

Lancaster Theological Seminary

**The Expression and Experience of Staff Suffering
in the Context of Ambulatory
Oncology Care**

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by

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The Expression and Experience of Staff Suffering in the Context of Ambulatory Oncology Care
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ABSTRACT

This paper examines the shared suffering of an ambulatory oncology team. This project was undertaken to explore the grief experiences associated with the unique relationship-building culture of ambulatory oncology care. While there are studies that examine the existential pain associated with relationship building and loss, the literature stops short by only including the experiences of clinical team members, excluding the voices of administrative employees and the entire clinical team, which includes both clinical and non-clinical employees. This study's intent is to peer into the grief of the team, from nurse, to physician, to administrative staff. The method for this study is thematic analysis in the form of structured interviews using open-ended questions. The hope for the research is to look for patterns, themes, and in depth meanings as a way to answer the research question. I chose this type of research to reflect more deeply upon the experiences and stories of the participants. Due to my history as part of the cancer center culture, Investigator Brenda M. Alton, PhD interviewed me as a way for me to grasp my own experience to better understand theirs. I was able to search for overt and underlying themes, identify my grief and, ultimately, to express a shared reality of the deeper human condition as experienced in the ambulatory oncology setting. Fourteen staff members from various disciplines were interviewed regarding their experience of patient death, involvement with the patient's family, and grief associated feelings post-death. They were also asked about the sense of loss associated with their position in the patient's family structure. Common themes highlighted are sadness, poor boundary maintenance, self-esteem concerns, lack of practices of resilience, suffering due to the loss of significant relationships due to patient deaths, questions of meaning, and understandings about, God, end of life, and the afterlife.

For my dad Bernard F. Richards, Jr. and brother Joseph A. Richards

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Table of Contents

ABSTRACT.....	iii
ACKNOWLEDGMENTS	v
Introduction.....	1
The Context of the Research.....	2
Central Terms.....	4
Ambulatory Oncology Staff in the Literature.....	7
Missing in the Literature	12
The Research Question	14
The Significance of the Research Question for Ministry.....	14
Suffering in the Context of the Oncology Team.....	16
Presuppositions and Assumptions.....	18
The Research Method	20
Participants.....	24
The Interview	26
Perspectives on the Interviews.....	31
Initial Impressions.....	33
The Consequences of Suffering: Short-Term; Long-Term; Personal and Professional	40
The Importance of Boundaries and Awareness of Power.....	47
The Secular and Philosophical Understanding of the State of Suffering as Part of the Human Condition.....	50
Suffering as Inspiration to Create and Act.....	51
Major World Religions' View on Suffering	53
The Nones and Other Religious Belief Systems.....	55
Lessons of Suffering for the Ambulatory Oncology Team	57
Application of Lessons	59
Conclusion	63
ANNOTATED BIBLIOGRAPHY	65
APPENDIX.....	80

Introduction

The purpose of this study is to explore how employees in an ambulatory oncology setting experience and express their suffering related to the death of patients. It strives to identify the unique and shared experiences of suffering by the ambulatory oncology team, including determining behaviors that ultimately lead the team to burnout. Staff members were able to articulate their personal beliefs about suffering and death, the afterlife, coping, grief, self-esteem, and boundaries. This is not an intervention study, although many participants experienced emotional catharsis because of the interviews.

This project is not a study of the full myriad of suffering, nor is it an attempt to alleviate suffering. Instead, this became an opportunity to hear the stories, including mine, of medical professionals in a large cancer center. Moreover, this project seeks to identify behaviors or circumstances that compound staff suffering and to provide a forum for staff to express their needs, such as lunchtime support groups, and tailored spiritual or emotional support.

The Context of the Research

The UPMC Hillman Cancer Center of Central Pa. is a world-class cancer center that spans multiple counties in Central Pennsylvania. Connected to UPMC Hillman Cancer Center in Pittsburgh, Pennsylvania, Hillman offers cutting-edge cancer care. The newest treatments and clinical trials are readily available to our patients, and the prolongation of life is greater than just a few short years ago. Yet, with the opportunity for every new treatment, patients and staff experience the reality that a new treatment means that the cancer is growing, and that the previous treatment has stopped working. No longer lulled by the rhythm of the safety of the old routine, the new routine may provoke anxiety, and often-painful side effects may become reality. New treatments mean more contact with staff, as the medicines often throw the human organism off-kilter. When the delicate balance of fluids, electrolytes, and blood cells is disrupted, mid-treatment visits for fluids, blood transfusion/blood products, and potassium often become the norm. Some patients, experience a transformation as they move closer to death. Staff members tend to gravitate to the patient who lives to their fullest, fully alive in the midst of dying.

At this point, relationships between staff and family members can become stronger as the patients and their families look to the chaplain and other staff members for emotional support and guidance. Since patients often choose treatment up until nearly the moment of death, a patient who is treatable today may die next week. When the moment of death comes, the deep connection with them and with their loved ones is lost. In my experience, this causes suffering and we, as professionals, do not honor our grief. Because there are few ritual practices to memorialize loss, team members miss the opportunity to feel grief appropriately. The inability to embrace the emotions of sadness and grief as an individual fosters an insular stance: it causes us

to forget that we are connected to others. In her book, *Atlas of the Heart: Mapping Meaningful Connections and the Language of Human Experience*, author Brené Brown states that our feelings of sadness and grief, often the result of a negative event, can be vehicles of connection to others. This sense of connection to others manifests itself in greater empathy, a desire to feel physically or emotionally connected to others, “*even if what caused it (our suffering, my emphasis) is completely different.*” (Brown, 2021, 108)

In my work as a cancer center chaplain, I identified both a grief response and a trauma response in our team members. In my frequent rounding with staff, I recognized a lack of self-awareness and self-knowledge in many staff members due to what I perceived as a grief and trauma response, which appeared to compound the suffering of our team. This project offers a chance to give a voice to both the unique and shared experiences of suffering of the ambulatory oncology team. This is significant as it allows staff members to articulate their personal beliefs surrounding, suffering and death, the afterlife, coping, grief, self-esteem, and boundaries.

Central Terms

Terms for the project are ***ambulatory cancer center***, which is an outpatient care facility where cancer patients receive chemotherapy or radiation treatment, meet with surgeons and oncologists, and receive other therapeutic cancer care. Patients often have multiple visits each week. Staff and patients often develop close relationships as patients share stories, hopes, dreams, and even sorrows. Because of the closeness of these relationships, boundary issues are not uncommon. Boundaries are crucially important in cancer care. As relationships grow, so do opportunities for boundary violations. Staff members see each patient regularly, often several times a week. They get to hear their stories, meet their families, and perhaps begin to share their own stories. There is healing in the gift of self; however, as the relationship grows, so does the danger.

While an important part of the care team, persons who are in ***administrative*** roles do not provide hands-on clinical care. They include employees who check patients in or out, schedule appointments and tests, or those in non-clinical management roles.

Bereavement is the time after a significant grief event.

Boundaries are healthy limits of time and space between the patient and the professional, and the recognition of emotional and physical limits. According to the Mental Health America article, *Setting Boundaries as a Health Care Worker*, ***boundaries*** are “essential to any healthy relationship.” In the article, the author admits that health care workers often struggle to set necessary parameters. Advocacy for self is uncomfortable, albeit necessary. This is true, per the article, as well-placed ***boundaries*** can prevent burnout. (Mental Health America, 2020)

In the journal article, *Burnout in Healthcare: The Case for Organisational Change*, A. Montgomery and colleagues define **burnout** as “a response to prolonged exposure to occupational stressors.” (Montgomery et al., 2019)

The term **burnout** is often used interchangeably with the phrase **compassion fatigue** but **compassion fatigue** (*secondary vicarious trauma, secondary traumatic stress*), is the precursor to burnout, has many of its symptoms, and strikes those who care for others and are exposed to suffering. These people are often in the helping professions, such as nurses and other medical staff. The symptoms can include “exhaustion, disrupted sleep, anxiety, headaches, stomach upset, irritability, and numbness, a decreased sense of purpose, emotional disconnection, self-contempt, and difficulties with personal relationships.” (Psychology Today, 2023)

Disenfranchised grief is a "grief that persons experience when they incur a loss that is not, or cannot, be openly acknowledged, publicly mourned, or socially supported." (Doka, 2017)

Grief is a natural and universal response to the loss of a loved one. (Mughal et al., 2022)

Feelings of **grief** are also associated with other significant losses, such as job loss, loss of health, loss of relationships, and loss of what is meaningful in a person’s life.

The **palliative care team** consists of physicians and other healthcare providers who collaborate to address the physical, psychological, and spiritual needs of patients with life-limiting illnesses. They treat symptoms and side effects of disease and treatment. (National Cancer Institute, 2021) Social workers and chaplains are part of this team and provide psychological and spiritual care.

Relationship-Based Care (RBC) is a “philosophy, an operational blueprint, and a way of being that advances the culture of healthcare organizations by focusing on three key

relationships: the relationship with self, colleagues, patients, and families.” (National Cancer Institute, 2021)

Resilience is an interior system that allows a person or team to adjust to difficult changes in the midst of various stressors. (Nemeth et al., 2008)

Ambulatory Oncology Staff in the Literature

The role of the nurse in cancer care is highlighted in the article, “Nursing the Clinic vs. Nursing the Patient: Nurses’ Experience of a Day Hospital Chemotherapy Service.” Sonja Mcilpatrick PhD and colleague’s hermeneutic phenomenological study of the differences in the experiences of ten day-hospital oncology nurses compared to nurses working in an inpatient setting. The authors recognized the need to explore the nurses’ experience in an ambulatory setting (day hospital chemotherapy), particularly since they provide the key role of delivering chemotherapy, as well as their “central role in offering emotional and psychological support in all settings to people with cancer and their families.” Mcilpatrick et al’s work indicates opportunities to evaluate and reconfigure how we offer support to our oncology nurses.

Inpatient cancer care does not allow the nurse to form as deep of a bond with the patient and family as the outpatient world does. Mcilpatrick’s article nursing experience in inpatient versus outpatient oncology settings. The data “identifies both positive and negative dimensions.” A sense of autonomy was a positive conclusion, while the feeling of being “consumed by the (clinical) role” was a negative dimension. The conclusion also states that the feeling of being overtaken by the clinical role “could be simply a subconscious means of avoiding the stress of gaining too much intimacy with individual patients and their emotional problems.” (Mcilpatrick, et al., 2006, 1170-1178)

Literature on the experience of oncology nurses documents sources of burnout or spiritual fatigue as well as strategies to counteract it. A valuable article documenting the problems is *Strategies to Promote Coping and Resilience in Oncology and Palliative Care Nurses Caring for Adult Patients with Malignancy: a Comprehensive Systematic Review*, by Lucia Gillman, et al.

The article promotes strategies for resilience and coping in oncology and palliative team members. It does a good job of identifying the psychosocial distress that cancer care staff members experience, and states that “high levels of job stress have been correlated with the development of burnout, compassion fatigue and secondary traumatic stress, which in turn may influence staff absenteeism (due to sick leave), nursing turnover, patient satisfaction and patient safety.” These concerns appear to be universal in cancer care. The study looked at specific techniques to reduce stress and increase wellness. These include “appraisal-focused techniques that change the way the individual thinks, e.g. mindfulness-based stress reduction, emotion-focused techniques that involve releasing or managing emotions that accompany the perception of stress, e.g. distraction, exercise, music, meditation, and the use of humor.” Other techniques used were debriefing or storytelling, reflective practice, problem-focused coping, mentoring, or buddy systems. Multiple tools were used to measure burnout and coping in the extensive study, which also identified the need for additional “robust studies” for the future of our cancer care teams. Noted is the requirement to have the specific outcome of “resilience” in this study.

(Gilman et al., 2015, 131-204)

In their 2019 paper *Grief over patients, compassion fatigue, and the role of social acknowledgment among psycho-oncologists*, Adi Engler-Gross et al., study the grief response of oncology social workers and other mental health professionals who work exclusively with cancer patients. The paper acknowledges the impact of grief, or secondary traumatic stress (STS), in oncology professionals. They highlight how the “lack of social acknowledgment and support” negatively affects the bereavement process. This is in comparison to those who lose a family member or friend, when there is communal understanding that the griever has suffered a

traumatic event. However, as Engler-Gross, et al. highlight, when there is no sense of the right to grieve and/or social recognition of that right, that lack of social support “may impair the grieving person’s everyday functioning and emotional state.” The authors of this study note that most of the studies on this topic focused on physicians and nurses, omitting the experiences of the rest of the care team. (Engler-Goss et al., 2020, 493-499)

The paper *Disenfranchised Grief and Physician Burnout* puts into words the grief experience of physicians. The author, Deborah Lathrop, MD, MAT, writes, “Where there is loss, there is grief.” She goes on to state that “for those lamenting, even on an inexplicit level, grieving drains one’s physical energy, emotional stamina, and at times, intellectual capability.” To paraphrase, the grieving process affects the physician on a physical, emotional, and spiritual level. According to Lathrop, grief in the workplace, or, more specifically for the physician, disenfranchised grief, is a major contributor to physician burnout. She reflects that it is a common defense mechanism for the physician to suppress their awareness of grief. They compartmentalize it, tucking it away in a place where they believe it is hidden and no longer an issue. However, it is real, and per Lathrop, the thought that the physician has already achieved resiliency through their rigorous training, is false. Lathrop suggests that believing this way, the physicians’ grief, and suffering becomes disenfranchised by the system.” Her suggested way out of this systemic challenge is for physicians “to accept that their losses are real—and permanent.” (Lathrop, 2017, 375-378)

In her study, *Exploring Oncology Nurses’ Grief: A Self-study Introduction*, Lisa C. Barbour explores the development of relationships between nurses, patients, and their families. She highlights the clinical reasons for frequent contact with patients, such as chemotherapy, complications, and other symptom management needs. She connects the impact of longevity of

contact, the depth of relationships between nurses, patients, and their families, to nurses' emotional and physical symptoms, such as crushing fatigue. Some of the expressions I heard in my interviews mirrored her words. They are "frustration, concern, compassion, comfortable, shock, nervousness, bad, uneasiness, and anger." The oncology nurse, according to Barbour, experiences these common emotions as the patient moves from curative to palliative treatment. She notes how patients and their families rely on the nurses in that phase where terminal patients undergo treatment to lengthen life and minimize symptom burden. She admits that "when the patient dies, those nurses who have come to know the patient and their family experience loss but often have no formal opportunity to grieve." Interestingly, she expressed her surprise that she mentioned patients' families so often in her self-study yet could not articulate why she had such a sense of loss of those relationships. (Barbour, 2016, 233-240)

In their journal article, *Grief in Healthcare Chaplains: An Investigation of the Presence of Disenfranchised Grief*, Steven Spidell and colleagues highlight that in most studies, compassion fatigue or burnout is more palatable terminology amongst healthcare professionals than the explicit use of the word grief. They state, "Without recognition of grief reactions or the potential presence of disenfranchised grief, losses may be transformed into other emotions such as anger, anxiety, blame, helplessness, and guilt." They write that grief reactions can be either chronic or delayed, leading to burnout or compassion fatigue. Interestingly, Spidell and colleagues identified two indicators that, according to the authors, "may reflect the presence of disenfranchised grief." Both indicators are relevant to this project. (Spidell et al., 2011, 75-86)

The first indicator surrounds topics that chaplains find burdensome to talk about, such as suicide, death of a child, and tragic accidents. For the second indicator, Spidell and colleagues suggest that the presence of disenfranchised grief is related to the chaplains' behavior. Chaplains

may not understand that there are limits to their emotional and spiritual openness. The chaplain wants to be there for everyone, which leads to the likelihood of experiencing disenfranchised grief. Moreover, per the study, chaplains are at risk of unhealthy coping behaviors when they fail to recognize their limitations. It concludes that when healthcare chaplains do not address their grief, they too are at risk for burnout and vicarious traumatization.

Lastly, the literature review by Helen A. H. Sinclair and Conal Hamill titled, *Does Vicarious Traumatization y Nurses*, looks at Sinclair's experience as a ward-based oncology nurse. While she noticed benefits of her work, she also noticed "potential negative intrinsic changes occurring in nurse colleagues, possibly as a result of caring for individuals with cancer." In her ward, nurses were not enjoying the same activities that they used to, and they started distancing themselves from friends. They were also experiencing existential suffering, asking about the meaning of life. Sinclair's literature review noted that oncology nurses may experience vicarious traumatization. Noted in this book review are the same risk factors found in other articles, including the development of compassion fatigue, impact of secondary stress, and feelings of disconnectedness from others, such as patients and staff members. The thread of commonality seen throughout the articles is that both staff members and patients are at risk when the oncology team members do not possess the tools to release emotion and manage work-related stress. (Sinclair and Hamill, 2007, 348-356)

Missing in the Literature

While the literature focuses exclusively on nurses, physicians, social workers and oncology mental health providers, and even chaplains, what is missing are the experiences of non-clinical administrative staff, such as employees who check patients in or out, make and cancel appointments, and even managers of departments who may have frequent patient and family contact. Moreover, studies have not addressed the unique grief experienced by the ambulatory oncology healthcare team. Oncology team members, from physician to front office staff, are in relationships with each other just as they are in long-term relationships with their patients and families.

There is a dynamic unique to the outpatient setting that all outpatient oncology workers experience, where, as the patient declines, the relationship between the family and staff grows. This is due to the patient's inability to come to appointments unassisted, and, in my opinion, due to the patient's ongoing natural withdrawal from the world. It is my observation that as the patient progresses toward death, family members often reach out to persons who have had a positive impact on their loved one. All staff may experience feelings of positive self-esteem and other affirmative feelings due to an increase in power and position that is bestowed temporarily to the staff member by the family. Dependency by the family upon staff, while temporary, may have a negative grief impact on team members and the team as a whole. When the patient ultimately dies, the staff member loses both their former relationship with the patient as well as the position that the medical professional enjoyed in the patient's family system. The family goes on to grieve; however, the staff member grieves alone, often not understanding why the grief is so painful. Expressions of frustration manifest due to unresolved grief. Multiple instances

of unresolved grief may induce staff into greater risk for boundary violations, unhealthy coping, and, ultimately, burnout.

Furthermore, the practice and necessity of setting boundaries is not included as a major cause of staff suffering. In my opinion, significantly reinforced by this study, understanding and setting boundaries is imperative in an ambulatory care setting, particularly in oncology because of the intimacy and position of power that is given to staff by patients and their families. Boundaries and the use of power are explored later in this project.

The Research Question

The research question is, “What is the significance of staff suffering in ambulatory oncology care?”

The Significance of the Research Question for Ministry

Traditionally, professional chaplains are thought of as religious leaders. Many chaplains serve hospitals for their faith tradition as a short or long-term assignment. For example, local dioceses assign Roman Catholic priests to a hospital, or in our case, hospitals, to meet the religious and sacramental needs of Roman Catholic patients. Other traditions assign liaisons, such as in the case of Muslims, Jehovah’s Witnesses, Buddhists, and Jewish patients. Professionally trained board-certified chaplains (representing any religious or spiritual belief) however must have master’s level theological education and four units of clinical pastoral education (CPE). Board certification comes after an arduous process which includes meeting with a certification committee to assess competence in thirty-one chaplaincy skills. Even then, the chaplain receives provisional status as she or he must complete two thousand hours of chaplaincy experience post-CPE, in addition to demonstrating competence in her or his chaplaincy skills to the committee. (BCCi, 2021)

In the context of a hospital system, chaplains wear many hats. Besides meeting spiritual and religious needs, chaplains also function as a part of the interdisciplinary team. Spiritual care is not only religious care; it has evolved into being a medical discipline. Additionally, we are workplace chaplains, providing an invaluable service to our healthcare teams. According to the journal article, *Hope for the Future: Intensifying Spirituality in the Workplace*, Joyce Batcheller,

James Davis, and Patricia S. Yoder-Wise connect physician satisfaction and patient safety scores directly to how well the health team collaborates. Employee engagement surveys may ask questions about the supportive nature (or not) of the workplace. If, as Batchellar, et. al write, we look at these questions through the eyes of spirituality, we see that the questions are rooted in spirituality. This is where chaplains step in, doing the integral work of employee engagement by assessing and addressing the spiritual needs of employees. (Batcheller et al., 2013, 309-316)

While this project will not explore the in-depth role of the chaplain as leader, educator, and administrator, this context does present an exciting opportunity for collaboration between chaplains and other team members. By raising awareness of the specific challenges of the team, implementing people-centered quality improvement projects, and providing education and the language needed to help staff set boundaries, we raise awareness of what is common in ambulatory oncology care. This way, everyone benefits. This includes a benefit to the organization's bottom line as happy employees lead to pleased customers.

Suffering in the Context of the Oncology Team

As chaplain for the UPMC Hillman Cancer Center of Central Pa., I listen to the stories of staff members, hearing, and feeling the lament of grief. Unlike in the hospital setting, ambulatory, or outpatient sites, allow for deep relationship building between patients and staff. As an oncology professional, I feel loss when a patient dies. I feel grief. My professional colleagues, from physicians to administrative staff and I are affected emotionally. We feel frustrated. We feel discouraged. We become frustrated with others and ourselves. This leads to feelings of exhaustion, physical symptoms, and, ultimately, burnout. Our work and home relationships suffer as we isolate ourselves from coworkers, family, and friends, often because we feel alone. Our feelings of loss and hopelessness seem endless because we have nowhere to go with our discouragement, hopelessness, and, sometimes, anger. We choose not to talk about it at work, and we cannot talk about it at home. We feel alone, so we sleep too much, drink too much, eat too much or too little, and do the bare minimum at home and at work. Physicians and advanced care practitioners may feel completely responsible when their patients decline. Nurses can feel discouraged that they cannot do more. Other employees often feel frustrated with physicians and other clinical staff because they do not understand why the patients undergo treatment for so long. We all feel the challenges posed by how difficult it is to care for those who are dying.

When we, as team members, experience the losses of the close relationships we had with their family members and friends, we grieve the loss of the position of power we had in their lives. After death, the prominence we held in their lives is gone, and what remains is a severed connection, feelings of frustration, and no language to explain what has happened. Our grief,

compounded by subsequent deaths, affects us on an emotional and spiritual level, as does the proximity to continued tragic circumstances.

In addition to experienced grief, ambulatory employees experience challenges with boundaries due to the nature of ambulatory care. In the outpatient world, staff members build meaningful relationships with patients, which often leads to confusion in the relationship. As staff members straddle feelings of friendship and their professional responsibilities, the blurred lines increase opportunities for personal, non-professional engagement. For example, when a staff member provides her personal cell number, work-related calls on off hours potentially leave the employee feeling as if they are always at work. The patient has been led to expect a quick resolution to the call, leading to increased work-related stress. The fruit of the lack of boundaries is that staff members move toward the point of burnout and despair.

Presuppositions and Assumptions

The presuppositions and assumptions that I am carrying into this work are the following:

- (1) As a lifelong Roman Catholic, I firmly believe in the Church's teachings.
- (2) This is not limited to the presupposition that there is one God in three persons; God the Father, God the Son and God the Holy Spirit.
- (3) I believe in the divinity of Jesus and that he suffered and died to redeem humankind.
- (4) I believe that the Roman Catholic Church contains the fullness of truth, and that Sacred Scripture and Sacred Tradition flow from one Sacred Deposit of the Word of God.
- (5) I believe that humans are in personal relationship with God and that prayer, in union with the will of God, can affect outcomes.
- (6) I presuppose that God allows humans to cooperate in creation, which includes the creation of babies, art, buildings, and other creative works.
- (7) I assume that this includes cooperation in Jesus' redemptive work, and that suffering is transformative for the individual, community, and entire world when done in union with Jesus' suffering and death.
- (8) I respect the role that religion plays in any person's life, no matter the faith or absence thereof.

The above presuppositions and assumptions help me to work through the shared grief with my teams and patients by remembering how instrumental my faith was when moving through a personal experience with grief and suffering. The defining grief event was the terminal injury of my father during routine surgery. The mistake ultimately led to a frontal brain bleed. It took my father nine months to die. Between the surgery and Dad's death, I

personally experienced a profundity of emotional and spiritual suffering, all while at the foot of my Father's cross.

While many of our team members do not express their experiences in such specific religious terminology, I found that my clinging to personal religious belief was a coping skill and a way for me to feel connected to something beyond myself. I wondered how religion helps our team members cope, if at all. I also wondered if team members could articulate their concept of something greater than self. This is something I explored with our team members, although it is not the focus of this research. While this paper does not do a deep dive into how religious belief or the articulation of religious belief helps with coping, based upon personal experience, it is my opinion that suffering has a purpose. That purpose is a greater capacity for love and to be loved, empathy, and awareness of the need for connection to community.

The Research Method

Originally, I intended to use a research method that would closely follow the format already created by UPMC Hillman Cancer Center of Central Pa.'s Relationship-Based Care team. I serve on our system's unit council and this project fits nicely within its dimensions of "Healing Culture, Patient and Family (in the center of care), Leadership, Teamwork, Interprofessional Practice, Care Delivery, System Design, and Evidence." I also attend UPMC Hillman's operations meetings to communicate the temperature of the team and provide feedback and insight regarding our employee engagement and satisfaction goals. I initially considered a mixed qualitative and quantitative approach as defined by Creswell and Creswell but as it only asks open-ended questions and prompts, this method was not optimal. Additionally, Creswell and Creswell admit that the validity of using a mixed research method for social and human sciences is still unknown. Therefore, once I refined the objective of this study, the mixed method approach did not lend itself to my desire to find what was brewing beneath the surface of our oncology staff. In addition, I felt that using surveys and worksheets to gauge grief and suffering was inappropriate. By doing interviews instead, I was able to witness tears, feelings of discomfort, and even moments of hesitation to answer questions with transparency. (Creswell and Creswell, 2018, 215)

I used the first six phases in thematic analysis for this project. In their 2006 paper *Using Thematic Analysis in Psychology*, Virginia Braun and Victoria Clark make the data analysis for a beginner like me less daunting and more approachable. Braun and Clark state, "thematic analysis is not wedded to any pre-existing theoretical framework, and therefore it can be used within different theoretical frameworks" which offers tremendous flexibility for the research. By doing

so, reflected reality is present and, as Braun and Clark highlight, a greater depth below the surface of “reality” may unravel. This is important because people are shaped by real-life experiences as individuals. (Braun and Clarke, 2006, 77-101)

In their Journal of Positive Psychology article titled *Thematic Analysis*, Braun and Clark assert that their method is used to identify, analyze, and interpret patterns of meaning within the qualitative data. As I asked questions in the interviews, it was clear that there were patterns forming across all disciplines. My job was to interpret the meanings of the patterns. As a chaplain, I am trained to listen to the meaning behind or beyond the words that a person is speaking. The questions were designed to prompt the subject to share thoughts, feelings experiences, and emotions. However, as Braun and Clark affirm, the research question is changeable. In fact, I changed it three times in the coding and theme development stage. As their article expounds, “the hallmark of this form of TA (Thematic Analysis) is its flexibility – not simply theoretical flexibility, but flexibility in terms of research question, sample size and constitution, data collection method, and approaches to meaning generation. TA can be used to identify patterns within and across data in relation to participants’ lived experience, views and perspectives, and behavior and practices; ‘experiential’ research which seeks to understand what participants’ think, feel, and do.” (Braun and Clarke, 2017, 297-298)

My intention for this research was to test what I hear in my work in the setting of an interview, and to “ask questions about the implications “of the patterns that I hear, see, and experience daily.

Table 1: Braun and Clark's Systematic Process

1. *Phase 1: Become familiar with the data.* According to Braun and Clark, this process is intimate. It is one where the researcher immerses herself in the data by reading and rereading.
2. *Phase 2: Create/Generate Initial Codes.* Per Braun and Clark, this is the phase that “involves generating succinct labels (codes!).” This better enables discovering relevant answers to the research question. Braun and Clark state that first coding the whole of the dataset is completed, and then the researcher moves on to a process of collating every code and every piece of relevant data.
3. *Phase 3: Search for Themes.* The researcher examines the codes looking for themes and patterns and reviewing the relevant data for practical use. Codes will correspond to the themes of sadness, poor boundary maintenance, self-esteem concerns, lack of practices of resilience, suffering due to the loss of significant relationships due to patient death, questions of meaning, and understandings about end of life and the afterlife.
4. *Phase 4: Review Themes.* This stage is where the researcher looks at the data again to make sure that the research question is answerable. It is where the story based upon the data may come to life and may reveal a meaning or theme.
5. *Phase 5: Define and Name Themes.* This phase is where exploration of the themes happens with their own breakout stories. Per Braun and Clark, the researcher gives these themes “informative names.”

6. *Phase 6: Produce the Report/Narrative.* This phase is where the researcher weaves the story and the data into a final project, “*in relation to existing literature.*” (Braun and Clarke, 2006, 77-101)
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This study received Institutional Review Board (IRB) approval from UPMC Central Pa. Region, the educational institution in which the research was conducted. Once the interviews were completed, I downloaded the recorded interview into an audio file on a secure UPMC server. The subjects received instructions to document in writing, changes or clarifications of their interview via a Word document. A Word document with the subject’s response, categorized by their numerical identifier, will remain on a secure UPMC server until the conclusion of this study. No personally identifiable information will be published.

Participants

UPMC Cancer Center, Central Pa. Region employees were invited to participate in a structured interview that was designed to evoke their experiences with suffering. The interviews were open to all UPMC Hillman Cancer Center, Central Pa. Region employees, no matter their role. Out of twenty-six team members who expressed interest in the study, fourteen were available for an interview. There were challenges with the interviews due to the need for coverage for approximately 60 minutes of staff time. Staff were asked questions about their thoughts and feelings surrounding a patient (or patients) whose death affected them on a deep level. The participants included physicians, advanced care practitioners, nurse navigators, infusion nurses, nurses from various practices, front and back office (administrative) staff, , medical assistants, social workers, a non-clinical practice manager, and a chaplain. The final sample included physicians, advanced care practitioners, nurse navigators, infusion nurses, nurse educators, social workers, chaplains, administrative office staff, clinical staff, and administrative (non-clinical) leaders.

Participating in the interviews was not without psychological risk. Therefore, I contacted the practice manager at PinnacleHealth Psychological Associates (PHPA) to make her aware of the study in the event a staff member felt triggered by the interview. In addition to notifying PHPA, I provided the contact information to the practice, a grief resource from LifeSolutions, as well as additional resources for care. I have provided copies of the educational material at the end of this study.

Once I explained the risks, I assured confidentiality, explaining to the subject that their employment is not contingent upon participation, nor will UPMC receive any information

regarding the mental health of the subject with the exception of threats of violence to self or others.

The Interview

I obtained signatures of informed consent for a taped interview and then provided an introduction with a summary of the focus of the work. I asked open-ended questions that centered around themes of sadness, poor boundary maintenance, self-esteem concerns, lack of practices of resilience, suffering due to the loss of significant relationships due to patient death, questions of meaning, and understandings about God, end-of-life, and the afterlife. The participants then took a few moments to recall one particular experience, or multiple patient experiences, involving the death of a patient. This patient was to be a patient whose suffering and death they felt greatly affected them personally. In addition, they also brought to mind the relationships that they had with people close to them, such as their family members. There were 55 questions, each building upon the other.

The questions were as follows:

- Tell me what you would like me to know about the patient's story.
- What is it about this particular story that caused you to talk about it today?
- When you first met this patient what was your impression of her/him.
- What did you like about her/him?
- What annoyed you about them?
- What did it feel like seeing your patient at treatment or in the office?
- What caused you the most stress about seeing this patient at treatment?
- How did you feel when experiencing these situations?
- What type of emotions did you feel as you started building a relationship with her/him?
- What emotions surprised you?

- How did your emotions regarding this patient affect your work relationships?
- Your home relationships?
- Your ability to enjoy what you used to enjoy?
- What physical symptoms did you experience?
- How did that impact how you feel about yourself?
- How did this patient challenge your boundaries?
- Give me an example of a time when you did not practice good boundaries with him/her or others in your life due to stress.
- What was your relationship with their family members or other loved ones when you first met?
- What did you like about them?
- What annoyed you about them?
- What was the significance to you regarding these relationships when the patient was undergoing treatment?
- What were the emotions associated with what you knew of the patient's family members as your patient moved through treatment?
- What did your boundaries with the patient look like when they were suffering?
- What about with their family members?
- How did your relationship with your patient change in the months, weeks and days prior to her/his death?
- How did your relationship with her/his family members changed in the months, weeks and days prior to the death?
- What were some of the things that family expressed to you prior to the death?

- How did that make you feel?
- How did you feel about yourself in relation to how the family perceived you?
- What did you like about it?
- What made you uncomfortable?
- What was it like to see your patient decline physically?
- How did you feel when she/he continued another treatment course (if applicable) when you knew from your experience that the end was close?
- What did that make you feel about yourself?
- What were some of your healthy coping mechanisms?
- Tell me about your unhealthy coping.
- What was it like when you last saw her/him?
- How did your faith affect how you felt in that moment?
- Through treatment?
- When she/he died what emotions did you feel?
- How did the death make you feel about yourself?
- What did your relationship with the family look like?
- How did you feel about that relationship right after the death?
- How did it change in the weeks and months after the death?
- What did that feel like?
- What do you wish the relationship with that family looked like today?
- What is your faith tradition?
- What is your understanding of God?
- What is your understanding of suffering and death?

- What do you believe happens when we die?
- How does your religious belief/lack of religious belief inform that belief?
- How does that affect how you live from day to day?
- If it was available to you, would you be interested in a staff support group during work hours, lunch and learns with lunch provided, or something else?
- What could UPMC provide for you as an employee that would make you feel further supported?
- Is there anything else you would like me to know?

I organized the data by listening and re-listening to the interviews, then coding what I heard on a “themes worksheet.” Themes identified included sadness, poor boundary maintenance, self-esteem concerns, lack of practices of resilience, suffering due to patient death/loss of relationships, questions of meaning, understandings of God and the afterlife, and end-of-life. More than one participant repeated many comments verbatim. I coded them into the themes listed on Table 2.

Table 2: Interview Themes

Themes	Comments
Sadness	Grief over the loss of connection with the patient's family. It made me sad that the patient's family didn't understand. I felt sad when I couldn't help my patient. It made me sad when I knew the patient was dying. It made me sad that I did not know my patient was dying. I do not see the patient's chart and no one communicated to me that she was going on hospice. Seeing my patient decline was sad. It made me sad and angry to see the patient continue treatment. I felt angry with her doctor for allowing it. Knowledge our patients will always die. Felt like the loss of a family member. It sucks. Hopeful at diagnosis, then I knew (they were going to die). Easier when the patient reaches acceptance but sad otherwise.
Boundaries	Thinks of patient as family member. Sharing cell phone number. No boundaries with the belief that boundaries become less important at end-of-life. The belief that boundaries cause more harm than good near death. Blurred lines between roles: I want to be her friend/She wants to be my friend. Visiting patients at home. Intentionally seeing patients in social situations. Friending patients on social media. Feeling one cares about the patient more than the family member. Taking on responsibility for patient actions. Wants to share faith through stories so that patients know Jesus. Visits become more friendly and sociable. Felt more like friends.
Self-Esteem	Loss of control. Cannot fix the patient. Not knowing how to make it better. Helplessness. Frustration. I try. I feel discouraged. Feelings of resentment at patient's family, self, and staff. The responsibility is mine. Feels loss and hopeless about self. I feel like I have/haven't contributed. I felt angry. Sense of failure. I don't know if I ever helped her completely. Frustration with self/system. Frustration with the doctors (for letting the patient undergo treatment for so long). I felt lost and hopeless. It challenges my faith.
Meaning	I feel like I've contributed. I feel honored and grateful to have been part of their care. I feel like I had purpose in that moment. God has a purpose for everything God is in control. God is loving and sent his son to save us. I can bring hope to those feeling lost and hopeless. Witnessing the process from suffering to acceptance is transformative. Watching the transformation of the person that happens through care makes it worth it. Makes me enjoy things more. The time we have is precious. I pay attention harder when I am with the people I love. I take less for granted than I used to. I love harder now than I did before. This job challenges my faith. I see so much suffering in this world. When I am with the dying patient, I see God.
Physical Signs	Took on pain that was not theirs. Hypersensitivity. Responding to feelings of Burnout. GI Symptoms/Upset stomach and diarrhea. Loss of interest in usually enjoyable activities, including sex. Isolation. Doing bare minimum. Sleeping too much. Decrease in patience. Drinking. Overeating. Undereating. Lack of motivation. Exhaustion.
Healthy Coping	Regular exercise. Exercise outdoors/running. Watersports Communing with nature. Hugging children. Family activities. Prayer and meditation. Yoga. Regular exercise. Religious belief/practices. Volunteering outside of work.

Perspectives on the Interviews

Being the first interviewee allowed me to understand the feelings associated with reliving the suffering and death of a patient. I felt uncomfortable sharing the intimacy of my patient encounters, as well as sharing times when I practiced unhealthy coping and had porous boundaries. For me, it felt difficult to verbalize the depth of emotional connection associated with a patient under my care. I moved between feelings of grief and joy, as well as feelings of power of position. As a caregiver, I examined the intent of my work with the patient, staff, and family members. It was a much-needed experience of vulnerability, one that was required if I was to expect the same level of candidness from my colleagues.

In conducting the interviews, I experienced the stories in real time. My emotions rose to the surface, as I knew many of the patients of whom staff were speaking.

I was also shocked at the willingness of staff to participate. There are still staff members who want to do the interview, and I plan to oblige as every staff member experienced emotional catharsis and an increased sense of purpose at the end of the interview. Many staff members stated, “It felt good to let it all out.” Most cried as they shared their experiences. I was stunned at my reaction, as I wanted to provide spiritual care during the interviews; however, I made it clear that I was there to hear the story and that clarifying questions were the only deviation from the script. I knew many of the patients’ stories, and I had a more complete view of the breadth and depth of their stories. I even conducted some of their funerals. As staff shared and cried, the grief was real for me too. I was able to see how one life affected many.

Lastly, when asked the question, “What can UPMC provide for you as an employee that would make you feel further supported?” Although the hiring of more chaplains was not a goal of this study, and the interviewer did not prompt these findings, seven staff members want our

health system to hire more chaplains to support their work. They also requested more flex time.

When asked, “Is there anything else you would like me to know?” Ten staff members thanked me for the work that I do with our patients, and five acknowledged the direct benefit our patients received from spiritual care at the end of life.

Initial Impressions

I heard the same words coming from our participants. For example, every participant used the word “frustrated” or “frustration” when asked about feelings related to specific experiences. The deviation, however, was in the perspective of the interviewee based upon their role in the cancer center. For example, a physician expressed a hierarchical view: one that was from the top down. The physician solely took upon themselves the responsibility for the patients’ health, while administrative staff members expressed frustration based upon lack of information and understanding. Interestingly, nurses had the most focused view with regard to self. While physicians and advanced practitioners had a more complete view concerning the whole patient in a physical way, and administrative staff had a more complete view of the patient’s personal life, nurses were mostly focused on their responses to the real-time physical, and sometimes emotional, needs of the patient. This was especially true for nurses who administered chemotherapy. There was little to no expression of their care within the context of the team, and it appeared as if their care of the patient was almost a singular act. Their use of the word “frustration” had its focus on therapeutic care, especially if they deemed a patient was non-compliant.

Boundary violations were universal. There were participants who did not or were not willing to admit to boundary violations; however, in questions that followed, boundary violations were inadvertently revealed. In one instance, a seasoned nurse denied crossing professional parameters, yet later shared a story of how a relationship grew that was positively life altering for all parties involved. While this situation had a beneficial outcome, it highlighted how intertwined our lives are with the lives of our patients, leading to an increased risk of assuming personal

responsibility for our patients' concerns. Despite this nurse's expressed awareness of the necessity of practicing professional boundaries, her heart dictated otherwise.

Interestingly, non-clinical employees could not articulate the necessity of professional boundaries. While clinical staff admitted having porous boundaries, they couched their answers with an excuse, apology, and even laughter. In comparison, those with administrative-only roles seemed not to understand the importance of maintaining both physical and emotional boundaries. This appeared to increase their experience of suffering and the risk of burnout, as they had fewer coping skills. In a sense, those more clinically educated made the choice to open the boundary gate, while administrative employees walked freely through it, not realizing it was there and/or necessary.

While I expected to hear about boundary violations, I was surprised at the frequency and near universality. With each terminal diagnosis, staff experiences the temptation to cross boundaries. For instance, a non-clinical leader shared how one particular patient "tore at her heartstrings" so much, that she wanted to invite him to her family's Thanksgiving dinner. He was several weeks from death and his decline had already begun. His dog was the most important thing to him and he did not want to leave his dog to join her because he knew it was their last Thanksgiving together. Instead, the staff member and her children delivered a homemade Thanksgiving feast to his home. She expressed that she "knew he was dying" and that she "could not stand that he was alone" on the holiday. As he continued to decline, she struggled with the approaching loss. She still becomes tearful when speaking of him.

In one instance, a staff member shared grief over a friendship that never quite made it to fruition. Toward the end of the patient's life, the staff member was to visit the patient in her home. They frequently sent texts to each other throughout the day, sharing common interests.

The patient wanted to meet so that she could show the staff member some of the things they had in common in person instead of through text. Unfortunately, the patient started to decline and asked her husband to call the staff member to cancel, stating that she did not want the staff member to “remember her that way.” The staff member and patient continued to exchange texts right up until the death. The staff member later learned that the patient had “longed to become friends” with the staff member. Besides feelings of sadness and regret that their desire for friendship did not come to fruition, the staff member expressed feelings of anger that the “patient made the decision for them” and that she “had no say.” She appears to carry her feelings of unresolved grief.

Administrative staff appeared to have greater feelings of sadness based upon their access—or lack of access - to patient information. Some staff members expressed feelings of anger that they had not known the patient was nearing death. There was no sense of closure and was no opportunity to say “goodbye” which led to feelings of anger, frustration and sadness.

Administrative staff members expressed that they “need closure” to move forward, expressing regrets and sadness that “no one thought to tell us that this was the last time” (that they expected to see the patient).

Additional expressions of sadness were associated with the patient’s family, before and after death. Staff members on all levels expressed sadness due to the loss of connection to the patient’s family. In addition, they expressed feelings of sadness, and often anger, when the patient’s family member did not appear to support the patient, or if the patient’s family seemed distant or to seemingly not understand the severity of the situation. All staff members expressed that they felt as if the patient was “family,” with some approaching the situation as a type of pseudo-family member. This phenomenon allowed the staff member to express a well-meaning

superiority to the family member due to the blurred lines of role in her or his life. Feeling psychologically connected as pseudo-family is a boundary issue that appears to draw the staff member into a greater experience of suffering. This is due to the real-time confusion of position in the patient's life.

Interestingly, I heard symptoms of spiritual distress, which mirror burnout, also known as compassion fatigue. Almost all participants expressed feelings of doubt, an occasional sense of a loss of purpose, resentment, bitterness, anger and frustration, avoidance, or desire to isolate from others, disengagement or disconnection from others, including family members, hopelessness, lack of motivation, and the inability to engage in faith practices. Lack of compassion or empathy toward patients was not present, but it was present in the data regarding family members and other team members. Lack of compassion was greatest toward the family of the dying patient, especially if staff members perceived that the family members did not appear to be supportive of the patient.

Surprisingly present in the study was grief over the loss of the relationships with the family members of the deceased. Most team members, especially those whose boundaries were more porous, acknowledged the sense of loss associated with the drastic break in the relationship due to the death. Captured in the data was how the relationship with the family increased as the patient neared death. There appears to be a unique space in the time leading up to death, as the patient withdraws from life. Family members often grow in relationship with staff, as they "know" them through the experience of their loved one. This forms what appears to be an instantaneous, close bond as the family member(s) tries to hold on to their loved one. The sense of role in the therapeutic relationship becomes even more blurred, and staff members and family members both gain something from the connection. Family members have the experience of

comfort in being close to someone that their loved one felt close to. The staff member enjoys an elevated sense of position in the relationship, which often includes a boost to the ego as well as the experience of a greater sense of power that lasts up to the moment of death, and often a little beyond. Ultimately, the break comes, the ego boost immediately leaves, and the increased feeling of power dissipates. This experience magnifies our loss of someone for whom we genuinely care and feel emotionally connected to as “family.” As the family moves on to grieve together, the staff member is alone, feeling like an outsider. Collectively, briefly addressing grief superficially as sadness is the norm. What is not considered is the profound loss associated with the addition of the ego boost and increase of power, coupled with dramatic loss.

The concept of “feeling like family” explains the expressions of anger toward patient’s family members, particularly when the family members acted in a way that did not appear supportive (in the opinion of staff) of their dying loved one. Multiple staff members, from physician, to administrative staff, expressed feelings of confusion over their place in the relationship. Staff members expressed feelings of judgment and anger towards family members who made choices counter to choices they wanted to be made for the patient. These choices most often centered on presence. Whether presence at appointments, rides for chemotherapy, or even visits at home, staff members expressed difficulty in disconnecting from their sympathetic emotions of the moment. They found difficulty assimilating a more complete view that the patient may have contributed to the negative history with her or his loved ones.

Lastly, participants in the study who were questioned about religious belief, their understanding of God, the afterlife, and were able to articulate their beliefs well appeared to have greater stores of resilience from which to draw. A Table Talk titled *SPIRITUAL RESILIENCE* by Dr. Sarita Wilson-Guffin Director; Spiritual Care Le Bonheur Children’s Hospital, defines

spiritual resilience as “the ability to maintain a positive spirit even in the face of adversity.” Dr. Wilson-Guffin states that a person, regardless of religious affiliation, can seek strength through a “higher power.” According to Wilson-Guffin, when one is in a difficult situation, the person should form their own set of beliefs, principles, or values as a way to overcome setbacks in their personal or business life. The goal is the reduction of suffering. (Wilson-Guffin, 2020) It is about overcoming and getting through, which we all want to do. We want to maintain a positive spirit in the face of adversity because adversity does not feel good. Most participants believed that their patients are in a better place, absent from suffering, with God, with those they love, in Heaven, and out of pain. The one non-Christian participant stated that she does not like the term “God” yet rather likes to think of a return to a “collective consciousness.” Only one participant mentioned the existence of Hell and admitted a theology that believes that only Christians who profess belief in Jesus Christ are in Heaven. She was not sure if all are there, yet expressed feelings of responsibility and grief for her patients who did not “accept the gospel message.” (Feinberg, 2023)

I was surprised by the responses to questions about religious coping. Staff members struggled to articulate their beliefs about God and the afterlife. Most stated that the afterlife was a “place of no suffering” and that our “patients are now at peace.” Others expressed feelings of responsibility regarding the patient’s assurance of salvation. One staff member expressed disappointment in herself that she did not ask the patient directly if he “knew Jesus as Lord and Savior.” She appeared to struggle with guilt that she “did not have the courage” to ask him and that “he might not be in heaven.” During the interview, she began to cry, not because the patient had died, but because “he might be in hell.”

This is in comparison to the staff member who preferred not to use the word “God” as a/the divine being, as she articulated a concept of a “collective consciousness.” She described the afterlife as a state where the separated consciousness returns to the collective. She expressed belief that the consciousness contributes to the body of knowledge: that what the person learned on earth while united to the body is information that is then available to help future humans. She stated that she “likes to think what we learn can be of help to others.” Her concept was well thought out, authentically hers, and a source of comfort to her. Interestingly, she expressed greater feelings of peace regarding her concept of the afterlife than the staff member who expressed feelings of guilt for not assuring that her patient was “saved.” It appeared as if the one staff member’s faith required something more tangible to hold on to as a way to find peace with death, where the other could let go because she was more comfortable with what she could not control.

The Consequences of Suffering: Short-Term; Long-Term; Personal and Professional

A literature review by Helen A. H. Sinclair and Conal Hamill titled, *Does Vicarious Traumatization Affect Oncology Nurses*, looks at Sinclair's experience as a ward-based oncology nurse. While she noted the benefits of her work, she also noticed "potential negative intrinsic changes occurring in nurse colleagues, possibly as a result of caring for individuals with cancer." In her ward, nurses were not enjoying the same activities that they used to, and they started distancing themselves from friends. They were also experiencing existential suffering, asking about the meaning of life. Sinclair's review enumerates many of the same risk factors as in other articles, including the development of compassion fatigue, the impact of secondary stress, and feelings of disconnectedness from others. There is a thread of commonality sewn throughout the articles. (Sinclair and Hamill, 2007, 348-356)

Robert J. Wicks, in *Overcoming Secondary Stress in Medical and Nursing Practice: A Guide to Professional Resilience and Personal Well-Being* identifies the dangers of secondary stress. He breaks down this type of stress into three components: chronic secondary stress, otherwise known as burnout, acute secondary stress, or PTSD, and "unique unhealthy aspects of the medical healthcare culture." While he notes there is much overlap, Wicks lists twenty common causes of burnout. (I used fourteen for this study.) The themes I discovered during my interviews with staff are on his list. Understanding them is key to formulating healthy strategies to counter compassion fatigue, therefore, leading to taking the necessary steps to avoid burnout. (Wicks, 2006, 14-25)

Table 3: Wicks' Causes of Burnout

1. Inadequate quiet time –physical rest, cultural diversion, further education, and personal psychological replenishment.
2. Vague criteria for success and/or inadequate positive feedback on efforts made.
3. Guilt over failures and over talking out time to nurture oneself properly to deal with one's own legitimate needs.
4. Unrealistic ideals that are threatening rather than generally motivating.
5. Inability to deal with anger or other interpersonal tensions.
6. Extreme need to be liked by others, prompting unrealistic involvement with others.
7. Neglect of emotional, physical, and spiritual needs.
8. Poor community life and/or unrealistic expectations and needs surrounding the support and love of others for us.
9. Working with people (peers, superiors, those coming for help) who have burnout.
10. Extreme powerlessness to effect needed change of being overwhelmed by paperwork and administrative tasks.
11. Serious lack of appreciation by our superiors, colleagues, or those whom we are trying to serve.
12. Sexism, ageism, racism, or other prejudice experienced directly in our lives and work.
13. High conflict in the family, home, work or living environment.
14. Serious lack of charity among those with whom we must live or work.
15. Extreme change during times in life when maturational crises and adjustments are also occurring (e.g., a 48-year-old physician who is being asked to work with patients diagnosed with cancer at time when she has just been diagnosed with cancer herself

16. Seeing money wasted on projects that seem to have no relation to helping people or improving the health care system
17. Not having the freedom or power to deal with or absent oneself from regularly occurring stressful events
18. Failure to curb one's immature reasons for helping other and to develop more mature ones in the process
19. The "savior complex"—an inability to recognize what we can and cannot do in helping others in need
20. Overstimulation or isolation and alienation

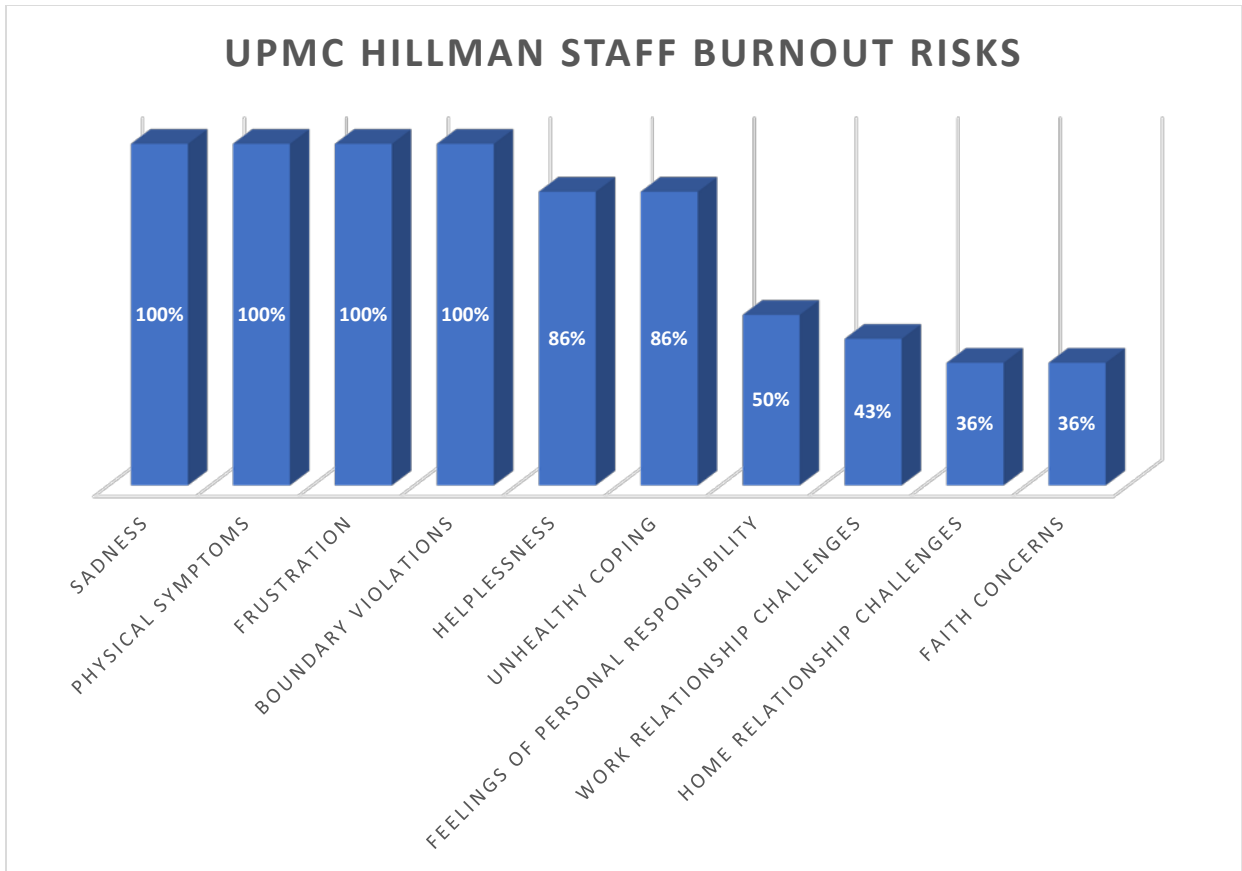
(Wicks, 2006, 20)

While Wicks admits that his list is certainly not comprehensive, he does state that the cause of burnout is some type of deficiency, such as the lack of education, opportunity, free time, or a chance to ventilate, to name a few. Most interestingly, he states that the *lack*, whatever it may be, causes *frustration* (my emphasis). He notes that healthcare professionals are always at risk for burnout. In healthcare, there is risk of impaired performance as grief and anxiety experiences compound, moving the person from burnout to distress. Wicks as consequences of burnout as apathy, inability to judge effectiveness of work, loss of interest in professional resources, such as learning opportunities, intermittent periods of irritability, depression, and stress that never seems to go away. Eventually, the healthcare worker may experience a form of vicarious post-traumatic stress disorder (PTSD), which, according to Wicks, drags us down and sweeps us away, leading to what he calls "severe emotional impairment" that leads to "inadequate treatment of patients due to one's emotional state." This state leaves the worker at risk, affecting the team as a whole. Furthermore, these iterations of burnout create challenges for the healthcare system, which

includes the high turnover of employees, negatively affecting the system's bottom line. This leads to additional occasions for burnout due to short staffing and increased workload.

Ultimately, and most seriously, Wicks states, burnout and its subsequent move to deeper levels of psychological crisis may very well put the patient in physical peril.

Table 4: Identified Staff Burnout Risks



Each person in the study expressed feelings of sadness regarding their losses (Table 4).

While we may all be sad at times in our lives, the complexity of this expressed sadness falls more along the lines of complicated or disenfranchised grief. In addition, grief related physical symptoms, expressions of frustration and boundary violations were also unilateral across disciplines. When staff members feel a profound sense of loss yet do not give themselves permission to grieve appropriately, there is a psychological impact. This impact was apparent at

the start of most of the interviews. Most participants immediately started to cry when reflecting upon the patient. This was even before I asked the first question. All participants stated that their patients “felt like family.” As mentioned in my initial impressions, a pseudo-family relationship happens in the ambulatory oncology setting. Despite the artificial construct of this relationship, the feelings of loss appear to be as intense as when one loses a natural family member. When the feelings do not feel justified by the staff member, the feelings are buried, and the person attempts to move on. Unfortunately, this is not a singular instance, so staff members experience multiple instances of trauma, often in a very short timeframe. Without the tools to process the losses, the trauma of grief builds up, physical symptoms occur, frustrations happen, all of which leads to psychologically, physically, and spiritually unhealthy individuals and teams.

Every staff member interviewed experienced physical symptoms that were attributed to work with oncology patients. A sense of extreme exhaustion was the symptom mentioned most often. Hypersensitivity was another symptom, especially concerning the inability to enjoy entertainment that provokes an emotional reaction. There were also expressions of hypersensitivity to non-care related instances, such as in “fearing the worst” when family members are ill, or in their personal relationships. Hypersensitivity, feelings of frustration and burnout can all lead to over or undereating, drinking too much alcohol, and other methods of self-medicating. An example of this is wanting to disengage from home relationships. Other physical manifestations contributed to their work are gastrointestinal issues, such as stomach upset and diarrhea. Some staff members admitted a decrease in the desire for previously enjoyed activities, such as outings/social activities with friends or family, a decreased in enjoyment of and desire for sex, and less patience for assumingly “trivial” conversations with family and friends after work. These conversations seem superficial to the employee in comparison to the

work experience, leading to frustration at home. Conversely, work relationships are less affected, due to the shared experience of work-related stress.

By listening to the stories of our team members, I was able to hear suggestions that may begin to start the process of healing for us all. I asked each team member about their interest in team support groups and educational opportunities during work hours. All team members expressed openness to the opportunity to participate in a team support group, with many stating, “It would be a good place to get my feelings out.”

There is a great need and opportunity to provide training on various topics found on Wicks’ Causes of Burnout table. Unexpectedly, I learned that those who are less clinically educated are more prone to inadvertent and less overt boundary violations. Most staff members violated boundaries with their recollected patient in one way or another. Those who did not have some type of formal clinical education did not seem to understand the necessity of setting boundaries.

For example, administrative employees did not express feelings of compunction regarding the sharing of personal contact information, such as a cell phone number. Most staff admitted that these patients contact them outside of normal working hours. Without a clear understanding of the necessity of a proper work /life balance, the staff member feels obligated to respond or meet the patient’s needs in real time. Whether their feelings of obligation to respond is due to a desire to be liked, failure to curb one’s desire to help, our “savior complexes,” or even the unrealistic expectations that we have for ourselves, the intent for doing so requires further investigation.

We must educate staff members regarding the necessity for boundaries. This includes solidifying and communicating the process for all patient communication, especially when patients require clinical help. In addition, we can coach our teams to use their power in a healthy

way. We do this by suggesting tools such as the use of personal focus on phones, and by providing gentle language to redirect patients who call or text for health concerns outside of hours. To summarize, one seemingly small boundary violation has the potential to trigger multiple causes of burnout. This includes overstimulation, which leaves the healthcare worker emotionally, physically, and even spiritually depleted. Creating and implementing an achievable action plan to counter the spiraling of our ambulatory oncology teams is imperative to the health and well-being of our oncology teams.

The Importance of Boundaries and Awareness of Power

In his book *Just Ministry, Professional Ethics for Pastoral Ministers*, Father Richard Gula provides a framework for professional boundaries in the context of pastoral ministry. In my professional experience as chaplain, relationships in the oncology setting are deeply spiritual, affecting both patient and staff members in an intimate way. It is not unlike the experience in a faith community, where there is at least one weekly connection coupled with various levels of contact throughout the week. Getting to know the patient and building a trusted relationship is central to healing.

Hospital systems are highly hierarchical, just like the Church, with each person possessing a certain level of power, even in the most collaborative of teams. Healthcare workers, especially those who do not have clinical training, are often reticent to acknowledge or understand the power we possess in our roles as healthcare workers. In addition, we have a suspicion of power, as it feels arrogant or abusive if we admit a power imbalance in the relationship. However, if we, as Father Gula recommends, look at power as a capacity to influence, we can then be careful to be ethical in all of our interactions. While speaking for the context of pastoral ministry, Father Gula's advice concerning the proper use of power is relevant to the healthcare setting. He articulates well that the way to honor that the source of power, God, is through the building of healthy relationships. (Gula, 2010, 121)

Wicks speaks of this as he talks at length about the power of transference. While we normally believe that transference is a psychological principle reserved for physicians, clergy members, or others in authority, transference happens within the context of the whole of a therapeutic setting. This is especially true in an ambulatory cancer center. Wicks states that

patients, and sometimes coworkers, “transfer positive or negative feelings onto physicians, nurses, or other healthcare professionals.” (Wicks, 2006, 52-53, 57) It therefore makes sense that non-clinical administrative staff may not have the self-awareness to realize that they are an essential part of the healthcare team. Therefore, it is imperative to increase awareness of their power in the therapeutic relationship.

This knowledge of power is important in our ambulatory oncology setting, as we lack an understanding of or willingness to practice boundaries. Father Gula speaks of three types of boundaries that are important in the context of our unique power. Father Gula describes boundaries of time, which is a boundary that shows a commitment to the other. An example of this is limiting how many projects we take on to safeguard our emotional, mental, spiritual, and physical health. He moves on to boundaries of space, which is a way to respect limits on where our care occurs. For example, if we are working with patients in the name of the hospital system, we provide care in a specific, safe location. Moving the relationship outside of the clinical setting into the social realm, such as in a coffee shop or somewhere else, confuses the relationship. Ultimately, keeping our role clear and professional as healthcare workers protects both the patient and us, as it limits confusion regarding the meaning and purpose of the relationship. Lastly, he speaks of boundaries that honor physical and emotional limits. This set of boundaries is expansive as it can mean anything from unwelcome physical touch to getting too involved in another person’s life. It includes gossip and breaking confidentiality. (Gula, 2010 130-131)

The crossing of boundaries can cause personal and communal distress. The lack of appropriate boundaries is a major contributor to spiritual distress, particularly when it comes to breaking trust. It has the potential to cause distress when we overlay our professional relationships with personal needs, such as using the interaction to receive emotional fulfillment.

Many who work in helping roles are here because the work feels more like a calling than a job.

When our feelings lead, we may cross boundaries to fulfill a personal need. Getting to the root of our motives for crossing boundaries requires personal reflection. Doing a good thing for a patient or their family member(s) is not wrong as an outcome, per se; however, if the action is done for self-fulfillment, such as to look or feel good, then it only serves the ego. This does not mean that good feelings are wrong or bad; rather, they become problematic when they are our only motivation. This work often requires sacrifice, and there are many day-to-day tasks related to patient care that are burdensome. This includes many of the administrative tasks, such as scheduling, making phone calls, and documentation. The formation of healthy boundaries is the foundation needed to serve others with purity of intent. The practice of healthy boundaries and examining intent are, in my opinion, some of the greatest remedies and protections against distress and unnecessary suffering.

A common boundary violation in the research is Gula's boundary of space. Most interviewed provided their cell phone to a patient at one point in their career. Many staff members formed relationships with patients outside of the clinical setting, with some meeting patients in their homes. Others met patients in social settings usually reserved for close friendships. This causes confusion in the relationship, as mentioned by Father Gula. In my opinion, based upon the interviews, this boundary violation has the potential to cause the greatest distress in our teams.

The Secular and Philosophical Understanding of the State of Suffering as Part of the Human Condition

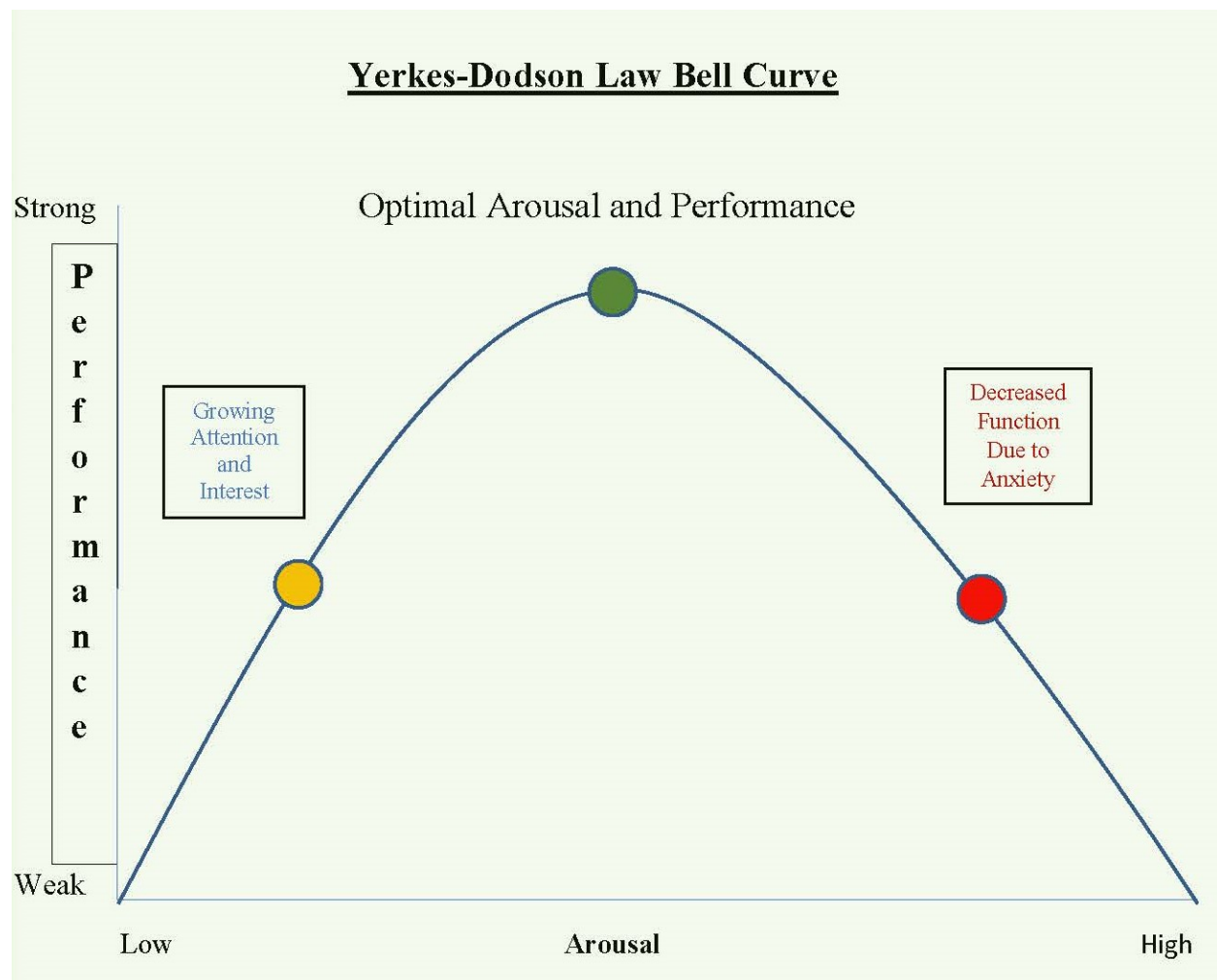
In his classic work, *Civilization and its Discontents*, Sigmund Freud highlights the human need for contrasting feelings in order to experience happiness. He states that humans begin in a state of restriction; therefore, “unhappiness is much less difficult to experience.” He clearly states how humanity is threatened by suffering: “from our own body: which is doomed to decay and dissolution and which cannot “even do without pain and anxiety as warning signals; from the external world, which may rage against us with overwhelming and merciless forces of destruction; and finally from our relations to other men.” Ultimately, Freud admits that what causes suffering is out of our control. He wants to find the meaning of life, yet devoid of a higher purpose or belief in something greater than humanity, Freud admits that it may not be possible to answer this question. Therefore, while we as humans may at times have feelings of happiness or contentment, and while there may be strategies in which suffering may be mitigated or avoided for short periods, suffering is humanity’s inevitable fate. (Freud, 1930, 54)

In his article, *Why Emotional Suffering Persists*, Peter Michaelson highlights that human suffering is a chronic condition. It is a passive condition consisting of “unresolved negative emotions,” of which a lack of self-knowledge magnifies. In summary, our suffering comes from a natural “unconscious appetite for displeasure.” Ultimately, we are born to suffer and suffering is an internal process. (Michaelson, 2012)

Suffering as Inspiration to Create and Act

In Clinical Pastoral Education (CPE), the chaplain or pastoral student learns the Yerkes-Dodson law. To summarize, in this psychological law, an optimal level of stress is required for the human organism to act.

Table 5



(Yerkes-Dodson, 1908)

As you can see from the diagram, there is an optimal level of arousal required for optimal performance. Too little stress or anxiety produces the same result as too much, as manifested in

behaviors such as lack of motivation, feeling that life is meaningless, and the inability to realize one's full potential. This is why the reality of death is so important: without the risk of the inevitability of death, there is no reason to move past boredom and comfort to create. A healthy understanding of suffering, death, and the limitation of time and health of body, inspires the person to act sooner rather than later for fear of running out of time. The sense that life is limited inspires the person to act, whether it be to create legacy, enjoy experiences, explore interests, and mostly, to express love in its various forms.

Major World Religions' View on Suffering

In the article *Religious Perspectives on Human Suffering: Implications for Medicine and Bioethics*, Fitzpatrick and colleagues assert that in Judaism, the goal of prayer is to avoid suffering, if possible, and to have the strength to endure it when it happens. Healing is also the goal of prayer. In the Jewish tradition, the belief is that suffering is both individual and collective, and that suffering always calls for a response. In the same article, the authors make the argument that the “social welfare, charity, medicine, and science needed to respond to suffering are acts of justice, the response of the human, the argument of the human hand against an unjust and as yet unredeemed and darkened world.” Ultimately, for the Jewish person, healing comes by having a perspective on the moral suffering of the individual and/or collective, that “pain, grief, illness, and befallenness are understood as disorder, without spiritual value, and not linked to spiritual journey or transformation,” and that we have a God who suffers with us, walking alongside us in exile. (Fitzpatrick et al., 2016, 159-173)

Catholic/Christian teaching uses both faith and reason to understand suffering. In the Catholic faith, suffering is seen as a consequence of sin. (Catechism of the Catholic Church, 418) However, just as Jesus' suffering has a redemptive effect for all of humanity, individual suffering, when united to the will of God, is also redemptive, and can be transformative. Fitzgerald and his collaborators point to the close relationship between suffering and spiritual growth. The authors infer that by understanding and accepting our human condition, and uniting our suffering to God in prayer, we both acknowledge our helplessness and enter a gateway that allows us to share in Christ's sacrifice on the Cross. This leads us to a gateway of love, despite our human condition, allowing us to love unselfishly by taking on the suffering of all. This

ultimately gives meaning to our suffering as we look beyond ourselves and become active contributors to Jesus' redemptive work.

In all the major world religions, there is a component of the natural and the divine. In Islam, suffering can come from the human or even from God, as nothing in life happens without the permission of God. Hindus believe in the law of cause and effect, called karma. Both Muslims and Hindus may avoid the alleviation of suffering, as suffering serves a religious purpose. For the Muslim, there is "merit to suffering" as it may expiate some of the person's sins. For the Hindu, suffering may be a "test of faith" or a "means for gaining knowledge." Buddhists also believe that humans learn from suffering. They see opportunity in it by creating a place for great empathy. In a sense, the sufferer then becomes a great healer because they are able to understand suffering on a deeper, more personal level. All the world's major faith traditions believe that suffering is inevitable. (Fitzpatrick, 2009)

The Nones and Other Religious Belief Systems

An article by the Pew Research Center concludes that the number of Americans who do not identify with any religion is growing at a rapid pace. According to the 2012 article, “one-fifth of the U.S. public – and a third of adults under 30 – are religiously unaffiliated today, the highest percentages ever in Pew Research Center polling.” (Pew Research Center, 2012) Linda Woodhead who, through her research, wrote that there was a “rise of no religion” whose members formed a “new cultural majority” confirms this. The term that she coined for identifying this non-religious group is “nones.” (Woodhead, 2017, 246) This flourishing faction is an important challenge for any chaplain, particularly in the context of ambulatory oncology care.

Rowan Williams, a contributor to the book *The Christian Theology of Chaplaincy*, concluded in his chapter titled *All Faiths and None: Theological Issues in Multi-faith Chaplaincy*, that there is a rising group of persons who “search for meaning and purpose outside of organized religion.” He describes these individuals as being located within the “interstices of the patchwork of faiths and beliefs to be found in contemporary society. This, as he admits, is an increasing challenge for those who strive to grasp how this population works through the trials of life, without, according to Williams, “diluting what is distinctive and valuable in every faith tradition.” (Caperon et al., 2017, 76)

Cultural humility on the part of the spiritual care provider is a necessity as we move into a world that increasingly renounce traditional religious practice. Ultimately, care for the “nones,” including those with ideologies that move outside of traditional theistic understanding, must acknowledge that the individual is the expert regarding their personal belief system. This is

especially true if the spiritual care provider does not agree with the other's ideology or theology.

In my opinion and experience, when the spiritual care provider strives for understanding through listening, it creates space for authentic connection.

Lessons of Suffering for the Ambulatory Oncology Team

Wicks does not shy away from the darkness healthcare workers experience as they suffer. In fact, he uses the word darkness, a word in the spiritual care world that is often associated with John of the Cross' Dark Night of the Soul. (John of the Cross, n.d., 19) The difference in concepts is that while John of the Cross deems the experience of spiritual darkness as necessary to move forward in the life of prayer. The classic Dark Night is an entryway to greater depths of prayer, ultimately leading to union with God.

Whereas John sees suffering as necessary, Wicks understands the darkness caused by burnout as completely unnecessary. Wicks writes about how we absorb the pain of others through our senses, mainly through the hearing of stories. In 1994, he started doing psychological debriefings with a group of Rwandan relief workers who, after evacuation from the Rwandan civil war, were experiencing many of the same symptoms that our ambulatory oncology staff have verbalized. They were prone to feelings of guilt, futility, and other emotional challenges due to their proximity to war.

After listening to their stories, he provided educational materials specific to the manifestation of symptoms, such as sleep issues, flashbacks, etc. Lastly, he did something akin to what is called in Christianity an Examen or Examination of Conscience. Wicks calls it a "countertransference review" where he asks himself the questions of "What made me sad? Overwhelmed me? Sexually aroused me? Made me extremely happy or even confused me?" Per Wicks, this practice demands brutal honesty and increases self-awareness. According to Wicks, it also lessened the pain and other symptoms that he was experiencing due to his own vicarious trauma. (Wicks, 2006, 34-35)

Vicarious, or secondary, trauma or suffering is a phenomenon of interconnectedness. The Rwandan relief workers did indeed suffer trauma; however, Wicks too suffered trauma, albeit secondary, due to his listening stance. In the context of ambulatory oncology work, staff members are in proximity to suffering on a constant basis, continually exposed to the pain of others. The difference between the suffering of Wicks and our oncology team is that Wicks had an understanding that he was not carrying his own pain. His self-awareness strategy helped him to let go of suffering that was not his to carry in the first place.

Growth happens, despite proximity to suffering, as we become more self-aware. As we increase in our knowledge of self, we begin to look at our own challenges more objectively. Wicks infers that we often have negative self-talk that contributes to our sense of suffering. In my work with patients, I find that a non-judgmental stance and the tool of reframing may move a person from a stance of cursing self (e.g., “I am such an idiot.”) to a stance of blessing oneself. (e.g., “There is opportunity in every mistake. Thank you, God, for the opportunity to practice humility”) Once our negative self-talk changes, our thought process becomes healthier, leading to Wicks’ “classic signs” that a person values change. These indicators, according to Wicks, include having an ability to let go, not being self-righteous, being curious and not judgmental, being awake to the present or mindful, and, most importantly, learning, reflecting, and applying wisdom to daily life. It through our growth in positive self-talk that we see ourselves as good instead of failures.

Application of Lessons

Staff members often come to me with symptoms of burnout. The research not only confirms that it exists in our care setting, but also highlights that it is a chronic issue. Just like the palliative chemotherapy that we give to our terminal cancer patients, our response too must be palliative in nature. This “disease” of burnout is much like a malignancy infecting the healthy cells in our team. In a limited group of staff members, and because of personal experience with grief and loss, I have prescriptively taught modified versions of simple, achievable spiritual practices. For example, I prescribed a version of the practice of Sabbath to a staff member who was clearly experiencing burnout or compassion fatigue. She expressed to me that she “became angry every time her (office) phone rang” and was ready to give her notice. Her anger was a symptom of a larger problem. After extensive listening, the staff member received instructions to schedule a 90-minute time of Sabbath, one time a week. The time was immovable. A month after utilizing the practice, she reported that she experienced better coping and an increase in job satisfaction, even in the midst of a busier than normal schedule. While this staff member eventually moved on to another position outside of the Cancer Center, she stayed relatively happy during her remaining employment with Hillman. The “treatment” of a spiritual practice helped the staff member cope better, if only for a short time. With more sustained and dedicated programs, education may breathe life into our suffering team.

Education, including the implementation of a continuous quality improvement (CQI) project, is an appropriate way to educate our teams. In collaboration with the Relationship-Based Care Leadership and Nursing Education, team members from every discipline have the opportunity to create an educational offering to raise awareness of the major themes of this

paper, including understanding and acknowledging our grief. This, of course, would include the practice of boundaries. For example, some staff members have given patients their personal cell phone numbers. These patients often call after hours for work-related issues. After providing education as to why keeping this boundary is important (necessary work-life balance, there is already a process in place for emergent, after-hours calls, safety of patient, liability, etc.), we can then move to teaching the needed language to help the staff member reclaim and maintain that boundary for the future. Moreover, if individual staff members contribute to the initiative and if it is presented in a fun way, such as the creation of videos, complete with advertising posters, playbills and popcorn, it will hopefully increase buy-in and engagement.

Lastly, all employees expressed a desire to participate in support groups during work hours. These may come in the form of support and/or accountability groups. These groups have the potential to strengthen work relationships, moving them away from such compelling familial feelings toward their patients. These support/accountability groups have the prospect to address this phenomenon, and may help with feelings of disenfranchised grief and vicarious traumatization. Lawrence S. Cunningham and Keith J. Egan acknowledge the joy of friendship. In their book *Christian Spirituality: Themes from the Tradition*, they explore the spiritual dimensions of friendship. They dive into scripture and how it “emphasizes the notion of covenant” when speaking of friendship. Telling stories of friendship through the sharing of personal letters, there is an apparent spiritual aspect and common language that friends use with each other. Stories included from the classical tradition makes it is easy to discern that friendship is a gift from God. Cunningham and Egan quote Augustine who stated, “There is no true friendship unless You (Christ, my emphasis) weld it between souls that cleave together through that charity which is shed in our hearts by the Holy Ghost who is given to us.” There are also

models of monastic life and the friendships found there amongst individuals who are joined in a single purpose, that is, to serve God authentically in the spirit of community. Speaking to friendship in the twenty-first century, they state, “friendship is more than personal, more than a one-on-one relationship. Friendship is a movement toward community that yet maintains the intimacy of friends. A society that does not foster friendships will soon come apart at the seams.” They encourage their readers to become familiar with the “great traditions of friendship,” particularly through the multitude of historical and literary sources available. This enables understanding the deeply spiritual and religious aspects of friendship. (Cunningham and Egan, 1996, 163-166)

Oncology workers are a community. Cancer care teams share a specific mission: to heal and to serve cancer patients. This healing often comes through medicine yet it is also achieved through the compassion and care of whole teams. By working together in our common mission collectively and holistically, we have an opportunity to collaborate to fulfill that mission. In the context of our ambulatory oncology teams, the longstanding understanding of the spiritual aspect of friendship may be of importance. In their chapter on friendship in the book Cunningham and Egan state, “Cicero knew that friendship makes people better citizens. In the ancient world, friends took time to engage in conversation. Then as now friends as conversation partners raised the quality of life.” (Cunningham and Egan, 1996, 167-168) This too can be true when we as a healthcare team recognize and honor our communal grief through conversation, whether formally or informally. This may allow our workers to find opportunities to increase quality of life, to hold each other accountable for boundary violations, and to become happier healthier people within the context of their work.

Oncology workers care for the patient with competence and love, as a whole person. The opportunity we have moving forward is to work toward building a healthy, spiritually well community in our teams *first*, with a strong foundation. This foundation includes self and group work to strengthen the boundaries with the patients, to examine intent, and to acknowledge the existence of power.

Conclusion

Boundary violations are at the root of the team's suffering and are prevalent at all team levels. Most suffering, whether it be from disenfranchised grief, feelings of inadequacy, or suffering due to the loss of significant relationships after a patient death, can all be traced back to porous boundaries. Notably, boundary violations differ between clinically educated versus non-clinically educated staff. Clinically educated staff, such as physicians, advanced care practitioners, nurses, and chaplains, must make a conscious decision to open an imaginary protective "gate" provided by their training before they violate the boundary. They express awareness of the boundary violation(s) and make an excuse as to why the violation was necessary. On the other hand, the administrative staff interviewed for this study do not appear to have the same protective "gate" as clinical staff. There is only a wide-open path leading to a plethora of opportunities to violate professional boundaries. This may be due to less clinical education or proximity to patients and families in the more relaxed setting of a waiting room. This requires more exploration. In all instances, the intent for the boundary violations is often the result of the desire to help the patient. Often, it is a misguided attempt to make life easier for someone who is suffering greatly. Other times, it is the result of a desire to get to know the patient more deeply. In any case, boundary violations place individual staff members at risk of burnout and, ultimately, the greater team and health care system through both absenteeism and the high cost of employee turnover.

Moving forward, all ambulatory oncology team members must be educated in the importance in the practice of professional boundaries, be given the language to use when patients and their family members press boundaries, and given encouragement to hold team members at

all levels accountable for such violations. Other offerings must include support or accountability groups as a way to work through and honor the emotions of failure, discouragement, sadness, and frustration, while holding each other accountable for unhealthy behaviors. In addition, the creation of ways to honor patient deaths is imperative, as team members require closure. Individual teams can design the ritual, including elements that help, and disregarding others that do not. This can be as simple as reading each name out loud at a staff meeting, or by memorializing patients in a more creative way, such as creating a “obituary book.” Ultimately, this study provided salient insight as to the needs of individuals and teams, as well as the opportunity to move forward in a beneficial way. We must do this by shifting the focus of relationship building between staff and patients, to encouraging team members to reinforce their work relationships with education and relational programs. This approach must be collaborative to be sustainable with the goal of creating healthier, more balanced, and ultimately, stronger teams.

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Barbour, Lisa C. "Exploring Oncology Nurses' Grief: A Self-Study." *Asia-Pacific Journal of Oncology Nursing* 3, no.3 (2016): 233–240. doi: 10.4103/2347-5625.189817.

<https://doi.org/10.4103/2347-5625.189817>

This is a self-study pertaining to grief post-patient death. The author noticed feelings of sadness and helplessness upon the death of her parents, yet found that she also experienced feelings of frustration, fatigue, and anger. She suggests additional studies on this topic, including whether some type of public memorial/ritual would lessen nurses' suffering.

Batcheller, Joyce, James Davis and Patricia S. Yoder-Wise. "Hope for the Future: Intensifying Spirituality in the Workplace." *Nursing Administration Quarterly* 37, no. 4 (2013): 309–316. doi: 10.1097/NAQ.0b013e3182a2f9ae

Spiritually rooted "servant leadership" is key to a healthy workplace environment. Acknowledging the worth of the individual begets a culture of person-centeredness. Spirituality is broadly defined, however, as is servant leadership and person-centeredness. The article also integrates psychosocial and physical issues as a model for workplace wellness. While the article addresses the need for spirituality at work.

Bhutani, Jaikrit, Sukriti Bhutani, Yatan Pal Singh Balhara and, Sanjay Kalra. "Compassion Fatigue and Burnout Amongst Clinicians: A Medical Exploratory Study." *Indian Journal of Psychological Medicine* 34, no.4 (2012):332-337. doi: 10.4103/0253-7176.108206

Defined as having two components, compassion fatigue consists of burnout and secondary traumatic stress. Exposed to other's trauma on a consistent basis, oncology team members experience a negative affective state. This negative state relates closely to spiritual distress, as many of the named symptoms overlap. A suggestion of "better working conditions" marries well with this author's research topic, as strong spiritual health can contribute to a stronger community. One of the challenges of the study is that it is not cancer specific and admittedly heterogeneous.

Board of Chaplaincy Certification Inc. "Qualifications for Board Certified & Associate Certified Chaplains." Last updated February 2021. <https://www.apchaplains.org/bcci-site/becoming-certified/qualifications-for-board-certified-associate-certified-chaplains/>.

Chaplains undergo rigorous training to become board certified. They require a Master's level education, four units of clinical pastoral education, in addition to faith tradition endorsement, and 2000 hours post-CPE clinical/pastoral care work prior to certification.

Braun, Virginia and Victoria Clarke. "Thematic Analysis." The University of Auckland. Accessed January 13, 2022. <https://www.psych.auckland.ac.nz/en/about/thematic-analysis.html>.

This provides detailed steps to identify patterns and meaning to answer a research question. It highlights a flexible research method that allows the research to move between various frameworks.

Braun, Virginia, and Victoria Clarke. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology* 3, no.2 (2006): 77–101. doi: 10.1191/1478088706qp063oa.

This is a detailed systematic guide in doing Thematic Analysis, including the reasons as to when to use it. In this outline, the reader learns how to deliberately and systematically search for themes or patterns in the research in the context of the reality of the subject.

Brown, Brené. *Atlas of the Heart: Mapping Meaningful Connection and the Language of Human Experience*. New York: Random House, 2021.

Brown maps out eighty-seven human emotions and experiences. Grief experiences and subsequent sadness are the result of a painful occurrence; however, Brown highlights how these “negative events” are often the pathway to greater connection with others. She goes on to remind the reader that the result of these traumas creates greater empathy, connection, and have the potential to make us better humans.

Caperon, John, Andrew Todd, and James Walters. *A Christian Theology of Chaplaincy*. London: Jessica Kingsley Publishers, 2017.

In his section “All Faiths and None: Theological Issues in Multi-faith Chaplaincy,” contributor Rowan Williams offers his chaplaincy experience with persons who do not identify with a religious tradition. He holds fast to his beliefs as an Anglican priest concerning the question of human suffering, admitting that it is difficult to minister to those whose beliefs do not align with his.

“Catechism of the Catholic Church.” Accessed March 2, 2023.

<https://www.usccb.org/sites/default/files/flipbooks/catechism/106/>.

Part One, Section 418 teaches that all human suffering is the result of sin. According to the Catechism, “human nature is weakened in its powers, subject to ignorance, suffering and the domination of death” due to Original Sin.

“Compassion Fatigue,” | Psychology Today. Accessed February 27, 2023.

<https://www.psychologytoday.com/us/basics/compassion-fatigue>.

Healthcare workers and others in caring professions have prolonged exposure to other’s trauma. This leaves the worker vulnerable to secondary or vicarious trauma. Compassion fatigue manifests itself in physical symptoms, often acute, as well as mental health symptoms. Ultimately, the person becomes numb and no longer wants to give or care in their work.

Creswell, John W., and J. David Creswell. *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*. 5th edition. Los Angeles: SAGE Publications, Inc, 2018.

This book is an authoritative publication, which provides the reader with the steps required to design a research proposal. It includes case studies, writing prompts and discussions, and assists the reader in choosing the correct methodology to answer the research question.

Cunningham, Lawrence S., and Keith J. Egan. *Christian Spirituality: Themes from the Tradition*. Mahwah, N.J.: Paulist Press, 1996.

In their chapter of friendship as a spiritual practice, the authors look at the historical expression of communal friendship, focusing on the monastic era. Christian tradition’s model of

communal friendship, when understood as a God-given gift, provides a model for our current-day sanitized versions of “friendship.” These sanitized or pseudo-friendships come in the way of social media relationships. By focusing our healthcare teams on our common mission, we have the opportunity to create holistically healthy teams.

Doka, Kenneth J, “Disenfranchised Grief and Trauma.” In *Handbook of Traumatic Loss*, edited by Neil Thompson., Page 4, New York: Routledge, 2017.

The author is a bereavement expert who created the terminology for unacknowledged grief. This grief often happens in miscarriage, abortion, suicide, ex-spouses, or other losses that are generally not recognized or are stigmatized.

Engler-Gross, Adi, Gil Goldzweig, Ilanit Hasson-Ohayon, Rony Laor-Maayany, and Michal Braun. “Grief over Patients, Compassion Fatigue, and the Role of Social Acknowledgment among Psycho-Oncologists.” *Psycho-Oncology* 29, no.3 (2020): 493–499. doi: 10.1002/pon.5286.

This study concludes that this population (oncology specific social workers and other mental health professionals) is exposed to a multitude of painful emotions as they build close relationships with their patients. A significant finding of the study is that the lack of social acknowledgment of grief over patient loss leads to higher levels of secondary traumatic stress.

Feinberg, John S. “Evangelical Theology.” The Gospel Coalition. Accessed March 1, 2023.

<https://www.thegospelcoalition.org/essay/evangelical-theology/>.

In the Evangelical Christian tradition, a person must accept that Jesus is their God and died on the Cross as atonement for their sins, to achieve eternal salvation. , Relationship with Jesus ensues. Such traditions believe that this is the only means to salvation. All others, per their tradition, have no means of salvation and go to Hell.

Fitzpatrick, Scott J., Ian H. Kerridge, Christopher F. C. Jordens, Laurie Zoloth, Christopher Tollefsen, Karma Lekshe Tsomo, Michael P. Jensen, Abdulaziz Sachedina, and Deepak Sarma. “Religious Perspectives on Human Suffering: Implications for Medicine and Bioethics.” *Journal of Religion and Health* 55, no.1 (2016): 159–173. doi: 10.1007/s10943-015-0014-9.

This paper looks at medicine and its goal of the elimination of suffering. While that is a laudable objective, the authors question, through the lens of teaching of world religions, whether this aspiration is ultimately beneficial to society. The article moves through the major world religions, providing concise catechesis for each tradition.

Freud, Sigmund. *Civilization and Its Discontents*. Translated by James Strachey. New York: W. W. Norton, 1961.

Freud is the father of present-day psychology. In his classic work, he asserts that humans are preordained to suffer and, ultimately, even our own bodies betray us. To Freud, it is easier to be miserable than it is to experience happiness due to this predestined suffering. He goes on to write about our most basic urges and discontent due to humanity’s compulsion to create freedom limiting laws and structures.

Gillman, Lucia, Jillian Adams, Robyn Kovac, Anne Kilcullen, Annita House, and Claire Doyle.

“Strategies to Promote Coping and Resilience in Oncology and Palliative Care Nurses Caring for Adult Patients with Malignancy: A Comprehensive Systematic Review.” *JBI Database of Systematic Reviews and Implementation Reports* 13, no.5 (2015): 131–204. doi: 10.11124/jbisrir-2015-1898.

This review centers on the psychological wellbeing of oncology nurses. While the conclusion admits that the findings cannot concretely suggest definitive interventions that build resilience and coping, the review provides recommendations. These are fostering team connections formally and informally, providing training and other education regarding stress management and reduction, and a forum for processing emotions.

Gula, Richard M. *Just Ministry: Professional Ethics for Pastoral Ministers*. New York: Paulist Press, 2010.

In his work with pastoral ministers, Father Gula notes the reasons for appropriate boundaries, why it is unhealthy to cross them, as well as extensive teaching on the subject of appropriate use of power. While his work is intended for persons in ministry, many or most healthcare workers have sense of a “higher calling” in their work. This sense of call leads to the same pitfalls that professional or lay ministers experience in the church setting.

John of the Cross. *Dark Night of the Soul*. New York: Riverhead Books, 2003.

Written by St. John of the Cross, during captivity, John had a mystical experience that led to one of the greatest teachings on spiritual suffering in history. While John was Roman Catholic, his work spans across religious traditions and is even relevant in the secular world. John speaks

of the necessary experience of perceived spiritual darkness as a way for God to wean us from attachment to the pleasures of the senses. Instead, the spiritual suffering heightens our taste for God for God's sake alone.

Koloroutis, Mary. *Relationship-Based Care: A Model for Transforming Practice*. 13th ed. Minneapolis, MN: Creative Healthcare Management, 2004.

Relationship-Based Care is a model for creating healthy teams. In this program, staff members are encouraged to adopt a team view through comprehensive education, relationship building, team building, and commitment to coworkers. Koloroutis' bestselling guidebook for nurses provides the framework for creating and managing healthy, whole-person focused teams.

Lathrop, Deborah. "Disenfranchised Grief and Physician Burnout." *Annals of Family Medicine* 15, no.4 (2017): 375-378. doi: 10.1370/afm.2074.

This reflection calls attention to the grief experienced by physicians. Physicians are expected to be strong and they often compartmentalize their feelings, leading to greater suffering. Often, the system discounts or disallows these feelings. This leads to burnout. Lathrop suggests validating physicians' feelings as real and naming them. Lathrop also suggests examining the systemic challenges that minimize grief experiences.

McIlpatrick, Sonja, Kate Sullivan, and Hugh McKenna. "Nursing the Clinic vs. Nursing the Patient: Nurses' Experience of a Day Hospital Chemotherapy Service." *Journal of Clinical Nursing* 15, no 9 (2006): 1170–178. doi: 10.1111/j.1365-2702.2006.01495.x.

This was a comparative study of outpatient infusion nurses with previous experience with inpatient cancer care. The nurses in the study expressed frustration with the necessity to be focused clinically while wanting to address the psychosocial needs of their patients.

Mental Health America. “Setting Boundaries as a Health Care Worker.” Accessed February 28, 2023. <https://mhanational.org/setting-boundaries-health-care-worker>.

The author(s) are clear regarding the risks associated with poor boundary maintenance. They highlight the risk of burnout as healthcare workers, encouraging the reader to take care of self as the best way to take care of others. The discomfort of expressing limits to how we spend our time or how to put limits on how we use our space is affirmed, yet the author(s) compassionately affirm that setting boundaries is an act of kindness to self and subsequently, others.

Michaelson, Peter. “Why Our Emotional Suffering Persists”. |*OpEd News*. December 17, 2012. <https://www.opednews.com/articles/Why-Our-Emotional-Sufferin-by-Peter-Michaelson-121217-472.html>.

Our suffering persists, according to Michaelson, because our egos require protection. He speaks of how we “practice self-deception” (to protect our ego out of unconscious fear) as a “psychological defense system. He surmises that humans are attached to these deeply negative feelings leading to unresolved emotions, such as the fear of rejection or being criticized.

Montgomery, A., E. Panagopoulou, A. Esmail, T. Richards, and C. Maslach. “Burnout in Healthcare: The Case for Organisational Change.” *BMJ* 366 2019): 14774. doi: 10.1136/bmj.14774.

Burnout is a systemic problem in healthcare, not an individual hurdle. The authors express that it is insidious, infecting the team as a whole before it is noticed. This is due to our ability to remain behind a mask, performing priority tasks while ignoring those that take more energy, such as providing people-centered care to the patient. The results are patient safety concerns, decreased productivity, and patient satisfaction, financial risks, patient safety, and long-term viability for the organization.

Mughal, Saba, Yusra Azhar, Margaret M. Mahon, and Waqas J. Siddiqui. “Grief Reaction.” In *StatPearls*. Treasure Island (FL): StatPearls Publishing, 2022.

<http://www.ncbi.nlm.nih.gov/books/NBK507832/>.

Grief is a response to significant loss, in particular, the death of a loved one. The article chronicles grief, its types, and stages in a concise way. One such grief is disenfranchised grief in healthcare. The highlight that healthcare workers do not accept that they have the right to grieve as other loved ones grieve; however, they often experience feelings of profound loss when a patient dies.

Nemeth, Christopher, Robert Wears, David Woods, Erik Hollnagel, and Richard Cook. 2008.

“Minding the Gaps: Creating Resilience in Health Care.” In *Advances in Patient Safety: New Directions and Alternative Approaches (Vol. 3: Performance and Tools)*, edited by Kerm Henriksen, James B. Battles, Margaret A. Keyes, and Mary L. Grady. Rockville (MD): Agency for Healthcare Research and Quality (US).

<http://www.ncbi.nlm.nih.gov/books/NBK43670/>.

This paper admits that the healthcare system is not working in foundational ways. The article contributes this to an aging patient population with multiple comorbidities, fragmentation in healthcare, and how the systems that are in place, such as technology and systems, create stress for the worker. This paper recommends getting to the heart of how resilience works, and how to implement systems in a way that does not overburden the healthcare team.

National Cancer Institute. “Palliative Care in Cancer.” Last reviewed November 1, 2021.

<https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/palliative-care-fact-sheet>.

Palliative care is an essential service to persons with cancer and their families. An assessment of physical, emotional, and spiritual symptoms stemming from the disease process are assessed within the context of the interdisciplinary team. Palliative team members are comfortable setting goals of care and having end of life conversations with patients and families.

Pew Research Center. “‘Nones’ on the Rise,” October 9, 2012.

<https://www.pewresearch.org/religion/2012/10/09/nones-on-the-rise/>.

This in-depth report of the growth of the religiously unaffiliated, coined the “nones,” explores the reasons for the exodus of many from organized religion. It looks at trends among mainstream religions, as well as generational differences, in addition to how people now identify, and/or how they express their spirituality.

Pietragngelo, Ann. “Yerkes-Dodson Law: How It Correlates to Stress, Anxiety, Performance.”Healthline Media. October 22, 2020.

<https://www.healthline.com/health/yerkes-dodson-law>.

According to the Yerkes-Dodson Law, there is low arousal, optimal arousal, and high arousal. On both sides of the curve (low and high arousal), there is a lessened ability to create and act. In low arousal situations, a person may feel that what they are doing is rote. Boredom sets in and there is no motivation to do better. In high arousal situations, there is an overload of stress. This may include a “fight or flight” response. Stress becomes unmanageable, leading to poor performance. In an optimal level situation, there is enough stress to act, such as when a student is facing a deadline. Without the deadline, there is no reason to complete the task. With it, the student feels motivated to do the work.

Sinclair, Helen A. H., and Conal Hamill. “Does Vicarious Traumatism Affect Oncology Nurses? A Literature Review.” *European Journal of Oncology Nursing: The Official Journal of European Oncology Nursing Society* 11, no. 4 (2007): 348-356. doi: 10.1016/j.ejon.2007.02.007

Per the review, “vicarious traumatism is a process through which the therapist's inner experience is negatively transformed through empathic engagement with client's traumatic material.” While not in an oncology context, this review proves suffering in the therapeutic relationship.

Spidell, Steven, AnneMarie Wallace, Cindy L. Carmack, Graciela M. Noguera Gonzalez, Crystal L. Parker, and Scott B. Cantor. “Grief in Healthcare Chaplains: An Investigation of

the Presence of Disenfranchised Grief.” *Journal of Health Care Chaplaincy* 17, no.1-2 (2011): 75–86. doi: 10.1080/08854726.2011.559859.

Healthcare chaplains have a “heightened awareness” concerning work-related grief. Through their extensive training, they understand how it easily turns into disenfranchised grief. Due to the nature of their work, training, temperament, and “unrealistic self-expectations,” related stressors leave the chaplain vulnerable.

Vachon, Mélanie, and Alexandra Guité-Verret. “From Powerlessness to Recognition the Meaning of Palliative Care Clinicians’ Experience of Suffering.” *International Journal of Qualitative Studies on Health and Well-Being* 15, no. 1 (2020): 1852362. doi: 10.1080/17482631.2020.1852362

This study defines and acknowledges the experience of suffering in palliative care clinicians. It highlights their feelings of powerlessness very well. These feelings of powerlessness contribute greatly to the suffering of the clinicians. Besides the need for clinicians to address that they are suffering persons, it stresses that “rethinking experiences and available support” is imperative. This “rethinking” is a hope of my project.

Waldman, J. Deane, Frank Kelly, Sanjeev Arora, and Howard L. Smith. “The Shocking Cost of Turnover in Health Care.” *Health Care Management Review* 29, no.1 (2004): 2–7. doi: 10.1097/00004010-200401000-00002.

Although this article is from 2004, there is no denying that employee retention is significant to the health care system’s bottom line. An academic research center was studied with the annual operating budget of \$17-29 million. (Today’s equivalent is \$27,376,826- \$46,701,644). There is

no denying that employee retention is significant to the health care system's bottom line. The study found that the "magnitude of the turnover cost" in their context of academic medical center, "was astounding." In fact, the cost of turnover "represented 3.4-5.8 percent of the annual operating budget." This article stresses that retaining employees is imperative to the bottom line of any health care system.

Wicks, Robert J. *Overcoming Secondary Stress in Medical and Nursing Practice: A Guide to Professional Resilience and Personal Well-Being*. 1st edition. Oxford ; New York, N.Y: Oxford University Press, 2005.

In this comprehensive work, Wicks extensively covers compassion fatigue and vicarious secondary post-traumatic stress disorder. He underscores the need to strengthen one's inner life, using wisdom from world religions. His identification of burnout risks to the healthcare team is extensive and relative to the work in ambulatory oncology care.

Wilson-Guffin, Sarita. "Spiritual Resilience." Methodist Le Bonheur Healthcare, April 15, 2020. <https://www.methodisthealth.org/files/faith-and-health/Spiritual%20Resilience%20MSK%204-15-2020.pdf>

In this table talk, Dr. Wilson-Guffin teaches that resilience is when good or positive coping skills match the situation. This includes awareness of what is happening internally when one is under stress.

Woodhead, Linda. 2017. *British Academy Lectures, 2015-16*. British Academy.

The author's 2016 lecture (based upon her research) looks at the statistics surrounding the fastest growing "religious" group in the United Kingdom and United States. She explores how, who, where, and why Britains are running from traditional religious belief.

"Yerkes-Dodson Law: How It Correlates to Stress, Anxiety, Performance." 2020. Healthline.

October 22, 2020. <https://www.healthline.com/health/yerkes-dodson-law>.

This article breaks the 1908 psychological theory into an easy to understand article. To summarize, humans require enough stress to act, yet not so much stress that the person becomes paralyzed. Either too much or too little stress result in inaction.

APPENDIX

IRB Approval Letter



UPMC Harrisburg

UPMC Central PA Region
Institutional Review Board

Thomas Pineo, D.O.
IRB Chairman

111 S. Front Street
Harrisburg, PA 17101

PO Box 8700
Harrisburg, PA 17105-8700

717-231-8394

Inquiries:
Nancy Fisher
IRB Coordinator
fisherml2@upmc.edu

DHHS OHRP Registration:
IORG0001079
IRB000001476
FWA00001055

June 19, 2022

Michele Richards Conway, MDiv
Principal Investigator

Re: Expedited Review of a New Study – Minimal Risk

22E026 -- The Experience and Expression of Staff Suffering in the Context of
Oncology Care

We received your request for an Expedited Review of a New Study – Minimal Risk.

Reviewed was a proposal to conduct interviews on the experience of suffering of interdisciplinary staff members of an ambulatory care oncology team. Approximately 15 members of staff of the UPMC Hillman Cancer Center will be interviewed about their thoughts and feelings surrounding a patient whose death impacted them the most. Interviews will be audio recorded and subjects will be given the opportunity post-interview to listen to their individual recording and clarify in writing any thoughts or statements that they think are necessary. Subjects will also be educated on support services available to them to address any grief, sadness, suffering or trauma that they may be experiencing. Data will be collected and analyzed as outlined in the proposal, in accordance with the minimum necessary standard, and no personally identifiable information will be published.

This qualifies for expedited review as per 45 CFR 46.110, 21 CFR 56.110 and Policy IRB# 07. An exemption has been granted as per 45 CFR 46.104(d)(2) and Policy IRB# 08. This action will be reported to the Institutional Review Board at the next scheduled meeting.

Thank you for your continued cooperation. If we can be of any assistance to you, please call our Board at (717) 231-8394. Any requested follow-up should be addressed to our Board and forwarded to Nancy Fisher, IRB Coordinator, UPMC Central PA Region IRB, 111 S. Front Street, Harrisburg, PA 17101.

Sincerely yours,

Thomas Pineo, DO

Chairman
UPMC Central PA Region
Institutional Review Board

TP:nf

IRB Consent

CONSENT FOR RESEARCH UPMC CENTRAL PA REGION

UPMC Central PA Region
IRB Approved
07/19/2022 NLF

NOT VALID UNLESS DATED

Study Title: The Experience and Expression of Staff Suffering
in the Context of Ambulatory Oncology Care

Principal Investigator/Researcher: Michele Richards Conway, MDiv

Subject ID/Initials: _____

You are being asked to participate in a research study. Before you agree, the following will be discussed with you:

The purpose of this research is to identify a collaborative narrative about suffering and the human condition within the context of Oncology healthcare workers and staff who care for people being treated for cancer. This research is being done for educational purposes as well as to develop a stronger support system for professionals involved in the treatment of cancer patients.

Approximately 15 staff members from the UPMC Hillman Cancer Center Central PA will participate.

The study procedures include your participation in an in-depth interview conducted by the researcher. This interview includes approximately 55 questions about your experience with a patient whose death you feel has particularly impacted you. This interview will take approximately two (2) hours of your time and will be digitally recorded for audio. A short time after the interview, not necessarily the same day, you will be provided the opportunity to listen to your recording and make any corrections or clarifications to what you said that you think are necessary. You will be asked to make any corrections in writing, and they will be kept by the researcher with the original audio recording.

The risk to you for your participation is minimal but that does not mean that there is no risk. Talking about traumatic experiences may help you to process them but talking about them may also trigger Post Traumatic Stress Disorder (PTSD), anxiety, depression, feelings of hopelessness, grieving, loss of faith and other mental health concerns. In order to help alleviate those concerns, the researcher will provide you with education about what resources are available to you should any of those things happen to you. There may also be unforeseen risks associated with your participation.

The benefit to you for your participation may be that you feel better mentally and emotionally because you have expressed your feelings about how a patient death affected you, and that you have shared this experience with another person who has had a similar experience. However, this benefit is not guaranteed to you, as every person processes their feelings differently based on their own life experience.

Your participation in this study is a personal choice, is voluntary and not required as part of your employment. The alternative is not to participate.

For purposes of the research, you will only be identified with a code consisting of a number plus your initials and your identity will only be known to the researcher. All of your answers to the interview questions will be treated as strictly confidential and will be kept securely by the researcher in a locked office in a locked filing cabinet and/or on a password-protected, secured network drive maintained by UPMC. Gathered information will be used for research purposes only, and information will never be shared with your employer or manager unless there is a safety concern and/or it is required by law. At the conclusion of the research project, all materials and information will be destroyed by the researcher.

There is no cost to you for participation in this study. You will not receive any payment for your participation. In addition, there is no compensation for illness or injury that you may associate with your participation in the study.

If at any time after you have chosen to participate you become uncomfortable and wish to change your mind and withdraw from the study you have the right to do so. Please inform the researcher of your intention to end your participation. You may be asked to do so in writing. The researcher may also choose to end your participation if it is not in your best interest. You will not be penalized or lose benefits if you refuse to participate or decide to stop.

Any time you have questions about the research, you may contact Michele Richards Conway, MDiv at 717-657-7502. If you have questions about your rights as a research subject or what to do if you are injured, you may contact the UPMC Central PA Region Institutional Review Board (a group of people who protect the rights and safety of research subjects) at 717-231-8394.

If you agree to participate, you will be given a copy of this document after you sign it.

Signing this document means that the research study has been described and that you voluntarily agree to participate.

PARTICIPANT'S SIGNATURE:

_____ Signature	_____ Date
--------------------	---------------

SIGNATURE OF PERSON CONDUCTING CONSENT:

_____ Signature	_____ Date
--------------------	---------------

Pre-Interview Education

**If you feel as if you are in immediate danger to
yourself or others, please dial 911.**

For persons who have non-emergent mental health concerns or feel
triggered from the study:

- Call Pinnacle Health Psychological Associates (**PHPA**) at

(717)231-8360

- Ask for the on-call therapist for assessment (and wait for a callback, if
necessary)

or

Call **LifeSolutions** at

1-800-647-3327

Both services are available 24/7

For general information from LifeSolutions regarding grief as well as
other concerns, please visit

<https://upmchs.sharepoint.com/sites/infonet/Benefits/HealthandWellness/MyHealth/Pages/Life-Solutions.aspx>

For spiritual concerns, page the on-call chaplain by calling the hospital
operator at 717-782-3131. Please request the Hillman Cancer Center
Chaplain (M-F 8a-4:30p).

LifeSolutions Overall Services Flier

LifeSolutions®

Employee Assistance Program



LifeSolutions employee assistance program (EAP) can help you balance your work and personal needs to become healthier, happier, and more productive.

Our trained professionals can help with:

- Stress, anxiety, or depression.
- Parenting resources.
- Caregiving support.
- Financial and legal worries.
- Overuse of alcohol.
- Grief and loss.
- Work-related challenges.
- Making healthy lifestyle changes.

Our consultation and problem-solving services include:

- Short-term coaching and counseling in person, by telephone, or via video.
- Parenting resources and options for children.
- Support for those who are caring for an older loved one.
- Community referrals and information to address many everyday concerns.
- 24/7 phone support for immediate help.

We offer various support services for workgroups, including:

- Disruptive event management (workplace crisis support).
- Personal and professional development trainings.

You have access to free, 30-minute consultations with a licensed attorney and/or a certified financial adviser. During these consultations, you can address:

- Legal concerns, such as landlord/tenant issues, real estate transactions, bankruptcy, child custody and other family matters, estate planning, immigration issues, and criminal matters.
- Debt management, credit concerns, student loans, mortgages, retirement planning, and financial hardships.

Our interactive website includes thousands of tools to help you and your family address most major life issues. Available resources include:

- Skill builder courses and articles.
- Wellness, fitness, nutrition, and emotional well-being materials.
- Expert-led webinars on personal development, health topics, and caregiving.
- Financial education tools and legal forms, educational information, and discount offers.

Remember, EAP services are private and confidential, and they are available to you and members of your household at no cost.

**LifeSolutions@upmc.edu
+1 800-647-3327 (TTY: 711)**

To access the Work-Life section of our website, go to www.lifesolutionsforyou.com, click Login, and enter your company code: UPMC.

Click on the Work-Life Resource Portal under Featured resources.

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LifeSolutions Coping with Grief Flier

LifeSolutions

Coping With Grief and Loss



Grief and loss are inevitable parts of life. At one point or another, we will all experience the death of someone we care about. Sometimes the loss is anticipated, such as when a family member or co-worker suffers an extended illness. At other times, the loss is sudden and unexpected. It leaves us struggling to cope with feelings of disbelief, anger, sadness, and confusion.

Whatever you may be feeling, treating yourself with kindness and compassion, seeking support when you need it, and giving yourself time to grieve can help.

Grief is a natural response to loss. It is not a sign of weakness or inability to cope. There is no right or wrong way to grieve - each person's path and pace will be different. For example, one person may find comfort in sharing their thoughts and feelings with others; another person may need quiet time to reflect on the loss. Both are normal responses. Be attentive to what will work best for you and honor that.

Tips for coping with grief

- **Allow yourself time to grieve.** Pay attention to what feels right or helpful to you. Don't judge your reactions or compare yourself to others.
- **Understand that grieving can include many reactions,** from sadness and crying to distraction, confusion, anger, resentment, or numbness.
- **Know that the most acute distress usually occurs right after the loss.** You will likely experience peaks and valleys, but most people find that their grief becomes more manageable over time.
- **Take good care of yourself.** Pay attention to what your body needs. Try to get enough rest, stay active and eat healthy foods. Avoid unhealthy ways of coping such as overeating, smoking or using drugs or alcohol.
- **Know that feelings may come and go.** It's OK to find ways to enjoy life while you are grieving. Moments of levity provide a balance and are part of taking care of yourself during a difficult time.
- **If it helps you, talk with others and stay engaged with your family and friends.** Let people know what they can do to support you. If something does not help, share that as well.

workpartners 

- **Find activities that nourish your mind, body, and spirit.** Journaling, quiet meditation, or meeting a friend for coffee can provide moments of peace or comfort. Find what works for you.
- **Seek professional guidance** if you are concerned about any symptoms or grief reactions you are experiencing, if you are having trouble functioning in daily life, or if your grief seems to be worsening.

LifeSolutions offers counseling sessions to help with grief and loss. Additionally, our website features Griefwords, a comprehensive library of articles and book excerpts about grief for bereaved families as well as bereavement caregivers. Additionally, you can find our online course, Overcoming the Loss of a Loved One and webinar, Dealing with Grief and Loss.

Speak with a professional

LifeSolutions' services are **free and confidential**. They are available to you, anyone living under your roof, and your dependents (up to age 26).

Call or email us to ask questions or schedule an appointment.

LifeSolutions@upmc.edu
+1 800-647-3327 (TTY: 711)

To access the Work-Life section of our website, go to www.lifesolutionsforyou.com, click Login and enter your company code: UPMC.

This information is not a substitute for professional care or your organization's policies. If you have or suspect you have an issue related to the material presented here, consult an appropriate professional.

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UPMC Health Plan, on behalf of itself and its affiliates, complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, creed, religious affiliation, ancestry, sex, gender, gender identity or expression, or sexual orientation.

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ATENCIÓN: Si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-855-869-7228 (TTY: 711).

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