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Self-care in the practice of oncology social work : a project based upon the self-care practices of twelve oncology social workers

Lindsay Cotter

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Lindsay Cotter
Self-Care in the Practice of Oncology
Social Work

ABSTRACT

This qualitative study explores the ways in which oncology social workers employ self-care. Twelve oncology social workers throughout the nation were interviewed and their personal narratives addressed the role that self-care plays in a field with compassion fatigue, death and other intense emotional reactions to patients and families dealing with a cancer diagnosis. A semi-structured interview explored why participants chose the field of oncology as well as self-care practices they found helpful throughout their careers. The interview guide also included a focus on the rewards and challenges of the work and how outlooks on life were impacted as a result of the work. Findings indicate that while the field is subjected to a substantial amount of emotional challenges and many risks for compassion fatigue, oncology social workers recognize the need for self-care and that they practice self-care in a variety of ways. The data also identifies the need for agency support as a facilitator of self-care.

Self-Care in the Practice of Oncology Social Work

A project based upon the self-care practices of twelve oncology social workers, submitted in partial fulfillment of the requirements for the degree of Master of Social Work.

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CHAPTER I

Introduction

Oncology social workers help patients and families cope with and adjust to a cancer diagnosis. Oncology social workers provide resources, emotional support and tools for patients and families to navigate their medical/spiritual/emotional/physical journey. This role of an oncology social worker also requires clinicians to experience loss and sadness and confront issues of mortality. Self-care is seen as important to the field of oncology as it allows clinicians to better cope with the emotional demands of the work and find a balance (McGarrigle & Walsh, 2011).

The purpose of this study was to explore the ways in which oncology social workers employ self-care in this field where compassion fatigue and burnout are prevalent. This study explored twelve oncology social workers' narratives on how they utilize individual self-care while navigating the emotional stress involved in their work. This study assumed the importance of self-care as a sustainability measure in the field of oncology social work.

Social work training programs often lack focus on confronting issues of death and self-care practices for new clinicians, and therefore this study is beneficial to the field and those considering entering a field with so many risks for compassion fatigue. Social work schools frequently do not address issues of coping with death or loss in a field such as oncology and may not help students develop skills to address and accurately assess the risks for compassion fatigue. Rohan & Bausch (2009) suggest that what is traditionally taught in social work schools results in a disconnect with the field of oncology and a "lack of emphasis on how to work with those who

are facing life threatening illness" (p. 94). Though social workers may be more prepared to address some of the demands of clinical work in general, social work schools do not adequately address death and dying.

The following chapter explores the research to date in regards to the negative effects of compassion fatigue and explores practices for decreasing such negative symptoms through the application of self-care practices. The methodology chapter describes in detail the process by which the research was conducted and the challenges and limitations that were faced. The research findings chapter examines the patterns of responses from participants, while the discussion chapter explores the connection of noteworthy thematic content in the data to existing literature on self-care in oncology social work.

CHAPTER II

Literature Review

This review of the literature will focus on defining compassion fatigue in oncology social work and the ways that self-care practices are seen as necessary to this field of practice. The review will end with studies of self-care practices and their impact on oncology social workers.

Compassion Fatigue Risks

Oncology social workers act as advocates for patients and offer supportive counseling to patients and families. When the cancer prognosis is not positive, social workers are the members of the oncology team that help patients with frequently very strong feeling of loss and fear of death. Stearns (2001) stated that in the field of oncology, grief is cumulative over time, as “oncology health care providers see more death in a year than most others see in an entire career or even in their lifetime” (p. 224). The field of oncology requires social workers to continuously confront suffering, illness and death, presenting them with risks for compassion fatigue, vicarious trauma and even, at times, burnout.

Terms such as burnout, vicarious trauma and secondary trauma are found throughout the literature and refer to the broad understanding of compassion fatigue. Bober and Regehr (2006) state that vicarious trauma has been compared to compassion fatigue, since it “focuses on the cognitive schemas or core beliefs of the therapist and the way in which these may change as a result of empathetic engagement with the client” (p. 1).

The field of oncology social work is susceptible to burnout, compassion fatigue and other forms of vicarious trauma. Davidson (1985) studied oncology social workers and found that the stress working with cancer patients carried over into their professional and personal lives. The study focused on the negative effects of oncology work, most notably, experiencing vulnerability and heightened awareness of mortality. It is noteworthy that he also focused on positive aspects of the work, particularly a greater appreciation for life.

Killian (2008) conducted a mixed methods approach to data collection and interviewed 20 clinicians working with trauma survivors. One major theme from the interviews suggested that the clinicians working with trauma survivors were able to easily identify their stress in the form of bodily symptoms such as headaches or lack of energy (p. 35). Other themes the clinicians identified as factors contributing to compassion fatigue include: high caseload demands, personal history of trauma, irregular access to supervision, lack of a supportive work environment, lack of supportive social network, worldview and the ability to recognize and meet one's own needs (Killian, 2008). The three variables that most contributed to burnout include work drain, lack of morale, and neuroticism; the four variables that most contributed to compassion fatigue include therapist's sense of powerlessness, work drain, emotional self-awareness, and trauma history. All of the above variables were examined using the Social Support Index, the COPE instrument, and the Professional Quality of Life III: Compassion Fatigue and Satisfaction subscales (Killian, 2008).

Cunningham (2003) focuses on empirical findings regarding the traumatization of social work clinicians, specifically those who work with human induced trauma such as sexual abuse and those working with naturally caused trauma such as cancer. Cunningham's study explored the possibility that clinicians experience intense emotional reactions with exposure to client

trauma (2003). Cunningham's focus on the nature of trauma suggests varying degrees of stress by social work clinicians. Using the Traumatic Stress Institute Belief Scale, he measured the clinician's worldview and disruption with cognitive schemas. The 182 participants were asked to estimate the number of clients with a history of sexual abuse or cancer diagnosis in their caseload in the past six months. Questionnaires also included the length of trauma work and personal history of trauma. The study findings concluded that clinicians working with clients who were sexually abused reported more disruption in terms of safety, trust and self-esteem (2003, p. 455). The study also concluded that there was an association of clinicians with a history of sexual abuse working with sexual abuse as a population. In addition, the number of years of experience also impacted the study findings. Cunningham (2003) found that clinicians with more years of experience with their respective population reported fewer disruptions in cognitive schemas, hypothesizing that more experienced clinicians develop skill sets along their careers to cope with the intense demand of the field. He also found that oncology clinicians may experience more turnover with varying approaches to treatment, such as groups, family work and providing resources—which may provide respite from directly dealing with clients' death for oncology clinicians. The study also concluded that those clinicians who are new to the field may experience increased levels of distress.

Cumulative Compassion Fatigue

A career in oncology social work may impact the clinician gradually over time. Interestingly, Supple-Diaz and Mattison (1992) found that fourteen seasoned oncology social workers indicated they would not prefer a caseload entirely consisting of cancer patients, whereas thirteen respondents who were new to the field preferred a caseload of strictly oncology

patients. This study suggests the impact of patient related issues increases over time and may impact the social worker in a variety of ways, including self-protective ways.

Killian's research suggests exposure to traumatic content for the majority of the work week, such as a full caseload of cancer patients, could lead to acute distress (2008). Compassion fatigue can be related to one event such as listening to a family describe the details of a loved one's suffering or it can be the result of long term exposure in the field of oncology (Alkema et al., 2008, p. 104). Alkema, Linton and Martin (2008) point out that compassion fatigue is a professional hazard for those who choose any field of helping others.

Much of the literature to date focuses on compassion fatigue and its effects on clinical practice, suggesting that it may impact the quality of care patients receive (Keidel, 2002). McGarrigle & Walsh (2011) state that professionals experiencing vicarious trauma or compassion fatigue have limited ability to express empathy and are unable to be sufficiently available to clients.

Negative experiences in the oncology work environment can lead to the negative interaction with patients. Whippen and Canellos (1991) set out to quantitatively assess the extent of burnout in clinical oncology workers. Their questionnaire was sent to 1000 random subscribers to the *Journal of Clinical Oncology*. All participants identified as some type of oncologist, whether it be medical or research based. The researchers collected responses from 598 respondents and 56% of respondents felt some degree of burnout in their professional life. The study also found similar statistics for suburban and rural oncology work burnout (55%) and that of urban practitioners (56%). Whippen and Canellos (1991) also found that 56% of the participants accounted frustration or sense of failure as a major contributor to their feelings of burnout; while 34% identified depression, 20 % identified disinterest in practice and 18 %

identified boredom as factors contributing to burnout. The majority of these respondents felt burnout was inherent in oncology work, while 19% felt it was a natural progression since fellowship, and 17% believed that their individual experience was unique. When asked what might alleviate some of this stress, 69% reported more vacation or personal time. An interesting observation was also made throughout the course of the study; of those who finished training before 1979, 49% recommended sabbaticals to help alleviate burnout; and of those whose training ended since 1980, only 34% recommended that trainings may be helpful. Despite these findings, 80% of respondents identified their careers as meeting their expectations from training.

In an exploratory study of compassion fatigue in oncology social workers designed by Simon, Pryce, Roff, & Klemmack (2006), it was found that 57% of the 21 participants experienced difficulty staying asleep and felt trapped by their work; 38% of participants responded to outbursts of anger or irritability with little provocation. Due to the exhausting nature of the work, the study reported, 42.9% of the participants found it helpful to remind themselves to be less concerned about the well-being of those they help. It is noteworthy, however, that the same study found the more advanced an oncology social worker's licensure, it was less likely they experienced "compassion satisfaction" with the work. This study suggests that more researchers need to highlight the ways that self-care may alleviate the intense emotional demands of oncology social work in order to cope with reactions of irritability or anger and to develop skills to implement boundaries so they do not find themselves overwhelmed with patient situations.

Workplace culture

While oncology social workers are trained to work clinically with patients and families in the clinical setting, workplace dynamics may also demand their attention, attuned as they are to

conflict, distress and problem solving. Rohan & Bausch (2009) identified social workers as the most prepared among the oncology health professionals to tackle some of the intense emotional issues patients present. The same study also identified the unique role on the team that social workers possess, being a source of additional support to other team members, highlighting the extra emotional material that social workers manage on a regular basis (Rohan & Bausch, 2009, p.97).

Nearly all of the literature to date discusses the impact of team work on oncology job satisfaction. Some literature suggests the team can be a source of support for oncology social workers whereas other literature suggests conflicts within the team can negatively impact the worker. Bradley and Sutherland (1995) concluded that social workers reported higher levels of stress as a result of working with the structure and climate of an agency, particularly if morale was low (2002, p. 258). A study by Rabin and Zelner (1992) found that lack of job clarity contributes to high turnover and burnout regardless of the setting; therefore job clarity could also be used as a measure to prevent compassion fatigue.

Bober and Regehr (2006) conducted a study of ways to reduce vicarious trauma with 259 participants, 47% of which were social workers. The questionnaire utilized The Impact of Event Scale to interpret data, which measures symptoms of avoidance or blocking thoughts or images. In addition the Traumatic Stress Institute Belief Scale was also used to assess participant trauma symptoms. The study also conducted a coping subscale where each participant rated self-care activities to the degree to which they saw the activity assisting with the demands of trauma work. They found that beliefs in self-care activities had no direct connection to allotting time to engaging in these activities.

Social workers experience a variety of stressors inherent in the profession. Lloyd et al. (2002) explore "sources of stress and stress outcomes (especially burnout) that are experienced by social workers" (p.256). The study describes burnout as "experiencing exhaustion and the inability to give of themselves on a psychological level" (Lloyd et al., 2002). Some examples of stress that may contribute to burnout and exhaustion include lack of recognition, the disconnect between social worker values versus agency expectations, as well as the social work role being unclear to the rest of the team and perhaps not valued as a result. Changes in the healthcare system also impact social workers through budget cuts or limited support from supervisors or staff, all of which contribute to social work stress.

Some research suggests social workers have limited opportunities for develop coping skills through social support. Evans and Villavisanis (1997) suggest that full-time therapists socialize less and thus eliminate some of the opportunities to address trauma work. For example, a study conducted by Bober and Regehr (2006) found that mental health providers such as social workers, nurses, psychologists, and physicians agreed that self-care activities such as supervision or leisure activities were useful. However, there was often little to no time allotted for these activities. Therefore there is a gap between what people believe and what they actually do.

Diverse caseloads may assist oncology clinicians with taking a break from intense emotional content. Davidson (1985) conducted a study of 36 social workers and found that most did not want an entire caseload of cancer patients. The reasoning for this was determined by three factors: depression, identification with patients, and equating cancer with death. In a study of social work practice and stress by Sze and Ivker (1986) findings concluded that 60% of their sample identified themselves as under stress, with hospital social workers among the highest percentage of this group.

Each individual's role in an oncology clinic, consisting of physicians, nurses, and social workers, contributes to an effective treatment approach. Physicians in American culture, for example, are more conditioned to depersonalize the patient and have less regard for empathy (Rohan & Bausch, 2009). Luckily other professionals in the oncology setting, such as social workers, are trained to emphasize the "subjective experiences of patients" in order to help guide and support the emotional aspects of a cancer diagnosis (Rohan & Bausch, 2009). Oncology nurses play a somewhat mixed role in that they must attend to the medical aspects of treatment but also are witnesses to the complex emotional and psychological issues surrounding a cancer diagnosis. When the various professionals in an oncology setting work together to support their complementary roles in treating patients, the expectation is improved treatment for patients and families (Rohan & Bausch, 2009).

In a study of social work with terminal patients, Davidson and Foster (1995) discuss the importance of social worker expectations, as extremely high ones may lead workers to feel like a failure. In order to manage this challenge clinician's are encouraged to take time to recognize small interventions like finding resources for the client or sitting with a client during an uncomfortable blood draw.

Davidson and Foster (1995) suggest that it is the role of the social work manager to "develop programs and interpret these services so that health care management will recognize their benefits. Social work managers need to promote psychosocial services across the continuum of care" (p. 2). Such services may include: health maintenance, prevention and education, counseling and planning with chronically ill patients, their families and loved ones in their preparation for dying. Davidson and Foster (1995) suggest that barriers to compassion satisfaction may include lack of resources or staff support. They also suggest that social workers

“recognize the limits of their ability to change and improve the lives of their clients” (p. 8). This sentiment is evident not only with clients dying of AIDS as in this study, but also in working with cancer patients. In addition to clear work descriptions, it is important for oncology social workers to have realistic expectations for treatment and work with clients. Agency and team support may account for some of the ways in which oncology social workers utilize self-care. Supplemental consultation, such as supervision or colleague support, may assist the worker to address the issues of grief and loss they may be avoiding by steering the discussion to neutral topics, arriving for sessions late or leaving early. Davidson and Foster (1995) suggest "spirituality, humor, tolerance of mistakes and self-awareness may balance martyrdom and selfless giving that could engulf the worker" (p. 8). The authors refer to these self-care practices as enhanced clinical skills which add to the value and satisfaction of their work with dying clients.

Figley (2002) refers to compassion satisfaction as the positive opposite of compassion fatigue. Compassion satisfaction focuses on the rewards one experiences as a helping professional. Literature also suggests that social support is a primary factor in self-care and coping with compassion fatigue as it allows a space to process the traumatic aspects of working with trauma survivors (Conrad & Kellar-Gurnther, 2006).

Rohan & Bausch (2009) studied the ways in which oncology health care professionals make meaning of their work and what specifically sustains them during highly emotional moments. The study concluded that the need for team cohesion in an oncology setting is imperative for survival as the majority of the participants relied on feeling supported with the help of the team consisting of social workers, nurses, and physicians.

Issues of Mortality

An oncology social worker is “more likely to see only those patients who are either very ill or are having difficulties adjusting to living with cancer” (Rohan & Bausch, 2009, P. 47). Frequently the circumstance by which an oncology social worker meets with a patient is based on a poor prognosis, depression, anxiety, or difficulty coping (Rohan & Bausch, 2009). Rohan & Bausch (2009) also found that some clinicians' level of worry in an oncology setting has exceeded "normal" worry, and that this impacts their functioning. Such worry is often focused on loved ones developing cancer. This is sometimes called a parallel process and/or vicarious trauma, in which clinicians experience similar feelings as their oncology patients, such as avoidance, denial, fear, and having been traumatized (Stearns, 2001).

Research suggests that oncology social workers may be drawn to the field based on past histories of personal loss. Supple-Diaz and Mattison (1992) surveyed 27 participants in Michigan regarding the factors that affect coping and overall satisfaction in oncology social work. The study found that not only were social workers drawn to oncology social work due to personal loss, but also they believed such loss qualified them to work with their population. Twenty-six out of the twenty-seven participants indicated that patterns of personal history and coping styles played a role in how they approached treatment or which interventions were chosen. The four major factors that impact coping and satisfaction include history of personal loss, organizational factors, patient-related factors, and social support.

Because oncology social work forces clinicians to address death and loss, it requires clinicians to address individual issues of transference and countertransference around such topics, such as past experiences. Davidson and Foster (1995) explain that in the 1990's, “the advent of AIDS, and the complexity of its biopsychosocial effects have heightened awareness of

the difficulties inherent in death and bereavement work” (1995, p. 2). Prior to this phenomenon mental health professionals may have had limited resources and knowledge surrounding the multifaceted nature of working with death and bereavement. Davidson and Foster (1995) explain the importance of supporting social workers as they encounter stressors of grief and loss; the article also offers resources for administrative strategies to facilitate this gap.

Self-Care Practices

Data from the numerous studies indicate that self-care in the field of oncology social work helps clinicians to cope with the sometimes exhausting demands of the field. Collins (2005) describes self-care as an individual's ability to balance personal, professional, emotional, mental, physical, and spiritual components in order to live in a balanced and energized manner that assists the individual in coping with daily stressors. Rohan & Bausch (2009) describe self-care strategies for coping with work related stressors as focusing primarily on maintaining balance and perspective. They point out that the concept of self-care refers to the importance of addressing work-life and personal-life triggers that may potentially negatively impact the self and perhaps the work with clients.

Overall the literature suggests that the field of oncology social work is easily susceptible to compassion fatigue, burnout and vicarious trauma, and that self-care coping behaviors have the ability to act as a preventative measure. Collins (2005) examined spiritual self-care practices that social work practitioners can incorporate as a coping mechanism to deal with the effects of stress and lessen burnout. She describes that the “cost of caring, empathy, and the emotional investment of unconditional giving may lead some social work practitioners to disregard their own personal self-care” (p. 264). Collins describes self-care as a spiritual act that also requires a level of self-awareness and self-love, which she points out are also values of Christian living.

McGarrigle & Walsh (2011) focused on contemplative training and presented data on participants who described a variety of stressors in daily lives which negatively impacted their clinical functioning and resulted in negative consequences when unmanaged. When participants did not attend to their stress, essential social work skills such as listening and being nonjudgmental were more challenging. Responsibility to manage stress was also seen as a responsibility of the work place to "facilitate professionally accountable and ethical behavior when providing services to clients" (McGarrigle & Walsh, 2011, p.221). Their study also concluded that mindfulness was recognized by participants as a means to cope with stress and as a skill that could be taught and practiced as a benefit to self-care and reflection. The omission of self-care practices can result in loss of sleep, emotional exhaustion, reduced morale, feelings of despair, and even high staff turnover, all of which may impact patients (McGarrigle & Walsh, 2011). The study collected quantitative data on a mindfulness training with social work practitioners that showed a significant increase in mindfulness and significant decrease in stress pre- to post-training. The Mindfulness Attention and Awareness Scale pre-training had a mean of 3.6 and a post-training mean of 4.2. The Perceived Stress Scale pre-training had a mean of 16.8 and a post-training mean of 12.1. McGarrigle and Walsh (2011) explain "the increase in mindfulness may have made it possible for participants to be more aware of their stress and the need to attend to their stress. The decrease in their stress levels indicates they managed their stress, which may unfold as an enhanced sense of wellness" (p.220).

Employing self care practices to offset the challenges of compassion fatigue can even lead to compassion satisfaction (Radley and Figley, 2007). Alkema et al. (2008) conducted a study with 37 hospice workers and found that as compassion fatigue increased, the number of self-care activities decreased. Using the Self Care Assessment Work-sheet, the study found that

self-care may be a holistic approach, as participants described engaging in one self-care activity were more likely to engage in other self-care activities as well.

Spirituality as Self-Care

Spirituality is a major theme throughout the literature that aims at addressing the effects of compassion fatigue. Collins (2005) suggests utilizing spiritual practices for self-care that embody strength and love from within. Such practices include: Sabbath Keeping, Finding Holy Silence, Expressing Gratitude, Expressing Spiritual Essence, Developing a Sense of Compassion, and Embracing a Principle of Stewardship. Collins describes Sabbath Keeping as a time to "stop doing all the things we do, to pause and to be still long enough to honor creation itself" (2005, p. 267). Examples of Sabbath Keeping include: attend church or create an opportunity with others that helps build your faith, spend time with family/friends to appreciate their company, share your gift of time with someone who is confined, take a nap or quietly enjoy an activity, and stroll your neighborhood and observe the season changes.

In order express gratitude, Collins (2005) suggests taking time to acknowledge privilege, opportunities and power. Ways to practice gratitude include focusing on blessings that you have rather than what is missing, view each day as a gift, start a gratitude journal. Expressing spiritual essence is grounded in the idea that there is a "larger purpose for each life" (p. 270). Collins (2005) also focuses on the importance of compassion as it "allows us to open our hearts to concern for ourselves as well as others" which can "reduce the tendency to fixate on inconsequential and petty events by experiencing or being sensitive to the challenges that others routinely encounter" (p.271). Embracing stewardship implies the interconnectedness of life on Earth and a higher power and that we should use our time and resources to do good in any ways we can, like helping others or preserving creation's valuable resources. Although Collins

primarily focuses on Christian-guided spirituality practices, many of the strategies she presents are also found in mindfulness practices.

Killian (2008) also found that spirituality was a major theme for self-care strategies as it allowed clinicians to focus on something outside of the individual (p. 37). Killian (2008) administered a questionnaire to 104 therapists specializing in trauma which concluded that social support, managing work hours, and internal locus of control at work were the three biggest factors in buffering clinicians from the effects of compassion fatigue.

Summary

Compassion fatigue can have drastic and negative effects not only on the clinical encounter, but also in one's personal life. Given the negative implications of compassion fatigue it is important to highlight the benefits and preventive nature of self-care practices in the field of oncology and how developing coping strategies and making time for self-care practices helps to minimize the negative implications for practice.

Despite the field's challenging and at times emotionally exhausting demands, some oncology social workers make a conscious decision to remain in the field of oncology, suggesting the field may offer some rewards. Rohan and Bausch (2009) found that participants in their study identified obtaining intense emotional connections, gaining inspiration, and gaining wisdom and perspective as some of the rewards of oncology social work; many in their study discussed "the gift" that they received from patients.

In gaining a deeper understanding of the challenges of oncology social work, the opportunities for reducing the inherent risks of the work become clear. Self-care practices have the ability to act as a buffer to compassion fatigue.

CHAPTER III

Methodology

The Phenomenon

This study explored how oncology social workers discuss self-care as important to navigating the emotional stress involved in their work. Oncology social workers may need to develop self-care skills in order to adapt to the field of oncology for this work to sustain them over time. Most of the research to date focuses on the highly intense emotional demands of oncology social work, which can lead to compassion fatigue or burnout. Narrative data from this study spell out how self-care practices are viewed as ways of avoiding burnout and as ways of continuing to work in this field of practice.

Study Design

Twelve oncology social workers were interviewed to obtain qualitative data on how they employ self-care to help them with the stress involved in their work. A nonprobability, purposive method of sampling was utilized. A qualitative approach to data was used to obtain personal narratives, and a semi-structured interview guide was used. The voice recorded interviews were transcribed by this researcher and examined for patterns and for possible associations with demographic data.

Sample

Twelve oncology social workers were interviewed in early 2013. Inclusion criteria were that participants be licensed oncology social workers who worked for a minimum of four years. Participants exhibited a range of age, race, gender, sexual orientation, and ethnicity and previous and current experience in the field of oncology social work. Experience with a specific oncology population was not a requirement. Participants had a wide range of experience in multiple settings such as in-patient, out-patient in hospital setting and private practice, among other settings.

The recruitment for this study involved collaborative efforts with this researcher's oncology supervisor, E.J., who has worked in the field of oncology for nearly twenty years. E.J. distributed this researcher's recruitment email through the Association for Oncology Social Work (AOSW) list serve as well as forwarding it along to colleagues who were available for the study. E.J. did not add a personalized request for colleagues to participate in this study, but rather forwarded along the recruitment email and contact information for this researcher (See Appendix A).

Participants were encouraged to contact this researcher if they were interested in participating in the study and met the study requirements. Responders were contacted to ensure that inclusion criteria were met, to review Informed Consent and to set an appointment time to conduct the interview. Eleven interviews were conducted via voice recorded telephone sessions and one interview was conducted in person.

Participants were asked to give their time for a 25 minute interview to discuss oncology social work and the role of self-care in this field of practice. Particular attention was given to participants' emphasis on self-care practices in their discussion of these topics. Participants were

assured of adherence to ethical practices in this research, including strict confidentiality. Participants were informed about the precautions that were taken to ensure ethical research practices as determined by Federal standards and approved and monitored by Smith College Human Subjects Review Committee. Each participant returned the Informed Consent prior to the interview (Appendix B). The informed consent form explained the nature of participation, along with the risks and benefits of participating in the study. Participants received a copy for their records.

Instrumentation

At the beginning of the interview, participants were asked demographic questions which included age, gender, racial/ethnic/cultural identity, years in oncology practice and the primary practice setting along with type of client population, licensure and state (Appendix C). The demographic data were used to describe the sample and to seek association with qualitative data.

A semi-structured interview, guided by the interview guide was used (Appendix D). Most of these questions were not asked directly but helped guide the interview in response to the material presented by participants. All voice recorded data was transcribed by this researcher and stored in a secured location with password protection.

All data collection was managed in a confidential manner, and findings are presented in a way that disguises participants' identity. Some quotes illustrative of thematic data from the qualitative findings are presented. The data has been secured electronically via password protection. The data will be secured for three years which is required by Federal regulations. When the data is no longer needed, it will be destroyed.

Data Analysis

Data analysis included the identification of repetitive and discordant themes in the qualitative data and an examination of the quantitative data for associations with thematic findings. Qualitative data was illustrated by using quotations from the interviews being careful to not identify any participants. Quantitative data and measures of association were presented using descriptive statistics.

The interviews were recorded and later transcribed by this researcher and kept in a secure location. Only this researcher and the research advisor had access to the data. The transcripts were examined for repetitive themes related to participants' perception of the importance of self-care to their work as oncology social workers. Attention was paid to any possible association of these themes with demographic data.

Limitations

Due to the small size of this convenience sample, ensuring diversity was not feasible. An additional limitation was the inability to conduct face to face interviews. Further limitations will be discussed in the Discussion Chapter.

CHAPTER IV

Findings

The findings were based on the data collected from twelve participants, who were asked how self-care practices are viewed as ways of avoiding burnout and ways of continuing to work in this field of practice. Following a semi-structured interview format, participants were encouraged to discuss additional thoughts related to their work, including why they chose to work in oncology social work, rewards and challenges of the work, their definition of self-care including how it has changed over time, and the impact of oncology care on their lives.

Demographic Findings

Demographically, the sample can be described as follows. The average years of oncology work experience were 19 years in the field. The range of years in the field was averaged between 5.5 years to 34 years in the field of oncology. Ten out of the twelve participants worked with an adult population while only two participants identified working with children as their primary population. The youngest participant was 44 while the oldest was 64. The average age of the participant was 54. Ten of the participants identified as female and two as male. Similarly ten participants identified as Caucasian while one identified as European and the remaining participant identified as brown stating “we are all brown, it’s a political issue.”

Thematic Findings

Influences That Led to Oncology Social Work

The semi-structured interview encouraged participants to discuss how they became involved with oncology social work. Some of the discussion of this point centered on previous life experience, some on “practicality,” and some on a personal connection with cancer patients.

Previous Life Experiences. Four participants discussed how their social work career was in fact a career change later in life and how their previous work experience and age gave them skills that they could apply to their work. One participant says, “There is a benefit to having some age and grace and grey hair, because people feel as though they can relate a little better I think. I think I already had good coping techniques.”

Six participants discussed their previous personal involvement with cancer or medical crises in their families as a contributing factor in seeking out a career in oncology social work. This portion of participants either witnessed or experienced the effects of a medical crisis which strengthened their connection to the intense emotional work of the field and perhaps prepared them for such work. One participant thought about her experience with a medical crisis in the family, her financial concerns at the time and how it prepared her for the field. She explains “I spent a lot of time in the hospital with my husband and I felt, you know I can do this, I can learn how to help other people navigate the medical environment.” Her graduate program helped secure a hospital internship with a small stipend as well. She says, “So I credit the grant with keeping me in the program and saving our family to a certain extent...that’s how I ended up in oncology social work and it’s turned out to be very gratifying.”

Practicality. Eight participants discussed how their involvement with oncology was incidental due to specific family needs at the time or the types of internships offered during their

masters program. Many participants discussed their involvement with oncology social work as a practical and logistical measure that made sense at the time of their graduate training. One participant explains “I chose that [internship] serendipitously because...I needed someplace that was close. That was the only reason. Nothing to do with the content of the internship...and I loved working with cancer patients while I was there. I just found it satisfying and interesting and I liked it.”

Other participants also discussed how their involvement with oncology social work was completely happenstance in the beginning but later discovered a unique connection to the cancer population. One participant was assigned an oncology internship and explains, “That was not the placement I wanted. I wanted to be at a college counseling center or something like that. And I fell in love with it.” Another participant reflects back on her journey with oncology social work, “I think it was just fate.”

Job security was a guiding principal for one participant as she discusses the practicality of an oncology career. She explains she chose the field “because actually I couldn’t figure out what else to do and I knew that there would always be job security and I knew I always wanted to help people so I figured, you know, and that’s the route I chose.”

Interest in Cancer Patients. More than half of the participants described a connection with working in the field of oncology that has held their attention throughout their careers. One participant articulates that, “I don’t know why I just liked it. The more I did it the more I fell in love with it. And since then I’ve always chosen to be in oncology.”

One hundred percent of the participants discussed the experience of witnessing death and loss. One participant articulates that “People tended to get real when they got cancer. I started dealing with the real stuff of living”. This same participant worked as a social worker in the

court system where he experienced very little job satisfaction and witnessed a great deal of dishonesty from clients. One participant discussed the resilience she witnessed from patients as a factor for keeping her connected to the field. She explains, “I saw a lot of people who were going to be cured. Even those who were having reoccurrences were fighting the fight and going on with their life. I got to meet some pretty inspiring people, frankly.”

Rewards and Challenges of Oncology Social Work

The study encouraged participants to discuss the rewards and challenges of the work in regards to the implications for self-care practices. Patient interactions were among the most rewarding aspects of the field, while the emotional challenges of the field acted as a challenge for many clinicians. Interestingly, participants reported agency culture to sometimes support as well as hinder the role of social work.

Patient Interactions. All participants found that interacting with cancer patients and their families was the most rewarding aspect of the job. In fact, many participants even referred to this intimate interaction as a “privilege” or “gift.” One participant articulates that, “it always strikes me how surprising it is we are so graciously welcomed into most people’s lives. I think I’d say go away. And most people don’t do that.” Similarly another participant describes her experience with oncology social work, “it feels very sacred to be invited into somebody’s life at a time when things are pretty tense and there’s a lot going on for folks. I think it is an amazing privilege to think that people actually let me in when all of that is going on already.”

Some participants discussed the privilege of bearing witness to the amount of resilience in their oncology patients and how this impacted their own outlook on life. One participant articulates her experience:

I think we are fortunate in that we are working with a lot of people who you come to admire for their capacity and resilience in the face of a medical crisis and their ability to change and capacity to face whatever life throws at them. And even if they don't [survive] I think you get to spend time in their lives and learn about their life values and reflect on their life and find out what's important to them and that's inspiring too.

A theme that emerged in the data was how emotionally challenging oncology work can be since it involves so much loss. Four participants described how they have learned to cope with the emotional challenges of the work and how they endured this emotionally difficult work. One participant explains, "Certainly there is sadness often associated with it, but there is sadness associated with life. And again my life has been made more serious I am sure by the work that I do, but also has been so much richer and more full and I have learned so much." Overall participants are aware that the work can be exhausting, but that the rewards make up for that.

One challenging aspect of the work is the unpredictability of a diagnosis. One participant describes, "The biggest challenge is you are constantly adjusting to what their illness is doing. You are constantly adjusting to the latest cat scan, the progression of the disease, that sort of thing."

Agency Culture. Discussion of the agency culture by participants was both positive and negative. One participant, for example, has been with the same agency for 34 years and explains "There have never been times when the work itself, the politics, about the place or the institution was really difficult." One third of participants identified agency culture as a contributing factor to self-care. One participant explains she's never left because her career with the agency has been so rewarding and autonomous. She explains, "It is a fabulous job. We are appreciated. It

works. It's why everybody stays." Community support from colleagues and through supervision was noted by two participants as a beneficial self-care practice.

Other participants described the impact of agency culture on performance and various degrees of job satisfaction. For example, one participant describes her decision to leave an agency that did not seem to value social work. She found that at her new hospital, "It renewed my sense of purpose... This hospital system very much values social work services for patients and it is not just a marketing tool. I mean we are involved in decisions at the highest level and even at as far as processes of paperwork and referrals and all of that. So it was invigorating."

Yet, other agencies may not be as aware of the role of social work as one participant described. She explains, "The job that a social worker does is mostly behind a closed door. So they [administration personnel] don't really have a good idea of what all you're doing. They think maybe you are handing out gas cards or they don't understand the level of involvement. So that can be sort of frustrating."

Similarly agencies that do not value social work can impact the clinical functions and morale of the social work department. One participant explains, "At my previous position, a lot of things were driven by budget and then when you hear your immediate supervisor make a comment in a meeting that social work services are a luxury then you kind of know- okay that is a philosophy that I can't win."

The role of social work is generally not money producing for agencies. Therefore one participant creates a yearly spreadsheet for her quantifiable contributions to the agency in order to justify her position in an agency that sees her role as a "luxury". She describes her approach in more detail:

I personally keep a spreadsheet every year of money I bring either into the practice or into the patient to keep the patient coming here. So then I can show at least I can cover my salary every year. Or if a patient wants to leave the practice because they don't like their physician or whatever and I am able to keep them in the practice but maybe switch them to a different physician then I count that revenue as money that I save this practice. Quite often I bring in ten times my salary in what we call downstream revenue. If I keep somebody here and they've got \$285,000 worth of chemotherapy, needless to say I don't make \$285,000, but that is a big save for the practice.

Other challenges included dealing with the frustration of lack of resources in the field and within agencies. Four of participants identified obtaining resources as a challenge. Additional education has made it possible for one participant to navigate the business model of a hospital setting. She explains:

The hospital wants patient beds turned and wants patients discharged, and families are often not feeling quite ready ...I chose after a while to go back and get a degree in business as well because I felt that I didn't have the knowledge and the language more than anything or as much of that language as I wanted to be able to speak to the decision makers at the administrative level of the hospital to get my patients what it was I felt they needed.

In discussing agency culture, 25% of participants compared their experiences with inpatient settings versus outpatient settings. One participant explains her long career was the result of an outpatient setting in particular. She explains, "I don't think if I was working on an inpatient oncology unit that I would have been able to stay. I think that you deal with end of life in a different way on inpatient and I think I would have left sooner."

Ethical Dilemmas. It is interesting to note that two participants described ethical dilemmas in their career. These participants sometimes don't always agree with the medical model of treatment, for example when patients are very elderly or when treatment would impact quality of life. One participant explains her dilemma, "It is really tough because you can see them [the patients] knowing that we can probably keep them more comfortable if we weren't injecting them with all these drugs. Also just the way that cancer programs are run nowadays sometimes adds to the conflict."

Social work school training was also an ethical dilemma for another participant as she believes, "I don't know if the schools of social work are preparing students as well nowadays as they did. I see some social workers graduating who should not be practicing. And schools are so desperate for money they don't often counsel somebody out."

Thoughts About Self-Care

All the participants discussed the beneficial ways self-care practices have not only informed clinical practice throughout the years, but also enhanced personal time off. The following data also address the evolution of self-care, specific self-care practices and how implementing work boundaries and assertiveness in the workplace contribute to self-care; themes related to changes in self-care and changes in individual professional expectations may occur over time.

Evolution of Self-Care. The data suggested that self-care is an essential aspect of oncology social work as tool for long-term success and balance. One participant sums this up succinctly, "you really have to take care of yourself otherwise you are going to burn out pretty quickly."

Half of the participants described “being aware” as the main component to their self-care. One participant describes self-care as “just being aware of the stresses that this particular kind of work puts on you and doing something about those stresses.” Another participant described self-care as a type of responsibility, explaining “if we truly love what we are doing then we need to be able to take care of ourselves in order to survive, because this job will chew you up and spit you out.”

A major thematic finding was that self-care plays a huge role in oncology social work because clinicians need to develop skills to decompress the emotionally exhausting content. Many participants described giving themselves permission to mourn and experience some hurt because it is inevitable. One participant articulates further, “It’s always hard when someone your age dies. I’ve really had to learn to create some boundaries so I can do my job but at the same time, I’m not a robot. And I don’t want to be a robot. I want to be able to express my emotions; I don’t want to desensitize myself from difficult situations.”

One participant described her family dynamics as a contributing factor to creating healthy boundaries and supporting long lasting self-care practices. She explains when her children were young, “I realized that that was a plus at that time because I had to leave here at a certain time and I had to be fully present when I was home. And it really helped me to have a good balance.”

The study found that there was a learning curve at the start of an oncology career. One participant discusses her experience in the field:

I first started as a social worker in the hospital, I’d come home every day and cry. And my teenager would say ‘mama, if you are going to come home and cry every day, you are not going to be able to do this job’. Somehow I developed the skill of sort of being able to put a distance between myself. You have to put on your game face and keep going.

Parenthood and family life were seen as a contributing factor for shaping self-care practices. One participant describes earlier in her career, “when I first was working in oncology I would have to come home get dinner ready and then be mom for that part of day and that was always hard because sometimes I felt I just didn’t have anything else to give.” Many of the older participants discussed their free time since families have grown. One participant describes, “I am at a point in my life where the kids are out of the house, and so if I want to go and lay in bed and read a book at 8 o clock at night I can do that. Or if I want to go for a walk or take a bath I can do that because my time at the end of the day is just that, it’s my time.”

Some self-care reflections were characterized as routine. One participant explains, “I don’t think and I don’t think my colleagues who have been here for some time think about self-care. It just becomes who you are. It’s who you are— it’s what you do.” Three participants believed they have a balance in terms of self-care.

Though the study suggests fluctuation in self-care practices throughout an oncology career, not all participants reported being successful at it. One participant discussed his self-care thought process. He explains, “In my position I think I make excuses for it. It would be helpful if I did much more physical stuff. But again that heroic expectation of I’m going to work out or walk everyday—it gets in the way. So I don’t really have a balance. It is always an adjustment for me.”

Self-Care Practices. Themes in the data identified a variety of self-care practices for oncology clinicians. Meditation, diet, yoga and exercise were the most common self-care practices for ongoing sustainability. Giving oneself permission to take time off or travel was also very important for some participants. Family and friend support also contributed to some clinicians’ self-care as a way to vent and decompress the difficult emotional content of the work.

One participant discussed the importance of “making time” to practice self-care. She explains, “I make time to hang out with friends, I make time to be at conferences. I make time to train for a marathon, there’s different pieces.”

The data suggested many unique self-care practices, such as driving long distances or spa pampering. One participant explains further, “I get massages whenever I can. I love to drive in the country. I do simple things. I don’t think I need a lot of money to do self-care.”

Music was also a theme for one quarter of participants. One participant used his passion of playing music in a band as a way to stay true to his roots and create balance from oncology social work. Another participant discussed her ritual of belting out musical songs in her car after a day of work to prepare her for being present when she arrived at home. One participant expressed her passion for cooking and baking. Another participant took advantage of her personal time off. She explains, “I do not wear a watch on the weekends. I am not on call and I do not take my pager home.”

Social work support was also important to one fourth of participants. One participant explains, “Another thing is I am active on a national level. I think that is a different diversion for me. And I get to use another part of my brain. That kind of balances out all the day to day clinical work that I do.”

Rituals were reported as ways of caring for the self, for example weekly massages or movies. One participant explains her Friday ritual:

I get *People* magazine delivered to my house and every Friday night I go home I put my sweats or whatever on and I read *People* because it is just food for the brain and you don’t have to think about anything. Then I either watch a really sad sappy movie, which for me the queen of sappy movies so far has been an old old movie “The Way We Were”

with Robert Redford and Barbra Streisand. Or I watch a really funny silly movie and so far “Dumb and Dumber” takes the cake. So that I either just laugh or I cry and I get all the emotion of the week over with.

Healthy Boundaries. Many of the participants discussed the idea of not “fixing other people” and not feeling guilty about their inability to do so. One participant explains, “I can empathize with somebody but their problem isn’t my problem.” Many participants discussed the idea of accepting a patient’s journey by maintaining healthy boundaries from the work. The same participant articulates further:

I don’t take stuff home. I make it a point to don’t take stuff home. I think it’s my philosophy of life. We are all on our journey. We all receive packages for this journey. Not all the packages are wrapped in pretty paper and the inside is not always good, but that is their journey. Their package. I have my own. And my role here is to support them in their journey carrying that package. It’s not my role to remove that package for them or to deny that package that they carry or pretend it doesn’t exist. So I keep my boundaries knowing that is their package.

Half of the participants discussed the importance of boundaries in the therapeutic setting. One participant discussed how boundaries also contribute to her self-care balance. She explains, “Well I set some pretty good boundaries ... like where I work they wanted a lot of volunteers for weekend events and fundraisers, and I did some of that at first but then I found all my time is going towards you know “cancer”. It’s like, I need my weekends and my evenings to be mine. So I try and limit that....generally I try to keep my time off my time off.”

Ability to Say No. The ability to say no was reported by two of the participants as one of the challenges to self-care. One participant explains, “that it is really difficult for me to say no I

am not here...I am still learning. It's still always a struggle." She reflects further on her behavior earlier on in her career. She explains, "I've become more assertive in my job...So I think I've become more outspoken with hospital administration, with my colleagues. I've really learned a lot more about working with other social workers and how we can support and help each other."

Another participant reflects on her journey to also become more assertive in her role. She explains:

I didn't know or I wasn't willing to say no to things. I was blessed with a lot of, recognition is not the right word, but a lot of request to speak here or do that or write this chapter or work on this piece of research or whatever... I don't know that I knew what balance felt like and I also don't know that I knew it was okay to say no. and I don't know if I trusted that if I said no they would ask again. So it took a while to kind of trust the process.

Reframing Professional Expectations. All of the participants discussed the impact of expectations on job performance, both positive and negative. Many participants found it was helpful to reframe expectations, as one participant describes, "it's more about being present with people and being alongside them on the journey and I think that makes all the difference." Five participants described letting go of the notion that they need to "fix patients," and that this letting go contributes to a more manageable career. One participant explains, "I didn't go into it [social work] to change the world. And so I didn't maybe have to deal with the disappointment or disillusionment." She discusses her reframing in more detail, "If I get one call per day from a patient where I was able to answer their question or help them with a strategy or resource, or just let them feel like they were heard and maybe that's a low standard, but then I feel like it's been a worthwhile day. There's a lot in my day that doesn't feel so worthwhile." Nine participants

described the little things they are able to do for a patient as rewarding and as a way to make the journey a little easier on the patient or family.

Half of the participants discussed the ability to reframe job expectations to provide job satisfaction, such as accepting their presence during a patient's journey as helpful or focusing on concrete needs or resources as a sign of doing a good job. This also includes providing information for patients and families, providing tangible resources for financial assistance, or how to go about discussing a diagnosis with an employer—all small contributions to patients and families dealing with a diagnosis which clinicians found rewarding in the face of intense emotional content. One participant explains that “Sometimes it is the really concrete things you can do for somebody, like fill out their paperwork.”

Participants discussed the unpredictable nature of the work and that simply being present with patients was found to be very gratifying. One participant describes, “The biggest reward is when you know that you've done something that has made a patient's life just a little bit easier. Whether it is getting them a ride, whether it is getting them a free wig, whether it is giving them a hug, it's just that is the biggest reward.”

One participant described the realization that reframing her role in the oncology field helped her experience the role more fully. She explains:

I needed to ground myself before I walked into the rooms of my clients and not bring my spirituality in, in the sense of talking about it but bring it in with me in the sense of you know I didn't have to have any answers, I didn't have to fix folks, I didn't have to save their lives, you know, none of that. I just needed to show up and be present. And the way for me to be able to do that was to be grounded and be in connection with that.

While some participants expressed the ability to reframe job expectations and performance into more manageable outcomes, changing work expectations can be challenging, as one quarter of participants discussed. One participant described the evolution of technology as an obstacle to self-care practices and balance. She explains, “I was here long before there was voicemail. Email didn’t exist. When you were here you were here when you were off you were off. And that is no longer true...the expectation for sure is that people are available much more if not all of the time.”

Another participant described how his sense of innate heroism impacted his journey and development as an oncology social worker and how it required reframing. He explains:

The problem is, I have this innate sense of heroism and that is a nice motivator in some ways but it is also a very big handicap, the sense that we can save people or rescue and there are some times when that happens and that’s nice, it’s just not why we are here. So that was a big change. A change of identity for me; that struggle being helpful is very simple and in some ways very complex....the work was just more than I expected...as time went on I realized that I had something to give in my presence. And that took a long time to realize that really was enough. And there really wasn’t any reason to think less of that.

Changes in Self-Care Over Time. And while family dynamics seemed to help create necessary boundaries during earlier years of their careers, some participants found a decline in self-care practices when children were out of the house. One participant explains, “Truthfully it is a little bit harder now because they are grown and they aren’t home waiting for me. Sometimes I don’t leave when it would be good for me to leave because I don’t have to go for somebody else.”

Nine of the participants expressed some ideas or areas for improvement in terms of self-care. Some of these improvements included taking frequent breaks throughout the day to rest and recharge, or making more time for meditation or prayer, in addition to more exercise. Some participants wanted more challenges to reinvent themselves and continue to learn about oncology through CEU's, conferences or projects. One participant identified decreasing her work hours as the most optimum for self-care. Another participant identified reframing the illness aspect and moving more towards a wellness approach with patients. She explains, "I want to start moving away from illness to more wellness. Because that is something that I really enjoy. I'd like people to be more healthy."

Impact of Oncology on Outlook on Life

Many participants discussed the ways in which oncology social work has impacted their lives, usually for the better. Oncology social workers confront many existential themes of spirituality and mortality on a daily basis and therefore this study address the ways in which clinicians gain meaning from existential lessons learned in an oncology setting.

Oncology Life Lessons. All of the participants described a life that was made more rich and valuable because of work in oncology social work. Nine of the participants described the value of life in any given moment. One participant explains, "The most valuable lesson that I've learned ...is to value today. I learned that from oncology and hospice which was also helpful in raising my children because I was able to temper expectations I had of my family. Because I could be real present to what's happening now and that's been a good thing." Another participant explains, "I take nothing for granted." Another participant explains her philosophy, "Probably my favorite saying I have acquired since I started working here is a saying I made up:

there's life and then there's life threatening. Someone today has two kids, she's a single mom and she's not going to live. So that kind of puts it all in perspective. So life and life threatening.”

Mortality. Three quarters of participants discussed the role of mortality and spirituality in their everyday lives. One participant described her career as a gift. She articulates, “So being in this profession for me has been a gift. Because I am very aware of my mortality and I don't take life lightly. I enjoy. I take advantage. I live n the moment and I enjoy my moment and my present. I see it as a gift everyday because oncology has taught me we don't know when our time is up so I'm going to make the best time I can every day.”

Spirituality. Half of the participants explicitly identified themselves as spiritual beings and made reference to a “higher power” with various definitions as a contributing factor to self-care. One participant describes her faith as follows, “Spiritually supports me. It is a loving support system that walks with me every hour of my day and night. And that's where I get my strength and get my quiet time with. That's who or what I am grateful for and respect.” Another participant identifies spirituality as “connecting to something whatever it is and I don't know how you can call it whatever you call it but, something that's bigger than me and part of the universe and contributing back to the universe.” Another participant says a prayer before interacting with each patient to help ground and support her.

Summary

Many of the thematic findings were consistent with the data discussed in the literature. The nature of the study however made possible to identify themes that were not previously discussed or were not shared by other clinicians. Therefore the data suggest a rich and complex study of the role self-care plays in the field of oncology social work.

CHAPTER V

Discussion

Introduction

This chapter will discuss the themes from the data, particularly as they relate to the literature. While most of the narrative data centers on self-care practices, participants also discussed influences that led to a career in oncology, the rewards and challenges of the work including comments on the influences of agency culture, and how the work has impacted their outlook on life. The chapter will conclude by discussing the study's implications for oncology social work practice and research and its limitations.

Influences Leading to Oncology Career

One third of the sample began oncology social work as a result of a change in career. As they reported, previous professional experience influenced some clinicians to develop self-care practices along the way before they entered oncology. However, as Alkema, Linton and Martin (2008) point out in their data on hospice care, anyone in a helping profession is susceptible to the professional hazards of compassion fatigue.

Personal experience with a medical crisis or cancer motivated 50% of participants to seek out oncology social work. This is consistent with the data from Supple-Diaz and Mattison (1992) that show that experience with personal loss acts as a catalyst for working in the field of oncology. Perhaps for some individuals, personal experience with cancer and/or death leads to a

desire to help others with these issues. It is also possible that these personal experiences may result in an increased awareness of the need for self-care practices.

In addition to personal experience, graduate training also acted as a catalyst for pursuing a career in oncology since many of the participants who found themselves in an oncology placement gravitated toward careers with that specific population. It may be noteworthy that one theme that emerged in the data was that even when social workers took oncology jobs for practical reasons, like needing a job, oncology proved to be a compelling and meaningful field of practice for them.

Rewards and Challenges of Oncology Work

The study supports the view that when an individual identifies a connection with a certain field, sustainability measures will undoubtedly be taken to withstand challenges and that stepping up to those challenges significantly outweighs the negative effects of the job (Evans and Villavisansis, 1997). The data also support the literature that states that oncology work *is* often seen as a “gift” or a “privilege” (Rohan and Bausch, 2009).

The professional connection with cancer patients and their families may result in an uplifting view of patient and family resilience—certainly a rewarding aspect of the field. However, continuously bearing witness to loss, death, bereavement and grief presents numerous challenges and risks, including compassion fatigue. Rohan & Bausch (2009) emphasize that the oncology therapeutic setting is based on the premise that patients and families are coping with a poor prognosis or are experiencing difficulty with coping. The fact that clinicians are able to enter into a patient’s journey at one of the most personal times in their lives suggests a very deep and intimate connection with patients.

So much intimacy between patients and clinicians can leave clinicians with intense emotional reactions to loss and at risk for compassion fatigue. As Bober and Regehr (2006) point out, when entering into a therapeutic relationship with oncology patients and their families, clinicians' use of empathetic engagement with clients fluctuates greatly with each unique interaction. This distinctive connection and reaction to each patient's journey may impact the clinician in sometimes negative ways when they are left to cope with the loss and sadness of the work. Not only do clinicians have the opportunity to impact the journey, but are also impacted as well. However, as the literature suggests, and the data support, the intense emotional rewards can outweigh the emotional challenges of the field.

Although it is noteworthy that research suggests grief is cumulative over time (Stearns 2001), participants in this study did not identify an increased difficulty coping as years in the field increased. Perhaps their utilization of self-care practices increased over time which may account for managing the cumulative grief.

Agency Culture

Agency culture impacts oncology social work in many challenging and rewarding ways as the data suggest. Some participants in the study described agencies as promoting social work, and they were more likely to express job satisfaction, autonomy and respect. Reported practices that contributed to this type of culture include decision making at many levels as well as clear job expectations.

Agencies that place a high value on training opportunities and supervision were seen as contributing to job satisfaction and sustainable self-care practices. The study suggests that the role of an oncology social worker is not entirely independent but rather is impacted and perhaps enhanced by a supportive environment. Davidson and Foster (1995) also point out how

administrative strategies to improve the working environment to support social workers and the complexity of their role will enhance job satisfaction.

The study and the literature point to some ways that agency environment impacts clinicians. Killian (2008) examined themes contributing to compassion fatigue such as the impact of working environment, caseload demands, personal trauma, lack of support from colleagues, friends or supervision. Similar themes were also reported in this study. In addition, Bradley and Sutherland (1995) report high levels of stress for social workers working within an agency structure with low morale, a theme also supported by the data in regards to agency culture.

A clear understanding of the role of social work might result in administrative recognition for work with clients and families and therefore act as a buffer to compassion fatigue. Lloyd et al. (2002) presents examples of agency culture contributing to burnout through lack of recognition or not fully understanding the role or value social work offers. The data anecdotally support this view that individuals working in an environment where social work is valued are at lower risks for compassion fatigue while those clinicians who work in agencies that do not fully understand the role of social work are under additional stress to prove or defend their value.

Davidson and Foster (1995) suggest that lack of resources or staff support may inhibit “compassion satisfaction”. The study reported 25% of participants, all of whom worked in adult cancer settings, found obtaining resources for patients and families as a challenge. In comparison, the participants who work in a pediatric setting had no trouble obtaining resources for patients and families; in fact obtaining pediatric resources was identified as a rewarding aspect of the field because clinicians were able to make the patient’s journey that much easier.

Perhaps there may be more resources put into pediatric cancer care as opposed to adult cancer care, which might cause additional stress and feelings of helplessness for those working with adults.

A small portion of participants discussed ethical dilemmas that they encounter in their career as a challenging aspect of the field, such as treating patients when quality of life would be at risk or sending graduates into the field who lack preparation. The fact that some participants voiced concern about whether treatment should be as aggressive for patients when quality of life may decrease shows clinicians may have trouble following medical protocols they disagree with, particularly when these protocols are a threat to their emotional intimacy with patients and families. Such negative interactions can also lead to feelings of burnout (Whippen and Canellos 1991).

Self-Care

This study supports theories that self-care practices increase job satisfaction and function as a tool to enhance personal time off. The study also suggests that self-care practices are essential to job satisfaction as well as a coping mechanism to balance out the intense emotional demands of the work.

The data suggested mindfulness and self-awareness, as self-care skills, enable clinicians to more fully empathize with the emotions of patients as well as to realize when their own emotions need to receive priority. One of the most important self-care practices may be to experience the complex emotions presented by the very nature of oncological work. Many clinicians discussed giving themselves permission to feel pain and acknowledge its presence. They suggested that in order to sustain themselves, it might be essential to take time to experience loss and heal from it as well. As McGarrigle & Walsh (2011) point out, the findings

affirm that mindfulness practice assists with self-awareness, coping with job stressors and work reflection.

In addition to creating more opportunities for job satisfaction, this study suggests that the implementation of self-care practices decreases the risks for compassion fatigue. The study presented one participant who described “putting a distance” between herself and the content of oncology at times as a way to “put on a game face” and meet expectations. McGarrigle & Walsh (2011) imply that professionals who experience compassion fatigue have limited ability to express empathy. It may be however that putting a distance between the clinician and the patient may be acting as a protective factor for emotional distress.

Family life may contribute to self-care practices as a distraction from oncology or even as an obligation to set boundaries away from oncology work. Many of the participants discussed how raising families during their career helped formulate boundaries so it was not “cancer all the time.” More generally the data suggest that filling personal time with some outside obligations may contribute to the development of self-care practices.

Davidson (1985) suggests that the stress involved with oncology work has a tendency to impact one’s personal life, such as heightened awareness of mortality, including greater appreciation for life as well as increased vulnerability. Although, increased vulnerability was not a theme that emerged in the data it could be that discussing personal perspectives on vulnerability such as personal health or fears around cancer was too difficult for participants to discuss in a telephone interview.

Participants did discuss positive self-care practices through the utilization of hobbies, such as music, singing or other activities that promote a life away from cancer care. The theme that emerged was that oncology work could be all consuming and that it was important to

establish joyful distractions and activities. Research from Whippen and Canellos (1991) suggests that some of the stress in oncology work might be alleviated by increasing vacation and personal time, which was a self-care practice that was also discussed by participants.

Maturation may be a contributing factor to self-care. The data suggest that participants grew, adapted and evolved their self-care practices throughout their careers. Cunningham (2003) reported that the more experience clinicians had in their career, there was less experience of trauma from the work compared to those clinicians with less experience. This implies that self-care practices for oncology social workers develop over time and are enhanced with more professional experience, age and life lessons. Simon, Pryce, Roff, & Klemmack (2006) staked a differed claim, that the more advanced a professional's licensure is, the *less* likely they are to experience "compassion satisfaction." This claim was not supported by the data from this study.

Staying physically active may help clinicians to keep more balanced energy levels during times of acute emotional distress. Meditation and yoga were practices that many participants in the study used, perhaps suggesting a positive trend towards Eastern practices and its effectiveness on work-life balance. In addition, because the field of oncology is faced with such emotionally difficult content, living in and appreciating the moment was reported as a simple measure that brought participants ease. Therefore the ability to find a silver lining or acknowledge the beauty amidst pain can be a sustainable factor for a career in oncology.

Reframing job expectations into more manageable outcomes contributes to increased job satisfaction as the study suggests. Killian (2008) focused on variables that contributed to compassion fatigue, the most notable being the sense of powerlessness clinicians feel. Perhaps the study participants were able to reframe this sense of powerlessness into the power of presence and found value in bearing witness and helping patients navigate their journey.

The power of presence, i.e., the healing interaction of being present with a patient, was a theme a majority of the participants discussed as a rewarding aspect of the work. Davidson and Foster (1995) also discuss the importance of recognizing small interventions like providing resources or being present. Adding the power of presence into one's job expectation may account for a more rewarding career or at least the ability to measure small successes throughout the day when clinicians have little control over what the disease is doing.

Impact of Oncology on Outlook on Life

Mortality is certainly an aspect of oncology social work that clinicians witness countless times throughout their career as was reported by participants. Perhaps because oncology social workers are more aware of issues of mortality there is an increase in the role spirituality plays in their lives, and perhaps it functions as a protective factor to manage career demands.

Collins (2005) describes spiritual practices as a way to practice self-care. A connection to spirituality can also be a way to accept and heal from some of the pain witnessed in the field.

One participant takes comfort from the interconnectedness of life as he describes how oncology social work has impacted his outlook on life and influenced his spirituality:

At the time when I started working in the hospital, I didn't think there was any driving force, conscious or unconscious that brought me to hospital social work. But honestly in retrospect, I think there was one of the things that happened to me in that first year was some connection with all the time I spent in the hospital as a teenager and some of the people that helped me during that difficult time. I think connecting with other humans and connecting with nature is what my spirituality is about. That is kind of how my spirituality has evolved over time. I also confronted my own mortality through the life and death of many people I've worked with.

Killian (2008) also focuses on spirituality as a healing measure to connect the individual to something larger.

Implications for Oncology Social Work Practice

Further preparation of social workers for work in oncology should be reassessed, since training programs rarely focus on issues of mortality or on issues of vicarious trauma or self-care. Schools of Social Work and oncology settings may want to consider implementing stronger support systems that encourage engaging in difficult content but also ways to manage this.

While some clinicians may be wary of invasive and aggressive treatment for patients who may have increased difficulty of recovering from such treatment, the field of oncology is driven by revenue-producing treatments as opposed to palliation. Therefore clinicians who might want more consideration of psycho-social issues in a patient's treatment plan may contradict agency values and encounter resistance.

Social work schools may have so many other competing demands related to curriculum content that they may not be able to offer extensive training that would prepare students for oncology work. This lack of emphasis on death and bereavement and on the culture of aggressive cancer treatment may add to the stress of oncology work for social workers. Rohan and Bausch (2009) also identify that there is a disconnect between what is taught in social work schools and what is presented in the field of oncology. Additional social work training may also assist in the ability to navigate agency culture in conjunction with clinician values.

Implications for Oncology Social Work Research

It would be beneficial to the field for future research to focus on agency culture and solutions regarding compassion fatigue as well as manageable self-care tasks that can be

conducted during the work day. Additional research may also provide psychoeducation for administrative and managerial personnel to understand the complex and dynamic role of social work. Further research may also help shift agency culture to collaboratively and effectively assess the risks for compassion fatigue and support additional self-care practices.

Limitations of the Study

The sample in this study is limited by size, race and gender. It is not possible to generalize from such a small sample, and the sample is over 80% white and female. The number of years in the field was also a limitation with the average years in the field being 17. Perhaps including clinicians with less than four years experience would have yielded more insight into self-care practices and reasons for staying in the field. In addition, telephone interviewing was a limitation since it did not allow for non-verbal communication cues.

Conclusion

The study focused on twelve oncology social workers and how their careers have been sustained with the help of self-care practices. The study suggests if social workers are committed to careers of helping others, then it is their responsibility to implement self-care practices in order to decrease risks for compassion fatigue and to enhance the clinical role. This study may be particularly relevant to recent graduates who are considering working with a population with intense emotional concerns, such as death and bereavement.

This study addresses the important role self-care plays in the field of oncology social work as a buffer to compassion fatigue and burnout in the field. Such information is not only relevant to the field of oncology, but to all professionals who encounter intense emotional content in their care-giving work.

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Appendix A

Recruitment Email to Potential Participants

Dear _____,

I am an MSW student conducting qualitative research for my Master's thesis at Smith College School for Social Work. I am exploring the ways in which oncology social workers employ self-care. I am looking for participants who are licensed social workers who have been in the field of oncology for a minimum of four years. Participants will be asked to participate in a 25 minute voice recorded interview as well as answer some demographic questions.

If you are interested in participating in this study, please email me at lcotter@smith.edu. Would you please forward this email to anyone you know who might be interested in this study?

Thanks you for your time and help!

Sincerely,

Lindsay Cotter, MSW Student
Smith College School for Social Work
Lcotter@smith.edu
(xxx) xxx-xxxx

Appendix B

Informed Consent Form

Dear Participant,

My name is Lindsay Cotter and I am a Smith College School for Social Work graduate student. I am conducting research for my master's thesis to learn more about the ways in which oncology social workers employ self-care given the emotional demands of the field. The study has been approved by the Smith College Human Subjects Review Committee and is guided by Federal standards. The data may be used in presentations or publications on this topic. You are invited to participate in the study because you are a licensed social worker with at least four years of experience in the field of oncology.

Your participation is voluntary. I am asking you participate in a 45 minute voice recorded interview (face to face interview preferred). Interviews will be voice recorded in person and via telephone or skype with the use of an electronic recording device. The recording device electronically converts the interviews into MP3 files which will then be transcribed by this researcher. You may refuse to answer any of the questions asked during the interview. The interview will consist of open ended questions and probing questions to gather more information for this qualitative study. Because this study focuses on self-care, you will be asked questions about your personal self-care practices throughout your career in oncology. You will also be asked why you chose the field of oncology and to discuss some of the challenges and rewards of the work.

Interviews will allow you to share your personal and unique experience working in the field of oncology as a social worker. Your confidentiality will be protected in many ways. The demographic questionnaire and the audio recording of the interview will be translated into numerical codes, thereby eliminating identifying information. You will not be asked to include identifying information. Only the research advisor and I will have access to the raw data. Some illustrative quotes from the qualitative findings will be presented, though without including identifying information such as demographics.

Demographic questions such as number of years in the field, type of oncology population and gender will be asked. All identifying information will be removed from the findings. Interviews will be voice recorded and then transcribed by this researcher. Participants will be given a numeric code for the purpose of the transcription. All material will be password protected and only accessible to this researcher and the research adviser.

The study presents minimal risks to participants. Benefits to participation in this study include the opportunity to help increase the body of research on how self-care is employed in a field with a tremendous amount of emotional stress and compassion fatigue. Participation in this study is voluntary. Participants may refuse to answer questions or opt out of the study until April 1, 2013. If a participant decides to leave the study, responses will not be used for the findings. No compensation for participation is provided.

All data from the study will be kept in a secure location for a period of three years, as required by Federal guidelines, and data stored electronically will be fully protected. The informed consent forms will be stored in a locked file that is separate from the interview data. If the material is needed beyond a three year period, it will continue to be kept in a secure location and will be destroyed when it is no longer needed.

If you have any questions or concerns about your rights or about any aspect of the study, you can contact me at (xxx) xxx-xxxx or the Chair of the Smith College School for Social Work Human Subjects Review Committee at (413) 585-7974.

Thank you for your interest in the study.

Sincerely,

Lindsay Cotter, MSW Student

BY CHECKING THE BOX BELOW THAT SAYS "I AGREE," YOU ARE INDICATING THAT YOU HAVE READ AND HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS; AND THAT YOU AGREE TO PARTICPATE IN THE STUDY. Please print a copy of this page for your records.

_____ I disagree _____ I agree

Subject signature/date

Researcher signature/date

Appendix C

Demographic Data

Please provide some demographic information for the study:

Age:

Gender:

Racial/ethnic/cultural identity:

Number of years in oncology practice:

Primary practice setting:

Client population:

Type of licensure:

State:

Please note that the demographic information will be coded and transcribed by this researcher. Participants will be assigned a numeric code for the purpose of the transcription to remove identifying information from the findings. All material will be password protected and only accessible to this researcher and the research advisor.

Appendix D

Interview Guide

- Can you describe why you became involved with oncology social work?
- How do you define work related self-care?
- Some people say self-care creates a work-life balance, is that true for you in oncology?
- In what ways has your self-care evolved throughout your oncology career?
- Do you find your outlook on life has changed since working in oncology? How so?
- Have you ever considered leaving the field of oncology?
- What improvements could be made to your self-care in the field of oncology?
- What have the rewards of working in oncology social work been for you?

Appendix E

Human Subjects Review Approval Letter



School for Social Work

Smith College

Northampton, Massachusetts 01063

T (413) 585-7950 F (413) 585-7994

December 17, 2012

Lindsay Cotter

Dear Lindsay,

Thank you for making the requested changes and for your care and consideration in your other responses. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Best of luck on a very interesting study!

Sincerely,

A handwritten signature in black ink that reads 'David L. Burton'.

David L. Burton, M.S.W., Ph.D.

Chair, Human Subjects Review Committee

CC: Bruce Thompson, Research Advisor