Hospice nurses, spiritual development and a changing health care paradigm

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Hospice nurses, spiritual development and a changing health care paradigm

Abstract
Recently researchers have become increasingly interested in how we are going to care for our growing elderly population. Little, however, has been done to examine the personal attitudes toward death, dying and spirituality of the professionals who care for the terminally ill. The purpose of this study is to examine spiritual development among hospice nurses who work in palliative care. Data were obtained using qualitative, in-depth interviews with 20 hospice nurses (4 males, 16 females) from ages 36 to 61. The interviews were conducted at three different hospice organizations located in the northwest, northeast and New England regions of the United States. Analyses examined the personal adversities, individual experiences with death and dying and life-course in an effort to explain occupational choices and faith/spiritual development of the respondents. In conclusion, although all three aspects for spiritual development were found, the most salient influence was the gradual maturation of faith. Their faith was established before their occupation at hospice, and thus was instrumental in pursuing such a career. It was also found that low death-anxiety is associated with higher levels of faith.

Keywords
Sociology, General, Gerontology
HOSPICE NURSES, SPIRITUAL DEVELOPMENT AND A CHANGING HEALTH CARE PARADIGM

BY

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BA, St. Lawrence University, 2004

THESIS

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This thesis has been examined and approved.

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August 2, 2007
Date
DEDICATION

For the men and women
Working for Hospice...
ACKNOWLEDGMENTS

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ABSTRACT

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Recently researchers have become increasingly interested in how we are going to care for our growing elderly population. Little, however, has been done to examine the personal attitudes toward death, dying and spirituality of the professionals who care for the terminally ill. The purpose of this study is to examine spiritual development among hospice nurses who work in palliative care. Data were obtained using qualitative, in-depth interviews with 20 hospice nurses (4 males, 16 females) from ages 36 to 61. The interviews were conducted at three different hospice organizations located in the northwest, northeast and New England regions of the United States. Analyses examined the personal adversities, individual experiences with death and dying and life-course in an effort to explain occupational choices and faith/spiritual development of the respondents. In conclusion, although all three aspects for spiritual development were found, the most salient influence was the gradual maturation of faith. Their faith was established before their occupation at hospice, and thus was instrumental in pursuing such a career. It was also found that low death-anxiety is associated with higher levels of faith.
INTRODUCTION

Due to an increase in life expectancy rates, where the average American is expected to live to be approximately 76.6 years of age, the United States is experiencing a growth in elderly individuals who are spending longer periods of time in end-of-life stages (Harrison, Ford and Wilson 2005; Kiernan 2006). As a result of this extended time that older individuals are spending in the later stages of adult life, more and more elderly are suffering from chronic and degenerative diseases. Terminal diagnoses such as cancer, heart disease, Alzheimer’s and AIDS have prompted changes in the health care system, with many individuals opting for palliative care versus curative measures (Chrystal-Frances 2003).

Palliative care or pain management is a relatively new phenomenon in the United States dedicated to holistic care and a type of treatment employed by an organization known as Hospice (Wasner, Longaker and Borasio 2005). Hospice care provides terminally ill patients and their families with physical, emotional, and spiritual care in an attempt to help their patient die with dignity (Harrison et al. 2005). The first hospice established in the United States was founded in New Haven, Connecticut in 1972 and it has since grown to include more than 2,500 hospice organizations around the country (Harrison et. al. 2005). While hospice utilization has grown to provide care for over 400,000 patients annually in the three decades since its beginning (Coile 2002), there has been very little research that has examined the health care professionals responsible for the care of terminally ill patients, particularly the hospice nurses.
In addition to greater utilization of hospice care there has been a simultaneous growth in the amount of attention social scientists are devoting to the study of spirituality and spiritual development. Robert Wuthnow (1998), a social scientist interested in spirituality, attributes this attention to an increase in Americans’ dramatic fascination with spirituality in pop-culture and he along with other researchers focus on the changes and shifts of American religion and the factors explaining spiritual development (Bellah et al. 1985; Wuthnow 1998; Roof 1999; Dillon and Wink 2007). The aim of this thesis is to contribute to the latter –i.e. in the factors explaining spiritual development. As identified by the literature these factors include; adversities/negative life events (Wink 1999), exposure and experiences with death (Reed 1987; McGrath 2003), and age or a gradual maturation where particular life stages explain spiritual development (Atchley 2006; Dillon and Wink 2007).

Given these factors, Hospice nurses are particularly suitable to focus on the different explanations that previous researches have found to be the most salient in spiritual development. Research in the fields of religion, spirituality and aging indicates that health care professionals are susceptible to adversities experienced as a result of working with the terminally ill. Being at the bedside of dying patients often challenges the palliative care worker’s sense of self because they are a witness to the pain experienced by their patients and families (Currow and Hegarty 2006:123). Irrespective of their work at hospice, nurses may also be influenced to take a job at hospice or develop increased spirituality as a result of adversities experienced in their personal lives. For example, the loss of loved one or the stress of a divorce may act as life changing event (Wheaton 1999: 179) that can influence the occupational and/or faith trajectories of the
hospice nurse. Separate from the adversities resulting from exposure to death, end-of-life experiences (i.e. for those who are terminally ill) have also been associated with spiritual development (Reed 1987). Lastly, age is another factor that has been found to explain spiritual development (Atchley 2006; Dillon and Wink 2007). Within the scientific study of religion researches have found that a gradual maturation is the greatest explanation for increased spirituality. This finding suggests that age and later adulthood is associated with spiritual development (Atchley 2006; Dillon and Wink 2007).

The aim of this thesis is to reveal the complexities of spiritual development by studying hospice nurses and their individual trajectories to becoming nurses. Specifically, I hope to identify the factors associated with spiritual development and the role spirituality plays in palliative care (as well as the role that hospice plays in the spiritual development of hospice nurses). To date, there is no literature that examines only hospice nurses in the social sciences, how they come to care for the dying, and the role that hospice has on their spiritual development.

There are several layers of intricacy within the literature on religion and spirituality. On one hand, over the last few decades, researchers have made great progress in building our knowledge about religious behavior (Iannaccone 1990). For example, by using survey instruments such as the General Social Survey (GSS), we can empirically test trends in church attendance (Hout and Greeley 1987) and Americans’ beliefs in life-after-death (Greeley and Hout 1999). However, there are many questions that cannot be answered using survey data. Determining the differences in religion and spirituality, the meanings and experiences individuals attach to religion and spirituality, or how people become religious and/or spiritual are examples of issues that often cannot
be answered through the use of a survey. With regards to spirituality in particular, researchers like Wade Clark Roof (1999) argue the term still remains a bit of a "buzzword" in the social sciences because scholars are more comfortable with analyzing religion in its traditional, church based forms because they are "intact entities, cut off from their environment" (Roof 1999: 295). Therefore, although we are learning more about religion and spirituality and the meanings they hold for individuals in the United States further research is needed on spirituality and spiritual development.

To place this thesis within the context of previous research on both health care and the social science of religion, the first chapter examines in detail pertinent literature that spans a wide range of topics from the changes in American health care delivery to developments in American religion and spirituality. The first chapter focuses on America's transformation with regards to its medical care systems for the dying and discusses persistent inadequacies in death education. The discussion of these topics is situated within the larger social contexts of religion and spirituality in the United States. There follows a concomitant review of literature on stress and bereavement as they pertain to the development of faith, as well as research that proposes the life course an explanation for spiritual development. The chapter also explores the effects of exposure to death and the effect that death experiences have on individuals' spiritual development.

The second chapter describes the methods I used in collecting the data for this thesis. I used a qualitative approach utilizing in-depth interviews with twenty hospice nurses and discuss the method and techniques used to analyze the data. In this chapter I also discuss the limitations present in regards to the methodology selected.
The third chapter examines the various trajectories of nursing and hospice for the women and men in my sample. Most of them made their ways to nursing and hospice in more conventional ways: unlike the nurses in chapter four, the nurses introduced in chapter three arrived at hospice via a job opening, part time work, or early exposure to gerontology. Chapter three also explores the relationship between hospice practice and the larger medical world within which hospice functions. The nurses evaluate their medical training as preparation for their work in palliative care, as well as share their views on the larger medical communities’ support and acceptance of a non-curative, holistic approach to nursing care.

Chapter four is about adversity and negative life events as influences on the nurses’ occupational and faith trajectories, and, as such, chapter four serves as a bridge to chapter five in which the nurses share their personal faith narratives. In chapter four, the nurses discuss how negative or adverse life events, such as the death of a child, facing a terminal illness, taking care of dying parents, and their own divorces have led them to work for hospice and changed their faith, or whether the adversities they have faced have solely influenced their faith.

Chapter five is about the religious practices and beliefs of the hospice nurses in this sample. First, the hospice nurses give retrospective accounts of their faithful histories and their church attending childhoods. Then they share their current religious/spiritual practices: some say they are religious and spiritual, some label themselves as only spiritual, and some are still seeking. Respondents share how they practice their faiths and define what being a religious or spiritual person means to them.
Chapter six explores the experiences the nurses have had working around death. The nurses share stories about certain events that happened during the processes of their patients’ dying, some of whom saw loved ones who had already passed away, and some of the nurses clearly perceived that their patients “had one foot in this world and one in the after-life.” They also talk about the varying roles religion and spirituality has played for their patients at the end-of-life. The second part of this chapter discusses how being around death and watching these experiences has influenced the nurses’ own personal notions of death and whether working at hospice has influenced how they feel about their own deaths.

Chapter seven presents my conclusions about this study. The three major findings from this study are; firstly, that hospice nurses come to their job with an established faith and their job plays a low to moderate role in their spiritual development. Secondly, the most significant factors in explaining spiritual development are adversities and age. Divorce was the most significant life adversity that increased spiritual development along with age as factors which increased faith. The third major finding was that nurses’ who reported higher faith also reported lower death-anxiety. In this chapter I also discuss the implications, how this sample fits into the larger spiritual development literature, and the limitations that are present in this thesis.
CHAPTER I

LITERATURE REVIEW

*The Pendulum of Care*

According to Paul Starr (1982), the practice of moving the sick out of the home into the hospital for medical treatment only began in the United States in the 1920s and 1930s. The only patients that had been taken from the home for institutional care prior to that time were those who went to mental asylums. The ill had been simply cared for at home by family, friends, and home visits from physicians. In his social-historical accounts of the changes in the medical system, Starr explains that industrialization and an increase in the geographic mobility of Americans initiated the practice of hospitalizing the sick (Starr 1982:72-77).

At the turn of the twentieth century, doctors discontinued making home visits to treat the sick. The industrial era brought about significant changes in the structures of work and family which dramatically decreased familial care of the ill (Starr 1982). At the same time work and family structures were changing hospitals gained credibility due to their hygienic and sterile techniques, along with advancements made in medical technology and equipment. (Starr 1982) This meant that the doctor-patient relationship moved from the home and into the hospital.
In a 1913 analysis of the shift from home to hospital care in the United States, Henry Hurd stated,

> Fewer families occupy a single dwelling, and a tiny flat or contracted apartment no longer is sufficient to accommodate sick members of the family...The sick are better cared for [in hospitals] with less waste of energy, and their presence in the home does not interrupt the occupations and exhaust the means of wage earners...the day of general home care of the sick can never return. (Hurd 1913; Starr 1982:74)

Today, however, nearly a century later, research shows that new federal policies and funding such as Medicare and Medicaid, which offer great incentives for managed care (Harrison et al. 2005; Emanuel 1996), invalidate claims that “general home care of the sick” will never be practiced again. Managed care in this sense is a term referring to a patient whose family or friend serves as his or her primary care giver and who has decided not to take any life-prolonging measures, thus the basis for the term ‘managed care’ to mean palliative or pain management care. Palliative care is what hospice organizations specialize in. And although hospice offers services to patients in long term facilities such as nursing homes and hospitals, a large proportion of their patients die at home.

A recent study done by Jeffrey Harrison and Associates (2005), using data collected from the American Hospital Association (AHA) and the Bureau of Health Professionals (BHP), indicates that “hospice programs are a viable alternative for proving cost-effective care” (Harrison et. al. 2005: 83). Hospice became a federally funded organization in 1982 through Medicare (medical support for the elderly) and Medicaid (medical support for lower economic families and individuals) (Harrison et. al. 2005). End-of-life care accounts for 27% of Medicare’s budget, and economic evaluations of
costs done by E. J. Emanuel (1996) show that hospice saves Medicare 46.5% of their expenditures on a patient who receives hospice services for the last month of his or her life (Emanuel 1996). According to Emanuel, hospice is cost-effective also because of the increase in the number of patients who elect "do-not-resuscitate" practices and the decrease in inpatient hospitalization because family and friends are serving as health care providers.

The cost-effectiveness of hospice and end-of-life care is causing the pendulum to swing back toward home care of the dying. Hospice is in a unique relationship with Medicare in that Hospice is the only organization in which Medicare reimburses directly for the care of beneficiaries who are referred by a physician with six months or fewer to live (Harrison et. al. 1996). Therefore, because hospice is cost-effective, saving the federal government's health care costs for the growing elderly population, there are great incentives for palliative care.

From Ideology to Practice

Because hospice offers cost-effective health care, comfort, and dignity at the end-of-life, recent studies have become concerned about how to improve death education for medical providers (Nelson et. al. 2000; Downe-Wamboldt 1997). Death education has only started to receive greater attention in the last few decades (Downe-Wamboldt 1997). Survey research done in the United States found that although the majority of nursing and medical schools offer some sort of death education via elective classes, less than 25% of health professional students ever take death education courses (Dickinson and Fredrick 1992). Thus many medical and nursing students graduate from school, feeling that their training did not prepare them adequately to care for the dying (Downe-Wamboldt 1997).
However, according to Nelson et al. (2000), health care professionals are not inadequate at caring for the dying because of poor accessibility to death education classes but rather because educators in medical schools face a more fundamental challenge in terms of how to teach students to care for the dying (Nelson et. al. 2000). Nelson and his colleagues are a group of thirteen death educators who work in various medical and nursing schools around the country. They argue that students are inadequately trained to care for the dying because educators are not sure exactly what to teach their students; they believe that education in caring for the dying must integrate the psychological, social, spiritual, and cultural challenges for the patient and health care provider (Nelson et. al. 2000). The greatest challenge to medical and nursing students is for the students to examine and understand their own views of and approaches to the psychological, social, spiritual, and cultural elements on a personal level before being able to adequately care for a patient. Although death education is receiving more attention and the challenges are being identified, there are still no studies that research how the views of the medical professionals who are choosing hospice as a career are developed.

The Medical Professional and Spirituality

“People are living longer lives and particularly a longer end-of-life” because of medical advancements in technology (Kiernan 2006). Stephen Kiernan made this statement on National Public Radio in talking about his book Last Rights, in which he discusses the medical tradeoffs that can be made to enable Americans to end their lives slowly (Kiernan 2006). Knowing how to care for individuals medically is a relatively new phenomenon, and our present-day medical system can keep people alive for years longer than they were able to do in past generations: people used to die immediately from
congestive heart failure, cancer, or even AIDS. But today people are able to spend longer periods of time *living* in the process of dying.

To date, few studies have been undertaken with regards to spirituality, spiritual needs, and the medical professional (McGrath 2002; Hermann 2001). Most of the studies that have been done have looked at how nurses can be more sensitive to acknowledging the needs of their patients, rather than focusing on the spiritual nature or development of the nurses themselves (Wasner, Longaker, Fegg and Borasio 2005). Wasner et al. (2005) conducted a study with 63 participants who were nurses, hospice volunteers, physicians, and social workers who received a three and a half-day spiritual care training course. The participants were asked to fill out a questionnaire before, immediately after, and six months after the training. Wasner et al. (2005) found significant positive results in terms of self-perceived compassion, an improved attitude towards one’s own family, and a reduction in work-related stress. Thus, spiritual care training for medical professionals can have a positive influence on the well-being of individuals who work around dying patients (Wasner et al. 2005).

Although Wasner et al. (2005) found that spiritual care training can be beneficial another study found nurses who reported the workplace as stifling to their spirituality (Grant, O’Neil and Stephens 2004). As Wuthnow (1995) has discerned, it is impossible to discount the fact that many individuals derive a great deal of meaning from their work and, therefore, that work *itself* inspires spiritual growth. But there is also no denying that the workplace is “continually subject to rationality” (Grant et al. 2004:265). Don Grant (2004) and colleagues recently conducted a first-time study with 597 university nurses who completed a survey consisting of both closed- and open-ended questions. The study
explored nurses' attitudes about what role their **personal** spirituality should **play** in the workplace (Grant et al. 2004). The findings from this study suggest many nurses feel that their work is an expression of their spirituality but struggle because they feel that they are not encouraged to express their **personal** spiritual beliefs in the workplace (Grant et al. 2004). What these studies do not address, however, is how individuals become spiritual or what factors influence their spiritual development.

**Placing Religion and Spirituality in Culture**

Since the time of sociology's forefathers Max Weber (1904-5/1946-1958) and Emile Durkheim (1912), social scientists have been researching the role that religion plays in society. Despite the fact that these two theorists have separate and distinct views on what the role of religion is, both have made paramount contributions and a lasting interest in the sociological study of religion. More recently we have made great advances in the empirical examination of our society's religious behavior. However, there are still many questions that have been left unanswered.

In his classic and controversial work Weber argued, that capitalism, as a product of rationality, would create a society where religion is culturally irrelevant. In short rationality would replace our need for religion. In his book, *The Protestant Ethic and the Spirit of Capitalism*, Weber argued that particular forms of religious beliefs are the cause of the “development of an economic spirit, or the ethos of an economic system” (Weber 1904-5: ix). More specifically he asserts that during the Protestant Reformation, individuals initially immersed themselves in fulfilling worldly duties as a sign of dedication to achieve salvation; later, individuals abandoned the religious and ethical meanings of working hard in exchange for the pursuit of wealth and material gain (Weber...
1904-5:18). Weber explicitly states this idea when he writes, “in this case we are dealing with the connection of the spirit of modern economic life with the rational ethics of ascetic Protestantism” (Weber 1904-5: ix).

In Weber’s later work he further states his concerns about the effects of the rational world on its workers and their pursuit of material gain (Weber 1946/1958). He states, “It is horrible to think that the world could one day be filled with nothing but those little cogs, little men clinging to little jobs and striving toward bigger ones…” and fears that bureaucracy will lead to the “parceling-out” of the souls of modern men (Weber 1946/1958; Grant et al. 2004: 265). Weber’s predictions are relevant to the modern day hospice worker because they work in a bureaucratic system, as a branch of the medicine which is very structured and rational, and would seemingly be examples of the little ‘cogs,’ Weber is referring to. However, the hospice organization’s mission is to care for the physical, emotional and spiritual entities of their patients. Still studies have yet to place the role of hospice nurses’ spirituality in the context of their work to see if their work does, like Weber predicts, parcel-out their souls.

Emile Durkheim (1912), like Weber was very interested in the importance and implications that religious practices have on society. Durkheim was not interested in distinguishing the difference in religious denominations but rather the undeniable reality of religion (Durkheim 1912: 204-205) and the importance of collective, ritualistic meaning (Durkheim 1912; Bellah 2003: 31). Durkheim’s definition of religion is “A Religion is unified system of beliefs and practices relative to sacred things…” (Durkheim 1912:47). As Robert Bellah (2003:31) explains, for Durkheim ritual is about the “sacred in a sense in which the religious and the social are almost interchangeable.” This meaning
sacred objects become sacred when we give collective meaning and definitions to them and thus not only do we have this in churches, but at the very core of society is ritual and collective meaning.

Another point that Durkheim makes that is applicable to hospice nurses, who are trained in medical science, is that science does not deny religion in principle (Durkheim 1912: 204-205). He states, “Religion exists; it is a system of given facts; in a word, it is a reality.... Also, as far as religion is action, and in so far as it is means of making men live, science could not take its place...it seems destined to transform itself rather than to disappear” (Durkheim 1912: 204-205). Here Durkheim explains that science and religion are alternative (though not incompatible) belief systems, where both can exist; stating that “religion is reality” and unlike Weber’s predictions, will not disappear. Medicine as an example of science shows that Durkheim is right in that religion will not disappear but in fact as seen through organizations such as hospice spirituality and religion are present within it.

*Modern Vitality in American Religion & Spirituality*

More recently, researchers like Roger Finke and Rodney Stark (2003) examine religion in our culture. Finke and Stark (2003) explain that religion in the United States can be understood in terms used to describe a capitalist system (Fink and Stark 2003: 100). They use this analogy to discus how the United States has a rich religious economy in which numerous denominations and churches exist (Finke and Stark 2003). Using Finke and Stark’s (2003) analogy, religious institutions comprise a market where their members are consumers, and churches accommodate their services and structures according to the needs of their attendees (Finke and Stark 2003: 103). Like our capitalist
system, which offers consumers endless commodities, our religious marketplace also offers a wide variety of religious practices to choose from. Finke and Starks’s analogy emphasis that believers do not have power in the process of constructing meaning from religious doctrine but rather only in that fact that they have authority as consumers and can always switch to another church supplier (Dillon 1999: 27).

Today, the faithful in America includes individuals who identify themselves as not only religious, but also spiritual. Thus not only do we live in a ‘rich religious economy,’ (Finke and Stark 2003) but also a “rich spiritual marketplace” as well (Roof 1999). The General Social Survey (GSS) shows that about 89% of Americans identify themselves as a part of a Protestant or Catholic denomination (Firebaugh 1991). But according to Michael Hout and Clause Fischer (2002), more than two-thirds of those individuals who identify themselves as having a specific religious affiliation define themselves as both religious and spiritual (Hout and Fischer 2002). Therefore, Americans not only have a history of varied denominational traditions, but many are also spiritual seekers, which can include the incorporation of religious, church-going practices, or an exclusive, individual practice (Dillon and Wink 2007).

In his book, *Spiritual Marketplace*, Wade Clark Roof (1999) provides a generalized schema of spiritual and religious identities. He explains that individuals such as “Born-Again Christians, including Evangelical, Pentecostal, and Neo-Pentecostal Christians” see themselves as both religious and spiritual individuals; “Dogmatists, including Fundamentalists, Institutionalists, Moralists, Neotraditionalists” only see themselves as religious; and “Metaphysical Believers and Spiritual Seekers” only see themselves as spiritual. (Roof 1999) And although Roof’s general schema is just that -
general, it does illustrate both the diversity and the complexity of American religions and spirituality.

With the growing complexity of the composition of American faith, recently researchers have become increasingly interested in spirituality (Roof 1999; Wuthnow 1998; Bellah et. all 1985; Dillon and Wink 2007), even though both religious and spiritual-seeking have long been a part of American history (Dillon and Wink 2007). Roof believes Americans have a growing interest in the “cultivation of the inner self and personal growth” (Roof 1999, Wuthnow 1998), and Hout and Fischer (2002) explain the shifts that have occurred since the 1960’s, including a growing number of individuals who don’t identify with a particular denomination but explain having a private religion.

Despite the increased exploration of spirituality, however, traditional, ‘church-going religion’ has remained fairly consistent. Michael Hout and Andrew Greeley’s (1987) research indicates that there has been very little change in church attendance from 1940-1984 (Hout and Greeley 1987). The vitality of spirituality, both as an independent and interdependent entity of religion, has been growing since the 1960’s (Dillon and Wink 2007; Roof 1999). But as Michele Dillon and Paul Wink (2007) discuss in their recent book In the Course of a Lifetime, “the first ‘spiritual awakening’ dates back to the 1830’s and 1840’s and is associated with the emergence of the transcendentalist movement and such renowned figures as Emerson and Thoreau” (Dillon and Wink 2007: 119). But the dramatic increase of faith-seeking outside of the traditional domain of the church is believed to have begun in the 1960’s (Wink 1999, Dillon 2007; Roof 1999, Wuthnow 1998).
One explanation for the 1960’s and 1970’s being identified as a time of a “spiritual boom” is that “religion is socially produced, or more accurately, we might say it is constantly being reproduced” (Roof 1999: 79). Thus, socio-historical events are influential on the ways in which Americans are practicing their faith. The 1960’s were a time of social transformation; changes in occupational and geographic mobility (Roof 1999) which sparked Americans to search for more meaningful ways to enhance religious connection or personal spirituality. The Vietnam War could also be viewed as transformative socio-historically. It was as if spirituality became a new trend or commodity in the religious marketplace at that time.

Although religion is socially-constructed and, as Roof (1999) states, it is constantly being reproduced, in the decades following the 1960’s there have been changes in how people practice, overall presence and significance of faith in American culture has remained constant. Therefore, the need for studies that explore American’s religious and spiritual development and attitudes about their faith and practices remains important. Americans have created a religious experience that is uniquely different from those in other global societies because of the freedoms we possess both to construct the identities of our faiths and because of the American celebration of individualism (Demerath 2003; Dillon and Wink 2007). Religion’s existence as an entity separate from the state enables Americans to integrate religion and church into their lives but very much on their own terms (Demerath 2003). N.J. Demerath, III (2003) explains that after the 1960’s there was still great respect for American institutions such as church-going, but a “distinctive value placed on the individualism” was added to the mix (Demerath 2003: 350). Thus, although religion is socially constructed and provides critical social functions
and opportunities such as support, relationships, parental socialization, religious transmission to children, and shared meaning, religious identities are still a contextual celebration of the individual (Iannaccone 1990; Roof 1999; Demerath 2003; Berger and Luckmann 1966; Dillon and Wink 2007). We possess the freedom to build our own individual religious experiences. Therefore social scientists are needed in the field of religion to define and explain the patterns attributed to the many religious identities and their meanings that exist in our culture.

Defining Religion and Spirituality

Along with growing options for religious practice in this country, there has also been an emergence of individuals who are ‘non-church goers’ but who still have a strong faith in God or a higher power (Roof 1999; Dillon and Wink 2007), consider themselves ‘spiritual,’ and thus have expanded the potential meaning of the concept of possessing faith. This recent emergence of ‘spirituality’ has added yet another layer of complexity to the definition of ‘religion’ and what its relationship, if any, is to the concept of ‘spirituality.’ Within a sociological framework, “religiousness” and “spirituality” have a wide variety of definitions, many of which conflict (Wink and Dillon 2002).

Many sociologists turn to Wade Clark Roof’s (1999, 2003) definitions of these two terms. Roof (2003) states that “‘religion’ refers to scripture, ritual, myths, beliefs, practices, moral codes, communities, and social institutions, the outward and objectified elements of tradition,” (Roof 2003), whereas the word “spiritual, when used today, may refer to the inner life that is bound up with, and embedded within, religious forms, or much more loosely in keeping with humanistic psychology as a search on the part of an
individual reaching, through some regime of self-transformation, one’s greatest potential” (Roof 2003:138).

More specifically in Roof’s (1999) book he did research consisting of focus groups, follow-up telephone calls and a panel study over the course of eight years (Roof 1999: 3) in an attempt to define and understand the religious changes that have transpired post-World War II, with the baby boomer generation (Roof 1999: 315). Roof argues for the importance of “the role of narrative and its embodiment in ritual and practice. Religion in its most basic sense is a story involving symbol, metaphor, and language, all having the power to persuade and to fan the imagination” (Roof 1999: 297) Thus he argues that the way we construct religion, through metaphors, symbols and language is how we create meaning, self-awareness and relate to others (Roof 1999:297). Therefore, extending Roof’s argument in the role of narratives and the constructions of meaning, hospice nurses will contribute to the constantly transforming “religious and spiritual terrain” (Roof 1999:3) and help us distinguish the varying factors involved in spiritual development.

American Spirituality: A reflection of a secular culture

While a theorist like Erik Erikson (1984) argues that individualism allows one to focus on the self to enhance one’s ability to be open and giving to others, other theorists argue that individualism does not results in such positive outcomes (Weber 1904; Parsons 1949/1954; Bellah et al. 1985; Fink and Stark 2003; Bregman 2006). Within the literature, discussions about secularization are commonly tied to Max Weber (1904-05). Max Weber (1904) and later Talcott Parsons (1949/1954) argue that America is a Protestant, secularized society, institutionalized to work hard in capitalism, one, Weber
and Parsons argue, which in there is a significant decline in the authority of religion, a greater focus on the importance of the individual (Parsons 1949/1954: 394). Parsons states, “religious individualism, in the sense in which it became institutionalized in the Christian church” gave new autonomy to the individual (Parsons 1949/1954: 394). Religion has shifted individuals’ attention away from communal needs toward hardworking behavior in the name of personal gain (Weber 1930: 18).

More recently, Robert Bellah and his colleagues contributed to the debate on spirituality as a reflection of a secular society (1985). For Bellah et al, (1985) this religious, individualistic, meaning-seeking behavior is called ‘Sheilaism’ (Bellah et al. 1985:221) Sheila is the name of a woman Bellah discusses in his book, Habits of the Heart: Sheila named her religion after herself (Bellah et al. 1985). ‘Personalized religion’ exemplifies how difficult it is to understand religion and spirituality via individual’s experiences and the meanings they attach to their faith and therefore the continuing need for the scientific study of religion and spirituality. Some theorists argue that spirituality is a way for the individual to construct meaning and still be committed to rational world (Roof 1999). Roof (1999) uses the term “reflexive spirituality” to mean the “intentional, deliberate, self-directed approach to the cultivation of religious meaning” (Roof 1999: 74-75; Besecke 2001). Modern theorists argue that reflexive spirituality is an attempt to bridge this tension between rationality and transcendent meaning (Besecke 2001; Roof 1999), in that spirituality is an individual phenomenon, an attempt to relate to religious symbols and practices (Besecke 2001). Unlike Bregman’s (2006) notions of spirituality as a secular ‘glow-word,’ Kelly Besecke (2001), in an analysis of religious langue and its meanings, argues that reflexive spirituality is a cultural resource, a
common language used to make meaning in a rational society and not a representation of our narcissistic identities. A latent benefit in studying hospice nurses is to further contribute to the secularization debate, in whether de-institutionalization religion is narcissistic, by investigating the practices and meanings in which the nurses attribute to their faith.

**Adversities and Negative Life Events: Influences on Faith**

Social scientists of religion (Stoebe 2004; Calhoun 2006 and Riley et al. 2007) and of mental health (Wheaton 1999) often examine adversities or critical life events such as bereavement, illness and stress in the light of significant life changes. Blair Wheaton (1999), a sociologist in mental health explains that stressors can be life-changing events such as; being fired from a job, getting a divorce or the death of a spouse or a loved one. Wheaton (1999) explains that many individuals who experience such events go through “post-traumatic growth” (Wheaton 2007). And although Wheaton does not discuss faith development as a result of “post-traumatic growth” an increasing number of studies are finding a correlation between religion and its benefits for both mental and physical health (Jones 2004).

End-of-life can also be a time of great adversity that brings about meaning-seeking, both for the individual facing his own mortality and for those involved in the patient’s process (Moremen 2005). David Currow and Meg Hegarty (2006), professors in palliative and supportive services, looked specifically at the adversities around death. Their analysis of the literature explained the experiences and challenges that nurse’s face in working around death; where death experiences serve as adversities. (Currow and Hegary 2006: 123). Currow and Hegarty state that there is a great deal of “suffering at
the bedside of the dying," where an individual’s sense of self is often challenged (Currow and Hegarty: 132). The challenges the medical professionals face when caring for the terminally ill are in witnessing the physical, emotional, existential, social, sexual, and possibly financial issues of the dying patient and his or her family in a way that is different from witnessing a sudden death in the hospital (Currow and Hegarty 2006). Health care professionals also face a challenged in feeling helplessness when unable to relieve the patients’ and their families’ suffering (Currow and Hegarty 2006).

**Death: The Afterlife, Fear & the Experiences**

Contemporary Americans are criticized as suffering from ‘death denial’ (Bregman 2006) in our inability to acknowledge and treat death. We live in a highly technological and medically advanced society in which individuals are living longer lives, both in sickness and in health. However, traditionally, people developed an understanding of death via religion, religious meanings, and death was then “most often linked to hopes of the afterlife” (Bregman 2006). But despite this so-called “death denial” for which we are sometimes criticized, recent studies have revealed that there has been an increase in Americans’ beliefs in life after death (Greeley and Hout 1999).

In their recent research using the General Social Survey data, Andrew Greeley and Michael Hout (1999) found that among American adults, there has been an increase belief in life after death. The data shows that 85 percent of Protestants believe in a life after death, regardless of their birth cohort (Greeley and Hout 1999). This percentage has remained constant among Protestants, while the percentage of Catholics, Jews, and individuals with no religious affiliation who believe in life after death has also increased (Greeley and Hout 1999): the number of Catholics who believe in life after death rose
from 67 percent to 85 percent between 1900 and 1970, while the number of Jews who believe in life after death increased from seventeen percent to 74 percent (Greeley and Hout 1999). This suggesting that if Americans are suffering from death denial it is not tied to beliefs in the afterlife, beliefs which are both independent and interdependent of faith. Recent studies on death-anxiety on the other hand reveal that fear of death are closely linked with notions of religion and spirituality.

In one study done by Paul Wink (2006) with Christian men and women from northern California, found there are different trends in death-anxiety for individuals who go to church versus those who are only spiritual. Although religiousness and spirituality are both positively related to a belief in the afterlife, findings from this study pointed to a significant interaction between religiousness and fear of death, in that those who were religious and believed in a life after death experienced lower death anxiety (Wink 2006). Spirituality however, was not found to buffer against death anxiety (Wink 2006).

Although Wink (2006) found that only religiousness buffered against death anxiety, another study done by Christina Rasmaussen and Mark Johnson (1994) found that spirituality also has a significant negative relationship with death anxiety. In their study the Temper Death Anxiety Scale (TDAS) and the Spiritual Well-Being Scale (SWBS) were administered to 208 undergraduate students finding that as the belief and certainty of the after-life increased, death anxiety decreased (Rasmaussen and Johnson 1994). The interconnectedness of death-anxiety and faith is significant to the study of those who care for the dying, because those with high levels of death anxiety are certainly not going to pursue a career in palliative care. And if lower levels of death anxiety are
associated with religion and spiritually, it is of great importance to examine the constructions of these faiths.

Apart from studies that have been done on the after-life and fear of death, little research in the social sciences can be found about end-of-life experiences (i.e. visions of deceased relatives, seeing the "white lights") associated with spiritual development. What studies have done is to examine whether Near-Death-Experiences (NDE) are a reflection of physiological versus spiritual phenomenon. For example a recent article appeared in Omega: the Journal of Death and Dying entitled, "Are They Hallucinations or Are They Real? The Spirituality of Deathbed and Near-Death Visions." In it, Betty Stafford examined whether dying experiences were a physiological/biological or mystical/spiritual phenomenon. She found that the strongest argument against visions being just hallucinations comes from a study performed by a group of Dutch doctors who declared that near-death experiences occur when the 'electroencephalogram (EEG) is flat-lined,' or when the patient is considered clinically dead. When a patient is having hallucinations, on the other hand, there is significant brain activity (Stafford 2006).

Like Stafford (2006), Maggie Callanan and Patricia Kelley (1992) explain that Near-death experiences can take several different forms. Callanan and Kelley (1992) are two hospice nurses who differentiate between death experiences that happen suddenly such as drowning or a heart attack versus the experiences that happen as a result of prolonged illnesses such as AIDS or lung disease (Callanan and Kelley 1992: 16). Although they explain that these experiences can be similar the more sudden fatal incidents are what the medical communities refer to as Near-Death Experiences, such as out-of-body sensation as if they were hovering above their bodies and watching
themselves from a distance or they indicate seeing ‘the light’ (Stafford 2006). Callanan and Kelley call the death experiences of those dying from a terminal illness “Nearing Death Awareness” (Callanan and Kelly 1992:16). Though these hospice nurses share narratives from their patients from over a decade of working around the terminally ill and make distinctions in death experiences, they along with scholars in the social sciences have yet to address whether being witness to these near-death experiences is associated with spiritual development.

**Life Course as an Explanation of Spiritual Development**

One of the assumptions that has been made in the literature about spirituality and palliative care is that when an individual is terminally ill they tend to increase in faith or meaning seeking (Wasner, Longaker and Borasio 2005). This is contradicted however in more recent studies (McGrath 2003; Atchley 2006) suggesting that patients at the end-of-life do not seek spiritual or religious comfort (McGrath 2003) and that deeper spirituality can be explained not by terminal illness but rather are due to personal growth experienced in achieving particular life stages (Wink and Dillon 2002).

One longitudinal study by researcher Robert C. Atchley (2006) examines spiritual growth in later adulthood, in which Atchley explains that, “Most people develop a personal system as a result of decades of learning through their life experiences. Some people don’t learn much from life, but most do…” (Atchley 2006: 21). Atchley believes the personal systems we develop create our values, aspirations, and fears, and by late middle age, many adults, because of their life experiences, have developed self-confidence and “a feeling that they can influence their own fate” (Atchley 2006: 21). He states that spiritual development begins to be actively pursued in midlife when people
start asking questions like, “Is this all there is? What does it all mean? What will happen to me when I die? How can I leave a legacy?” questions which are inspired when individuals begin to age and experience the deaths of family and cohorts (Atchley 2006: 22).

The aging process, as an explanation to spiritual development was also found in a study done by Robin Moremen (2004/5). Moremen conducted in-depth interviews with twenty-six older women who were not experiencing bereavement from a significant loss or suffering from a terminal illness which are commonly associated with spiritual seeking (Moremen 2004/5: 309). From the interviews Moremen found that in the absents of bereavement and impending death that spiritual questioning can be explained by a “natural part of the aging process as one approached the end of the life span” (Moremen 2004/5:309). This suggesting that individuals seek meaning in late adulthood because of the adversities they encounter as they age, introspecting about the experience associated with their own deaths, and the deaths of close friends, parents or a spouse. In a quantitative study done by Fortner and Neimeyer (1999) found that fears concerning death tend to decline with age. This is that although age is an explanation for spiritual development in relation to death it is not necessarily fear of death that increases spirituality.

that God was dead, and the decade ended with millions of Americans discovering that God could be approached and made relevant to their lives in more ways than they had ever imagined” (Wuthnow 1998:53). However, as presented in the findings from a longitudinal data set in which individuals interviewed as children in the 1920 and 30s where then interviewed four times in adulthood. From their study Paul Wink and Michele Dillon (2002) found that “All participants, irrespective of gender and cohort, increase significantly in spirituality between late middle (mid-50s/early 60s) and older adulthood” (Wink and Dillon 2002: 79).

Within the literature on the sociology of mental health but separate from the discussion on spiritual development are findings that later adulthood is also associated with higher levels of mental health (Mirowsky and Ross 1999). Mirowsky and Ross (1999) cross-tabulated four surveys and found that each sample indicated the greatest prevalence of well-being in from 40-60 years old (Mirowsky and Ross 1999). One possible explanation for this phenomenon cited in the sociology of mental health literature is that well-being is mediated by time (Roxburgh 2004), and perhaps this, too, influences spiritual-seeking. As mid- to late-adulthood marks a time when there tends to be a greater stability, (e.g., children leaving home, job security, self-confidence, experience), individuals have more time to ponder the meaning of life, and, in particular, their lives.

**Gaps in the Literature**

The hospice philosophy stresses the great importance of spiritual care. This form of holistic healing incorporates the physical, emotional, social, and spiritual well-being of a patient (Vassallo 2001), but this approach is not necessarily taken because patients
begin to seek meaning as they are dying but rather to provide continuity in the quality of
the life of dying patients. There is evidence indicating the great importance of one’s
perception of religion and spirituality on one’s response to death, but there is scant
research that indicates that this ‘inward journey’ is triggered by a terminal illness
(Hermann 2001) and to what extent established beliefs on spirituality and death are
needed to adequate care for the dying.

There is very little literature that merges health care and the spirituality of the
medical professionals. From the gaps in the literature this thesis questions if hospice
nurses come to hospice with established views on faith and death; What role does their
job at hospice have on their construction or established death and faith beliefs and within
the development of their views on spirituality and death what offers the greatest
explanation for these views (Adversities, Death Experiences or a life course perspective).
CHAPTER II

METHODS

In studying the sociology of religion and spirituality both quantitative and qualitative measures are advantageous (Wuthnow 2003). Many researchers utilize poll and survey data to establish changing trends in church attendance, percentage of persons in particular denominations, and American beliefs about life-after-death (Hout and Greeley 1987; Greeley and Hout 1999). Qualitative studies on the other hand have also contributed data in regards to religion and spirituality, allowing for greater insight into the nuances of religious and spiritual discourse (Becker and Eiesland 1997).

It has been noted that there is a significant amount of inconstancy and indistinctness within the literature on the meanings of spirituality due to the "multiple meanings of the term spirituality" (Wink and Dillon 2003: 916); thus, given the complexity of meanings using a qualitative approach in researching spiritual development allows me to gain a clarity that can otherwise be ambiguous. This is to say that although measures and statistics taken from source like the GSS on religion and spirituality give us great insight into American's reported beliefs by taking a qualitative approach allows us to further explain and examine spiritual development among individuals in this country.

Among the literature on religion, spirituality and its relevance to nurses, questionnaire-based methods were used to study the nurses attitudes about spiritual care training (Wasner et al. 2005; Tuck 2001). And although this type of methods can be useful, given the nature of this particular study, in looking at spiritual development via
life events and experiences around death and their influences on faith, the nurses would not have been able to give a detailed account of their experiences and the meanings attached to them.

**Sample**

I used a qualitative approach using semi-structured interviews that lasted from 30 to 90 minutes, with registered nurses who are currently employed by a Hospice organization. The development of questions began after taking the Hospice volunteer training course in the winter of 2006, in New England. Upon growing interest in the organization and the sociology of religion and medicine I submitted an application to the IRB with intent of interviewing hospice nurses. The hospice nurses that were interviewed are employed at three different hospice organizations; located in Northwest, Northeast and New England.

The participants of this study were all volunteer and recruited by distributing a consent letter to an administrator in each hospice (the hospice director, volunteer coordinators and team leader). After contacting a representative (the administrator) in each office, they distributed copies of an informed consent letter to the nurses. The nurses that were interested contacted me or I was given the names of nurses, by the administrator, to call who would be interested in being interviewed. In scheduling the interviews some of the nurses called me to set up a time to meet in-person or a time that would be appropriate to call for a phone interview. The face-to-face interviews were conducted where the interviewees felt comfortable, many of them at their hospice office or a coffee shop. After meeting the nurse and explaining the interview procedures the nurses were asked for consent in tape-recording the interview.
This study consisted of interviews with twenty hospice nurses. Three nurses were from the Northwest and five nurses were from New England, all of which were interviewed face-to-face. The remaining twelve nurses were from the northeast and were interviewed over the phone. Of the sample, sixteen nurses were female while the other four nurses were male. One male was interviewed from the Northwest and New England while two males were interviewed from the Northeast.

The hospice nurses that were interviewed ranged in age from thirty-six to sixty-one years old while the majority of the nurses were forty to fifty years old and only two nurses under the age of forty. There were eight nurses who were raised Catholic while seven were raised Protestant. Today, zero percent of the nurses are only religious while nineteen of them identify as being spiritual, five of which say they are both religious and spiritual. One nurse reported being unsure about her faith. (See Appendix A for Summary Characteristics)

The U.S. Department of Health and Human Services survey of Health Professionals shows that the number of Registered Nurses (RN) is at a new high of 2.9 million (Steiger, Bausch, Johnson and Peterson 2006). Within the registered nursing sector less than 1% works in Palliative care while the highest number of nurses that work in a specialty field is in Family practice (Steiger et al. 2006). In comparing the characteristic of my sample to national statistics there are many similarities. Like my sample, national statistics show that 96% of registered nurses are female while only 4% are males (Steiger et al. 2006). The average national age (surveyed in 2004) of RNs is 46.8 years old with only 8% under the age of 30. The average age of my sample is 52.4
years old (but at the time of survey approximately 49 years old) with only two nurses under the age of 40.

Nationally, the majority of nurses get a bachelor's degree in nursing (63%) while 40% receive an associated degree and 4.5% earn their master's in nursing (Steiger et al. 2006). Half of the nurses in my sample earned a bachelors degree, while nine graduated with an associates and only one with a masters degree in nursing. The majority of RNs (84.9%) in the United States are white (non-Hispanic) while only 3.2% are black or African American (Steiger et al. 2006), my sample consisted of only white nurses. In the national sample of RNs 70.8% were married and 18% were divorced/separated/widowed (Steiger et al. 2006), in my sample however, nearly half of the nurses are divorced.

**Data Analysis**

Each interview was transcribed and analyzed by coding for patterns and themes. The themes that were coded for included the nurse's trajectory to nursing and hospice, the adversities that influenced their occupational choices and/or faith, their religious trajectories and the affects of being around death has had on their personal notions of death and faith. I asked the nurses’ questions about why they wanted to be a nurse how they took their positions at hospice. I also asked them questions about how nursing school prepared them for hospice and how they view the medical community’s acceptance and support of hospice. I was trying to establish whether the nurses were exposed to death and dying in their training or if there was another explanation, for example personal adversities, that led the nurses to hospice.

I also asked the nurse about their faith or meaning seeking trajectories, to examine their path to hospice or their experiences (such as being around death) once at hospice,
influenced their faith in any way. I wanted the nurses to share their narratives about being a hospice nurse, and the meanings they give to their faithful and occupational lives. For instance, in order to work around death does an individual have to have gone through or suffered from a personal adversity? Does being around death influence the nurse’s spiritual development or their own personal notions of death? What experiences are needed to pursue a career in palliative care? And does an occupation in hospice contradict how they were trained as nurses? Or our larger societal norms of keeping people alive?

Hospice nurses are a unique population of individuals who can contribute data to both the social sciences of medicine and religion. With their exposure to death and dying and the experiences that are associated with it, their narratives shed light on whether medical professionals must have an established spirituality and notions of death before working around it and what constitutes the greatest explanations for spiritual development. The men and women that work for hospice are exposed to many challenges in taking care of the terminally ill (Currow and Hegarty 2006) and due to the small number of studies involving hospice nurses this study seeks to explore these experiences and their influences.

**Limitations of the Methodology**

One limitation to this study is that the narratives from the nurses are their retrospective accounts of their experiences and faith. Even though the nurses can recount their nursing trajectories with accuracy; personal recognition of something like spiritual development is a bit more ambiguous. It is also hard to accurately recount childhood
religion, for example remembering the details why they went to church, how often and when they stopped.

Another limitation to this study is the small sample size and its lack of diversity. This sample is pronominally white women. Although this study cannot be generalizable to the larger population due to its method and its small sample size, it does offer some leading hints for future studies. In looking at personal and spiritual development, having a greater age span would greatly contribute to the sample. Only two of the nurses were under the age of 40, the remaining nurses were 41-62 years old.
CHAPTER III

MEETING THE HOSPICE NURSES

It would seem highly unusual, and perhaps even inappropriate to some, that a child would dream of becoming a nurse whose responsibilities were solely to care for terminally ill patients. It would seem as equally improbable that a medical student would choose to pursue a career in palliative (pain management) care because the driving philosophy behind a physician’s training is focused primarily on learning to practice curative medicine and not on managing death and dying (Nelson et al. 2000; Downe-Wambolt and Tamlyn 1997). Death’s acceptance as a natural part of life in the general social context has been slow and precarious at best over the years. Medical schools have just in the past 20 years incorporated classes on issues surrounding death and dying (Nelson et al. 2000) and less than 1% of RNs in the United States are specialized in palliative care (Steiger et al. 2006). Therefore, the nurses in my sample offer great insight into how one comes to a career in caring for the dying, particularly given that they work in a small specialized field which is not encourage in medical training.

From the narratives in my sample, three main themes emerged as occupational trajectories; the veteran nurses, palliative care exposure and occupational second time-around. The nurses also discuss their nursing education as preparation for their work at hospice, and their views of how the conventional, curative, medical model has regarded the hospice organization over the years.
Nursing Trajectories

The Veteran Nurses

Although there were varied trajectories to nursing and then to hospice among the twenty RN's that I interviewed, there were six women who have all been in the field of palliative care and part of hospice's 30-year-long maturation process from its volunteer years to the organization's becoming a federally-recognized branch of medicine. Given that the first hospice organization was established in 1972 (Harrison et al. 2005) and many of the nurses in this study have been nurses for 30 to 40 years they offer unique insight into the occupational trajectory to hospice. They began their careers at a time, at which very few occupations were open to females, and the only nursing degree available consisted of a three-year program which no longer exists. Beth, Amanda, Liz, Rose, Christina, and Emily are among the longest-practicing nurses in this sample, and all recount childhood memories of wanting to be a nurse.

Beth is a 53 year-old woman who has been a nurse for 32 years. Beth remembers that from the time she was a little girl, she wanted to be a nurse; but in looking back, she is not exactly sure why. She explains,

I'm not really sure where the exposure came from, except, when I grew up, I mean, um, I was a child of the seventies, so, I mean, at that time women were directed toward secretarial work, teaching, or nursing. There wasn't the diverse...no nurses in my family. It's funny when you look back at pictures and stuff. There was a Christmas when I was six or seven that I got a nurse's cap, and I guess, from what my mom said, that's where it started.

Beth told me that she used to take care of "little neighborhood animals," not knowing that this was the birth of her care-taking passion. Before working for hospice, Beth spent time working in obstetrics and "on the floor," which is how many nurses refer
to working on a general or medical surgery (or “med surg” as the nurses refer to it) floor in the hospital. Beth told me that she knew a lot of people who were involved in the grassroots effort to get hospice started in the late 1980’s, and although she attended an informational meeting, she was not ready to “jump-in” and work for hospice back then.

It was not until years later that she finally applied for a nursing position with hospice. Beth spent several years working at an inpatient cancer center. The patients’ surgery and treatment were all done at the cancer center, and thus she was able to establish long-term relationships with her patients and their families. Beth said there was no hospice available to the patients, and therefore, “many of the patients died with us.” The cancer center gave Beth the exposure to working with patients who were extremely ill, but the environment was still a largely curative one. It also gave Beth the experience of building longer relationships with her patients, which is unique among most other forms of nursing. Beth explained that it was for the long-term relationships she was able to build with her patients and families and a “desire to get back to that kind of nursing” that inspired her to finally apply for a job with hospice sixteen years ago.

Rose, like Beth, went straight to nursing school from high school. “I went into nursing school right after high school. That’s was what you did: you were a teacher or a nurse.” Rose is a 60 year-old woman who has been nursing for 39 years. At the age of 21, upon graduating from nursing school, Rose went into the Army for two years and worked “med surg” for a little while until she started to have children. Rose is a mother of five and explains that when her children were grown and “didn’t need her anymore,” she returned to work on a rescue squad. After having taken so many years off from nursing, Rose was not confident in her nursing abilities. But after working on the rescue
squad for a while, she realized that she hadn’t lost all of her nursing skills. One of Rose’s friends was working for hospice at the time, and she suggested Rose try working in hospice. Shortly after that, hospice was looking for a nurse, and Rose took the position, seventeen years ago.

Although Amanda has only been with hospice for a few years, she has been a nurse for 41 years. She knew when she was fourteen years old that she wanted to be a nurse. As a teenager, Amanda and a friend interviewed a nurse for a school project. After the interview, Amanda and her friend promised each other that they would both be nurses, and they kept their promise to each other. Amanda earned her degree in three years at a prestigious medical school in New England, and after graduating, she said, “I did the hippie thing: I moved to California for thirteen years during the 1960’s.” As a young nurse in California, Amanda worked on the floor for a few years before returning to the Northeast to raise her children in a less “commercialized” environment.

Amanda worked as a nurse at first in long-term care in a nursing home. She became accustomed to end-of-life care and loved the relationships she was able to build with her patients and their families. She said that she was unaware that hospice even existed until she worked in the nursing home. As her own retirement grew near, Amanda wondered if there was another area of nursing that she would enjoy working in before she retired. After her exposure to hospice from working in the nursing home, she decided to take a job with hospice.

Liz is also a veteran of 30-years in nursing, and she, too, said, “I always knew I wanted to be nurse.” Like Amanda, Liz attended a three-year nursing program that no longer exists. As a teenager, Liz also volunteered in the local hospital and became
interested in geriatrics and psychiatric nursing. She said that after graduating from nursing school, she worked in many different areas, such as obstetrics, psychiatry, and geriatrics. It was in working with the elderly population, however, that Liz found her passion.

As an adult, Liz went to work in an “extended care facility” section of the local hospital and was, like Beth, a part of a group that founded a hospice movement in her town. In the 1980’s, Liz and three other nurses started a volunteer hospice group and made unpaid visits to terminally ill patients who needed their help. And although Liz made her way back to hospice, when her hospice group had first begun, she said it was too much work with a family and a job to have hospice patients, as well. Liz continued to work for another thirteen years in the extended care facility until it closed and then worked in home health for about fifteen years. Finally, two years ago, when there was an opening at hospice, she took it.

Emily has been nursing for 35 years and with hospice for nine years. She is a 56 year-old woman who has worked in many different areas of nursing throughout her career. Like the other women I interviewed, Emily always wanted to be a nurse and has worked “on the floor” and also as a case manager. But her time on an IV team both made the most profound influence on her decision to pursue a job in palliative care and also illustrates a larger sociological theory. Max Horkheimer and Theodor Adorno (2002), as two of sociologies contemporary theorists seek to “explain why humanity, instead of entering a truly human state, is sinking into a new kind of barbarism” (Horkheimer and Adorno 2002: iiiiv). They argue that society’s destructive misuse of the Enlightenment, which gave us reason has created a society which has not freed itself but rather has
enslaved our society by its rational, 'entirely refined' and over classified characteristics (Horkheimer and Adorno 2002: 136). This is that we have created such a detailed, categorized and refined world with our reason (i.e. technology and science) that rationality, which was supposed to be emancipating, has led to irrationality and enslavement. Emily demonstrates society’s misuses of reasons and technology in explaining her experiences on the IV Team.

When I worked on the IV team, I was on the code blue team, and I think that was my first exposure to dying in the hospital and with people being resuscitated and seeing how unsatisfying that was for everybody. And I think that’s what kind of planted the seed, although I didn’t get into hospice until many years after that. Back in those days, in the early 1970’s, that was when all the big, um, oh, high-tech sort of machine stuff was coming on the scene, so everybody was put...everybody was resuscitated, and everybody was put on these all these machines. It just got to be not the kind of nursing I went into nursing for, and I think that what I found in hospice was that idealistic sort of reason that I went into nursing for...[not to] put someone on the machine to see what the machine would do and not what your body was going to do.

Although, it was her experience working on the IV team that first “planted the seed” about what kind of health care she preferred, it was not until after taking care of her own elderly parents, going through a divorce, and looking for part-time work that Emily started working for hospice.

Christina, much like the other five nurses, is a member of a fascinating group of health care professionals who are changing the way Americans live while they are dying. Christina has been a nurse for 30 years and talks about how she “was doing hospice before there was a hospice.” Before starting with hospice just a few years ago, Christina was a psychiatric nurse and then a home care nurse. As she was working in these areas, she started to develop her own philosophy of non-curative, holistic, end-of-life care before hospice was practiced in the United States. Therefore, now Christina feels lucky to
work with hospice because the organization practices what she believes in: holistic care that is fostered by the many members - nurses, social workers, physicians, bereavement and spiritual counselors - of the hospice team.

**Palliative Care Exposure**

Another theme found in my data was of nurses who found their way to hospice after being exposed to palliative care. Linda, Cathy and Kate who became hospice nurses after taking care of their own parents and being exposed to end-of-life issues. Linda is a 54 year-old woman who has been a hospice nurse for a year and a half. Until 1990, when she earned her associate degree from a Christian nursing school, she had stayed at home and raised her children. Linda was inspired to go back to school after taking care of her mother-in-law who was diagnosed with ovarian cancer. She spent six months going through all of the treatment and chemotherapy with her mother-in-law and in the process was inspired and encouraged by those around her to go back to school to be a nurse. Although Linda worked on the floor after graduating from nursing school, she said, “I went into nursing school specifically to be a hospice nurse.” Cathy, too, became a hospice nurse after caring for a loved one. Cathy is a young, 36 year-old hospice nurse who earned an associate degree specifically to become a hospice nurse. Before graduating in 2004, Cathy was taking care of her father-in-law who was suffering from congestive heart failure. She explained that in taking care of him, as “a lay person,” she found herself frustrated because she was not able to understand the medical terminology. Longing to understand and having an interest in palliative care, she returned to school as an adult to become a hospice nurse.
Kate, on the other hand, had been a nurse for 28 years. Out of all of the nurses that I interviewed, Kate has held the greatest variety of nursing jobs. She has worked in the United States and Germany as a military wife, holding nursing jobs in labor and delivery, on the hospital floor, in a doctor’s office, on a military base, as a school nurse, in a management group, and as a port-a-medic. It was not until her own father got sick and received hospice care that Kate decided that hospice might be a good fit for her. After taking a hospice volunteer course, she decided to take a position in hospice, and after a year, Kate feels that it has been a good fit for her.

Brian’s and Laura’s paths to nursing and to hospice do not follow as closely or as clearly the general trajectories of those of the nurses described above. Neither had a childhood dream of becoming a nurse, and working with dying people had never been an ambition of either one. Initially Brian dropped out of college because he did not know what he wanted to do with his life. Brian is now in his early 50’s and has been working for hospice for about six years. After dropping out of college and traveling to Europe and Africa, Brian went to live with his sister and brother in California, both of whom in the medical system. Brian explained that they both seemed to be happy and making a good living, so he decided to go with his sister to work one day to further explore working in the medical profession. Brian’s sister worked in a head injury clinic, and Brian remembers feeling “moved by what she did.”

Brian returned to school to earn his nursing degree and became a traveling nurse. He said, “In my training, I had been through oncology units in the hospital and thought that those units were very sad and very scary, and I did not want to be around people going through that.” Ironically, however, when Brian was looking for a placement as a
traveling nurse, one of the only positions available in the Rocky Mountains where he wanted to be placed was “a position working evenings in the oncology unit.” With a bit of hesitation, he took the position, ended up spending time with several dying patients, and he discovered that he felt it was special work. As he accumulated work experiences, Brian stated, “I had a different vision for myself, and that was working for people at home.” So that is what he did as a home care nurse. But soon after he had made that transition, Brian’s position was cut. At the same time, an job opening with hospice became available, so Brian took the job with the hospice facility as an administrator.

Laura is a young hospice nurse now in her mid-30’s. At the time I interviewed Laura, she had been a nurse for seven years and had worked with hospice for about four months. At the beginning of her work career, Laura was not sure she had the confidence to enter a medical profession and certainly had not imagined that she would wind up providing end-of-life nursing care: “It never crossed my mind that I would help someone to die well.” She first earned her bachelor’s degree in communications to gain the confidence she needed to go back to school to earn not only earn an associate degree but also a Master’s degree in nursing.

Laura first spent five years nursing in a long-term care facility “by default” because that is where she got her first job right out of school. She stayed at the nursing home, thinking that she would move on into labor and delivery when a different opportunity presented itself. Although her plan was to move to labor and delivery, Laura said having her own daughter “instantly satisfied my needs” to be around babies:

I discovered that I liked the population of people I was working in long term care with Alzheimer’s and dementia, and I was good. You know, I would say that having my daughter brought out that caring side of me, and I realized I was in the right place.
While working as a long term care nurse, Laura found she valued providing end-of-life care the most. For Laura, working hard with patients to give them a good end-of-life is “the payoff; it’s like the reward.” But Laura found there were many constraints and barriers to adequate resources in providing good end-of-life care at the long-term-care facility where she was working, so she went to a couple of hospice meetings to “just to sort of pick their brains” on how to improve end-of-life care in long-term facilities. She found she shared common goals with the nurses she met at hospice as far as improving the end of life for those in long-term care, and when she was approached with a job offer from the hospice facility, she took it.

*Occupational Second-Time Around*

For Meagan, Leslie, and Todd, nursing was an occupational “second-time-around.” Unlike the other nurses that I interviewed they did not come to hospice after an experience with death, nursing or because they had had childhood dreams of becoming medical professionals. Instead, in their adult lives, they decided to go back to school and start new careers in a medical field. Meagan is a 47 year-old nurse who was a “candy striper” (volunteer) as a little girl but “never thought of having a career in nursing.” Meagan graduated from high school a year early with intentions of going to college, but it was only after fifteen years, two children, and a divorce that she actually did go to college. As a single mother, she knew she wanted and needed to go back to school but was unsure about what she wanted or would be able to do. She thought about teaching or counseling because, like Laura, she was intimidated by the nursing program. But after further investigation into the nursing curriculum and a little encouragement from her friends, she enrolled in nursing school.
Meagan graduated with her associate degree in 1992. During nursing school, Meagan took a gerontology class for which she wrote a paper about hospice, and she was so interested in it that she took a volunteer training class. Like many nurses who’d just graduate from nursing school, Megan went right to work at a hospital on the floor. Then a year later, she was offered and gratefully took a job at hospice, and it has been fourteen years since.

There is a similarity between Leslie’s and Meagan’s paths to nursing. Leslie is a 49 year-old woman who did not go to nursing school until she was 28 years old. Leslie had worked in nursing homes as a young girl and had planned on going to nursing school, but, like Meagan, Leslie got married, had children, and then, upon getting divorced, decided to go back to school. She had always enjoyed working with older people, and “death had always fascinated” her in that she found great satisfaction in making people comfortable at the end of their lives. Leslie was working at a nursing home when her sister, who is an LPN (Licensed Practical Nurse) with hospice, suggested Leslie apply to work with hospice; she did and has been working there for fourteen years.

Out of all the nurses that I interviewed, Todd took the most unusual path to nursing. Todd is a 50 year-old man who has been an RN for three years. But before becoming a nurse, Todd was a park ranger and a teacher. It seems like an unlikely career trajectory for him to have taken, but an aptitude test eventually steered him, with his particular strengths, in the direction of nursing. Following the nursing path, Todd first worked at psychiatric centers and worked night shifts at hospitals, but Todd was still not satisfied. Then the mother of one of his friends, who is a hospice nurse, suggested that he apply for a job where she was employed. He did so, and he has been there for two years.
Nursing School Preparation

As many of the nurses’ trajectories suggest and as many of them would say, exposure to death seems to be the best preparation one can have for a job in palliative care. But many of the nurses also pointed to what they experienced as a lack in their nursing educations preparation of them for working in hospice. For the majority of the nurses in my sample, nursing school did not train them for their jobs at hospice as they represent the larger American student body who report leaving school feeling under prepared and inadequate in caring for the dying (Neslon et al. 2006). As the primary role of medicine in our modern society is to cure, to save, and to prolong life, courses on death and dying are usually elective are taken by less than 25% of health care professionals (Dickerson et al. 1992).

Feeling Prepared

Colin was among the minority in my sample claiming that he felt nursing school did prepare him for his job at hospice. This is however because he went to nursing school specifically to be a hospice nurse and states that nursing school did prepare him for hospice, but “...only because I knew what I would looking for with hospice [so] I could see the deficiencies and ask for the “filling-in” ‘cause death and dying were not a huge part of any curriculum.”

Colin said that although he did not receive a lot of education specifically on death and dying in nursing school, he is aware that it has been given more attention recently. There is now a program called ‘ELNIC,’ which is an end-of-life nursing consortium that is trying to enhance awareness of hospice. Therefore, although Colin felt prepared to be a
hospice nurse, it was because he knew what he was looking for and what he needed to know to do his job because of his personal experience.

Beth related to Colin but says that “nursing school [both] did and did not prepare her.” Beth attended a Christian nursing school where there was “strong focus on spirituality and family, [which is] a good baseline for understanding disease,” and she believes he education probably prepared her for a career in death and dying more than would nursing schools that are not affiliated with a particular faith. Apparently, many nursing schools separate the treatment of an individual’s illness from the patient’s family and faith. But Beth believes that to completely understand how to treat an illness, it is equally important to understand the patient’s family and faith.

Beth said, however, that even though many of the nursing students in her class went to church and that her school encouraged spirituality and family, the school’s curriculum offered little education on death and dying. The nurses were exposed to some death when they participated in rounds in the hospital, but there were no formal courses on recognition of death, on how to talk to families or patients about death and dying, and no alternatives to curative treatment were explored. Beth felt that she was somewhat prepared for hospice from her nursing training, primarily because there was a religious component to her education, but many of the nurses felt that their training did not deal with death and the dying processes. Sara’s perspective is that, “No nursing program prepares you for hospice;” she believes only exposure and experience gives a nurse the training he or she needs. Sara’s point that hospice is as much like any other occupation or life circumstance - you learn as you go, and death is not an anomaly is affirmed by social theorist such at Erving Goffman. Goffman (1959) argues that we are all performers in
our everyday life and that “pre-established patterns of action” in which we perform and are called a part or a routine (Goffman 1959: 16). Thus, as Sara points out in her performance of “hospice nurse” it was the routine of her job that enables her to be around death and that death training is irrelevant because it is lacking real death exposure or performance.

*Unprepared by Nursing School*

Being that palliative care is a relatively new phenomenon in the United States it is unsurprising that there are no social science studies focusing on the hospice nurse and their preparedness for working around death. Therefore, without a point of reference the following narratives offer as reference point for future studies. Sara has noticed recently that palliative care education has begun to be offered, so maybe things are changing. Amanda, too, said that 30 years ago, nursing school did not prepare her for death: “They did not teach that back then,” and she hopes maybe they are doing a better job now. But even the nurses who have received their training in the last two decades, like Colin, Laura, and Meagan, say that nursing school still does not regard death and dying as a part of medicine. Laura talked about how nursing school does not prepare nurses or physicians for palliative care:

There’s that perspective that you go to nursing school to save people; you make them better. That’s why long term care gets such a bad rap because in order to feel like you’ve done a good job, you have to let go of the idea that you’re going to make people better, and [saving] is what’s valued.

Laura was embarrassed to tell people that she worked at a nursing home because ‘saving people’ is so highly valued, and nurses are not taught the importance of comfort care:

I remember one person sort of like looked at me sympathetically [after telling them that I worked at a nursing home] and said, ‘Well, that’s ok.’ Then she
continued to go on tell me how she - and this is a direct quote - literally saved lives: ‘I literally save lives,’ and I thought, ‘Well, that’s what you value.’

Laura never thought she would work to help people die well, but like many of her fellow hospice nurses, she feels honored to do so now. In the following chapter, I will address this point in greater detail: although many hospice nurses at one point felt death was scary and mysterious, they now feel that being a part of this time in their patients’ and their families’ lives is a great honor, as Laura does.

Christina did not find that nursing school prepared her for hospice because 30 and 40 years ago, when she was in school, hospice was not even a concept. But like Laura, Meagan, went to school in the 1990’s and said that other than an elective gerontology class she took, there was not a lot of discussion in any of her classes about death or comfort care. Meagan thinks the reason for the lack of available education in end-of-life care is that nursing schools and educators are “geared toward the boards;” the boards comprise the nurses’ final examinations they must pass to become registered nurses, and there is very little on the boards about palliative care.

Leslie and Rose also said that nursing school did not prepare them for hospice because death was not discussed. Many of the nurses who have been practicing the longest say that death education was not a part of their training. But they believe the younger generations of nurses are getting a better education on the subject. It seems however, that regardless of when the nurses in this sample went to nursing school the majority of them felt unprepared for their jobs at hospice. Those who did feel prepared, like Colin and Heather, had reasons such as knowing what to look for and religion as explains for the unique experiences. Heather’s feelings about being more prepared than
the other nurses because she attended a Christina nursing school further ties death and spirituality, in that having established views enables one to care for the dying.

**Health Care: Palliative versus Curative**

Hospice, as discussed is still a relatively new organization but only having been in the United States for nearly three decades many of the nurses talked about being in an "ideological medical transition." And although there are great incentives to palliative care, both for quality of life and finical reasons (Harrison et al. 2005), many nurses talked about the tension and misunderstands about their work. However, the nurses who have been with hospice the longest have also noticed a growing acceptance and understanding of end-of-life care.

Meagan firmly believes that the medical community’s acceptance of hospice cannot be a choice and that change is inevitable, given our country’s expanding, aging population that is also living longer. She says,

In the next ten years, things are going to change drastically - ten to twenty years. Because all the baby boomers are going to be of that age (of needing more medical care), we’re starting now...Therefore, you’ve got maybe a family of seven kids, and each of those kids is having one to two kids and know those kids are moving away, so there are a lot of things that are changing. That’s why they say the medical profession is the one to get [a job] in [because there will be] lots of job security.

Meagan brings to light issues of finances and support. The financial issue is what many people in the political and medical professions refer to as the “dependency ratio problem” (Newman 2004): there will soon be a larger number of retirees (the “baby boomers”) collecting social security than there will be workers supporting them. The second issue, that of support, is that people are having smaller families whose children
are then growing up and choosing to live in different geographic locations, and so then the question arises: who is going to take care of those who are growing older?

Beth also described changes that have occurred in the delivery of medical care out of the home and into the hospital, which she called the "pendulum of care." As mentioned, Paul Starr (1982) explains that industrialization and urban life caused the dawn of a new medical regime (Starr 1982). In the 1940's and 1950's, work became mostly available in city factories, and so people were forced to leave their homes in the country and to move into smaller dwellings in the city (Starr 1982). This meant that no one was left at home to take care of the sick and elderly; in the new, smaller city dwellings, there was less space in which to take care of them, and thus sick individuals began to go into the hospital (Starr 1982).

But Beth, like Meagan, sees a new "pendulum of care" that is swinging out of the hospitals and back into the home. As the cost of medical care rises, as more and more Americans are living without medical insurance, and as hospice is a cost-effective alternative, these nurses believe the rising hospice census is not a fluke, but that it will also continue to rise (Emanuel 1996).

Beth sees within the medical system a wide range of levels of acceptance. She knows doctors trained in the 1940's and 1950's who are open to hospice and young doctors who are closed to it. She also has noticed that more doctors and other members of the medical care system at large are getting training in palliative care and that hospice is beginning to be seen as a part of the "whole spectrum of care." Often it is the patients, and not the physicians, who are asking for a referral to hospice. Therefore, even though more people are utilizing hospice and the hospice census has steadily increased, as
Meagan sees it, "It is [due to] a lot of repeat business," individuals and families referring each other to hospice versus the patients' physicians making the referrals.

Leslie and Rose also commented on how there has been an increase in education and acknowledgment of end-of-life care among the general population in the last decade. Leslie said, "People know what hospice is today. Years ago, the hospice nurse had to walk in and explain [what they were there for], and the patients were a bit surprised." And although not the entire medical system is supportive and some doctors are still resistant, more people are getting involved and taking advantage of hospice services.

Although many of the nurses are concerned about hospice's being misunderstood, Linda felt more respected as a hospice nurse as opposed to the other forms of nursing she has done before. She feels that hospice is perceived well by medical community and that she is taken more seriously as a nurse: "Nowhere else does that ever happen." Heather also feels respected for her work as a hospice nurse. She said that she has seen hospice change tremendously. She thinks that that medical community used to think that "all you hospice people do is hold hands." Now Heather believes hospice is seen as the expert in pain management.

Laura talked about being thankful for the tension she feels between the medical system and hospice. She laughingly said, "thank goodness" about the fact that our medical system has the technology and desire to save lives and that it still feels a bit uncomfortable with the idea of helping individuals terminate treatment and die. She explained that although hospice is sometimes seen in opposition to the conventional medical model in which lives are saved, she believes they are still very similar. "Everything is task-oriented. Even death can be task-oriented, and you try and keep death
away from that [rationality], but it is still structured...It’s hard not to ‘medicalize’ it.”
Laura said that even though hospice is not built on the medical model because it employs palliative and not curative care, “It’s hard to care for dying patients within government [Medicare and Medicaid] regulations; there are complications - weight loss, medications - that just don’t fit.” Laura raises an interesting issue: there exists a problem about utilizing hospice that does not arise because of medical/professional ideology or ethics but is rather due to an institutional barrier to hospice. Hospice is treated and funded as a specialized branch of medicine in that has the same bureaucratic structure, but given the nature of hospice care, it really belongs in a class of its own.

Heather acknowledges hospice’s potential inability to mold to further regulations. She said, “Hospice is becoming more main-stream.” Although Heather believes that that fact is positive, at the same time she feels that if hospice becomes too main-stream, then it will be more heavily regulated. Hospice has had fewer rules and regulations governing it in the past than did the conventional medical model, but the more people that access it, more money is spent on it, and “that always encourages scrutiny.”

Emily, like Heather, has noticed how hospice is becoming more widely utilized and accepted: “Every year, we see more people become more accepting of hospice.” However, although more people acknowledge the validity and value of hospice, Colin is concerned that medical schools are still not training their students’ adequately in death and dying and therefore are also still not referring patients to hospice. He said, “It’s a huge disconnect in the education world.” Colin has also found that when people refer to the “H-Word,” meaning hospice, they think they are giving up the other “H-Word,” or hope. This misperception is difficult for the hospice nurses who are so proud of the fact
that they are trying to help people live well through a very important part of their life, their death. As Amanda said, “Many people think that we hasten death,” and therefore the patient and family loses hope because they have not been properly educated.

Hospice as an Improvement on Care

Evan also struggles with this perspective: “The medical system looks at hospice and thinks we want to help patients to die.” But as Evan says, hospice is not about helping people die: it’s about helping them live. Holistic medicine is not embraced by medical system, and hospice is considered holistic, because, as Brian explained, “Our mission is to care for the mind, body, and spirit.” But as Heather, and nearly every one of the other nurses I interviewed, said, “Having to rely on your team: that’s really what makes it [hospice] holistic.” The nurses repeatedly said that they would not be able to do their job without the support of the entire hospice team, which includes everyone from the volunteers and other nurses to the office staff, physicians, social workers, and spiritual care givers. These nurses feel that nowhere else in medical care system can you find an equivalent interplay of professionals who need and utilize each other’s expertise to make their organization run smoothly.

Before she had worked in hospice, Christina had worked in other nursing environments and wished she had had a collective group of people with whom to work and from whom to get support. Now that she works in hospice, Christina finds it is nice to have a team meeting to talk about patients and to work through issues.

Brian agreed that the organization of hospice functions as well as it does because of the team component:
Hospice care is an improvement on the conventional [medical] model because it acknowledges death, and sometimes the right thing is no to do anything, and it's an assumption that you want everything done, and there is not opportunity for people to express whether they want something done or not...adds another dimension. It's more patient-centered; in the hospital [patients] are a captive audience in your space; when you go to their home, it's just another whole level of respect.

Rose also said that one of her favorite things about working for hospice is being given the privilege of going into the homes of her patients. She said that it is an honor and, like Brian, feels that it changes and improves the patient-nurse relationship. Perhaps if Beth is right about the 'pendulum of care' swinging back to our having health care provided in the home, more and more nurses will find themselves privileged to work in the private settings of their patients' homes.

Many of the nurses believe that working for hospice is the best job they have held in the medical industry, even though there remains a bit of tension in their work due to outsiders' lack of understanding what hospice is all about. Meagan also made a few suggestions on how to help with the lack of utilization in hospice. She said that although medical communities are getting better, doctors are still not being that realistic. Meagan finds it difficult when doctors suggest that their patients try a 12th round of chemotherapy, instead of discussing alternatives. She says that she is trying to educate patients to ask questions about the side effects of treatments and the outcomes of treatments, so they can evaluate for themselves what medical path they want to take. Meagan believes that doctors continue to offer those endless rounds of chemotherapy, for instance, even if they are not that hopeful about the outcome, "...because of the reactions of people; they'd rather not see people sad, they want to offer hope." Christina is a bit more pessimistic that
Meagan about this issue in that she believes the physicians are motivated to try to continue treatments out of interest in costs and profits.

Meagan and a few other nurses brought up the fact that they believe that our younger generations are not socialized around death. Meagan said, “We are removed from death; younger generations do not watch the death process [anymore].” Meagan thinks that it’s important to take kids to “friends’ and neighbors’ wakes so that it’s not such a foreign thing...Make it normal thing...There’s nobody that’s going to get out of here without [being around death] unless they die as a child.” Perhaps then if Americans were all exposed to death in the course of their lives, as the hospice nurses are, then we would not have such a ‘death denial’ in this county.

In sum many the nurses in this sample represent the majority of health care professionals leaving their medical training feeling unprepared for dealing with dying patients (Nelson et al. 2000). And although many of the nurses articulate feeling a tension between pain management and the conventional curative medical system many of them feel the growing acceptance in both medicine and society. These nurses having come from a variety of different occupational backgrounds (i.e. nursing homes, oncology and doctors offices) before coming to hospice but the question that remains what other influences such as life adversities, their faith and death exposure has on their ability to work in palliative care.
Embedded in many of the nurse’s trajectories to hospice, were personal reviews of negative or adverse life events that influenced their decisions to work in palliative care. Although, as explained in chapter three, many of the nurses took a position at hospice because their job opening it is not surprising that there were also nurses who were exposed to death and or hospice in their personal life, which inspired them to work in end-of-life care. But there is also another intersecting layer; this is the influences their negative or adverse life events had on their faith.

Recently there has been a growing interest in the relationship between life adversities and faith as a form of coping (Wink 1999; Pargament 2003; Stoebe 2004; Thomas and Cohen 2006; Tedeschi and Calhoun 2006). Kenneth Pargament et al. (2003) stated that for many individuals “religious beliefs, practices, and relationships are commonly involved in the process of dealing with stressful life experiences” (Pargament et al. 2003). Thus, suggesting that life-changing events such as exposure to death exposure, bereavement illness, or divorce (Wheaton 1999) may not only encourage an occupation with hospice but also a resurgence or birth of faith during that time.

Before exploring the nurses ‘faith trajectories,’ in chapter three, the following narratives reveal the webbed experiences of how life adversities have affected the nurses to turn to hospice and or faith. Adverse or negative life events, pertaining to the nurses in
study are defined as taking care of and the death of a loved one, personal illness, and divorce. This chapter, as a bridge from chapter three to chapter five between; firstly influences of adverse and negative life events that led the nurse to hospice, the second is adversities that led the nurse to both hospice and being more faithful and thirdly, adversities that led the hospice nurse to be more faithful.

**Adversities & Hospice**

Colleen is a soft spoken woman, in her early sixties, who has lived most of her life in the northwest region of the Rocky Mountains. Colleen, like the other veteran nurses in Chapter one, has been nursing for 40 years. And like their narratives expressed that she was “doing hospice before hospice existed.” Although Colleen knew she wanted to be a nurse since she was 5 years old, she did not become passionate about palliative are until the death of her own daughter. Colleen explained,

When I had my family, my first daughter was born with a heart defect...which was corrected at the clinic...but left her profoundly brain damaged, she wasn’t that way at birth and so then I thought this must be the reason that I went into nursing, that God directed me on this path so that I could raise this child who was obviously going to need a lot of help...then my oldest daughter died when she was fourteen and then I went into hospice.

When Colleen states that she “went to hospice,” she further explained to me that she did not simply start working for hospice she was actually one of the founding members of the organization she in now employed by. As explained to be by a few of the nurses in Chapter one, the implementation of hospice in this country was a great grassroots effort by nurses, patients and families around this country. After the death of her daughter, Colleen, with a few other nurses began a ‘Volunteer Hospice;’ this is not to be confused with the volunteer component that hospice has today, where lay individuals can take a volunteer course through hospice and visit terminally patients. In the late 70s,
nurses like Colleen, were volunteering their time, without pay, to take care of patients and families in an attempt to help them die more comfortably. Therefore, not only did the death of her daughter direct her to work for hospice but it inspired her help change the face of modern medicine.

What is also evident from Colleen, is her faithful convictions: “God directed me on this path,” she said. Colleen was raised an American Baptist Christian and now attends a non-denomination church but does not see the death of loosing her daughter as an acute time that influenced her faith. Colleen, unlike many bereaved parents, does not see the death of her child as a “spiritual turning point” but rather as a critical event that influenced her to help other families and patients who were dealing with terminal illness (Thomas 2006: 65). Colleen did say however, that “you can’t help living and maturing and not have your faith grow.” Although Colleen’s faith is evident in her dealing with the adversities in taking care of and the death of her daughter, this event did not change her religious or spiritual practices in anyway.

Linda and Cathy, like Colleen, also came to work for hospice after partaking in the care of a terminally ill family member. Linda is 54 year old woman, from the northeast who was inspired to go to nursing school as an adult because of her experience with her dying mother-in-law. Linda explained that her mother-in-law was suffering from ovarian cancer and in spending the last 6 months, helping her get through chemotherapy treatments, explained “I went into nursing school specifically to be a hospice nurse.”

Cathy also went to nursing school as an adult, specifically to be a hospice nurse. Cathy, like Linda lives in rural area in the northeast and graduated from nursing school in 2004. She explained to me that in taking care of her father-in-law, who was suffering
from digestive heart failure, she became ‘frustrated as a lay person,’ not being able to understand all of the medical technology involved with his care. In desiring to understand and having a passion for health care she returned to school to get her associates in nursing and has been working for hospice for 3 years.

Although Linda and Cathy talked about how their adversities of taking care of their terminal in-laws influencing them not only to work for hospice, but to become nurses in their adulthood, they do not feel that these experiences have influenced their faith. Like Colleen, Linda talked about an already existing faith, which we will revisit in Chapter five, that gave her strength during hard times but did not change them at all. Cathy too does not feel that the negative events have changed her spirituality. What she did say however, is that working at hospice has strengthen her coping mechanisms and taught her how to deal with the death of a loved one. Cathy explained to me that she lost a grandson to SIDS in 2004, when he was 5 months old. And although she does not recognize a difference in her faith what she learned in her experiences at hospice and in their hospice training she feels has helped her grieve, problem solving and help her family with their bereavement process.

Emily, like the previous female care takers, also came to hospice after taking care of her own parents. But Emily also said that it was a combination of taking care of her ‘elderly parents,’ and a divorce which finally inspired her to pursue a job at hospice. Emily is among nearly half (9/20) of my sample who have experienced a divorce as a negative or life changing event. Although, divorce in the United States is a prevalent that approximately one in five adult who marry will divorce (Krieder 2005), the frequency does not diminish the hardships in the everyday lives of those who go through them and
are life-changing events (Wheaton 1999). And thus is the case for several of the individuals that I interviewed.

_Adversities, Hospice & Faith_

A terminally ill person in hospice must have a primary care giver. This care giver does not have to be a medical professional and is frequently a family member, which was the case for Colin. Colin is in his mid-fifties and is a tall, simple-looking man with light blue eyes. As an undergraduate in the 1970’s, Colin was a pre-veterinary medicine major. Colin explained that although he did want to go to veterinary school and become a veterinarian, at the time those programs were admitting primarily women and minorities, and so he went into the “real world” of banking and retail instead for twenty years.

I was therefore extremely intrigued about what had caused Colin to shift off the corporate executive track into work as a hospice nurse. With no hesitation and only a few minutes into the interview, his answer was straightforward:

I lost a partner to AIDS in 1996 and got involved with Hospice as his support during that time. And after the death I said (to myself), ‘I need to be doing something more meaningful with my life,’ and so went to school specifically to be a hospice nurse and to hopefully work here, and upon graduation 2001, was hired here...I would not do any other type of nursing. I have no interest in it.

Colin was his partner’s primary care giver. Upon his partner’s receiving his diagnosis, Colin took a volunteer course to “find out all he could about death and dying.” Along with taking care of his partner of ten years, he also served as an active volunteer for hospice. Colin endearingly spoke about how grateful he was for his volunteer training and experience because, as he explained it, he went through “anticipatory grief,” a recognition of “what was coming down the pike” for him.
Colin’s personal adversity led him to be a hospice nurse, but he also feels that the experience of his partner’s death has made him a more spiritual person, too. Colin believes that “a lot of people experience [this] because they are watching someone who is dying search for meaning and reconnection.” Colin’s partner was raised as a Catholic, but his partner did not identify with Catholicism until the end of his life when he began using rosary beads and symbolic icons from his childhood to reconnect with his faith. Colin said, “It increases your spirituality as you witness someone else doing it.”

Evan, like Colin, tells a story of adversities that led him to become a hospice nurse and a more spiritual person. But unlike Colin, the adversity Evan had to wrestle with was his own mortality. When I called Evan to set a time for an interview and he answered the phone, I attributed his raspy voice to the fact that either he’d been running or was a smoker. The rhythmic cadence of Evan’s descriptive speech was punctuated by his clenching for breaths of air. Before I could begin asking Evan my usual opening interview questions, Evan asked, “Do you know anything about my story?” When I told him that I was not familiar with his story, he began,

I was told that I had advanced throat cancer. I had no risk factors. I never smoked. I never used tobacco. I have never used drugs. I have no sexually transmitted diseases. There was no...everyone in my family lives into their 90’s. I thought I had a bad wisdom tooth one summer and ignored it, and I finally went into the dentist, and the next thing I know, a day later, I went to an ENT (ear, nose, throat) specialist, and I was told I had stage four terminal cancer that had metastasized...This was three and a half years ago...Now I am in remission.

Evan is a 52 year-old graduate of a prestigious university in New York and, like Colin, had wanted to attend veterinary school but did not get accepted. Choosing an alternative path, Evan decided to follow in his sister’s footsteps and went back to school to become a registered nurse. He has been a nurse for fifteen years, and after graduating
with an associate’s degree in nursing, Colin went to work as a floor nurse in a rural hospital and then as a nurse in the emergency room. He spent the majority of his nursing career, seven years, working at a correctional facility. Then he was diagnosed with cancer:

Well, I got cancer, and I was supposed to die. I went through surgery; I went through radiation; I did all the things that you’re supposed to do as a conventional patient. Then I went back in, and they said, ‘The cancer’s back, and you’ve got three months to live.’ And one of the nurses [at the cancer center]... uh, had lost her husband to throat cancer, and she kind of adopted me, and she said, ‘I know there’s a lot of herbal treatment and holistic treatment out there, but I’d really like you to try this one.’ And, uh, I did, and three months later went back in, got checked, came home, and I got an immediate call back from the cancer center, and they said, ‘We’ve got some news for you.’ I was expecting to hear that you...you know...I didn’t have a whole lot of time, and they said, ‘Mr. Evans, you’re in remission!’

Evan explained that his remission was bittersweet because in trying to contact the nurse who told him about the life-saving herbal medicine, he learned that she had died the night before from an asthma attack and never knew that she had saved his life.

Evan has only worked for hospice for about three months, but he felt he was uniquely qualified to work there because of his own life experience; although he has not worked there for a long time, he feels comfortable and believes the families whom he supports and his co-workers are happy with his performance. Evan’s personal life adversities had a dual effect on him: to becoming a hospice nurse and to develop religiously and spiritually, as well. He explained that he was raised as a Methodist and was active in the church as a child and teenager. He reported that he then “drifted away from it” as he grew older, but then said, “I came back to, uh, it when I got cancer like a lot of people do. I mean, it’s kind of typical…” Evan’s experience supports my original
assumption that when facing a terminal illness, people tend to seek religion and spirituality. For Evan, seeking religion led him to a reconnection with his former faith.

Colin’s adversities arose in the form of living through the death of his partner, where Evan confronted the very real possibility of his own death, and both of them explain a change in their own spiritual and religious development due to wrestling with these adversities. Colin and Evan are examples of how a major life adversity, particularly death, can affect religious practice and spiritual seeking. These two hospice nurses have experienced death: one watched his beloved die and the other approached his own mortality, and have come to work for hospice because of the impact their experiences had on their lives. My original hypothesis was that adversities were catalysts for religious or spiritual growth; it seems that for Colin and Evan, these life events solidified a faith that had been looming, and is typical for those who are grieving for facing such hardships in their life (Tedeschi 2006). And although researchers like Richard Tedeschi and Lawrence Calhoun (2006) explain that grief can lead to a loss or a strengthening of faith, for Colin, Even and the following nurses their adversity increased their faith.

**Adversities & Faith**

It is not possible to quantify the effect an adversity can have on an individual’s everyday life. It does seem that society believes certain adverse life events impact individuals more seriously than others do, as if society has agreed upon an unwritten stratification of the severity of the impact a variety of different life challenges “should have” upon people. And although some adversities are experienced as life-altering for the individual, those same life challenges are generally valued or considered to fall at the low-impact end of the scale by the general public.
For example, it is unimaginable that parents should lose a child, and when we learn about individuals, like Colleen, who have lost a child, we extend them our sympathy immediately, whether or not we even know the family. It seems, however, that if a child loses a parent, the value assigned by society to the difficulty of this particular adversity varies. If a ten year-old child loses a mother, father, or both in a car accident, for example, the death seems horrific; but if a 65 year-old man loses his 90 year-old mother, that man’s loss is generally regarded by society as having less of an impact on him than the parental loss of the ten year-old has on the boy.

In talking about life events that have shaped their religious and spiritual trajectories, nine hospice nurses, mentioned divorce. Brian talked about how his faith has been shaped by his divorce. While the grief from his divorce did not inspire him to attend nursing school or become a hospice nurse, it did impact his spirituality:

I would say that this work has influenced my spiritual beliefs. There have been a lot of things that have influenced my beliefs...having gone through a divorce and all the things that go along with that, having my child involved, and listening to the counsel of others from different spiritual backgrounds that have really shaped part of my spiritual beliefs.

The dynamic interplay of Brian’s work at hospice, his divorce experience, and the counsel he received from people of other faiths did indeed shape his religious or spiritual beliefs. Here Brian articulates the integration of his work at hospice, going through a divorce, and that of other people, to show the dynamic interplay of experiences that shape our religious and spiritual beliefs. Here Brian states that he feels that since being at hospice his spiritual beliefs have changed but, as we learned in chapter one it was not a negative event but rather timing and a job opening that led Brian to work at hospice;
where his divorce on the other hand he sights as being an event that “influenced my beliefs.”

Liz, like Brian, talked about her divorce as a life event that has made her more faithful. As we learned in chapter three, Liz has been nursing for three decades and explained that just simply knew she wanted to be a nurse as a child. But what Liz also explained to me is that she has always been a very faithful person too but wonders if her divorce reaffirmed her faith.

Liz explained that in her adulthood, there was period of time when she stopped going to church but still believed. She stated, “I am not sure whether it was because I got older or went through a divorce and decided “you know what I have to get my ‘crap’ together.” But I’m not sure what it was.” Liz’s inquisition about her age versus her divorce, as the medium for a resurges of her faith, are two possible explanations for spiritual development in the larger social context. Although her age and divorce are not mutually exclusive entities, age and the maturation process are one explanation for spiritual development (Dillon and Wink 2007); while as discussed, grief or the stress of an event like a divorce is another. Therefore, for Liz, irrespective of her divorce perhaps she would have been at a time in her adulthood that would have been marked with a higher level of meaning seeking and an introspective ‘purpose of life,’ quest. But that the culmination of her age and divorce inspired her to reconnect with her faith.

Like Liz, Meagan is also unsure what life events that have increased her spiritual development. Again, as we learned, Meagan went to nursing school as a single mother after a divorce. But the interesting thing about Meagan is that she does not sight many of the stressful life events that she has endured as influential on her occupational or faith
path. As Meagan explained to me, she learned about hospice from a paper that she wrote for a gerontology class she took in nursing school and recognizes this experience as her propelling force to work for hospice. But also intertwined in Meagan’s story was her own father’s terminal illness and death. When Meagan was 23 years-old her father died, after a ten year battle with “Parkinson’s, Alzheimer’s and lung and heart failure.” She explained that in the last five years of his life, he had a hospital bed set up in his house while her mother took care of him. Because palliative care was still relatively new (Harrison 2005) Meagan’s parents, along with most Americans, were unaware of organizations like hospice. Meagan stated that her regret is that “if she knew then, what she knows now,” her father would have died peacefully at home, instead of in a rescue squad on the way to the hospital.

The foreshadowing of Meagan’s father’s death to her own occupation with hospice was unrecognizable life event; she does however, talk about how going to Al Anon meetings played a significant role in her spiritual development. (Al Anon is a support group for people who have alcoholic and recovering alcoholics in their life). As with her father’s death, Meagan did not state that the dissolve of her marriage influenced her occupationally or faithfully; she simply said that after her divorce she needed to go back to school in order to get a financially stable job to take care of her children. Meagan said,

My work with hospice has increased my spirituality by leaps and bounds...Well, I shouldn’t say it was all hospice because I definitely, I was involved in Al Anon for many years, and that’s what gave me foundation. It wasn’t really church that did it for me...I used to say the word ‘why’ a lot: why someone so young, why three people in the same family, why in such a short period of time, and now I don’t find myself doing that. For me, my spirituality is very, very simple, and I just believe that we are all being guided, which I have to say makes my life so much easier just because I can, um, I know that someone is helping me, and not
that I’m not making decisions everyday, but I think we are given a lot of help.

Therefore, although Meagan did not explicitly identify a critical life event that made her more spiritual she does recognize her time attending, Al Anon when she was married to a recovering alcoholic (her husband had many years of sobriety but was also active in Alcoholics Anonymous), as influencing the spiritual person she is today.

In summary, half of the nurses in my sample experienced stressors such as loss of a loved one, divorce or personal mortality, which were life-changing events. Bereavement and stress accounted for five of the nurses which led them to pursuing a job at hospice, while the other five experienced spiritual development as a result of their negative life events. And as explained by Wheaton (1999) it is very common for individuals, like the nurses in this sample, to experience “Post-traumatic growth,” after negative life events.
CHAPTER V

EVERYDAY RELIGION AND SPIRITUALITY

*Faithful Histories*

Being a parent increase the likelihood of going to church (Dillon and Wink 2007; Edgell 2003). Research indicates that even for parents who are not particularly religious they still find it important to be exposing their children to religious socialization. This is that parents find it important for their children to have the social and supportive opportunities available in the church setting (Dillon and Wink 2007). The trends in church attendance do suggest however that even if individuals experiences a drift in their early adulthood once they get married and have children they resume their church attendance.

Unsurprisingly, like many American adults, the hospice nurses I interviewed usually recounted having had richly religious childhoods and having experienced faith and organized religion in three major thematic ways. Some of the hospice nurses talked about a childhood drifting from the church, followed by a reconnection, while others recounted an explicit recollection of an unpleasant, faith-related experience. And the most pattern found was the nurses remembered their parents taking them to church for a period of time, which I will refer to as parents leaving the ‘church-door open’ phenomenon.
Drifting to a Reconnection

Liz is an energetic woman in her late 50’s who says that since she was a little girl, she “just knew she wanted to be a nurse.” Liz has been a registered nurse for 30 years and worked as a hospice nurse for two years. As a little girl, she and her family attended a Fundamentalist Baptist Church. As she grew older, Liz stopped going to church for a while; she maintains today that she was a believer during her absence from the church but that she was “just not practicing” anything at the time.

Liz now attends an independent bible school. She is not sure what made her want to reconnect. She explained, “I am not sure whether it was because I got older or went through a divorce and said to myself, ‘You know what? I have to get my ‘crap’ together.’ But I’m not sure what it was.” Liz’s experience of attending church as a child and then stopping for a number of years before reconnecting is similar to Evan’s religious past. Evan was born and raised a Methodist. At the age of 52, Evan continues to be an active member in the Methodist Church. Evan explained,

I was raised in a Methodist Church, and I was active in it as a child and a teenager, and then I kind of drifted away from it when I got older, and then I came back to, uh, it when I got cancer like a lot of people do. I mean, it’s kind of typical...

Here, Evan cites having to deal with adversity in his life as the main motivation for his having reconnected with the church. Evan does not question what it was that made him return to church; Liz, too, faced adversity in the form of a divorce, which as she stated could have been a contributing factor in her return to organized religion, but she is unsure of what it was that actually caused her to reconnect.

Liz’s and Evan’s early life experiences, ages, and grappling with adversity in the form of divorce or mortality induced in each of them an introspective compulsion to seek
meaning in their lives. Unlike Liz and Evan, the following nurses had an unpleasant religious experience that made them turn away from the church, although they had been raised in actively religious families.

Leaving the Church

Brian is a tall man with a slow, thoughtful rhythm in his speaking voice. Brian is in his late 40's and the only male hospice nurse in his office. As I waited for Brian to join me to talk in his office, I noticed that the phrase ‘Carpe Diem’ (seize the day) danced across his computer screen, and I could see everywhere signs of a busy life: neatly organized piles of papers, binders, and folders decorated the entire space around his desk.

When I asked Brian if he was raised in any particular religion or faith, he replied with a chuckle,

My father was a Lutheran minister. And that’s not what I practice now, but I’ve had a lot of influence from the teachings. Just my experiences alone in living with a person that said all this stuff and seeing how imperfect he was and then watching him on the pulpit almost like he was another person.

Brian was not saying that his father was a dishonorable man; instead, Brian found it hard to believe in a church in which he watched his father cloak himself in sainthood as its minister, only to see his father behave in a less than saintly manner at home. Brian did not express lavish words of protest against the church or any organized religion: he simply felt that it was not for him.

Todd, on the other had, was raised a Roman Catholic. After sixteen years of Catholic schooling, however, Todd feels justified in saying, ‘They are just wrong on many points.’ Todd has turned away from the church. Todd says that if he were to associate himself with any religion, which he doesn’t, he would call himself a Protestant. After been raised Catholic, he is ‘looking for something a little better.” After coming to
understand the Catholic Church’s positions on certain issues, Todd’s unpleasant, childhood religious experiences have lead him to choose a life without it.

Loraine, like Todd, was raised as a Catholic and remembers going to Sunday school as a little girl and then as a young teenager. Loraine told me that she then stopped going to church in high school because of a “couple of youth leaders (who) started bickering.” Loraine remembers thinking, “That’s not the way you should act in that space.” Once Loraine had stopped going to church, no one seemed to care: no one asked her to return or showed interest in learning why she had stopped going. Like Brian, Loraine clearly states that she has nothing against the church, but it just did not suit her. Loraine’s unpleasant experiences, like Brian’s, were associated with church leaders who were supposed to emulate the teachings of the church but did not; Todd’s reasons for leaving were due to his personal disagreement with the doctrine itself.

*The Church-Door*

Many of the hospice nurses I met shared vivid memories of attending church with their parents. Laura, a young nurse who is new to hospice, explained to me that although she is unsure about her own faith, she still takes her daughter to church when she can. It was in talking to Laura that I identified a theme emerging among my data that I will refer to as the ‘Church-Door:’ once people become parents, regardless of their religious affiliations, lack of religious affiliations, or prior practices, they still seem to feel it is important to take their children to church for a certain amount of time, exposing their children to religion and faith and thus leaving the ‘Church-Door’ open for their children. These nurses fit into a larger societal norm which values having children exposed “formal religious socialization” (Dillon and Wink 2007: 83). Dillon and Wink (2007) explain that
it is not uncommon for church attendance to increase, regardless of faithful convictions, when parents have school-age children. In this sample we can see that the nurses are on both sides of these findings; as children they were taken to church for religious socialization and as parents going to church until their children were grown.

Emily is an open, 56 year-old who has been a nurse for 35 years, working in hospice for nine years. She describes herself as a spiritual hospice nurse but not religious one. Emily was raised as a Presbyterian and explained to me that although currently she feels the most connected spiritually to the natural world, “I was raised in the Presbyterian Church, went to Sunday school every Sunday, and went to church until my own children were grown.”

Emily did not mention ‘a falling out’ with the church or disliking religious teachings, but she does say she is not a religious person. Like many American parents, however, she still felt it important to take her children to church. Other nurses articulated the same story about their own parents. Meagan, for example, is the youngest of five, was raised on a farm, and can remember going to the Methodist Church until she was eleven years old. She remembers her mother taking her and her siblings to Sunday school regularly. Then, all of a sudden, they just stopped going to church. Meagan is unsure of the reason why they stopped going to church; she never talked about it with her mother, but it seems likely that, like Emily, Meagan’s mother took her children to church until her youngest was almost a teen or once he or she was ‘old enough not to have to be taken any more.’

Cathy remembers going to the Roman Catholic Church until she was five years old. Cathy, like Meagan, was raised on a farm, and Cathy’s mother, like Meagan’s, took
her five children to church every Sunday morning until it was too difficult to manage both taking so many children to church and continuing to work on the farm. Cathy did return to the Catholic Church as a teenager; she received her first communion, was confirmed, and then after that she stopped going to church again. Although Cathy stopped going to church with her mother when she was only five, it seems that her exposure to church during the time her mother did take her was enough to create a desire in her to return as a teenager to explore religion further. However, at the age of 36, Cathy no longer identifies herself as being religious or spiritual.

Christina’s and Heather’s memories of attending church are strongly associated with their parents. Both of these hospice nurses were raised attending a Catholic Church. Christina states that she “defied her parents” and stopped going when she was twelve, whereas Heather attended “sixteen years of Catholic schooling, and that was enough.” Heather explained, “I come from a religious background where religion was kind of imposed,” and stopped going to church the day she left her parents’ house. Both of these women see themselves as spiritual people, but neither continues to hold the religious torches of her past.

The hospice nurses who articulated such rich religious, church-attending practices from their childhoods describe different experiences of faith in their adult lives. Symbolic of our country’s current religious and spiritual culture, so, too, do the hospice nurses describe the various ways in which they view and practice their faiths.
Practicing in the Present

Ritualized Spirituality

Theorists like Durkheim (1912) and Bellah (2003) stress that rituals are the crux of our society and culture and serve as a defining element in religion (Bellah 2003). In his article, ‘The Ritual Roots of Society and Culture,’ Robert Bellah cites Durkheim by explaining that, “‘Profane time’ is ‘monotonous, slack, and hum-drums’ where ‘sacred time’ is characterized by ‘collective effervescence’ and ‘devoted primarily to ritual’” (Bellah 2003). This is sociologically significant because one of the tensions between religion and spirituality is that spiritual practices have been criticized for being privatized, whereas religion involves collective ritual. Linda exemplifies the ‘ritualized, spiritual person.’

Linda is a cheerful, 52 year-old woman who attends bible study a few times a week and who is very forthright about the role God plays in her life: “I gave my life to the Lord in 1980.” She expressed her open love for the Lord throughout my interview of her, and she professed her firm belief that being a hospice nurse is what God intends that she do. Linda was not raised as a Christian, and as one of nine children, she and her sister were the only ones who went to church. Linda said,

“I went [to the Catholic Church] with my girlfriend in high school, and I thought that was just, that was as close I was ever going to get to God, right there. All the candles and the stained glass, and I loved it. I loved every minute of it.”

After listening to Linda talk so easily and candidly about the salience of Christ and God in her life, I was then slightly surprised when she explained further that she sees herself as a spiritual person and not a religious one. When I asked her to try to make a distinction between being religious and spiritual, her answer was,
When I hear the word religious, that connotates to me more of by-the-book, ‘I go to church on Sunday, I put my dollar a week in, and I help the poor and I do this and I do that.’ Spiritual to me...I think I like spiritual better because to me that means I have really given my whole life to do the work of God. I know who He is. That means I read my Bible a lot. It certainly does mean healing the poor and doing this for other people, but it means really doing what the Bible says. It’s not like I just go to church on Sunday, and the rest of my week is whatever. It’s everyday; it’s gettin’ up and reading the Bible and praying every day and discipline.

Linda, like many Americans, represents an ironic defiance in theory. It might seem easy to pin Linda into a very religious niche, as she lives her life for the Lord. However, although she describes practicing a highly ritualized spirituality, she does not see herself as religious. Linda is among the one-fifth of Americans who see themselves as spiritual, but not religious (Dillon and Wink, 2007); they consider themselves born-again Christians.

Sally, a 60 year-old woman who has been nursing for 39 years, describes herself as a very spiritual person, not a religious one, but as a born-again Christian. She remembers the exact moment that she was born again; it was November 11, 2000.

I even know exactly when it happened and how it happened. I always went to church, but it was always, um, it was religious, and then I developed a relationship, and I knew Christ was alive at that moment.

Sally explained to me that she had been at a retreat where she ‘intensely praying’ a lot, and then there was a profound moment when she realized her own spirit. Sally, like Linda, lives a highly ritualized, spiritual life, but although she still attends church, she has divorced religion from her faith. Sally attends church every Sunday and is the music director for her church choir:

I am very active in my church and in Christian communities beyond my church, but I don’t like the word religion because that denotes, um, the legalistic, church part. But spiritual? Yes. Yeah, I am a strong believer in my faith.
Despite the fact that they demonstrate characteristics often associated with religious people, Sally and Linda do not see themselves as religious but rather as spiritual people.

As Roof (1999) has explained, religion is a social construction that is reproduced and remolded for our current needs (Roof 1999). He explains that there are many individuals like Linda who are very faithful individuals with highly ritualized, social and private practices who say they are spiritual but not religious. This is they have a personal relationship with the lord and are thus spiritual.

Linda and Sally represent many Americans who speak of ritual in terms of spirituality, although the word ‘ritual’ was once used to define religious discourse. Linda’s belief system illustrates how religion and spirituality are socially-defined. This means that although spirituality is associated with individualism (Bellah et al. 1985; Roof 1999), as sociologist Peter Berger and Thomas Luckmann (1966) stress that we can not separate the fact that our everyday realities are social constructed. This meaning that although we associate spirituality with individualism, this form of faith, as Linda clearly demonstrates by going to bible study, how important the collective and social experience is for her to construct meaning. Another important point is that religion and spirituality will continue to change and reform to some degree as Roof (1999) has stated and finally, theorists can try and make clear definitional distinctions between religion and spirituality, but the everyday reality is such that individuals may not.

Colin, like Linda and Sally, declared that he was a spiritual but not religious person. Colin was raised in a Congregationalist Church but recently converted to Judaism. When I asked Colin if he considers himself a religious or spiritual person, he replied, “Yes, I’m Jewish,” and with a slight laugh, he continued, “I’m very spiritual...as
opposed to religious.” When I asked Colin to explain the difference between what ‘spiritual’ versus ‘religious’ means to him, he said,

Religion is formalized; it’s a space. You go to a church, you go to a Synagogue, um, you are in a community of like-minded people with the same belief. To me, that’s religion: its doctrine is how things have to happen, where spirituality is more what you make of it. You take the tools, and you create your own experience based on what religious [teachings that you know].

Colin further explained to me that he used to go to synagogue, but then he stopped going. Now he practices what he calls “Friday Shabbat” and says that his spirituality is about “the rituals, prayer, meal, being out in the world and doing good things, which make hospice nursing and Judaism seem to go hand in hand.” Colin is another example of how fundamental rituals are in our everyday reality.

Colin’s practice does beg the question, however, of whether our private rituals can have a social role. If Colin is practicing his Friday night ritual alone at his house while many other Jewish Americans are doing the same thing in the privacy of their homes, does that give any social significance to the practice? Many Americans commonly engage in a TV-watching ritual: they all watch the same television show at the same time on the same night – and on a weekly basis - in the privacy of their individual homes. But they all do this so they can talk about the television show the next day with others who also saw it.

*Going to Church & Being Alone*

Many Americans describe themselves as religious and spiritual. In fact, approximately ‘two-thirds of Americans who have a religious affiliation’ say that they are both religious and spiritual (Hout and Fischer 2002). This is the case for the following hospice nurses. Sara is a soft-spoken woman in her mid-50’s who describes herself as an
Evangelical Christian. But unlike Linda and many evangelical Christians, Sara says that she is both a religious and spiritual person. She explains,

If you are just a religious person, you are just doing things by rote. A person who is just religious might say, ‘I go to mass everyday because the church says I need to go to mass everyday.’...It’s very ritualized and perhaps not into your spirit or your whole way of life. Um, I definitely feel like I am both because I do believe in going to church.

To Sara, ‘ritualized’ means without thought or a personal connection with an expression of a particular religion. However, she, like many Americans, dismiss the importance of ritual in their own lives. Sara sees her religion as part of her spirituality, but her religion is a combination of both the practice of going to church once a week and a private, spiritual practice in her everyday life.

Priscilla explained she “believes in going to church,” but along with going to church, she also has a private, daily spiritual practice that is comprised of her ‘quiet time in the morning to journal.’ Although there are many Americans who say they are religious and spiritual, Priscilla is a good example of those who practice religion in a church and who also have a private, spiritual practice, as well.

Evan, like Sara, says that he is both religious and spiritual. Evan is a 52 year-old man who has been in nursing for fifteen years and has been working with hospice for three months. Evan describes spirituality this way: “[It] is a belief in a higher power, uh, God, however, whatever you want to call him, but it’s a belief in a higher power that there is something else out there.” He says that there are just some things that you can’t explain, but he finds great “comfort and pleasure” knowing there is “something” else out there.

Evan likes to go to a Methodist church when he can but also says that he takes “a
great deal of spiritual satisfaction from the sun coming up and the sun going down.” Because he is in his barn at four every morning, taking care of his horses, he does see the sun come up every morning. Evan is like many individuals who define their spirituality by virtue of a very unique private practice.

There is, however, another type of spirituality that does not involve or require a specific practice or ritual but rather allows for a much looser definition and identification of spirituality. This is the case with the majority of the hospice nurses that I interviewed and that can be readily seen in the following testimonies.

The ways of being Spiritual

Spirituality is what is practiced by the majority of the individuals in this study, as well as by one-fifth of Americans who describe themselves as spiritual but not religious (Hout and Fisher 2002). The difference between ‘Spirituality’ and ‘ritualized spirituality’ is largely defined by practice. Unlike those who are opposed to church or do not attend church, individuals who are spiritual do not possess any convictions against the church and express instead a very open, free form of faith. Many of them do not incorporate a ritualized practice of any kind in their faith but still ‘feel connected’ spiritually by other means, such as being ‘at one with nature,’ engaging in ‘open-prayer,’ feeling deeply connected to other people, and hospice nursing. As Roof (2003) writes, although spirituality can be “bound up with, and embedded within, religious forms,” which more closely describes individuals like Sara and Evan, it can also be “much more loosely in keeping with humanistic psychology as a search on the part of an individual for reaching, through some regime of self-transformation, one’s greatest potential” (Roof 2003).

For those who practice New Age Spirituality, Roof’s second definition is more
fitting. For example, Brian calls himself a spiritual person but says that he does not have a specific practice of his faith. He says that he prays in what he calls an ‘open form of prayer.’ He believes in a Creator but states,

I don’t have a hard, firm believe that this is the way to God...or those things. I just know from my own personal experience that there is a creator and that there are rules and there are laws in life - just like blood turns red when you cut yourself - that are in place, but things in the Bible or the Koran I don’t think I catch it all...”

Another example of this more loosely defined, unritualized form of spirituality is the way that Christina practices her faith. Christina says that she “considers herself a very spiritual person.” In describing how she practices her spirituality, she indicated that she likes to be alone, recently bought a new home, and loves to be outside and take walks. Along with enjoying her solitary time, Christina also clearly stated that, “I practice spirituality in just how I am with other people because I consider what I do a very sacred thing, taking care of people in their most vulnerable moments...I just feel that that’s a gift that I have.”

Interaction with other people as a spiritual practice is also an integral part of how Cathy views her faith. Cathy has been a hospice nurse for nineteen years, and although she went to church as a little girl, she believes that she has only become a spiritual person in her adult life. Cathy’s and Christina’s view other people are fundamental to their spiritual beliefs, and this conviction brings to light an important tension that exists among the scholars of the sociology of religion.

Some researchers have characterized spiritual seeking as narcissistic. Spirituality has been called the ‘me-first’ religion (Wuthnow 1999) because many American who see themselves as spiritual often practice their faith in introverted, privatized, and highly
personal ways. This is in contrast to how organized religion facilitates interaction, community, and social services. But here we can see that although individuals may practice their spirituality in a privatized fashion, they may still view their spirituality as having a social component because they believe other people play such critical roles in their faith.

Although Cathy described herself as a spiritual person with a simple faith, she said that once in a while she still goes to church because she “likes the rituals.” Cathy’s version of spirituality could be said to suggest the idea that perhaps church is not about faith, but about ritual; for people like Cathy, whose faith is seemingly formless in its spirituality, still like to attend church for its ritual elements.

**Seeking Meaning: Not Religious, Not Spiritual, Not sure**

Theoretically, it seems like a simple empirical question: are you a religious or a spiritual person? But the fact of the matter is that for many Americans, there is no clear-cut answer. There are many individuals who are unsure or still seeking for meaning. In this study, I found that most of the hospice nurses stated that they were spiritual; a few said they were both religious and spiritual; and none said she or he was strictly religious or atheistic. But I interviewed one woman who is unsure about what she believes.

Laura is in her late thirties. She has been a nurse for seven years and a hospice nurse for only about four months. To my question about whether she considers herself spiritual or religious, Laura replied,

> Myself, I hope, I...I always say I want to be a Buddhist. That’s what I’m working on...Just sort of that being, not holding on to things, especially the negative. It takes a lot of work. Uh, I don’t know.”

Laura is a good example of the uncertainty experienced by a person who is still seeking
meaning. Therefore, although she has some notion of what being spiritual means to her, as a Buddhist, she would neither define herself as a spiritual person nor deny the fact that she is. In asking Laura further about what it means to her to be a Buddhist or if being a Buddhist has a spiritual or religious aspect to it for her, after a moment of thought and silence, she said that she could not say Buddhism had no spiritual or religious aspect to it because she “gives value to [religion and spirituality].” Obviously, Laura is respectful of both religion and spirituality but whether she is spiritual seeker, because she talks of being a Buddhist is unknown. The interesting thing about Laura is she was one of the youngest hospice nurses that I interviewed; therefore, in taking a life course perspective perhaps she is in the process of introspecting about her own faith.

Laura is like many parents of young children who, regardless of their own religious or spiritual beliefs, will try, as she states, 'to keep it open' for their children. Even if Laura is not sure of what constitutes her personal faith, she tries to expose her daughter to religious ideas and practices to keep ‘the Church-Door’ open for her daughter. Therefore, although Laura says that she “believes there is a balance” in the world and yet is still unsure of what creates or causes that balance – be it a god or higher power, she still believes it is important to take her daughter to church when she can.

In summary, it is clearly demonstrated by the fact that every hospice nurse had memories of going to church as children, that they represent the larger American practice of parent’s exposing their children to religious socialization. From their church attending histories, five of the nurses still attend church, while fourteen say that they are spiritual and one is still unsure. Of the nurses who are spiritual, their patterns of practice range from ritualized bible and prayers to being alone and nature. One of the most important
features of this chapter is that nineteen of the nurses have established faiths while only one, while still respectful of religion and spirituality is still unsure. The questions still remains however if whether their beliefs we established before working at hospice and what role experiences around death have had on their faith.
CHAPTER VI

HOSPICE NURSES ON DEATH & FAITH: PATIENT AND PERSONAL

As witnesses to dying patients, hospice nurses are exposed to a variety of end-of-life experiences and challenges (Currow and Hegarty 2006). The challenges of caring for patients who are dealing with end-of-life through their own cultural and spiritual beliefs about death, demand the nurse to not only tend to the physical aspects of their patient but also their emotional and spiritual dimensions as well (Patrick et al. 2003). Thus, caring for the dying reveals the interdependent relationship between death and faith. Recently researchers have suggested that death-anxiety is greatly decreased if a person is religious or spiritual (Wink 2006; Rasmussen and Johnson 1994). And that death-education does not buffer the fears of the individuals but rather significantly increases their fear of death (Maglio and Robinson 1994); therefore, supporting that death-anxiety is strongly associated with faith beliefs and not exposure or death socialization.

Along with questions of how being around suffering patients effects those individuals who are exposed to the dying process, is the less addressed question of how the patients dying process and the experiences associated with it, irregardless of suffering, effects those around them. For example, the narratives of the hospice nurses in my sample illustrate the ways in which being around death has effected/or not effected their own personal notions of death and faith. To further explore the effects of being around death and its relationship to faith I asked the Hospice nurses questions about their experiences in being around death and how these experiences influenced their personal
notions of death and faith. In answering the questions the nurses shared their retrospective accounts of whether they have witnessed their patients seeking faith at the end-of their life and about what their patients (and a few personal) experience in the final stages of death; in visions of loved ones that have passed away and the unexplainable moments surrounding death. Finally, with the amalgamation of the experiences, from being around death, the nurses talk about their own personal notions of death and faith.

**Death Bed Conversions**

While some theorist connect spiritual development with age (Dillon and Wink 2007), there are other who associate increases in faith with end-of-life experiences regardless of the stage in life the individuals is in (Reed 1987). The following narratives are the nurses' contribution to the debate on spiritual development and whether end-of-life experiences, are times of spiritual development. In asking the nurses if they witnessed their patients seeking spirituality and religion at the end of their lives, their answers varied greatly. There was not a polarized “yes/no” divide among them, but rather many of the nurses commented on how they had expected to witness more faith-seeking on the parts of their dying patients than they did see. The nurses’ experiences of this particular phenomenon fell into three main categories: some patients did seek religion and spirituality for the first time in their lives on their death beds. However, most of the nurses reported either that dying patients ‘reaffirm’ a faith that they had once held or that ‘patients die the way they live,’ without any changes in their faith.

**Death and Becoming More Spiritual**

Linda and Sara, like researcher Pamela Reed (1987) find that there is something about the death process that makes individual more religious and spiritual. In a study with
300 terminally ill patients, controlling for variables like age and gender, Reed found end-of-life experiences are associated with greater spirituality (Reed 1987). Linda found the same association in taking care of her father-in-law. She explained that when he was sick, and throughout his life, he had always believed religion is "...hog-wash; it's just a book," referring to the Bible. But then, when he was dying, Linda said that he prayed with her. Linda believes many people disregard religion and spirituality throughout their lives but that when they are faced with death, they start to think about faith. Linda expresses a common thought in society: that the fear of death and its finality inspire people to question mysticism and wonder if there is anything else after this world.

Sara, too, said that she sees patients at the end of their lives seeking religious and spiritual meaning: "For many people, it's a religious or spiritual thing. For others, it's a life review, [a way of determining] was my life meaningful?" Sara, like many of her fellow hospice nurses, also talked about dying patients who do not seek meaning through faith but rather by becoming more introspective about the meaning and importance of their own lives and the meaning of their relationships. Although Sara and Linda state that they have witnessed patients having "death bed conversions," other nurses believe that even though they themselves have not witnessed such a process, perhaps it still occurs.

For example, Brian said, "I have heard of it from team members. I don't hear it as much as I would expect." He said that maybe it is not common to hear about patients' faith-seeking, not because they aren't doing so, but because the patients' rapport with the staff is not close enough to share any meaning-seeking they are doing. Todd and Christina also wondered if patients do question their faith but simply did not talk about it with their nurses. Todd's experience fell in line with those of some of the other nurses on
this point: he himself had not witnessed or taken part in a lot of meaning-seeking by his
patients at the end of their lives but that he had expect to see it when he started as a nurse.

Christina also wondered about her patients processes of seeking meaning at the
end of their lives but believes that they “just don’t go there with me. At this point in my
work, I deal with mostly the elderly, so I find it’s different because most of the time, they
have already explored the meaning of their lives, and they’re sort of at a different place
than a younger person.” Christina then added, as did many nurses in answering this
question, that she has seen a lot of patients reconnecting and repairing relationships…”
Cathy also said that although she knows her patients seek faith “to a certain degree,” she
does not “see an overwhelming amount of it.” But she, too, does see many of her patients
trying to mend relationships before they die.

A Reconnection to Faith & Dying the Way You Live

Pam McGrath (2003) is another researcher who found that that terminally ill
patients do not religious comfort but rather adhere to a verity of spiritual perspectives
(McGrath 2003: 881). This is that patients do not experience religious conversions on
their death beds as a form of coping which is exactly what Emily, Leslie, and Beth have
experienced. These nurses found that most of the religious and spiritual seeking their
patients do is a reconnection with religion versus a first-time search for faith. Emily does
not see many ‘foxhole Catholics;’ these are individuals who had not been religious or
spiritual earlier in their lives, but who, once they are in trouble, start asking God for help,
and that “most of these folks follow the same religious pattern they have always had.”
Leslie said many of her patients had once made a spiritual connection, had not exercised
it much during their lives, but that they return to that religion or spirituality at the end of
their life. Beth calls this a reaffirmation of faith: patients have had a “faith belief,” strayed away from it, and then returned to it. She further explained that she can count on her two hands the patients that have not had a belief or faith. Beth feels that the hardest patients and families are those who do not have faith: “It is so final and traumatic.”

Many of the nurses expressed uncertainty about at what level their patients seek faith at the end of their life, while a few nurses stated that many of them “don’t go there.” For example, when I asked Colleen if she is aware of her patients seeking faith as they are dying, she said, “No. I don’t know what faith you have, but...if you accept the Lord as your Savior, it is not going to happen [suddenly] on your death bed.” Sally and Meagan also said that they believe their “patients die the way they lived.” Sally has been surprised that she has not seen more dying patients seeking meaning. Once at a palliative care conference, Sally spoke with an elderly pastor about the fact that she does not see more people seeking faith at the end of lives, and he said, “You don’t see a lot of death bed conversions. I do find that people die the way they live.”

Meagan repeated these sentiments: “One thing I learned in gerontology is that as people grow older, they just become ‘more so.’” She elaborated by saying that if a person is shy or talkative as a young person, they just becoming ‘more so’ with age and in death. She continued to say, “If I walk into a house, and there is a cross on the wall, my job is easier already.” And although Meagan feels that if her patients are faithful it makes her job easier, Laura is less convinced.

In talking about her patients’ faith-seeking Laura said,

Um...it’s hard...it’s something...it’s something I’m still working on, because I think for some...for me...in way I think that people...sometimes I think that it’s a bunch of hullabaloo...you know...um...that not everybody has to ‘go there’...it’s not necessary for patients to ‘go there’ to die a good death...” (Here she was
quoting a physician from a hospice video she recently watched.) “Not everyone needs to die in this ‘psycho-analytical-grace.’ Some people can just die, and that’s ok, too. We should not expect that people have to do all this work.

Laura emphasized that she currently works with a patient whom she thinks could benefit from talking about faith and how it could have an important role, but Laura feels it is not necessary. Some of the nurses indicated they are aware that some of their dying patients are seeking faith; others believe maybe patients are seeking faith, but they, the nurses, are just unaware of the patient’s seeking process; and some say patients don’t seek at all. Laura says that she is simply not one of those nurses who look to fill the ‘spiritual care role’ with her patients because many of them don’t need ‘to go there.’

‘At the Bedside:’ Personal Notions of Death

As discussed, research has shown the significant relationship between death-anxiety and religious and spiritual beliefs (Wink 2006; Rasmussen and Johnson 1994; Maglio and Robinson 1994). This is that faith and notions of the afterlife make individuals less fearful of death. But what is less known are how individuals feel about their own deaths when they are surrounded by it. As death professionals, we would expect the hospice nurses’ to have low death-anxiety, because as we have learned all but one of them reported to be religious and or spiritual and due to their constant death exposure. Their narrative patterns in talking about their own notions of death were; having no death-anxiety because hospice, faith, and age, having a set ideology about their own deaths before hospice, ‘death detail,’ a new look at life and thoughts of the after-life.

Faith and Death-Anxiety

Supporting the studies that link death-anxiety to spirituality (Wink 2006) the following explained that they are not afraid of death because they have a strong faith.
Linda, Sara, Amanda, and Sally say that they are not afraid of death and that their feelings about their own death were set before they came to work at hospice. Linda said,

I was really settled, very, very settled, before going into hospice because... uh... I'm a very spiritual person, and I, I believe, I'd given my life to the Lord many years ago. I believe that there is a plan for my life, and I’m not afraid of...pretty much, I'm not afraid of anything. My philosophy is 'I go,' and if it's my time to go and the Lord's going to take me, then he will. I mean, I'll try not to be foolish and do foolish things, like walk out on thin ice. But I don't let things hold me back that some people might be afraid of.

As an example of her trust in God and the absence of her fear of death, Linda told me that she has always wanted to fly, and she is about to take her pilot's test. Apparently people tell her all the time how dangerous flying is and ask her if she’s afraid, but she tells them, “If indeed I don’t come back one day, then, Amen! I’m with the Lord, and don’t you cry.”

Sara also says that her faith extinguishes her fear of death. When I asked Sara if working around death has influenced her personal notions of death, she said,

I need to preface [my answer] to that questions with a statement that I’m a very strong Christian, and I was before I came into hospice. And sometimes I wonder how people can [work in hospice] without having faith, how they could be a hospice nurse without having a faith to fall back on, or to believe in. But I’ve never been worried about my own death or what will happen in the future.

Sara said that although hospice has not influenced her notions of death, her work at the bedside of dying patients has taught her more about what to expect of the process of dying and death.

Many of the nurses talked about Americans' misconceptions of death due to its portrayal on television and in the movies as an acute event, instead of as a process. Although death can be sudden and happen in seconds or minutes, many deaths, such as
those caused by terminal illness, are longer processes with recognizable stages. This more realistic view of death is what Sara means she has acquired in the course of her work. But this knowledge has not changed the way she feels about her own death. Amanda believes her work at hospice has made her think more about her own death:

Certainly, you develop a hope that maybe you’ll die a certain way. I tend to have a very strong faith, so that’s teaching me more and more that you only have control over certain things, and the rest is out of your control...I think it is important for people as they get older to do the work of just thinking about these things.

Amanda recognizes her faith as the reason she is not afraid of death, but she also includes the importance of age and development as integral to the process of thinking about mortality.

*Facing ‘Death Detail’*

Some of the nurses talked about how they are not afraid of death and about how working at hospice has also encouraged them to face and manage some of the more practical details of their own passing, such as creating advance directives and sharing their end-of-life wishes with their friends and family. An advanced directive is a document that outlines the protocol and wishes an individual desires be put into action at his or her own death, and it designates a power of attorney or power of attorney for heath care, people to make decisions for the individual if he or she were unable to make them him or herself.

Sally said, “I don’t think [my fear of death] really changed at all” because of her work in hospice. Sally now feels that death is just a part of life. Although there was a time in her life when she was fearful of it, she does not now find it as morbid, abnormal, or mysterious death as it once seemed. She said, “I think I came to terms with it many
years ago.” Sally, like Laura, feels that she is comfortable with death, and working at hospice has influenced her to ‘start a folder in her mind,’ of the things she would like to have happen or to have others do at the end of her life. Like many other hospice nurses, Sally has become much more aware of what one might call the subtle nuances of ‘death detail.’ These details can include the songs and poems you want performed at your memorial service, whether or not you want a service, whether you want to be resuscitated if something happens or cremated when it does.

Colin was not afraid of death before working at hospice and reports coming to hospice with a prior acceptance of his own mortality. However, working at hospice did inspire him to take care of some of the technical aspects of the end of his own life. Laura also talked about preparing her advanced directives and a living will, as a result of working at hospice. However, although she has accepted her own mortality, “it’s more of the practical things,” that she has not taken care of yet.

Although unlike the previous said that working at hospice has made death less scary she also talked about the comforts in knowing how to take care of the ‘death details,’ after having been around it. Kate stated, “Death does not seem like a scary process anymore,” because of her exposure to it through hospice. Kate told me that although she has only been with one patient as he passed way, she was holding this patient’s hand, and it really changed the way she viewed death because her dying patient was peaceful and not fearful. She said that she is also less fearful of the aftermath of death, too, such as the details that arise as a result of a person’s death: funeral and burial arrangements, the expenses that follow a death, and the detailed work involved in taking
care of all of these things. Kate has found it a comfort to learn how all of it gets taken care of.

A Different Look at Life & Thoughts of the After-Life

Contrary to studies that have shown death-anxiety is lower for religious and spiritual individuals (Wink 2006; Rasmussen and Johnson 1994; Maglio and Robinson 1994) Heather believes that, “Everybody is afraid of death” to some degree at some point in their life. Heather believes that working for hospice has profoundly changed her, not in the way she views her own death, but rather in the way she views her life. Working with dying people has changed her perspective on things like love and money.

Beth explained that as she has gotten older, working for hospice has taught her “not to sweat the small stuff.” She says that working with terminally ill people “keeps you focused.” Beth believes it has even influenced the way she has raised her children in that she now understands how important it is to tell people you love them, and to live your life without worrying about next week or next month because you never know what can happen. Leslie too, feels that working for hospice has changed the way she lives her life. She talked about how even though she works around death and dying, she does not think about her own death because the deaths she is witnessing is not her own. Leslie raises an interesting point in this vein: although her exposure to death has made dying “less scary” for her, others’ experiences of death do not necessarily predict how she will feel about her own death. And although she does not know if she will be fearful at the time of her death, like the other nurses, she does have a greater appreciation for life.

Sara and Brian gave similar responses when I asked if hospice has made them more faithful people. Although they did not both reply with a definitive ‘yes’ or ‘no’
answer, they both talked about how seeing their patients near death has made them question the after-life. Brian said, “I would say that this work has influenced my spiritual beliefs.” On the other hand, Sara does not believe her faith has necessarily grown stronger as a result of working at hospice. And the interesting thing is that although Brian recognizes the influence of his work at hospice on his spirituality and Sara does not acknowledge its influence on her beliefs, they both uncannily said, “The one thing that does make me wonder” is the idea of the afterlife.

Brian explained further that he took physics and chemistry classes in his training to be a nurse, and he found that learning about the hard sciences actually helped him form his beliefs. He stated,

For example, we learned that there is really not that big a difference in the molecules that make up a rock and the molecules that make air. It makes it very possible that there are so many things that are going on that we are not aware of.

He found that in “seeing people of different faiths having similar experiences, such as seeing people after they have already died,” he realized how “thin the veil” is from what we experience and what else might be in existence at the same time as that which we experience.

Sara was also curious about what she had witnessed when her patients were actively dying or within days of death. Although she said that her work at hospice has not made her faith stronger, she stated,

One thing that it has made me wonder about sometimes is when I see someone who I know isn’t Christian. I’ve actually seen them die and the look of joy on their faces...you could tell they were seeing something incredible. And you’re thinking are they seeing Christ? And you know they don’t believe. That has happened a couple of times, and I’ve thought, ‘What is happening?’

Witnessing their patients experience what the patients describe as a ‘near death
experience' has made both Brian and Sara wonder about the afterlife. But I wonder why one saw this as an influence on his faith, while the other one did not.

One possible answer to this question comes from my interview with Sally. Sally said that her work at hospice has not made her more spiritual person. She said that she can see how, if a person does not practice or “integrate faith completely into their life, hospice could make them more spiritual.” But for her, faith is in everything she does, so hospice does not have a singular or unique effect on her spirituality. Thus, she makes a valid point: perhaps experiencing a patient’s near-death experience would have a more profound effect on individuals who do not practice a faith than that same experience would have on a person like Sara or Sally who feel like they connect spiritually in everything they do daily.

_Age, Death and Spirituality_

As supported by current research, which finds spiritual development associated with age and a gradual maturation incurred by particular life stages (Atchely 2006; Dillon and Wink 2007), so too is there great evidence in my research which suggests this causal link as well. For example, when I asked Amanda how her transition to hospice went after working for so many years in other fields of nursing, and she replied,

I love it...I think it’s my age, too. I couldn’t have done this at 35. I don’t know if I could have done it at 45. I think at those ages for me, anyway, um, there’s a natural push to [be involved in] healing and preserving life. But as you get older, you start to relate [to older patients’ situations:] you only have so much time left to live, too. You start to be concerned about what you’re doing with your life and what legacy you’re going to leave and what’s important at the end of life, so you start to think more about that. And in nursing, in medical care, in nursing especially, if you tend to have...if you’re introspective, you’re going to really look at those issues...and you’ve dealt with people in their lives...if you’ve been a nurse all your life constantly, those are normal things for a nurse to think about...for me, anyway...for a lot of women I know, anyway.
Amanda’s comments underline the intricate relationships among medicine, death, and age. It seems that age, as Amanda explains, is directly associated with the curative mode. It seems that in the United States particularly, we believe in a technology sophisticated enough to dominate the body, but there comes a point, perhaps with age, that we must each grapple with the reality of our mortality, despite our powerful medical knowledge. The nurses referred frequently to age and important life experiences as what enabled them to work at hospice, among other things, and this point is reflected intermittently throughout these chapters.

Heather also expressed an uncertainty about what has had the greatest influence on her spirituality: “I don’t know how much of that is hospice and how much of that is my age. I’m sure if I did not work for hospice, my spirituality would have evolved anyhow. I’m just not sure how much.” Colleen also said that, “You can’t help living and maturing and not have your faith grow.” These hospice nurses illustrate an important concept: the first is that perhaps maturation offers an explanation for spiritual development and introspective recognition of this process.

Heather offered some insight into the variety of nursing trajectories found among the nurses in this sample. As an administrator now at the hospice organization for which she works, she has seen and worked with many nurses and now believes it is “…not real possible for a young nurse to graduate from school and come [directly] to hospice because they need life experiences.” Heather seems to be further expanding on what Amanda touched on earlier in talking about her age, saying that perhaps one needs a certain amount of exposure to death and socialization before feeling comfortable in this line of work. Heather simply stated, “It is hard to work around death unless you have
some life experiences with it, and thus it is highly unlikely to ever see young nurses, in their twenties, applying at hospice."

In summary, the majority of the nurses came to hospice with established views on death which for many of them was tied to a faith. Among these hospice nurses with whom I spoke, the things that have affected their own notions of death are their life adversities and age. It is unsurprising that the majority of nurses in my sample are in their mid- to late adulthoods and many of them equate greater age with the ability to confront and work around death.
CHAPTER VII

CONCLUSIONS

In conclusion, I believe that a quotation from Roof’s (1999) book, Spiritual Marketplace, offers an illustrative reflection of the complexities of American religion and spirituality in which the hospice nurses in this sample are emblematic of. He states,

Religion in the United States is like a brilliantly colored kaleidoscope ever taking on new configurations of blending hues. Not just popular religious beliefs and practices, but religious institutions themselves undergo transformations in form and style, encouraged by a democratic, highly individualistic ethos and rapid social and cultural changes (Roof 1999:4).

The purposes of my thesis is to narrow in on the latter part of Roof’s statement, in examining the hospice nurses “individualist ethos” to further understand how they contribute to spiritual development. Greater utilization of palliative care paralleled with the increased interest in spiritual development makes hospice nurses a suitable sample to test the factors that previous literature has provided as explanations of spiritual development.

The three main conclusions from my study suggests that the majority of hospice nurses are spiritual with established views of death, they have low death-anxiety which is related to their level of spirituality, and adverse life events and age offered the greatest explanations for spiritual development. Nineteen of the nurses I interviewed reported themselves as being spiritual, five of whom said they were both religious and spiritual and only one of the nurses said that she was unsure but respected both. In defining themselves as spiritual or religions, the nurses supported Roof’s classifications of
religious and spiritual identities (Roof 1999: 176-179). For example individuals like Linda, a born-again Christian, see themselves as “spiritually minded Christians” (Roof 1999: 176). Unsurprisingly, as supported by previous research, having young children increases the likelihood of parents taking their children to church (Dillon and Wink 2007:83) as the nurses recounted very vivid church-going childhoods. In comparing the hospices nurses past religious and spiritual histories to their present, many of them do not practice what they were raised in and none of them talked about “spiritual childhoods.”

Research indicates that life adversities, such as bereavement from the death of a loved one or the stress and grief suffered in a divorce can be life-changing events (Wheaton 2003). These life changing events can include a turning point in spiritual development and meaning seeking but for the hospice nurses in my sample their life adversities did not constitute significant faith development. The majority of adversities that led the nurses to hospice involved taking care of a dying family member. The six nurses that faced adversities as a result of caring for a dying child or parents said that their experience influence them to take a job at hospice but did not influence their faith. Only two nurses talked about a traumatic life event in dealing with death as influential in working in palliative and increasing their spirituality. The most significant life-changing adversity reported by the nurses was divorce (just under half of my sample has been divorced) which led the nurses to their jobs at hospice and increased faith. With the exception of two hospice nurses who cited a particular event that made them more spiritual, most of the nurses expressed their spiritual development as much more fluid, diffuse process.
As far as death experience and being around the end-of-life stages of their patients, as "death professions," I did not find a significant impact of these events shaping the nurses' faith. A few nurses said that they witnessed their patients become more spiritual on their death bed or reaffirm a faith from a previous time in their life but for the most part there were no "Eleventh-hour conversions of aging sinners preparing at last to meet their Maker..." (Iannaccone 1990: 301). What all twenty nurses did share, however, were the stories of their patients having near death visions or unexplainable experiences in their final stages of death. However, being witness to death or being witness to the bereavement experiences of patients' families did not increase spirituality. Exposure to death, however, did influence the nurses' 'philosophies of life,' and 'death detail.' More specifically, being around death has made them 'not sweat the small stuff' and it has encouraged them to take care of their wills and sharing their personal end-of-life wishes. Two of the nurses also said that being around death has not made them more spiritual but has increased their curiosity about what the after-life is like. Therefore, although a few nurses said that working at hospice has influenced their spirituality, I found the hospice nurses had preexisting faith before their work at hospice and death experiences did not cultivate significant faith or a spiritual awakening.

Personal notions of death, as found in the literature, were also closely tied to existing faiths beliefs (Rasmauseen and Johnson 1994; Wink 2006). The greater their faith or spirituality the lower their death-anxiety or complete absence of fear was. Throughout this thesis it becomes evident in the nurses' narratives and their responses to my questions that their own views on death and spirituality are associated with their age and experiences. Understanding and acknowledging mortality as many of these nurses
point out comes with maturing and age. As Amanda stated she is unsure that she would have been able to work at hospice when she was 35 or 45 years old because she was not ready to face her own personal feelings regarding death and the dying process. Amanda’s sentiments firmly support a life course perspective- that later adulthood is a time of increased spirituality which is associated with facing end-of-life issues. Therefore, it is not a coincidence that the average age of nurses in my sample is 52.4 years old. As Heather, a hospice director, commented “it takes age and experience, life experience, to work at hospice.”

Implications and Future Studies

As Roof suggests, religion and spirituality are transformed by “rapid social and cultural changes” (Roof 1999:4) and while the majority of the hospice nurses in my sample represent the baby boomers or the “lead generation” from this study I am inclined to argue that spiritual development is not completely explained by a cohort effect. This is that spirituality became more distinctive as a social and cultural transition in American religion spearheaded by the “Boomer Americans” (Roof 1999:294). Today because of their size and positions in later adulthood have great influenced on “moral and religions moods” (Roof 1999:294). Therefore, although it is impossible to completely disentangle the cohort effect versus the life stages as influences on spiritual development my sample suggests that it is experiences and life stages in facing mortality that increase spiritual development. Future studies will be needed to clarify this issue, for example when generation X is old enough to test for the possibilities of age and life stages to explain spiritual development.
The current study has very important implications for the death educators in our medical system. Studies show that the majority of health care professionals are leaving medical school feeling inadequately prepared to care for the dying (Nelson et al. 2000). It has been suggested by death educators that the challenges involved in caring for the dying stems from the health care professionals understanding their own views on death and spirituality. Caring for the dying differs from curative modes because patients bring various cultural and spiritual beliefs that are not always rooted in science to understand their own death. The experiences of death and dying requires that patients face the physical, emotional and spiritual challenges of their own death, thus calling for professionals who have established views that would enable them to effectively address the challenges surrounding death (Nelson et. al 2000). But what is important for these educators to know, as this study supports, spiritual development which is associated with personal perceptions of death via explanations such as age and life adversities, suggests that death education may be ineffective.

In this study I have tried to generate a greater insight in to the factors explaining spiritual development through my interviews with hospice nurses. In my attempt to add to growing interest in the sociology of religion and spirituality I have discovered the interesting position that the social scientists of religion are in. This is that we live in a highly religious and spiritual country, which as Roof states is like a kaleidoscope with changing configurations and blending hues (Roof 1999:4). However, though religion and spirituality in our country will continue to change, like a kaleidoscope, there are patters and measurable constructions which we will be needed to research in an attempt to study their meanings and the implication they hold in society.
REFERENCES


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APPENDIX A

SUMMARY TABLE OF INTERVIEWEES

<table>
<thead>
<tr>
<th>Nurses</th>
<th>#Years Nursing</th>
<th>#Years w/Hospice</th>
<th>Age</th>
<th>Religion/Spiritual</th>
<th>Raised</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Colleen</td>
<td>40</td>
<td>20</td>
<td>62</td>
<td>Both (non-denominational)</td>
<td>American Baptist</td>
</tr>
<tr>
<td>2. Liz</td>
<td>30</td>
<td>2</td>
<td>56</td>
<td>Spiritual (Independent Bible school)</td>
<td>Baptist</td>
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<tr>
<td>3. Brian</td>
<td>15</td>
<td>6</td>
<td>48</td>
<td>Spiritual ('Open Prayer')</td>
<td>Lutheran</td>
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<tr>
<td>4. Colin</td>
<td>5</td>
<td>5</td>
<td>52</td>
<td>Spiritual (Jewish)</td>
<td>Congregational Church</td>
</tr>
<tr>
<td>5. Sara</td>
<td>32</td>
<td>15</td>
<td>55</td>
<td>Both (Evangelical Christian)</td>
<td>Non-Denominational</td>
</tr>
<tr>
<td>6. Laura</td>
<td>7</td>
<td>4 months</td>
<td>36</td>
<td>Unsure</td>
<td>Non-Denominational</td>
</tr>
<tr>
<td>7. Amanda</td>
<td>41</td>
<td>2</td>
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<tr>
<td>8. Christina</td>
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<td>51</td>
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<td>Catholic</td>
</tr>
<tr>
<td>9. Evan</td>
<td>15</td>
<td>3 months</td>
<td>52</td>
<td>Both (Methodist)</td>
<td>Methodist</td>
</tr>
<tr>
<td>10. Linda</td>
<td>17</td>
<td>1.5</td>
<td>54</td>
<td>Spiritual (non-denominational)</td>
<td>Catholic</td>
</tr>
<tr>
<td>11. Cathy</td>
<td>3</td>
<td>3</td>
<td>36</td>
<td>Spiritual (Prays)</td>
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<tr>
<td>12. Meagan</td>
<td>15</td>
<td>14</td>
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<td>Methodist</td>
</tr>
<tr>
<td>13. Emily</td>
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<td>9</td>
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<td>Presbyterian</td>
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<td>14. Todd</td>
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<td>50</td>
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<td>Roman Catholic</td>
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<td>15. Kate</td>
<td>28</td>
<td>1</td>
<td>50</td>
<td>Spiritual</td>
<td>Catholic</td>
</tr>
<tr>
<td>16. Sally</td>
<td>39</td>
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<td>60</td>
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<td>Catholic</td>
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<tr>
<td>17. Heather</td>
<td>38</td>
<td>19</td>
<td>59</td>
<td>Spiritual (People)</td>
<td>Catholic</td>
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<tr>
<td>18. Leslie</td>
<td>21</td>
<td>14</td>
<td>49</td>
<td>Both R/S-catholic</td>
<td>Catholic</td>
</tr>
<tr>
<td>19. Rose</td>
<td>39</td>
<td>17</td>
<td>60</td>
<td>Spiritual</td>
<td>Protestant</td>
</tr>
<tr>
<td>20. Beth</td>
<td>32</td>
<td>16</td>
<td>53</td>
<td>Both (Catholic)</td>
<td>Catholic</td>
</tr>
</tbody>
</table>
APPENDIX B

INSTITIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN SUBJECTS IN RESEARCH AUTHORIZATION

University of New Hampshire

Research Conduct and Compliance Services, Office of Sponsored Research
Service Building, 61 College Road, Durham, NH 03824-3585
Fax: 603-862-3564

7/6/2006

Barr, Amy L
Sociology, Horton SSC
4 Carriage Way
Durham, NH 03824

IRB #: 3753
Study: A Closer Look: Hospice Nurses and the Medical System
Approval Date: 6/29/2006

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Expedited as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 110 with the following comment(s):

In the fourth line of the fifth paragraph of the consent form, the researcher should replace "child abuse" with "abuse of incapacitated adults" and remove "communicable diseases."
Please forward a copy of the revised consent form to the IRB prior to recruiting participants.

Approval is granted to conduct your study as described in your protocol for one year from the approval date above. At the end of the approval date you will be asked to submit a report with regard to the involvement of human subjects in this study. If your study is still active, you may request an extension of IRB approval.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, Responsibilities of Directors of Research Studies Involving Human Subjects. (This document is also available at http://www.unh.edu/osr/compliance/irb.html.) Please read this document carefully before commencing your work involving human subjects.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB

Julie F. Simpson
Manager

cc: File
Michele Dillon