. He kept telling me about living in Egypt, Germany, France, and all these places. And he's Norwegian. His given name is [xxxx]. And so I said [patient's name], how did you end up living in some many different places? And he said well my father married this Norwegian woman and he lived in Knoxville, TN where I was born and my sister. And then apparently the marriage went on the rocks and the father took off with the two children. And he said every time my mother would locate us we would move again. (laugh). Then he's talked about being on a farm with some relative that he ended up being sent to or something which I didn't pursue to prior, but he told me all about the farm. And so he's had a real disjointed hard life.

E: So you don't see him right now then?

I see him periodically.

E: Do you see another patient?

No she's [volunteer coordinator] trying to get a hold of the people. You see there's a lot of patients that are just not uh volunteer appropriate. And uh so we do what we can.

When I can when I have ... there are situations where you feel like this is a real need and you can go in and visit and not only with the patient but with caregivers or caregiver and family whatever the case may be but the family dynamics with some of these cases is the biggest problem.

E: Can you tell me about your first assignment?

Oh yes. That's one of my main stories. I'll tell you about my first patient was down in [name of town]. He was 91 years old. I can't remember what his diagnosis was it seemed like it was non Hodge skin lymphoma or something like that. Anyway uh I went do there with the nurse and this fella liked woman.

E: So you went with the nurse your first time?

The first time yes.

E: Was that good? Were you nervous?

No. Um. We got to talking and right off we found out that we have a lot of things in common. He had a cabin in [name of town] and I knew where he lived down in [name of town]. And I asked him about an old fella down there that had a convenience store sort of a country type of convenience store. And he said oh I sold him that property. And so we just kind of connected. You know. And uh. Like I said he was 91 years old he had a seventy two year old girlfriend and she really took care of him. She made sure he had his meals. He lived alone in an apartment that belonged to his grandson and they kind of looked after him. He had been independent uh but I'll go into that later. But he was just as alert as could be and he liked to play dominos. And I got there one day and his brother and sister-in-law were playing dominos with him. They said well we'll leave and let you play with him. And I played with him for two hours.

E: Did you see him on a weekly basis then? And you played dominos?

Usually I try to see a person on a weekly basis if it's appropriate. And I try to limit my visit to two hours. With a lot of people two hours is too much. But now the real twist in this thing is he crawled around on his hands and knees. He was a real tall man and fairly thin and he wore dress shoes and the toes on his dress shoes were all scuffed up....from crawling around on the floor. And I asked his grandson about that and he said oh he's been doing that for about seven years. He fell one time. And uh.. he had enough mind of him and his ego was such that he could crawl around and maintain his independency and uh one of his neighbors there one day said he say him walk to the mailbox and there it was on the curb, walk to the mailbox and fell as he was going back to the house and he never got up he just crawled on back to the house. And I'd be playing dominos with him and he'd be sitting there on the kitchen chair and he'd say well I better go to the bathroom and he'd slide off that chair and crawl to the bathroom and hike himself up on the stool and come back the same way. I mean it was wild.

E: Did you know that before you went into this environment?

I don't think that the first time I was there with the nurse that I saw him crawl.

E: Did somebody tell you beforehand?

No.

E: You were just there and he crawled?

Yes.

E: What did you think?

Well just like I told you. He was aware enough and his ego would allow him to crawl. It was a natural thing to do. And this girlfriend she was there and she really cared for the old fella. One day he told me about his cemetery plot, what a beautiful spot it was, all of the arrangements he had made. The next week he wanted to know what I thought about him marrying this gal. That's the kinda guy he was...(laugh). And I said well [patient's first name] I know if you marry her and move to her house you're gonna loose a lot of the care that you're getting from your grandson and his wife because uh I don't about the grandson but his wife was there all the time and she was really fond of him. He was somebody who was easy to get along with. But uh, he was... he had a good mind. He was bouncing this getting married bit off of me to see what I thought. Come to find out they had already been married. (laugh). They had gone down to [name of town] and gotten married. Well he had a grand daughter that had a son in prison and was caring for one of her grand babies...what the situation was I don't know. But she would show up occasionally but they could never depend on her when she would show up. And then after it came out that they had married. He said well He said I just wanted to make her a partner and uh he had quite a bit of money. He had talked to me about he had a $100,000 bond coming due and he had questioned me as to what he ought to do, reinvest it or what. So he told me that he had left a portion of his wealth to this new wife, which was his fourth wife, and he had a fifty wedding anniversary with his third. When you get to live to be 90 years old you do a lot. Any way, he said he was leaving so much that she was to receive the interest off of it. And when she died then it would go to the heirs. But there was still an amount besides that that would be distributed to the heirs. Well, a couple weeks after the funeral this granddaughter called me and she

E: Wait, were you there when he died?

No.

E: You got a phone call...

No. I knew he was near death and I went down there after church on Sunday because I think I had been there a couple days earlier and I knew he wasn't going to last much longer. And when I walked in he was bedfast at that time.

E: And how long had you been visiting him?

I saw him for five months. And it's unusual to have a long term because a lot of them patients die before the ink's dry on their paperwork. But that's another thing that is still an advantage... ??? But anyway...

E: So you got a call...

No I didn't get a call I just went down there because I knew he didn't have long to live. And I walked in and I went into the bedroom where he was and picked up his hand and talked to him a minute. And looked at his fingernails and his fingernails were filed. And he wasn't in any shape to really visit.

E: You knew that he was close to death because someone told you or?

Observation. And of course as I have said in some of these papers, a volunteer is part of the team. And you communicate with the rest of the team.

E: Did you have volunteer training?

Yes, we went through pretty much a whole weekend.

E: So when you went there that day you kind of knew based on what you had learned in training?

Well I had seen him go down hill and the nurse may have told me that he was actively dying. I don't remember because that was in 94 and uh anyway I visited with him maybe two minutes and that was enough for the situation he was in. So I went back out and visited with the family for probably 45 minutes and I said well I am going to go back in and tell him goodbye and uh I went back in there and picked his hand up and said well [patient's name] I'm gonna leave now. And he always said BYE-BYE, that's the way he bid you farewell. And uh I looked at his fingernails and they were starting to turn blue and I left there about 1:30 and he died about 4 o'clock. But uh anyway the grand daughter called me and was gonna tried to break his will he had made

E: Because he had married this new gal.

Yeah, leaving some of the money. She [granddaughter] was after his money that was apparent. The granddaughter was after all she could get. And she called me and wanted me to testify about him and I said you're not going to get what you want out of me. And uh she ended up dropping it. And I communicated a few times with his wife after that. She called me on an occasion or two but uh I haven't talked to her of course she's probably dead now she had cancer too.

E: Is that your most memorable experience as a volunteer? Or what is your most memorable experience?

(Laughs) Usually they try to give you several weeks in between patients ... and they had a deal to go into the [name of town] prison... on a pilot trial basis to see what we could do there. And they called me and told me about it and that that uh they would like for me to be on the team. They knew my patient just died but they figured I would be the best one to put on that. So, then they told me that he was 33 years old and had AIDS. And I thought ohh wait a minute let me think about it. So I got to thinkin about it. And I

E: What made you apprehensive? The age or the illness?

No. just the fact that uh I didn't want to make a snap judgment on it. The fact that he was in prison, he had AIDS, he may be gay, and what it turned out he wasn't gay.

E: So that made you a little apprehensive?

Well I just had to digest it first before I said yes I'll do it and then it meant driving down there. I think it's about 25 miles down there. But anyway I told them I would go so the whole team of us went down there.

E: The whole team being...

Nurse, social worker, chaplain, and there wasn't a need for a home health aide. We all went down there, got ourselves fingerprinted, and in the FBI files (chuckle) and we got badges just like an employee to wear. I still got mine. I 'd down there and press the button and they'd see my badge and open the door. I had to go through eight security doors to get back to the infirmary. And uh when we went down for our orientation...

E: And the orientation was about the prison or the facility.

The facility in general and what to expect and how to handle something if something did happen you know because you're in prison. But anyway they gave us an orientation and the social worker had to walk across an open area to another building and of course there are times when they have lock down when there's not anybody on these yards. And she chose to walk across there when there is lock down because it could be a little...well anyway we went through this and I got a big article about it and they told us they thought he would live three months or no thirty days. And uh we walked into the nurses office, they just had one nurse on the perimeter and she had .... And uh sit down and she said well I know you [volunteer's name] but I don't know the rest of these people. And I didn't know who in the heck she was.

E: She knew your name?

Yeah. Well she my wife's cousin was married to her brother-in-law and she lived here in town and I guess at some time I had met her but I didn't remember but anyway uh . We did not actually go in and meet him on that initial orientation. We could see through the door that there was somebody in the room.

E: Tell me about the first time that you met him. Were you by yourself?

Yeah.

E: And what was it like?

This all started on July1, 1994 and I had heard of and read enough that I wasn't worried about the AIDS because a lot of people are spooky about AIDS. We've had AIDS patients that the parents were taking care of them and the church people would come to visit and they wouldn't even sit down. AIDS is not something that you have to treat like that. Anyway, I walk... I may have gone down with the nurse.

E: Were you nervous?

No. I was...it was more like it was an adventure...the fact that it was a prison. And you see what really made it kinda sticky was that the way in there there were two rooms that were 40 x 40 or maybe 50 x 50 they were good size rooms and you see every person that goes into the department of correction is processed through there and the biggest part of the time when I went through there both of those rooms were standing full of people being processed through the system and I had to walk through. The ones that were there being processed were always in jumpsuits, criminals, and the ones that belong there were in jeans and T-shirts. And uh I had to walk through there. That's why they told us... cautioned us and told us what to do.

He was in bed and I went in and introduced myself to him and uh shook his hand and uh shortly after that the nurse said that when he found out that we were coming he started eating again and uh he had been in three state prisons, one federal and in juvenile detention in California. Uh in visiting with him he had been in a bar room brawl and been stuck with a knife and he thought that might have been where he found out he had AIDS. He found out he had AIDS when he was processed in the prison this particular time and he said boy you think that wasn't a blow to me... they told me I had AIDS. And he had told me about that he had worked in the oil field for a period of time and that was when then the economy went down and he was without a job ... because I had asked what had got you in prison this time.

E: Did you feel comfortable asking him that?

Yeah.

E: Did you visit him for awhile?

Yeah. I started on July 1 and he died Dec. 9. Another long patient and I haven't had one that long since. But anyway he was telling me well the oil field went down and he had to support his family so he started dealing drugs and of course taking them too. I had a $500 a day habit but it was easy money. He was selling drugs just to support his own habit and uh I thought oh boy. And some people I told that I was going down there, including my

sons, thought what was I doing going down there wasting my time going down there to see somebody like that. And I said well he's a victim of his own mishap life. And it was a pilot project to they wanted to see what we could do in a situation like that which at the end of it I never found out and none of the nurses never did find out what the real result as far as the department of corrections are concerned if they liked us being there or what.

E: How often did you visit him?

Once a week. In fact I had surgery and got my wife to drive me down there to make a visit because I wasn't able to drive yet. Luckily she went in with me and luckily those rooms were not full of inmates. And.

E: Were you there when he died then?

I'll get to that. Uh anyway he rallied, he started eating. I went through a period of time when he had lesions on his lips and he was beginning to go down hill again and he had gotten a medical parole had been granted to him ... this was about the first of November. And the social worker and the nurse were afraid he wasn't gonna live long enough to get transferred out of prison. He had two wishes, he wanted to see his 34 th birthday and he didn't want to die in prison because he was not a convict.

E: A medical parole means what? That they would put him in a hospital?

It was up to him I guess but of course the condition he was in Medicare would take over. But anyway let me back up to his birthday. His birthday was September the 17 I think. And uh we asked security if we could bring him a cake and ooh no can't do that. So the nurse faxed the warden a letter about it and he gave us permission to bring a cake and uh we had a nurse that was really a nice person. In fact she was back in the hospital a few months ago and I ran into her and she is wide-eyed, not cross eyed, but wide –eyed – you couldn't tell if she was looking at you. But she was real personable. She was a touchy personable person. And he really got fond of her. And when we took that cake in the whole team was down there and uh he got in his wheelchair and came out of his room into the living room for lack of a better word and uh she held his hand and kinda stroked his arm. And he was really moved by us bringing him that cake and it got to every time I went down there he asked me about her and she uh she had somebody else go down to the clinic part of the time because he was just too fond of her. But anyway, now okay we got the birthday over. We served everybody in the infirmary cake. And he he had tears in his eyes. But his family had divorced him. He had a stepmother visit who stayed in contact with him and I wrote letters from him to her and she would send him ten or fifteen dollars a month so he could buy candy stuff like that. But back to this parole, this is all in print too. We had a chaplain that had been a catholic priest, and he decided he would rather be married to a woman then the church and so he broke out of being a priest and uh he knew the priest that had been at [church] and he had moved and he was now the governor's priest. And uh then somebody else knew somebody that was on the pardon parole board or something. Anyway they pulled strings and got his paperwork hand carried. Normal channels was a month to six weeks and he wasn't gonna make it that

long. Anyway I was there on Friday and he was hallucinating. He was picking little red wires out of the air and I couldn't hardly understand him when he talked. And I knew they were working on his transfer. Well the following Monday he was transferred to a rest home up in the city that catered to AIDS patients, that was there main business. And uh he rallied again. He even participated in an AIDS march downtown in his wheelchair.

And uh I visited him there. This was the first of October. The first of December he started down hill again. Saturday....I'm not sure but the nurse called me and said [name] he's dying and they want somebody to sit with him and we're covered up with intakes and can you go up there? And I said yes I'll go up there.

E: Without a doubt you knew you wanted to go up there?

Yeah. And uh so I went in and there stood the social worker. And she said [name] there are other things that I need to be doing but I felt like this was the most important place to be. So they had just taken his blood pressure and it was 40 over zero and of course he was comatose and he was laying on his side facing the wall and he was covered up and so I sat down there and carrying on and reach over and rub his blanket and say "[patient's name], you can let go you're not dying in prison." And I'll bet there was at least five of the workers there who came in and told him they loved him. You know they say hearing is the last thing that goes. Of course his breathing was labored and I sit there for about an hour and all of a sudden I noticed a drop off in his frequency and how deep he breathed. And uh I thought well should I tell somebody? What the heck are they gonna do? He's gonna die. And so in about another twenty minutes he quit breathing. And you know I felt like it was a blessing you can go ahead and get it over with. And it didn't bother me so much that he died but it bothered me to go out into the hall and tell them he was dead. And uh they were gonna call his step mother and I said why don't you let our social worker do that because she has been in contact with her. And she would probably hear it from her and so they did. But for some reason after that they didn't want us coming to that nursing home. One of our aides said that, well we had a girl one of our aides commit suicide. And that I'll tell you that threw us all. She had the prettiest pale blue eyes and have you gone to an IDT meeting? Well they are.... Volunteers can. The IDT meetings are like chart rounds. They review patients every two weeks, half of them each week. And you find out about family dynamics, how they are being treated, what they are being treated for, and you don't go in cold on a case.

E: We lost track...

Oh the home health aide, she told me later long that she had gone up there to bath [AIDS patient's name] and that the day that she found out that the day she had committed suicide that she was so distraught that she did not clean up properly in the bathroom, bath I guess, and they got perturbed at that. Yeah she was a nice looking, probably 25 maybe 27, and I'd go to these IDT meetings and she'd sit across the table sometimes and her eyes were blue that was just hard to believe. It really hit everyone hard.

E: Did she commit suicide after the patient passed away?

No. This was. She had problems that none of us were aware of and I don't recall.

E: How did this affect you personally? (patient's death) Why was it memorable?

It's memorable because of the prison and all of the other circumstances. My wife probably didn't tell you that she attended the death of a friend of ours – she was shy – and didn't show you that article. She's timid in that area. It's just the whole gamut of it – getting him transferred and how they went about it.

E: But did the whole experience have an impact on you on a personal level?

Let me say this about that. And if you haven't read it you need to. There's a little book called Final Gifts. It is short stories by hospice persons. And the Elizabeth Kubler-Ross *The Wheel of Life* – it is one of the most enjoyable reads I've done. And all she did … she was… reading this Final Gifts gives you a much different view of death. Death … to most people death is a spooky thing. And uh so when I sat with him there this was his only alternative. There was no way he was going to survive. And I sat there and prayed that he would go ahead and die. And so you know how could I be very upset about it? (laugh). There was no way I would rather have it. But I had an experience sometime later that all of these… you said how did it impact me?

E: Yes, did it?

Uh, I have got three prosthesis, both shoulders and my knee that's been done twice. And on the second knee operation they put me in a room, they didn't have a private room and they put me in with a real elderly old man who had broken his hip, of course they had to fix his hip, and he was so out of it- when they tried to do anything to him he squealed like an animal. The next morning I lay there, of course the curtain was drawn between us, and I could hear him gurgling, and he was not able to roll over or anything, he wasn't able to clear his throat and he was drowning in his own juices. And I called the nurse, nursing station, and it happened to be right at shift time, and it took them 17 minutes to get somebody out there. Now it wouldn't have made any difference but it's just the fact that it shouldn't take them that long. In fact the first person that came in was a little gal that took temperatures and blood pressure. She wasn't even a full fledge nurse but she got a hold of him and here they came with a crash cart. And I was in the second bed, and here they come in with a flash cart and at least half a dozen doctors and nurses. And the head nurse of the floor came over and said do you want us to get you out of here? Well what chance did they have of getting me out of there? I said no I've been a volunteer at hospice long enough that uh I know that this is uh just part of life. And uh so I think through the hospice training and the experience that I've had with hospice kept that from really de-railing me. But um they worked on him for 2 or 3 minutes and the doctor said there is nothing to save here and they stopped. But uh..

E: Can you tell me about a bad experience?

Oh there's been several there were difficult because of family dynamics. Well for one thing I think lung cancer patients are the most angry – at least that's my own observation. And I have mentioned it to some of the nurses and that is the feeling that I get. And I think that they are angry at themselves because they made themselves vulnerable to lung cancer. And uh we had a situation – out north east of town – that apparently this old man had really been around had girlfriends and stuff and his wife got stuck with taking care of him while he was dying. And she was as mad as a wet hen. And uh, the dynamics were just … he had cheated on her and then she ends up having to do this.

Then I went out to one place….

E: There was tension?

Yeah. You could tell that there things are not the way they should be here.

E: Wow that's interesting.

Like I say when they are angry they take it out on whoever they can take it out on. And I only made one visit down near [town] and he was so far gone and sedated that there was nothing I could really do for him so I visited with his wife. And they had their daughter and two little grandchildren living with them, at best I remember they were maybe 5 and 6 years old. And she was worried about the effect it would have on the children if he were to die at home.

E: The wife or the daughter?

The wife. And uh I talked with them and I said you know that is one of the main thrusts of hospice is to allow people to die at home. And uh so I didn't know how much…. You have to kinda play it by ear and not go into a field that you shouldn't be in and so I talked with her about it and I went back to the office and I let the nurse and the social worker in on the situation anyway. She however it happened.. I don't know how long… but maybe he died before she could get him moved but anyway he ended up dying at home.

E: And did you visit him? Was he your patient?

I only went down there one time. He was completely out of it. He was comatose or so sedated that he was sleeping all the time. But I told the nurse and social worker you know as far as I'm concerned those children are going to react more to how the other people the adults react about his death and they agreed with me. But I didn't feel it was my place to tell her (patient's wife) that – it was more a professional persons place to tell her that. But patients tell volunteers things that they won't tell a professional person sometimes. In the case that you have a long term relationship with them they tell you a lot a lot sometimes. I brought pizza into that guy in prison one time.

E: Long-term patient – would you consider that 6 months?

Well the two I had were about five months a piece. And that's unusual to have that long term. But now there's a patient here in town and there's an article about him in the paper and I don't know if you can retrieve it. The same writer that wrote..... she wrote this other article. And I called her. This guy was an ex-POW and he was on hospice. And I visited him for I don't know how long but he finally improved and went off hospice. And I still stopped to see him once and awhile because he this was such a wild interesting thing. He said that he was in a reconnaissance group in France looking for German tanks and that all of a sudden from behind a hedge row a tank for the German soldiers appeared and they had a little shoot out and one of his guys was injured and he was bending over this guy to help him and this German officer said to him, he spoke English, and he said in the position he was in and everything he thought he could have taken him this German office out. But the tank was standing there with this machine gun staring looking down this throat and so he surrendered. They gave him stuff to bandage this guy up as best they could and he said they put him they set him on the front of the tank. And they started on their way and that some English spitfires or whatever they were appeared and they ran that tank against a telephone pole so that it would look like it was disabled and so they didn't attack it. He ended up in this prison and I never could get out of it just how long he was there. I don't know if it was something he had just blanked out or what. But anyway they asked for volunteers to work on German farms and he figured ... they were getting bread and water... that anything could be better then..... so he volunteered. Well he remembers the name of this man and his kids and what all he did there. And he said that they came they delivered him to the farm in the morning and picked him up in the evening. But he ate meals with this family and everything and he knows the daughter's name and anyway this family had a son that was a prisoner of war in England. And he thinks that maybe that was why they treated him so well. But uh they said they were friendly to him and that he helped feed the pigs and that he boiled the potatoes before they gave them to the pigs. And I have found out since that in Europe that is a common practice to boil stuff like that before you give it to the animals which in this country I don't think they do. And anyway he was back and forth with this farm and one time well he apparently there was a number of POW's in this ... I think they were just keeping them in a farmhouse they had taken over. And uh he told them that he had a tooth ache. And he told me that he had been playing poker ....well they were paying him a little bit for working for these farms and uh they had been playing poker and he had won these guys money. So they gave him a bicycle and a guard rode along on the bicycle to take him to the dentist. And uh the guard told him he said you know there, now he's polish, and uh the polish language and Russian language are fairly similar, and he told him that he was gonna have to pay the dentist. And he said he pulled out this role of money (laugh) that he had won and this guy said oh you rich American. But uh they uh got him fixed up and he has no ill feelings against the Germans. He said they when they transferred him from one place to another, I don't remember what the different spots where, they stopped by the Eiffel Tower, and the French were throwing them candy and stuff, and the Germans were trying to keep them from it and they couldn't stop them. But it was such an interesting story. I called [writer] and told her briefly what it was and she did an article. And I don't know why I don't have a copy of it but I don't.

E: Have you ever turned a patient down?

Not exactly. I can't recall exactly but I think there's been a time or two that the situation and everything.

E: Like situation in terms of care facility or family or disease or age of the person?

Disease and age of the patient has never bothered me. There's just been a couple of cases that I can't bring to mind that after visiting them a couple of times I told them that I didn't see any point and they agreed. I can't recall just any one as there has been too many of them.

E: What would you share with a new volunteer?

These are the same thing. Well you want me to read this or. Okay this is to the group – reads paper – My name is Harry Deaver.....

And um I usually tell them that death is not the worst thing in life. There are things that are much worse and we see a lot of that.

Paper read

Now uh something that we usually tell the family and the patients, at least I don't hear it emphasized much anymore, maybe I should mention that to [volunteer coordinator] that the patient is boss. If the patient doesn't feel like you being there, if they don't feel like visiting, or having to be attentive to you, you excuse yourself and come back later. Maybe ?? or something.

Paper read

Patient I helped bury – another lung cancer patient. I went up there for maybe 6 or 8 weeks to see him. And he had worked in the oil field and hadn't saved a red cent. He had a sister that worked for Safeway as a butcher and had bought a little house. And she died and left him that house, that's why he had a roof over his head. And he had been married for this gal for 13 years and as I say it seems to be like lung patients are angry. He wasn't very nice to her (the wife) and uh he died and uh they called me to be a pallbearer. I don't remember if hospice called me or .... That's the only one I've ever been a pallbearer. But anyway come to find out well ...they said she had gone to his buddies at the pool hall where he had hung out when he was able... to get somebody to help bury him – they wouldn't do it. That's how awful he was. So the chaplain and I, a neighbor, and a couple people that the wife had baby-sit their children, served as pallbearers. But you know the guy – it's pretty bad when his so-called buddies won't help bury him. And uh so that was that story.

E: Was he that bad to you?

No, no. He treated me alright. And you can take a lot of these and copy them. I've tried to keep all these things that I've worked up and I've got a lot of notes in the margins on this. I've even wrote the Forest Gump statement on here "life is like a box of cherries" and that was kinda like these patients where you never knew what you were going to get.

E: What does volunteering do for you personally?

It's giving back to society. I ran a TV shop in the same building for 44 years. Society has been done well to me. Then uh after I had been in hospice for a couple of years...are you familiar with Steven ministry? Well I didn't know anything about it until, I go to [name of church], they announced that, put up a bulletin, set out fliers in the bulletin, that they were going to have a Steven Ministry training. And what it amounts to is in a big church the pastoral staff cannot cover all the crisis that come up. They have to take the worst ones. And so this is a fifty two hour training course that you go through to help this crisis. Sometimes childbirth is a crisis, divorce, loosing your job, emotion problems, and so uh when I saw that I thought well this kinda dovetails with hospice. So I went through the training and I stayed active for about five years before I retired from that. But uh, it, I found out that it is a wide spread program, all churches, it's not limited to any particular church. We went to a meeting up in the city and uh there the Catholic church, the Mennonite, you name it because it is a good program. And we took referrals from other churches if we had Steven Ministers available. I had an old fella that he had nursed his wife for a couple of years, she had a long drawn out illness and he was .... And uh they asked me to see him. And I went to him, we met at church, and we visited. He told me about the situation and I said well did your church take care of things on that, their responsibility. And he said oh yes, I was pleased with it. And then I asked him a couple questions. And he had just kinda got to the point that he didn't want to get up in the morning. He was depressed and a lot of times that happens and he told me about that he tried to take these walks. And it was easy to tell that he was beat down emotionally and also physically. And I told him I said you know, and in Steven Ministry you're not suppose to try to fix them you are suppose to be there for them and be their friend and listen to them. But this was so apparent that I turned to him and I said you know if you can get out and do things and get some exercise and get your physical strength a little better I think that the other part of it will take care of itself. Well the next week when I met with him he said you know I don't think I need you anymore. And so we visited and that and I parted with him.

E: Because he was feeling better?

Yeah. I mean it just took a little booster was all it took for him and he got involved in the senior's program there in {name of church} even though he was from [name of church]. And had a girlfriend for a short period of time and the poor old fella had a stroke and got in a rest home and died. But he had a few good days and uh we had a Catholic guy that we had at our church that they asked me to see. I saw him for 8 months. He handed out cards kinda in memory of his wife, that uh in essence said appreciate em while you have them. When I first saw him, supposedly he was depressed. In fact he had been pronounced clinically depressed because of the death of his wife. Well he told me to

begin with that for the last few years they just hadn't been able to communicate. And further into visiting with him he revealed to me that he had had an affair and she found out about it and that's when things didn't communicate real well. But anyway he did not want to get well. He was punishing himself. I saw him for 8 months and I never made one I-iota difference in that guy. And uh I had told him right from the get-go, I am not prepared to deal with somebody like you. And I said but I will continue to see you. Well then after I had seen him about 7 months, our leader gave me a video to watch and it plainly said that Steven Ministers are not prepared for depression, to deal with people with depression. And so I had him come over to the church and I played that for him. And I said this is what I've been telling you. And I said I will see you maybe its 3 more times but at that point you still are just determined not to get well, I'm gonna quit. And so I saw him those times, we met, except that one time that I showed him that video, we met at Red Lobster. He ordered the exact same thing every time. The waiter or waitress that waited on us knew what he wanted and he had his lunch there every don't remember if it was every day but I wouldn't be surprised if it was everyday. But he was ex-military and he didn't have a good relationship with his children. And anyway I finally just cut him loose because I was wasting my time. Well that's not hospice...

E: Do you get nervous at all when you go to meet a patient for the first time now?

Well its been so long. I don't go anywhere without calling first. I just tell them I'm {name}, I'm a hospice volunteer and I understood that they would like to have a volunteer visit and they accept it or they turn it down. To start with I first, well in my training, I went with a chaplain to see a patient up in the city and then I went with a nurse to see my first patient. And then of course we went as a team down to the prison, that was to start with. But uh after you've down it awhile you kinda know how to present yourself and I don't feel it necessary to go in with a nurse or somebody.

E: But initially you liked going with a nurse?

The first few times you know to kinda learn the ropes and uh.

E: How do people react to you when you identify yourself as a hospice volunteer?

I tell them these people are going to die anyway.

E: But what is the response?

Oh how can you do it? And in a lot of cases I tell them that if they would read Final Gifts, they would change their mind about death and dying.

E: Do people ever ask you about your experiences?

No. It's just I am fairly free... I believe in hospice and every opportunity I get to put forth the name, three-fourths of the people that are on the rolls right now did not know that hospice existed before that. And that's why I try to get articles in the paper. I had one

deal that was interesting. This poor old guy had brain cancer or he had a tumor on his brain that was inoperative, so it may not have been cancer. But anyway his sister was taking care of him. He had worked for the sanitation department and uh I would she had to go pick up her children at a certain time and so I would be there so she could pick up her children which didn't require even an hour, only 45 minutes. But um one time she didn't wake him up when I came and when she got back with the children that woke him up. And he was quite upset that she hadn't told him and I was there. He was such a sincere guy in his condition now. You know there's some situations where you really feel like that you're helping and there's others that you don't feel so much that way. But usually um I stayed with one guy a few times that but I don't know what kind of cancer he had but he paced. He'd lay down for two minutes and then he was up again. He couldn't get comfortable. And he was just like a cage animal and uh that was probably the most nerving situation I had. Well there was nothing you could do for him and um you could tell that he was in a bad way.

There use to be Steers a food store … one of the Steer boys…..
They called me to go out and sit with this old man and I had known him for years. And uh they told me that if he got to laboring that I should put oxygen on him. Well I had never put oxygen on anybody and he was comatose. So he got to where I felt like he needed his oxygen and I tried to put it on him and I didn't know how to tighten it up so that it would stay where I wanted it so I called the office and talked to the nurse and she told me how. But he died the next day. Some of them do not want to or they would rather not take a patient that they know and I feel the opposite. I feel like if it is somebody I know that I can be more to them then I can to a stranger. And uh years ago, my first two or three years with hospice, there was a patient that came up that was a retired kernel and he had worked at the ROTC up in [town] and had been a customer of mine and he always had me fix his mother's set. And I saw his name come up and I didn't act on it right away. Back then I was more……well I was young enough it didn't bother me back then. So after IDT I called his wife from the office and told her who I was and uh I guess she said something to him if he would like me to come out and he said yes. And I went out there and that guy was sitting up, propped up in bed just as chipper as you would want anybody to be and he had pancreatic cancer which usually is a fast moving one. And I had a heck of a nice visit with that old guy. And set up with his wife that I would come back in a week and she was going to go do her shopping and uh when I called to make sure it was alright for me to come she said that he was so bad that she didn't want to leave him. And he died a couple of days later. You know I wish now why didn't I get on this right away when I saw him, I may have had a patient I don't know. But I I feel it a privilege to do what I can for those people that I know and other people can't take it if its somebody they know that's dying. I'm 75 and I look at dying as a mystery.

E: That was my last question –

If you are a Christian and a church goer, if you if it's made any difference to you, why I feel like it's a mystery. You have promises but no guarantees. And I'll tell you just one situation two incidents. There was a Chinese woman in this country, its in that book, that was dying. And they found out that her sister in China had died. And she was so bad they

didn't want to tell her that he sister had died, and I used died you know this "passed" and "you lost one" and that's another thing you don't want to tell children that you lost somebody because they think that maybe they'll find em. But anyway, they didn't want to tell her, this person, but she saw her sister standing by her bed and they never see anybody that is alive, and she did not know that her sister was pre-deceased. And another situation where a couple of guys had been childhood friends and grew up together, went to college together, but somehow they got separated. And this one guy died and when he was on his death bed he saw his friend by his bed and the family found out later that he had pre-deceased him. And the chaplain we had then said that he thought that that was god's way of making death a little bit easier on people. But most people say ah they're hallucinating or something like that.

Story of second cousin –

Since my wife and I have been married, we've been married 18 years, I have had 16 surgeries. And I say that I've had good care in the hospital but I've never had the care that a hospice team gives a patient. Because they are really dedicated.

Story of women drawn up with 24 bed sores with 3 or 4 near to the bone. So I say there are things worse then death.

Transcripts~Participant 3

E: Can you tell me how you got involved with hospice?

Actually I got involved with hospice because I know [woman's name], the office manager. And he had worked together at the time called {name of nursing home}on Robinson. And uh she was the Assistant Activities Director. And I saw her one day in Walmart and I said I've been looking for something to do. So I had been a volunteer there for quite awhile, a couple years. In fact {woman's name} had been to my home with a bunch of the older people. I used to have dinners. They don't allow to much of that now you know of the nursing home but they'd come out, a couple three times I had dinners out at my house and a big group of them, and I lived in a bigger house. But uh I love [woman's name], she's just the sweetest person in the whole wide world and that's basically the reason I went back is because [woman's name] was kinda there. This has been about two years ago.

E: What's your current level of involvement? Do you have a patient now?

I have a patient, I have two patients I have been seeing. One is bereavement and one is a patient actually.

E: Patient at home?

One is in a nursing home and the bereavement is in her home.

E: Is it typical that you have two patients?

Uh yeah and usually I have been more involved than in the past then I have been in the last few...in fact I dropped out for a little while. We remodeled our house and stuff and one the reasons I kinda dropped I kinda we I lost one of my ladies that I really loved. She was just a real sweetheart and I kinda backed off for a little while. And then we were re-doing the house so I didn't go back until about June this year.

E: Can you tell me about your first assignment?

Um well I looked forward to it. You know, I always enjoy working with....of course older people but I'm older people too. (laugh). Over 63 they're older. I felt very I was very enthusiastic about it. I guess one of the first ladies I had I went to her home, she had she had lung cancer and she was staying at her home and I went to her home. And I did that she was kinda a stand offish lady and they weren't really breakin in with her, the volunteers, and I went over there and cleaned out her flower beds for her and that kinda broke the ice and I know she told the volunteer coordinator that the only volunteer she had was me. So.. And uh she uh I visited her home several times and I took her to the grocery store one time I can remember and I'd bring her maybe a sandwich or a malt or something like that, one of those deli sandwiches. And then she she had caretakers that were with her, she wound up having caretakers that were with her 24 hours a day. And I

guess that they dropped off and then her son, she only had one child, and I may be going into too much detail... it was a male child and he was in ____ and I think he was having to run down quite often. She was a little cantankerous and that's the reason why she couldn't really keep the home health people, I think with her, the ones that were stayin with her. She ran, I think she had four she ran off. And I knew that you know that I knew what her situation was and she wasn't someone I really got really attached to but she really thought I was great. Boy she that really and she was put in to a mental facility she was put into one of the Medicaid nursing homes and it was really really she wanted to burn the place down, she wanted to do this, she wanted to do that. And uh she wound up in the mental department at the hospital for awhile and I went to see her there. And when I went to see her she was not very she was paranoid and uh you know being away from her home and she was very _____ and angry but uh then she wound up going out to {name of nursing home} which is a pretty nice facility, even though its not a fancy one. They have a lot of good staff there and the other one was very crowded and I'm sure the noise level was probably very high at it. But uh she was there in fact it was about I guess it was about 11 months ago that she died.

E: So she was a long term patient?

Yeah, I had her for quite. It was very hard to get in with her. I had to call her and she would make excuses and so I guess she just ... sometimes she wouldn't let... the volunteer coordinator send someone out here and she wouldn't let them in. But uh...

E: Do you remember the first time you met here?

Yeah, in fact I called her by the wrong name the first time I met her (laugh). And uh she did invite me in and she I think she had company I can't remember. But uh but I talked to her for a little while and explained what I did. And I'd call her once a week.

E: This is one of your first patients?

This is one of my first patients since I've been involved with hospice.

E: Were you nervous about meeting your first patient?

A little bit. But you have to realize that I'd done volunteer work. That I was kinda just looking forward to it.

E: You weren't nervous... just a little?

A little bit. Not much. About as much as I am right now.

E: Were you with her when she died?

No. The one patient that I had gotten involved with uh I am trying to think I had gone out to see her when I was being trained. The nurse, LPN's worked with the patients at that

time, but it was for my training I went to see this one lady. And she was there with her son and daughter. And I went with the nurse as part of my training.

Okay and I met her. I sent her a card you know and I think I called her once and finally they decided they wanted a volunteer. And I would go out there and volunteer. Uh I think it was one day, I think on Mondays. I came out there and stay I think about 3 hours on Monday afternoon. And then it progressed to ... I had a marital problem my husband and I separated, we've been married for a long time, but he was having a terrible time.. we just separated. So I went to work and worked for her as a paid annual what do you call it. I did that for probably six hours a week, like three hours one day and then three hours another day. And uh so I got into a ... she was a lovely lady I really like her. She was real, she was just a real person. I mean so many of them are not themselves, they're... she was in a healthy situation and had a wonderful daughter and son-in-law and she had built a room onto their home. And I say she loved the patient, she just adored the patient. One time I had told her, I had teased her a lot, when I come back I think I'm gonna bring a six pack, which of course you don't do that, but I said we were teasing her, she said she liked Miller's Lite. And anyway I went to, I'm a smoker and she was a smoker, so I would take her outside and she didn't smoke in her daughter's home, and I'd take her outside and we'd sit she had a nice patio and we'd sit and have long conversations about her life, about her background, about her husband and where she lived and all that kind of things. But uh well she did finally get to where she couldn't get out of bed. And I said she was a pretty good size lady so I am not medically trained so I just know go call hospice if something happened and I never had that situation with her. But uh I read to her and we talked and we watched TV, she loved Murder She Wrote, and I was always there at that time in the afternoon for Murder She Wrote, so she would watch that. But she really wanted you to be quiet when she was watching that, she was very interested in that. But uh then she got bed ridden and she didn't ... like she put the patch on so she couldn't smoke anymore and uh she uh I don't know she was just a great person and I really liked her. And I remember one time, it was around uh, actually it was I think February of this year and uh the last uh well I need to go back and recap Christmas time. I had my family come in but I had a little time so I ran up there to give her a Christmas gift, ____, only they had me come over and stay with her on New Year's Eve. You have to realize that my husband and I were still not together at that time. And I went and got or had my husband pick up, he was living down the street, but he was still coming in and out at that time but anyways he was we weren't really, we'd go out to eat and all that stuff. But anyway you don't want to hear about that part. I had him get some Miller's Lite in the bottle and I cleaned out a bottle really good, left the label on it. And I went down to Albertson's and I had them put flowers in it. And uh had a ribbon thing on it and it had welcome to 2003 and so uh well I want you to know I kept my word and I brought you some Miller Lite so we all got a good kick out of that (laugh). But anyhow she, it was about the last probably about the last three weeks that she was alive that she uh she didn't know where she was and she always recognized me. And she would tell me, of course she may have told all the women that I don't know, if anybody is going to watch after me you're my favorite. (laugh) But she would uh always when I come in she be in a she would always grab my hand and talk to me and smile at me. And she was pretty elusive still that last three weeks and then one day she went, it was probably the later part of

January, I can't remember what date in February that she died. But uh her daughter, the reason I came over is because her daughter worked, and you know she was working at that time, and she didn't know where she was. And I said you're in your daughter's house and she didn't want to buy that. And I had one of the ladies came by from hospice that brought the Ensure by for her, and uh I talked to her a little bit and then went comatose...she came out, but she uh got on the phone and talked to her daughter and said {volunteer's name} doesn't know where we are either! And we need to get... she was just...it was funny but it was really kinda scary for me because I thought I never you know I know I am gonna have to expect things like that you know its just... she was just not sure where she was, she thought she was in somebody else's house. And then later on, I think the last time I went by there I was just to go by there, Monday and Friday I believe it was that I spent the afternoons, and then she had other people come in but were nurse aides I think or maybe even LPN's that came in and sit with her once in awhile, people very professional. And uh I forgot what my thought was... the last time I saw her that's what it was the last time I saw her I went over and held her hand and I said I'm gonna go home now. And she says, and her daughter was there with her on the other side of the bed, and she said am I gonna go home with you? And her daughter was just ohhhh, you could see her cringe and of course her daughter was very sensitive and just was very I don't know how she did as well as she did. You know there was a lot of teasing and cuttin up and fun and stuff that we all did amongst each other but uh ... Friday morning when I was getting ready to go over in the afternoon I got a call from the volunteer coordinator and she had told me that she had passed away. Well this was like 8 o'clock in the morning and I was over there by 9. Of course, she had made uh, the patient made us promise to sit there with her for several hours after she passed on because they are afraid of being alive, a lot of them are, and uh so I went over to sit with the family and with the patient. And I say when she, that morning you know and her daughter had always worried about being gone when she passed away, her daughter had gone through this with the husband. And she wanted to be right, she would wear herself out, wanting to make sure she was there. And uh her mother had told her I want you to be here holding my hand when I pass away. Well, it didn't work out that way. Her daughter had gone to answer the door and one of the other people that were sitting, the more professional person. And when she came back she was gone. And uh she was, of course it was with great timing, the girl knew exactly what to do to fix the body you know and of course it takes sometimes two to three hours to pick the body up. And uh she uh... we had a great.

E: You went over right away?

I went over right away and was able to sit in the room and uh you know and talk to her daughter and son-in-law and the patient. And of course the nurse and the daughter were very close and they just gave each other the hardest time, teasing each other and like I said all of the family thought the world of the patient and I say I sat there and then they had uh they did come and they the nurse and I gave the family a little time by themselves when they came to get the body. They say, the son-in-law called me and told me when they had the body at the funeral home so it was kind of a sad time for me.

E: Was that the first patient that you had that died?

No, the other lady had died in December the one I was telling you about that I did the flower beds and that kind of stuff. And I've had some of like right now I have one that's in a nursing home. She's the sweetest little thing in the world but she can't I don't I think what I've done is really backed off from a real close attachment but it takes a certain person to really get attached to also and I say that was a .. but she was really special but she was special to everybody that met her... except {name of chaplain}. She did not like [name of chaplain]. He's a chaplain. They had a very much involved with uh her daughter worked at the league in the church and the minister from the league from church was there quite often and she was very fond of him. And uh in fact he went with them to take the ashes back to Kansas and they you know had the services up there. But then I got to meet the other, there were two daughters, one lived in Kansas and then when I went to the [name of husband] went with me, uh to the viewing and uh I got to meet the other daughter. And she came over and put into my hand a coin. And she said Don't, I think I am going to start crying here in a minute. Anyway she said take this home with you and it was one of those appreciation gold plated coins that you are suppose to pass on to anybody you appreciate a great deal. So I thought that was real sweet. I'm sorry...

The other lady that died now she .... I was good to her, but attachment I didn't have. This was the one that died about December that was in [name of nursing home]. She was she she wanted to use her dying as a weapon against people I think. And she would this is not the way you would treat a terminal person and blah blah blah. You know and that was to me was I guess if you aren't yourself I don't know how to explain it but some people just have some things about them that you know that push you way. And that was some of the things that pushed me away. I could see that she was cantankerous with the and bossy with her other people there. In fact I was asked to be a private sitter for her and I said no. I could see that that would not work. It would not be good it would be I would wind up with me you know just like she ran off the other people and I wasn't willing to sit with anybody for that length of time. A few hours at a time was all they could have.

Another lady that I had just had her for a very short time. And this was actually private sitting, even though the hospice provided them with my name. This woman was 56 years old and she was another lung cancer person. The lady that died that I was so close to she had female organs that type of cancer. Another lady I was around her for maybe two weeks and they hired me just kinda over I think it was Wednesdays for all day long. And she was of course younger than I am, 56 years old, and uh she, but I was only there for a very short time. I had only went there three or four times before she died. And I was not with her when she died either. But the fact that this was a lady I thought so much of when she died she had a smile on her face. Which I thought was great. She had the cutest little smile on her face. But I tell you what this woman uh well you see the other two that I talked about that died were so emaciated, and so sickly looking, and bones sticking out. This woman, her skin looked healthy, and she just she looked I mean you couldn't tell she looked healthy and I said to her you just look so healthy. And she looked healthy when she died but they it was just uh you don't uh.. I mean you could see the other ones was when you see how emaciated they become and all their changes and that kind of

stuff. But she was definitely in a loving atmosphere. The other two were not, like I said it was a very, I'm sure her son you know it was costing them a lot of money for this 24 hour care and he was probably just at his witt's end and he had to do something with her and sell her house to be able to pay for her care. Well she didn't live very long after he did that and he put her in a nursing home.

E: Your most memorable experience?

My special lady I told you about.

E: How did this impact you personally? Your experience with your special lady?

I think it was I think I was very sad and I withdrew from hospice for awhile and of course I had so much going on in my personal life too. That was a big thing because I didn't know if I wanted my husband back or not. Anyhow it was ... but she definitely was the most outstanding thing I have got as far as a pleasant, warm fuzzy feeling. The others were not warm and fuzzy.

E: Can you tell me about a bad experience?

I think I've already told you.

E: The cantankerous lady...

Yeah, I think that one ... I can't say that was a bad experience for me. I guess the worst experience I've had is that I have a friend that uh her husband was in the VA and she insisted that I be... she just... she volunteered me to be her volunteer. Which I first of all, she had known me for years, first of all she knew my situation and she also I felt like she was really overstepping her bounds by saying I want her to volunteer for him. For one thing, I don't like to do male patients. I'm sorry I just don't.

E: Why?

I think because I've been around, as a child and as a young woman, I've had bad experiences with old men. I think I've ... and I don't mean that they're all dirty old men I just mean that I don't want to be groped and that kind of stuff when I'm around them and that's just paranoia and a personal preference, a paranoia that I have. But it wasn't a situation like that with him at all, he was completely. He had so much dementia and so much shrinkage in his brain that he was not ... and I knew the guy he was a really nice man ... and he had been at least seventy or five or so before I ever met him. But he was this friend's husband and I say uh she wanted me uh she didn't understand very well, in fact she is one of my bereavement patients right now, she didn't understand very well about the difference between coma and someone with real extreme dementia. And she wanted me to read to him. And I went up there and I probably didn't go to see him a half dozen times before I just told the volunteer coordinator I said he doesn't know if there's anybody there. Because he would jabber all the time that I was reading and I couldn't

really get anything... I was not patient with him uhuh I didn't feel, I tried to be, but I didn't feel like I was doing any good there. I didn't think that he was aware that I was there and I felt like it was an effort and I like to feel a little rewarded about that I've done a good job that I have done something and I got nothing from him like he even knew anybody else was in the room. And uh so that to me was the most unpleasant situation.

E: And then so did you stop going?

I didn't completely stop but I you know kinda didn't go in very often and he did pass away. Yeah. I'd say one of the times I went in there he yelled and hollered and jerked ... well I don't know if I can say... but the catheter. And I uh and he uh and I uh I didn't tell his wife that but I say she she was a very pleasant person. I'd known her a long time. And known her a lot better then I knew him and uh. But that to me was not a pleasant situation.

E: Because you didn't feel like you

I didn't feel like I was doing any good. I felt like I'm wasting my time, my energy, my efforts and that there was no way that... you know if there was any recognition at all, I think I could have done it, you know been okay with it, and even going in to someone that has that is in a coma. When I worked over at {name of rest home} I had a man that came every day and his wife was, this has been years and years ago, way before {name of office manager} was probably actually a grown up. Do you know her?

E: No, I don't.

Well you need to meet her. She's just a very, she's a beautiful woman, very sophisticated lady. She was a college kid. She's always had a wonderful spirit and a good personality. Well anyhow, I was working over there and I went into there and this man kinda got to know me. And he went in everyday, his little wife just lay there frozen you know, and couldn't say anything and they had to turn her, they were really, the nursing home was really good with her because he was there constantly which helped and uh he went in everyday and read to her. And he brought me in there one day and I had come over to the side where she was (mocks position) like that and he introduced me to her but he was I think in a situation like that I think maybe she was comatose in a way. But maybe she did hear some of this. But the contrast I saw with her and him, you know as far as the other fella I was talking about, the VA. It was like no one was there. And I don't mean that she didn't really act like she recognized but she did kinda make eye contact with me.

E: Have you ever turned a patient down?

Oh yes.

E: For what reason?

Like I said the one where they wanted me to be her sitter. I did that. And uh when they've uh, in fact she asked me last week, her letter before the meeting this last week. Oh she called me at the house she wanted... there was a couple of people they needed sitters for and I told her, of course, I had so much to do.

E: Yeah with all those people (referring to participant's Thanksgiving Dinner of 30 people).

No, I haven't really, I can't say I have really turned a patient down. I am getting ready to turn one patient down and ask for re-assignment. And that is my bereavement patient and that is just kind of a personal situation.

E: What advice do you have for a new volunteer?

Go in there and be yourself and just you know I think try to be a blessing to people. I think you go with the attitude that you want to be a blessing to somebody everyday that that's a good attitude to have. And I don't know that I am a wonderful volunteer. I use to, when I first volunteer I use to do a lot of nails and that kind of stuff and run errands, maybe have bird houses out there I'd go in there and put bird feed in there something of that nature. I was usually doing something for them. But since I have been a hospice volunteer I have offered to write letters and uh but I haven't really done much of that. Well, I did do nails a time or two. That's not a normal thing. I usually just go in and chat with them. I guess I'm getting lazy in my old age.

E: No, no, no.

I am a really good gift giver. If I know someone I like, I'll check on my patient, like this one little lady I have right now, I say she's as sweet as can be and she cannot make a sense one that makes any sense, but she tries. And uh, I check on her and make sure she doesn't have any kind of, I'm getting way off the subject you were asking me what I uh

E: That's fine.

But she has trouble eating. She doesn't have much of an appetite and I have taken her like a root beer frostys and candy bars and that kind of stuff and I don't to... in fact I need to go in ... I may go in on Thanksgiving Day and bring her a box of chocolates or something you know.

E: Going back to advice would be to be yourself

Yeah I think be yourself and just try to be as much of a blessing. And good cheer as you can be. Be a lifting person and sometimes that's a little hard to do. But as I say it's good to be able to bring them up a little bit, make them feel like they are important. I think a lot of times the older people feel like there's such a separation between them and younger people and we get as you get older you get a lot of, I don't know if I am saying this right, with my son especially, how do I , it's an attitude like, I don't know how to put it. Like I

have to give you room because you are elderly and can't think straight. Do you know what I am talking about?

E: No.

Well, I say my son. One time, not too long ago. Now I have a really bad habit of this, I start on one subject and wind up on something else. That's not good concentration. And he'll say, Mom you always do this, he'll say it right in front of his wife. You always start off and nobody knows what you're talking about. And I thought "Well I'll tell you what you little whipper snapper you just need to learn how to follow a complex conversation." (laughs). But this is.... I get... well I have one friend that is 85 years old, I mean she's just a friend, and she goes to the same bible study I go to. And she is sharp as a tack. But she talks about she has a younger neighbor who will come up and put her hand on her back, "Are you alright?" She said, "why do you want to know?" So you know it's kinda condescending like type thing that we get as we get older. And I think that you know that sometimes people make you feel peculiar and the older you get people make you feel like that. I think we need to have more respect for the elderly. Especially the older I get I want more respect (laughs).

E: What does volunteering do for you personally?

I think that I feel like that everybody should something in this world to make it a better place. And I say that's what I, you know that you go out with this idealistic thing and you run into this campaign for something else and it kind of throws you a little bit because you have this... I really do I feel like people need to really reach out in their communities and be part of the community and make it a better place. And I say I don't know any other better way to do that, now its not the only thing I do. I took five or six reams of construction paper to the school but anytime I can find something, You see I am a really giving person and I say sometimes I give to the point that I am probably not real practical with it and I really like you know giving my time to something that is rewarding is, you know to feel like, I don't think its so much that I feel like appreciated as much as I made it a better day for somebody.

E: What are your thoughts on meeting a new patient for the first time?

I think it's you know I really kind of when {name} told me, when I got this lady recently uh about July I guess. I do make specifications about what I want. I really prefer to have someone, I told her I want healthy situations as much as possible. You know that's real hard for a person. But you know this lady is real sweet and uh how I feel when I meet them for the first time is....

E: Do you call first?

It depends on the situation. If they are in a home, yes you call you don't just drop in or you have a regular set schedule to show up you don't ever just. Now with the bereavement I have, the daughter, now I say she works at {xx} and every once and

awhile I'll just drop in to her office and I have dropped in in the past. I was going out to the Vo-Tech one day to pick up my grandson, which is the only time I've ever done that, and she was there and I dropped in for about five minutes and said hi and that I was thinking of her.

E: When you go to meet a new patient for the first time do you get nervous at all?

Not really nervous. Uh I like to find out a little bit about them as far as. I like to talk to the staff. You want to know if there is anything you should be watching for, like don't bring them sweets because they're diabetic, something like that. And but I ..

E: What are the main things that you are most concerned about knowing?

I think I like to know... gender is a big issue with me. And that's my own personal thing. I'm just kinda really withdrawn and like I say I have been groped a few times and I just don't really care about that at all.

E: Type of disease? A big deal?

No. In fact that is one of things that the volunteer coordinator asks when you know... if you've had... they even ask you about HIV. And I would be I think I would be a little bit unnerved by that but I don't think that it would be a no. I don't particularly care about bodily fluids as far as people that are you know uh you know like they are vomiting are something like that. If they are sick I don't want to do that. But now as far as, but with the other lady, of course I changed her diaper and everything. That was a hard thing to get used to because you know I am not trained and I had never been used to touching a woman and you know that's a big chore cleaning a woman up, probably a bigger chore for a woman then it is for a man when they you know. And it's a very prolonged undertaking and this woman, the one I liked so well, she had worked for other people. She knew exactly what to do to help you out, as far as you know the way she arranged .... When she actually come to the bedroom. And I say sometimes... well I got in one situation where the woman was, you know I would clean her up and she would just keep on going and I'll say at that time I was, this was the first time I had never done anything like that, and I thought I'd clean her, I got to the point, you know you really have to clean those people up good, and I say they keep on going on you, you may be there an hour cleaning them up. So that's a little something as a volunteer I wouldn't do that. Our part would not come involved with anything like that. Now as far as emptying the ___- bags that wouldn't bother me.

E: What about age?

Age? Wouldn't bother me.

E: When a patient made an impact on your personal life – would that be your special lady?

Yes, I think so. Uh some of them. You know I have volunteered at {name of rest home}. I had a lady that really was attached to me and I was not attached to her. She in fact, this was so funny, cause I spent a lot of time with her, she'd come up and bring me back to her room and we'd sit there and just chat.

E: She'd come get you?

She was very possessive. She would take away my time from... well I talked to [office manager] about that. Well there was one lady that died that I was very sad about, there, that was just as sweet as she could be. But this woman even though I spent a lot of time with her, I guess they thought I would be very upset, and it didn't bother me at all, she passed. But uh, you just, it's just certain people that you just feel like, you feel very tender towards. Of course now in their personality

E: Do you think time plays a factor?

I probably got to know her better because I spent so much time with her. Uh and I say that, of course I couldn't have known anybody better then I knew this other lady because I changed her diaper because I loved her and so its just a blending of personalities and spiritualities or whatever you want to call it. I loved her because she was just plain people, there was nothing pretentious about her. Uh she was you know there was nothing fake about her.

E: How do people react when you tell them that you are a hospice volunteer?

"How can you stand that!" I just tell them, boy you know it's really a very fulfilling thing to do.

E: Do they steer clear of you?

They don't think I'm weird.

E: Do they ever ask you to share your experiences?

I think I have done that but not because they asked. Not really specifics but you know...

E: What are your thoughts on your own death?

Well I think we always like to qualify that, like it fascinates us, but you know you know from experience watching other people that sometimes illnesses will be prolonged. And if I could specify just give me a heartache like that – but I think you know we all don't get out of this alive and I'll say I think I've learned a lot about maybe, of course some of these people are really sick, but I think the fact that you can stay yourself and be a real person and be just straight forward and honest with yourself and honest with other people. Uh and I don't if that's making any sense to you or not but uh that's a real idealized to me to be able to go to your maker being who you are. You know and not be a

self deceptive or deceptive person to other people and having a you know, like manipulate, and I probably unconsciously do some of that but I don't like to manipulate, I don't like to be manipulated. Now I say I think that's a... as far as my death I hope its going to be a easy but who knows. I have had cancer, breast cancer, and I , when I got into that I really was not given a lot of hope by my oncologist. It was kinda just like we'll have to wait and see and uh I of course I was taking, I had the type that they pumped in me over 24 hours so I had to take a pump with me in a container that pumped into my port and I'll be real honest there were times that I was so sick that I could care less if I lived or died. It was just not... it was just up to the good lord you know whether I made it or not. I just didn't care. You know you just get that sick. You know that wanes and then it ebbs because it depends on your chemo and I'd be sick for a week and it was every three weeks, so with that... of course I had really bad experience as a kid. I had an older brother that died. I was ten years old and I was forced to listen to how much pain he went through. My father was very not sensitive to us as far as what he told us and I say he was the oldest and I wound up being the oldest when he died. It was very difficult. You know and we had to view the body and my younger brother was 7 and my sister would have been like about 4 at the time he died. She of course remembers nothing about it but he does.

It was a very difficult time. I think it made it hard about me

Transcripts~Participant 4

E: Can you tell me how you got involved with hospice?

Well I think what lead me to get involved with hospice was my interest in my volunteer work at (name of hospital) back in the 80s. My mother died as a result of Leukemia which sort of fueled my interest in the field of cancer, chronic and terminal ailments. And uh I was working full time when my mother died and then when I became a volunteer, we were treated so well they were so kind to her at the hospital that I thought one of these days when I get the estate settled and all that I want to do something to give back and to return. So after all of that happened then I saw an ad in the newspaper that said we need volunteers. And I approached the volunteer director at that time and she didn't have anything available in oncology, they had never had volunteers in oncology. And I told her that's where I really wanted to be placed. So it took awhile for her to work that out for me and I was there for over 4 ½ years, still working full time while I am doing my volunteer work on Saturday mornings. And then I changed jobs and went to work from the city to the state and had more responsibility there, gave up my volunteer work for a time, and that was okay, that was in 1991, January 1991, and that's when hospice of OK County first began. And I really wanted to do that, in fact I called for an application form, still have the application form in my file, filled it out and thought now I don't really have time to devote to being a good hospice volunteer right now so I'll put it on the back burner. Which is what I did. And you know, that was '91, I retired just a year ago uh in June, which was 2002. So one of my goals in my retirement was to connect with hospice and become a volunteer. And so I promised my first year retirement to my husband because I had taken a lot of my time away from him with my job and so after that then I just uh I called the volunteer coordinator up and said hey I have an application form. So anyway I went through the class in July and um then became effective as a volunteer in August. And I've had two patients so far. I still have one.

My first patient was a good friend of ours. He was in our RV group and I was able to be her hospice volunteer which was really precious to me and then she passed away in October and so my little hospice patient now is a little, she's almost 94 years old.

E: Is this the one having a birthday?

Yeah. I saw her last night. And she is in an assisted living location in [name of town] and I went to see her last night for about an hour. She is just delightful. So um that's all of it.

E: Do you see them weekly?

Yes.

E: How many hours?

Now with my friend Dot who died I would be there up to three and four hours a week. But with {name of other woman} because she is in assisted living environment usually I

don't spend more then an hour with her. And recently the volunteer coordinator gave me the information on her and she said it was just occasional visits but its become like I really need to see her you know this week, every week

E: But you do?

Yes, and she too! You know we just have bonded. Now this is interesting, her daughter, her only daughter and she is adopted is 55 years old. And she lives like in Plano, TX, somewhere around Dallas, is a single woman, has been married and divorced a time or two with no children, and has cancer. Some sort of lymphatic cancer. She says its right here and its not lung cancer. So I don't really know she can't really interpret it well enough to tell me what the diagnosis is but she is undergoing chemotherapy. So there her daughter is all the way down there by herself, she has friends, and then here is {name of patient} up here by herself. But they made they pact whenever she moved her mother out of the house and sold it that you know she wouldn't be able to move up her and care for her and that was okay but she was going to place her somewhere where she would be well cared for. And so this woman is okay with that. That's fine, she understands. Her pain is that she cannot be with her daughter.

E: At this time?

At this time, right. But you know she's spiritually very strong and she just has a lot of faith that god will take care of all of it.

E: Can you tell me about your first assignment. Were you nervous?

No I wasn't because you know I knew these people they were friends of ours. And I had one situation early on when I went to visit and that was the husband was going out to do his errands and leave me with the patient and he left her medication and everything right there. I mean some of it was, oh what was it... a very strong narcotic I always want to say opium but it's not it's for pain... anyway he left it and he told me you know now I have just given this to her but if she needs another dose she can have it. And I said okay. Well I hoped and prayed I wouldn't have to give it to her because you know I can't do that. They can measure it out and I can give it to the patient and the patient can take it. But I'm not to administer medication so I was a little concerned about that. I told the volunteer coordinator about it and the next time I told the husband that I could not physically give her medicine. Now if it was pre-measured I could hand it to her and she could take it but I was not to administer medication so we got that worked out and that was the only thing I was concerned about there.

E: And then your second patient – can you tell me what it was like when you first met her?

Well, I can. She's pretty much bedfast. Uh and she was uh oh kind of distant at first, I tried to warm up to her. You know it was kind of a social exchange. I explained who I was. I think she had a little trouble understanding that because the hospice nurse had been

in and then another administrative person like that, like three hospice people had been in and she couldn't, and then the other thing was that I guess it was her nurse was also a Wanda but she was black (laugh) and she's just darling, I met her there one time and so we got to know each other. And oh the patient just loved her, she said she gave the best baths I've ever had. And so now she's been relocated and is not there. But anyway she says, the patient says that you know the people there at {name} are so good to her. And the hospice people are so good to her. And I'm always taking her chocolate. She loves chocolate. Last night I took her, I don't know if you've seen these bon-bons at Walmart, in the bag with the gold foil, well I introduced her to those last night and she (whispers, I'm not sure if she can have them) well I gave her one and she had never had one. And they are chocolate on the outside and then they have a little wafer thing and then inside that is a kinda a peanut butter thing and they are really yummy.

E: So she enjoyed those.

She did. She asked me to hide them for her. So I did.

E: Tell me about the time that one of your patients died.

That would be {name}.

E: Were you there when she passed?

Oh no. She passed away at about 2:30 in the morning. Um so I knew that she was near death the last time I was there.

E: Tell me about that.

Uh she uh You know when her husband would leave she would always say she wanted something to eat but she wasn't even really hungry so you know that's one of the symptoms. And her medication was there and she would sleep most of the time and usually she would be up in their family room sitting up with her feet propped up and had a long oxygen tube that was attached to this big unit. And the tube was long so that she could get up from where she was and use the bathroom without having to you know wind it up or anything. It was just long enough to allow her to do that. And she slept most of the time but when she did get up she would like her back sort of rubbed because the cancer was metastatic, all over, she was having difficulty breathing and it seemed like when she got up and then settled back down that if you would just rub over her, it would help her, to settle and sleep again. And so I did that and she just did a lot of sleeping. Fortunately she passed in a very peaceful way. They told me that
You know I just lost a very dear friend she died on Saturday and we buried her last Tuesday.

Tells story of friends diagnosis - She had a malignant tumor in her colon. I really believe that she went undiagnosed for more than a year. I really believe that she had a brain

tumor because she was falling all the time. Her memory was just not like what it use to be.

But I saw her on Thursday and she died the next day. At the time her family had told me that the last few days she had been talking to loved ones that were already dead. And what was interesting, this was probably more interesting than my patients have been so far because I was able to tell them what to look for in those final days and hours. In fact I had my little book, did the volunteer coordinator give you a little booklet? Well I gave that to her daughter to read because you know I remember wanting to know with my mother what to expect. I had asked the nurses and they still couldn't give me any answers.

And then there was one nurse with my mother. She was an LPN, her name was Virginia, I'll never forget her. _____- and then she began to tell me this what to look for, based on what I've seen many times, she probably won't last much longer. And she was just right on the money.

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And later on with my friend and her family, that book helped me direct them to the breadth of it, that she was experiencing that her family couldn't understand that the book well defined for them. There is a lack of oxygen in the blood stream you know in the dying process and it comes _____. I was able to explain some of that to them and sort of help one of her sons who was not accepting what was going on with that and it really, and they told me later, how much the information did help them.

E: Going back to your first patient, did they call and let you know she died.

They called.

E: Can you tell me about your most memorable experience as a hospice volunteer?

With my hospice patient... um.. probably the most memorable experience was a week ago on a Sunday night and I had gone to uh see my patient and they had for some reason started setting the residents around the dining room table early that evening at the assisted living area about 3:30. And I had figured I would probably go for a short visit before they started doing it but for some reason they began early and so uh in that happening I got to meet some of the other residents and they were beginning to sit around the tables there. And there was one new little resident and she was just, I think she is probably pre, well I think she's got dementia, but probably pre-Alzheimer's type. And she was just so despondent and she was in a wheelchair. And she had met my hospice patient who had encouraged her about her stay with the living location as she's not feeling well about it. And so I got to meet some of the others and we sort of formed a little support group for her, uh the other residents and my patient just kinda formed a little support group. And it was just such a good feeling. They were all trying to help her and my hospice patient was so encouraging and we just hugged and bonded and it was really good. I came away from that just feeling so good.

E: Tell me about a bad experience.

I think probably that would be with the assisted living home too. I met one of the caregivers there one evening and she was there late that evening off her shift and she told me that the pay, those residents pay an enormous amount of money for those rooms, and they only pay the caregivers the minimum amount with absolutely no benefits and so that made me feel really bad. And I think well you know what do these people look forward to? That may explain for some of the abuse in some areas and that whole vast world out there. Not necessarily in assisted living but I'm thinking more of the nursing homes.

E: How did the death of like your first patient impact you personally?

Umm well I could say that I will miss her and I have missed her. Um I

E: In other words, did you learn anything about being involved with her, being involved as a volunteer?

How precious life is, how precious time is.
How thankful we should be to know one another and not to be afraid.
We take it for granted the time we have left.

E: At a conference I went to it was reported that the average time spent in hospice is 21 days. It's a shame. I've read a lot of studies that say that death education is on the rise and however many people don't take advantage of what hospice has to offer.

And you know the volunteer coordinator covers that in her training. These various reasons why like they just don't know, they haven't been introduced to hospice, others are very proud and fearful. And denial, a lot of people are in denial. I have..

E: not necessarily the patient but the family.

Oh yeah. You know when I was a volunteer in the hospital I'll never forget one family there. The husband was dying of cancer. The wife was a very domineering strong-willed individual and she scared the nurses and doctors to death. She was afraid. She was the one who was fearful of this disease that afflicted her husband. She did not want to take him home to die.

E: So she was afraid of that.

Yep, they lived in a rural area out in {name of town}. He wanted to go home to die. She did not want to take him to die because it was just she and her son and her son was a teenager and uh um she did not want to do that. And so because of her fear and anxiety about his condition she gave everybody just unmitigated hell. So that was real interesting.

And then I recall another negative experience at the hospital. Cause I was there four and a half years so I got to know a lot of people, patients and employees. But um there was a young woman who was dying of cancer. She was probably early 20s and she came from a very fragmented family and she hadn't seen her dad in years. And so when I approached her, as a volunteer on Saturday mornings and exchanged pleasantries with her, she unloaded on me about her family. And she said I don't ever want to see him. And so I tried to...I said look I am very sorry about that. You know I wish there was something I could do to tell help. To release some of that anger. And you know she said oh you just don't understand. It's just been a horrible life. And so you know I saw that. I understood later that she did have her mind about that and her dad did come and see her. I was so glad to hear that.

And then there was another situation with a patient, it was a guy who, _____. And you could tell as one entered the room that oohhh he was crippled. He was really angry at everything, the world wasn't there. To put it mildly he was just _____. And so you know I don't take those things personally. So I went in and gently introduced myself and asked him if there was anything I could do, bring him whatever. And he says what do you care? What's it to you? I'm just here as a patient you don't have to bother with me... blah blah blah. Well anyway we struck up a conversation. I just said okay let me have it. You're angry, let me have it. I won't take it personally. And he did. And you know later he thanked me for just allowing him to unload. And you know in my work and in my maturity in the past, I recognize that when people are angry and spout off at you it's not to you it's at you. And its not personal. And they just need to vent and once they vent it's just like they unravel and everything is okay. So I've learned not to be real sensitive about the anger stuff but I am sensitive to their needs. And the sensitivity to their needs that I view there is that they just need a sounding board. And that is it.

E: Have you ever been in a position to turn a patient down?

No.

E: Reasons why you would turn a patient down?

Oh, well we talked about this in class (referring to her training). The only reason I would turn a patient down I guess is if they were just some sort of bi-polar and you know. But then the volunteer coordinator has assured us that they would never put a volunteer in that position. I can't think of any reason why I would because I enjoy a challenge.

E: Okay. Um what advice would you share with a new volunteer?

Advice I would share... well I would just bless them so much for choosing a pathway um . I think some of the most important advice, at least this is what I hear from a lot of people, is they just need to be good listeners. That's not just in a volunteer role. That's in everyday life. We all need to be better listeners.

E: What does volunteering do for you personally? What do you get out of it? Why continue to volunteer?

I love to help people. I love to give. I believe that in giving to others you also are serving God. You're not just.... _____ and I think I have been endowed with that sort of spirit. It's important that we do appreciate the gift that we have and to share them with others.

E: What are your thoughts on meeting a patient for the first time? Have they changed from the first patient?

Well she did call me about Geneva. She said that I would enjoy her and that she's there and she's just somebody that I could see you enjoying being with. So then you get your information sheet usually in the mail or the telephone call and then I always feel anxious at that point. Not anxious anxious but excited about going to meet somebody new. I love being around people. Uh so I am always interested and my curiosity is peaked about who they are, what they are gonna have to say, what kind of needs they have, how I can fulfill their expectations.

E: You didn't call her first because she is in a nursing home. Otherwise you would call first?

Oh yeah absolutely.

E: So when you went to visit her you were just anxious to meet her and find out what she was about.

Yeah.

E: You just went in and chatted with her, introduced yourself?

Yeah. And I always ask if there is a special time of week they'd like me to come. Special time of day, is there anything special that they would like me to do. I do windows and toilets, too. But oh uh you know in an assisted living situation environment its just totally different than the home.

E: But with your first patient you had known her so you just called?

Yes, and it was interesting then because I knew that they had called on hospice. Now let me back up here. She had been struggling with cancer for 9 years. And a couple years ago they had hospice out there because she was not doing well so hospice came out. And then she got better and so {name of patient} told me jokingly she said you know I just had to fire those hospice people because I was just wasting their time. And so um she got better and then uh she took a turn and they called hospice. And I knew that they had called hospice. And so I went to the volunteer coordinator, this was after my training, and I said I have a friend and they called hospice and I really, if there is not a problem with

that, I really would like to be her volunteer. And I said I would prefer that you call and visit with {name of patient's husband} to make sure its okay because I know, I knew, they were very private people. And I did not want to invade the privacy, if that was the case. And if that was the case it was fine with me. I understood perfectly. So I said to the volunteer coordinator will you please make that call because I think that ...I think it would be better if you called rather than me. And so she did and now that was fine with them. And so that worked out very well. And so I just established...

E: And so you just went over after the volunteer coordinator called.

Well no then I called. I called and talked to the patient's husband and I said I would like to come, what is the most convenient time of day to come. And so we worked that out and I went to visit him and her and we worked out a forthcoming time of week and day to visit. And so I would go and sit with her and we would talk or I'd rub her back you know watch TV or whatever. And he would go out and do errands which was really helpful to him. But they had a daughter who lives in {name of town}and she would come up once a month and stay for a week. And they would cook and put food away in the freezer and so she provided a good lot of care giving for that week too. So they wouldn't need me when she would come.

E: Tell me about a time when a patient may have impacted your personal life?

Um well I think I did sort of answer that because it has such a great impact on your personal life when you see people who are struggling. And it makes you stop and appreciate your wellness, your family, and the time that you have together.

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We all have a tendency to do that. You know we go along life's highway and nothing happens. But then you hear about others who have been approached at an early age with a chronic illness and a possible terminal illness at an early time in their life and it just takes you back. So

E: How do people react to you when you identify yourself as a hospice volunteer? Like in casual conversation....

Oh this is real easy. Oh they're taken back and they say oh I couldn't do that. You must be a special person to be able to do that. And I say well I don't know that I am a special person but I know that I I have a I feel like I have a gift of being able to do that. But you know they really are taken back.

E: Do they ask any other questions outside of that? Are you ever asked to share your any of your experiences?

No and I am very careful with that too. If they aren't interested in hearing about it that tells me a lot about them. And the fact that you know they don't have a comfort level with death and dying and they don't want to know about it. And so I don't but now if you

are interested then I will just on and on and on because you know it is so important and I don't know why people are so reluctant and so fearful of death. It really can be a very beautiful time in one's life and uh it's going to happen to all of us. None of us are going to survive it. Uh and uh I can't understand why people don't want to know more about it... don't want to prepare for it. Because in doing so I feel like that it gives them a better quality of life if they do. A better appreciation...

E: What are your thoughts on your own death?

Well I am looking forward to it and I am not a suicidal sort of person. But um I'm just I know that this is gonna happen and I want it to be special for my family. I want them to understand and appreciate the process. I am not fearful of it at all. I think I will be going to an absolutely beautiful place.

E: Do you think your involvement with hospice will help you achieve that?

Absolutely.

E: For your family, too?

You know I have some in my family who don't wanna care about it or want to talk about either. And I hope to be able in time, at the appropriate time and places, be able to share some of my experiences with them, in terms of patients as well as my own thoughts and feelings about it.

Transcripts~Participant 5

E: Can you tell me how you got involved with hospice?

Well, I am a 25 year cancer survivor and having survived it at the time I was lead to think about some friends who didn't survive the same illness. One younger and then one older both in a coma and both did not survive. I know I survived because of a lot of prayer from family and friends at two different locations. And so when I survived I asked the question why. Why me? You know so I figured God had some plan for me and I better find out what it was. So hospice over the years has kinda been on my mind but its been over 25 years since my illness and it took me a long time to be able to confront ever talking about it, it took me years, two decades before I could even do that. And uh also one of the friends that died I couldn't pitch in and offer support because it was too close to my illness and my wife did a lot of that and I always felt kinda guilty about that. The second one I was able to provide really good support and then later on in life um it was kinda in the back of my mind, {name} who was an employee of hospice, came to a church discussion group and talked about hospice. And so that tipped me over. I knew more about it and I was ready. That was about four years ago.

E: What is your current level of involvement with hospice?

I'm a volunteer. I have one patient. I see the patient once a week and I attend the monthly meeting of volunteers and the social events usually. And, that's it. I am not an office worker, I don't like the office. I just want to go see patients.

E: How long are your patient visits?

I'd say 15-30 minutes. And I specialize, I like structure and so therefore I go to the nursing homes.

E: Can you tell me about your first assignment?

It was exciting. I went through the training and then very shortly after that got my first assignment and I was excited. It was in a home and the man had cancer. And uh his wife needed respite relief, she needed to go to a movie or something with some in-laws and so I went over there.

E: Did you call first?

Well we yeah we set up an appointment. I called her and uh she told me what she wanted me to do and what time to show up and I did and she introduced me to the patient and it was fine. She went to the movie. The one complication was that he needed to get up to use the port-a-potty and he needed help so I helped him but we're really not suppose to do that. We are suppose to call nurses but it wasn't practical to do so ... sometimes you just have to roll the dice and hope no one falls.

E: Were you nervous at all at first?

Not really cause I had already gotten some caregiver training through my church and had also been a volunteer for the American Cancer Society. So I had already been out and to see people already in one other sequence of events. So I had done it before and uh I am very good with people. And I mean I am very good one on one and know it and so I am confident about those matters and I just feel like I am in charge when that kind of thing comes up. I'm the volunteer, I'm the healthy one, God's my co-pilot. I'm just not _____.

E: Were you there when the patient died?

No. I got a call. That's usually the way it works. The director of volunteers will call and say this person died and sometimes I'd go over to the family. I don't always. I just kinda play it by ear. But not that time.

E: How long did you see the first patient?

Two or two and a half hours, long enough for her to go to a movie.

E: No I mean over how long of a period?

Oh it was only I think that was a one time deal, a one time shot.

E: Tell me about a time when one of your first patients died.

Oh.(long pause). I recall one patient that I was called in late in the game. She was a lady, terminal, in a nursing home, with cancer. And I saw her several times and uh then toward the end I called in for respite care just to kind of to be there to so the family could leave the bedside and uh had some support on that. And uh I am able to handle that okay because any hospice volunteer knows that you have to hold back a certain portion of yourself. You give care and you give concern and love but you have to hold something back and give just too much of your heart or your heart will be broken constantly over and over again.

E: So tell me about this time when one of your patients died.

I handled it. I knew she was going to die and I was there just to provide respite to the family.

E: Was it just you and the patient?

Yes, she was comatose and drugged with pain killers. And uh I have not had problems in that regard. I know it's going to happen. In fact I have had two patients taken off rolls, who didn't die. One, another nursing home here, a stroke patient and I kept going to see him and see him and he'd eat and eat and he couldn't talk much because of the stroke. He was alert and I could elicit some responses out of him. And he just kept getting better and

better. And they took him off rolls – he was no longer eligible for hospice because he was not dying within six months. He was not certified by a physician to die in 6 months and uh this last one that I had, another nursing home. He didn't go like they thought he was going to. Which I think is great (smile).

I think its coincidence but some part of me you know -------. I'd love to see it happen. I'd love to see everyone one of my patients get taken off rolls but I know that that's not going to happen. It's the exception.

E: Tell me about your most memorable experience as a hospice volunteer.

That's difficult. I suppose that some snapshots. I was nervous when I had to help that patient from the bed to the port-a-potty because I knew, now that was my first patient, I knew that I was really violating the rules. And I was nervous about that but I was careful and uh that was one moment.

E: Its memorable cause you were nervous.

I was nervous yeah because I don't like to break the rules. The rules are there for a reason and theres litigation issues and you know. Ummm

E: Would it be better if I asked for you most memorable patient?

Umm. Let me think. Um well I think it's the one I got right now.

E: Okay. Tell me about it.

He's an Alzheimer's patient and he's 87 at {name of home}. And uh I was expecting a patient like the last one which was kind of non-communicative you know he didn't make any sense. In fact I wrote a poem, I am a poet also, and I wrote a poem about visiting an Alzheimer's patient and uh he was the subject of this poem. You know you say something and they answer it from somewhere else, I mean they are in another world. It's different and the last line from my poem is he answered with a sliver of wit only he could see. So uh I was expecting that kind of situation, but no uh this guy

E: Well tell about when you first met him.

This one, the one I am with now?

E: Yes.

Probably, let's see I've only been seeing him about a month, about a month ago or so.

E: And since he is in a nursing home you don't call, you just go.

You just go. That's why I like nursing homes. I like being able to show up and see him. And usually they are sedated so usually I can only catch him at lunch. Which is always interesting cause one the challenges of this, going to nursing homes, there are pluses and minuses, is that frequently you gotta catch him at the café, the dining hall. And the problem there is it's like a zoo. There is always going to be one patient, or resident, that is what I call verbally distressed. I mean there is a shout coming out of their mouth every half second. Every half second. And you are over here sitting at the table and uh there's that background of that, eating on you. And you are trying to communicate. And when I sat down and introduced myself to him.... He's blind, and so I ... this is going to be a challenge. He's blind and then...

E: You knew that though from the paperwork?

Oh yes, you always know when there's anything exceptional like that – they say you're dealing with a blind Alzheimer's patient that is 87 years old. And so you know, I really expect a challenge. So I introduced myself and he said oh, tell me again your name. And I said... and then we were communicating instantly. He was not.... He was cogent from the get-go. And so we have conversations. He's slumped down you know and he's blind and I but his mind is sharp. So I was really pleasantly taken back. Uh and so this whole experience with him I would have to say it's my most memorable.

E: Why?

Cause, I am able to communicate. See that's the whole point. I thought when I began my experience as a hospice volunteer that my experience as a cancer survivor would be relevant and that we could use this. Nothing could be further then from the truth. Cause the whole point to being a volunteer is to elicit communication from the patient. The volunteer is totally irrelevant other than being vessel to pull out and communicate from the patient, the patient outward, not from the volunteer inward where you give them these pearls of experience. They don't care. They don't know. They are trapped in this shell, in this cave. And frequently the only human outside contact they have from aside the staff is the volunteer. I mean they are where housed. People where house these people. And they never, they have relatives but their relatives never come to see them and so the goal I mean instantly was to reach them and to get them to talk, however, you can do it. Uh so when I was able to elicit immediate conversation from this fella I said oh thank you thank you.

E: Was that fulfilling?

Oh very fulfilling. Very fulfilling. Because then you're doing your job and you feel good walking away. Now it's a challenge because of all the chaos that's going around you but that's the price I pay for having the structure I want.

E: And the structure is in terms of just being able to stop by?

I know the patient will always be there. I know I can go at the time I want to go. I know there will be no weird relatives around. There will be no barking hounds. It will not be in the middle of the boonies. It will not be in {name of town} or wherever. Uh my patient are 9 –5, Monday through Friday, in [name of town]. It's in my chart, they know it. The volunteer coordinator is very good about it. They'll always.... I like to joke I specialize in lonely old men in nursing homes. And uh I figure someday I'll probably be one (laughs). So I am paying some dues in advance. I just am a structured kind of guy. I don't like surprises. Do not like them, don't want them. Okay that's well and good. But the price I pay in the nursing home is that usually they are gonna be asleep in their room. Now I have visited them in their rooms but it just seems to work better out in the dining hall. They're alert. It's just the one time they are alert, they are not drugged and uh whatever. But you are gonna deal with the X-factor of the noise and the weird... and it's draining, it's hard. After 15-30 minutes I am out of there. I can only take so much. I'm a normal human being. That said um it's really nice to get to lean down and you just try to think of anything, say anything to get a response and I am getting a response out of him. Whereas the previous one, there would be some response but it would have absolutely nothing to do with the question cause he was in late stage dementia and uh so he got, there was something going in, which elicited a response, but it came from outer space somewhere which is the tragedy of Alzheimer's, its just a horrible disease. We should never have to go there, that and a stroke, are two ways you don't want to go.

E: How did your experience with this patient impact you personally?

Uhm. It's fulfilling that... it makes me feel more at home. Which is why we volunteer, I think all of us. I think we get more out of it then the patients do. I think if you interview the volunteers they would all say the same thing – that uh we get more out of it then the patients. And you have to experience that to really understand us but civilians. Civilians is what I call people who are not hospice volunteers, are not in the game. They're civilians, they don't have any clue and most of them don't have the stomach to do what we do. But uh anyway it's just you walk away feeling better then you did when you walked in and I think about it sometimes and say "But for the grace of god, go I." And they are just where housed. They are trapped over there. And he doesn't seem unhappy, that's the interesting thing. Sometimes they are content, they are resigned, it's a combination of resignation and contentment. This is their lot this is where they are. Their family is... most people that serve um and the nurses and uh whoever they deal with that is their whole life plus the one person that comes in off the street once a week and that's me. So that's important. I mean it has to be an improvement in their day to change somebodys actually cared enough to walk in

E: and visit

And of course they kinda forget from one time to the next. But he's seems to be a little more cognizant of the fact that I have been there. The one before it was a new adventure.

E: each time?

That was the first line of the poem I wrote – "he never knows me." That was the first line, because they don't. I mean that's most of time. They are living totally in that second and every second is a new second. So

E: Tell me about a bad experience.

I'm not sure I've had any because I have been so structured. If we have to... can we take in the administrative side of things?

E: Yeah or whatever. Sure or with a patient....

I'm not sure I've had any bad experiences with the patients. Oh well there was one disappointing kind of situation. The patient was in a nursing home, he was on old guy, he was kind of incredulent type of reputation. And uh he uh he would not he could not communicate at all. And so uh it was strictly me trying to do something worth while. And so I read bible psalms to him, and so uh I'm not sure how much he appreciated it. He was kind of a ...I don't know how to say it... he would occasionally talk to the nurses but he would always be some difficult person or so.
I'm not sure what kind of background he had. He may not have wanted to hear psalms but the psalms did me good. And I had never read psalms before so I said this is a good time for me to read psalms and so I read a lot of psalms. I got something out of it and uh... I don't know how much he did. It was not so much a negative experience you just didn't know exactly how much good you were doing for that particular patient from the patient standpoint. I haven't had any bad experiences. I have been somewhat, what's the word, surprised at the many changes that have taken place at the hospice office. It seems to me that in the four years I have been there there has been a lot of turnover. I must say that I feel like they have been understaffed, underpaid, overworked, and my feeling, and nothing is going to back to them right, I think that I have just been under the impression that there's been some chaos over there for monetary and administrative reasons. And I sense some frustration at the volunteer director level, overworking, a lot of change, and turnover, a lot of turnover of the volunteer director.

I have been universally impressed with the directors of volunteers they are really really special people. They like to go see patients themselves and yet uh I think in the last instance the volunteer director wanted to go out and see patients and they just changed her job description around to the point where she couldn't really go do that. Now there are certain reasons that they have to do things administratively to make things more business like. I felt sorry for her because she really wanted to go out and make contact with patients and couldn't. Uh but they were all good people. They all have strengths of their own and um I am real impressed with our current volunteer director. She's um really a trooper and effective at what she does. It takes a special kind of person to be the director of volunteers in that setting. Well I think everyone is underpaid. I think also I have been disappointed in the lack of public knowledge of hospice. It's an extraordinary misunderstanding. The biggest surprise I have ever gotten was when a family that I know of a good friend requested me as a volunteer, terminal from esophageal cancer, and an educated person, a very educated career kind of guy. When I showed up he said well I

guess this means no more water and food and I just my jaw just dropped. Here was a guy, an educated guy, didn't know what hospice is, that we were there to give palliative care and support and not kill him. That, I will never forget that as long as I live. I knew then that we've got to educate the public. There was a wonderful series, Bill Moyers, I have seen most of that and that was probably one of the best things ever done. But see most people don't watch that television and uh. The job is not getting done to educate the public on the basic services of hospice.

Well first people fear death and dying. They don't want .... Our society.... Death and dying is not in. Sex and vigor is in . Society does not want to deal with our mortality and so consequently that's a bad deal for hospice because hospice is all about death and dying. But people don't understand that death is a continuation it's a continuation of life and you have to be kind of a religious person to understand all that. But it's a young persons society and yet there's more and more elderly people and therefore never have we had more of a need of the understanding of death and dying as the population ages, the baby-boomers, etc. I don't know what's got to be done but some kind of national effort needs to be made. The president needs to declare a national hospice week or whatever because it is simply not getting done. When you have educated professional people at that level misunderstanding then we just, we are in a world of hurt in terms of the... so that's... the biggest disappointments are outside.

E: Have you ever turned a patient down?

No. My requirements are rigorous and clear that the volunteer directors all know that. They just don't call me. Patients I've turned down has never happened, never will happen. I turn down office work all the time. People just didn't understand its not in my chart and call me can you come down and file for an hour – NO. I 'm just not gonna do it. I've got my time to spend in other ways.

E: What advice do you have for a new volunteer?

Okay first of all....Soak up every bit of that training that you can. Actually my training it was only about, it seemed like it was only about 3 or 4 hours on a Saturday morning. Something like that. The training was it was barely adequate. I mean it was adequate. Of course I was benefited already from having caregiver training which was huge it was 10 hours of training over there. And then I had previous experience just as an American Cancer Society volunteer. So I was ... had the benefit of having had some training before I went over there. I'd have to say though that the training at that point was barely adequate now its been rigorously increased I think.

All of it is just kind the person who walks in the door. It takes a special kind of person and they are gonna take whatever training is there and then its just common sense, a lot of it is common sense. Uh what was the question again?

Okay so first of all really really soak up your training. And then I think probably you know I didn't have this I think I would go with a trial run and I think that they do that...

E: You didn't have that?

No I didn't. They didn't have them at the time. And I didn't so much need it but I can see where one of these college kids comin in, we have a lot of college kids. And you know there is a big difference in common sense and just course sense..

E: And with age.

Age! My god, I was like 58 years when I went over there. These people are like 19 and 20. They don't have a lot of experience. So uh I'm gonna say, especially for the young ones, they need to know about a regular volunteer, or one of the regular volunteers, uh visits for a time or three and then they will be fine. Okay that's the first advice.

Second advice is be a good listener. It's all about listening. It's all about the patient. It's not about you. That is the first thing I would say. Like I thought it was going to be about me sharing all of this valuable, applicable experience that I could relate to as a cancer patient. No not in the least. It's all about the patient and get them to open up – not you opening up to the patient. But figure out the way to elicit some response in the patient to open up to you. And that just takes some probing and it also helps to know a little bit you know something about their experiences or interests or ... they're there on the chart. Like the one I talk to now they said certain interests, well its good to now that. But just be prepared to do whatever you have to do to spark something in that patient that gets them to talk, if they are capable of talking. If they are not, then you're kind of on your own to use common sense and instinct to communicate in such a way that hope you are sparking something positive inside. And then finally it comes down to sometimes just knowing that they know you are there and you care. It may just come down to that. Just by seeing you you in your presence, that's good enough. So you just check your ego at the door, check your life at the door, become a hollow, empty vessel when you walk through that door. It's not about you at all. You just you just have to put yourself aside and say what can I do to make a difference with this patient today. Every time. That would be my advice. That would be the advice I would give. Be patient oriented, be a listener.

E: What does volunteering do for you personally? Why do you continue to volunteer?

Because it nourishes me, just like my poetry does. It makes me feel worth while. You become the closest thing to an angel on earth. It's the closest you'll ever get. Because you are doing something special, you know you are, every time. Because these people are incredibly lonely. They are incredibly lonely and you are their angel. Even if its only 15 – 30 minutes you are an angel and you're gonna be there every week, four times a month. More when you get into terminal situations. So it just uh fills you up and puts things into perspective for me. It puts the little things in your life into perspective. You know getting stuck in traffic jam, having an argument with someone that is healthy and a loved one and how trivial these matters are compared to what you just left. Compare your life to a life of utility, frustration, pain. I mean its another world over there, those homes. Just walking

into one of those nursing homes, its an experience. There are a lot of people who just won't do it. It's like a war zone. It just makes you gratified and thankful for what you've got – your health and your mind and the ability to get in to the car and go to your house or whatever. It just makes you so... it grounds you as a human being and keeps things in perspective. Don't feel sorry for yourself as much. Or if you do start feeling sorry for yourself correct it very quickly with one memory from the last week. Okay do you really have it this bad compared to.... That's why we all do it to be honest. We're helping them sure, but we are really keeping ourselves grounded. Plus there's something about getting to play an angel for awhile. I think we all got a little of it in us. I think that every hospice volunteer, if you really scratch'em hard, they would admit that they feel like that uh God's touched them a little bit, given them a little bit of an edge.

E: What are your thoughts about meeting a new patient for the first time?

I'm comfortable with it because I know I am in charge. Now that may sound weird compared to what I just said but I know its in my hands and there again I am an unusual case because I am in such a structured environment. I've set it up. I don't have to be too uptight about extracurricular concerns like relatives and dogs and extra extraneous things that bother me. Uh I know that whatever whoever I meet I am going to handle it. God's gonna, with me. I am a very religious person. I am reading Rick Warren's Purpose Driven Life right now and its helping me. We are all put on earth for a purpose. It's a very powerful book... everything happens for a purpose. One of my purposes has turned out to be is to help people in this way, its kind of a ministry. Ironically enough I am not into organized religion. I am a member of a church and I go on Sunday and I go to the special. But I am not in a men's group and I am not a deacon, I used to be one at one time. I am not all about structure of organized religion. It just doesn't appeal to me. Yet I feel like this is my ministry. This is where I can really make a difference. And there are some guys over there that would not be able to do what I do. They do the thing at church, which has to be done, those things have to be done, I mean the church would fall apart if they didn't have some leaders doing what they're doing. But its just not my bag. I do this. They can't do what I do and I can't do what they do but it all works out in the grand scheme of things. If that makes sense. So that's the way I look at it.

E: How do people react to you when you identify yourself as a hospice volunteer?

Out in the lay? Well its very encouraging lately. I saw {name} over in the English department. She was at the gym and I walked through the gate and she said are you still a hospice volunteer? And I said yeah of course. And she said well and she gave me an experience. And they've all... increasingly theres more hospice stories around. People are finally getting the message and you are seeing more relatives and friends and she was... they always invariably say what a great experience it was. How much hospice made a difference for the patients and the family.

E: What about someone who doesn't know you are a volunteer and it comes up casually?

Oh let's see. Uh They usually ignore it, frankly. They might think, oh uh I don't know if I could do that. And there again you get that shadow, death and dying, hospice equals death. That's the way... that's the equation in the lay public. Hospice equals death and it makes them uncomfortable and it makes them change the subject. So I accept that. You don't want to cram it down their throats. I'm proud of it. I put it on my website. I just filled out some fraternity public thing on a web site, fraternity registration. It's one of the first things I listed, hospice volunteer, 25 year cancer survivor. You know make them think about it. Be proud of it. By talking about it, it educates ... just a little bit of education around here's a guy whose an OU alum, pretty sharp, hospice volunteer.. ..humm. Just put it in their mind. If he can do it, maybe I should. Plant a seed see if it grows.

E: What are your thoughts on your own death?

This is helps me a lot. Also it helps to be a religious person. And I think uh that God put me in front of this book, Purpose Driven Life, for a reason. Um I know now that we're given life for a short period and that all of it is preparation for heaven or hell. Everything you do and every decision you make is ... God's watching. Every trial is a test. I use to think it was Satan, that was the tester, but then I realized that it was God testing us, shaping us, that trials strengthen our character and all of this stuff is for... our character. And uh so I look at it that way as preparation.... What have I got 22, 25... my mother's maybe 87 my dad died at 86, I'm 62. I'm in better shape physically then most of my... even if I die at 65 that's only 30 years – so its out there and it comes fast. So I am just going to take care of myself so when the judgment day happens I go the right way. And heaven is what its all about. I don't even want to think about the other place. So life is just as far as I am concerned and Rick Warren is concerned, is preparation for the afterlife. So that's the way I feel about it. I am just preparing myself and hospice is one of the best things I do. It's got all of these pluses on the ledger to offset some of these debits I've got there.

Transcripts~Participant 6

E: Can you tell me how you got involved with hospice?

I work there. (laughs). So I wanted to.... I worked in the business office and I did payroll and I wanted to get more involved with patients, kind of a more hands on role.

E: Out of curiosity or?

Uhhh, well I am also a psychology major and so I was debating at the time on whether to go to a more counseling side of psychology or the research side and so I thought I would try that side to try to help me figure out that aspect. And I have a lot of experience with death in my personal life.

E: So it was an easy decision?

Yes.

E: What is your current level of involvement with hospice?

I mostly do respite care because of my school schedule. When they need somebody.

E: So you don't have a specific patient assigned to you?

Not a patient. I have been assigned to one of the nursing homes so when I have time I will just go and randomly visit any of the patients there.

E: And so when was the last time you did respite care?

Not too long ago. It was a month ago.

E: How often do you do it?

I would say once a month.

E: How long have you been a volunteer?

Since July (5 months).

E: After you did your training in July did you get a patient?

Yes.

E: Tell me about your first assignment.

Uh it was a female. In the nursing home that I go to. I would just go and stop in and visit her and she would never remember who I was.

E: Well tell me about the first time you went. Were you nervous?

No. I had known her through her chart. So I knew quite a bit about her before I ever even went.

E: Well tell me about the first time you met her.

The first time I met her she was asleep (laughs). She was on medication that kept her sleeping a lot and so I tried different times and finally found a good time that worked for her and me, which was kind of first thing in the morning.

E: Weekly?

Uh uh. She did not live very long. She passed away I guess right before school started.

E: So how long had you visited her?

I probably saw her about maybe 5 times and there was another patient that I was asked to stop in and see occasionally and I did that, in the nursing home.

E: Let me go back to your first patient, when she died, how did you find out?

Um, the volunteer coordinator called me and she didn't say. She said I need to talk to you about your patient. But you know having worked there I know what that means so I knew that she passed away. And she was reclining.

E: Do you remember your last visit?

Yes.

E: Tell me about your last visit.

It wasn't very pleasant. When I found her she was in the uh you know the room where everybody is at...

E: the cafeteria?

It was like a gathering room of sorts. And um she was spitting up, she had this handful of vomit that she was holding and I was trying to get somebody to come and help her. It took me awhile to find her for some reason, so I went and visited the other patient, so then when I found her the state that I found her in, it took me probably about I'd say 15-20 minutes to get somebody to help her with that.

E: Was she in a wheelchair?

Yes. And uh she died I guess a couple of days after that incident.

E: Was that the first patient that you had that died?

Yes.

E: Tell me about a time then that another patient of yours died. Did you have another patient after her?

No. I was never assigned one after that because when school got started it was more difficult because the nursing home that I had they don't allow visitors until like 9:30 which is... I have to be at class and so it made it more difficult for me to be assigned one and so that's when I started doing respite care.

E: Tell me about your most memorable experience as a hospice volunteer.

I don't know that one is more memorable over the others. I find it just interesting to go and hear their stories. Like the last respite care that I did was a woman and um she told me a lot about her life history and I found that kind of interesting. She was single, and she worked on a farm, she had a farm, she took care of her parents, and she told me about how her parents come to visit her even though their way gone and so uh that was kind of neat. And she asked me questions and we conversed back and forth. She was bed bound but I found her very interesting.

E: And that was just a one time visit?

Yeah.

E: Did she pass?

I don't know.

E: Cause usually the respite care is just the one time.

One time yeah. Its to give the caregiver a break that they can go out and do shopping. They had to go to a wedding.

E: Did your first patient impact you in any way personally?

Um I can't say it impacted me.

E: Tell me about a bad experience as a hospice volunteer. Would you say your vomiting experience?

Yeah. I would say that was the worst I've had only because I was disappointed that it took me so long to get her help. When she's in a nursing home and I found that... I was disappointed in the nursing home not in the visit or the patient.... And another time at the same location I ... going to visit that other woman and I didn't know what she looked like. I knew her name. You know I know these people by name but not by face. So I asked where she was and nobody knew and nobody wanted to really help me find her. So I had to find another hospice worker who knew her to actually show me

E: And the hospice worker was there?

Yeah, after about 10 minutes I found another hospice worker, one of the social workers. She helped me find her.

E: Have you ever turned down a patient?

Uh I have only turned down because of time conflict, not because I didn't want to go?

E: What are your requirements in terms of patient care?

I think I would probably have a problem feeding somebody, if they asked me to feed someone. Maybe smoking.

E: Did you request nursing home patients?

It didn't matter to me but I live down the street from this nursing home so it was convenient.

E: What would you share with a new volunteer/advice?

It's a lot of fun.

E: Explain that.

I find it interesting.

E: Well a lot of people wouldn't say its fun. Tell me more about what you mean by that.

Well for me the fun was that the people came off of the chart and instead of becoming a name they become a real person with real stories, real life stories and stuff like that and so I found that interesting. When you read the obituaries or I go to the cemetery a lot you know and so when I am at the cemetery and I see all of these names I sit there and try to imagine I wonder what they what their life was like you know and stuff like that.

E: What does it do for you personally to be a volunteer? Does it contribute to your life in any way?

Probably. I guess because of my own fears. I probably not really a fear but I am guessing that I will probably be one of those ones that end up in a nursing home that nobody comes to visit. Because all my family my family all died, I don't know if you knew that. My husband, children, they all died. My extended family is not very large and so I guess

E: giving to so that you can get back?

Yeah, probably.

E: What are your thoughts about meeting a patient for the first time? Especially because you are in respite care and meet so many new patients.

Well I try to envision what they look like before I get there. Is that what you are asking?

E: Yeah. Do you ever get anxious or excited – how would you describe how you feel?

Ummm. I guess I don't know. I don't think I've ever thought about it. I think of what they might look like before I get there.

E: What kind of response do you get when you identify yourself as a hospice volunteer to others?

Um well when I mention it to older people like my grandparents or something like that they are like ohh yeahh – they want to know what's going on kind of thing. Younger people tend to think just like oh that's really cool. But older people are kind of like oh I don't know if I could do that.

E: Older people like what?

I'd say 60 and above – middle-aged think oh that's great you're young you have time. If they only knew I was 36 (laughs).

E: What are your thoughts on your own death?

My own death. I have my own plot. I have my own tombstone with name on it and uh some days I wonder when is this coming (laugh). But other than that I don't really think about it. It's just part of life

Transcripts~Participant 7

E: Can you tell me how you got involved with hospice?

REFER TO NOTES – First part of tape not available.

E: First patient/assignment.

My first patient was [name of patient]. She had um renal cancer that was in the liver and the lung and the volunteer coordinator at the office told me that she was not very receptive to hospice but that I should go to the home and visit with her and her family. So I went over there that morning. She was sitting on the couch and she was very frail looking. And Um I was nervous because it was my very first patient and I didn't want to have big lulls in the conversation but I didn't want to prattle either. So I talked with the son and the daughter a little bit and then I asked {patient's name} questions and I told her how important hospice care was to ensure her quality of life and good health care and that it would be also helpful to her son and daughter because then they don't have total responsibility for her care. And she really needed someone to be there most of the time.

E: Being that this was your first patient was the volunteer coordinator with you?

No. I probably would have been more comfortable but and also after being around the hospice staff as long as I have you learn a lot more things to say, comforting things and things that don't just come to your mind but then having heard them for them then you can use those same phrases you know when you're talking to people so. And even working with the volunteer coordinator at like a desk where the companies are pledging (referring to holiday fundraiser) we want them to pledge hospice of xx county because we are not within the united fund, we don't get any monies from them unless a specialty people you know specially pledge with us. So I learned a lot about that and what to say. You know you don't want to be begging but you want to say you know about hospice and its so important and if you do just remember us in your pledges. But anyway with [patient's name] okay then I spent an hour with her that day and then the next week the family moved her to a nursing home in {name of town, state}and it was on my way to work, I was still working three days a week, so on my way to work those three days I would stop and visit with her, it was usually right before breakfast or many times right after breakfast because I'd stop about 8 o'clock in the morning. She was talking to me at that time and she did talk to me for probably a month and then it was like she didn't, she couldn't anymore I mean she was almost partially comatosed. Um but for that first month she talked to me and she said how she liked chocolate and so I would pick up a Hershey bar and take it to her when I would go. Um if I was up in that area grocery shopping I would pick one up, stop by in the middle of the afternoon and give it to her then. Um the nursing home was probably the worst nursing home I have been to in {name of city}compared to the others I have been as far as cleanliness and friendliness. Although you did have to sign in at the desk and many of the nursing homes don't ever have you sign at the desk and I think that's ridiculous because anyone can walk into a nursing home. But {patient's name} I think she expired in June and I got her in March – so that was only 4 months.

E: How did you find out that she died?

Um hospice always calls me. But when she died I was not home and didn't get the phone the message because I was out of town visiting my mother so that's one funeral I didn't go to. I've gone to many funerals. My next patient was {name of patient} and she lived in [name of city] and she was already very terminal, two weeks I think.

E: What was the break in between patients?

{Name of first patient} died in June and I got {second patient} on July 15.

E: Tell me about the first time you met {name of second patient}. Were you nervous?

No I wasn't nervous at all. Because [name of patient] I never saw [name of patient] except her back. Her bed her hospital bed faced the wall, she was facing the wall, she was asleep the whole time I was there and all I did was give the caregiver, her daughter, some time to go to her own home and prepare dinner and do things like that. I just went so that there would be a body there. She was on... she had a catheter in, she was on oxygen, she was breathing very uh heavily and so I never even talked to her. And I got her on July 15 no that's when she died. I got her June 26 I was wrong before (looking through her book). My first patient died in June of 2000 and I got the second patient on in July. (About two weeks). Sometimes there's a day in between patients sometimes theres a couple weeks depending on what the case load is.

E: Tell me about one of your patients died. A memorable death...

The death that was memorable was...

E: Let's talk about this... the first patient you sat with that died and you were there.

I never was. Now a friend of mine that I went to see, died, well I saw her several times. But three days before she died I went over and she asked me to give her a shower. And I said "[lady's name], aren't the aides coming to give you a bath?" Yes she said but I want a shower. I just feel like I need a shower. And I said well don't you want your husband to give you a shower." "No I want you to give me a shower now." So she could hardly walk, we took the walker into the shower. And I went in with all my clothes on because I mean I didn't know how else to do it. I had to be in there with her. So she hung on to the nozzles sort of or the faucets after I got the water temperature and everything and got her in there. And I just bathed her and hung on to her and toweled her dry and she died three days later. And I wasn't there then although I was there the day before she died. And they he didn't ever put in a hospital bed until two days before she died. But her husband wasn't very caring. The day before she died I asked him I said don't you have any swabs so I can swab her mouth out. No I don't. I said well can you run to the pharmacy and get some. And he didn't bother too. So I took a straw and put water in it and pinched it into her mouth that way because her mouth was so dry. You know towards the end their mouths get so dry and gumming and white mucous kind of stuff forms. And so that was very upsetting to me and what was more upsetting was when I went to the funeral and the husband sat in the front pew screaming and crying and carrying on.

E: Tell me about your most memorable experience as a hospice volunteer.

Okay my most memorable experience was {name of patient}. She was the one I had.... She had brain cancer, breast cancer, no breast cancer with mets to the brain. When I got her, her husband, she was um 76, her husband was about 75, he they needed so much more money to supplement their social security that he went back to work at 73 to be a school bus driver. So that's the one I went to visit three times a week whenever he had to drive the school bus in the afternoon and he had someone else a relative coming in the mornings, when he drove the school bus. But I walked into that room, she was already in a hospital bed.

E: This is the first time you met her.

This is the first time. And she looked at me and she had the biggest smile on her face. She had pure white hair, she had this round angelic face. She was like a lot of 76 year olds, she was probably a little more rotund you know laying in the hospital bed. But she just she looked like an angel to me and every time I came she had a big smile on her face and I always gave her a kiss hello and a kiss good-bye on her cheek. And I swabbed her, I changed her diaper, um I read scripture to her because I found all kinds of um Nazarene literature around so I knew that they belonged to the church of the Nazarene. So I read to her from one of those books. And she talked about her family, she only had one daughter and one grandson and they came to visit her now and then but her daughter was bi-polar and her daughter was having problems with her terminal illness. And she was very good about taking her pills. Um every Wednesday when I was there the aide came to give her a bath and that was the first time I helped give a patient a bath. And that it was a learning experience for me and the patient was so good and we would lotion her up because their skin can get so dry.

E: Tell me when you first met her; you walk in and this woman gives you a big smile.

Yeah. I walked over, I didn't kiss her that day cause I you know a lot of people don't like touching unless they're comfortable with you. So I walked over and I picked up her hand and I talked to her and I told her what my name was and why I was there. And she said she was so glad that I was there. And um she told me that she liked to watch TV and her husband had positioned the TV right at the end of her bed. And she told me the TV shows she liked. She liked to watch Cosby, and some of those half hour sitcoms. So I would turn those on for her.

E: So why is she memorable?

Well she's memorable because she was such a sweet, sweet, angelic lady who appeared to me to be at peace with what life dealt her. I mean she could deal I mean she knew what was happening.

E: So there wasn't one isolated event that makes it memorable... just the whole patient.

Yep. It was the total patient care and the way she responded, the way she acted. Um her husband was very very involved and was always asking questions of the nurse, me, and he called hospice. I mean he was a very very concerned husband. I mean he took such

E: That's memorable, is that the exception?

That is very much the exception. I mean that woman always had a dry diaper when I came. And I have been to many many patients where it looked like they've been sitting in that wet diaper for hours and there was a caregiver in the house. So I just thought her husband was a saint for taking care of her the way he did and I went to her funeral.

E: Did the hospice call you when she passed?

Yeah.

E: Do you remember your last visit with her?

That was in 2000. I can't remember what I had for breakfast. Well I mean toward the end she could no longer speak. Um she was pretty much under drug influence you know and kind of out of it. So my last I would say probably the last month I was there there was no communication at all and prior to that she had she couldn't speak either but she could grip my hand and she could follow my eye and she could say yes and no if I asked her if she wanted juice or a soft drink or something she could respond at me. But it was it was just a gradual thing. And the last month why she just she didn't speak to anybody anymore.

E: How did this experience impact you personally?

Well I think that it impacted me personally because I could picture someone in my own family being in the same predicament and I think the members of my family would be more like this patient then they would some other patients that I've had in that my mother is very calm, very, never been very excitable and that's the way this patient appeared to me. She always took every day as it came, did what she could and she was a very faith conscious person like my mother and uh that's why I try to get to Iowa as often as I can to visit my mom because I think she needs that kind of comfort. I'm her only daughter and when I call her on the phone I can just see the smile on her face. And the patient's husband wrote hospice and thanked them about and named each one of us that worked over there and he sent me personal thank you notes about how appreciative he was of the care that I gave him and his wife. And that's also highly unseal. Hospice also always sends a thank you note when the patient dies but for the family too that was a first for me. And that made me feel special. And I saw him after that. I went to visit him a couple of times. The first couple of months she was gone and he was okay.

E: Tell me about a bad experience as a hospice volunteer.

Well I guess the worst experience was the patient died and I didn't know it.

E: Tell me about that.

Okay this was a patient.... Had hepatitis C and she was only 42 years old. And the volunteer coordinator told me that the first visit she went to visit her and this girl met her at the door with a glass of coke in one hand and a cigarette in the other and she said that all the while I talked to her the cigarette burned down like almost gonna burn her finger. And then she said she dropped the glass of coke on the floor and the glass just splashed everywhere and she said this girl just had no business walking around with a glass of anything she needed a plastic cup. Because she had like tremors, she had diabetic reactions because her liver was involved. So the volunteer coordinator called me and asked me to go and visit her.

E: We're you nervous?

I was nervous about the Hepatitis C. I thought well its rubber glove time the whole time I'm there, that's all I could think. Um well in the meantime before I got there, like I was suppose to go there in two days, the day before, a friend came and picked her up and took her to his house. So the volunteer coordinator called me and I went to his house to take care of her. She was lying

on the couch. She looked jaundiced. She picked up a pack of cigarettes from the coffee table and then she looked at me and then she put them back down. And I said can I get you something to drink and she said yes I would like have a coke out of the refrigerator. When I went to the refrigerator there was nothing so I got her an ice water. This house had birds with feathers everywhere. I mean this house was.... But anyway I stayed there for like 2 and a half hours and she she... she fell asleep on the couch for probably two hours. Then the last half hour she woke up and her friend came home. And when she woke up she talked needing more of her things, if she was going to stay there she needed more of her things. So um then her friend came home. He apologized for the shape of the house and all that. And he said I am moving her to a nursing home and I said what nursing home. And he said [name of town]. So I left and then I called the volunteer coordinator and she said well Pat I'm glad you went. She said I don't think anybody else would have gone. And I said well they are moving her to a nursing home in [name of town]. And she said well its up to you if you want to visit her or not. So the next week I decided that yes I would go to the nursing home so I did. She was in a wheel chair, they were wheeling her out doors. So I told one of the aides I'll go ahead and wheel her outdoors. So we went out to this little patio thing they had. So we did that for about 40 minutes and then I wheeled her back in and she went to the bathroom. I put her in bed. I tried to get her to eat her lunch. She didn't want to eat anything. And she said Pat will you tell my friend to bring me some more sweat pants so I can ... she said I need those because I ... its getting cold when I go outside to have a cigarette. I said okay I will give him a call. Well in the meantime, I can't recall what holiday or it was when we took a flying four day trip up there (Iowa) and back, so I was gone four days. Because I saw her on Wednesday, we got back on Sunday. So on Monday I called her friend. It was he and his wife whose home she had stayed with. I called him on his cell phone and I said Robert, {patient's name} said she needs more sweat pants and sweatshirts. Could you drop them by the nursing home for her?" And he said Pat I am leaving her funeral right now. And I felt like about this high. So I said oh Robert I am so sorry I said I just saw her Wednesday morning and he said she died Friday. And so the funeral was this morning on Monday. And so I called the volunteer coordinator. I was kind of upset. She hadn't left a message on my machine. And she said well Pat I'm sorry I didn't know if you were still seeing her or not. And apparently that was the weekend that they had like 12 people die. So I can understand. I mean because she is very very good. But I really felt bad. Here I am calling him in his car just leaving the funeral. And the volunteer coordinator said well I wonder how many people were at the funeral. I said well Robert and his wife and I _____. That was probably my worst experience.

Another experience I had was {patient's name}. A young woman, she was probably 50, she had melanoma. She had she kept passing out. Lymphoma. And her husband first found her one day laying on the floor. She was like 49 she was. Had three children, one was a high school senior still living at home. And um her husband was a building contractor. He owned all the Big O Tires here in town. And um they none of them could face the fact that mother was going to die. And so uh the aide would come to give her her bath while I was there and she would scream in pain. And the aide would ask if she's had the medication and I said I don't know because I am not suppose to give it. So from then on when I knew the aide was coming I would call her husband at work and I'd say did you give her the pain medication. Oh no I didn't, I forgot. Well what the aide told me was that he did not want to give her the pain medication because the pain medication made her dopey. And see when he came home from work he wanted to sit and talk with her and he didn't want her dopey. So but then we started giving her the pain medication before we gave her a bath because she was like huge bruises all over her body and just to turn her was so painful for her.

But the first time I went to visit her her husband was there, she was sitting in a recliner. And I said now can she get up and walk? And he said no if you can you can get her into this wheel chair here. And I said is she ____ and he said no she's got a diaper on. So he was leaving her...

E: Was she sitting there too?

She was sitting there too. But he didn't really want hospice there from what I understand. He was leaving her alone in the day and going off to work and clumping her down in this chair and putting some food beside her and there she'd sit in that wet diaper all day. Well the patient was a little bit heavier then I was and I mean it was a chore to get her... it was all I could do to get her into the wheel chair. And the first day or two I was there I did wheel her out onto the patio for fresh air. Um but uh even uh I couldn't and then one day I went there and he said he left her in bed and he said well she can stay in bed all day. Well at least I could change her diaper. But the bedroom was like a lot of bedrooms. It was dark and uh I don't know I just felt very uncomfortable sitting in the bedroom with her much more so until they could move her to a hospital bed.

E: Was she able to communicate?

Not really. She... it effected her speech. She could scream no no no, yes yes yes. Um but she never really talked about her children or husband or obviously she had a lot of friends because everyday I went every time I went there were cards there, there was candy there, there were pies, there were cakes. You know brought things for her. She had a lot of friends and was very very loved. And unless I had seen this picture of her which was in the obit I had never seen her looking like that. I mean I not have known it was the same person because she was... like I say she was a little heavier then I was but her arms were like this big around and her legs were this big around and she was full of bruises everywhere. So uh that was a case where I mean the husband in my opinion should have been thinking of her pain more then his needs as far as talking with her. Um once and awhile the two sons and the husband would come while I was there for lunch and they'd bring her some lunch otherwise I would fix her something whatever I thought... that was the patient I was there for like five hours. I was there from 8 – 1 or 2 and uh. But I mean I just... its hard to say how your own husband would react I guess but um it's very important that patients have their medications ____. And not being an RN or qualified I don't really have any business giving it to them except that I could call him and he said he no he didn't give it to her. So then I'd call hospice and say can I give it to her and they say well yes if you know how to give it you know relieve her pain before the aide gets there you better give it to her and I just did what was on the bottle.

E: Um have you ever turned a patient down?

No. In fact we were just discussing that a couple of weeks ago at training, patients that have turned us down.

I have never had one that turned me down. But all of times some of the patients that I get are farther along. Some of these gals have patients where they can take the woman shopping and take her to the grocery store and take her to get her hair done and kind of be her friend you know. But you see I have never had that. I have always had where there in a hospital bed just ready to go.

E: What would you share with a new volunteer? What advice?

I guess it would be to go in low key and feel the patient out and I don't recall that I have ever discussed their illness with them as far as that goes. I mean its like they are aware of it and I am aware of it um and I just. I attend to their needs. I try to lotion them. I try to keep moisture in their mouth. I wash their eyeglasses for them because a lot of time family doesn't think of that. And of course I wear glasses and so its very important to have clean spectacles. I do that a lot. And I fix them snacks if they want it and ask if they want snacks or food and if they do I'll feed it to them. Or if the family has something set out or tells me what to feed then I'll go ahead just do that to. I have also done housework. One house I went to her husband was not a housekeeper and the refrigerator was so bad that one day when she was sleeping I just took everything out of it and cleaned the whole thing. I put everything back in but I cleaned the interior because there were spills and drips and sticky and gooey you know. He didn't have time and some men don't think of things like that. But other than that I haven't done a lot of housekeeping that I can think of. But now when I went to {young cancer patient mentioned above with husband from Big O Tires) house her senior high school girl would not go to school. Her dad would leave for work thinking she's gong to school and she wouldn't go to school. She would sit in there on the phone. So after about two days of that I just called him and said do you realize she's not in school. She's was just taking advantage... well I mean there was no point in me being there if her daughter was going to stay home and then sit on the phone and talk with her friends. You know...

E: Any other advice you would have for a new volunteer?

Well I always carry a little satchel with me, a little canvas bag. And in it I have scriptures, I have poems, I keep a set of rubber gloves in there. I keep a couple of extra ___ straws in there so that if I get to someone's house and they can't drink out of a cup and there's no little straws I have it. If they'd like for me to read to them I can. Um and a lot of the homes they say all of the homes will have rubber gloves. Sometimes they do but I can't find them. And if I have to change a diaper or whatever I just assume have them so I bring my own. And I always bring a paperback book because a lot of times the patients will nap and I'll just sit there and read my paperback book.

E: What does volunteering do for you personally?

I guess its for something meaningful to do. I am not a big shopper. I don't enjoy going to the stores shopping all the time. Um my friends that I golf with are younger then I am and they are not retired. So I have the week to myself. I golf with them on the weekends. So during the week I feel like I might as well be doing something constructive. Walking up and down the street, I take a walk everyday but that doesn't me all day you know. And I have met some really super nice people in the hospice organization. The staff, the chaplain.

E: What are your thoughts about meeting a patient for the first time compared to your first patient?

Well see I don't have any apprehension now since I..

E: Why don't you think?

Well its because uh going into somebody else's home that is terminally ill that doesn't know me and I don't know them, I mean its like taking your first airplane ride or skydiving. I mean....It's not something I have ever done before and I am a little fearful of doing it.

E: So how is it for you now?

Well it depends on the people. But for the most part it is very very easy. Um because I just go in and they know I'm coming. I had a gentlemen and he had a smile from ear to ear and say Hi I'm Pat, how ya doing? I'm glad you're here. He talked to me all the time. He had a wheelchair but he got himself in and out of it. And uh _____ but his wife would needed me two or three hours to do some grocery shopping and Christmas shopping.

E: Why do you think its different now? Do you think its experience or something else? Because you had the apprehension before and now you don't – but it's the same setting?

But its like it's like maturing. I am maturing in hospice. Like you do with any other situation that you get into for the first time okay. And um I just I just feel more at ease going into people's homes now and I ask more pertinent questions. I walk into people's homes and I always ask their phone number. Before I guess when I ... I guess the first couple of times you start out of course in a nursing home you don't have that at all, and then with my friend over here I knew her son's phone number so I didn't have to ask then. And then I got somewhere, I can't remember where, I think it was {name of patient}'s home, and I wanted to call her husband and I didn't know what number to call. So its very important. And I had another gentleman patient and his wife was taking a computer course because she wanted to put all of their stuff on computer and she had started this before he got real bad I guess so she continued to go so she gave me the number to the school whenever anything urgent and then if she I usually asked them how long they anticipate being gone so I have some idea. And so if she was gonna like grocery shop after school then she would call me and she'd say everything going okay I'm going to stop at the grocery store and I'd say yes. Because its kind of nice to know how long you're going to be there, whether you're expecting a nurse coming, or the other thing they need to be aware of is the pharmacist delivering drugs. I didn't know that I was going to be signing for drugs or I did not have it in my training remember... it may be something they didn't even mention in my training. But see hospice provides the drugs for these people and the pharmacy has to deliver it so you have to accept that... if it needs refrigerated... and that's another thing like when the you want to know how long they are going to be gone, you don't know if they've got medication, its nice to find out are they mediated enough until you get back or what needs to be done in the interim.

E: How do people react to you when you identify yourself as a hospice volunteer, to like lay people?

Well most of my friends and people I know socially think that being a hospice volunteer is seeing a patient. There are other things they can do. And then the other day I came from the office, the training, and I still had my badge on and I went to the grocery store to pick up some groceries and the little, the young man checking my groceries said you work for hospice. He said do you get paid for that? I said not I am a volunteer. Well from what I hear it's a very good organization.

E: Isn't that nice.

Yeah, because on other occasions I've worn it in the store no one has said anything. In fact I thought maybe its something I shouldn't be doing. Until recently the volunteer coordinator or someone said it doesn't hurt to have your badge on because its publicity for us.

E: But you say most of the time people don't ask?

No, strangers don't.

E: One final question: What are your thoughts on your own death?

Um well my husband and I have a legal power of attorney for the kids if anything should ever happen to us. I mean I'm ready anytime. And I think he feels the same way. He still has seizures. Eight years ago he had _____ and he's not a diet.

Discussion about change in their diets so that it is more healthy.

I'm ready to go. I've my obit partially done. And I've got everything lined up the songs I want sung and my family all knows that.

We didn't do anything the first 40 years but now its time. And I have my mother writing her will and obit. I said mom I don't know all of the organizations that you have volunteered for, she was a big volunteer.

It's easier if you lay it out. Then its done the way you want.

E: Did you train in July then or?

Um I began training as soon as my course started, actually a couple weeks after so that would put it like more mid-September.

E: And what lead you to get involved with hospice?

Well basically I really had not idea what hospice even was until the beginning of the school year. And uh I wanted to get involved with it because I wanted to be in some sort of volunteer organization so I decided to take this class at OU called community citizen. And what is required of you is that you do thirty hours of community service. And they give you all of these ideas because they don't expect you to just come up with it you know come up with an idea of a place here in {name of town} that could do it... and hospice was an option and they explained what it was so I thought that would be interesting for me.

E: Why did you think it would be interesting?

Because um I just think that I don't know how to explain it. I really was just it's a way of like giving empathy and being a very supportive emotionally which I find attractive. That's attractive to my personality type and um ... I just felt like I could really contribute to that organization. I know a lot of places you go and volunteer and basically you file papers or ... you do a lot of office work. Which is good because is supports the organization and an organization really needs that, its an integral part. But in hospice you really get hands on training with people and you really get a lot of experience dealing with all types of people. Just having respect for them, developing that respect for people who are incapacitated or unable to provide for themselves. I think that's really good.

E: You wanted hands-on work. You wanted it to be more than just filing then.

Yeah I think you know everybody wants that. That's definitely. But hospice I think is a little bit more intense emotionally for some people. Some people aren't as affected by it, by the fact that the patient is there because they are very sick or they are incapacitated or they're dying. And that's kind of a ... people I guess are a little bit hesitate to participate in hospice because of that... because of the death aspect. So

E: What is your current level of involvement with them now?

Basically I am just the bottom rung volunteer. I don't know what else to describe it as.

E: I mean do you have a patient that you are seeing.

Oh yes yes. I am seeing two patients. There are at the same nursing home but their both hospice patients at {name of hospice} and um they are in [name of town] actually. Um would you like me to describe the patients?

One pat..., they're both women. One patient I think, not been on hospice very long. The other I am not quite sure about because she's really new to me. I've only had her for like a couple weeks. And um the first one, the first lady who just got on hospice, I believe um she suffers from dementia and uh pretty much I think has a form of cancer. I'm not sure. But anyway she is very talkative and very forward with you. She spoils everyone, she's very friendly, she's very gregarious and she loves to talk. The only problem is she really doesn't know who she is talking to or where she is. Even, like I think she might even be confusing me with somebody and its just very hard. Its very hard to convince them otherwise. Its very hard to tell them ... so you just kind of just going along with what they kind of believe. It sort of makes it easier. I think maybe its a lot like maybe Alzheimer's patients. You try try to convince them, tell them over and over something is true and they just don't get it. So the best thing to do is just kind of let it go and get on to the conversation which is the important thing. That you talk to them. That you interact with them is some forum because it probably helps them move on a little longer, and it kind of, it kind of finishes out their life with a little bit more you know happiness I guess.

E: How often do you see her?

I see her about once a week and the other lady I also see about once a week. But I see them at different times because one lady, like the woman whom I just kind of got added on to recently she is bi-lingual, she is Mexican and her daughter comes and visits her. And her daughter specifically requested that a patient come or excuse me a volunteer come and see the woman at dinner and helps like. Like I guess the woman has a little trouble eating. She doesn't really like the food that she is served. So she wanted to have somebody there to kind of help her, make sure that she eats besides just the employees. She has to eat with so many others, especially at dinner time. There are so many people there, they can't keep up with everybody. It's kind of difficult, especially when a lot of their people need help with their eating. And there just aren't that many employees there that, you know all hundred of them, and so I think it's a good idea that volunteers come down and kind of makes sure ... because some of them are on very restricted diets and don't really like their strict diets at all. And I don't blame them but this other woman is not on a strict diet and I go and visit her because she needs some help at dinner time. And then usually right after dinner... She is also confused. She really has no idea where she is and so I just usually spend a little time with her after dinner and then hopefully if all goes well I take her to her up to her room and hopefully she'll like won't forget like get a an employee come in and get her ready for bed and stuff. Cause if you don't then she won't go to her room, cause shes is confused and doesn't even know that's her room. So if you get her there and help her change and stuff then she'll go right to sleep. So that's kind of the purpose of that.

E: What was it like when you got your first assignment. Tell me about your first assignment.

Well actually my I guess my really very very first assignment wasn't with either of these women. I went on these trial runs with the volunteer coordinator because we were just kind of visiting different nursing homes and seeing which ones I felt comfortable with and the locations I felt like I could connect with. And my very first visit was actually pretty alarming because

E: We're you nervous?

Oh I was a little bit nervous but I thought you know they're just they're you know old people ohh how bad could it be? Seriously its not like I'm going to a prison or something where I'm in danger. I was just I was a little nervous because I didn't know what was going to happen exactly but I had a general idea… from the training. Of course most of the training is about family and when you're in a nursing home I don't really have that much family interaction so I haven't really dealt with a lot of families or with any families to speak of. But you know you are given bereavement training though… I don't know how I would do that. Probably just do a card and give them flowers or something like that because I don't really know them. So but basically that's my first visit was at a very, it was kind of like at a very upscale nursing home I guess you might say. It was nicer inside than more nursing homes are.

E: Nicer then what you expected?

Yeah it was like uh I don't know.

E: Like a hotel?

Maybe like a hotel with the standard nursing home style rooms and everything. But nice where there was like nice furnishings like pretty nice. And the woman that we went to visit and go see, again I think she had cancer, maybe she even had bone cancer. But she was kind of vocal but not like in a pleasant way. I felt like it was very disturbing to hear her because she was in so much pain. She was just, I mean she could have been, she might have had dementia but I don't think so. I think she was pretty aware of what was going on and that was the frightening thing. Because she knew where she was, what was going on and she knew that she was dying. And she was in still so much pain and I don't know why they couldn't do something to help her with that but

E: So tell me about it – you walked into the room and …

Well actually we found her she was sitting out in a wheelchair and cause we'd been looking around for her and she wasn't in her room so we went looking and found her. She was like "Um I'm so sick I really want to go back to my room. Take me back to my room." So were like okay. We wheeled her back in there and like helped get her in bed. She just.. she just… was very unhappy and so we tried to give her some water and she had like a lot of like demands like not demands yeah kind of demands. And she was just like no move my computer, move my feet, be careful you know. And she was just very

clippie cause she was just really in pain. And it was just really uncomfortable to be in that situation because I had never been, tried to like move someone before, especially someone in pain and they're like don't touch me but move me and you're like AHHHH I don't know what to do (laugh). So it was really uncomfortable and strange and hard. It wasn't a happy experience. So…

E: That was your first experience. Did you see any more patients that day?

Well um we went on a couple of trial visits and I think maybe after her, the one we visited, we might have gone to another nursing home and seen another woman. But I think for like the first few visits a lot of the patients either weren't there or they were asleep so we didn't bother them.

E: So one of the women you have now is actually your first patient?

No, that woman I've never seen again. She is actually a patient of another volunteer that I know.

E: So who was your first official patient?

The woman who recently got on hospice that I see right now.

E: Tell me about the first time you met her.

Um let me think. I don't know. It wasn't a very memorable experience.

E: Did you go with somebody?

I think she I went to go and visit all by myself. I went to like several nursing homes before that and I actually went to that one so I knew how to get there but…

E: And so your first patient you still actually have then?

Oh yes. I have had for I guess maybe I mean she's been there for awhile. I get the feeling that she's been there a long time because she had like cards and stuff and they're like 1997 and so I think she's held out awhile, deteriorating slowly. And she's just I think pretty much has always been very very friendly very open very willing to talk so that was a positive experience I guess.

E: Tell me about the first time one of your patients died.

Now that I can sort of vouch for. I had this one woman that I was assigned to. I went to go see her. When I walked in there the bed was empty. And like everything cleaned out and I was like oohhh. And they informed me that she had just died that morning (an employee at the nursing home told her)

Actually no the first person who told me was her roommate. And she was kind of sad. Cause I think they had been friends and so. I was like I'm really sorry and I gave her a hug and stuff and that was it. I left. I didn't know what else to do. I'm not really sure.

E: Did that have an impact on you - on a personal level?

Um well I guess not really because it wasn't like I even got to see her. You know um the woman being really upset or being sad like somebody died and you tried to console. Like that was bereavement right there. Yes the roommate.

E: And you felt like you handled it okay?

Well sort of. It was awkward. I had never like you know you console your family when a family member dies. But it was totally different to try to because you are not part of that grief at all. You're totally from the outside and you're just trying to make it better somehow and you don't understand. I don't know. I was just like.... I hope I'm... am I doing.. am I making it worse or making it better... what should I be doing in this situation. It's kind of hard. It gets too I think every time you do it I think you get better at it. You get more of an idea of what they want from you and what you... what they want to hear, what is appropriate to say to them. Sometimes like ... depending on your personality its easier or harder for you to be consoling. Some people just... maybe have a harder time empathizing but their showing sympathy.

E: It's a new experience.

It surely is.

E: Tell me about your most memorable experience as a hospice volunteer.

Most memorable.....Let's see. I guess um let's see what would I have to say. I guess really the first lady that we visited was pretty probably had the biggest impact on me in shear terms of reality, the reality of it. There are people out there who just suffer day in and day out, incredible unbearable pain that never ends. And that everyday she'd wish she'd die.

E: And that's what made it memorable for you?

Yeah that really pressed upon me the reality. I guess the first couple of times I went to the nursing home I wasn't really prepared for the, its kind of shock to see the way that, for the state that they are in is a big shocker.

E: Can you even prepare for that?

Not really, not unless you have a relative or you're just specially connected to that. I mean I think that you could watch videos or.... Just to see them there and everybody's

different. Everyone has their own problem out of their, I don't know how to describe it. But it was very very awakening, very

E: Tell me about a bad experience.

Well I guess the bad experience that I've had most recently was when I the very first time that I went to visit my second new patient that I got.

E: Now is this the bi-lingual woman?

Yes, the bi-lingual woman and she just she's Mexican. And she speaks kind of both depending on her state of mind. She will... if she thinks she's talking to an English speaking person she'll speak English. And I guess maybe sometimes she thinks that maybe I'm Spanish and so she speaks Spanish to me.

E: So what do you say back? Do you speak Spanish?

Hardly any. (laughs). I just tell her you know I only speak a little Spanish. Or I try very I'm sure broken Spanish to talk to her you know using very small phrases just to try. I'll say "como da teses" or "no oble espanol." Stuff like that to try to jar her into realizing hey I don't speak your language. But yeah she speaks both pretty fluently but the first time I went to visit her and she was in her little cafeteria eating. It was I think maybe she might have hearing problems or problems understanding you. And like I tried to say hey how are you doing. And she got really confused, almost like belligerently confused. Like she wanted to know why I was there and why I was bothering her. She was just like what are you doing. And I was like well I'm a volunteer and it didn't really click. And so she was like, kind of like we need to talk, we need to talk. She like lugged me out of the hall and was like okay now what do you have to say to me. Like why are you talking to me? And I was like well I wanted to know how you are, how you are. And she didn't quite get it. And I got really unnerved and I was so like flustered and I was like this woman thinks that I am following her around for now reason and she wants me to leave her alone and she just... But like eventually I like I kind of just like stayed with her and I was like hmmm, I don't know what to do if this doesn't work out. She doesn't accept that I'm there to see her.

E: Did you all go back to sit down and eat?

Yeah I think we might have but she wasn't hungry at all so they weren't gonna make her eat. We walked in there... she's one of those patients who's still very mobile and so she walks around constantly, just moving. And so I just walk with her. And like so that first time I was just like basically yelling and trying to make my words as clear as possible. She would, she talked even in English she's a little garbled I think mostly from being elderly and also from her having an accent. Both of those make her a little difficult to understand and so I was hopelessly confused by what she told me. And I was like please can you say it again with you know some sort of hope that I might have some sort of a

response. Cause I didn't want to give the wrong response or I don't know, but um. That was really really unnerving because I thought she was angry at me.

E: So how did that first meeting end?

Well I managed to I think I sort of clarified why I was there. Like she thought I was there for some reason that I'd never even thought about. I think something to do with her personally. And like maybe I was there to collect money or I wanted something from her. And she would ask me what do you want from me. What do you want from me. And I would say nothing, I don't want anything. And so, and finally she just said well okay so are you done. And I am like YES I am done (laughs). She was like okay well I'll see you later then.

E: How was it when you back the next week to visit her?

Umm well I just kind of like first of all the first time I went in I had my coat on. I think maybe she didn't like the coat. So I left the coat in the car next time and I think maybe it made me look more friendly. And so I just like came up to her and I held her hand and I put my arm around her and I was like hey how are you, and acting more friendly. And she was like, she kind of gave me like a look. But she wasn't like, she was like a lot more friendly and she kind of talked about stuff but she wasn't on her guard like she had been last time. She was just and she was talking about all sorts of things to me like she would repeat herself over and over and over and she would talk about her family like she didn't have any family or she couldn't find them and didn't know what they were going to do for her, she needed to find a job cause and so anyway. I don't know I think just things from her life that she'd experienced.... And she just wouldn't hold still so I hold her hand and like cause she kind of like leaned on me after a while and like to get her balance and everything and so we just walked like over that nursing home. She was like well what do we do now? And I was like well.....Um you know and I was like well I really don't know what you are suppose to do, shall we ask someone? So I like pointed and we went over and she asked the lady and she's like well what do I do now? The woman, I don't know, an employee of some kind said well want you need to do {patient's name} you need to go and sit in your room and watch television and then it will be time to go to bed. And she goes oh okay. And so we got as far as the hallway to her room, cause I guess she kind of knows where her room is, cause I had no clue, and she was like and she turned to me and well what do we do know? I'm like well we're going to do what the lady told us and you know why don't we just go to your room and we'll watch TV. And then we get in the room and she's like wait a minute, we don't have money to pay for this room. And I was like but that's okay you don't have to pay and I tried to explain to her that you don't have to pay to stay the night and sit in the room. So basically um eventually got her in and sit down on the bed and after that she didn't jump up or anything. She was just kind of stable. And then the employee, another woman came in and we like put her nightgown on and she was just really compliant. She was like she told the woman too she was like No tango deniro and the woman was like no honey you don't need money to stay here. So I don't know she'll just kind of go along with it if you just kind of lead her. I kept wandering why she kept asking me you know what is this, who

are you, what do you want from me like and I realized finally that she was just waiting for, she wasn't trying to be belligerent, she was just waiting for directions because that's what she knew to do, just ask what do I do you know tell me what to do

E: Now you understand that.

But that's what she wants is to be guided by everyone.

E: Have you ever turned a patient down?

I think we visited a woman... I don't think so... I don't really remember... we visited like maybe five or six people and not all of them were there, available or anything like that. So I don't think I've turned a patient down. I think I can answer that truthfully.

E: What would you share with a new volunteer?

Well. I guess just be as caring and compassionate as possible. Realize that its not at all about you or your feelings and if they say things that are unpleasant to you or if they do unpleasant things its definitely because of you or as a result of anything you've done. So if they get hateful or if they get upset in any way its probably about not you so don't be so self-conscious about it. Just you know you have to keep in mind that you are there to help them not the other way around. So you have to be the one who kind of takes charge, and you've been trained and should have a good idea of what is acceptable to do and what is not as far as helping them or you know explaining things to them. You know you only do what you can or what you feel is right and don't worry so much about trying to... or doing something wrong ...don't worry so much about doing something wrong.

E: What does volunteering for hospice do for you personally?

It just definitely gets me, first of all it gets me off the campus which is a good thing probably. Kind of a relief and kind of a way to get away from the college life. You kind of get in your comfort zone, surrounded by people just like you all the time. Getting into hospice really gets you into territory where people really do have very legitimate very real needs. Basic needs like being helped with being clothed and bathed and being talked to. Like on campus, I don't think you rarely have to ever worry about finding someone for you to talk to if you really need to. Which is wonderful but for these people they really don't have that many resources and a lot of them I think throughout their lives have been very connected in different organizations and their families, they've been integral parts of things and been social and they probably miss it even though they're not able to do it. And so for me personally to get to interact with someone who really needs it is really rewarding and so it just kind of gives me a different perspective, and probably more humility or like a way of like to relate to people. Even here like my friend I realize that people just sometimes need to be treated especially kindly and we don'T always make that effort to be kind. And be careful with people like maybe we should and so it kind of gives me a chance to practice that.

E: What are your thoughts about meeting a patient for the first time?

About meeting a patient for the first time?

E: Have they changed now that you have been a volunteer for a couple of months? Your perspective of meeting them... were you nervous going into it or has it changed?

I think its kind of the same. I think it was a little easier. But like every time its just like meeting a new person so you don't really know what the person is going to be like and it could be someone who is very much in pain or very distressed sometimes like {name of Mexican patient} can be or it can be someone who is very laid back, very easy going – you don't know what you're going to get unless they have background on the person.

E: So do you get nervous?

Yeah, you get a little nervous.

E: Or is anxious a better word?

Yeah maybe a little anxious or curious, sort of like when you are going to take a new class or something. You're just kind of unprepared I guess is the best way to describe it. And if you get kind of get antsy about being unprepared you worry about things.

E: Unprepared for how to handle it or?

Yeah.

E: What kind of physical condition they are going to be in?

Where you are going to find them is always my worry.

E: Because they are in nursing home.

Because they are all about and they're doing stuff. Which one, you know if they're not in their room there is no way to tell which one they are. And then you have to ask someone. So that's really kind of ... finding them is a little... cause you don't want to get the wrong person and feel silly and but its kind of not a big deal and you have to remind yourself of that. It's okay and you'll get it down eventually. So

E: How do people react to you when you tell them that you are volunteering for hospice? Especially a friend or someone not in the medical field.

They just kind of think that its interesting that I would want to do that. I guess. Its just not something that looks very attractive to people.

E: Especially for a young person. How old are you?

I'm 20. Um A lot of people I think when they think volunteer they think big brothers, big sisters um you know pets, like volunteering at a shelter or volunteer work working with children is very popular. Because its fun, its fun to work with kids, its fun to play with animals. Its maybe not so quite fun if you have to … I think um working with senior adults is kind of an acquired taste. Um its not for everyone and its not always enjoyable. Although I'm sure little kids can have their moments and they're like ohhhhh. But I think senior adults are kind of left out sometimes in the volunteer spectrum.

E: Do people ever ask you about your experiences?

Yes, especially people that I know a lot. They'll say hey did you where were you. And I'll say I was doing my hospice volunteering. They'll saw hey what did you do, how was it. And I tell them about kind of basically what I told you. I think I've told the {Mexican woman's name} story more than once. About her wanting to know what I wanted.

E: How do people respond when they hear the story?

A lot of them, a lot of the stories I tell are kind of humorous so they're like… oh that's really cute or something like that. They thinks its funny they're not like oh my gosh what are you going to do. They're just like yeah stuff happens. Cause I think a lot of people have had or have known people or been to a nursing home so they can kind of understand… but yeah I mean… I go with the flow.

E: Its kind of like time stops.

Yeah that's one of the most interesting things is that when you get older apparently or when you develop this, sort of ____, is that you don't seem to have a concept of time and you don't seem to be able to form many new memories. It seems like or be able to remember things. That's interesting.

E: Do you think {Mexican patient's name} remembers you?

That is so difficult to say. I think maybe she does.

E: To some degree.

Uh oh. And I know my other lady does because she um my volunteer coordinator went in to visit her one time, cause she goes around and does a periodical check on the patients, and my lady said oh hey you're back, you already came once this week. And she got me confused with the volunteer coordinator but she does remember that I come.

E: What are you thoughts on your own death?

You know that's an interesting topic because I have known kids like in high school that have died. And its kind of like at any time I could go. I have a friend and her father just

recently got cancer like in his lungs. They got so bad that they couldn't operate. So I think maybe um just kind of having watched people. First of all if I ever get that old I'm not sure I think I would rather just die quickly and not have to experience humility and all sorts of really kind of almost humanizing aspects of becoming older, like incontinence and not being able to dress and feed yourself. You just kind of loose that dignity and I am not really looking forward to that but maybe I'll be so out of it I won't care. So I think that's pretty far into the future, that's the way I look at it as a young kid, a young adult person. And its thankfully its something I don't think about very much because its so far in advance of everything I have planned.

Transcripts~Participant 9

E: And what lead you to get involved with hospice?

Well I work for the company so.

E: How did you end up working for the company?

My dad works for the company and I am very interested in health care. It's a profession I am considering at school. Especially working with the elderly.

E: So how did you … you started working here… how did you get to be a volunteer?

Uh uh.

E: What's your current level of involvement?

I'm a volunteer.

E: And how often do you volunteer?

Two to three times a week.

E: And tell me what all you do?

Um, it just depends on the patient. Some patients I go and I sit with and they are asleep the entire time that I am there. But they sleep because I'm there they know that somebody's there with them they're okay to sleep. And um a lot of times I go and just talk and just kind of hang out.

E: And so are you doing respite care?

Yeah.

E: And so you don't have a patient?

Yeah I have two patients. Well I have one now, one just passed away over the weekend.

E: And how long have you been it?

For about I think three months now.

E: How old are you?

21.

E: Did you go through training then?

Yeah.

E: With the volunteer coordinator?

Yeah.

E: Can you tell me what it was like when you got your first assignment?

Um. I wasn't too scared because I've done stuff like that before.

E: Like what stuff?

Uh I used to work at a disability home where I was the director of activities so I would go and just sit and entertain and enjoy others company.

E: So tell me about your first assignment, your first patient?

Well the first time I went and saw her she was not doing very good. She's doing much better now but she was not doing very good. And she and she was real loud and kind of disoriented so it was a little... I guess that made it a little awkward.

E: Tell me about it.

Okay. I went in and I tried to talk to her about the things that she liked to do and she just said fishing and that was it and I tried to get her to elaborate on it some more and she just said that she liked to do it and I just I don't know it was kind of hard to get her to ... talk.

E: Was she in a nursing home?

Yeah. We uh the volunteer coordinator took me and introduced me cause it was my first one ever. So she took me and we just met with her and the family.

E: So you weren't really nervous?

No.

E: But awkward huh?

Yeah, it was a little awkward cause she wasn't... she seemed okay with me being there but she a little irritated.

E: The patient was?

Yeah. She felt like she just wanted to be all by herself.

E: So you did to talk to her for a little bit and then you left and then how often do you see her?

I see her once a week for two hours.

E: And what do you guys do?

Uh, she sleeps some of the time I'm there. She's doing a lot better and so she's spending a lot of time with her daughter up during the day. And I get there at uh in the afternoon so she kinda takes a nap for about the first hour I'm there usually, cause she's so exhausted from the day. And then we just talk and that's pretty much what we do... we just talk.

E: Can you tell me about a time when one of your patients died? Maybe your most recent one?

Yeah, she just died.

E: Tell me about the first time you met her and how often you saw her.

The first time I met her she was asleep well I didn't meet her. The first time I went she slept the entire time I was there. She never even knew I was there. And it just she never really remembered me.

E: Why?

Oh I don't she just didn't remember me. She didn't have any family or really any visitors at all. And she was in a lot of pain even under hospice care and everything she was still in pain and she never had anybody come and visit her. The nurse told me I was the only person that came and sat with her. And she always in a lot of pain, nearly every time I went to go see her. So, it didn't hurt me ... um terribly bad. I know that sounds bad but she passed away because

E: But how long had you been visiting her?

Probably about two months. She was real nervous, she never

E: And what did you do during the visits?

With her, um I just sat and held her hand and just talked to her. And she would always say just hold my hand, just hold my hand, and she was just she was constantly moving and she was so nervous. I would come in, on the days she was awake, she would just be yelling for somebody to come and sit with her and hold her hand. Yelling out the door for somebody to sit with her. I feel like I like I like I made a difference in just being there because she was so anxious all the time. She could never relax.

E: Did hospice call you and tell you that she passed away?

Yeah.

E: Tell me about your most memorable experience as a hospice volunteer.

Okay my other patient um that I sit with she went to after the first couple of times that I went she was real kinda wanted me there but didn't want me there and she like I don't know if they... her medicine was affecting her or what but she got real mean and hateful and she was real ugly to her caregiver and her family...

E: Like saying...

Things, terrible things. Calling everybody killers and um she was just she... I didn't even recognize her when I would go and she was like that for over two weeks. And um it was just ... I couldn't believe it I've never seen somebody just completely turn. It was like she was possessed by the devil. I never seen anybody act like that before. And they put her in a nursing facility for some respite care for her family for I think about a week I don't know and when she came home she was wearing jewelry when I went and saw her, she had her nails painted, now she gets um now she gets almost all day long, where before she slept all day long and she was only up for long enough to eat and go to the bathroom basically. And she um she even went out of the house and got her hair done. And it took everything out of her that she had but she but she actually did go do that. And she's up and alert and that's nice.

E: A transition.

Because they've gotten her medicine all straightened out and she's not ... she's still in pain because of the disease that she has, which is _____, you just can't regulate somebody's body like that. It's just natural frustration. But she's doing so much better now and I just want to see her because she's so excited at times and it's nice.

E: Can you tell me what it was like the first time you met her?

Um, I guess it was just awkward like I said just because she wasn't sure if I was needed and uh

E: And she was at home?

Yeah she was at home. And when its just me and her she just talks to me and everything else. And then when there's somebody else there she won't talk as openly with me. I don't know if its just because someone is there or...

E: How does this experience have an impact on you personally?

Um, it really made me believe more in hospice because I know that its because, I mean besides my belief in God that hospice was such a blessing in her life and got her medicine straightened out and able to get her I guess help get in a nursing home so her family could have a break because they were .... Um I talked to her daughter, the caregiver, and she was in tears talking to me and she doesn't even know me. I can't imagine what she was really feeling and she loved her mom and her mom is calling her the devil and killer and just saying hateful ugly things to her. It just... it definitely made me love hospice.

E: Tell me about a bad experience.

Um...going and seeing... my other patient was in a nursing home, the one that just passed. She was in a nursing home and I went in well I don't know its just kinda gross. I went in one day and she had gotten up and walked around and just went to the bathroom all over her room, all over her floor and it was a pretty bad experience. It stunk the whole time I was there.

E: So what did you do, call somebody?

Yeah. Well they had just ... it had just happened right before I got there so they were already taken care of it.

E: You just had to wait while they cleaned everything up?

Yeah. I stood out in the hall and waited until they cleaned it all up so I wouldn't get in the way. That was a pretty bad experience. And she almost fell one time I was there and that was a bad experience.

E: What happened?

She tried to get out of bed without help. But I was there to catch her and ...help her.

E: And you just pushed her in bed?

Yeah, I just helped her get back into bed until somebody came because she was too heavy for me.

E: And so it's a bad experience...

Because it scared me so bad. I guess that's it. I really haven't had any bad things happen.

E: Have you ever turned down a patient?

I almost turned one down.

E: Tell me about that.

Um she ... just the excitement about the family. The family kept calling and kept calling and kept calling and wanting a volunteer.

E: Kept calling the volunteer coordinator?

Yeah and we're just so overly pushy like I just didn't even want to go out there. But then when I did end up going out to their house she was just fine.

E: So you did end up going.

Yeah, I ended up going because I just felt like if they really wanted somebody that bad then they were desperate to get out of the house.

E: But they were pushy?

They were really really pushy. I couldn't believe how pushy they were. She called like I don't know four or five times in a day. And she wanted me to come out that day and we had set it up that I would start coming out the next week, she wanted me to come out that day. I was like oohh I would love to be able to go out that day but

E: Is she still a patient.

No.

E: Where you there when she passed.

No.

E: Have you ever been?

No.

E: You just get a phone call.

Yeah.

E: What advice do you have for a new volunteer?

Okay I've got two I would tell them if they wanted to volunteer. First thing I would tell a volunteer is that um a patient will complain about their pain and the caregiver will um not because they don't love them but this just happened to me recently, they're always with somebody and they said oh she's just she's always like that.

E: The patient is always like that?

Yeah and the one that was really anxious all the time that just passed away she was always like that and well come to find out that she had a fractured hip and so she really was in a lot of pain. And they... and nobody knew and she had a fractured hip and so just my... things you know you never... never let them say too many times that they're in pain because you don't know if they really are in pain and even if they don't even if they don't have anything wrong with them maybe they just need that extra attention like for her I was the only one that went and sat with her so while you're there if you can give them attention it won't hurt you. And you're there anyways, just to give them that hour or two or three hours of attention that they might not get at all for the rest of the week.

And then my other thing I would tell a volunteer is to never underestimate how important it is that you're there. Cause when I would go in and I would sit with that lady, um my first patient that ended up having to go into a nursing home for a week and her daughter just crying because she hadn't had time to even go to the grocery store and get them some kind of food. She had just been there and her mother had been so hateful to her and all that she wanted was just an hour just to go out or just two hours just be able to breathe and relax and not stay at home. Just whatever and

Sometimes I go out there and all that woman does is sleep. The whole time... like I went yesterday and she was up for like five minutes for the two hours I was there, she slept the rest of the time. That, just to make sure that that woman is safe you know, her daughter can know just its so important to that family. It might not seem like a big deal to me at all because I'll just go and bring a book and I'll just read and I would have done that anyways. So its not that big of a deal to me and but it makes such a big difference to that family.

E: What does hospice do for you personally?

Uhh I've been volunteering in different organizations for 8 years now, since I was in high school and I've volunteered... I've volunteered in probably 15 different organizations and you can just see the impact each organization. Just from changing a light bulb to vacuuming, picking something up for somebody, and running an errand for somebody or just going right now and sitting with somebody. Just to be able to see the difference you can make in someone else's life. Just by doing something just that seems terrific or just by doing it seems like a terrific grand gesture. Just that's how I see it.

E: It's like time stands still. Do you agree?

Yeah, I guess I agree with that. It makes everything else seem .... Everything else not seem important. When you go and with somebody that truly is in pain. I sit and think sometimes I just think I think just people always say that the elderly revert back to being a child and so they get treated as a child. Well I do not believe that any elderly person should ever be treated like a child even though they might need to be fed or they might need to be wearing a diaper. That person... they had a job, they had kids, they had a house, they drove a car, they did everything that we did and they have lived a life that doesn't deserve to be treated like that. So I guess in that sense... I don't know if that

answered your question. I don't think it did but. I guess it just does make everything seem not important because one day you're going to be like that and you can only hope that the way you treated somebody else would have an impact on they way you are treated.

E: What are your thoughts about meeting a new patient for the first time? Have they changed?

Uh my only concern, keep in mind I'll be getting a new patient cause my just passed away, is that they'll be in a nursing home and I do not like going to nursing homes.

E: Tell me why?

Um I feel that I make... with this woman that I went and sat with because she really needed direct care all the time because she was so anxious I felt like I did make a difference. But there's paid staff there that get to go home at the end of the night you know and get to relax. When I go into a home its this family that doesn't get paid to stay there and not work and doesn't even have time to go and do anything for themselves, go get a haircut or go get something to eat or do anything like that, just it feels different. You know helping... I feel like I making more of a contribution to society or I made more of a difference in the not in that person's life but in the family's life. I feel like I made the same difference in both of their lives but not in the family's life.

E: So you just hope its not a nursing home... any adjectives to describe it? Do you get anxious, nervous, excited?

I always... I never really think about it. I always hope I can find the place that I am going and get there on time. But, no I don't think I really have any concerns about it. That's all...

E: Especially because you're young.....how do people react to you when you identify yourself as a hospice volunteer, with people outside hospice...friends, people you meet?

Um, I don't know. A lot of the times people are just really anxious to learn about hospice who don't know what hospice is. Really anybody who knows me knows that I volunteer anyways because I'm a really big advocate for volunteering no matter what you do.

E: The people who do know that you are in hospice do they ever ask you about your experiences?

Um, not really. I mean they ask me what I do but they don't ask me specifically about the patients that I see.

E: What are your thoughts on your own death?

Uh, I just read a story, watching all of the hospice videos and everything, and I just read a story the other day about a man that came to know the lord in his old age and he said that its all been wasted time, its all been wasted time. And in watching the videos and learning at school what I am learning, and going and sitting with these patients um. When I talk to them, they have had so many wonderful life experiences and they don't have any fears about dying because they have lived such a fruitful life. That's how one was, one of my patients she said that she had been married for 35 years and it was a terrible marriage. But then she got married again and she was only married for 6 years before he passed away and she wished that she had had more time with him because God really showed her what true love was. And I just really feel like if I open myself up and I let myself enjoy life and not waste my time on ___

Transcripts~Participant 10

E: Can you tell me how you got involved with hospice?

I uh guess November of 2002 my dad passed away in a week. He spent one week at home on hospice so like I was familiar with it then. And I started back at school here and knew it was important to me. And then an undergraduate in my lab was doing hospice and uh it just came up and he told me all about what he does, how much time he has to give. And I was like well it sounds like something I want to do. So I just started like last semester (August 2003).

E: The fall?

Fall of 2003.

E: And so you've been a volunteer for about three or four months?

Uh yeah about four.

E: How old are you?

26.

E: What is your current level of involvement with hospice? Do you do patient care?

I'm a volunteer for patient care. Um I have one patient fully until he passed away. And then I've been assigned another patient that I went to see once. And he didn't request it... and so I am still currently assigned to him but I haven't seen him in about three weeks but I am probably going to try one more time but then I don't think he desires to have a volunteer.

E: Can you tell me about your first assignment? What it was like? How you felt about it?

The first they always have someone go with you and it was a respite sitting which it doesn't mean I'm not assigned to that patient. They said can you sit for this hour, they need that. You know his caretaker needs to go out. And his name was {xx} and so we went and he was a military guy and basically sat in his home and asked him probably three questions and he talked for about an hour straight through. It was really great, just getting there and I guess the volunteer coordinator came with me. We walked in and then she went and did something and we just started talking and we talked. She came back in and sat down but we just talked the whole time. She questioned him a little but manly it was just him talking for about an hour straight.

E: So it was a good first experience?

Oh yeah I really enjoyed it a lot. I learned a lot about him, just to hear his journey and his history.

E: Were you nervous before you went?

I think I was probably more nervous that the situation would be similar to my dad's and I didn't ... like I didn't want it to be about myself. Like I wanted to be there for the patient so I didn't want to be all emotional or ... you know I wanted to be there with them.

E: Did you see this patient again or was it just respite care.

No. It was just respite care. One time.

E: Tell me about the first patient you were assigned.

It was great. His name was {name of patient} and he was a retired minister.

E: Tell me about the first time that you met him.

He was in a nursing home and he was 89 years old so real weak, real frail, depressed, didn't wasn't choosing to eat... like that's all the things I learned going into that so I wasn't sure, like my expectations, I wasn't sure if I was gonna be talking to myself, or if he was coherent. So this guy looked really frail, really old, but just real receptive, couldn't talk a lot. So I'd say like oh I heard this about you is that true, --- yeah, yeah that's true..um--. And then I asked him a few things he'd share about some family or about other people and then I asked him about his church, being a minister just different stuff so.

E: Did the volunteer coordinator go with you?

No.

E: Did you have any problems finding him the first time?

No.

E: He was in his room?

Yeah he was in his room. He was pretty much, from what I understand I thought he was always going to be in his room. But that wasn't the case throughout but. Yeah so he was in his room I came up I knew his room number and kinda just walked around the nursing home.

E: Did you go in and introduce yourself?

Yes I just said this is who I am. I'd really like to visit with you and talk, whatever you'd like. And uh kinda in and out at different times, like getting tired talking, but and throughout all the visits not just the first one but, are you sure like I'd really like to visit with you do you do you want that, is that alright. Yeah Yeah. He'd look around... I was all well I'm gonna leave now. So it was good the first time.

E: How long did you visit with him?

I think it was probably two months. I don't have all the records but at least 6 to 8 visits.

E: And the patient passed away?

Yeah he passed away um I think right at November.

E: Were you there when he passed?

No.

E: You just got a call.

Yeah. I saw him I think probably Friday. I saw him and then the volunteer coordinator called me on Saturday or Monday and said he is really really weak and just wanted to let you know that. And I was like yeah I just say him and then he passed away I think in a day or two.

E: That was your first patient and the first patient that you had that died?

Yeah.

E: Tell me about your most memorable experience as a hospice volunteer.

Um Actually probably just... just to talk with {name of first patient}. Um so few times like he he had a high school sweetheart and then he was married and his wife passed away or divorced, but then they got reconnected with his high school sweetheart like when he was 80 and they had written letters back and forth. So one day, like it was closer to the end and like he...we didn't talk a lot, but he had some cards on his desk and a few of them were from her and some other people so just... got to read those and read them out loud to him and I think that he was coherent and could hear some of it. But I just know it was real impactful to me to know what was going in their lives and to be a part of it. Like it was really, it was really memorable.

E: Did his death have an impact on you, like in your personal life?

Yeah it uh it made me evaluate like why why I want to do it and the realization like that choosing to be in a relationship with them it is going to affect them. And like I think probably being my first patient I was real hopeful like oh we're gonna, like so many

strides communicate so well like its gonna be really great thing. And I don't think that happened. I mean we talked some um, so it made me kind of reflective on you know was I present enough? Or was it was I there to care for what he needed? And then sometimes just evaluate okay so what what do I want to learn from this for my next patient. What have I got... what memories am I going to take to it just of our interaction so. I think its just a reminder of mortality too. I think about it a lot.

E: Tell me about a bad experience.

My most recent one. It was at the VA home. It's my new assignment. His name is {patient name} and...

E: And you've only seen him once?

Seen him once.

E: So this was the first time you met him?

Yes. And so like I didn't get .. completely understand.. like so it's a VA, he smokes, in a wheel chair, but he's going through a lot of depression and they think that a volunteer would be good for him. This is from the volunteer coordinator. So I just went out there, its actually a big place and I have been out there before. So I drove and it was kind of familiar.

E: Were you nervous going out there?

I was kind of, I was anxious but I was kind of like this is going to be good. A new relationship. But then I al... I think I get nervous with hard of hearing. Like so go there and finally found the room and he was in the doorway about to wheel out. And I looked, are you {patient name} because there were two different names on the door. UHH WHAT? And I was just like...Yeah, I'm {patient name}. So um I am from hospice, I'd like to volunteer, I'd like to meet with you and talk with you if you're interested. And like I don't know if he ... like he definitely has hearing problems "what, huh?" And then it was "no, no I don't want to meet. I'm about to leave." Like he was going to smoke or something. Well I can come at different times I just didn't know what works for your schedule. I'd like to meet with you. "No, no, no". Like he was constantly like forget it. And so ... at first I was like am I not communicating right or is he just not interested ... so after a few minutes of that I'm like I'm pretty sure like this isn't going to work. So I said thanks I'll try to come again. And then I called the volunteer coordinator and said did he request a volunteer and she said no but the nurses thought it would be good for him. So I'm like okay. Well I'll try again I guess but probably its not going to be anything. And that was right before the Christmas holidays and so I haven't...

E: So why would you say that's a bad experience, in your own words?

Well, I think I like it was kind of discouraging for our relationship. I mean I'm probably not going to... I want to go back and attempt again just cause I think that would be weak if I ... well it wasn't good for me so I'm leaving. So preferably I'd like to go again but I think trying to have a relationship with somebody that obviously doesn't want one I mean its not necessarily a good idea so

E: Have you ever turned a patient down?

Not for any like health reasons, manly just location or time. Those are the only reasons.

E: Do you have any preferences?

The volunteer coordinator gave us a sheet to fill out and at first like I did want someone coherent, someone not in a nursing home like I hadn't had a nursing home.... I've done a lot of nursing home stuff but never something that I really enjoyed. Um so like I preferred not that environment ... but my first one was in a nursing home so now I think I don't have any real preference as far as nursing home. Like I'd like them to be able to talk but...but I think I had some really good times with my first patient when he wasn't totally there.

E: What advice would you share with a new volunteer?

I think, especially getting to know some of the volunteers, uh like I think I'd like just to share that it should be about the people and their own hospice. Like I think, not a lot just a few in particular, they think that volunteering is about them. Like ohh I'm doing a lot and I just think that self-centeredness in general is not good but then especially in that setting where people are passing away to go and make it about yourself like that's probably...

E: Any other advice?

Just to ask a lot of questions. Be a good listener. But also be open to sharing. It shouldn't be a one way relationship by any means, to be closed off would be....

E: You really depend on the patient then.

Yeah.

E: What does volunteering for hospice do for you personally? How does it add to your life?

I think the main reason as a Christian like we should care for people regardless of where they are in life, and what they are and I think the dying, generally people are afraid or don't want to talk about it, don't want to be present. I think it was a real, it was a real joy and pleasure to be present when my dad passed away. And know how much he meant to me and our relationship but also just in that its like a significant part of life, like just

sharing that with other people, I think is a real, real pleasure, and it's a privilege to be a part of their life whether its one week or however long. And just provide love.

E: What are your thoughts about meeting a new patient for the first time? And have they changed since your first patient?

Um I think I'm not as apprehensive as far as if the situation is more then I can handle or like just, like I think I'm more comfortable now with the idea of dying and so

E: Why?

Um I think just being around people more.

And I think more, now especially after being turned away too, like I feel better like... its not reflective of who I am like if they you know the first time I see them if they don't want to talk or do like its like regardless its not reflective of who I am. So I think that...

E: So before you would have taken that personally?

I think so. I think I would have. If that would have been my first patient I would have been like oh I am a terrible volunteer.

E: Would you say you still get nervous?

I think probably there's still a little bit on a first visit, I think definitely. But I'm far more secure and excited.

E: How do people react to you when you identify yourself as a hospice volunteer?

People that like I think have similar passions about Christianity or people like willing to understand ask more questions, are really interested, like well how did you get that you know what's the story behind that, a few people. I think other people are confused, like what's hospice in general, but then also like "so that's what you do." And I think, especially people who probably know like that have been around death because of my dad maybe, they are confused. Like that's kind of weird, but good I guess.

E: Does anyone ever ask you what you do or about your experiences?

I've had a few co-workers ask me, like what do you do.

E: Do they ask in detail or in general?

Usually in general. And I don't know why that's the case, if it would be uncomfortable with specifics or...

E: What are your thoughts on your own death?

Um I think in the last two years I have thought more significantly about it.

Um like I think of the idea of it and read I think a lot of authors that don't shy away from that topic and I have another book that I am about to start reading.

E: Which one?

Its by Henry Nowland, The Gift, I just got it for Christmas and I haven't read it. I'm a big Nowland fan I just read another book about the balance of joy, sorrow and life on ministry. It was real good. I am real reflective on reading, like that you can't separate those and you can't just be all excited about life and celebrate life and not think about death and dying. You know its on the horizon or part of it and so. I think more about the people I love and cherish about their dying more than my own. I think the gift, I guess it's the gift of dying, like I think that I hope that when I do die that I have the opportunity to see it as a gift and have the time. Like I think it would be really great to be able to... to know that its coming and reflect and be able to pass it on to others to deal with it.

E: Two years ago do you think you would have thought about it this much? (referring to his dad's death)

No. And to see how my dad handled it too, like made it really tactful. Know that it can be um that it can be you can face it without fear and just everything that I... I guess my perception of death before hospice, afraid and fight it instead of welcome it and

E: So you were afraid before and now you think you're not afraid.

Yeah I think ideally I would not be afraid, but I am. I feel like I'm not ready to die.