

Lancaster Theological Seminary

**Renewing the Spirit of Hospice: A Spiritual Response
to Compassion Fatigue in Hospice Workers**

A Major Project Submitted to the Faculty
in Candidacy for the Degree of
Doctor of Ministry

by

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Lancaster, Pennsylvania
May 2020

Renewing the Spirit of Hospice: A Spiritual Response to Compassion Fatigue in Hospice
Workers

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**Submitted by the author in partial fulfillment
of the requirements for a DMin degree
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April 30, 2020

Abstract

This project explores the impact of spiritual practices on the experience of compassion fatigue in hospice nurses, social workers and chaplains. Quantitative data was gathered by comparing scores on the Professional Quality of Life (ProQOL) survey before and after participation in six weeks of spiritual practices. Spiritual practice guides were accessed through a website, Spirit of Hospice, which was designed by the researcher. Qualitative data was gathered through semi-structured interviews with participants, resulting in the identification of four key themes. Implications of this research suggest methods for addressing the spiritual effects of compassion fatigue in hospice workers and the utilization of hospice chaplains for spiritual support to hospice workers.

For Grandma Patsy

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Chapter 1: Introduction

Topic

Burnout is a word that is getting a lot of buzz these days and it is being discussed quite commonly across many fields and professions. The World Health Organization has recently added occupational burnout to its list of diagnosable conditions, defining it as “a syndrome conceptualized as resulting from chronic workplace stress that has not been successfully managed. It is characterized by three dimensions: 1) feelings of energy depletion or exhaustion; 2) increased mental distance from one’s job, or feelings of negativism or cynicism related to one’s job; and 3) reduced professional efficacy. Burnout refers specifically to phenomena in the occupational context and should not be applied to describe experiences in other areas of life.”¹

Organizations from healthcare to corporations are beginning to count the costs of burned out employees. “Burnout is estimated to be attributed to 120,000 deaths per year and \$190 billion in healthcare spending. This doesn’t include burnout’s toll on decreased productivity, an increase in errors, absenteeism, and other organizational costs. Companies with moderate-to-severe burnout have a 376% decrease in the odds of having highly engaged employees, 87% decrease in likelihood to stay, 22% decreased work output, and 41% decrease in the perception of the employee experience.”² Rarely will you find someone denying that occupational burnout

¹ “Burnout Is Now An Officially Diagnosable Condition: Here’s What You Need To Know About It,” accessed October 11, 2019, <https://www.forbes.com/sites/karlynborysenko/2019/05/29/burnout-is-now-an-officially-diagnosable-condition-heres-what-you-need-to-know-about-it/#3f8b13642b99>.

² “Burnout,” O.C. Tanner - Appreciate Great Work, accessed October 11, 2019, <http://www.octanner.com/global-culture-report/2020/burnout>.

is a real phenomenon. What is lacking, however, is a clear consensus on what causes burnout and what should be done about it.

The discussion of burnout among healthcare professionals is not a new one, though in recent years it has gained validity. A study released in 2019 by researchers from Duke University Health System, examined the growing workforce demands for palliative care professionals. Anticipating the increased need for palliative care services from 2019 to 2059, researchers examined whether there will be enough palliative care team members to meet these needs. Over 2,000 palliative care and hospice physicians, nurses, social workers and chaplains were surveyed regarding their job satisfaction, burnout and intention to leave the field early. As a result of the findings, researchers made five suggestions for increased training and educational opportunities surrounding palliative care. Among their recommendations, was the encouragement to, “create policies that prevent the worsening of the burnout rate and support resilience.”³ Prevention of burnout is the key, as burnout is considered by most professionals to be an irreversible condition. It is unlikely that someone experiencing high levels of occupational burnout will be able to remain in their current position.

So how do individuals and companies prevent burnout? It seems that one way is by identifying what comes before burnout. A term getting slightly less buzz than burnout, but well-known among helping professionals is compassion fatigue. Charles Figley refers to compassion fatigue as “the cost of caring.”⁴ “The term compassion fatigue was first used in the context of the study of burnout in nurses nearly two decades ago. At that time, Joinson (1992) coined the term to describe the ‘loss of the ability to nurture’ that was noted in some nurses in emergency

³ Arif H. Kamal et al., “Policy Changes Key To Promoting Sustainability And Growth Of The Specialty Palliative Care Workforce,” *Health Affairs* 38, no. 6 (June 1, 2019): 910–18, <https://doi.org/10.1377/hlthaff.2019.00018>.

⁴ Charles R. Figley, ed., *Compassion Fatigue: Coping with Secondary Traumatic Stress Disorder in Those Who Treat the Traumatized*, Brunner/Mazel Psychosocial Stress Series, no. 23 (New York: Brunner/Mazel, 1995).

department settings.”⁵ In 1995, Figley edited the book⁶ on compassion fatigue that earned him the reputation as the pioneer of compassion fatigue research. Figley’s work has done much to normalize the experience of compassion fatigue among those in helping professions. Figley has “called compassion fatigue a ‘disorder that affects those who do their work well.’”⁷ Beth Hudnall Stamm⁸ is another prominent writer in the field of compassion fatigue who, with Figley, developed the Professional Quality of Life (ProQOL) assessment tool that measures caregivers’ levels of compassion satisfaction, burnout and secondary traumatic stress.⁹ While burnout is common, among healthcare professionals it seems that compassion fatigue is even more prevalent. However, the good news is that unlike burnout, compassion fatigue is treatable and can be reversed.

I am entering this crowded conversation surrounding burnout and compassion fatigue in the workplace, not simply to add another voice, but to offer a different perspective and fill a gap. While hospitals are doing research and trying new things to address compassion fatigue among their staff, there seems to be a lack of this in hospice. In my five years working as a hospice chaplain, I have seen and experienced the deeply meaningful services provided by hospice caregivers. Providing compassionate care to patients and family members receiving hospice services is what many team members describe as not simply a job, but a calling. However, this deeply empathetic profession exposes hospice team members to compassion fatigue, and while

⁵ Deborah A. Boyle, “Countering Compassion Fatigue: A Requisite Nursing Agenda,” *OJIN: The Online Journal of Issues in Nursing* 16, no. No. 1, Manuscript 2 (January 31, 2011), <http://ojin.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol-16-2011/No1-Jan-2011/Countering-Compassion-Fatigue.html>.

⁶ Figley, *Compassion Fatigue*.

⁷ Françoise Mathieu, *The Compassion Fatigue Workbook: Creative Tools for Transforming Compassion Fatigue and Vicarious Traumatization*, 1st ed, Routledge Psychosocial Stress Series (New York, NY: Routledge, 2012), 9.

⁸ B. Hudnall Stamm, ed., *Secondary Traumatic Stress: Self-Care Issues for Clinicians, Researchers, and Educators*, 2nd ed (Lutherville, Md: Sidran Press, 1999).

⁹ Mathieu, *The Compassion Fatigue Workbook*, 25.

the need for hospice services is increasing, so too is the need for hospice staff who can sustain the good work they are doing.

Another element missing from the conversations surrounding compassion fatigue is spirituality. Chances are if you hear about compassion fatigue, you will also hear about self-care. However, I would agree with Beth Hudnall Stamm's analysis that self-care is a lacking term. "Self-care implies somehow that (a) the person should take care of keeping the problem from happening, and (b) if it does happen, it is the individual's fault. We know that this is not true. Certainly, an element of self-care is important, and for many, when organizations cannot or will not help, it is the only alternative by default. However, it is neither the answer nor the source of the problem."¹⁰ Furthermore, little has been discussed about incorporating spirituality into self-care practice. Current models of self-care and compassion fatigue prevention address the physical, mental and emotional depletion of healthcare workers but there seems to be a lack of research about spiritual depletion.

Chaplains are equipped to provide the kind of care and interventions that address and alleviate compassion fatigue. However, there is very little structure to how hospice chaplains can offer support not only to patients and families, but to staff. In studies of compassion fatigue in hospice staff, spiritual and emotional self-care have proven to be the most effective at increasing compassion satisfaction and decreasing compassion fatigue.¹¹ As a hospice chaplain, I feel like it is a significant time to look closely at the spiritual practices and spiritual resilience of hospice workers

¹⁰ Stamm, *Secondary Traumatic Stress*, xx.

¹¹ Karen Alkema, Jeremy M. Linton, and Randall Davies, "A Study of the Relationship Between Self-Care, Compassion Satisfaction, Compassion Fatigue, and Burnout Among Hospice Professionals.," *Journal of Social Work in End-of-Life & Palliative Care* 4, no. 2 (June 2008): 101–19.

Historical Foundations

From the very beginning of the modern hospice movement, it has been impossible to separate medicine from spirituality. The modern hospice movement is attributed to Dame Cicely Saunders.

In the 1960s in London, England, Cicely Saunders introduced a new way of treating the terminally ill, which she called “hospice care.” Saunders, a trained nurse, social worker, and medical doctor, held that humans should be able to die with dignity and at peace. This viewpoint originated from her medical experience as well as her religious commitment as a Christian. The religious basis of hospice care permeates Saunders’s whole approach to the terminally ill, and her vision resulted in the founding of St. Christopher’s Hospice in 1967 in London. There, Saunders developed a program of care for the dying based on three key principles: pain control; a family or community environment; and an engagement with the dying person’s most deeply rooted spirituality.¹²

Saunders was a committed member of the Church of England. In the early days of St. Christopher’s Hospice, Saunders was often pushed to clarify whether the medical or spiritual aspects of hospice care were the most important. Saunders “took the view that the medical and spiritual are inextricably mingled. ‘I long to bring patients to know the Lord and to do something towards helping many of them to hear of him before they die, but I also long to raise standards of terminal care throughout the country from a medical point of view at least, even where I can do nothing about the spiritual part of the work’ (Saunders 1960b).”¹³ Many believed that St. Christopher’s should be created as a Christian community which was directly tied to the Church of England. However, after deliberation around this, Saunders decided to take a broader approach, defining St. Christopher’s as an interdenominational organization that did not exclude

¹² Kelli I. Stajduhar and Harold G. Coward, eds., *Religious Understandings of a Good Death in Hospice Palliative Care*. (Albany, NY: State University of New York Press, 2012), 1.

¹³ Kelli I. Stajduhar and Harold G. Coward, 13.

anyone. While she was clear that the organization was founded on Christian principles, she wanted it to be much more than that. This decision led to St. Christopher's becoming a place "which fostered the contributions of various disciplines, facilitated research and teaching, and where others came to develop their own ideas and skills. So defined, the vision could be successfully emulated or elaborated, thereby enabling its spread both nationally and internationally in the following years."¹⁴

Hospice has come a long way since its early days in England. As hospice and palliative care have spread around the world, many of the Christian principles upon which the hospice movement were founded, have seemingly faded. Hospice has widely moved away from a religious identity and begun to speak more of spirituality. Yet, just as Saunders believed from the very beginning, hospice work still provides an opportunity for practitioners to unite the medical and spiritual dimensions of their lives. "A succinct articulation of the interrelationship between hospice and faith comes from the Polish anesthesiologist Tomasz Dangel, founder of the Warsaw Hospice for Children: 'When I was working at the hospital, I felt that my professional life and my personal life were two different lives....Working in a hospice, I really feel I can follow my Christian values; so now my life is not divided into two parts, it's one whole life.'"¹⁵

It is clear when one looks at Cicely Saunders' life that she lived with an intentional effort to integrate the various parts of herself into her work. She pioneered the hospice movement with an awareness that just as she could not silo parts of herself, hospice patients and workers were complex people who belonged to systems of belief, identity and communities. Rather than viewing hospice as a place that represented death, she viewed hospice as a journey that was rich with potential. "Saunders held also that hospice should be a place of spiritual growth for both

¹⁴ Kelli I. Stajduhar and Harold G. Coward, 16.

¹⁵ *Ibid.*, 17.

patients and staff, and this growth could occur not only in a Christian context but also in religious traditions other than Christianity, and even in the absence of any religious commitment.”¹⁶

When St. Christopher’s began, even though it was formed as an interdenominational organization that provided care for all, the entire staff was made up of practicing Christians. While chaplains were part of the team at St. Christopher’s, the responsibility for providing spiritual care to hospice patients belonged to all of the team members. As the hospice movement spread and the church began to experience a diminished role in society, the role of the chaplain shifted. “In an increasingly pluralistic and multicultural society, inter- and multifaith chaplaincy is taking on renewed prominence.”¹⁷ This shift has led to the prominence of spiritual care over religious or pastoral care. The interfaith chaplain role is complex and can often lead to role confusion not only for the chaplain but for the entire hospice team. One scholar has reflected on the many roles performed by the hospice chaplain which includes “(among others) ‘shaman,’ ‘miracle worker,’ ‘Bible answer man,’ ‘social worker,’ ‘friend,’ ‘guide,’ ‘student,’ ‘healer,’ ‘teacher,’ and ‘servant.’”¹⁸

¹⁶ Kelli I. Stajduhar and Harold G. Coward, 3.

¹⁷ *Ibid.*, 281.

¹⁸ *Ibid.*, 283.

Theological Foundations

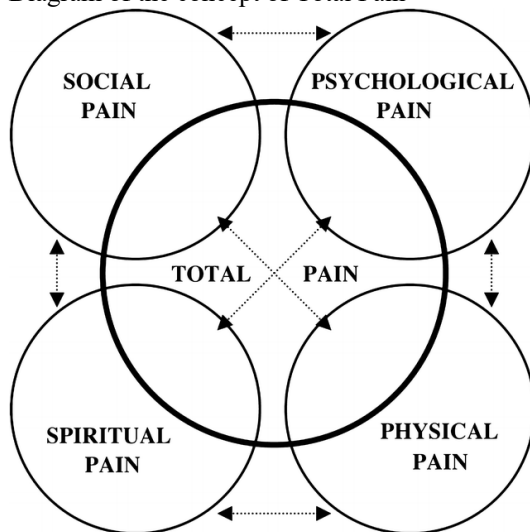
Saunders believed that hospice was a place of spiritual growth not only for patients but for staff as well. This spiritual growth may come in many forms but in this section, I will highlight some of the spiritual and theological themes that may arise for hospice patients, family members and staff.

Pain and Suffering

Cicely Saunders has had an enormous impact on the understanding of pain in hospice. Saunders created the concept of “total pain” which is the basis for hospice and palliative care. Saunders believed that pain could be physical, psychological/emotional, social and spiritual. She believed that pain in any one of these areas directly impacted the whole person. Figure 1.1 illustrates the concept of total pain and the relationship between the four dimensions.

Figure 1.1

Diagram of the concept of Total Pain¹⁹



¹⁹ Anita Mehta and Lisa S. Chan, “Understanding of the Concept of ‘Total Pain’: A Prerequisite for Pain Control,” *Journal of Hospice & Palliative Nursing* 10, no. 1 (2008): 26–32.

Hospice workers are trained to alleviate pain, while maintaining an awareness that pain can come in many forms and may require more than medication. Suffering is a term often used interchangeably with pain, but many hospice leaders differentiate between the two. “Pain and suffering are related, but not necessarily the same. Pain, whether physical or emotional, has a physiologic basis. Suffering, on the other hand, arises when we apply meaning to or tell ourselves stories about the pain we are experiencing.”²⁰

The meaning-making that comes from the experience of suffering is a prominent theological theme in hospice. Hospice patients, family members and staff are confronted with some of life’s big questions. It is often during these times of pain and suffering that people must confront the theology of pain they have developed throughout their lives, whether those things are conscious or unconscious. Maybe a hospice patient has lived their life without ever stopping to ponder whether God allows suffering to occur or causes suffering because of sin. Facing the end of life for oneself, a loved one, or encountering it daily as a hospice worker, makes it impossible to avoid these kinds of questions. People often search for meaning in the pain, reaching out to those around them, or reaching inward to the answers that may come from their own lived experience. Others may find comfort in the models of suffering found in their faith tradition. For example, Christians may find comfort in the knowledge that Jesus experienced pain and suffering and overcame death.

Transcendence and Hope

The story of Jesus’ resurrection and triumph over death in Christianity also speaks to the themes of transcendence and hope. Many faith traditions hold the belief that there is something that comes after life, whether this is the promise of new life and resurrection, or simply freedom

²⁰ Anita Mehta and Lisa S. Chan, 28.

and the absence of pain in a physical body. While the question of what comes after death can be a cause of suffering or spiritual distress for some, for others it can provide hope in the face of suffering. The theme of hope is particularly meaningful in hospice. Hospice workers are often meeting patients and their families after many medical interventions and treatments have proven ineffective at treating or curing an illness. Many hospice patients have spent weeks, months or even years pursuing treatment and curative measures with the hope that they would find a way to prolong their life. Perhaps they have been holding out for a miracle, and instead they are now coming to terms with the fact that they have a terminal diagnosis with a prognosis of six months or less to live. This is a life-altering event for both patients and their loved ones and is often a season when hope is shifting. While a hospice patient may have been hoping for a cure, perhaps now they have hope for how they will spend the time they have left. Addressing this area of potential spiritual pain in patients and their families is vital for those working in hospice. As hope shifts to that which lies beyond the physical experience of pain and illness, perhaps a hospice patient begins to experience transcendence and a renewed sense of spiritual growth.

Ritual/Lamentations

Gary Myers writes about the importance of rituals in end of life care.²¹ Often rituals are an important aspect of the grieving process and the movement towards hope and transcendence. Myers believes that the medical field often offers rituals which he refers to as restorative rituals. These are the treatments and procedures that are often done for critically ill patients to keep them alive as long as possible. While these restorative rituals are done to prolong life, Myers believes that they often prevent the opportunity for lament and transformative grief by offering false hope or the illusion of a cure for death. In contrast to these restorative rituals, Myers describes

²¹ Gary E. Myers, "Restoration or Transformation? Choosing Ritual Strategies for End-of-Life Care," *Mortality* 8, no. 4 (2003): 372–87.

transformative rituals offered by spiritual and religious communities. “Rituals of transformation begin with the conscious recognition by patient and physician that something crucial has been lost or irrevocably changed, and they are sustained by the continuing shared awareness of the loss by physician, family, and community, who are willing to wait expectantly for the transformation of hope and meaning to occur.”²²

Hospice patients may find great comfort in the rituals of their faith tradition. Prayers, scripture readings, sacred songs, confession, sacraments and religious imagery may provide peace and relief from spiritual distress. Hospice workers, particularly chaplains, can help identify these spiritual or religious rituals that may provide added comfort for patients in hospice. Families may also have rituals that are important to them. Hospice patients may find meaning and a sense of normalcy in participating in as many of these family rituals as they can. Rituals are also important for those working in hospice. Many hospice interdisciplinary teams begin their weekly or bi-weekly meetings with a ritual to remember those patients they have served who have died since the last meeting.

Liminality

Saunders often spoke of hospice patients as living while dying. The hospice experience can be full of paradox and contrast for patients, families, and caregivers. One term I have found particularly meaningful is that of liminality. Liminality refers to thresholds or an in-between space between two situations or statuses. The space between life and death can be called liminal space. Philip Browning Helsel writes about the similarities between pastors and undertakers as they work in the liminal spaces of death. He writes, “a minister's continual encounter with death at times threatens to overwhelm other aspects of his life. To be a minister is to be profoundly and

²² Gary E. Myers, 385.

frequently reminded of the significant aspects of our existence over which we have no power, the limited nature of our own lives and the lives of the ones we love, and to search for ways to retain hope in the face of these circumstances.”²³ While Helsel speaks here of ministers, I believe that all hospice workers have a similar experience, as their work provides them the opportunity to daily occupy the liminal space between life and death.

Presuppositions

As a hospice chaplain, it is impossible for me to enter into a project of this kind without some presuppositions. When I began this project, I was working with the assumption that all hospice workers have experienced or will experience periods of compassion fatigue in their work. Hospice workers are spending a great deal of time in liminal or in-between spaces. It is my belief that this space is spiritual in nature and that many of the effects of compassion fatigue are not simply related to physical and mental exhaustion but are caused by spiritual distress. I share the conviction of Cicely Saunders, who believed that hospice provides an opportunity for spiritual growth, not only for patients but for hospice workers who are accompanying people on their journey towards death. I also began this project with the belief that hospice companies have a responsibility to address what Figley calls the “cost of caring” in their workers. I believe that efforts to support hospice workers have not been given the time and space needed to make a difference. I also had the presupposition that hospice workers would want to have resources available to them that would help them identify and address their experience of compassion fatigue. In addition, I brought to this project the belief that hospice chaplains have the training

²³ Philip Browning Helsel, “Liminality in Death Care: The Grief Work of Pastors,” *The Journal of Pastoral Care & Counseling* 63, no. 3 (Fall-Winter 2009): 1–8, 2.

and background necessary to provide and facilitate interventions that will meet the spiritual needs of hospice workers.

Research Question

The goal of this project is to answer the question, *would the provision of spiritual opportunities and practices for hospice workers have any impact on their experience of compassion fatigue?* In addition, this project will highlight the voices of hospice nurses, chaplains and social workers, seeking to hear directly from them about the rewards and challenges of this profession.

Research Method

The research method used in this project combined both quantitative and qualitative elements in order to fill a gap left by other studies of compassion fatigue. Quite a few studies have used Beth Hudnall Stamm's Professional Quality of Life assessment tool, which offers quantitative data on how people experience compassion fatigue, compassion satisfaction and burnout. What seemed to be lacking as I completed a literature review on the topic, were the stories or qualitative reflections on what it is like to work in hospice. Participants were surveyed twice during the study to compare the quantitative data before and after experiencing spiritual practices. Participants also participated in semi-structured interviews with the researcher to allow them the opportunity to reflect on their experience of working in hospice.

In order to answer the research question, it was evident that a group of participants would be needed. When considering programmatic offerings for spiritual support, the feedback I

received was that it needed to be accessible without taking too many resources away from patient care and staff productivity. This feedback led me to the creation of a website, which would serve as a spiritual support resource to be used by hospice team members wherever they are on a given day. The website also allowed me to open up the project to those who worked in hospice agencies in other states and regions. In her book on Secondary Traumatic Stress, Beth Hudnall Stamm includes a chapter on addressing self-care needs of medical professionals through virtual community building. She says, “these ‘fingertip communities’ can improve the caregiver’s access to opportunities for self-care, which in turn improves the probability of mentally healthier caregivers, ultimately leading to better care-giving.”²⁴ Utilizing technology to provide opportunities for hospice workers to engage in spiritual practices became an important aspect of this project.

Participants in this project included hospice nurses, social workers and chaplains. This project involved three research stages.

- Research Stage One: Professional Quality of Life Survey
- Research Stage Two: Interviews
- Research Stage Three: Follow-Up Professional Quality of Life Survey

Nineteen participants completed stage one, which involved electronically completing the Informed Consent Form (Appendix 4) and answering the thirty questions on the Professional Quality of Life (ProQOL) survey (Appendix 1). Eleven participants completed stage two, participation in a semi-structured interview with the researcher, and ten participants completed

²⁴ Beth Hudnall Stamm, “Creating Virtual Community: Telehealth and Self Care Updated,” in *Secondary Traumatic Stress: Self-Care Issues for Clinicians, Researchers & Educators*, Second (Lutherville, Md: The Sidran Press, 1999), 179–208, 203.

stage three, the follow-up survey, which included the same thirty question ProQOL survey, as well as some additional questions to provide feedback about the study.

The interview in stage two included four pre-determined questions and one debrief question to assess for any distress participants may have felt as a result of participating in the study. These were semi-structured interviews with pre-determined questions that allowed the researcher the freedom to ask follow-up questions or pose questions in a different order, depending on the participant or the feel of the interview. Questions were chosen to elicit stories and reflections on both the challenges and rewards of working in hospice. Some elements of appreciative inquiry were used in the creation of the interview questions and are discussed in greater detail in chapter three. Interviews were recorded and analyzed for themes.

Between research stages two and three, participants were given access to the Spirit of Hospice website (www.spiritofhospice.com) which included six weeks of spiritual practice guides that led participants through one spiritual practice a week. The spiritual practices included art, music, nature, journaling/writing, prayer/meditation and body/movement. Six weeks after their interview, participants were sent the follow-up survey that contained the ProQOL questions as well as some questions about how they experienced the website and the spiritual practices. Participants were also given the opportunity to schedule a follow-up interview with the researcher if they reported any feelings of distress as a result of participating in the study.

Chapter 2: State of the Field

Significance of Project

"Hospice does not look upon death as a defeat. Hospice gives 'hope in a hopeless situation.' It encourages the terminally ill and their families to come to terms with death. It helps them say good-bye to each other. Hospice's hope is to establish an atmosphere in which the patient and family can positively deal with their fears and concerns."²⁵ Creating this kind of atmosphere takes a high level of empathy, compassion and dedication. During my five years working as a hospice chaplain I have witnessed the many ways that hospice workers journey with patients as they transition from this life into the mystery of death. I have also witnessed the way that hospice workers journey with the family members of patients, equipping them to provide care to their loved ones in their final stages of life. These daily encounters with patients and families leave a lasting impact on the lives of hospice workers. Many hospice workers will tell you about the families and patients they've met through the years. However, sometimes the effects of working in hospice can cause lingering grief, exhaustion and fatigue.

This project is significant for me because I deeply believe in the mission of hospice and have deep gratitude for the many patients and families I have met in my years working as a hospice chaplain. I have also experienced periods of compassion fatigue in my work and witnessed it in my coworkers. In the conversations I have had with fellow hospice team members

²⁵ Denise Glavan, Cindy Longanacre, and John Spivey, *Hospice, a Labor of Love* (St. Louis, MO: Chalice Press, 1999), 10.

about their experience of compassion fatigue, I hear things like, *I don't know how much longer I can do this job*, or *Maybe I'm not meant to work in hospice*.

Hospice chaplains are trained to come alongside people of diverse backgrounds and help them identify those things that bring them strength and comfort. Chaplains are a representative of the spiritual dimension of life, many times seeking to bring light into what many people consider their darkest days. Within the hospice interdisciplinary team, chaplains are spiritual representatives in a secular environment. Just as chaplains bring light into the lives of those receiving hospice services, chaplains have much to offer to their fellow team members.

Hospice is a rapidly growing field and the recruitment and retention of quality staff is vital to providing quality care to patients and families. Compassion fatigue has been proven to lead to burnout if it is not treated, causing people to leave their work as helping professionals. Something must be done to stop the flow from compassion fatigue to burnout and the loss of skilled, compassionate, high quality hospice employees. Chaplains are uniquely qualified to support hospice workers experiencing compassion fatigue.

Key Terms

As in any profession, hospice has its own vernacular. Understanding the following terms used throughout this paper will facilitate deeper understanding and clarity.

- Compassion Fatigue (CF)- “Compassion fatigue refers to the emotional and physical exhaustion that can affect helping professionals and caregivers over time. It has been associated with a gradual desensitization to patient stories, a decrease in quality care for patients and clients (sometimes described as “poor bedside manners”), an increase in clinical errors, higher rates of depression and anxiety disorders among helpers, and rising rates of stress leave. Helping professionals have also found that their empathy and ability to connect with their loved ones and friends is impacted by compassion fatigue. In turn, this can lead to increased rates of stress in the household, divorce, and social isolation. The most insidious aspect of compassion fatigue is that it attacks the very core of what brings helpers into this work: their empathy and compassion for others.”²⁶
- Secondary Traumatic Stress (STS)- Often used interchangeably with compassion fatigue to describe the same phenomenon. Originally developed to describe the experience of those working with victims of trauma. Compassion Fatigue is considered to be a less “off-putting” term by many professionals.²⁷

²⁶ Figley Institute, “Basics of Compassion Fatigue Workbook,” July 2012, http://www.figleyinstitute.com/documents/Workbook_AMEDD_SanAntonio_2012July20_RevAugust2013.pdf, 4.

²⁷ Stamm, *Secondary Traumatic Stress*, 11.

- Burnout- “The burnout syndrome has certain characteristics that can be described as exhaustion mixed with anxiety and depression. The progression of depleted personal motivation leads to personal problems: negative self-esteem, poor attitude, reduced efficiency and effectiveness. Stress that has intensity, duration, and persistence produces burnout.”²⁸
- Compassion Satisfaction- “Stamm defines the construct of compassion satisfaction as the pleasure that a helper gets from doing their work well and the ability to contribute to the well-being of others.”²⁹
- Professional Quality of Life Assessment (ProQOL)- A tool developed by Charles Figley and Beth Hudnall Stamm to assess levels of Compassion Fatigue or Secondary Traumatic Stress, Compassion Satisfaction and Burnout. It is a thirty item self-report measure of the positive and negative aspects of helping professions. It is the most widely used measure for compassion fatigue and compassion satisfaction. The ProQOL assessment tool, explanation and scoring guide are included in Appendix 1.
- Hospice- The National Hospice and Palliative Care Organization (NHPCO) defines hospice as care that “focuses on caring, not curing and in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are

²⁸ Figley Institute, “Basics of Compassion Fatigue Workbook.”, 5.

²⁹ Cynthia Harr, “Social Work & Christianity” 40, no. 1 (Spring 2013): 74.

available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.”³⁰ Someone is eligible for hospice if a doctor has given them a diagnosis with a life expectancy of 6 months or less.

- Palliative Care- Palliative care may be referred to throughout this study. Hospice care falls under the broader category of palliative care, but not all palliative care is hospice. The Center to Advance Palliative Care defines this type of care as, “specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient’s prognosis. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.”³¹
- Total Pain- This term was created by Cicely Saunders, the founder of the Hospice movement and is still widely used as a framework for providing palliative and hospice care. “Saunders coined the term total pain to take into account a broader conceptualization of pain to include physical, psychological, social, emotional, and spiritual components (Clark 1999).”³²

³⁰ “Hospice Care Overview for Professionals,” website, *NHPCO* (blog), n.d., <https://www.nhpco.org/hospice-care-overview>.

³¹ “What Is Palliative Care,” Website, *Center to Advance Palliative Care* (blog), n.d., <https://www.capc.org/about/palliative-care/>.

³² Kelli I. Stajduhar and Harold G. Coward, *Religious Understandings of a Good Death in Hospice Palliative Care.*, 4.

- Hospice Workers- In this study when discussing hospice workers, I am referring to members of the hospice Interdisciplinary Team. Members of this team include medical directors, nurses, social workers, chaplains, bereavement counselors, physical therapists, home health aides and volunteer coordinators. There are other hospice employees- schedulers, office staff, nurse managers, etc. but for the purpose of this study I will be focusing my research on hospice nurses, social workers and chaplains.
- Interdisciplinary Team – Medicare requires that each hospice patient be discussed in an interdisciplinary team meeting twice a month. Attendees of this meeting and members of the interdisciplinary team often include the medical director, a manager, nurses, social workers, chaplains, bereavement counselors, physical therapists, and volunteer coordinators. The home health aides, another vital part of the hospice team, are generally not in attendance at this meeting.
- Spirituality- Most writers agree that codifying spirituality is an arduous task. It is very difficult to find a definition of spirituality that can be agreed upon. I appreciate the following definition of spirituality for the purpose of this study. “The integral nature of relationship to spirituality suggests both a vertical and a horizontal dimension. The vertical dimension has to do with the person’s transcendent (beyond and/or outside self) relationship, the possibility of a personal relationship with a Higher Being—God—not necessarily as defined by a particular religion. The horizontal facet reflects and “fleshes out” the many ways in which a personal relationship with the Divine influences our

beliefs, values, lifestyle, quality of life, and interactions with ourselves, with others, and with nature.”³³

- Spiritual Distress- “Spiritual distress is manifested as disharmony within the human spirit. It involves a person’s belief system, religious practices, value system, and meaningful relationships. Spiritual distress is evidenced through concerns about life, death, and suffering. There is discomfort surrounding issues of a religious nature, such as the existence of God or some form of Higher Power, the fairness (or, more likely, the unfairness) of life, religious practices, faith, and a personal spirituality.”³⁴
- Spiritual Practice- A spiritual practice refers to a regular performance of an activity or action meant to illicit a spiritual experience and lead to spiritual growth or development. Many people refer to spiritual practices as things that move one closer to connection with something beyond one’s self whether that is God, peace, or something else. The resource created for this project includes nature, music, art, prayer/meditation, journaling/writing and body/movement as spiritual practices.
- Chaplain- “While there is variation in role and scope of interfaith chaplains, the term chaplain is generally used today to designate religious leaders who are commissioned by faith communities to provide religious and spiritual care to a group of people outside of the parish. Most chaplains are ordained, associated with recognized faith traditions, and

³³ Harold G. Koenig and Verna Brenner Carson, *Spiritual Dimensions of Nursing Practice*, vol. Rev.ed. (West Conshohocken, Pa: Templeton Foundation Press, 2008), 6.

³⁴ Harold G. Koenig and Verna Brenner Carson, 302.

graduate from seminaries, divinity schools, or rabbinical schools. While spiritual care responsibilities are primarily directed toward patients and relatives, health care chaplains in particular also increasingly provide care to staff. Chaplains are responsible for facilitating appropriate religious practices for people of their own faith, for contacting religious leaders that are not of their own faith to conduct religion specific rituals at the request of the patient and family, and for conducting such rituals if these religious leaders are not available. In the context of health care, a primary role of the chaplain is also to assess and respond to the spiritual needs of patients and to educate the rest of the team on religious issues.”³⁵

- Liminality- “The concept liminality is connected to an awareness of threshold, margins and boundaries. The term limen refers originally to rituals that demarcate the passage from one life phase to another. Essentially then, liminality implies an ambiguous phase between two situations or statuses.”³⁶
- Transcendence- “In philosophy and theology, to transcend is to go beyond the limits of lived human experience. Hospice workers accompany people who are traveling beyond the limits. The reality of the dying process involves a progressive series of disconnections

³⁵ Kelli I. Stajduhar and Harold G. Coward, *Religious Understandings of a Good Death in Hospice Palliative Care*, 280-81.

³⁶ Daniel Louw, “Compassion Fatigue: Spiritual Exhaustion and the Cost of Caring in the Pastoral Ministry. Towards a ‘Pastoral Diagnosis’ in Caregiving,” *HTS Teologiese Studies/Theological Studies* 71, no. 2 (October 13, 2015): 1–10, 2.

from life, which requires the process of letting go. Thus, transcending life involves both the need to detach and separate from life as it has been lived.”³⁷

³⁷ Joyce Zerwekh, “Transcending Life: The Practice Wisdom of Nursing Hospice Experts,” *American Journal of Hospice and Palliative Medicine*® 10, no. 5 (September 1993): 26–31, <https://doi.org/10.1177/104990919301000509>, Abstract.

Literature Review

Much of what has drawn me towards this study of compassion fatigue comes from my own experience as a helping professional and the stories I hear from my colleagues. Several years ago, following my work as a chaplain resident in a busy Philadelphia trauma center, I was describing my feelings of numbness and exhaustion to a close friend. This friend gave my feelings a name, “vicarious traumatization”, and pulled out a book she had just finished called *Trauma Stewardship*.³⁸ I borrowed the book and felt immense relief as I realized that what I was feeling was not uncommon and I was not alone in my experience. As I made the transition from chaplain resident to full-time hospice chaplain, I was relieved to have a respite from the fast-paced intensity of the trauma room. However, I began to experience a slightly different form of fatigue, that I now know as compassion fatigue.

The study of compassion fatigue has come a long way since the mid to late nineties. A quick search of compassion fatigue will bring up books on compassion fatigue in nurses, trauma workers, veterinarians, EMS drivers, grief counselors and many more. Charles Figley, Beth Hudnall Stamm and others have given the experience of compassion fatigue a name and a framework. However, my experience in hospice has made me wonder if compassion fatigue is widely understood by caregivers and organizations. Furthermore, I have wondered how compassion fatigue can be addressed by institutions, and what role spirituality could play in the treatment or prevention of compassion fatigue.

³⁸ Laura van Dernoot Lipsky and Connie Burk, *Trauma Stewardship: An Everyday Guide to Caring for Self While Caring for Others*, 1st ed, A BK Life Book (San Francisco, CA: Berrett-Koehler Publishers, 2009).

I have discovered several studies of compassion fatigue as it relates to the field of hospice. One study I've found particularly helpful has studied the relationship between self-care, compassion satisfaction, compassion fatigue, and burnout among hospice workers.³⁹ This study surveyed 37 hospice workers about the types of self-care activities they participate in and correlated the results with their score on the ProQOL Assessment. The results of the study "could suggest that while engaging in a variety of self-care strategies may prevent burnout and compassion fatigue, only emotional and spiritual self-care and personal-professional balance are predictive of higher levels of compassion satisfaction."⁴⁰ The study also found that compassion satisfaction was significantly correlated to emotional and spiritual self-care activities. This study encourages future research to be done around the types of self-care activities that can increase compassion satisfaction and diminish compassion fatigue. This study speaks directly to the need for employers to provide spiritual and emotional opportunities for their employees and "future research should explore ways in which hospice care employers can assist, and perhaps require, their workers to take part in holistically focused self-care activities."⁴¹

I have encountered quite a few journal articles in the fields of pastoral care, palliative care and social work, that examine the experience of compassion fatigue and spirituality in helping professionals. One study found that "among hospice workers, it is generally believed that hospice (IDT) team members are more 'spiritual' when compared to other workforce settings other than clergy."⁴² The study also found that hospice team members "who integrate their spiritual beliefs into their work are more likely to self-actualize and those who self-actualize

³⁹ Alkema, Linton, and Davies, "A Study of the Relationship Between Self-Care, Compassion Satisfaction, Compassion Fatigue, and Burnout Among Hospice Professionals."

⁴⁰ Alkema, Linton, and Davies, 114.

⁴¹ Alkema, Linton, and Davies, 114.

⁴² Leah Clark et al., "Spirituality and Job Satisfaction among Hospice Interdisciplinary Team Members," *Journal of Palliative Medicine* 10, no. 6 (December 2007): 1321–28, <https://doi.org/10.1089/jpm.2007.0035>, 1322.

are more likely to integrate their spiritual beliefs into their work as well.”⁴³ Another study examined the potential for spiritual growth among those working in hospice. “Thus for hospice workers, or indeed anyone who swims daily in an ocean of suffering and death, the initially disruptive experience of compassion fatigue may well bring about a deepened, more mature and more resilient faith.”⁴⁴ Another study of compassion fatigue and spirituality in trauma therapists serving in Romania, speaks to the need for further exploration into spirituality and its impact on both compassion fatigue and compassion satisfaction. “While few studies have investigated religion and spirituality as protective factors against compassion fatigue, fewer still have explored the phenomenon of growth or compassion satisfaction that results from the protective force of spiritual and religious strategies.”⁴⁵

A common thread through all of the studies and articles I have encountered, is the encouragement for organizational leadership in addressing compassion fatigue. “Efforts to reduce the risk of compassion fatigue among health care professionals should focus on education and staff interventions that address these areas. If self-care is just a workshop that one hears on orientation or during CE units, not much impact will be felt. However, leaders are encouraged to take an honest look at how the organization's culture promotes or distracts from a professional's well-being.”⁴⁶ “Organizational leaders should be intentional about promoting compassion

⁴³ Clark et al, 1327.

⁴⁴ Gretchen Thompson, “Pilot Study: Exploring the Relationship between Faith Development and Compassion Fatigue in Hospice Practitioners,” *Chaplaincy Today* 23, no. 2 (Autumn/Winter 2007): 25–31, 27.

⁴⁵ Mary Newmeyer et al., “Spirituality and Religion as Mitigating Factors in Compassion Fatigue Trauma Therapists in Romania,” *Journal of Psychology & Theology* 44, no. 2 (2016): 142–51, 143.

⁴⁶ Jason T. Hotchkiss and Ruth Leshner, “Factors Predicting Burnout Among Chaplains: Compassion Satisfaction, Organizational Factors, and the Mediators of Mindful Self-Care and Secondary Traumatic Stress,” *Journal of Pastoral Care & Counseling* 72(2) (2018): 86–98, <https://doi.org/10.1177/1542305018780655>, 86-98.

satisfaction through the planning and implementing of activities that encourage spiritual renewal as well as self-care." ⁴⁷

Several studies have been done correlating compassion fatigue and compassion satisfaction with spirituality, and numerous writers encourage continued research about spiritual self-care and organizational programs to address compassion fatigue. However, I have found few examples of staff support programs in hospice. The only example of programmatic staff care I found came from an outpatient cancer clinic in Seattle.⁴⁸ Chaplains at this clinic responded to staff needs by offering four programs. They combined both short-term and long-term offerings that included labyrinth walking, day retreats, chaplain-led support groups and discussions around existential themes. They found these programs met a variety of staff needs and greatly increased the sense of camaraderie among staff. Within a book on pastoral care, I found one chapter addressing staff support⁴⁹ written by Reverend Robin C. Brown-Haithco, a chaplain from Emory University Hospital whose sole function is providing chaplaincy support to staff. She encourages similar support programs for staff in other settings. "The staff support program will be a visible reminder to health care administrators of the importance of caring for the soul and heart of staff who care for patients and families within their health care institutions. A lot of research is being done on creating healthy work environments. It is my belief that caring for staff is primary to creating this healthy work space."⁵⁰

Two books have provided valuable information and have been written as guidebooks for those in caregiving roles. Robert J. Wicks has provided a guide for doctors and nurses on how to

⁴⁷ Cynthia Harr, "Social Work & Christianity," 81.

⁴⁸ Stephen D King, Debra Jarvis, and Marilyn Cornwell, "Programmatic Staff Care in an Outpatient Setting," *The Journal of Pastoral Care & Counseling* 59, no. 3 (2005): 263–73.

⁴⁹ Reverend Robin C. Brown-Haithco, "Spiritual Care of Staff," in *Professional Spiritual & Pastoral Care: A Practical Clergy and Chaplain's Handbook* (SkyLight Paths Pub., 2012), 209–18.

⁵⁰ Reverend Robin C. Brown-Haithco, 217.

overcome secondary stress⁵¹ and Francoise Mathieu has written a workbook on compassion fatigue for caregivers.⁵² Both of these resources provide information that is meant to facilitate reflection and a deeper awareness for caregivers about their levels of compassion fatigue.

Mathieu's workbook outlines the four steps to wellness according to Charles Figley.

1. Take stock of your stressors.
2. Look for ways to enhance your self-care and work/life balance.
3. Develop resiliency skills.
4. Make a commitment to implement changes.⁵³

The four steps are described in greater detail in chapters 11-15 of the workbook. Each chapter ends with homework and writing assignments as well as recommended reading. I appreciate the specificity of this workbook and its focus on things like healthy eating, physical exercise and paying attention to how compassion fatigue may be affecting one's body. This workbook does not speak much to spirituality, however, many of the exercises and assessments would be useful for any caregiver experiencing or hoping to prevent compassion fatigue. This would also be a great resource for hospice workers to complete as part of a group or in a workshop setting.

It has been helpful to reflect on the historical foundations of the hospice movement, particularly the work of Dame Cicely Saunders, the founder of the modern hospice movement. Several books and articles have proved helpful in understanding her work and history. One article highlighted her contribution to the field of hospice and palliative care through the concept of total pain,⁵⁴ which considers pain as not merely physical but social, emotional, psychological and spiritual as well. Another book provided an excellent background on Cicely Saunders and

⁵¹ Robert J. Wicks, *Overcoming Secondary Stress in Medical and Nursing Practice: A Guide to Professional Resilience and Personal Well-Being* (Oxford; New York, N.Y: Oxford University Press, 2006).

⁵² Mathieu, *The Compassion Fatigue Workbook*.

⁵³ Mathieu, 85.

⁵⁴ David Clark, "'Total Pain': The Work of Cicely Saunders and the Maturing of a Concept," University of Glasgow, *End of Life Studies* (blog), September 25, 2014, <http://endoflifestudies.academicblogs.co.uk/total-pain-the-work-of-cicely-saunders-and-the-maturing-of-a-concept/>.

the beginnings of the hospice movement, as well as a thorough reflection on what constitutes a “good death” in many major religious traditions.⁵⁵ This book has also been helpful in creating the theological framework for this project.

Harold Koenig and Verna Brenner Carson have written an extremely thorough and influential book examining the spiritual dimensions of the nursing profession.⁵⁶ The authors collaborated with many chaplains to create a resource which defines spirituality in health care, examines key attributes of both theistic and monotheistic religious traditions, and explores spiritual needs that may be present in both patients and nurses. The book has been used as a textbook for nursing students and encourages the reader to think about their own definition of spirituality and their attitudes about death, illness and suffering. Throughout the book there is an awareness that spiritual needs are not just attended to and met by professional chaplains but can and should be addressed by the entire medical team. The book identifies the spiritual themes and questions that may arise for patients and also acknowledges that these same issues may affect professional caregivers.

When people struggle to make sense out of life and in that struggle they grapple with tough questions, such as, “Why me?” “Why now?” “What does it mean?” and “What difference do I make?” they are attempting to define the relationship of their lives to ultimate truth and reality. Nurses and other health care professionals not only witness patients and families as they grapple with these questions; nurses grapple with the same questions themselves as they face the limits of their skills and abilities to make people better, to ease pain, and to create a healing environment.⁵⁷

The final chapter of Koenig and Carson’s book reflects on how spirituality should be incorporated into nursing education programs as well as the healthcare workplace. The

⁵⁵ Kelli I. Stajduhar and Harold G. Coward, *Religious Understandings of a Good Death in Hospice Palliative Care*.

⁵⁶ Harold G. Koenig and Verna Brenner Carson, *Spiritual Dimensions of Nursing Practice*, vol. Rev. ed. (West Conshohocken, Pa: Templeton Foundation Press, 2008).

⁵⁷ Harold G. Koenig and Verna Brenner Carson, 74.

discussion of creating a “spiritually infused work environment”⁵⁸ is particularly helpful in thinking about creating a spiritual response to compassion fatigue in hospice workers.

In my exploration of how hospice chaplains can serve as chaplains to hospice workers, I have encountered the Faith at Work movement.⁵⁹ David Miller, a professor at Princeton University, studies faith and work, doing extensive research and writing on the topic. Most companies offer some kind of Employee Assistance Program (EAP) to their employees. Often, this comes in the form of a phone number to call for counseling or other resources during a crisis. Some companies, however, have responded to the isolation and life challenges of their employees by hiring corporate chaplains. Miller has found that these kind of chaplain positions have many potential benefits for companies as they, “add value to companies, potentially helping create lower turnover rates, increased levels of focus, and reduction in stress-related illnesses.”⁶⁰ Marketplace Ministries and Corporate Chaplains of America are some of the largest providers of chaplains to corporate settings. Tyson Foods runs its own in-house chaplaincy program, “with more than 115 chaplains based in different factories around the country. Company-wide, this works out to roughly one chaplain on staff for every 1,000 Tyson employees.”⁶¹ These corporate chaplaincy programs exist in order to provide opportunities for employees to bring their whole selves to work. An extensive reflection on corporate or workplace chaplaincy could be a project of its own. However, I mention it here as further evidence of the diverse roles that chaplains can play in workplace settings. In addition, the Faith at Work movement may provide a wealth of knowledge to hospice companies seeking to provide for the spiritual needs of their employees.

⁵⁸ Harold G. Koenig and Verna Brenner Carson, 378.

⁵⁹ David W. Miller and James Dennis LoRusso, “Faith at Work: Spiritual Needs Don’t End at the Start of the Work Day,” *U.S. Catholic* 83, no. 9 (September 2018): 19–21.

⁶⁰ Emma Green, “Finding Jesus at Work,” *The Atlantic*, February 17, 2016, <https://www.theatlantic.com/business/archive/2016/02/work-secularization-chaplaincies/462987/>.

⁶¹ Emma Green.

Chapter 3: The Research

Spirit of Hospice Resource

Drawing from my own experience as a hospice worker and conversations with other hospice employees and managers, I chose to create a spiritual resource for hospice employees as the framework for my project. I considered writing a weekly email, inviting hospice workers to participate in one spiritual practice each week. However, I soon came to the conclusion that creating a website with all of the information needed to participate in the study as well as spiritual practices, articles, podcasts and videos relating to hospice might be the best medium. Utilizing technology to provide opportunities for hospice workers to engage with spiritual practices became an important aspect of this study.

Dame Cicely Saunders' concept of "total pain" plays an extremely important role in hospice care and the interdisciplinary team process. "There can be little doubt that when Cicely Saunders first used this term she was in the process of bequeathing to medicine and healthcare a concept of enduring clinical and conceptual interest. It emerged from her unique experience as nurse, social worker and physician – the remarkable multi-disciplinary personal platform from which she launched the modern hospice and palliative care movement. It also reflected a willingness to acknowledge the spiritual suffering of the patient and to see this in relation to physical problems."⁶² Drawing on this definition of pain and the hospice movement's focus on

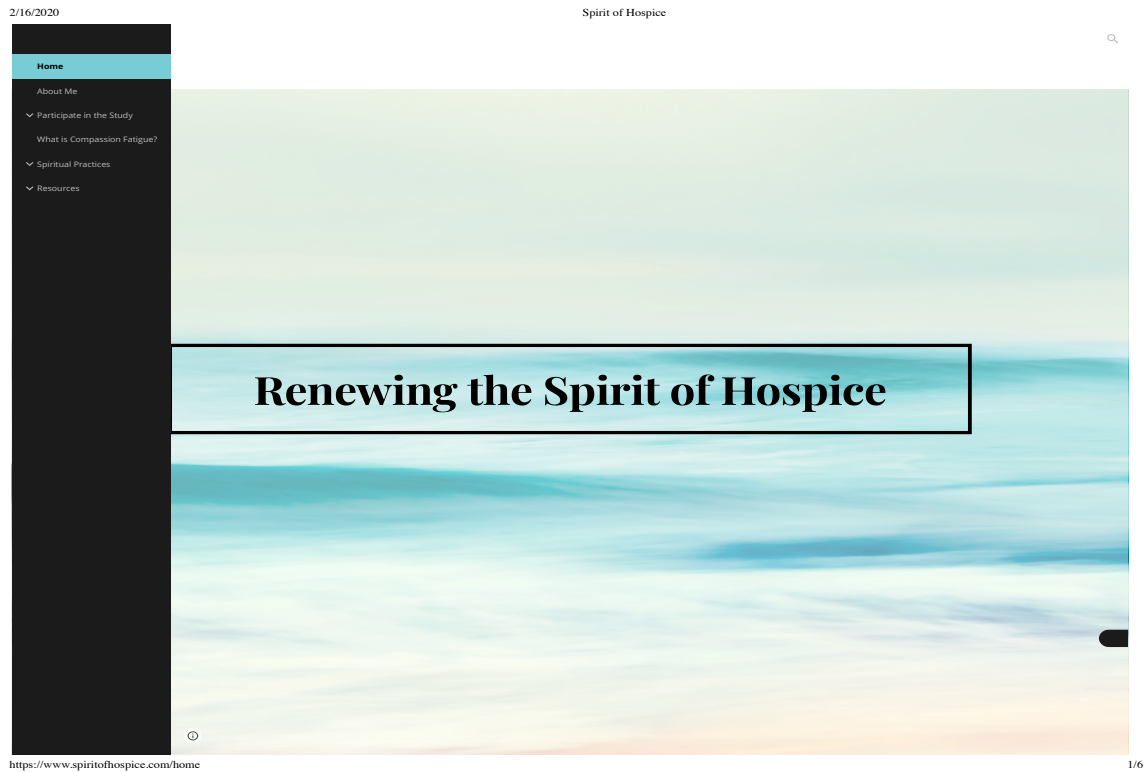
⁶² David Clark, "Total Pain: The Work of Cicely Saunders and the Maturing of a Concept."

‘total pain’, I knew that I wanted to create a resource that would address hospice workers as whole people, seeking to meet their emotional, physical, spiritual and social needs.

Spirit of Hospice Website

The website is called, Spirit of Hospice, to correlate with the theme of this study. After researching domains and searching for the most user-friendly website platform, I decided upon “Google sites.” I found Google sites to be very user friendly for someone with little web design experience. Using Google Domains, I purchased a Domain name for my website (www.SpiritofHospice.com) making it easier to access. The Spirit of Hospice website became the home for not only the weekly spiritual practices, but for all of the information needed to participate in the study. The surveys and consent forms were created using Google Forms and embedded directly into the website. The website included a menu to direct users to all areas of the site. I will outline each section of content found on the Spirit of Hospice website.

Home Page:



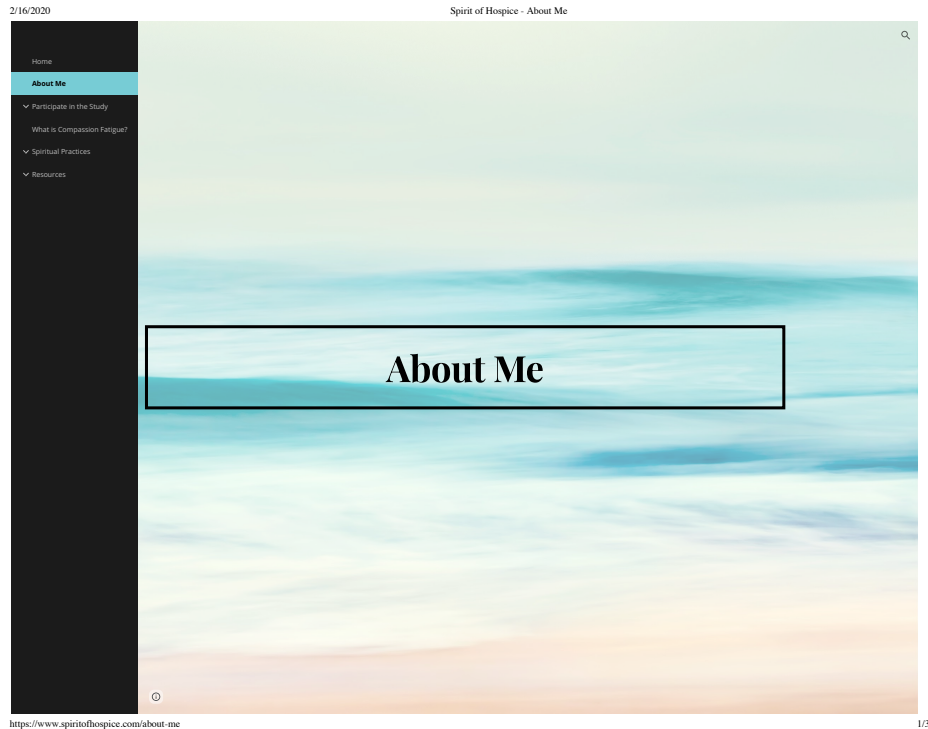
“The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.”
-Rachel Naomi Remen

Welcome! I am a Doctor of Ministry Student and a Hospice Chaplain who is exploring the experience of compassion fatigue among hospice workers and how spiritual practices might be used to alleviate some of the symptoms of compassion fatigue.

This website is a space for those working in hospice to find rest while also learning about compassion fatigue and spiritual practices.

You will also find all the information about participating in this study on compassion fatigue in Hospice.

About Me:



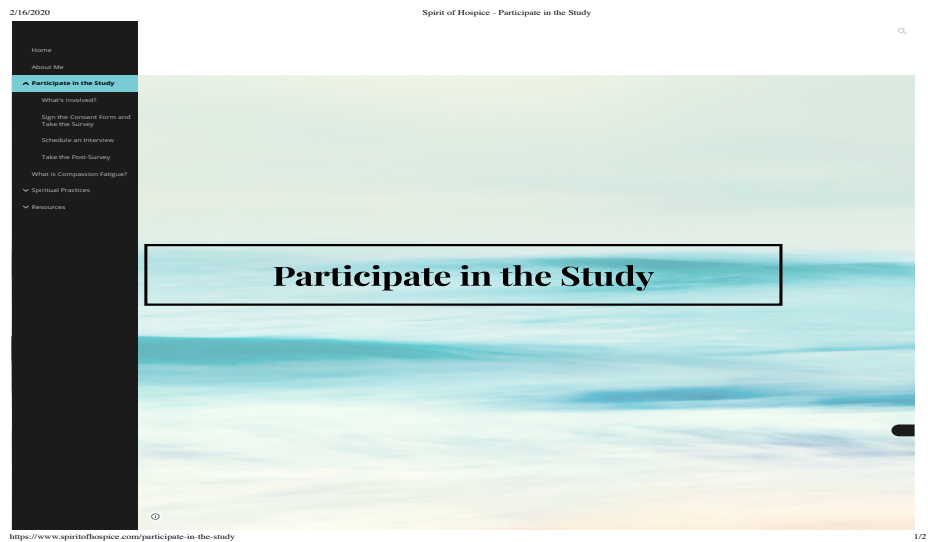
Hello!

My name is Faith Fitzgerald and I have been a hospice chaplain for the past five years at Main Line Health in the Philadelphia area. I'm currently working on my Doctor of Ministry degree at Lancaster Theological Seminary.

For my Doctor of Ministry Major Project, I am studying compassion fatigue in Hospice staff. I will be conducting interviews with hospice staff from various companies and exploring how spiritual practices may be able to help sustain the work we do each day in hospice.

On this site you will find all the information you need to be a part of this study. You can learn more about compassion fatigue, schedule a time for an interview, learn about spiritual practices and follow along each week as we experience a different practice together.

Participate in the Study:



For my Doctor of Ministry Project I am studying compassion fatigue in hospice workers.

Wondering what you would have to do to participate in the study?

Find all the information here: (link to What's Involved Page)

What's Involved?:

1. Sign the Informed Consent Form and Take the Survey (link to Consent Form and initial survey)
2. Schedule a 50-minute interview with me (link to Calendar page to schedule an interview)
3. Follow the guides found on this site to use one spiritual practice a week for the next 6 weeks (link to Spiritual Practices page)
4. Take the Follow-up Survey and provide feedback (link to follow-up survey)

What is Compassion Fatigue?:

2/16/2020 Spirit of Hospice - What is Compassion Fatigue?

Symptoms of Compassion Fatigue

- Loss of Purpose
- Anxiety
- Sleep Disturbance
- Hypervigilance
- Pervasive Hopelessness
- Self-doubt
- Inability to Concentrate
- Disorientation or Forgetfulness
- Withdrawal/Isolation
- Apathy
- Anger
- Emotional Rollercoaster
- Decreased Sexual Intimacy
- Feeling Overwhelmed
- Poor Self-care
- Appetite Changes
- Minimization
- Loss of Purpose

Charles Figley, who is often considered the pioneer of compassion fatigue research, has called compassion fatigue, "a disorder that affects those who do their work well."

Here are some key terms often used in the discussion of Compassion Fatigue in caregivers:

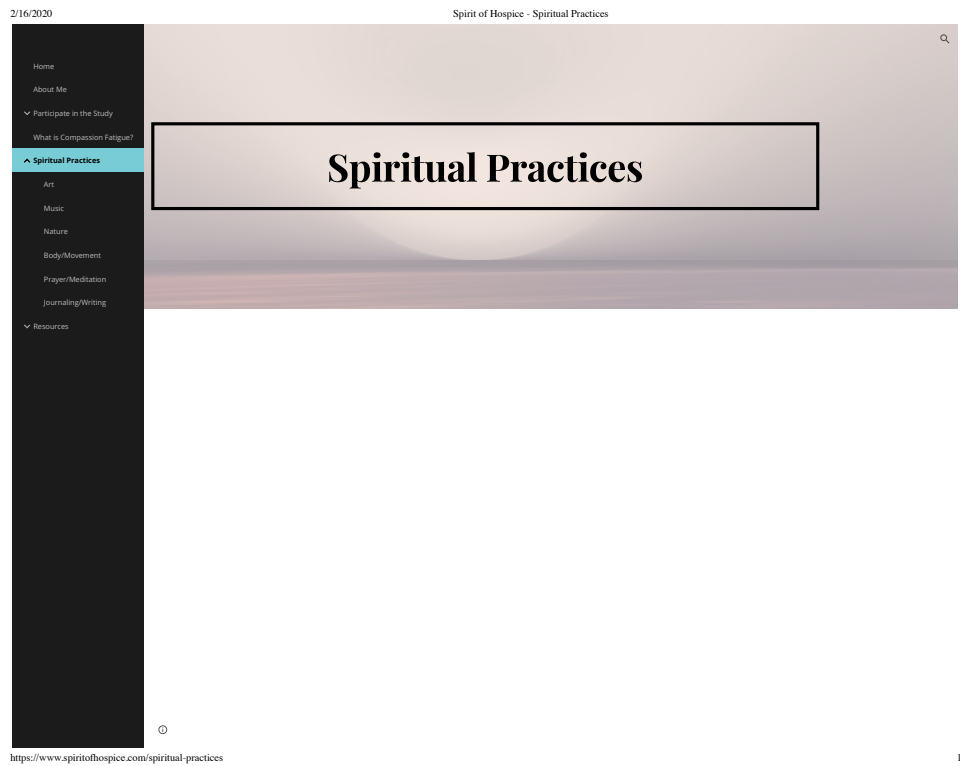
- **Compassion fatigue**- The emotional and physical exhaustion that can happen to caregiving professionals over time. "The most insidious aspect of compassion fatigue is that it attacks the very core of what brings helpers into this work: their empathy and compassion for others." [1]
- **Burnout**- "Exhaustion mixed with anxiety and depression. The progression of depleted personal motivation leads to personal problems: negative self-esteem, poor attitude, reduced efficiency and effectiveness. Stress that has intensity, duration, and persistence produces burnout." [2]
- **Secondary Traumatic Stress (STS)**- A term often used interchangeably with compassion fatigue to describe the same phenomenon. Used frequently when discussing vicarious traumatization in caregivers after working with those experiencing trauma.
- **Compassion Satisfaction**- The pleasure or sense of well-being that a helping professional gets from doing their work.

[1] [2] Charles R. Figley, ed., *Encyclopedia of Trauma: An Interdisciplinary Guide* (Thousand Oaks, Calif: SAGE, 2012).

<https://www.spiritofhospice.com/what-is-compassion-fatigue>

This page includes the diagram above, as well as definitions of Compassion Fatigue, Burnout, Secondary Traumatic Stress and Compassion Satisfaction, as defined by Charles Figley.

Spiritual Practices:



This page includes links for the six spiritual practices which include Art, Music, Nature, Body/Movement, Prayer/Meditation and Journaling/Writing. Each spiritual practice page will be detailed in the section: Spiritual Practices for Hospice Workers.

Resources-



Watch: This page includes links to several videos related to hospice:

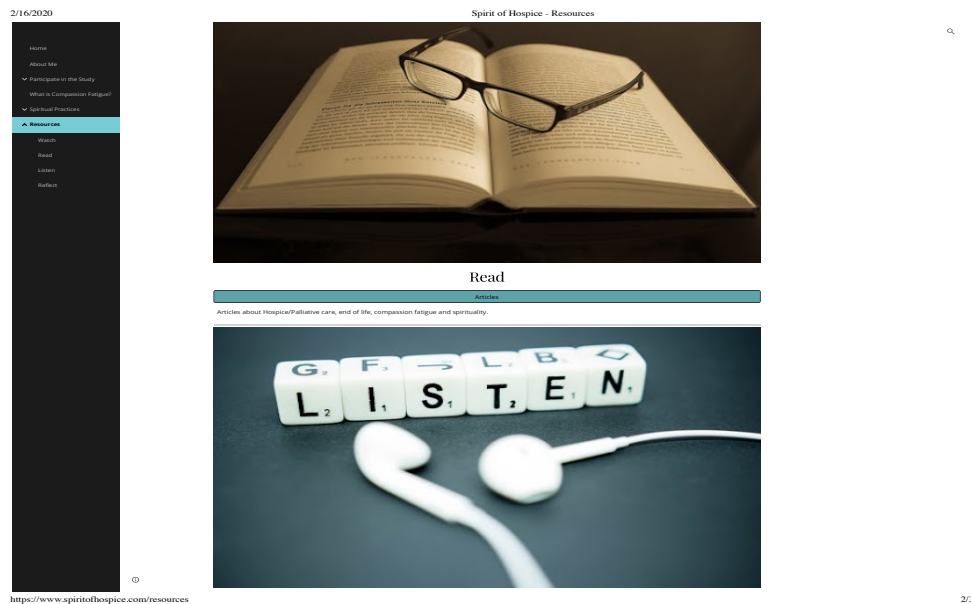
1. Ted Talk from Kate Bowler⁶³
2. Ted Talk from Patricia Smith⁶⁴
3. Ted Talk from BJ Miller⁶⁵
4. Video of Michael Kearney, M.D.⁶⁶

⁶³ Kate Bowler, *Everything Happens for A Reason and Other Lies I've Loved*, TED video (TEDMED 2018), https://www.ted.com/talks/kate_bowler_everything_happens_for_a_reason_and_other_lies_i_ve_loved.

⁶⁴ Patricia Smith, *How to Manage Compassion Fatigue in Caregiving*, TED video (TEDx San Juan Island, 2017), <https://www.youtube.com/watch?v=7keppA8XRas&feature=youtu.be>.

⁶⁵ BJ Miller, *What Really Matters at the End of Life*, TED video (TED Talk, 2015), <https://www.youtube.com/watch?v=apbSsILLh28&feature=youtu.be>.

⁶⁶ Eliot Jacobson, *Dying in Grace #31, Using Nature for Self-Care, with Michael Kearney, M.D.*, YouTube video, vol. 31, *Dying in Grace* (Santa Barbara, CA: TVSB Studios, n.d.), <https://www.youtube.com/watch?v=JpvziyotdTE&feature=youtu.be>.



Read: This page includes a link to an article about hospice workers from the PEW charitable trusts publication.⁶⁷

Listen: This page includes links to several audio recordings from podcasts:

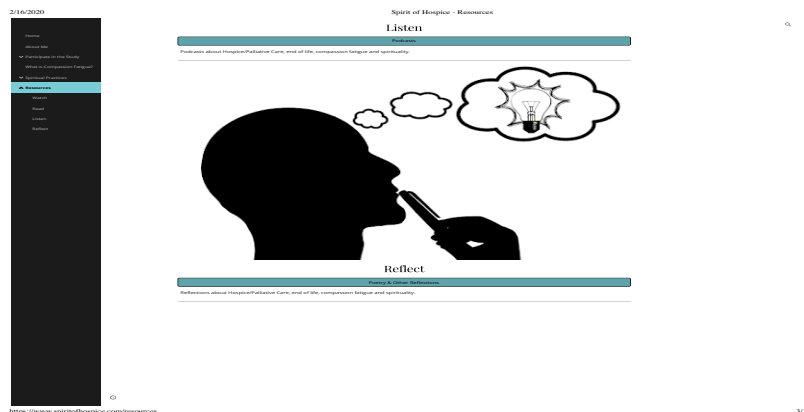
1. Dr. BJ Miller speaking on death on Oprah’s SuperSoul Conversations podcast.⁶⁸
2. Rachel Naomi Remen speaking about Fixing vs. Healing on the On Being podcast.⁶⁹
3. Jonathan Prescott, chaplain speaking about incorporating contemplative practices into hospice work from the Heart of Hospice podcast.⁷⁰

⁶⁷ Michael Ollove, “‘My Soul and My Role Aligned’- How Hospice Workers Deal with Death,” *Stateline, Pew Charitable Trusts* (blog), July 26, 2018, <https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2018/07/26/my-soul-and-my-role-aligned-how-hospice-workers-deal-with-death>.

⁶⁸ Dr. BJ Miller, *How to Die*, Podcast, Oprah’s SuperSoul Conversations, 2018, <https://podtail.com/en/podcast/oprah-s-supersoul-conversations/dr-bj-miller-how-to-die/>.

⁶⁹ Rachel Naomi Remen, *The Difference Between Fixing and Healing*, Podcast, On Being with Krista Tippett, 2018, <https://onbeing.org/programs/rachel-naomi-remen-the-difference-between-fixing-and-healing-nov2018/>.

⁷⁰ Jonathan Prescott, *Improving Your Care Through Contemplative Practices*, Podcast, vol. 43, The Heart of Hospice, 2019, <http://theheartofhospice.libsyn.com/improving-your-care-through-contemplative-practices-episode-043>.



Reflect: This page includes some of the poetry and other readings that I have shared during Hospice Interdisciplinary Team Meetings.

A Prayer for All Who Work in Hospice⁷¹

May the passion you have for life fire the compassion you have for others.

May you know that when you do small things with great love you change lives.

May the blessings you receive mean more than the hours you work.

May you remember to keep both feet on the ground while tending to those who have one foot in heaven.

May you be grateful that your daily encounter with death and dying brings you a deeper appreciation of life and living.

May you never lose sight of the fact that it's not the length but the depth of life that really matters.

May your work be grounded in the knowledge that grief is the emotional, physical and spiritual price you pay for the priceless gift of love, and that the only cure for grief is grieving.

May you know that while no one may build a monument in your name, the way you make your mark in this life is by erasing the frown on someone's brow.

And, may you start each day remembering the last words spoken by Steve Jobs before he died: "Oh wow! Oh wow! Oh wow!"

Amen.

⁷¹ Elizabeth Kaeton, "A Prayer for All Who Work in Hospice," *Telling Secrets* (blog), August 19, 2015, <https://telling-secrets.blogspot.com/2015/08/a-prayer-for-all-who-work-in-hospice.html>.

Blessing of your Work
by John O'Donohue⁷²

May the light of your soul guide you.
May the light of your soul bless the work
You do with the secret love and warmth of your heart.
May you see in what you do the beauty of your own soul.
May the sacredness of your work bring healing, light and renewal to those
Who work with you and to those who see and receive your work.
May your work never weary you.
May it release within you wellsprings of refreshment, inspiration and excitement.
May you be present in what you do.
May you never become lost in the bland absences.
May the day never burden you.
May dawn find you awake and alert,
approaching your new day with dreams,
Possibilities and promises.
May evening find you gracious and fulfilled.
May you go into the night blessed, sheltered and protected.
May your soul calm, console and renew you.

I Worried⁷³
by Mary Oliver

I worried a lot. Will the gardens grow, will the rivers
flow in the right direction, will the earth turn
as it was taught, and if not how shall
I correct it?
Was I right, was I wrong, will I be forgiven,
can I do better?
Will I ever be able to sing, even the sparrows
can do it and I am, well,
hopeless.
Is my eyesight fading or am I just imagining it.
am I going to get rheumatism,
lockjaw, dementia?
Finally I saw that worrying had come to nothing.
And gave it up. And took my old body
and went out into the morning,
and sang.

⁷² John O'Donohue, *To Bless the Space between Us: A Book of Blessings*, 1st ed (New York: Doubleday, 2008), 164.

⁷³ Mary Oliver, *Swan: Poems and Prose Poems* (Boston: Beacon, 2012), 39.

Found

By Frederick Buechner from *Lecture to A Book of The Month Club*

Maybe it's all utterly meaningless.
Maybe it's all unutterably meaningful.
If you want to know which,
pay attention to what it means to be truly human
in a world that half the time
we're in love with
and half the time
scares the hell out of us...
The unexpected sound of your name on
somebody's lips.
The good dream.
The strange coincidence.
The moment that brings tears to your eyes.
The person who brings life to your life.
Even the smallest events hold the greatest clues.

Spiritual Practices for Hospice Workers

Spirituality can be a difficult term to define, as it generally means something different to each person you ask. I knew that for this project, I wanted to focus on spiritual practices, assuring that they could be accessed and utilized by people of all (or no) faiths. I decided to include six spiritual practices, inviting participants to incorporate one practice each week for six weeks. The spiritual practices that participants were invited to utilize included art, music, nature, body/movement, prayer/meditation and journaling/writing. Each week included a quote about the spiritual practice, some questions to consider, and a suggestion to try that week. Some weeks included links to videos, podcasts, apps or other tools that could help hospice workers incorporate the practices into their daily and weekly routines. The content of each week's practice from the Spirit of Hospice website is detailed below.

Week 1: Art

*"You can't use up creativity. The more you use, the more you have."
-Maya Angelou*

Questions to consider this week:

- Have you ever used art in meditation or as part of your self-care routine?
- What types of art mediums are you most drawn to? (pencils, markers, paint, clay, crochet/knitting, etc.)
- How might creativity and art help you reflect and recover from the work you do each day?

Suggestion to try this week:

Try taking some time each day this week after work to use art as a meditation tool.

Maybe you have a favorite art practice you've neglected lately, and you want to commit to doing that each day this week.

If you're like me and don't consider yourself particularly artistic and could use some guidance, try making mandalas.

Mandala means "circle" and mandalas are often used in reflection or meditation practices. Maybe you've colored mandalas before.

Try making your own mandala each day this week and see what you can learn about yourself at the end of the week as you look back at them.

Materials:

- paper
- crayons, markers or colored pencils, watercolors (you choose your favorite!)

There are no real rules here. You can either draw a circle on a sheet of paper and then take time to fill the circle. OR you can start with a dot in the center of the page and fill out from there.

Link to video from Spirituality and Health if people want to watch instructions for making a mandala

Week 2: Music

"I think music in itself is healing. It's an explosive expression of humanity. It's something we are all touched by. No matter what culture we're from, everyone loves music." -Billy Joel

Questions to consider this week:

- What types of music speak to you the most?
- When was the last time you heard a song that you feel was speaking directly to you?
- How do you like to engage with music? Do you like to sing? Do you play an instrument, or did you take music lessons as a child? What do you think it would be like to make music a part of your daily spiritual practice?

Suggestion to try this week:

- Make a playlist for your week. Maybe you like to use Spotify or Pandora. Take a few minutes at the beginning of the week and put together some songs that bring out some emotion in you. Songs that make you happy, songs that help you reflect, songs that give you energy or make you feel peaceful.
- Listen to this playlist each day as you drive to and from work. Turn the music up, open a window and allow yourself to feel the music moving you.

- Turn on some of your favorite music to liven up mundane tasks like documentation or even chores around the house. Pay attention to what might change within you.
- Ask a coworker or a friend what music moves them or speaks to them.
- I don't expect the music that speaks to me, to speak to you in the same way. But, here's one of the songs that spoke to me throughout some of my harder days as a chaplain several years ago: Link to video of song Hallelujah by Mamuse

Week 3: Nature

"In every walk with nature one receives far more than he seeks." -John Muir

Questions to consider this week:

- Where in nature do you feel most at peace? Is it beside water, mountains, trees, animals, etc.?
- Can you recall a time in your life when you've been in awe of nature?

Suggestions to try this week:

Spend some time in nature this week...

- Go for a walk after work.
- Practice noticing the leaves or the sky as you drive from place to place.
- Stop in a park to eat lunch or just sit for a few minutes between visits.
- Do some of your documentation at the end of the day in a park.
- Roll down the window and feel the air as you drive from place to place.
- Take a few minutes this week to watch the video below about nature and gratitude featured in this Ted Talk by Louie Schwartzberger.

Week 4: Body/Movement

"If we're operating on automatic pilot...we are not sensitive to how we're being influenced by what we eat, where we live, the way we work, and our actions, thoughts, and emotions. When we're not aware of these connections, we also remain baffled why we're sick, tense, in chronic pain, or depressed." -Mirka Knaster

Questions to consider this week:

- How do you experience the symptoms of compassion fatigue or stress in your body? Where does tension generally settle in your body?

- Are you getting enough sleep, exercise, healthy food, water? What are some small changes or improvements you could make this week?

While providing care and support to hospice patients and families many times we can take on their experiences in our own bodies, this is called "somatic empathy." Maybe you've felt physical pain after working with someone experiencing a great deal of pain. Maybe after hearing a particularly difficult story or traumatic story, you've felt your heart racing or you are jumpy or hypervigilant for the rest of the day. Paying attention to the ways you experience stress in your own body can help you learn to regulate these experiences.

Suggestions to try this week:

- Focus this week on noticing and caring for your body as you do your work. Take time to pack healthy snacks and water in the car before you head to your daily visits.
- Commit to moving your body each day. Maybe this means going for a walk before or after work. Going for a run or attending a yoga class. Doing some simple stretches in the car between visits. How might movement become a part of a spiritual practice for you? How can you release the emotions you may have soaked up from your day through moving your body?
- Shake it off: Maybe Taylor Swift had it right. If you've spent any time around animals, you may have noticed that animals shake to release tension or stress. After facing a traumatic, scary or life-threatening situation, animals literally shake and return their bodies to their natural rhythm. Humans have lost this instinct along the way and we go on carrying tension in our bodies. This week give shaking off your day a try. Sure, you may not want to do this in public if you're worried about concerning others... but try shaking your arms and legs, jumping up and down and thinking about releasing all the tension and stress from your body following a work day.
- There's an app for that... try out the Breathe2Relax app which offers some free guides to paying attention to your stress levels and your breathing.
- Body Scan: Try out the video below to practice scanning and being aware of your body (link to video on Body Scan Meditation)

Week 5: Prayer/Meditation

"Just as you wouldn't leave the house without taking a shower, you shouldn't start the day without at least 10 minutes of sacred practice: prayer, meditation, inspirational reading."- Marianne Williamson

**Note: As an interfaith chaplain, my role with hospice patients and families does not involve endorsing a particular religion. Chaplains help people identify the strengths, practices, and/or beliefs that sustain them and bring meaning to this stage of their life.*

Similarly, I hope this page can provide some resources and guidance on prayer and meditation and maybe give you some ideas or techniques you haven't tried before, regardless of your particular faith background. I'll share some of the Ignatian Spiritual Practices around prayer that I have found particularly meaningful in my own spiritual life. Many of these tools will speak of God and a Christian approach to prayer. Feel free to use the tools that are most comfortable to you. While I will use the name God as the source of wisdom, peace and comfort for my own life and work, I hope you will feel free to use whatever name speaks to your experience of the holy or divine.

Questions to consider this week:

- How do you define prayer?
- Do you have a daily practice of prayer or meditation that keeps you grounded in the work that you do? If not, what, if anything, might change if you made time for this each day?
- Have you ever experienced the presence of God or something bigger than yourself while praying or meditating?

Suggestions to try this week:

- As the quote from Marianne Williamson suggests, commit to taking 10 minutes at the start of each day to pray or meditate on the work you will do and the patients/families/coworkers you will encounter.
- There's an app for that: Add an app to your phone to help you pray or meditate on the go.

Meditation App: I like "**Insight Timer**." There are lots of free choices to help you meditate on particular themes. There's even a "mindfulness at work" section

Prayer App: I like "**Pray as You Go**." This was created by Jesuit Media Initiatives and uses passages of Scripture from the Bible. You can listen to it while driving to or from work. There is music, scripture reading and time to reflect on the themes of the day. You can also find guided prayer on topics like Grief, Loneliness, Anxiety and many other themes. You can also find some guided prayers for awareness of the body and breath. As well as some guided Examen prayers.

- Try some different methods of prayer:

The Examen: the daily Examen is a prayer that can be done at the end of each day. It invites us to reflect on the day we've finished, acknowledging the moments of joy and connectedness to God as well as the moments where we might have fallen short. You can read a brief article about the Daily Examen here:

<https://www.loyolapress.com/our-catholic-faith/ignatian-spirituality/examen-and-ignatian-prayer/how-can-i-pray-try-the-daily-examen>.

You can also be guided through the Examen with the use of this video: (link to 5-minute Examen video)

Centering Prayer: Much like meditation, centering prayer involves silence and stillness. Rather than speaking to God, this practice of prayer invites us to simply rest in the presence of God. Sometimes people will choose a sacred word or phrase to return to when their mind wanders. You can read more about centering prayer here: <https://www.contemplative.org/contemplative-practice/centering-prayer/>

- Try some guided meditation. Dr. Michael Kearney is a hospice and palliative care physician who shares several free guided meditations on his website.

Week 6: Journaling/Writing

"Fill your pages with the breathings of your heart." -William Wadsworth

Questions to Consider this week:

- Have you ever kept a journal? Was it helpful to have a place to write and reflect?
- How does it feel to think about journaling each day this week? Intimidating? Daunting? Exciting? Inspiring?

Suggestions to try this week:

- Choose a journal. It doesn't have to be fancy. It could be a nice journal from a store, or simply a spiral notebook or composition book.
- Keep your journal with you each day this week and begin jotting down thoughts, prayers, reflections, memories, etc. It doesn't have to be coherent. Maybe all you write is a sentence a day but practice the discipline of writing each day.
- Gratitude has been proven to profoundly impact our brains. Use your journal to write down three things you are grateful for each day. OR use an app to do this. Try the Gratitude App- it's free and allows you to list what you're grateful for each day and even add pictures. This is a great way to look back at the end of a hard day or week and see that in the midst of it, you still have things to be grateful for.
- Finding a particular patient or family interaction hard to let go of? Try writing about it in your journal and then releasing it as you close the journal.

Participants

The hospice interdisciplinary team is primarily made up of a nurse, social worker and chaplain. In addition to these core team members there are also home health aides, physical therapists, nurse practitioners, medical directors, bereavement counselors, volunteers, music therapists, art therapists, and sometimes other disciplines. While each of these roles are important and make hospice the holistic program it is, for the purpose of this study I chose to invite hospice nurses, social workers and chaplains to participate.

After receiving approval from the Institutional Review Board and publishing the Spirit of Hospice website, I began to recruit participants for the study. The website helped to explain and distribute information about what would be involved, to potential participants. I knew I had access to quite a few hospice workers at my place of employment, but I wanted to draw from a wider area. I asked several of my colleagues with connections to other hospice agencies to distribute my website. I reached out to former Clinical Pastoral Education supervisors. I also utilized social media sites like LinkedIn and Facebook. After posting my website and information about my project on several Facebook groups for Hospice Nursing, Hospice Social Workers and Hospice Chaplains, I received several messages and inquiries.

My study was designed to involve three stages of participation. The three-stage process did pose some challenges for remaining in contact with participants and ensuring that all of the stages were completed. While the intention was to have the same participants in all three stages, some participants did not complete stages two and three. I believe that this challenge speaks to the difficulty of providing interventions to address compassion fatigue. While there was a great

deal of interest in the project, the daily demands of hospice work made it difficult for people to participate in ongoing spiritual practices or schedule a time for an interview.

Research Stages

Stage One: Professional Quality of Life Survey

Upon identifying a potential participant, they were asked to fill out the initial survey which included electronically signing the Informed Consent Form (Appendix 4). Nineteen individuals completed the initial survey and agreed to be a part of the study. Out of those nineteen, seven people were known to me prior to the study and twelve were people I had never met. The nineteen were made up of nine hospice chaplains, three hospice social workers and seven hospice nurses.

The assessment tool used for both the initial survey and follow-up survey was the Professional Quality of Life Scale (ProQOL). This tool, created by Beth Hudnall Stamm and recently acquired by the Center for Victims of Torture (CVT) is the most widely used tool to assess Compassion Fatigue, Burnout and Compassion Satisfaction. “The Professional Quality of Life Scale is the current version of the old Compassion Fatigue Self Test (Figley, 1995).”⁷⁴ The revision turned the sixty-six question self-test into thirty questions. “The ProQOL now consists of three subscales: Compassion Satisfaction, Burnout, and Compassion Fatigue. Initial data suggest that these subscales have excellent internal consistency.”⁷⁵

In Appendix 1, you will find the three handouts that are provided as part of the ProQOL assessment tool. The first page includes the 30 questions participants are asked to answer, along

⁷⁴ B. Hudnall Stamm, *The ProQOL Manual* (Sidran Press, 2005), 8.

⁷⁵ Stamm, 8.

with the introductory instructions for completing the survey. The second page gives descriptions of each sub-category (compassion satisfaction, burnout and secondary traumatic stress) with an explanation of what your score might mean. The third page is used for scoring the ProQOL and includes directions on how to find your score for each sub-category. Appendix 2 shows stage one participant responses for each question on the ProQOL. Reflection on individual questions and themes will be discussed in greater detail in Chapter Four.

Having gone through quite a few revisions and scrutiny by many scholars, the ProQOL is considered a very accurate tool for rating Compassion Satisfaction, Burnout and Compassion Fatigue. Participants are asked to answer the thirty-question assessment based on their experiences in the past thirty days. While I believe the ProQOL is a beneficial tool as a self-assessment, I question its effectiveness as a research tool. As with any survey tool, participants are asked to self-assess. While some questions are posed in positive ways such as question six, “I feel invigorated after working with those I [help]”⁷⁶ other questions such as question thirteen, “I feel depressed because of the traumatic experiences of the people I [help]”⁷⁷ may have a negative bias or stigma attached to them. While using the tool for self-assessment can draw someone’s attention to how they are feeling in a given month and facilitate positive changes, as a research tool I question the ability of participants to self-assess without self-judgment.

Several times in my research I encountered a participant who scored high on Compassion Satisfaction (CS) and very low on Burnout (B) and Compassion Fatigue (CF), yet when I interviewed them I heard stories of how tired they feel all the time and how overwhelmed and bogged down they feel by the demands of their work in hospice. While discussions of Compassion Fatigue are increasingly common among helping professionals, there does still seem

⁷⁶ “Professional Quality of Life: Elements, Theory and Measurement,” n.d., www.proQOL.org.

⁷⁷ “Professional Quality of Life: Elements, Theory and Measurement.”

to be a stigma and a sense of shame involved with confessing the feelings of sadness, exhaustion and ineffectiveness that accompany Compassion Fatigue. Self-reporting these symptoms on a tool that is used only for self-assessment is one thing but reporting them on a survey which will be read and evaluated by a fellow hospice employee or researcher could pose challenges for self-disclosure.

During interviews, I also encountered participants who shared numerous positive stories of their work in hospice and who have extremely healthy coping mechanisms but scored high levels of Compassion Fatigue and Burnout on the ProQOL. One such participant, Nancy, a hospice social worker who had just finished a difficult week of hospice work, acknowledged, “I really shouldn’t have taken that survey today!” Even the ProQOL manual seems to acknowledge how answers could shift on a given day, “your score may reflect your mood; perhaps you were having a ‘bad day’ or are in need of some time off.”⁷⁸ Despite its limitations, I found many participants acknowledging that they found it helpful to take the ProQOL and increase their awareness of how they have been doing. For that reason, along with the lack of any other well-respected tools to assess Compassion Fatigue, Compassion Satisfaction and Burnout, I found the ProQOL survey an appropriate tool for this study.

Overall, the nineteen participants who were surveyed in stage one experienced High levels of Compassion Satisfaction, Moderate levels of Burnout and Low levels of Compassion Fatigue. The scores for Compassion Satisfaction ranged from a low of 28 to a high of 50, making the average of all scores 42, just barely making it into the High category (a score between 23-41 would qualify as Moderate). The overall scores for Burnout ranged from a low of 13 to a high of 33, with an average score of 23, a Moderate level, again missing the next category by only one

⁷⁸ Stamm, *The ProQOL Manual*, 24.

point (a score of 22 or less would be Low). The overall scores for Compassion Fatigue ranged from a low of 13 to a high of 42, with the average of scores being 26, placing it in the Low category.

Stage Two: Interviews

Upon receipt of the initial survey, participants were invited to schedule an interview either in person or virtually, utilizing Skype, FaceTime or a phone call. During each interview, I wrote the date upon which I would contact the participant and ask them to complete the final stage, the follow-up survey. All interviews were completed during the months of September and October.

Upon follow-up with each person who completed the initial survey, eleven people agreed to the second stage, an interview. I completed five of these interviews in person at a location of the participant's choosing. This included several restaurants and coffee shops where participants took a break during or after their work day. Two interviews were done using FaceTime video calling and the remaining four were completed over the phone. Participants were told that an interview would be 50 minutes long. Most participants scheduled the interview during a work day while they were driving in their cars or during a lunch break. At times it seemed this may have led to participants feeling distracted or rushed. Only two interviews used the entire 50-minute allowance, with most interviews being between 20-30 minutes.

The interviews I completed involved four pre-determined questions followed by a debriefing question which was added at the suggestion of the Institutional Review Board, to assess for any emotional distress. These were semi-structured interviews that allowed me the flexibility to ask follow-up questions rather than adhering strictly to the pre-determined

questions. Upon analysis of the interviews, I listened for themes that had been addressed and any noteworthy quotes. I experimented with the order in which each question was posed. Originally, I asked about a story first and then asked participants to tell me what led them to hospice work. However, I found after the first three interviews that switching question one and two seemed to create more space and openness in the participants responses. The questions I asked each participant were selected carefully. While I knew that I wanted to understand the challenges and frustrations experienced by hospice workers, which led to compassion fatigue, I also wanted to nurture compassion satisfaction by allowing space to reflect on the positive aspects of hospice work.

Interview Question 1: What led you to become a hospice worker?

In my first two interviews, I asked this as my second question. However, I found that opening up with this question seemed to make the participants more comfortable. Focusing on how they ended up where they are and sharing the facts about that, seemed to be a comfortable place to begin and allowed trust and openness to be established between myself and the participant. This question also provided me with background information that allowed me to understand the person I was talking with a little better. Participants seemed to enjoy reflecting on the early days of their hospice careers and a time when they felt this would be the right career for them. Bringing these things to mind seemed to set the stage well for the second question.

Interview Question 2: Can you tell me a story of a time when you felt most fulfilled or satisfied with the work you do in hospice?

I phrased this question carefully, in order to allow space for participants to tell a story. While I could have phrased the question without including the word story, my hope was that participants would sense an openness and feel that they could use the time and space in the interview not just to report facts, but to share stories about their work. Studies have shown that the best way to decrease compassion fatigue is to nourish compassion satisfaction,⁷⁹ so this question, combined with the first question, was used to elicit feelings of compassion satisfaction in participants. Generally, participants were able to quickly call to mind this story. There were a few participants who took a few minutes to decide which story stood out to them. Several participants shared that they found it very meaningful to reflect on these stories, as they can often get overshadowed by the daily demands of their work.

Interview Question 3: Do you have any current or past practices that you do regularly to help you cope with the work you do in hospice?

This question provided helpful information about participants' comfort and experience with spiritual practices and self-care practices. While the answers to this question were very informative, I also learned a great deal from the initial silence this question was sometimes met with. Several participants acknowledged after a pause, that they don't have anything like this or had not really thought much about incorporating any regular practices or rituals into their days. This question also opened up space for participants to share about their spirituality. In response to ProQOL question 15, *I have beliefs that sustain me*, 9 participants responded *very often*, 6 responded *often* and 4 responded *sometimes*. These responses make it clear that the majority of participants find comfort and strength in their beliefs. This was further illustrated in the

⁷⁹ Alkema, Linton, and Davies, "A Study of the Relationship Between Self-Care, Compassion Satisfaction, Compassion Fatigue, and Burnout Among Hospice Professionals."

interviews, as participants shared about their strong faith, prayer practices, routine of listening to worship music and/or sermons in the car, and church or Bible study involvement.

Interview Question 4: If your manager came to you one day and offered to grant you three wishes for your hospice work, what would they be?

Drawing on some of the principles of Appreciative Inquiry, I used a variation of a common appreciative question “wishes for/images of the future”⁸⁰ for this question. While I wanted to know what participants found most challenging about their current work environment, I phrased it in a more imaginative way. While I wondered about how participants would respond to this imaginative exercise, this question provided some very rich information that I do not believe I would have elicited with a different method of asking the question. Several participants laughed and asked how realistic their wishes needed to be. This question seemed to allow participants the opportunity to dream a little in a way that was almost playful. One notable theme that came out of this question was the difficulty some participants had making wishes for themselves. Often the initial response to this question was something they wished for the patients and families they work with. Some people wished for more resources and supportive therapies they could offer to their patients. Others wished that their patients would experience love and comfort in their final days or that there were programs to help patients final wishes come true, similar to the Make a Wish program. One participant noticed this dynamic and acknowledged that it was often easier to wish things for other people than it was to make wishes about themselves.

⁸⁰ Tim Sensing, *Qualitative Research: A Multi-Methods Approach to Projects for Doctor of Ministry Theses* (Eugene, Or.: Wipf & Stock, 2011).

Alice, a chaplain, was one of many participants who wished for a raise, laughing as she said, “Maybe I should ask to be paid what I’m worth and then I’d see what happens, whether it goes down or up.” Several other participants acknowledged that while they love the work they do, they do sometimes wish they were paid more. Two hospice chaplains wished that there was some kind of sabbatical program like there is in parish ministry. Many people acknowledged that after several years, they could really use a break to pursue education or further learning, or just some time to work through the cumulative grief. Several people wished that there was more support for hospice employees seeking licensure or advanced degrees. While that is encouraged in nursing, several chaplains and social workers mentioned that they did not feel as supported in the outside things they were doing to better themselves. This question brought out some important themes in an almost playful way, as people made their wishes without focusing on whether they were realistic or not.

Interview Question 5: Debriefing- How are you feeling after answering these questions and/or the survey questions? Is there anything you would like to discuss, or any unpleasant emotions that came up for you while answering these questions?

The debrief question was designed to address any emotional needs that may have come up for participants during their participation in the first two stages of the study. What I did not anticipate was the way this question would allow participants to reflect on their experience of the study so far. Some participants shared about the new awareness they felt as a result of the survey and interview, while others shared about research that they had done on compassion fatigue in their own career and educational journeys.

Stage Three: Follow-up Survey

After the interview, the participant was invited to spend the next six weeks following the spiritual practices found on the Spirit of Hospice website. At the end of six weeks, I would send a message to the participant to thank them for their participation in the study and ask them to fill out the follow-up survey. The follow-up survey included the same 30 questions from the ProQOL assessment tool. In addition, it included questions to assess which spiritual practices participants used, how participants experienced the Spirit of Hospice website, how likely they are to incorporate the spiritual practices into their daily/weekly routines, what their company has offered to address compassion fatigue and any other feedback they would like to offer.

Of the eleven participants I interviewed, ten people returned the follow-up survey. The remaining participant was sent a reminder message on two occasions, but I did not receive a response or survey back. The follow-up survey included another opportunity for participants to report any distress they may have experienced as a result of participating in the study. If participants answered that they had experienced any distress they were directed to the second part of the survey where they would find a Debrief Form (Appendix 4) and be given the option to schedule a follow-up conversation with me for further discussion and/or support.

Results

Table 3.1. shows the results of the Spirit of Hospice study. The eleven participants who completed Stage 1 and Stage 2 are each given a pseudonym. Ten of the eleven participants completed Stage 3, and the one participant who did not return the follow-up survey is indicated in the table. The table shows each participant's job title, how many years they've worked in hospice, their ProQOL scores for each category (Compassion Satisfaction, Burnout and Compassion Fatigue) in Stage 1, the spiritual practices they used in Stage 2, their ProQOL scores for each category (Compassion Satisfaction, Burnout and Compassion Fatigue) in Stage 3, and the amount by which their scores increased (↑), decreased (↓) or stayed the same.

The scale used to measure Compassion Satisfaction, Burnout and Compassion Fatigue, assigns scores to categories- low, moderate and high (see Appendix 1). For Compassion Fatigue, an **increase** in scores is a positive thing, therefore if a score increased between the initial survey and the follow-up survey, it means that a participant's level of Compassion Satisfaction improved. For Burnout and Compassion Fatigue, a **decrease** in scores is a positive thing and if a score increased, it meant the participant was experiencing *more* symptoms of Compassion Fatigue and Burnout.

Table 3.1- Spirit of Hospice Study Results(Note: CS= Compassion Satisfaction, B= Burnout, CF= Compassion Fatigue)

Participant Pseudonym	Job Title	Years in Hospice	ProQOL Scores Before (Stage 1)			Spiritual Practices Used (Stage 2)	ProQOL Scores After (Stage 3)			Changes in ProQOL Scores
			<u>CS</u>	<u>B</u>	<u>CF</u>		<u>CS</u>	<u>B</u>	<u>CF</u>	
A- Elise	MSW	4.5	28	33	37	Art, Music, Nature, Body/Movement, Prayer/Meditation, Journaling	28	25	28	<u>CS</u> : Same <u>B</u> : ↓ by 8 <u>CF</u> : ↓ by 9
B- Donna	RN	4	48	14	13	Nature	44	15	18	<u>CS</u> : ↓ by 4 <u>B</u> : ↑ by 1 <u>CF</u> : ↑ by 5
C- Rebecca	CH	5	40	22	31	Art, Music, Nature, Body/Movement, Prayer/Meditation, Journaling	40	24	29	<u>CS</u> : Same <u>B</u> : ↑ by 2 <u>CF</u> : ↓ by 2
D- Wanda	CH	1	43	27	31	Art, Music, Nature, Body/Movement, Prayer/Meditation, Journaling	39	24	25	<u>CS</u> : ↓ by 4 <u>B</u> : ↓ by 3 <u>CF</u> : ↓ by 6
E- April	RN	2	50	17	19	<i>Did not complete follow-up survey</i>				
F- Nancy	MSW	3	30	30	26	Music, Prayer/Meditation	38	20	22	<u>CS</u> : ↑ by 8 <u>B</u> : ↓ by 10 <u>CF</u> : ↓ by 4
G- Sally	MSW	1	48	13	21	Music, Nature, Body/Movement, Prayer/Meditation	48	16	21	<u>CS</u> : Same <u>B</u> : ↑ by 3 <u>CF</u> : Same
H- Jerry	CH	6.5	41	24	23	Music, Prayer/Meditation	38	26	21	<u>CS</u> : ↓ by 3 <u>B</u> : ↑ by 2 <u>CF</u> : ↓ by 2
I- Alice	CH	6	41	23	24	Music, Nature, Body/Movement	40	25	21	<u>CS</u> : ↓ by 2 <u>B</u> : ↑ by 2 <u>CF</u> : ↓ by 3
J- Terry	CH	5	45	20	18	Music, Prayer/Meditation, Journaling/Writing	41	28	18	<u>CS</u> : ↓ by 4 <u>B</u> : ↑ by 8 <u>CF</u> : Same
K- Laura	CH	1	45	14	18	Music, Prayer/Meditation	45	17	18	<u>CS</u> : Same <u>B</u> : ↑ by 3 <u>CF</u> : Same

The last column in Table 3.1 shows the changes that occurred in people's ProQOL scores between Stages 1 and 3. It is evident that quite a few changes occurred, some scores changing by only a few points and others changing significantly. Three participants stayed at the same level of Compassion Satisfaction (CS) throughout the study, five participants experienced a decrease (↓) in Compassion Satisfaction and one participant experienced an increase (↑) in Compassion Satisfaction.

For Burnout (B) and Compassion Fatigue (CF), a decrease in scores between Stage 1 and Stage 3 indicates an improvement, while an increase in scores indicates a worsening of symptoms associated with Burnout and Compassion Fatigue. All ten participants experienced some change in their levels of Burnout (B) between Stages 1 and 3. Three participants experienced a decrease (↓) in Burnout and seven participants experienced an increase (↑) in Burnout. While results indicated worsening symptoms of Burnout in participants, scores for Compassion Fatigue appeared to have improved. Three participants stayed at the same level of Compassion Fatigue (CF) between Stages 1 and 3. Six participants experienced a decrease (↓) in Compassion Fatigue, while one participant experienced an increase (↑).

There were two participants with notable changes in their scores following their participation in the study. Elise, a hospice social worker, stayed at the same level of Compassion Satisfaction but her Burnout score decreased by 8 and her Compassion Fatigue score decreased by 9. Nancy, another hospice social worker, saw an increase of 8 points for Compassion Satisfaction, and a decrease of 10 points for Burnout and 4 points for Compassion Fatigue. Most other participants saw less drastic changes in their scores. However, for several participants, their scores moved enough to bump them to a different level in each category. Chaplains Jerry and Alice, and social worker Nancy, moved from Moderate levels of Compassion Fatigue to

Low. Two chaplains, Wanda and Terry, moved from High Compassion Satisfaction to Moderate. Chaplains Rebecca and Terry, moved from Low Burnout to Moderate, with MSW Nancy doing the opposite and moving from Moderate Burnout to Low.

These fluctuations in scores are predictable, as participants are instructed to answer the ProQOL questions in relation to what they have experienced in the past 30 days. As noted in my discussion of the ProQOL survey, this could mean that participants are self-assessing based on their mood or possibly even based on the kind of day they are having. It is impossible to know what other changes have occurred in the life of each participant in the six weeks they participated in this study. It is difficult to draw major conclusions about this data without knowledge of the other variables occurring in the lives of participants during this study. However, it does seem notable that nine out of the ten participants who completed Stages 1, 2 and 3 of the study experienced either decreased levels of Compassion Fatigue or maintained their current level throughout the study. Only one participant, Donna, experienced an increase in Compassion Fatigue and she was the only participant who used only one of the spiritual practices provided in Stage 2.

It is somewhat surprising to see the changes in Compassion Satisfaction that occurred for several participants. Many studies have spoken of the impact that nurturing Compassion Satisfaction can have on the experience of Compassion Fatigue in practitioners. One writer states, “compassion satisfaction mitigates the negative effect of compassion fatigue and burnout and is a prime motivator for continued service. For those in the helping professions, the positive feeling that comes from compassion satisfaction sustains, nourishes, and contributes to the mental, physical, and spiritual well-being of the professional which in turn promotes workplace

health.”⁸¹ With this in mind, I intentionally selected interview questions and included content on the Spirit of Hospice website that sought to nurture the feelings of Compassion Satisfaction in participants. Due to this, I would have anticipated some increases in Compassion Satisfaction following this study. However, I only saw one participant with increased Compassion Satisfaction while all others either stayed the same or decreased. With the majority of people experiencing decreased Compassion Fatigue, I would have expected to see increased Compassion Satisfaction, but in this small sampling of hospice workers, that did not appear to be the case.

The follow-up survey in Stage 3 contained the same ProQOL assessment as the initial survey in Stage 1, as well as questions about which spiritual practices participants used (see figure 3.1.), how they experienced the Spirit of Hospice website (see figure 3.2.) and whether or not they felt they would incorporate any of the spiritual practices into their normal routines (see figure 3.3.). I included a question about what their employer may have offered to address the emotional and spiritual effects of working in hospice (see chart 3.1.). There was also space to offer any additional feedback, suggestions or experiences they had as a result of participating in the study (see chart 3.2.).

⁸¹ Cynthia Harr, “Social Work & Christianity.”, 86.

Figure 3.1.

Which spiritual practice guides included with this study did you use in the past six weeks:

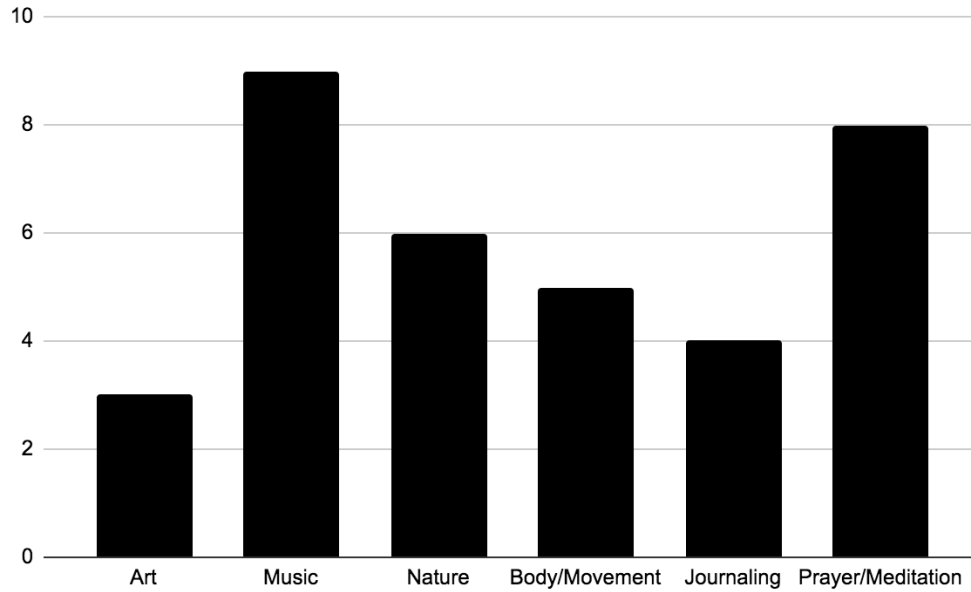


Figure 3.2.

I found the Spirit of Hospice website helpful and easy to use:

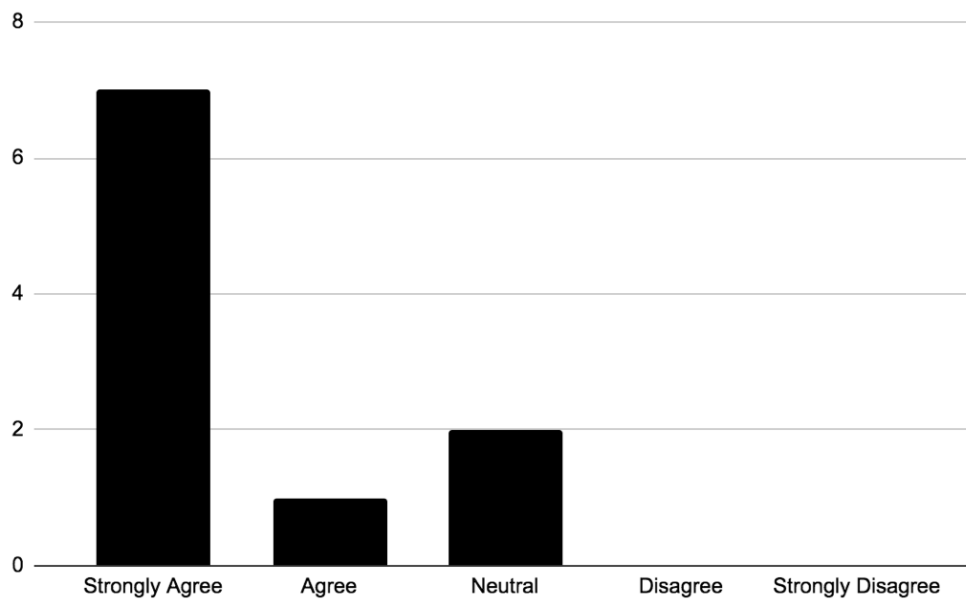


Figure 3.3.

Following this study, I've learned some things I will incorporate into my daily/weekly routine as a hospice worker.

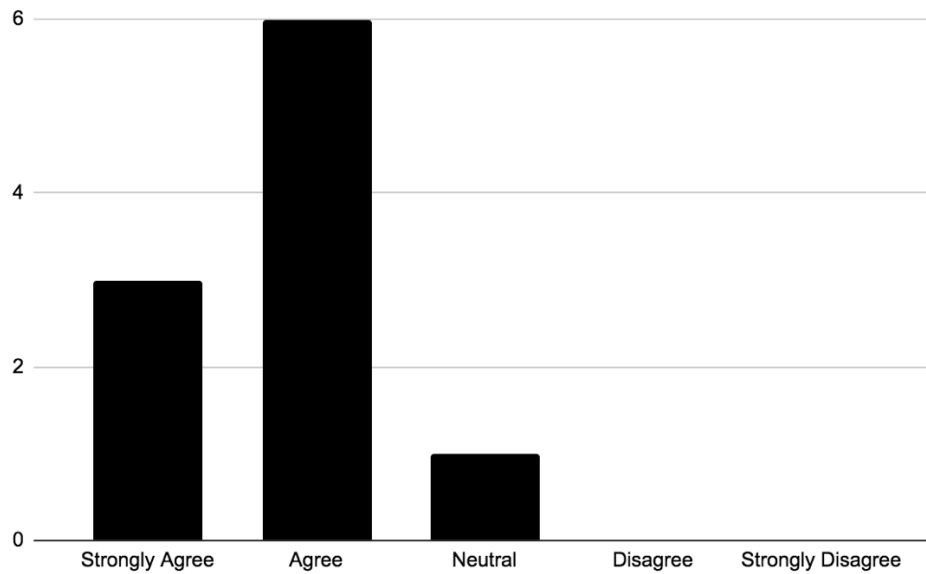


Chart 3.1

What (if anything) has your company done to address the emotional and/or spiritual effects of hospice work on employees?

-
- Nothing!
 - Weekly mindfulness emails
 - Decreased workload
 - Encouraging time off, training on self-care
 - Not much support offered from the company
 - Nothing at this time. (x2)

Chart 3.2

Is there anything you'd like to share about your experience with the study? Feedback, suggestions, experiences, etc.

-
- Deeply needed in our field!
 - A week for each topic was not long enough. I hope to incorporate some of these practices on an ongoing basis
 - No

All participants reported using at least one of the spiritual practices. Three participants reported using all six practices. Music was the most widely utilized spiritual practice with nine participants reporting that they utilized it. This was also apparent in my conversations with hospice workers. Several people spoke of the long drives between patients and how that alone time in the car gives them opportunities to listen to music, breathe, and get centered before their next visit. Art was the least utilized spiritual practices as reported on the follow-up survey. This was one of the most involved spiritual practices on the website and required time at home or outside of work hours. Prayer/Meditation was used by eight of the participants. Many people spoke during their interview, of the important role that prayer and meditation play in their daily routines. Overall, the feedback regarding the Spirit of Hospice website was positive and the majority of participants reported learning something they would incorporate into their routines. The feedback provided regarding what companies have offered to address compassion fatigue in their staff was also informative and highlights some of the frustration hospice workers have about the lack of interventions provided in their workplace. (charts 3.1. and 3.2.)

Chapter Four: Analysis of Themes

As a result of the eleven interviews I completed I was able to hear quite a few stories about the experiences of hospice workers. While each interview was unique, upon analysis of the interviews and ProQOL survey, I identified four major themes which I will expand on in this chapter.

Theme One

If the Shoe Fits: Hospice as a Calling

Hospice is an odd choice for a career. People think we're weird to work in a profession that deals with death every day. For us, that's totally normal. People ask us, "Why do you work with dying people? Doesn't it make you sad?"

Why do we work with dying people? I think a lot of end of life professionals ask themselves that every day. It's not that it makes us sad exactly, but sometimes we grieve over our patients, the loss that their families feel, and our own inability to change so many of the things that happen to them.

Including the deaths.

Why would anybody do that? It's not because of the regulations. It's not because of the surveys or the site visitors. It's not because of quality measures, HIS questions, compliance, or position statements. We don't do this work because of our credentials, degrees, or certifications.

We work with the dying because we care. We care about what happens to people when they're going through the intensely personal experience of a death, either their own or the death of someone they love.

It's because we were made to walk with our patients on their journeys. They're going to the place everybody goes to when his time comes to an end. We're not scared of death. We can witness things nobody talks about at parties and keep right on moving.

It's not that working with the dying doesn't affect us. We grieve but we don't show it. We cry but we wash our faces so we can be with the next family, the next patient. We counsel, comfort, embrace, teach, and guide.

Hospice professionals show up for the next death, and the next, knowing that they make a difference. They have skills and gifts and they're willing to use them.⁸²

*"You did not choose me, but I chose you and appointed you so that you might go and bear fruit- fruit that will last- and so that whatever you ask in my name the Father will give you."
-John 15:16*

Hospice workers are often quick to tell you that the work they do is more than simply a job or a paycheck, it is a calling. I have heard this sentiment many times in my years as a hospice chaplain and I heard it again during these interviews. In my conversations with eleven hospice workers, my first question asked participants to tell me how they ended up working in hospice. Donna, a nurse, answered, *"It was a calling, Hospice just felt right."* Elise, a social worker, also referred to the feeling of hospice just being the right fit. *"I went to my first palliative care meeting as an intern in the hospital and I loved it. It just felt like this really weird fit."* Rebecca, a chaplain, echoed this theme, *"I'm comfortable around difficult conversations and situations that a lot of people aren't comfortable with, so I thought maybe there was something to that. It was an opportunity that landed in my lap."*

For many participants, hospice was a second career. Some people came from hospital settings and expressed gratitude for the different environment hospice offers. Nancy, a social worker shared, *"I was drawn to the spirituality of hospice. Because in the hospital it's like walking on eggshells. It's not encouraged really to talk about spirituality, whether the patient follows a certain religion or not, it's really not encouraged. So that was one thing that brought me to it."* April, a chaplain who had spent most of her career working in acute care hospitals as well as a children's hospital replied, *"I didn't think I would like hospice. I didn't think I would*

⁸² Bauer, Helen, "Remembering Your Why," *The Heart of Hospice* (blog), November 3, 2019, <http://www.theheartofhospice.com/2019/11/03/remembering-your-why/>.

be able to discipline myself because all my life I'd worked 8-5 or 9-5 so I didn't know if I could plan my own day. But now I don't think I'd have it any other way. I don't know of anything I'd rather do."

Several participants came to hospice from nonprofits, other helping professions or parish ministry. Jerry, a hospice chaplain, shared about his work in hospice as opposed to parish ministry, *"I enjoy it very much. Some of the times it's very difficult. I enjoy parish ministry, I enjoy preaching, I enjoy officiating at communion on Sundays and those kinds of things. I've missed that. But I enjoy getting to know diverse populations of folks and patients that I'm ministering to."* Two participants shared about friends who heard of an open hospice position and called them to ask if they had ever considered working in hospice. While neither person had considered hospice prior to those phone calls, both decided to apply and are very happy with that choice. Wanda, a chaplain who had previously worked in multiple social service settings simply answered, *"I just thought I would like hospice."*

Some participants shared personal stories that led them to the hospice profession. April shared about her first encounter with hospice at the age of 13 and the way that impacted her desire to be a hospice nurse. *"My grandmother was on hospice when I was really young, like 13. And I don't know... I think I've always had the personality that would kind of fit well with doing this work. Just like a lot of compassion and all that kind of stuff. My grandma and I were super close and I just kind of saw the way that they took care of her and that just kind of made me want to take care of people, you know, people's loved ones."* Donna had worked as a nurse for many years but went into hospice work after she lost her husband very suddenly. She recalled in our interview how that experience has shaped her and given her a different perspective. Terry shared

a story that shaped her, from her time in Clinical Pastoral Education (CPE) while she was training to be a chaplain.

When I did my CPE, I met a man with a rare type of cancer that created a tumor on the side of his face and his facial features became like stone. During our visit he told me that he was ready to die, and as a Christian I thought, we pray for a miracle until the end, even though we understand we might not get the miracle, we still pray for and expect the miracle. So, I was very diligent about telling him to keep hope alive and he was very insistent that he was very much ready to die! He said he had fought long enough, and he had come to terms with it. I was really distraught at this Christian who had given up hope so I wrote it up as a verbatim [case study] and presented it... and my team tore me apart, particularly my supervisor. They told me I had no idea what it took for a person to come to terms with dying and that they should be able to die with their faith intact, and with dignity, and with an understanding and support that it was okay for them to be okay with dying. I kind of decided after that journey that I wanted to be able to sit with people and hear them say that, 'it sucks that I'm dying... but I'm okay with it.'

While the reasons and experiences were as varied as the participants I interviewed, it was clear through my conversations with hospice workers, that each person considered this to be a profession they were drawn to and uniquely qualified for. Participants acknowledged that there are often hard days or hard seasons, but most said they were grateful for the opportunity to work in hospice. These feelings were also evident in some of the ProQOL survey questions. On question 22, (figure 4.1.) *I believe I can make a difference through my work*, 9 out of 19 participants answered, *very often*, 8 answered *often* and 2 answered *sometimes*. Question 24 (figure 4.2.), *I am proud of what I can do to [help]*, had similarly positive scores with 10 of the 19 participants responding, *very often*, 5 responding *often*, 3 responding, *sometimes* and 1 responding, *rarely*. The last question on the ProQOL assessment received no responses of *never* or *rarely*. Question 30 (figure 4.3.) states, *I am happy that I chose to do this work*, 9 out of 19 participants answered, *very often*, 7 answered *often* and 3 answered *sometimes*.

Figure 4.1.

ProQOL Question #22: I believe I can make a difference through my work.

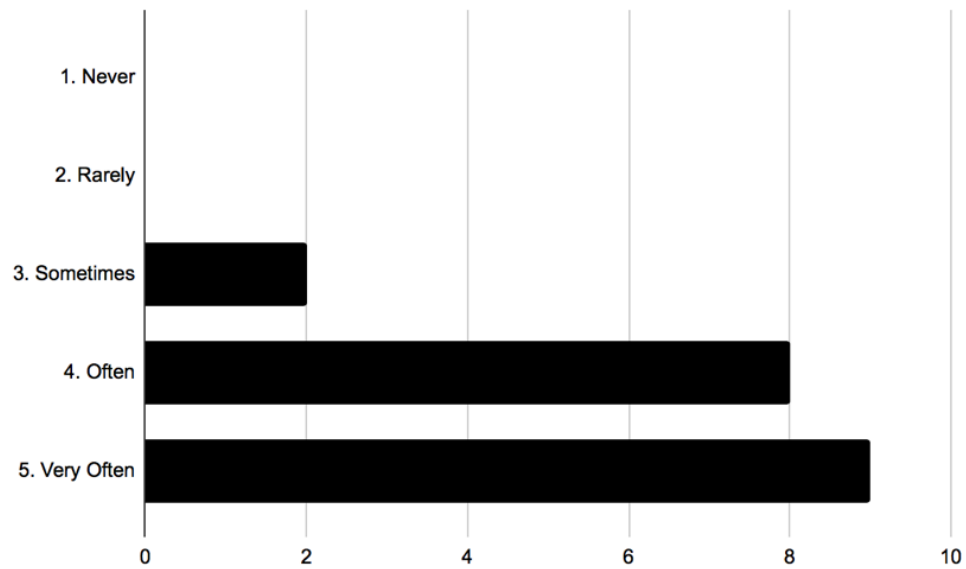


Figure 4.2

ProQOL Question #24: I am proud of what I can do to [help].

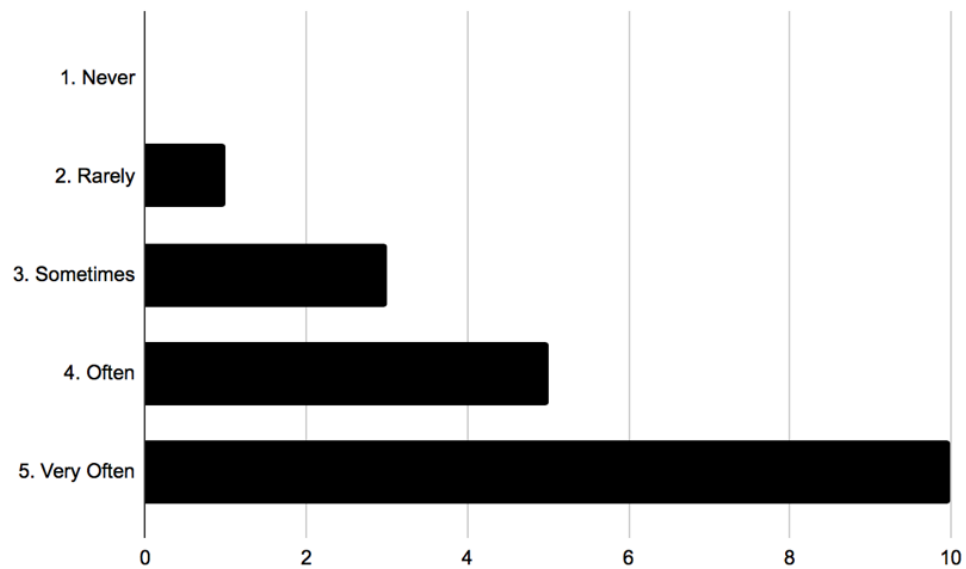
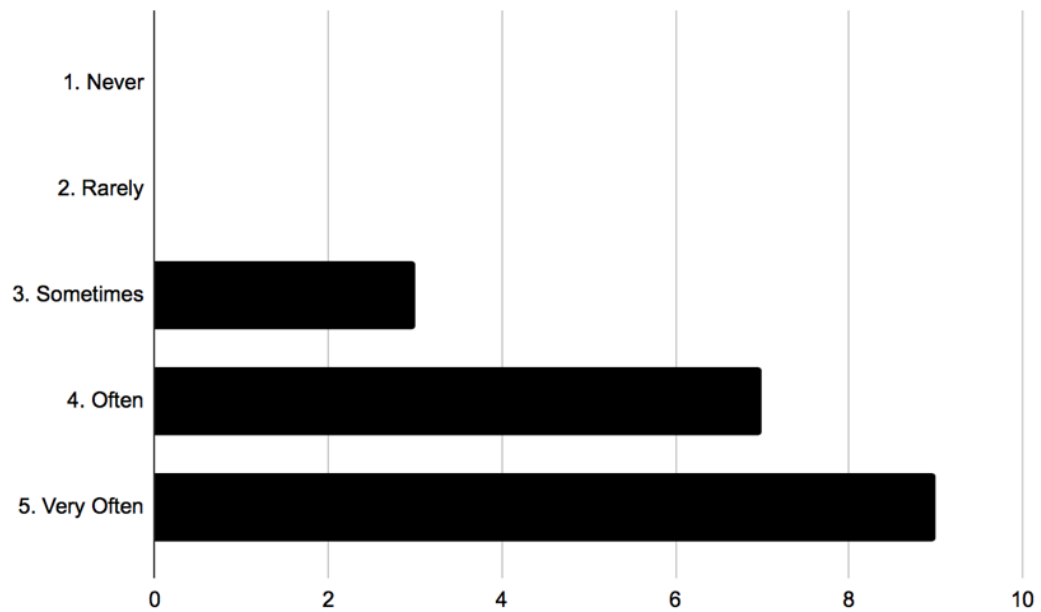


Figure 4.3

ProQOL Question #30: I am happy that I chose to do this work.



Theme Two

Love your Neighbor as Yourself

³⁰ *Love the Lord your God with all your heart and with all your soul and with all your mind and with all your strength.'*

³¹ *The second is this: 'Love your neighbor as yourself.'*

There is no commandment greater than these."

Mark 12:30-31

*"Self-knowledge and self-love are the fruit of knowing and loving God. You can see better than what is intended by the great commandment to "love the Lord your God with all your heart, with all your soul, and with all your mind, and to love your neighbor as yourself." Laying our hearts totally open to God leads to a love of ourselves that enables us to give wholehearted love to our fellow human beings. In the seclusion of our hearts we learn to know the hidden presence of God; and with that spiritual knowledge we can lead a loving life."*⁸³

-Henri Nouwen

"We hear the same old thing... Oh, you gotta take care of yourself... but you know, we as nurses hear that all the time but we're caregivers, and we just have a difficult time taking care of ourselves the way we take care of our patients. I think it would be better off to say... take care of yourself the way you take care of your patients."(Donna, hospice nurse) This tension between caring for others and caring for self was illustrated clearly through two of my interview questions and several of the survey questions on the ProQOL.

It's no surprise that hospice workers consider themselves to be very caring people as illustrated in response to ProQOL question number 29 (figure 4.4.) with 12 out of 19 participants answering *very often* and the remaining 7 participants answering *often*. ProQOL question number

⁸³ "Lead a Loving Life," *Henri Nouwen Society* (blog), n.d., <https://henrinouwen.org/meditation/lead-a-loving-life/>.

12 (figure 4.5.) states, *I like my work as a helper*. For this question, 9 out of 19 participants answered *very often*, 8 answered *often* and the remaining 2 answered *sometimes*.

Figure 4.4
ProQOL Question #29: I am a very caring person.

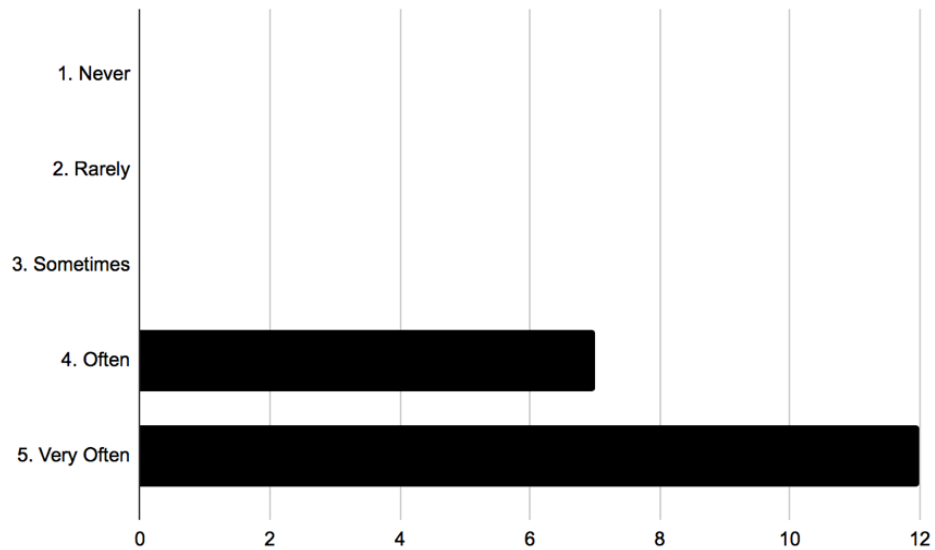
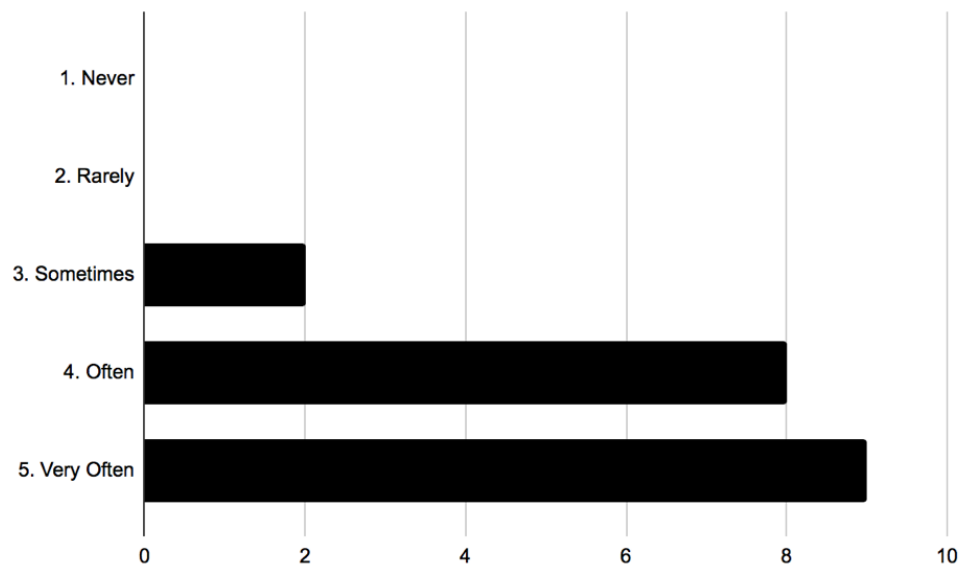


Figure 4.5
ProQOL Question #12: I like my work as a helper.



This point was further illustrated in the numerous stories I heard during the interviews. My second interview question asked participants to share a story about a time when they felt most fulfilled or satisfied with their work in hospice. There was generally little hesitation before answering this question. Participants could quickly call to mind the highlights of their work. The patients and families they have cared for have clearly left a lasting imprint on the minds and hearts of hospice workers. Alice a hospice chaplain answered, *“When I feel the most fulfilled is when I’ve really connected with the person and become friends with them and loved them as though they were going to live forever. I don’t think about them dying, I give myself totally to that relationship, knowing that they will die. It’s when a relationship occurs that is surprising.”* April, a hospice nurse early in her career shared about a young patient and family she cared for,

I had a pretty young patient and I got really close to her. As sad as it was that she was dying, she was really comfortable at the end and I came every day and the family really came to terms with everything. I guess it was fulfilling because we were all on the same page and we were all really close and she ended up being really comfortable at the end. I actually have a little journal book and I have a certain amount of people that I’ve written down, the people who have affected me the most that I don’t ever want to forget. That’s one of the people that I wrote down.

Rebecca, a hospice chaplain spoke about being with a family, as a patient she had cared for entered the active dying phase.

A patient I had for a year. I was going every two weeks and really got to know his wife and other members of the family. We just really seemed to click. The time surrounding his death was really meaningful and made me feel like I’m doing the work I’m supposed to be doing. When he was actively dying the family called me to come over and I just sat with them for hours. Just kind of being welcomed and invited into time that was for the family... but I felt like I was part of the family. It just made me feel like I’m in the right job.

Elise, a hospice social worker talked about being with the family of a patient regularly during their loved ones stay on hospice, *“Just being there meant something to them.”* Nancy, a hospice

social worker recalled a time when she was able to help the young son of one of her hospice patients.

One patient [who], her son was really overwhelmed with all of it. He was younger. It was just him, although he had friends and extended family, but it was just him, and he was just having trouble balancing caring for his mom and his own life. So, it was just, by the time the patient passed, being able to see how our visits were able to help him to kind of focus on tasks and just kind of meet him where he was at that particular time. And then by the end of it just to hear him talk about how appreciative he was for my help and for the visits. Where really during the visits, we never really talked about the patient, it was more talking about him and helping him to get through whatever that day brought him. That was one time where at the end I felt like I was helpful and had accomplished something.

Jerry, a chaplain, reflected on how one patient became a friend and encourager when he was working on his Doctor of Ministry project.

There was a gentleman who was a patient of mine. He got admitted to hospice with heart issues and they told him he would live about 6 months, but he lived for two and a half years and he was on hospice that whole time. He and I became really good friends. He was an older gentleman and he had had a framing shop in a small town for years that he had turned over to his son. But he had the old shop and the new shop. He gave his son the new shop and he had the old shop. He'd still go over to the old shop and get some lumber and build bird houses or he'd still frame some stuff. And so... I would go visit with him and we'd sit out on the front porch of the old shop and we'd talk about life and talk about ministry. When I started my Doctor of Ministry project he said, 'I think that's a good thing, I think you need to do that.' And so, when I submitted my DMin he was mentioned in the acknowledgments and I actually helped officiate his funeral when he died.

Terry, a chaplain, didn't recall a particular patient but reflected on the moments that are the most meaningful to her in her hospice work.

I think the times when people are ready to die and nobody understands that, and sometimes I'll hear, 'what's taking so long?' or 'why won't God just let me die?' and of course we don't have the answers to those questions but again, being able to sit with people in their moments of, 'this really sucks' or 'I really hate this', those are the most fulfilling ones for me, where I can let them say that to the 'religious authority'(uses air quotes) and not be judged but be able to say that.

In stark contrast to the immediate answers I received to my second interview question, my third question, *what current or past practices do you have to help you cope with working in hospice*, was often met with a long pause or silence. Following a pause, I sometimes heard participants talk about exercise and physical fitness, massages, going to therapy, prayer and meditation, journaling, listening to music and using their long drives to decompress. However, many participants acknowledged that they don't have practices like this, or struggle with incorporating regular practices into their daily routines. Donna, a hospice nurse laughed and answered, *"I cry, and then I move on."* Elise a hospice social worker acknowledged that she doesn't always take the time to think about how she is coping with her work, *"I don't think about these things enough... I just go through the motions and just do my stuff and go, go, go and I don't think about what's happened and how it's affecting me or that I should be doing something to take care of myself until I have the days when I'm curled up in a ball crying. Because it is our job... but it's different."* A couple of participants acknowledged that participating in this study and answering the ProQOL questions helped them pause and think about how they were doing. April shared,

I liked taking the survey, it kind of made me think a little more about how I'm feeling. It kind of becomes monotonous sometimes so it made me think a little more about how I'm feeling. Overall, I love being a hospice nurse. In September I had a really bad month but mostly it is kind of ups and downs. I know there's an end to it when I'm in a horrible slump with things. It's taken me two years to find out where to set my boundaries. I'm taking a lot more time off now which I never did within the first year. I'd taken maybe five days off in a whole year. I'm definitely trying to care more about myself because I think I was so immersed in the work that first year that I kind of lost what was best for me. So this whole thing is a reminder that I need to keep doing self-care, talking it out with people and doing what makes me happy on the side. Because you can like, especially since you're in people's homes, you can get lost, like I have a life outside of this, this isn't my whole life. But sometimes you can get kind of stuck in it.

Donna shared that she might have answered these questions very differently several years ago, but following a personal tragedy, she learned how to set better boundaries and care for herself.

“I lost my husband four years ago and I think I learned an awful lot [about how] to stand up for myself and take care of myself better. He had an unexpected massive heart attack right in front of me.”

As Donna’s quote at the start of this section so eloquently indicated, sometimes caregivers are the worst at caring for themselves. Loving the patients and families they serve seems to come naturally to most hospice caregivers. While there are often difficult days or seasons, hospice workers seem to be able to return to the stories and memories that remind them why they do this work. However, it was evident through my interviews and the ProQOL survey responses that there is a disconnect between the care, presence, empathy and love that hospice workers give to the patients and families they encounter each day, and their tendency to offer these same things to themselves. Jeff Gates offers a Christian perspective on self-care and the balance between love of self and neighbor.

When Moses, Jesus, Paul, and James (Lev 19:18; Mk 12:31; Rom 13:9; Jas 2:8) spoke of loving our neighbour as ourselves, they addressed the manner in which we were to care for others, i.e. in the same way we care for ourselves. As we naturally seek our own happiness and avoid misery, likewise, we should do so to others. In reality, we must care about ourselves before we can care about others, because our self-care is the model or standard of neighbour-care. Therefore, self-care cannot be wrong because it is ‘a rule and measure by which our love to others should be regulated.’⁸⁴

Gates goes on to state that we can only have and show compassion for others when we have compassion for ourselves.

Caring for ourselves enables us to more effectively care for others, but if we fail to care for ourselves, we are less able to care for others. The Second Greatest Commandment

⁸⁴ Jeffery Gates, “Self-Care: A Christian Perspective,” *Evangelical Review of Theology* 39, no. 1 (January 2015): 4–17.

teaches that people who do not love themselves cannot love their neighbour, and only those who have their basic needs met are able to help others. Just as we cannot save another drowning person if we are drowning, so if we have pressing personal needs we will concentrate all our energies on solving them and have little left for God and others.⁸⁵

While I agree that having one's basic needs met is extremely important to overall human functioning, I would take issue with Gates' statement here that *only* those who have their basic needs met are able to help others. However, I would agree that compassion shown for oneself greatly increases one's ability to show that compassion to others.

⁸⁵ Jeffery Gates,12.

Theme Three

One Body, Many Parts

¹⁴ Even so the body is not made up of one part but of many.

¹⁵ Now if the foot should say, "Because I am not a hand, I do not belong to the body," it would not for that reason stop being part of the body. ¹⁶ And if the ear should say, "Because I am not an eye, I do not belong to the body," it would not for that reason stop being part of the body.

¹⁷ If the whole body were an eye, where would the sense of hearing be?

If the whole body were an ear, where would the sense of smell be?

¹⁸ But in fact God has placed the parts in the body, every one of them, just as he wanted them to be. ¹⁹ If they were all one part, where would the body be?

²⁰ As it is, there are many parts, but one body.

²¹ The eye cannot say to the hand, "I don't need you!" And the head cannot say to the feet, "I don't need you!" ²² On the contrary, those parts of the body that seem to be weaker are indispensable, ²³ and the parts that we think are less honorable we treat with special honor. And the parts that are unpresentable are treated with special modesty, ²⁴ while our presentable parts need no special treatment. But God has put the body together, giving greater honor to the parts that lacked it, ²⁵ so that there should be no division in the body, but that its parts should have equal concern for each other.

²⁶ If one part suffers, every part suffers with it; if one part is honored, every part rejoices with it.

²⁷ Now you are the body of Christ, and each one of you is a part of it.

1 Corinthians 12:14-27

When asked about her wish for her hospice setting, Laura, a hospice chaplain, replied, "I wish the entire team had eyes to see just how valuable they really are and that we all flow together and connect with one another in ways we probably don't always realize as far as being a team unit." After a moment she went on to say, "We get very singularly focused on our part of the team and what we have to offer but we forget that just as all the parts of the physical body interact with the other parts and is intertwined... I think we forget to see the value of the other team members." Laura is speaking about the hospice interdisciplinary team working together much like the body of Christ Paul talks about in the passage above from 1 Corinthians. While

the other participants did not explicitly use this language or analogy, many people spoke about the importance of the team in hospice and what it looks like when it is functioning well and when it is functioning poorly.

Figure 4.6.
ProQOL Question #4: I feel connected to others.



Figure 4.6. illustrates the feelings of connection to others that hospice workers report experiencing. Despite these feelings of connection, several participants spoke of the isolation that can sometimes happen for hospice workers. Most hospice workers spend several hours in their car each day driving between visits and back to their homes. This isolation is magnified by the nature of hospice work. Team members often feel that their friends and families don't understand the work they do each day. Alice, a hospice nurse spoke about how much she relies on her fellow team members. *"Talking to my coworkers is really big. Calling them and unloading... I have my family and my friends, but they really don't understand. Or sometimes*

they'll just be like it's too much, like I can't hear about it. So it's good to have people that can relate to what is actually going on." Other participants indicated that they wished there were more opportunities for staff to get together informally to share about their caseloads and how they're doing and support one another. Nancy, a hospice social worker, wished that there was more support available for the staff, *"Just because it's a lot to just take on and to have to deal with and process and it would just be nice when we needed it, to have someone to process our days with because outside people really don't understand. You really don't have a full understanding if you don't do the work."* Elise, a social worker and Donna a nurse, wished that there were more informal times for hospice workers to gather and support one another or just do something fun together. Elise wished for, *"monthly team meetings that are just about being together...meetings for talking and supporting one another. Having that space is important. When we try to do that in interdisciplinary team meetings, we all just get cut off. There's no time for that."*

Wanda, a chaplain, shared a story about a patient and family she had been involved with. She was happy with how this situation had gone because each member of the team was involved, and all were working together to ensure the best outcome for the patient and family. *"I feel good about doing the best we could do to get them the resources they needed. Those kinds of things feel really good, mainly because it's not about me and what I'm doing, it's getting everybody else involved and getting the support they need."* April, a nurse, spoke about her feeling that the patient and families have a better experience if all of the disciplines are involved and are able to do more visits together. *"I'd like to be able to do a lot more joint visits with the chaplain and social worker. That is a lot better for our patients, I think. I wish that they had a smaller case load too so they could spend more time doing visits with me."*

While many participants expressed feelings of closeness and support from their fellow hospice team members, I also heard frequent expressions of frustration from hospice team members who felt they were not always seen and valued as part of the team. This sentiment was often expressed by the hospice chaplains I spoke with, who felt that their managers and fellow team members didn't always understand what chaplains do. Rebecca spoke about this feeling, *"You know, I just wish that chaplains were more valued and visible within the organization. Sometimes it's spoken about that we're valued and just as much a part of the team as everyone else but in practice I don't really see that."* Wanda wished that there could be more education about the role of chaplains, *"Not because they need to value me more but so they can explain to patients and families what we're there for."* Terry wished that there could be, *"more education on the importance of our discipline. I think we're still kind of on the bottom of the totem pole and the least respected."*

Hospice chaplains, social workers and nurses play different roles on the hospice interdisciplinary team, but all are important to a healthy team that meets the varied needs of the patients and families receiving hospice care. Hospice workers are providing a listening ear to those who need it most, yet it is clear that many hospice workers don't feel heard. While naming one of her wishes in response to my fourth interview question, Sally, a social worker responded, *"to be listened to more often."* She spoke about how she works with the chaplain to support the team members as well as patients. *"We end up like emotionally and psychologically supporting everybody, even the people in the facilities. And it's a bit much. The volunteers sometimes have issues too and they call me for support. It's almost like I'm, I tell people, I'm the paid secret keeper and sounding board and I get tired. I get mentally tired."* Rebecca, a chaplain, spoke about not always feeling like she is a part of the team during interdisciplinary team meetings.

“I’m more acutely aware of it when I’m in a meeting and have something to say and nobody gives me the opportunity to say it. That kind of sets me back for a while.”

One study of hospice social workers speaks of the interdisciplinary team model upon which hospice was built.⁸⁶ This study sought to examine interdisciplinary collaboration from the perspective of hospice social workers in Missouri. While the overall results of the study found that hospice social workers feel positively about the amount of interdisciplinary collaboration they experience on the hospice team, there was an acknowledgment of the dynamics of competition that can sometimes occur. “Competition between social workers and both nurses (Ben-Shira & Szyf, 1992) and chaplains (Lister, 1980) has been found in various practice settings. In a nationwide study of hospice professionals, social workers reported frustration as they perceived that nurses were assuming social work duties (Sontag, 1996).”⁸⁷ Another article from a Social Work journal discusses these dynamics as well. While most research being done on the interprofessional dynamics of hospice teams seems to be coming from the perspective of social work, this article addresses the competition dynamics that can occur between chaplains and social workers.

“The increasing emphasis on spirituality in social work (Canda, 1988; Joseph, 1988; Smith, 1995) brings health care social workers into what many consider the domain of chaplains. Just as social workers may compete with nurses for provision of psychosocial services, chaplains may view social workers as encroaching on their professional turf (Lister, 1980). At the same time, chaplains provide psychosocial care, which may be viewed by social workers as better left to social work (Furman & Fry, 2000).”⁸⁸

⁸⁶ Debra Parker-Oliver, Laura R Bronstein, and Lori Kurzejeski, “Examining Variables Related to Successful Collaboration on the Hospice Team.,” *Health and Social Work* 30, no. 4 (2005): 279–86.

⁸⁷ Debra Parker-Oliver, Laura R Bronstein, and Lori Kurzejeski, 282.

⁸⁸ Dona J. Reese and Mary-Ann Sontag, “Successful Interprofessional Collaboration on the Hospice Team,” *Health & Social Work* 26, no. 3 (2001): 167–75, 170.

This study suggests that one reason for this dynamic may be a lack of understanding and education regarding “other professions’ expertise, skills, training, values, and theory”⁸⁹ that is a result of “training health care professionals in isolation from each other (Lister, 1980).”⁹⁰ These studies and several responses from participants I interviewed in my own study suggest that education about the expertise and experience of each discipline may help address the competition among hospice team members.

Chaplain Linda F. Piotrowski, in her essay for fellow chaplains, discusses the continuum of care, with interdisciplinary care being the fourth level of care and transdisciplinary care being the fifth and highest level.⁹¹ Interdisciplinary care here is defined as “being willing and able to work with others in the joint evaluation, planning, and care of the patient.”⁹² Transdisciplinary care is defined as “making the commitment to teach and practice with other disciplines across traditional disciplinary boundaries for the benefit of the patient’s immediate needs.”⁹³ Her description of a truly interdisciplinary and transdisciplinary team experience is what she describes as sacred.

“Transdisciplinary team care requires that each member summon the courage to address patient needs and speak from the expertise of one’s own discipline while at the same time respecting the knowledge and insights provided by others from various disciplines. Patient care rounds as well as inter- and transdisciplinary team meetings are sacred times in which the inherent value and respect needed for each person- staff, team member, patient, and caregiver- are held as sacred. Disciplinary lines blur and at the best of times disappear as the group engages in uncovering what will best serve patient needs. The interdisciplinary process is more than just several health professionals gathered around a table to discuss a patient. Rather, each sits down and, in essence, brackets his or her professional-discipline identity, places it to the side, and assumes the new identity of “team member.” Integrated, smooth, coordinated, and congruent care, with the patient’s immediate needs at the center of the effort, makes transdisciplinary care. Individuals

⁸⁹ Dona J. Reese and Mary-Ann Sontag, 170.

⁹⁰ Dona J. Reese and Mary-Ann Sontag, 170.

⁹¹ Chaplain Linda F. Piotrowski, “Transdisciplinary Relationships,” in *Professional Spiritual & Pastoral Care: A Practical Clergy and Chaplain’s Handbook* (SkyLight Paths Pub., 2012), 240–48.

⁹² Chaplain Linda F. Piotrowski, 242.

⁹³ Chaplain Linda F. Piotrowski, 242.

come together without territorial professional boundary needs to guide their role and responsibilities. This is what makes it the highest form of care.”⁹⁴

It seems that the processes described here by Piotrowski are those of a highly functioning and perhaps exceptional team. While my conversations with hospice professionals suggest that this interdisciplinary and transdisciplinary process is far from the norm for most hospice teams, it is certainly something that should be aspired to.

My interviews painted a clear picture for me of both the strengths and limitations of a hospice interdisciplinary team. I greatly appreciate Laura’s equation of a hospice team as a body with many parts. Hospice workers seem to have an acute awareness of the importance of each part of the team, and yet there are still places where one part may communicate to another that they are not as necessary to the overall function of the team. This theme highlights a huge area of potential growth for hospice organizations. Nurturing the sense of collaboration and interdependence on a hospice team would have meaningful impacts on both the experiences of hospice workers and patient satisfaction.

⁹⁴ *Chaplain Linda F. Piotrowski, 243.*

Theme Four

So Much to Do, So Little Time...

*There is a time for everything,
and a season for every activity under the heavens:*
² *a time to be born and a time to die,
a time to plant and a time to uproot,*
³ *a time to kill and a time to heal,
a time to tear down and a time to build,*
⁴ *a time to weep and a time to laugh,
a time to mourn and a time to dance,*
⁵ *a time to scatter stones and a time to gather them,
a time to embrace and a time to refrain from embracing,*
⁶ *a time to search and a time to give up,
a time to keep and a time to throw away,*
⁷ *a time to tear and a time to mend,
a time to be silent and a time to speak,*
⁸ *a time to love and a time to hate,
a time for war and a time for peace.*
Ecclesiastes 3:1-8

Time is an important issue for hospice workers and in many ways can be seen as a paradox. While the daily demands of hospice can seem overwhelming and require skillful time management, for the patients receiving hospice care, time can seem to slow down. No longer pursuing curative treatments, hospice care allows patients the opportunity to spend the final days or months of their lives in their homes, long term care facilities, or inpatient hospice unit. As mentioned in the section on theological themes, hospice workers spend a great deal of time with people who occupy the space between life and death. This in-between, or liminal space can create feelings of uncertainty or ambiguity. This ambiguity, though not explicitly spoken of, was implied in many of my conversations with hospice workers. Jerry, a chaplain, wished that he was always “*able to be with patients when they transition from here to eternity.*” Laura, another

chaplain, made a similar wish that she “*would get to be there at the moment that each of my patients graduated into their next life.*” However, many hospice workers noted that this is often not possible because of large geographic areas and heavy caseloads. Navigating this liminal space between life and death while also meeting the demands of the growing hospice field can be very challenging for those who work in hospice.

Coberly and Shapiro speak to the stressors present for the hospice professional caregiver in their article. “Caregivers, too, are exposed to a number of stresses. One of the most common is a pervasive and intense fatigue that results from the work itself — a profound physical and emotional exhaustion that inexorably ensues for many who care for the dying. Another source of caregiver stress is maintaining the vigilance required to adequately meet the demands and needs of a constantly changing and uncertain situation.”⁹⁵

Two ProQOL survey questions address the feeling of overwhelm and endless caseloads faced by many hospice workers. Figures 4.7. and 4.8. illustrate the variety of responses to ProQOL Questions 21 and 26.

⁹⁵ Margaret Coberly and S.I. Shapiro, “Letting Go: Expanding the Transpersonal Dimension in Hospice Care and Education,” *The International Journal of Transpersonal Studies* 17, no. 1 (1998): 35–55, 38.

Figure 4.7.

ProQOL Question #26- I feel “bogged down” by the system.

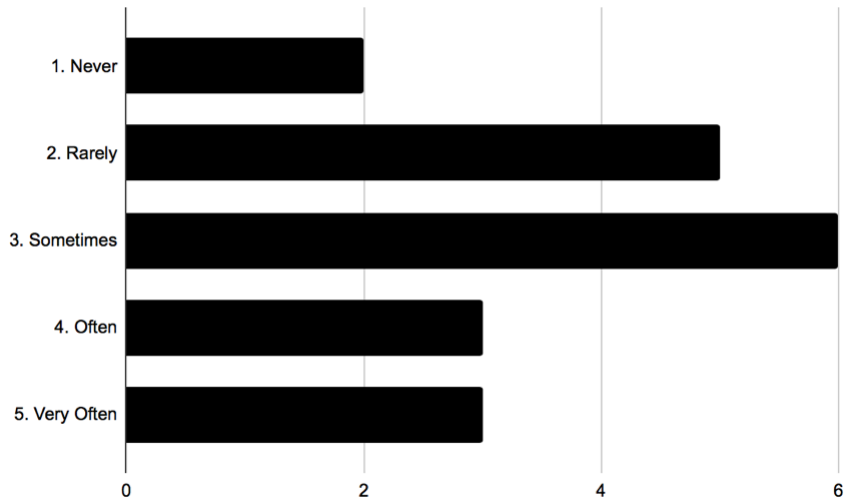
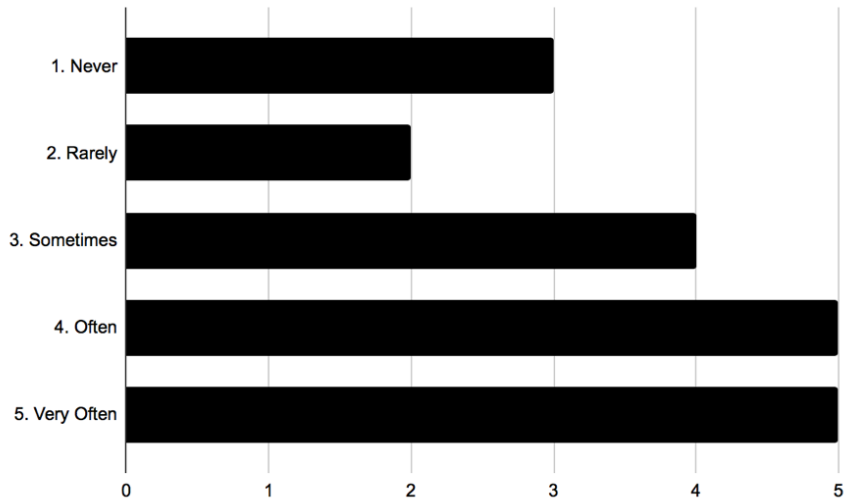


Figure 4.8.

ProQOL Question #21- I feel overwhelmed because my case [work] load seems endless.



Surveying and interviewing hospice workers from various regions and companies provided the opportunity to hear about how several different hospice companies are managed and how

employees felt about their workload. While the nursing role is pretty clear cut, I interviewed one social worker who also serves as the volunteer coordinator in her company, as well as several chaplains who also function as bereavement counselors. Some smaller hospice companies only have one chaplain and one social worker covering very large geographic regions. One chaplain I interviewed is the only chaplain covering nine different counties. Jerry, a chaplain, spoke about the health problems he experienced as a result of all the driving he was doing at his previous company.

I just switched agencies. The first agency I was with, I covered seven counties and 65 plus patients and the new agency I'm with only covers three counties and about 30 patients. I had to switch... I was driving 700 miles a week with the other agency and, my doctor... I started having some issues because I'm getting older, and my doctor said well your degenerative disc disease has now moved from your back to your neck. It's not going to get any better with you driving 700 miles a week, it's going to get worse. So, I switched and now I drive maybe 100 miles a week.

Other participants work in companies with large teams, but there are still very few opportunities to be together. Alice, a chaplain, shared, “*We have 23 chaplains, but we're scattered all over the state, so we don't ever get to see each other.*”

Many of the people I interviewed described a tension between providing the best care for their patients and families and meeting productivity expectations. April, a nurse, wished for, “*better ratios for my patients, once my caseload gets high, I lose that individuality with people. When I have 80,000 people on one day then I'm always just thinking about what I've got to do next and I'm not as present as I normally would be.*” She went on to share about how many visits she's expected to complete in a day, “*On a good day I see six people, on a bad day I see seven or eight. If I had less visits in a day, I could be more present and give even better care if I had less people to worry about.*” Jerry, a chaplain said, “*I think we need to focus on quality of visits not quantity.*” Hospice agencies are under many demands. Many operate with less staff than they'd

like to have, particularly when it comes to support staff like social workers and chaplains.

Medicare regulations must be met, and survey results are now accessible to the public at the click of a button, putting agencies in fierce competition with one another. Unlike many work places, hospice organizations have teams that do not always see one another. At times, this can lead to feelings of disconnect, with the field staff, those hospice workers out in the community providing care, and the office staff feeling separate at best, and adversarial at worst. Donna, a hospice nurse, touched on this feeling of animosity that can sometimes occur between field staff and management and the turnover she sees with many good nurses leaving hospice. *“I would want my coworkers to feel the same type of satisfaction that I do. Separate their work from management and not let management get to them. It’d be nice not to see the turnover.”*

Time is also one of the barriers to providing support programs to hospice workers. In my own experience as a hospice worker, many times managers feel that while they want to provide workshops and opportunities for self-care and reflection, there is simply not enough time. Many times, when opportunities are offered by hospice companies, hospice workers are too busy or choose not to attend. This can reinforce the idea that these activities are not needed or will not be well attended in the future.

Chapter 5: Next Steps

Limitations of the Study

The biggest limitation of this study was time. Finding hospice workers who could devote the time to completing all three stages of the project was a barrier. In addition, as one of the follow-up surveys stated, one week for each spiritual practice was not enough to make a significant impact on levels of compassion fatigue. The study served more as a brief introduction to spiritual practices that hopefully opened a door for participants to consider ways to incorporate new practices into their lives. As stated in the section discussing the ProQOL survey, this tool may be better suited as a tool for self-assessment and self-reflection than a research tool. Participants must self-report their experiences on the ProQOL survey and there appeared to be, in some cases, a tendency towards underreporting negative feelings. I do believe that the ProQOL is a useful tool to raise awareness, as many participants acknowledged in their interviews that taking the survey helped them pause and think about how they have been coping. Regularly providing the opportunity for hospice workers to take the ProQOL and assess any changes they may see over time may be a powerful tool for the prevention of burnout. Another limitation is the years of experience and distribution of job titles in stages two and three of the study. While the nineteen participants who completed stage one included seven nurses, nine chaplains and three social workers, there was difficulty retaining nurses for the second and third stage of the study. It appeared to be easier to recruit and retain fellow hospice chaplains to participate in this study, perhaps because of a sense of collegiality and support, as several hospice chaplains I spoke with had also completed Doctor of Ministry projects and wanted to

help. Participants in stage one ranged from one to twenty-one years of experience. However, those who participated in stages two and three generally had experience of six years and under, with several participants being in their first year of hospice work. The use of technology for this project may be a factor in this particular limitation. While the Spirit of Hospice website and electronic survey administration allowed for wide distribution of my project, perhaps those with more years of experience could have been less comfortable with technology or engaging with spiritual practices through a website.

Implications of Research

Robert J. Wicks, in his guide to building resilience among healthcare practitioners, speaks of the attitudes and behaviors that are capable of nurturing the spiritual dimension of life. “Included among them, the ones that do have great psychological value and are therefore of interest to us here-whether we are persons of a specific faith or not- are *silence and solitude*, *friendship and community*, and *listening and reflection*.”⁹⁶ These behaviors and attitudes parallel the four themes that appeared throughout my conversations with hospice workers. I believe they can provide a framework for meeting the spiritual needs of those who work in hospice.

Silence and Solitude

One of the themes highlighted in chapter four was the emphasis on time. Hospice workers are submerged in a busy medical profession. There is always more to do, more patients to see, more paperwork to fill out. It is tempting to say that there is simply no time for silence

⁹⁶ Wicks, *Overcoming Secondary Stress in Medical and Nursing Practice*, 88.

and solitude. However, many hospice workers spoke of the times when they are in a home with a patient or family on hospice and they find that words are simply not enough. Simply being present in the silence and stillness and mystery of death matters, most hospice workers will tell you. Hospice workers are no stranger to solitude. Most hospice workers are working remotely, driving from place to place to see their patients. The spiritual practice most widely utilized in this study was music and during my interviews with participants I frequently heard that the alone time in the car with music was extremely important and meaningful for hospice workers. Others told me about times they use their car rides for silence and when they arrive at their next visit or even at their own home at the end of the day, they take some space to breathe and let go of all they've seen that day. While participants did not explicitly label these things as rituals, the daily practice of turning off their work phones and tablets, documenting the day's visits and preparing to enter their homes at the end of the day, speak to the importance of ritual for hospice workers. Helping hospice workers identify these daily rituals that help mark the space between their own lives and the lives of their patients and encouraging the intentional use of silence and solitude, could have a big impact on the experience of compassion fatigue.

Friendship and Community

The themes of friendship and community were highlighted in chapter four under the themes, *love your neighbor as yourself*, and *one body, many parts*. Hospice workers spoke of the ways they rely on one another. While hospice work can feel isolating and hard to describe to others, hospice workers find comfort and camaraderie in the shared experiences of coworkers. Many people spoke of using their coworkers for debriefing difficult cases. Others spoke of their desire for regular opportunities to get together with their coworkers informally, not for a meeting

but simply to enjoy one another's company. Yet, as discussed in chapter four, there can also be barriers to this sense of group unity. Competition and lack of understanding among disciplines can threaten the spirit of teamwork, friendship and community. One recurring theme throughout my interviews was the desire for education. Hospice companies looking to nurture friendship and community can do so through opportunities for fellowship and shared purpose, but it can also be done through educating one another about the role and importance of each discipline. This education should happen frequently and regularly. Orientation of new employees should include opportunities to learn from each discipline and time shared with other nurses, social workers and chaplains. Social workers and chaplains should regularly lead education opportunities for fellow team members about their role on the team. While friendship and community cannot be forced, there is much that can be done to create a culture of openness and mutual support. This may be easier said than done, as creation of this culture involves engagement from all team members and company management. In a results-driven healthcare environment like hospice, it would be important to connect results, showing that this sense of community directly impacts patient satisfaction and employee engagement.

Listening and Reflection

In my fourth chapter, I shared many of the stories I heard from participants in this study. Hearing about the patients and families who have had the biggest impact on hospice workers as well as the events and people that led them to begin their careers in hospice, was very meaningful. Rebecca, a chaplain I interviewed said, *"It's nice to talk about a positive experience in my work and to remember that because it's not always like that, so to be able to share that story feels meaningful. Having a chance to share those stories in a space that is for that is*

important.” I agree with Rebecca and believe that creating a space for hospice workers to share the stories of the lives they encounter is important. Several participants, when asked about their three wishes for hospice, wished that they would be listened to more often. Others noted the barriers to feeling listened to in the hospice interdisciplinary team meetings and expressed that those meetings often cannot facilitate the sharing of meaningful stories, as there is simply not enough time. Providing space and opportunities for hospice workers to share and reflect on the moments that have been particularly meaningful, can decrease compassion fatigue by increasing compassion satisfaction.

Recommendations

Rachel Naomi Remen, author, educator and palliative care physician, writes about the experience of grief among healthcare workers in her book, *Kitchen Table Wisdom: Stories that Heal*. She says, “the expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.”⁹⁷ This quote was on the top page of the Spirit of Hospice website I created for this study and I believe it points to the reality and inevitability of what Charles Figley calls the “cost of caring.” Hospice workers, who do their job with empathy, dedication and compassion will experience times of grief and compassion fatigue. Normalizing this experience and addressing compassion fatigue before it becomes burnout is extremely important. Remen believes that “protecting ourselves from loss rather than grieving and healing our losses is one of the major causes of burnout.”⁹⁸ She humanizes the experience of burnout when she says, “people who

⁹⁷ Rachel Naomi Remen, *Kitchen Table Wisdom: Stories That Heal* (New York: Riverhead Books, 2006), 52.

⁹⁸ Remen, 52.

really don't care are rarely vulnerable to burnout. Psychopaths don't burn out. There are no burned-out tyrants or dictators. Only people who do care can get to this place of numbness. We burn out not because we don't care but because we don't grieve. We burn out because we have allowed our hearts to become so filled with loss that we have no room left to care."⁹⁹ Cynthia Harr, in a study on compassion fatigue among social workers, also emphasizes the importance of normalizing compassion fatigue, "it is important to recognize the reality of the difficulties and challenges of the job and normalize the experience of compassion fatigue as an occupational hazard, not a weakness of the practitioner."¹⁰⁰

It is my belief that many of the symptoms and potential treatments of compassion fatigue, are spiritual in nature. Fostering community, nurturing a sense of call and purpose, honoring the many roles of team members, seeing the interdisciplinary team as a body with many parts, and encouraging caregivers to care for themselves with the same compassion and love they give to their patients, are all pastoral functions, well suited to the role of a chaplain. Many corporations are acknowledging the spiritual needs of their employees. David W. Miller, director of the Princeton Faith & Work Initiative, writes about corporate chaplaincy programs in an article for *US Catholic*, he says, "today's corporate chaplains are part of a much larger movement to break down the cultural barrier between faith and work and to help people live out their faith in all areas of life, even on the job. Increasingly, employers are recognizing that people desire more than a paycheck from their job. They want their work to be meaningful and rewarding on a deeper, even spiritual level."¹⁰¹ In a brief survey completed by 78 visitors of the US Catholic website also cited in this article, 82% of respondents reported feeling spiritually and emotionally

⁹⁹ *Remen*, 52.

¹⁰⁰ Cynthia Harr, "Promoting Workplace Health by Diminishing the Negative Impact of Compassion Fatigue and Increasing Compassion Satisfaction," *Social Work & Christianity* 40, no. No. 1 (2013): 71–88., 77.

¹⁰¹ Miller and LoRusso, "Faith at Work: Spiritual Needs Don't End at the Start of the Work Day."20.

drained at work and 84% of respondents disagreed that counselors or employee assistance programs could do everything that a chaplain could do.¹⁰²

Companies like Tyson Foods, who employs more than 100 chaplains, are seeing the need for corporate chaplains to respond to the spiritual and emotional needs of their employees. I believe that utilizing chaplains for staff support in hospice companies would have a similar impact. In my interview with Donna, a hospice nurse, she said, *“I also think that hospice chaplains could reach out to nurses a little bit more too and say, ‘hey how ya doing? I heard so and so passed, are you doing all right with that?’”* My conversations with hospice chaplains explained why there is often no time for chaplains to have those kinds of conversations. Having more than one role, such as chaplain and bereavement counselor, traveling great distances and overloaded patient censuses make it difficult for chaplains to be present for staff. Hospice chaplains are often experiencing their own periods of compassion fatigue as well. For this reason, some places have encouraged the hiring of a support chaplain specifically for staff members. Reverend Robin Brown-Haithco serves as the support chaplain for staff at Emory University Hospital in Atlanta, Georgia. While she reports knowledge of only “two other designated staff support programs within pastoral care departments”¹⁰³ she emphasizes her belief that “staff support should be done by chaplains hired specifically for staff support.”¹⁰⁴

Designating a staff chaplain position devoted solely to staff support might be a tough sell for hospice companies who are short-staffed or dealing with budget constraints. It is my belief that such a position would impact the retention of high-quality, engaged employees and therefore impact patient satisfaction and the overall success of hospice companies. However, it is not

¹⁰² Miller and LoRusso.

¹⁰³ Reverend Robin C. Brown-Haithco, “Spiritual Care of Staff.”, 217.

¹⁰⁴ Reverend Robin C. Brown-Haithco, 217.

realistic to think that such a response is feasible for many hospice settings. My hope is that this research can bring a new awareness to the spiritual dimensions of compassion fatigue and pave a way for creative chaplaincy responses and interventions.

Areas for Further Research

It would be interesting to utilize this research and project model in a particular hospice setting over a longer period of time. Due to limitations of confidentiality and time, this study was completed over a six-week period with hospice workers from various settings around the country. While this created a rich variety of interview data, it made it difficult to substantiate claims about what may have been responsible for changes in ProQOL scores over those six weeks. It would be informative to have a hospice interdisciplinary team utilize the Spirit of Hospice website for six months rather than six weeks. Perhaps participants could track their levels of compassion fatigue, burnout and compassion satisfaction each month as they participate in one spiritual practice each month. This would also allow for the assessment of group dynamics and team collaboration if participants are all in one hospice setting. Further research questions could assess how participation in spiritual practices impacts interdisciplinary collaboration, employee retention, sick days, employee engagement, and many other areas. If hospice chaplains were responsible for incorporating and assessing participation with the Spirit of Hospice website, it would be interesting to see whether that had any impact on the chaplain's integration within the hospice team.

One chaplain who participated in the study, Wanda, shared that she is generally more likely to sustain spiritual practices when she is doing them with someone else. She invited a nurse who she worked closely with to follow the spiritual practice guides with her for the six-

week period so they could discuss them and support one another. With more time and resources, this would also be an interesting area for future research. In the hospice company where I work, chaplains and social workers follow particular nurses. Therefore, there is essentially a larger team made up of these smaller three person teams. It would be interesting to have some of these three person teams complete the spiritual practices together, agreeing to discuss them and find ways to stay in communication with each other. Assessing how this impacts teamwork and even patient satisfaction scores would be extremely informative. Would caregiver teams engaging regularly in spiritual practices and supporting and engaging with one another around spiritual practices have an impact on how patients and families experience the care they are receiving? Patient satisfaction scores are becoming increasingly important in hospice, with the new Medicare CAHPS survey now being reported publicly. It would be interesting to learn what role, if any, spirituality might play in impacting not only staff support but patient satisfaction as well.

With the hospice workforce growing and changing and the recruitment of new employees, many of whom will be young and new to the field,¹⁰⁵ interventions that utilize technology and virtual community such as the Spirit of Hospice website will be important. It would be interesting to expand the website and even consider including a podcast created for hospice workers to share stories and listen as they drive from house to house. Some new apps are being created for medical practitioners to assess their levels of compassion fatigue over time. It would be an interesting further study to find ways to foster community, spiritual practices, and

¹⁰⁵ Jim Parker, "Hospices Look to Millennials to Fill Staff Shortages," *Hospicenews.Com* (blog), May 17, 2019, <https://hospicenews.com/2019/05/17/hospice-providers-look-to-millennials-to-fill-staff-shortages/?fbclid=IwAR2FsmmOT5z4uFz29ps4CTxGgzn8wrDIRIY3SEAlmY9wJUUfl-IW5oQvUs>.

reflection through the use of technology that could bring together remote hospice workers despite the challenges of time and shared space.

Conclusion

The question this research project sought to answer was whether the participation in spiritual practices would have any impact on the experience of Compassion Fatigue among hospice workers. This project used quantitative data through the administration of the ProQOL survey, and qualitative data through the eleven personal interviews that were completed. The quantitative data seems to suggest that the participation and utilization of the Spirit of Hospice website had some impact on the experience of compassion fatigue in the 10 hospice workers who completed all three stages of the study. What was perhaps more informative, were the stories and voices of hospice workers that I had the opportunity to hear. While numbers and scores on the ProQOL assessment can paint a picture, the actual words of those doing the work of hospice each day in a variety of settings, provided a rich resource for understanding. Furthermore, the themes highlighted in the previous chapter provide many opportunities for growth, education and the creation of ongoing resources to meet the spiritual needs of hospice workers.

The hospice movement has come a long way since the days when Dame Cicely Saunders began St. Christopher's Hospice. However, despite all the changes in the field of hospice, the data and stories discovered through this research confirm that hospice is still rich with potential for spiritual growth. As hospice workers strive to eliminate the physical, social, psychological and spiritual pain of those they serve, they are being changed. Resources to nurture spiritual growth like the Spirit of Hospice website can promote transformation and encourage resilient and healthy caregivers who can overcome periods of compassion fatigue. I believe, as I did

when I began this research, that hospice chaplains are uniquely qualified to meet many of the spiritual needs of hospice workers. I hope that this research will encourage continued efforts to provide ongoing spiritual support to hospice workers and the utilization of hospice chaplains for this kind of support.

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Appendix 1

PROFESSIONAL QUALITY OF LIFE SCALE (PROQOL)

COMPASSION SATISFACTION AND COMPASSION FATIGUE

(PROQOL) VERSION 5 (2009)

When you *[help]* people you have direct contact with their lives. As you may have found, your compassion for those you *[help]* can affect you in positive and negative ways. Below are some questions about your experiences, both positive and negative, as a *[helper]*. Consider each of the following questions about you and your current work situation. Select the number that honestly reflects how frequently you experienced these things in the *last 30 days*.

	1=Never	2=Rarely	3=Sometimes	4=Often	5=Very Often
_____ 1. I am happy.					
_____ 2. I am preoccupied with more than one person I <i>[help]</i> .					
_____ 3. I get satisfaction from being able to <i>[help]</i> people.					
_____ 4. I feel connected to others.					
_____ 5. I jump or am startled by unexpected sounds.					
_____ 6. I feel invigorated after working with those I <i>[help]</i> .					
_____ 7. I find it difficult to separate my personal life from my life as a <i>[helper]</i> .					
_____ 8. I am not as productive at work because I am losing sleep over traumatic experiences of a person I <i>[help]</i> .					
_____ 9. I think that I might have been affected by the traumatic stress of those I <i>[help]</i> .					
_____ 10. I feel trapped by my job as a <i>[helper]</i> .					
_____ 11. Because of my <i>[helping]</i> , I have felt "on edge" about various things.					
_____ 12. I like my work as a <i>[helper]</i> .					
_____ 13. I feel depressed because of the traumatic experiences of the people I <i>[help]</i> .					
_____ 14. I feel as though I am experiencing the trauma of someone I have <i>[helped]</i> .					
_____ 15. I have beliefs that sustain me.					
_____ 16. I am pleased with how I am able to keep up with <i>[helping]</i> techniques and protocols.					
_____ 17. I am the person I always wanted to be.					
_____ 18. My work makes me feel satisfied.					
_____ 19. I feel worn out because of my work as a <i>[helper]</i> .					
_____ 20. I have happy thoughts and feelings about those I <i>[help]</i> and how I could help them.					
_____ 21. I feel overwhelmed because my case [work] load seems endless.					
_____ 22. I believe I can make a difference through my work.					
_____ 23. I avoid certain activities or situations because they remind me of frightening experiences of the people I <i>[help]</i> .					
_____ 24. I am proud of what I can do to <i>[help]</i> .					
_____ 25. As a result of my <i>[helping]</i> , I have intrusive, frightening thoughts.					
_____ 26. I feel "bogged down" by the system.					
_____ 27. I have thoughts that I am a "success" as a <i>[helper]</i> .					
_____ 28. I can't recall important parts of my work with trauma victims.					
_____ 29. I am a very caring person.					
_____ 30. I am happy that I chose to do this work.					

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YOUR SCORES ON THE PROQOL: PROFESSIONAL QUALITY OF LIFE SCREENING

Based on your responses, place your personal scores below. If you have any concerns, you should discuss them with a physical or mental health care professional.

Compassion Satisfaction _____

Compassion satisfaction is about the pleasure you derive from being able to do your work well. For example, you may feel like it is a pleasure to help others through your work. You may feel positively about your colleagues or your ability to contribute to the work setting or even the greater good of society. Higher scores on this scale represent a greater satisfaction related to your ability to be an effective caregiver in your job.

If you are in the higher range, you probably derive a good deal of professional satisfaction from your position. If your scores are below 23, you may either find problems with your job, or there may be some other reason—for example, you might derive your satisfaction from activities other than your job. (Alpha scale reliability 0.88)

Burnout _____

Most people have an intuitive idea of what burnout is. From the research perspective, burnout is one of the elements of Compassion Fatigue (CF). It is associated with feelings of hopelessness and difficulties in dealing with work or in doing your job effectively. These negative feelings usually have a gradual onset. They can reflect the feeling that your efforts make no difference, or they can be associated with a very high workload or a non-supportive work environment. Higher scores on this scale mean that you are at higher risk for burnout.

If your score is below 23, this probably reflects positive feelings about your ability to be effective in your work. If you score above 41, you may wish to think about what at work makes you feel like you are not effective in your position. Your score may reflect your mood; perhaps you were having a “bad day” or are in need of some time off. If the high score persists or if it is reflective of other worries, it may be a cause for concern. (Alpha scale reliability 0.75)

Secondary Traumatic Stress _____

The second component of Compassion Fatigue (CF) is secondary traumatic stress (STS). It is about your work related, secondary exposure to extremely or traumatically stressful events. Developing problems due to exposure to other's trauma is somewhat rare but does happen to many people who care for those who have experienced extremely or traumatically stressful events. For example, you may repeatedly hear stories about the traumatic things that happen to other people, commonly called Vicarious Traumatization. If your work puts you directly in the path of danger, for example, field work in a war or area of civil violence, this is not secondary exposure; your exposure is primary. However, if you are exposed to others' traumatic events as a result of your work, for example, as a therapist or an emergency worker, this is secondary exposure. The symptoms of STS are usually rapid in onset and associated with a particular event. They may include being afraid, having difficulty sleeping, having images of the upsetting event pop into your mind, or avoiding things that remind you of the event.

If your score is above 41, you may want to take some time to think about what at work may be frightening to you or if there is some other reason for the elevated score. While higher scores do not mean that you do have a problem, they are an indication that you may want to examine how you feel about your work and your work environment. You may wish to discuss this with your supervisor, a colleague, or a health care professional. (Alpha scale reliability 0.81)

WHAT IS MY SCORE AND WHAT DOES IT MEAN?

In this section, you will score your test so you understand the interpretation for you. To find your score on **each section**, total the questions listed on the left and then find your score in the table on the right of the section.

Compassion Satisfaction Scale

Copy your rating on each of these questions on to this table and add them up. When you have added them up you can find your score on the table to the right.

3. _____
6. _____
12. _____
16. _____
18. _____
20. _____
22. _____
24. _____
27. _____
30. _____

Total: _____

The sum of my Compassion Satisfaction questions is	And my Compassion Satisfaction level is
22 or less	Low
Between 23 and 41	Moderate
42 or more	High

Burnout Scale

On the burnout scale you will need to take an extra step. Starred items are "reverse scored." If you scored the item 1, write a 5 beside it. The reason we ask you to reverse the scores is because scientifically the measure works better when these questions are asked in a positive way though they can tell us more about their negative form. For example, question 1. "I am happy" tells us more about

- *1. _____ = _____
*4. _____ = _____
8. _____
10. _____
*15. _____ = _____
*17. _____ = _____
19. _____
21. _____
26. _____
*29. _____ = _____

Total: _____

The sum of my Burnout Questions is	And my Burnout level is
22 or less	Low
Between 23 and 41	Moderate
42 or more	High

You Wrote	Change to
	5
2	4
3	3
4	2
5	1

the effects of helping when you are *not* happy so you reverse the score

Secondary Traumatic Stress Scale

Just like you did on Compassion Satisfaction, copy your rating on each of these questions on to this table and add them up. When you have added them up you can find your score on the table to the right.

2. _____
5. _____
7. _____
9. _____
11. _____
13. _____
14. _____
23. _____
25. _____
28. _____

Total: _____

The sum of my Secondary Trauma questions is	And my Secondary Traumatic Stress level is
22 or less	Low
Between 23 and 41	Moderate
42 or more	High

Appendix 2

Stage One: Initial ProQOL Survey Responses

ProQOL Survey Question:	Never	Rarely	Sometimes	Often	Very Often
1. I am happy.			4	10	5
2. I am preoccupied with more than one person I [help].		3	9	5	2
3. I get satisfaction from being able to [help] people.			1	3	15
4. I feel connected to others.			2	13	4
5. I jump or am startled by unexpected sounds.	1	4	8	5	1
6. I feel invigorated after working with those I [help].		1	6	7	5
7. I find it difficult to separate my personal life from my life as a [helper].		5	11	2	1
8. I am not as productive at work because I am losing sleep over traumatic experiences of a person I [help].	8	8	1	2	
9. I think that I might have been affected by the traumatic stress of those I [help].	3	3	12		1
10. I feel trapped by my job as a [helper].	5	8	5		1
11. Because of my [helping], I have felt "on edge" about various things.	3	4	8	4	
12. I like my work as a [helper].			2	8	9
13. I feel depressed because of the traumatic experiences of the people I [help].	3	7	8	1	
14. I feel as though I am experiencing the trauma of someone I have [helped].	4	10	3	1	1
15. I have beliefs that sustain me.			4	6	9
16. I am pleased with how I am able to keep up with [helping] techniques and protocols.		2	5	10	2
17. I am the person I always wanted to be.			10	5	4
18. My work makes me feel satisfied.		2	2	7	8
19. I feel worn out because of my work as a [helper].		4	4	7	4
20. I have happy thoughts and feelings about those I [help] and how I could help them.		1	3	9	6
21. I feel overwhelmed because my case [work] load seems endless.	3	2	4	5	5
22. I believe I can make a difference through my work.			2	8	9
23. I avoid certain activities or situations because they remind me of frightening experiences of the people I [help].	9	3	5	2	
24. I am proud of what I can do to [help].		1	2	5	10
25. As a result of my [helping], I have intrusive, frightening thoughts.	8	6	4		1
26. I feel "boggled down" by the system.	2	5	6	3	3
27. I have thoughts that I am a "success" as a [helper].		1	5	7	6
28. I can't recall important parts of my work with trauma victims.	5	5	3	4	
29. I am a very caring person.				7	12
30. I am happy that I chose to do this work.			3	7	9

Appendix 3

Stage Three: Follow-Up ProQOL Survey Responses

ProQOL Survey Question:	Never	Rarely	Sometimes	Often	Very Often
1. I am happy.			1	4	5
2. I am preoccupied with more than one person I [help].		2	5	2	1
3. I get satisfaction from being able to [help] people.			1	4	5
4. I feel connected to others.			3	5	2
5. I jump or am startled by unexpected sounds.	1	4	2	3	
6. I feel invigorated after working with those I [help].		1	2	6	1
7. I find it difficult to separate my personal life from my life as a [helper].	1	4	5		
8. I am not as productive at work because I am losing sleep over traumatic experiences of a person I [help].	3	5	2		
9. I think that I might have been affected by the traumatic stress of those I [help].	2	6	2		
10. I feel trapped by my job as a [helper].	3	6	1		
11. Because of my [helping], I have felt "on edge" about various things.	1	5	4		
12. I like my work as a [helper].			1	6	3
13. I feel depressed because of the traumatic experiences of the people I [help].	1	8	1		
14. I feel as though I am experiencing the trauma of someone I have [helped].	3	6	1		
15. I have beliefs that sustain me.			1	2	7
16. I am pleased with how I am able to keep up with [helping] techniques and protocols.			4	5	1
17. I am the person I always wanted to be.		1	3	5	1
18. My work makes me feel satisfied.			2	6	2
19. I feel worn out because of my work as a [helper].		1	6	2	1
20. I have happy thoughts and feelings about those I [help] and how I could help them.			1	9	
21. I feel overwhelmed because my case [work] load seems endless.		2	7		1
22. I believe I can make a difference through my work.			1	6	3
23. I avoid certain activities or situations because they remind me of frightening experiences of the people I [help].	3	5	2		
24. I am proud of what I can do to [help].			2	4	4
25. As a result of my [helping], I have intrusive, frightening thoughts.	5	3	1	1	
26. I feel "bogged down" by the system.		6	2	2	
27. I have thoughts that I am a "success" as a [helper].		1	2	6	1
28. I can't recall important parts of my work with trauma victims.	2	6	2		
29. I am a very caring person.			1	5	4
30. I am happy that I chose to do this work.			2	4	4

Appendix 4

Informed Consent Form

I agree to participate in a research study on Compassion Fatigue and Spirituality in Hospice Workers conducted by Faith Fitzgerald and supervised by Reverend Dr. Marianne Sickles Grabowski from the Doctor of Ministry program at Lancaster Theological Seminary.

If I volunteer to participate in this study, I will be asked to complete the Professional Quality of Life Survey (ProQOL), complete a 50-minute interview with the researcher, utilize spiritual practices provided by the researcher for six weeks and complete a post-survey including the ProQOL and follow-up questions.

My participation is voluntary; I can refuse to participate or stop taking part at any time without giving any reason and without penalty. I can ask to have all of the information related to me returned to me, removed from the research records, or destroyed. I have the alternative to choose not to participate in this research study.

There is no expected harm or discomfort, either psychological or physical, to the participant. If I am at all uncomfortable or do not wish to answer a question or complete a task I do not have to.

The information I provide will be stored separately from my signed consent form. My information will remain confidential; the researcher will store all materials in a locked filing cabinet. Any electronic survey results will be password protected and only the researcher will have access to them.

The researcher will answer any further questions about the research, now or during the course of the project, and can be contacted at fitzgeraldfaith5@gmail.com or (910) 489-0710. You may also contact the Major Project Supervisor, Marianne S. Grabowski at touchstonecc@comcast.net or (443) 340-5263.

I understand the procedures described above, and my questions have been answered to my satisfaction. I agree to participate in this study.

This project has been reviewed and approved by the Franklin & Marshall College Institutional Review Board. Questions concerning your rights as a participant in this research may also be addressed to Marcus Thomsen, Ph.D., Office of the Provost, 102C, Old Main, marcus.thomsen@fandm.edu, (717) 358-4283.

Electronic Signature- I have read and understand the above Informed Consent Form:

(select Yes or No)

By typing my name below, I am electronically signing this Informed Consent Form:

Appendix 5

Debriefing:

The purpose of this study is to gain an understanding of compassion fatigue and compassion satisfaction in hospice staff. In this survey you have answered questions about the effect your hospice work has on you both professionally and personally.

Hospice team members work in close proximity to death, loss and grief each day. Your answers to the survey questions, interviews and engagement with spiritual practices will be used to learn more about how organizations and individuals can support and sustain hospice staff in the daily demands of caring for patients, families and one another.

It can be difficult to answer some of these questions and your willingness to participate in this study is greatly appreciated. If answering these questions and reflecting on the work you do each day has brought you any distress or discomfort and you would like to speak to someone about your thoughts, I am happy to meet with you to debrief and can refer you to resources in your area for ongoing support. You can also contact one of the following free and confidential resources:

Employee Assistance Program (EAP): Most hospice companies provide a 24/7 number to call, for example First Call EAP which provides crisis support as well as counseling services to employees and family members. Check with Human Resources at your company to find out what benefits may be available to you.

- CRISIS TEXT LINE: Text HOME to 741741 for free 24/7 text support
 - Crisis Call Center: (775)-784-8090

If you have any questions, concerns or complaints about this research, please feel free to contact me at fitzgeraldfaith5@gmail.com.

Thank you very much for your participation!

Faith Fitzgerald