

**A Narrative Intervention with Oncology Professionals: Stress and Burnout Reduction
through an Interdisciplinary Group Process**

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A DISSERTATION

in

Social Work

Presented to the Faculties of the University of Pennsylvania

In

Partial Fulfillment of the Requirements for the

Degree of Doctor of Social Work

2010

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Dedication

To each of my colleagues from all professions who work tirelessly day in and day out fighting cancer and doing it with heart. It is a privilege and an honor to work with each of you.

And

to the memory of each and every patient that has crossed our paths

Acknowledgements

This dissertation reflects the support, expertise, wisdom and knowledge of so many people. I wish to acknowledge my gratitude to each of them for their contributions to this research project.

I am grateful to the University of Pennsylvania School of Social Policy and Practice, fueled by the vision of Ram Cnaan and Lina Hartocollis for the re-creation of the DSW program. Without their innovative leadership this dissertation and the DSW Class of 2010 would never have been realized.

I am forever thankful to my intrepid Dissertation Chair, Ram Cnaan for his sound advice, honest critiques, always given with overwhelming support and encouragement. I feel that under his expert tutelage, I have been able to grow into a better researcher and practitioner.

Next, I would like to thank Jerri Bourjolly for her time, guidance, and knowledge and sensitivity to those who experience cancer. She has been an integral part of my decision to both pursue my doctorate and to study the oncology population. Her support began as far back as practice class while in my Master's program and over the years she was always willing to sit down with me and share knowledge and advice.

Additionally, I owe a debt of gratitude to Rita Charon, without whom this thesis would not be possible and who sparked my interest and affinity for narrative medicine. From the moment I attended her session on narrative medicine at Penn's Bioethics seminar in 2006, I knew I was hooked on this burgeoning field that combined all of my passions. I am so thankful for her support over the years and for agreeing to be on my committee, for speaking at the Kelly Writer's House Word.doc program, and for the amazing experience created for us in that first narrative medicine session in the Fall of 2006 and the subsequent advance training session a year

later. Her writing and pioneering spirit are what I aspire to and her contributions to the field go without saying.

I would be remiss if I did not also thank all of the members of the Columbia Narrative Medicine program, Sayantani DasGupta, Marsha Hurst, Craig Irvine, Eric Marcus, Maura Spiegel and Patricia Stanley and to all of the friends made at each of the Narrative Sessions.

A very special thanks to Jack Truten for his expert facilitation skills in conducting narrative sessions at HUP, his tireless work on Narrative professionalism and also for his friendship. Humble thanks to Alan Wasserstein who included me on the Narrative professionalism committee at HUP and whose continued advocacy and vision are sparking a grass roots narrative movement in our hospital. And to the visionaries at the Kelly Writer's House who entrusted me with the leadership of the Word.doc program while the funding lasted.

I would like to thank my first research mentor, Dr. Margaret Stineman, who planted the seed of returning to school and who supported my education in every aspect. I will never forget our time together.

I would like to thank Bernie Newman for taking a chance on me a blessing me with my first teaching endeavor and for taking an interest in my research. Additionally, I am grateful to Jonathan Singer whose friendship; guidance and advice not only helped me with teaching, but also gave me direction in my dissertation. Thank you for allowing me to discuss my research and for telling me about your research. I am happy to know that there are social workers like you teaching the next generation.

I am also forever grateful to the flexibility and support of my employer, the Hospital of the University of Pennsylvania and my direct supervisor, Associate Director and Director of the Clinical Resource Management and Social Work Department, Tracy Griffith, Patti Meehan and

Kelly Cooke respectively. Their support helped me balance the often-insurmountable challenge of my work responsibilities at HUP with my academic work. Additionally, I am so appreciative of the support of my colleagues, Deborah Lowenstein and Erika Parker who covered for me on multiple occasions while I took time off to work on this dissertation and who always had words of encouragement for me.

Numerous individuals were instrumental in helping me accomplish this project, by supporting the adoption of narrative oncology on each of the three inpatient units, by making it possible for nurses to attend sessions and for their encouragement; Kirsten McClintock-McGroarty, Mary Denno, Teresa Kider, Amy Moore, Katie Wiley, Kristen Wisniewski, and David Porter. I would also like to thank each of the nurses on each of the three oncology units, especially my colleagues on Rhoads 6 who supported me in all respects—there are too many of you to name, but I adore all of you.

I am thankful to my fellow cohortmates that took this enormous journey with me and who I will always admire. I cherish our three-years of memories. I want to especially acknowledge and appreciate Angel Hogan for everything that she does everyday, from the bottomless carafe of coffee and all the delicious meals that kept us going through those long days and evenings, to arranging dissertation defenses and helping the DSW program function with a smile and with kindness. I have never once heard you complain about anything.

I would be remiss if I did not thank my closest colleague and friend, Sabrina Jiles who endured countless hours of listening to my research, classwork, teaching and personal life. Without your friendship and compassion, I would have had a meltdown, plus it is fun to be your friend.

Lastly, I need to thank my soulmate, my best friend, my confidant, my cheerleader and coach, my husband George Saint-Louis, who always has my back, who loves me unconditionally and without whom I would not be completing this dissertation. Je t'aime mon cheri, maintenant et pour toujours!

ABSTRACT

**A NARRATIVE INTERVENTION WITH ONCOLOGY PROFESSIONALS: STRESS AND BURNOUT
REDUCTION THROUGH AN INTERDISCIPLINARY GROUP PROCESS**

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Ram Cnaan, Ph.D.

The increased prevalence of cancer diagnoses ensures that oncology healthcare professionals will be faced with more challenges than ever before in their work with cancer patients, especially in hospital environments. The literature demonstrates that professional caregivers are at risk for burnout (BO), compassion fatigue/secondary traumatic stress (CF/STS), job stress and job satisfaction and have minimal forums for which they can share their experiences. In an environment of ever-shrinking resources, it is imperative to use innovative methods to help the professionals cope with the day-to-day challenges of caring for terminally ill individuals. This exploratory mixed-methods study investigated the efficacy of a narrative intervention group with oncology professionals. Forty oncology health care providers from three inpatient oncology units completed the Health Consultants' Job Stress & Job Satisfaction Questionnaire (HCJJSQ), the Professional Quality of Life Scale: Compassion Satisfaction, Burnout and Fatigue Scale Version IV (ProQOL-CSF-R-IV), and the Maslach Burnout Inventory-Human Services Survey (MBI-HSS) with subscales of emotional exhaustion (EE), depersonalization (DP) and personal accomplishment (PA), pre- and post-intervention along with post-session evaluations with three Likert questions and three open-ended questions in addition to ten in-depth interviews. Statistically significant decreases were found in BO, CF/STS, EE, DP, and job stress with significant increases in job satisfaction from the first month to the fourth month. Professionals discussed the rigors of their work and their impressions of the

narrative oncology groups reporting overall positive experiences with specific appreciation for shared perspectives and finding comfort within the narrative exchange.

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List of Abbreviations

AAHRP	Association for the Accreditation of Human Research Protection Programs
ACS	American Cancer Society
BO	Burnout
CDC	Center for Disease Control
CF	Compassion Fatigue
DP	Depersonalization
EE	Emotional Exhaustion
HCJSQ	Health Consultants' Job Stress and Satisfaction Questionnaire
HHS	Health and Human Services
MBI-HSS	Maslach Burnout Inventory-Human Services Survey
NCCN	National Comprehensive Cancer Network
NCI	National Cancer Institute
PA	Personal Accomplishment
ProQOL-CSF-R-IV	Professional Quality of Life Scale: Compassion Satisfaction, Burnout and Fatigue Version IV
STS	Secondary Traumatic Stress
VT	Vicarious Traumatization

Chapter I

Oncology Healthcare Professionals: The Need to Care for the Caregivers

There's always this feeling like, "Well, maybe they won't be here tomorrow. And this is their – this is important to them. And they may not be here for much longer." So you have all of that you have to carry. --Jane Austen, Oncology Nurse

According to the Center for Disease Control (CDC) and other healthcare agencies, cancer is the second leading cause of death in the United States, exceeded only by heart disease (ACS, 2009; CDC, 2009; NCI, 2009). In 2009, it was estimated that 766,130 men and 713,220 women would be diagnosed with cancer of which 292,540 men and 269,800 women would die of cancer (ACS, 2009; CDC, 2009). According to National Cancer Institute (NCI), a study from 2001 to 2003 showed that women had a 38% chance of developing cancer at some point in their lifetime and men had a 45 % chance (ACS, 2009; NCI, 2009). The American Cancer Society (ACS) reported that cancer has surpassed heart disease as the number one killer of people in the United States under the age of 85 (ACS, 2009; NCI, 2009). These statistics suggest that everyone in the United States has a significant chance of being diagnosed with cancer or being affected by cancer through a loved one or friend.

The prevalence of cancer diagnoses increases the likelihood that social workers and other healthcare professionals will be presented with individuals struggling with cancer. Hospitals manage, monitor and treat the sickest cancer patients and continue to observe steady increases in acuity, turnover and even death. The rise in cancer cases also means that oncology healthcare professionals are faced with increased daily challenges to ease the emotional burdens of cancer patients, intervene in new and creative ways with shrinking resources, and to demonstrate the efficacy of their work with clients (Lauria,

Clark, Hermann, & Stearns, 2001). The potential to join with patients and families to find effective, strengthening, and enriching coping strategies is paramount to all oncology healthcare professionals.

Patients and families experience myriad issues and challenges when dealing with the various stages of cancer. Each person's perception of and psychosocial response to illness is unique. However, there is a universal expectation that, at some level, both the patient and family will experience distress. The definition set by the National Comprehensive Cancer Network (NCCN) contends that:

Distress is an unpleasant experience of an emotional, psychological, social or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, from common normal feelings of vulnerability, sadness, and fears, to problems that are disabling such as true depression, anxiety, panic and feeling isolated or in a spiritual crisis (NCCN, 1999).

Receiving a cancer diagnosis can be a highly distressing event that includes a multitude of psychosocial issues and challenges. Cancer sufferers frequently report a need for additional psychosocial supports to deal with the stress inherent with the illness (Newell & Sanson-Fisher, 2000; Sanson-Fisher, Girgis, Boyes, Bonevski, Burton, & Cook, 2000). Since 1999, the NCCN has been lobbying for regular psychosocial treatments for cancer patients, as evidenced by many actions, including the article, "The NCCN Guideline for Distress Management: A Case for Making Distress the Sixth Vital Sign" (Holland & Bultz, 2007).

Just as the individual with cancer suffers, the professional caregiver constantly exposed to her patients' distress, also experiences distress. The stresses that oncology

professionals face as a daily part of their routine practice include dealing with extremely sick and terminally ill patients and their families who require and deserve a great deal of emotional support in addition to high quality and optimal medical care. These professionals attend to these issues in an ever more complex therapeutic landscape with increasing financial stresses and ever increasing patient numbers, acuity and overall complexities. Often, the end result of the prolonged exposure to these stresses is reflected in high rates of burnout in oncology professionals. Mount (1986) described burnout as the end result of stress in one's professional life and resulted in feelings of apathy, suspicion, self-protection, disillusionment, and depression (Allegra, Hall, & Yothers, 2005; Mount, 1986; Whippen & Cannellos, 1991).

The nature of oncology work involves chronic loss, grief management, and comforting of the patient, their family members, and friends. While much of this practice with oncology patients involves management of psychological distress, as well as accessing resources, it also involves coping with the physical and emotional aspects of terminal illness. The circumstances under which the social worker or other health professional develops a relationship with patients can become close and sometimes resembles pseudofamily (Lauria et al., 2001). The task for the health professional involves empathizing and supporting terminally ill or potentially terminally ill patients and their loved ones. Many factors have contributed to this researcher's current interest in helping end-of-life care professionals. The expectation that the professionals who serve dying patients will always maintain *professional boundaries* and *distance* seems unrealistic with the competing expectation that they will also get close enough to empathize (Himmelsback, 1978; Lederberg, 1998; Lief & Fox, 1963).

Oncology professionals attempt to balance relational interactions while caring for their patients with the impact of overinvolvement and emotional exhaustion that comes from these intense transactions (Koeske & Kelly, 1995). They often struggle to maintain detached concern by intellectualizing, compartmentalizing and withdrawing from emotional stress (Pines & Maslach, 1978). Due to the constant rigors of this work, professional caregivers lose interest in their work, develop physical and emotional exhaustion and often lose concern for their patients (Koeske & Kelly, 1995; Pines & Maslach, 1978). Due to the complex nature of the hospital environment, these professionals are at increased risk for psychological strain and job dissatisfaction. Jayaratne, Davis-Sacks, and Chess (1991) found that “agency” workers reported higher stress and less personal well-being than their counterparts in private practice. Therefore, these professionals would benefit from interventions that help them to cope with the rigors of their work and assist in re-sensitizing them to the uniqueness of each patient.

This study proposes that narrative oncology is one vehicle that can help professional caregivers learn to care for and protect themselves and ultimately be more effective with their clients. ““As part of their [professional] training [healthcare staff] are taught to ignore their own needs,” says Shapiro. “No one teaches them how to protect themselves or mourn their patients. I treat the whole system--if the [professionals] are in better shape, the patients will be in better shape’” (Chamberlain, 1999).

This intervention, narrative oncology, is an innovative way to elicit dialogue and to help professionals cope with the stress generated by caring for persons who are terminally ill and by constantly being exposed to death and disease. This paper discusses the emotional and psychological risks that are faced by these professional caregivers

working in hospital-based oncology units, as well as the potential benefits of using narrative intervention to help them cope.

As stated above, the literature posits that oncology healthcare professionals have intensive encounters with suffering and dying patients and therefore may be vulnerable to burnout and compassion fatigue. The rigors of this type of work include, stress, coping, empathy, burnout, vicarious traumatization (VT), secondary traumatic stress (STS) and compassion fatigue (Figley, 1995; Maslach, 1976; Maslach & Jackson, 1984; McCann & Pearlman, 1990; Simon, Pryce, Roff, & Klemmack, 2005). All of these descriptions have nuanced differences in definition. However, the overarching theme is that stress is high and rewards are low (Figley, 1995; Maslach, 1976; McCann & Pearlman, 1990; Simon et al., 2005).

The literature discusses several overlapping domains or concepts discussed in the death and dying literature that include stress, coping, empathy, burnout, compassion fatigue (CF), and secondary traumatic stress. Numerous references also refer to STS and CF phenomenon as “secondary victimization” (Figley, 1982, 1983, 1985, 1989), “co-victimization” (Hartsough & Myers, 1985), “secondary survivor” (Remer & Elliot, 1988a, 1988b), and “vicarious traumatization” (McCann & Pearlman, 1990). Vicarious traumatization (VT) has been defined and refined further in the literature as the “negative transformation in the therapist’s (or other trauma worker’s) inner experience resulting from empathic engagement with clients’ trauma material” (Pearlman & Saakvitne, 1995). However, it is the opinion of this researcher that the nuance of vicarious traumatization is not completely applicable to the work of front line oncology workers. Quantitative findings from various sources report a lack of vicarious trauma in oncology professionals

(Cunningham, 2003; Dane & Chackes, 2001; Rohan, 2009). This researcher believes burnout and compassion fatigue better encapsulate the experiences of oncology physicians, nurses and social workers.

This study seeks to explore the concepts of compassion fatigue, compassion satisfaction, burnout, job stress and job satisfaction pre- and post- narrative intervention. In addition to the review of the literature, 11 years of inpatient hospital experience will impact this discussion.

While palliative care professionals deal with death regularly and inpatient hospital professionals deal with death occasionally, inpatient oncology is a mixture of curative medicine and palliative care, which creates a fine line between hope and resignation. Professionals on inpatient oncology units are confronted with death and suffering on a regular basis. The literature is voluminous in regards to burnout phenomenon in various work settings and within various occupations including positions in human services, or specific healthcare providers (Felton, 1998), e. g., pulmonologists, cardiologists, psychotherapists. However, few studies focus on the combination of physicians, nurses and social workers that share the burden of care and the increased risk for burnout in the inpatient oncology setting. Numerous careers have been studied but it is those in the provision of caring for one or more human beings in a health care setting that is the subject of this discussion. The articles chosen are by no means exhaustive but serve to illustrate burnout as well as contributing to the belief that narrative intervention would be an effective method to alleviate the symptoms of burnout.

Stress and Burnout defined

Stress is defined by Merriam-Webster (2008b) as “a state resulting from a stressor; a constraining force or influence especially: one of bodily or mental tension resulting from factors that tend to alter an existent equilibrium a physical, chemical, or emotional factor that causes bodily or mental tension and may be a factor in disease causation.”

Many have commented that stress is an antecedent to burnout, defined by this contemporary dictionary as exhaustion of physical or emotional strength or motivation, usually as a result of prolonged stress or frustration (Merriam-Webster, 2008a). Burnout is an example of an extreme ‘strain’ reaction. It affects the physical and mental health of the caregiver and may carry costs for the employing organization through absenteeism, staff conflict and rapid turnover (Maslach, 1976). Burnout may also affect the quality of care provided to patients and their families (Revans, 1976). Maslach's (1976) conceptualization of burnout, involves three distinct components: Emotional Exhaustion (EE), Depersonalization (DP) and reduced Personal Accomplishment (PA).

Maslach and Jackson (1981, p. 99) defined burnout as, “a syndrome of emotional exhaustion and cynicism that occurs frequently among individuals who do people-work of some kind.” Cordes and Dougherty (1993) conducted a review of literature relating to job burnout. They posited that the core dimension of emotional exhaustion is the first stage of burnout followed by depersonalization, which is employed as a coping strategy and finally, feelings of reduced personal accomplishment occur. Emotional exhaustion is often characterized by a lack of energy and a general malaise or feeling of being worn out (Felton, 1998). Depersonalization refers to a negative approach to treating others as objects. Some published research suggests that exhaustion leads to distancing oneself

from work, so that depersonalization may be viewed as a type of avoidant coping mechanism used to cope with emotional exhaustion (Maslach, Schaufeli, & Leiter, 2001; Thoresen, Kaplan, Barsky, Warren, & de Chermont, 2003). Exhaustion and depersonalization, therefore, are strongly related.

Keidel (2002) asserted that the difficulty in “straddl[ing] the medical world with its emphasis on cure and the hospice world of caring and providing comfort” (p. 201) becomes more than the professional can handle. Their negative feelings flow from perceptions of personal inadequacy, inability to control the patient’s symptoms, and conditions within the patient’s family and home. Often the boundary between the professional and being a friend becomes blurred therefore increasing chances of burnout and compassion fatigue (Keidel, 2002). Other contributing stressors, approached from a systems theory, are societal influences, the healthcare system, and the institutional systems. Western society does not “objectively value a ‘good’ death.” Regulations, mandated paperwork and insurance issues consume the time of the health care professionals that should be focused on patient care. Institutional stressors such as short staffing, financial agenda of institution contribute to resources allocated to dying patients (Keidel, 2002).

Compassion Fatigue, Secondary Traumatic Stress, Vicarious Traumatization, and Compassion Satisfaction defined

Compassion fatigue is defined as a direct result of exposure to client suffering and is complicated by lack of support in both the workplace and the home (Figley, 1995). The literature addresses several questions about how compassion and altruism deplete the caregiver, citing four major factors: poor self-care, previous unresolved human trauma,

inability to control work stressors and lack of satisfaction for the work (Figley, 1995; Radey & Figley, 2007). Radey and Figley (2007) built upon the existing literature in this area by challenging professionals to change the focus of the conversation from the existence of compassion fatigue and floundering practices to ways to cultivate compassion satisfaction and flourishing practices. They stated that, to prevent compassion fatigue, clinicians should attempt to notice and buttress the sense of satisfaction of working with suffering patients (Figley & Stamm, 1996; Radey & Figley, 2007). The authors gave numerous suggestions on how to begin addressing this paradigm shift from an avoidance of negative consequences to a nurturing of positive outcomes (Radey & Figley, 2007). Although, the authors specifically addressed compassion fatigue and compassion satisfaction in the context of the social work profession, it can certainly apply to other healthcare providers.

The literature and growing body of research now recognizes that indirect exposure to trauma and suffering create risks of significant emotional, cognitive and behavioral changes in the clinician (Bride, Radey, & Figley, 2007). VT, STS, and CF are now viewed as an occupational hazard of clinical work (Adams, Boscarino, & Figley, 2006; Bride, 2004 & 2007; Bride et al., 2007). According to Figley (1995), secondary traumatic stress is “the natural and consequent behaviors and emotions resulting from knowing about a traumatizing event experienced by a significant other—the stress resulting from helping or wanting to help a traumatized or suffering person” (p.7). Figley (1995, 1996, 2002) coined a more “user-friendly” term to describe STS, namely compassion fatigue.

The STS phenomenon has been called different names over the years. We suggest that compassion stress [STS] and compassion fatigue are appropriate substitutes.

Most often these names are associated with the ‘cost of caring’ (Figley, 1982) for others in emotional pain (Figley, 1995, p. 9).

Bride et al. (2007) described that although there are some distinctions between vicarious traumatization and secondary traumatic stress/compassion fatigue in regards to theoretical origin and symptom foci, the three terms refer to the negative impact on the clinician in work with traumatized or suffering clients/patients. The following model helps predict the onset of compassion fatigue and burnout:

This model is based on the assumption that empathy and emotional energy are the driving force in effective working with the suffering in general, establishing and maintaining an effectively therapeutic alliance, and delivering effective services including an empathic response (Figley, 1995; Figley, 2002). However, being compassionate and empathic involves costs in addition to the energy required to provide these services. Following are the eleven variables that, together, form a causal model that predicts compassion fatigue...” (Figley, 2002; p.1436).

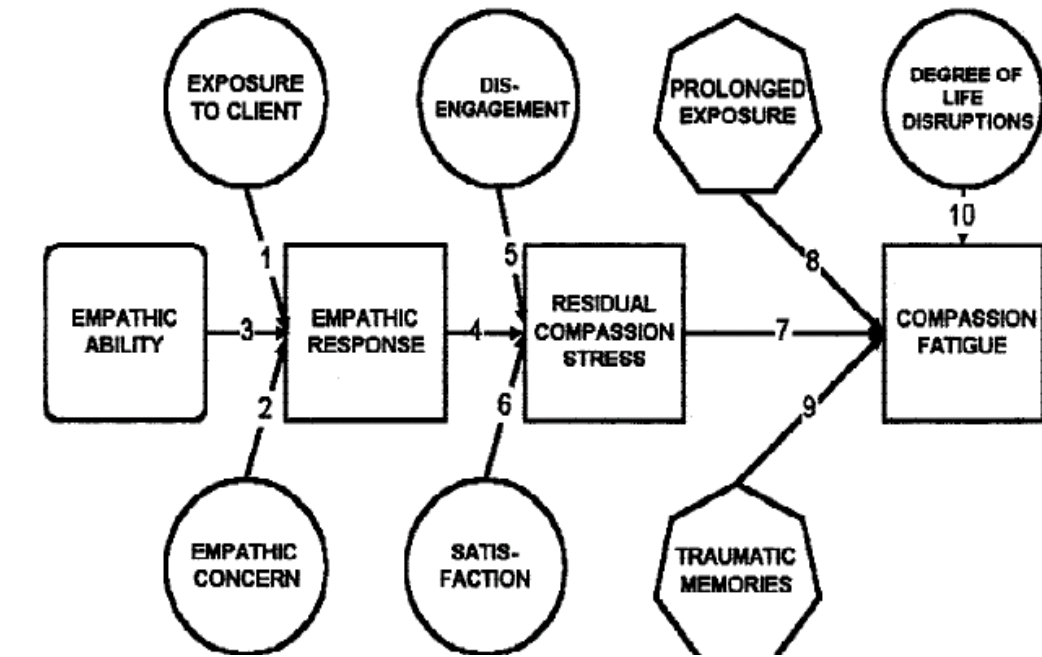


Figure 1: Causal Model of Compassion Fatigue (Figley, 2002, p.1437)

Figley's (2002) article suggests that the most effective way to avoid compassion fatigue and burnout is through enhancing job satisfaction and self-care.

Burnout has a broad definition, which includes issues of stress and distress, ranging from fatigue to major depression (CDC, 2008; Northwestern, 1991) but has also been equated with adjustment disorder and depressed mood (Van Liew, 1993). Many view the problems associated with job stress simply as burnout (Figley, 1995). Pines and Aronson (1988) defined burnout as "a state of physical, emotional and mental exhaustion caused by long term involvement in emotionally demanding situations" (p.9).

Burnout also appears in physical manifestations. Some stress-related health issues include exhaustion, anger, muscle pain, headache, insomnia, respiratory distress, hypertension, and gastrointestinal disorders (CDC, 2008; Felton, 1998; Van Liew, 1993). In 1991, Northwestern National Life published a landmark study entitled, *Employee Burnout: America's Newest Epidemic*. In this study, respondents reported 'often' the

presence or experience of “very or extremely stressful” circumstances. Since this 1991 study, much more research has been done and published on the topic of work related stress and burnout. It is recognized by the National Institute for Occupational Safety and Health (NIOSH) and has resulted in changes in the workplace (CDC, 2008; Northwestern, 1991). Some effects of this research are the growing number of Employee Assistance Programs (EAPs) in workplaces across the nation (CDC, 2008). According to Felton (1998), “Burnout is a professional occupational disease manifest in the many specialties of health care and will be a disorder as long as human values and worth are disregarded by inept policy makers and managers of human resources. In the ultimate, elimination of burnout will mean better care for clients and patients” (p. 248)

Stress, Burnout and Compassion Fatigue in Three Disciplines

The following sections will discuss stress in three healthcare professional groups: physicians, nurses and social workers. These professionals are the most basic members of the multidisciplinary oncology team (Penson, Dignan, Canellos, Picard, & Lynch, 2000; Penson, Gu, Harris, Thiel, Lawton, Fuller, & Lynch, 2007; Sherman, 1999; Stearns, 1993, 2001) and therefore it is important to study the experience of burnout and compassion fatigue within and across these disciplines. Stearns (2001) noted that “it is not possible to deliver good cancer care in isolation” (p. 225) and that when the team shares the intense experiences of oncology work, it can both increase the cohesiveness and the effectiveness of collaboration. “The team delivery of health care is never more crucial than in oncology” (2001, p. 214). Physician and nursing literature appears to have a more substantial body than that of the social work literature in regards to burnout and oncology patients or palliative care professionals. This section mentions palliative care

or hospice which are related to inpatient oncology and sometimes coexist in the same setting however, inpatient and home hospice care are nuances of caring for the terminally ill that focuses on comfort rather than treatment and will not be examined in detail. This study hopes to summarize and offer suggestions to oncology health care providers on how to cope with the combined effects of stress on these health caregivers.

Physicians and Burnout

“*Physician:* ‘We need to create an environment where people aren’t forced to practice turnstile medicine, especially in cancer’ ...” (Penson et al., 2000, p. 428).

Physicians find their occupations attacked by many fronts, often causing them to question their choices of careers (Felton, 1998). The dissatisfaction and lack of fulfillment come from within the profession as well as from outside critics. Some experts have noted that with increased burnout comes decreased patient care and decreased patient satisfaction. (Geller, Bernhardt, Carrese, Rushton, & Kolodner, 2008). Zuger (2004) referred to the trend in data that suggests dissatisfaction on the part of physicians breeds “poor clinical management, as well as dissatisfaction and noncompliance among patients, and that the rapid turnover of unhappy doctors in offices and hospitals may lead to discontinuous, substandard medical care” (p. 69). (DiMatteo, Sherbourne & Hays, 1993; Haas, Cook, Puopolo, Burstin, Cleary, & Brennan, 2000; Pathman, Konrad, Williams, Scheckler, Linzer, & Douglas, 2002; Zuger, 2004).

The external factors that impact dissatisfaction and lack of fulfillment in physicians have been described across the literature as, the growth of managed care, heavy (and ever increasing) clinical workloads, constraints on physicians’ clinical autonomy, malpractice crisis, expectations of physician care and broader scope, and with

the advances in medicine and new technologies there are increased patient expectations for effective treatment and cure (DiMatteo et al., 1993; Geller et al., 2008, Haas et al., 2000; Pathman et al., 2002; Zuger, 2004;). Geller et al. (2008) suggested that due to these external factors it is increasingly difficult for physicians to have meaningful connective experiences with patients. Felton (1998) quoted an Idahoan physician, “ ‘...Amid this cacophony, it becomes ever more difficult to attend to our societal and personal sworn duty of caring for the ill and tending to the infirm...the bureaucracy erodes our professional confidence and effaces the ancient numinosity [spirituality] of the physician-patient relationship’ ” (Felton, 1998, p.240).

A growing number of retreat like programs have been added proof that health care is suffering as a result of burnout. Some meetings are held by physician disease survivors (Commonweal, 2008; Remen, 2001) and others incorporate interdisciplinary team conferences to assist in coping, two of the most prominent are Schwartz Center Rounds (Schwartz, 1995) and Charon’s Program in Narrative Medicine at Columbia University (Charon, 2006). Both narrative medicine and Schwartz rounds attempt to bring a renewed focus on bioethics and humanistic medicine and to lead clinicians back to their interactions with patients. However, narrative medicine is unique, utilizing the written word and the reflections of group participants to create an intimate and comprehensive sharing experience of healthcare professionals. The narratives are a medium that allows the participant to focus wholly on the task at hand, to confer form to otherwise ignored emotions and allows professionals to build community and team affiliation.

According to Shanafelt, Sloan & Habermann (2003) there has been a plethora of studies on physician distress, but little is known about physician wellness. Distress and

burnout could have potentially serious implications for physicians. One study found a relationship between burnout and reporting suboptimal patient care. Due to constraints on physicians' time, the multiple pressures facing them from insurers, healthcare institutions, and patients promote a culture of self-neglect. Additionally, Physicians perceived professional role may leave less room for the expression of vulnerability than their counterparts in nursing and social work. Experiential stigma is more likely to be present and they are less likely to have supportive networks and participate in groups. Although, physicians reluctantly join groups, substantial benefits are often derived from membership (Garside, 1993; Shanafelt, Bradley, Wipf & Back, 2002).

The discussion of physician wellness and how to achieve it consists of recognizing that wellness goes beyond merely the absence of distress or burnout, but also includes being challenged, thriving and achieving success in personal and professional endeavors. Some recommendations from Shanafelt, Sloan, & Habermann (2003) include activities that promote creativity and involvement, such as research, the arts, self-expression and reflection.

Nurses and Burnout

“**Nurse:** ‘Connecting with the patient is the most important thing. I remind myself everyday that we are all human and that I’m not going to connect with all of my patients...I don’t feel good about that...’” (Penson et al., 2000, p. 430).

The literature discussing nurses and burnout speaks to similar issues as those plaguing physicians with additional factors as well. Nursing has been undergoing a shortage for greater than a decade and is predicted to continue for the foreseeable future (Aiken, Clarke, Sloane, Lake, & Cheney, 2008; Aiken, Clarke, Sloane, Sochalski, &

Silber, 2002). Aiken's landmark studies demonstrated that in hospitals (like the one to be examined in this study) with high patient-to-nurse ratios, surgical patients experience higher risk-adjusted 30-day mortality, failure-to-rescue rates, and nurses are more likely to experience burnout and job dissatisfaction (Aiken et al., 2008; Aiken et al., 2002). Also, nurses are continually exposed to the death and dying of their patients (Naef, 2006). The nurses at the hospital to be examined in this study have been increasingly exposed to death as patients are transitioned to inpatient hospice level of care more frequently sometimes beginning their convalescence in their hospital rooms where they were previously being treated with chemotherapy or radiation. The death and familial despair that used to occur elsewhere is now directly in their line of sight, the suffering is palpable and their emotions are often closeted.

Patients can present many demands and often communication with caring nurses is blunted or negligible because of medication, diminishing any substantial connection with the ailing person (Felton, 1998). Also, nurses feel a sense of personal failure, futility and powerlessness in the face of diseases such as metastatic carcinoma, melanoma, mast cell leukemia, as well as complications resulting from the treatment of these diseases.

All nurses, but oncology nurses especially have the added burden of handling mutagens (agents that can cause a genetic mutations), teratogens (agents that interfere with normal embryonic development), and carcinogens (cancer causing substances) that can cause some of the very diseases they seek to treat. They stand behind lead screens in hopes that the patient, who ingested a radioactive medication as part of his/her treatment will not expose them, but to properly care for that patient there are times that they must

touch and administer medicines to that patient. The administration of the various chemotherapeutic agents carries the potential risk to not only to its handlers, but may cause embryo-foetal toxicity (Felton, 1998; Shortridge-McCauley, 1995).

All healthcare workers including nurses regularly report disillusionment with the current health care system and its fluctuating rules and regulations seemingly designed to make the task of patient care that much more difficult. As a result, many nurses report being disillusioned with the very jobs they once felt passionate about (Demerouti, Bekker, Nachreiner, & Schaufeli, 2000; Felton, 1998). An anecdotal observation indicates that oncology floor or ward nurses leave after several years either for additional education or for administrative positions. The nurses that are currently on the floors to be examined in this study (on day shift) are mostly new or recent graduates who will be measured and discussed in greater detail in the methods section.

Social Workers and Burnout

“*Social Worker:* ‘I think the hardest part is that there is very little time for reflection built into the schedule anymore. If someone dies there are four more patients filling that space. I think there is something insidious about the unrelenting trauma, the vicarious loss that we all carry. We have to build in spaces where we don’t see patients...or to connect with the team...if you don’t find ways to do that, I think it will impact on our ability to work and communicate, not only with each other but also our patients and families that we care deeply about’” (Penson et al., 2000, p. 429).

Burnout manifests itself in social workers in a number of ways. The literature states today social workers experience dictates that due to the infinitely changing American healthcare system hospital social workers are often called to do more with less

and to assess disposition and to create a safe and supportive discharge plan to the maximum amount of people in the shortest amount of time (Felton, 1998; Gregorian, 2005; Hartman, 1991). The constraints and limitations have been described as oppressive and have the clinician always racing against an invisible clock whether it be the insurance coverage time ticking away or the need for the bed so another patient can fill it. It is easy to get lost in the numbers and fall victim to the patient in a vacuum scenario—they had no life prehospitalization. The patient was not a father, mother, sister, son, teacher, lawyer, construction worker, business owner, etc before they assumed the undignified and vulnerable role of patient. In the blood disorders especially, many times patients were working and healthy persons who had nondescript symptoms for a good length of time that can be attributed to something other than a leukemia or a lymphoma, but their ‘doctor decided to take their blood’ and now they are set for a 30 day course of induction chemotherapy with the unknown after that.

An oncology social worker must address many issues much like their counterparts in the other parts of the hospital, but they are supposed to have the ‘luxury’ of spending time with their patients and doing more supportive counseling. Much time is spent in the initial biopsychosocial spiritual (BPSS) evaluation where the social worker meets the patient and unlocks the first keys to their pre-hospital selves. The patient is given bibliotherapeutic materials and usually some crisis intervention and supportive counseling with the intent for regular or as needed follow-up by the social worker.

However, discharge planning often precludes the supportive and counseling aspects needed by patients and families. The discharge planning is often operated on a revolving timetable. Personal experience informs the following description; the social

worker may have 4-5 (often more) complicated placements on a 28-bed unit with 7 new BPSS evaluations and numerous crisis issues that arise throughout the day. Patient's medications including growth factor (e.g., Neupogen or filgrastim, used to stimulate the production of neutrophils, which are a certain type of white blood cell that protects against infection) are taken by many patients post-chemotherapy and are extremely expensive. Many Medicare products do not cover these medicines or the patient's co-pays are exorbitant well beyond their means, which is that of a limited income or of someone recently out of work due to disability. The social worker must try to help find the money and/or the medicine while not completely removing any hope from this man or woman who is now also dealing with cancer, loss of job or uncertainty about when they will return to work, and are simultaneously addressing the subject with their children while preparing them and their family for the road ahead.

The social worker is often touched by the stories of their patients and families and hopes for the best while knowing that many of them do not make it through the disease or its complications. It may be weeks, months or years, but the social worker's true feelings may dictate "despite maximal therapy, patients keep on dying" (Felton, 1998, p. 243). There is often little in the way of gratification for these health caregivers. The patients are depressed and know the grim outlook of their diagnosis and prognosis. These patients and families, though not always, may be in no emotional state to express gratitude and consideration. "For the health care professionals who want to see their patients get better, the milieu is laden with despondency, and when metastatic disease is noted, it becomes extraordinarily difficult to maintain a sense of hope" (Felton, 1998, p. 243).

Often the social worker becomes overwhelmed and may even feel helpless. Experientially, it can be described as being in the middle of the swirling tornado and deciding when to jump out. The social worker may have additional responsibilities placed upon them as a result of new legislation, hospital regulation or departmental policies. Their effort and the zeal with which they exert it may go unappreciated by the patient, the family or their supervisor and it may contribute to a self-questioning of competence and reason for remaining in the field. There often seems to be little or no recognition of stellar work and the financial remuneration is not commensurate with experience—the only incentive and likely, the most compelling one is the patient and their story. It is not difficult to imagine that disillusionment sets in and the temptation to depersonalize is strong (Felton, 1998; Himmelsback, 1978; Koeske & Kelly, 1995; Lederberg, 1998; Lief & Fox, 1963; Pines & Maslach, 1978). Burnout is on the horizon and is often preceded by callousness, hostility or numbness while ‘going through the motions.’

Three Disciplines: Similarities

There is a common thread in all of the literature describing the experiences of professional health caregivers which includes an initial desire, as prosaic as it might sound, ‘to help people’ which drives the doctors, nurses and social workers to begin this work in the first place. These professionals begin as optimistic and vibrant idealists that are beaten down by a bureaucratic, business-modeled system that is often run by non-clinicians. They emerge years later as if coming up for air, questioning their career choice, dreading the days ahead, looking forward to the next day off and their gazes become averted from the persons that they originally sought to care for. It is not that they want to become insensitive or distant, but it is because they have nothing left—they are

worn out with no outlet. They still care, but they need to be able to share these emotions with their peers and also with themselves. These health care professionals need to tell their stories and struggles experienced in their human service journey.

Summary

“Diseases like cancer, HIV, Alzheimer’s (and others) destroy their victims slowly and this fosters the establishment of strong emotional bonds between the sick person and the care provider. Their conjunction is unavoidable” (Marquis, 1993, p. 20). Deleterious effects of burnout, compassion fatigue and job stress are noteworthy for oncology professionals in the care of their patients. The taxing emotional expense of these oncology-specific stressors combined with professional stress and organizational issues are documented throughout the literature. Each healthcare professional’s caregiving voyage coalesces with the emotions and journey of their respective oncology patients merging their distress and stress. The concepts of burnout and compassion fatigue seem to systematically assist in exploration, definition and description of the disadvantageous aspects of constant exposure to death and dying.

This study seeks to discern the degree to which oncology professionals experience, burnout, compassion fatigue and job stress, if at all. Additionally, an examination of ongoing narrative oncology groups will be used to determine if burnout, compassion fatigue and job stress are impacted through this multidisciplinary group experience. Sociodemographic factors (marital status, social supports, education), coping strategies, teamwork, rewards of the work and the years in clinical practice contribute to the phenomenon of burnout, compassion fatigue and level of job stress. Additionally, professional socialization, role, division of labor and expectations combined with the

profound privilege and responsibility of caring for the terminally ill impact how each physician, nurse and social worker perceive their respective experiences of the components of burnout, namely emotional exhaustion, depersonalization and personal accomplishment. A better understanding of burnout and compassion fatigue along with examination of a cost-effective resource such as narrative oncology is important because the effects of continued job stress can lead to a professional exodus of the oncology workers due to the tolls of working with this population. Due to the scarcity of research in the examination of supportive resources for oncology physicians, nurses and social workers and the nascent development of the field of narrative medicine, this study is a first step in filling the void.

Chapter 2

Narrative Oncology: A Narrative Medicine Intervention with Oncology

Professionals

“But writing it makes you really reach down, pick a few key things, get them out and then you’re able to deal with those things” –Emily Bronte, Oncology Social Worker

This study intervention first combines the very important act of writing the story about indescribable emotions that accompany caring for persons with a cancer diagnosis, then reading it aloud to others with shared experiences, and finally inviting them to be witnesses to suffering. Each narrative, written by each health care professional in the proposed study through the narrative intervention group, confers form to their voices. This process assists and even teaches us that the written word and oral communication about the illness experience invite the reader/listener to translate the witnessing of suffering into empathy, care, and action.

Taking care of patients, whether it is in the role of social worker, physician or nurse involves the professional caregiver’s immersion into the stories of those for whom they care and along the way their own caregiving stories are created. These experiential stories incorporate patient care, past traumas, professional training, organizational stressors and individual character traits. Stories or narratives are an integral part of the practice of narrative medicine which forms the base of this researcher’s conceptual framework. Narrative therapy, narrative and literary theories (hereafter referred to as narratology), and recent neuroscience literature joined with a love of reading, writing, and the arts in concert with inpatient oncology social work experience also inform the researcher’s conceptual frame. Other contributors to the discussion on the importance of story sharing are the vast publications of personal and professional illness narratives.

Finally, Frankl's search for meaning derived from his experiences in a concentration camp provides parallels to the literature of professional caregivers and their experiences of burnout, compassion fatigue and job stress. The common thread between all of these interests and theoretical frameworks is that they form the basis of narrative medicine, which in turn gives the professional caregiver the opportunity to articulate the great privilege to work with sick and hurting people and to take heed of their suffering, to listen, acknowledge and share.

The theoretical foundations of narrative medicine have come to the foreground witnessing models from clinical fields other than medicine whose practitioners have been committed to *hearing patients out*, to being the active receptacles for patients' stories of suffering...[narrative medicine] is becoming available to doctors, nurses and social workers who want to buttress their skills to bear witness to their patients [and to one another] (Charon, 2006, p. 199).

What is Narrative Medicine?

Charon identified five narrative features of medicine—temporality, singularity, causality/contingency, intersubjectivity and ethicality.

Medicine is itself a more narratively inflected enterprise than it realizes. Its practice is suffused with attention to life's temporal horizons, with the commitment to describe the singular, with the urge to uncover plot (even though much of what occurs in its realm is, sadly, random and plotless), and with an awareness of the intersubjective and ethical nature of healing (Charon, 2006, p. 39).

Temporality

Temporality, the quality or state of being connected with time or the world, time in the oncology care providers world, the lack of it, the amount spent by both professionals and patient on the oncology service, the knowledge that life ends and that our time on this earth is sometimes fleeting, is the daily truism faced by the persons in this study.

Singularity

Although each oncology physician, nurse and social worker may find their collective stories to be true there is a singularity to each of their narratives. It is the belief of this researcher that narrative confers form and it is an accepted truth in narrative medicine that form confers singularity. By participating in a forum that produces oncology narratives, professionals can locate their singular impact that their caregiving makes. They can find their uniqueness in the sharing of their narrative semi-publicly with likeminded professionals. By attending to one another, representing their experiences, ideas and emotions and hopefully affiliating with one another and building a closer community.

This *attention, representation and affiliation* is also described by Charon (2006). It supports the theoretical orientation of these practices that *narrating* is an avenue toward consciousness, engagement, responsibility and ethicality.

Causality/Contingency

Narratives have plots and announce a series of events. Narratives attempt to make sense of why things happen, connect thoughts through motive or cause (Charon, 2006). There are a lot of unknowns in caring for the terminally ill. Why do some persons

respond to treatment and others do not? What causes leukemia? How long can I continue to work in this environment?

The plots that we encounter and create in medical practice are very practically and irrevocably about their endings. They point to human ends, using their geometries to understand or to imagine the vectors of life, the plottedness of life, the inevitability of death, and the narrative connections among us all (Charon, 2006, p.51).

Intersubjectivity

“The subject is the self-who-knows, the self-who-acts, and the self-who-observes,” (Charon, 2006, p.51). Intersubjectivity creates a relationship between the teller and the receiver. The act of sharing narratives creates and strengthens relationships and helps the individual to better understand themselves and their own experience.

Ethicality

By sharing narratives in the hospital setting, the receiver owes something to the teller by virtue of knowing it (Charon, 2006). The stories told within the conference rooms on the hospital wards and their tellers expect confidentiality and the receivers of this knowledge do as well. There is an unstated expectation that the tellers will be honest and forthcoming and the receivers will accept the gift of words with openness, support, understanding and empathy. The intimacy created in the act of reading or hearing another colleagues work is akin to the most coveted relationship between analyst and analysand (Charon, 2006).

One article discusses a meeting held at Dana Farber Cancer Institute in Boston with two facilitators known as Schwartz Center Rounds. Kenneth B. Schwartz was a

cancer patient at Massachusetts General Hospital who formed The Schwartz Center, a nonprofit organization dedicated to supporting and advancing compassionate healthcare delivery (Penson et al., 2000; Schwartz, 1995). Penson et al., (2000) describe the interchange between several physicians, nurses and social workers; quotes from this discussion will be injected into this paper. Also, monthly interdisciplinary Schwartz Rounds although not directly responsible for Narrative Medicine and Humanistic Medicine are a close cousin and attempt to produce similar effects. The belief of the narratologists is that the very act of writing helps us to slow down our thoughts and to give form to something that is otherwise shapeless (Charon, 2006). It is likely that narrative interventions are an effective vehicle to help in the reduction of burnout, compassion fatigue, apathy, and may serve to reenergize the emotionally exhausted clinician to again see the patient and their respective unique situation with fresh eyes.

By reconnecting with one's own experience of illness, whether as patient, family member or health caregiver, the professional is better able to identify with the singularity of each patient she cares for, as well as helping her to emotionally cope with challenges of working in the area of death and dying. The interest to pursue this topic and uncover the caregivers' stories was also triggered by the paradox of caring for a dying patient—the desire to have both emotional intimacy and simultaneous distance in an effort to provide excellent care but also to protect and preserve the professional and personal self. Healthcare often attempts to reduce a person to a collection of symptoms, looking at the individual as a patient, but not as the singular, unique being that was active before they were admitted.

Professional experience in caring for persons with cancer on an inpatient oncology

unit informs this researcher's narrative curiosities as well. The patients are often very ill and near death and many die in our midst. Each patient's life impacts each professional in a different way. Each patient has a singular experience and the caregiver shares in that journey in some manner. Between December 2007 and February 2008, professionals on the inpatient oncology unit to be examined in this study witnessed more than 15 deaths. The effect of all of the sorrow, pain and despair, felt by patients and families was palpable and was worn on the faces of the physicians, nurses and other caregivers of these patients. One nurse became tearful in a corner while organizing her medications to give to her next patient. She strained to speak through a cracking voice and looked through her tear filled eyes saying, "it's just so hard...I just came back from maternity leave and [the patient] has young kids..." Each doctor, nurse, nurse's aide, social worker, etc. that cares for terminally ill patients accompanies them on parts of their journey and thus "bears witness" (Charon, 2006) to each patient's narrative. It is the assertion of this researcher that just as the patient constructs a narrative so does the professional health caregiver. This discussion is not meant to be exhaustive, but merely refers to theoretical ideas and briefly references the neuroscience of psychotherapy and logotherapy in the context of the narrative. Just as those theorists that came before and after the work of White and Epston (1990), Charon, (2002; 2005; 2006), Cozolino (2002) and Frankl (1959/2006) gave us a language that delves into relationship-building, overcoming obstacles, and focuses on the importance of the therapeutic alliance, these prominent theorists' ideas are integral to maintaining the health of the professional caregiver and their respective patients. In a time where the practice of medicine, in response to managed care companies, demands evidence-based practice and requires measurable

outcomes, there is a possibility that the therapeutic process and the helping relationship will be lost. However, the resurgence of narrative methods combined with emerging neuroscientific proof assures that the therapeutic process continues in the narrative exchanges between patient and therapist, or patient and their narrative support group, or patients and themselves.

Perhaps, Coates (2002) was right after all, when she noted that Woolf (1947) channels the belief that “illness is the quintessential aesthetic experience” (p.242). Pain can return us to language that prompts us to invent the discursive means with which we might best capture the inexpressible sensations of our material bodies. Pain is a subjective experience, thus how would pain be measured in order to objectify it. Illness narratives like art demand that we inhabit an entirely different reality. We strive to give suffering a language so that others would understand.

We cannot easily translate one’s suffering experience into numerical analyses but the writer can create a narrative or the artist can create a piece that embodies the entire complex expression of feeling of anguish and pain. Through the language of aesthetic and artistry, we give meaning to the affliction experienced by the author or artist. By using narratives and the written language in a public professional setting, like narrative oncology, there is a linkage or shared understanding of the experience of the person or persons who wrote the story and the hearers that receive it.

According to Kleinman (1988), “an approach that takes the illness experience into consideration is a reconceptualization of medical care to include the empathic witnessing of the existential experience of suffering and practical coping with psychosocial crisis.” (p.10) The illness narrative speaks of the medical experience and gives the reader an

awareness of the importance of their story. The narrative describes how the sick person lives in their social network and responds to their symptoms of disability. Initially the topic of illness narrative seems a bit arcane, but then becomes crucial in a time where the healthcare industry ignores the person and their story. The writing down of lived experience and monitoring of bodily processes is both polysemic and polyvocal, giving many meanings and many voices to the body and self over time.

There is significance of patients' and their professional caregivers' subjective interpretations of painful experiences and there is a linking of bodily and emotional pain to distress experienced at family and social levels. There is meaning in each sick person's symptoms and suffering, established through patterns of gestures, expressions, sounds or words, such that the onlooker thinks they can understand the pain of another. Pain and suffering belong to universal domains of human experience. The symptoms or feelings present as meanings (in narrative) based on the understanding of the body and the self, as well as a feeling of weakness and limits of medicine in caring for the sick.

The narrative provides perspective on reality. The illness narrative acts to engage the unknown bridging from the past to some future hope—when there is no story, there is no hope. The narrative mediates between the mind world of thought and the outer world of actions. The example of an occupational therapist playing checkers connects the act to some kind of future change, giving meaning to this activity with a patient. Another example is the individual who undergoes cosmetic surgery and tells many stories discussing life after the transformational change—the pain experience is worthwhile as there are hopes of a new life. It is important that the patient's story is in line with the professional's story (outcome of surgery) so they can relate. There is social authority in

the healer finding repair through the body experience. All of this discussion matters because it allows the narrative to serve as a way to help others to care.

If the patient goes to his therapist to tell his story, is it likely that the therapist cares? When undergoing psychoanalysis, an individual may have participated in many years of talking about symptoms and having his neurosis weave into a story connecting it to their life. The purpose of narrative medicine or narrative oncology, like obtaining medical or psychosocial histories, finds the meaning in the context of symptoms. The story serves to connect the events that brought about the symptoms (of illness) to the context of the person's life. The sick individual begins to ask pertinent questions about their story as a whole and how the story affects others. For this reason, one asks is there anything in life that is not a story? Are we always living out stories or imaginations? The story serves to find our own personal truth and looking to see reality in a particular way rather than solely through scientific interpretation.

Among the most promising of narrative contributions to loss or posttraumatic events is through creative therapeutic procedures that foster meaning finding in the midst of emotional difficulties (Pennebaker, 1997). Neimeyer (2004) encourages the literal use of narrative strategies through writing and reflecting on traumatic experiences and that these practices should be more thoroughly and creatively developed to promote integration and transcendence of tragic transitions. Narrative medicine and narrative oncology interventions are the proposed methods for the sharing, writing and reflecting of the oncology healthcare professionals to be discussed in this research. The intervention groups will serve to deconstruct through writing and reflecting, externalize the problem through skilled facilitation and in so doing reconstruct a new co-created narrative of their

professional selves.

Whether the oncology professionals are physicians, nurses or social workers they are faced with the limits of Western medicine in curing some of the cancers that their respective patients suffer from thus, they confront death and dying daily while attempting to offer hope to these patients. This is often a daunting task and an argument is often anecdotally made that “[the inpatient professionals] don’t see the [patients] that get better,” and thus coping with the “finitude” of life impacts the stories of the professionals as much as the persons they serve.

The French philosopher, Michel Foucault whose thoughts and work heavily influenced the development of narrative therapy shared that:

Medicine offers modern man the obstinate, yet reassuring face of his finitude; in it, death is endlessly repeated, but it is also exorcised; and although it ceaselessly reminds man of the limit that he bears within him, it also speaks to him of that technical world that is the armed, positive, full form of his finitude (Foucault, 1973; p. 198).

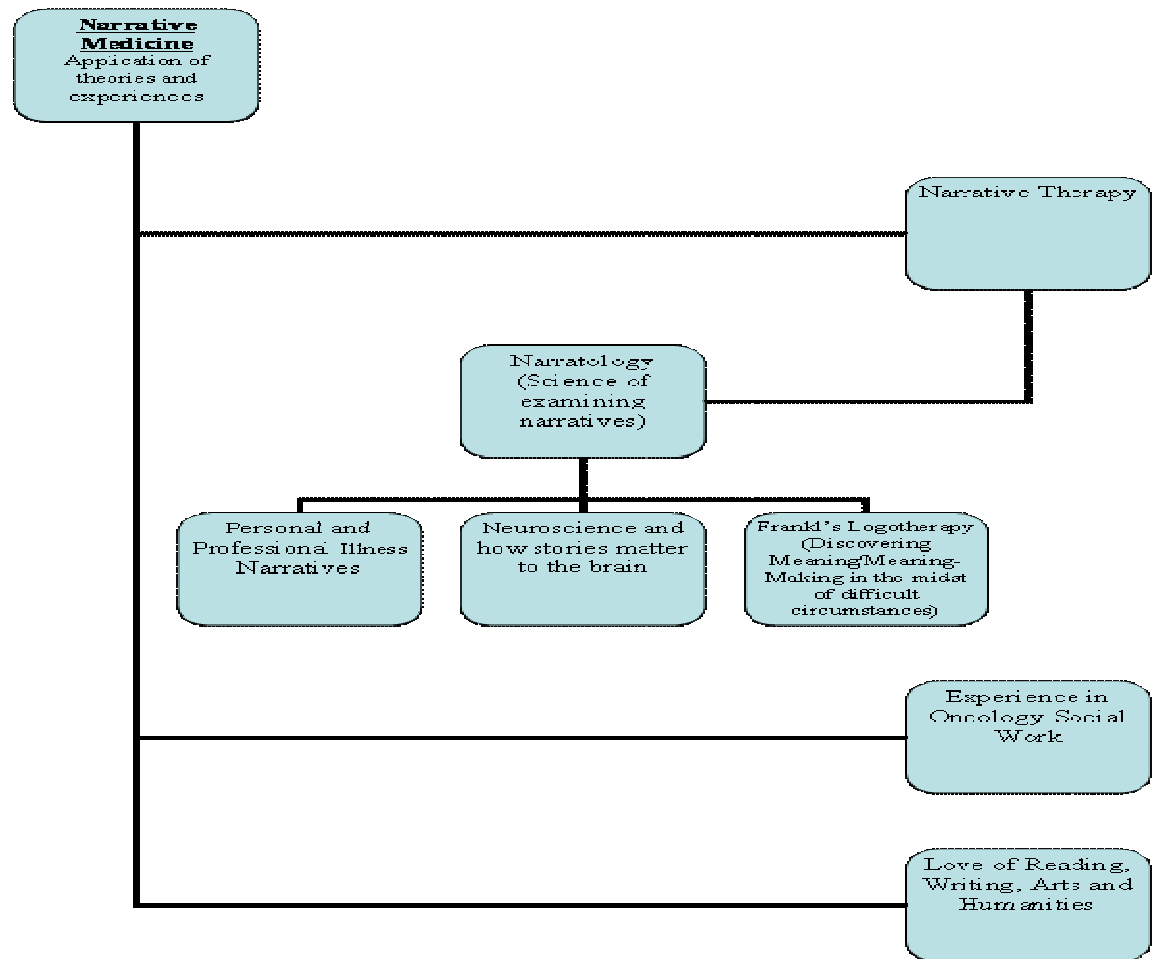
Through examining some of the literature on burnout, compassion fatigue, and job stress, a fitting connection is made with the precursors to narrative medicine.

Narrative medicine has a rich lineage in biopsychosocial medicine, primary care, medical humanities and patient-centered medicine with a theoretical base relying on literary theory, narratology and is nourished by trends in social work and psychology, family therapy, anthropology and social psychiatry (Charon, 2006).

Narrative medicine is the intervention that will be used in this research study and will be called narrative oncology. Numerous schools of thought influence it; however,

narrative therapy and the contributions that led to its development are one of the major contributors to this researcher's theoretical framework and the incorporation of narrative oncology into inpatient practice.

Figure 2: This Researcher's Conceptual Model in Chart form



Narrative Therapy

The narrative therapies or approaches are derived mainly from the works of White and Epston (1990). They began their collaboration in the 1980s and drew upon the works of Michel Foucault (French philosopher, historian, sociologist), Jerome Bruner (psychologist), Erving Goffman (sociologist) and Gregory Bateson (anthropologist and communications theorist) (Kelley, 1996; Walsh, 2006; White & Epston, 1990). Bruner

had been using narrative as an organizing metaphor for numerous years prior to the connection or use of it with family therapy circles (Freedman & Combs, 1996). Bruner wrote:

By the mid-1970's the social sciences had moved...toward a more interpretive posture: meaning became the central focus-how the world was interpreted, by what does meaning was regulated, in what sense culture itself could be treated as a "text" [story] that participants "read" for their own guidance (Bruner, 1986, p.8).

Narrative therapy integrates a variety of philosophical and sociological theories. Some of the ideas are drawn from the traditions of *existentialism* and *symbolic interactionism*. Existentialism, a twentieth-century philosophical movement emphasizes the uniqueness of each human existence in freely making its self-defining choices. Existential thought foundations come from Soren Kierkegaard (1813-55) and Friedrich Nietzsche (1844-1900) and are also notably represented in the works of Karl Jaspers (1883-1969), Gabriel Marcel (1887-1973), Martin Heidegger (1889-1976), and Jean-Paul Sartre (1905-80) ("Existentialism," n.d., Definitions section, para. 1).

Blumer (1969) coined the term symbolic interactionism and stated that it set out three basic premises:

1. "Human beings act toward things on the basis of the meanings they ascribe to those things."
2. "The meaning of such things is derived from, or arises out of, the social interaction that one has with others and the society."

3. "These meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he/she encounters." (p. 2)

Narrative therapy incorporates some ideas from *muticulturalism* and the solution-focused and cognitive theories. However, the most immediate influence to narrative theory is from the broad social theories of *postmodernism* and *social constructivism* or *constructivism* (Kelley, 1996; Walsh, 2006; White & Epston, 1990).

Societies construct the lenses through which their members interpret the world whether that society is in south central Los Angeles, in rural South India or in the corridors of an inpatient oncology unit. When both narrative and social constructionism are used as guiding metaphors for our work, we see how the stories that permeate our society constitute our lives in the people we work with (Freedman & Combs, 1996).

Narrative therapy states that humans create meaning within social contexts because it is believed either that reality is essentially without meaning or its true meaning is beyond us. Thus, in this postmodern social constructionism there is no objective reality that all people might agree on (Rodwell, 1998). There exists, however, a physical reality, but it is how we define and find meaning in our experiences, relationships, social situations and ourselves. Therefore, within a narrative approach our lives are seen as multi-storied, not single storied. In narrative therapy, the creators, White and Epston (1990) wanted *the client's* to be the authors of their stories and to partner with their *therapists* to deconstruct and eventually re-author a new narrative.

In rendering accounts of individual experience, once an event is identified, we want to link that event to preferred events that occur over time so that their meanings survive and so that their meanings thicken a person's narrative in preferred ways. Thus, once a

preferred event is identified and storied, we can ask questions and inquire about what might link it to other events in the past and the future (Freedman & Combs, 1996).

White (1990) wrote:

Social scientists became interested in the text analogy following observations that, although a piece of behavior occurs in time in such a way that it no longer exists in the present by the time it is attended to, the meaning that is inscribed into the behavior survives across time...In striving to make sense of life, persons face the task of arranging their experiences of events in sequences across time in such a way as to arrive at a coherent account of themselves and the world around them (White & Epston, 1990, p.9).

Stories in the narrative context are made up of events that are linked by a theme, which occurs over time and according to a plot. Certain events are privileged and selected out over others as more important or true. As the individual's story takes shape, it invites the teller to further select only certain information and to ignore other events so that the same story is told time and again. These stories that people tell shape their perspectives on their lives, histories and futures. The stories can be either inspiring or oppressive.

In White and Epston's (1990) narrative therapy, the person is not seen as the problem, but rather that there is a problem-saturated story that requires deconstruction, externalization, and later reconstruction forming a new co-created story. In the context of narrative therapy the therapist attempts to step away from oppressive parts of a person's story and discover untold narrative, intentions, hopes, desires, dreams and values and to discern the client's preferred way of being. The focus is not on the "expert" therapist solving the problem like a facilitator, but it is through these conversations that the client

and therapist will re-story and co-construct a new narrative for the client. Clients are often asked to view the story as if they were an outsider and to think about alternative outcomes for the protagonist in the story.

Deconstruction Stage

The person's story is heard by the therapist and then deconstructed, however, it is important not to deconstruct prematurely. The story needs to be told and carefully heard: What does the client view as the problem? How does the client experience the problem? What meaning does the client attach to the problem? How is the problem viewed in light of historical events? How has the problem evolved over time (Kelley, 1996)? The therapist develops rapport with the client and exhibits genuine empathy while developing trust. This stage is important for both parties to understand the client's reality more fully. Careful listening and reflecting are similar to other therapeutic approaches; however, the way the questions are worded is unique to the narrative approach (Kelley, 1996).

Externalizing the problem

White and Epston (1990) wrote:

Externalizing is an approach to therapy that encourages persons to objectify and, at times, to personify the problem that they experience as oppressive. In this process, the problem becomes a separate entity and is external to the person or relationship that was ascribed as the problem. Those problems that are considered to be inherent, as well as those relatively fixed qualities that are attributed to persons and to relationships, are rendered less fixed and less restricting (p. 38).

The therapeutic practice of externalizing a person's problem discourse attempts to distinguish the person(s) from the problem, which acts to maintain the dominant

discourse or stories about the problem (Madigan, 1992). Therefore, the problem becomes separate from the individual and is located outside them or the relationship that has been objectified, identified, and specified as having the problem. The problem is objectified and given a name ultimately de-pathologizing the individual client (White & Epston, 1990).

Reconstruction stage

The therapist or social worker in narrative approaches helps the client re-story or re-author their lives and issues through the use of metaphor, summary and reflection questions on the part of the therapist. The therapist notes that the client chooses certain words and is always attending to hidden strengths in their stories. The therapist does not assume that the story is not true, but respects the client and their story while helping them see different perspectives and hopefully motivating them to change or enhance change.

The basic principle that influences narrative therapy is that people categorize their experiences through language. A conceptual connection is made into the telling of a story and the study of it. The process of putting experiences into story form helps make meaning for the participants. However, it is also important to understand the study of stories and narrative theory, which is often described as narratology and is practiced by narratologists.

Table 2.1: Summary of Observed Characteristics of Narrative Therapy

Narrative Therapy
Creative, reflective, elaborative
Co-construct new story
Therapist is Influential but de-centered and collaborative

Recognizes many realities and truths coexist and sees reality as being socially constructed rather than given
Invites diversity, Societal dominant discourses influence what gets storied and how it gets storied
The historical aspects of a story are encouraged through skillful questioning on part of therapist
Therapist locates problems in discourses helping people see themselves as separate from their problems

Narratology

Narratology is the structuralist study of narrative or of stories. Traditionally, narratologists have concentrated on the criticisms of the narrative plot; however, contemporary narratologists have brought an emphasis or focus on the narrative act, or the presentation of a story, as a key component of the story's meaning (Culler, 1983). Stories provide the initial and continuing means for shaping human experience and without our stories people would be merely, "unevaluated sensation from an undifferentiated stream of events" (Pradl, 1984, p.1). The structuralist analysis of narrative seeks to understand how recurrent, elements, themes and patterns yield a set of universals that determine the makeup of a story. The ultimate goal is to move from a taxonomy of elements to how these elements are arranged in actual narratives (Pradl, 1984).

To raise the question of the nature of narrative is to invite reflection on the very nature of culture and possibly, even on the nature of humanity itself. So

natural is the impulse to narrate, so inevitable is the form of narrative for any report of the way things really happened, that narrativity could appear problematical only in a culture in which it was absent...far from being a problem, then, narrative might well be considered a solution to a problem of general human concern, namely, the problem of how to translate *knowing* into *telling* (White, 1980, p. 5).

The ongoing narrative oncology groups that will be evaluated in this study will take the experiences of the professional caregivers from silent unshared *knowing* into public writing and therefore *telling* of their experiences. Through the sharing of these stories in the group context the group participants deconstruct and externalize their caregiving stories and will ultimately co-author a new story.

Neuroscientific Influence and the Importance of Stories

Cozolino (2002) stated that there is an instinctive knowledge that we employ that urges us to talk through unpleasant experiences or to narrate our stories. Only recently has biology confirmed that our instincts have been correct. Restak (2004) acknowledged that while the brain operates via electricity and chemistry, it is also a product of the social and psychological world in which it finds itself. All we are and all that we can be cannot be considered separately from our brain. This clearly implies a direct relationship between our brain's organization and operation and what we can learn about the world and about ourselves as a part of that world. According to Cozolino (2002), as our brains evolved and became more complicated, language began to serve to govern or balance the different brain hemispheres and different processing of the brain modules, the primary ones being the integration of thought and feelings. The use of narrative and storytelling

activates the left hemisphere with language and with linear processing because the stories have a beginning, middle and end. Additionally, any “good” story has an emotional aspect and there is resolution of inner turmoil or crises. In a “good” narrative, both the right and left hemispheres integrate, sending information back and forth. The belief is that when a traumatic event takes place the activity that transpires between the right and left hemispheres is dissociated. An example may include that as someone walks down the street they are mugged at gunpoint. For the next several days they have a compulsion to tell the story to everyone that they have talked to since the incident. The growing consensus by the neuroscience experts such as Damasio (2000), LeDoux (2003, 2004), Restak (2004) and Schore (2003) is that the compulsion to tell the story diminishes through the storytelling, which uses language and social interaction as a naturally curative process, ultimately reorganizing the brain. When serious trauma occurs, like physical or sexual abuse of a child, there is usually no outlet for talking about the issue. The child may be threatened to not speak of the abuse. By not talking about the trauma the belief is that there is a deepened dissociation between thinking and feeling. This disconnection of the brain modules may cause long-term personality problems and psychiatric symptoms later in life (Cozolino, 2002).

Echoing the sentiment of past psychoanalytic theorists is this work of Cozolino (2002) which melds neuroscientific research and psychotherapy, creating a potent mix that confirms what social workers have long known to be true—that despite the theoretical orientation (e.g., cognitive-behavioral, psychoanalysis), both psychotherapy and the therapeutic relationship help those in need. This phenomenon has also been referred to as the *dodo bird effect*, when the relational aspects of the interaction affect the

outcomes rather than the nuances in each theoretical or psychotherapeutic model. Cozolino's research seems to reinforce the relational aspects of patient and/or client interactions and adds further resolve to the literature on the therapeutic alliance. This researcher believes Cozolino's and other related neuroscientific research can be translated to the healthcare arena and more specifically, to the professional caregiver constantly exposed to suffering clients. Much of the literature states that professionals that have time to decompress or process with colleagues have a positive effect in reducing symptoms of burnout and compassion fatigue (Pines & Maslach, 1978; Radey & Figley, 2007; Schwartz, 1995). A strong case is being made for the use of narrative through the intersecting fields of neuroscience and psychotherapy, where the use of narrative has shown to biologically bridge the divide of an individual pre and post-trauma (Cozolino, 2002).

Personal Illness Narratives-Patients and Professionals

Through examination of personal illness narratives professionals *bear witness* to the suffering that their patients experience thus informing their own caregiving narrative. "Telling stories about illness is to give voice to the body," stated sociologist and cancer survivor, Arthur Frank (1995, p. 18). There is meaning in each sick person's symptoms and suffering, established through patterns of gestures, expressions, sounds or words, such that the onlooker thinks they can understand the pain of another. Pain and suffering belong to universal domains of human experience. The illness narrative acts to engage and mediate between the patient's inner world of thought and the outer world of actions (Charon, 2006; DasGupta & Hurst, 2007; Kleinman, 1988; Mullan, 2006; Stanley, 2004). Telling and subsequently hearing the illness stories puts the experience into personal and

social contexts, gives coherence, structure, symbolism, and meaning to what may be an otherwise chaotic and *distressing* experience.

The literature speaks about the importance of narrative for the sick person and it is through narrative that there is a linkage or shared belief in the understanding of the medical experience of the person or persons who *wrote* the story. In addition to the explosion of illness narratives that have been published over the past several years, there is an equal movement of health professionals that are writing reflective essays to describe their practice (Charon, 2006; Frank, 1995, Kleinman, 1988). Charon (2006) described that:

by telling of what we undergo in illness or in the care of the sick, we are coming to recognize the layered consequences of illness and to acknowledge the fear and hope and love exposed in sickness (p. 262).

As professionals who experience the privilege of caring for the sick, we attempt to recognize each patient's individual and unique narratives. Additionally, those healthcare professionals need to have a forum to share their own caregiving illness narratives reflecting upon "layered consequences" of helping and healing the sick person. When faced with the finality and death of a young mother who struggled to find air while she fought with her whole will to survive another bout of her cancer and failed, the professionals at the bedside are faced with questions. How do we cope with this? How can we do this day after day? How does this affect our private lives? How does it affect our future care of patients? Were we, the interdisciplinary healthcare team more similar than different in our needs, concerns, and difficulties in dealing with this terminally ill population? Charon (2006) echoed these questions:

How can one develop the state of attention required to fulfill the duties incurred by virtue of having heard the accounts of illness? I have become very interested in the state of attention these days—it seems the most pivotal skill with which to endow a health professional who wants to be a healer. How does one empty the self or at least suspend the self so as to become a receptive vessel for the language and experience of another? This imaginative, active, receptive, aesthetic experience of donating the self toward the meaning-making of the other is a dramatic, daring, transformative move...[Henry] James called it ‘the great empty cup of attention.’ How did he know about emptiness? How did he know that, in order for one to heal the other, one has to empty oneself of thought, distraction, goals? One has to donate oneself as the amphora, the clay vessel that resonates with the sound of the breath, the sound of the self... (p. 263)

There is a movement to utilize the methods of oral historians and those who work in trauma studies as testimony to learn how they equip themselves as witnesses to others’ suffering (Charon, 2005). The illness narrative speaks of the medical experience and gives the *reader* an awareness of the importance of her story. The narrative is how the sick person or caregiver lives in their social network and responds to their symptoms and disability. There is a therapeutic component to the combination of reading, writing and sharing---healing. Pain and suffering belong to the universal domains of human experience. As more health professionals share their caregiving experiences, we are able to give their experiences and indirect suffering a language so that other professionals understand.

Mullan (1999) did not state that we should do away with quantitative data; on the contrary he encourages it, “the first-person essay, in fact, can lend perspective and vitality to issues that are appropriately and simultaneously being explored and written about in a quantitative and analytic fashion” (Mullan, 2006). McDonough (2001) spoke about his own zeal for evidence-based research and that his opponents on the Massachusetts House of Representatives were unimpressed with his “pile” [of research and data]. McDonough talked about the presentations of his colleagues speaking about real-world scenarios and that in the end, those stories trumped the “reams of evidence” he brought to the debating floor. As most legislators do, he had to pick his fights (McDonough, 2001).

Charon (2006) who coined the term *Narrative Medicine*, asserted that medicine was brought into the “narrative sphere” through qualitative social science (Charon, 2006). Some of these noteworthy narrative founders include, Elliot Mishler (1984), Richard Frankel (1983), Catherine Riessman (1990), and Candice West (1984), who collectively, “fundamentally altered medical practice by making medical discourse amenable to inspection and then analysis” (Charon, 2006, p. 95)

Several colleagues around the country have mentioned the importance of narrative approaches in social work; diagnosis is improved, patient satisfaction and adherence rise and litigation appears to decline as communication improves (Clark & Mishler, 1992; Riessman, 2002). According to Riessman & Quinney (2005), “a central area of narrative study is human interaction in relationships—the daily stuff of social work.” (p. 392) However, social workers have a surprisingly small corpus of systematic research in narrative approaches. Despite an eruption of narrative articles and research in other disciplines there continues to be a paucity of narrative research in social work (Riessman

& Quinney, 2005). The interests of this researcher are to explore the use of narratives from an interdisciplinary team perspective.

Frank (1995) said that illness stories repair the damage that made the sick person sense a breach of health that takes them out of their own world. In a sense the illness ejected the individual from life as they planned it to be and their illness story can serve to link the past to the present by drawing new maps and finding new destinations, thus, ordering the experience of the person's narrative in addition to providing meaningful reflection. There is an assumption made that the illness experience itself has no order and that later there will be another level of reality outside of the narrative experience. This philosophical discussion surmises that by knowing our experience, therefore it is given order. The narrative provides perspective on reality. The illness narrative acts to engage the unknown bridging from the past to some future hope—when there is no story there is no hope. The narrative mediates between the mind world of thoughts and the outer world of actions. Through exploring the narrative of this one professional, this researcher posits that it will help guide future research in testing and utilizing narrative interventions whatever the medium (art, writing, theater, or speech).

It is hypothesized that through identifying their own strengths and weaknesses in care giving, and the sharing of one's oral narrative, the health professional "bears witness" to the distress and suffering of illness and is better able to attend to the needs of their patients. It is additionally hypothesized that through the process of sharing and discussing these narratives the caregiver is better able to deal with the rigors of working with death and dying.

Meaning Making

In Frankl's (1959/2006) magnum opus, the narrative of his personal experience in the concentration camps, he described an extreme version of emotional exhaustion that occurred as a result of witnessing the constant exposure to the horrors of the concentration camps and brutal human loss. Along the way Frankl discovered that human beings' ultimate drive is to find meaning and purpose for existence. If one is able to find this meaning and purpose, then one can endure all of life's hardships, including suffering and death. "When we are no longer able to change a situation – just think of an incurable disease such as inoperable cancer – we are challenged to change ourselves." (p. 112)

Professional caregivers struggle with caring for the suffering and often suffer as a result themselves. Frankl (1959/2006), outlined three psychological stages that I believe are applicable to the healthcare professional serving the terminally ill and their constant exposure to death and disease. These stages are (1) the period following admission to the camp; when the professional first begins to work with the terminally ill (2) the period when one is well entrenched in camp routine; one is working with those patients in end of life care for an amount of time that has numbed them enough to continue to provide care in the midst of suffering, and (3) the period following his release and liberation (Frankl, 1959/2006) when the patient is free from pain and suffering and the professional is free to mourn or feel or share. Shock, and disillusionment encompass the first phase; the second, an emotional death of sorts occurs in order to protect the mind. A shell of apathy is built, known as the blunting of emotions and feelings. It is in this phase, a person ceases to be shocked at the horrors he sees on a daily basis. Frankl (1959/2006) later said of the second phase, "If my lack of emotion had not surprised me from the standpoint of professional interest, I would not remember this incident now, because there was so little

feeling involved in it" (p.55). The third phase involved a slow, gradual process of becoming acclimated with being "free." This psychological stage includes: depersonalization- things appearing not to be real. It is as if the mind does not trust the safety it now sees. The protective shell is no longer needed, the mind slowly begins to allow the resurrection of emotions and feelings to emerge, and thus the path to becoming human again starts to take place.

Logotherapy, developed by Viktor Frankl (1959/2006) out of his experience has become known as the "Third Viennese School of Psychotherapy." "*Logos* is a Greek word which denotes 'meaning.'" (p.98) According to Frankl, "Logotherapy focuses on the future." The "Existential" aspect of Frankl's psychotherapy maintains man always has the ability to choose, no matter the biological, or environmental forces. The last scope of this therapy is known as the "tragic triad," pain, guilt, and death. Frankl's "Case for a Tragic Optimism" uses this philosophy to demonstrate..."optimism in the face of tragedy and in view of the human potential which at its best always allows for:

- (1) turning suffering into a human achievement and accomplishment;
- (2) deriving from guilt the opportunity to change oneself for the better;
- (3) deriving from life's transitoriness an incentive to take responsible action" (p. 138).

Through the use of narrative, it is supposed that clinicians constantly exposed to death, disease and human loss can examine their own emotions about these situations. By examining their inner feelings about the difficulties of care, it is the supposition that they will be reenergized and thus able to identify with the singularity of each patient. In the case of Frankl, perhaps the mere act of writing his thoughts and feelings down contributed to his ability to cope with the horrors of his experience.

To summarize, it is the hypothesis of this researcher that the use of narrative medicine or narrative oncology interventions can alleviate the difficulty of coping that often accompanies distress experienced by cancer patients. Thus, we ask, to what extent is the use of narrative medicine competence, narrative social work, or in this study, narrative oncology (Charon, 2002) work effective in improving professional health caregivers' ability to cope with their constant exposure to disease, death and distress?

The proposed study attempts to offer an alternative lens for viewing issues related to coping with the rigors of oncology work. This lens will contribute in four substantial ways. The study will first provide some additional insight into current experiences of oncology professionals and their levels of job stress, burnout, compassion fatigue and compassion satisfaction. Secondly, the findings will provide a means for examining the levels of these constructs experienced by these professionals. Thirdly, findings will provide concrete data to augment the anecdotal findings from previous literature on the benefits of shared storytelling. Finally, the study will explore and evaluate the use of a narrative oncology groups.

Applying the above conceptual model, the research questions for this study propose;

- 1a. Does a narrative oncology intervention impact job stress, compassion fatigue, and burnout and/or job satisfaction, compassion satisfaction and personal accomplishment (subscale of MBI-HSS) from pretest to posttest of each monthly session over a four month period (NS1pre-NS1post, NS2pre-NS2post, NS3pre-NS3post, NS4pre-NS4post)?
- 1b. Does a narrative oncology intervention impact job stress, compassion

fatigue, and burnout and/or job satisfaction, compassion satisfaction and personal accomplishment from pretest of narrative session one (NS1) to posttest of narrative session four (NS4)?

2. What do oncology professionals report about the presence of monthly narrative oncology rounds?

Chapter 3

Research Design and Methodology

“I think it’s important. It’s important because it brought to my attention how I’m not dealing with my feelings. It wasn’t something I was aware of until I went to write it down...”

--Ayn Rand, Oncology Nurse

Research Design

This is a quasi-experimental of oncology physicians, nurses and social workers utilizing mixed-methods. As Padgett noted, “a mixed methods study applies the lenses of quantitative and qualitative methods to the same subjects of inquiry, same setting and roughly to the same group of respondents” (2004, p. 270). Riessman (1994) proposed using mixed-methods research designs to maximize the strengths and minimize the limitations of each approach. Recognizing that although the oncology and end-of-life literature addresses job stress, compassion fatigue and burnout, there is minimal discussion of interventions offered to these professionals. The exploratory nature of this study is best suited for areas where there is little empirical data (Fortune & Reid, 1999). Paradigm multiplism in the form of a mixed methods design, allows for triangulation of the research data while adding a depth of information (Padgett, 1983, 2003).

The following research questions and hypotheses were investigated:

Research Questions

1a. Does a narrative oncology intervention impact job stress, compassion fatigue, and burnout and/or job satisfaction, compassion satisfaction and personal accomplishment (subscale of MBI-HSS) from pretest to posttest of each monthly session over a four month period (NS1pre-NS1post, NS2pre-NS2post, NS3pre-NS3post, NS4pre-NS4post)?

- 1b. Does a narrative oncology intervention impact job stress, compassion fatigue, and burnout and/or job satisfaction, compassion satisfaction and personal accomplishment from pretest of narrative session one (NS1) to posttest of narrative session four (NS4)?
2. What do oncology professionals report about the presence of monthly narrative oncology rounds?

Hypotheses

H1a: After each of the four, once a month narrative oncology sessions, participants will report decreased burnout, compassion fatigue/secondary traumatic stress and job stress and also report increased compassion satisfaction, job satisfaction and personal accomplishment.

H1b: Participants will report decreased scores of job stress, burnout, and compassion fatigue/secondary traumatic stress as well as increased reports of job satisfaction, compassion satisfaction and personal accomplishment from narrative session one (NS1) pretest to posttest of narrative session four (NS4).

H2: Oncology health professionals who partook in the intervention will report a desire to have access to ongoing monthly interdisciplinary narrative oncology group.

Narrative Oncology Group Intervention

This study is the examination of a narrative oncology program. The initiation and subsequent meetings of the group existed before the study but were intermittent. Over a 12-month period approximately 5 groups were held. For this dissertation research project, Narrative Oncology was restarted after a 3-month hiatus with groups held the second

Wednesday of each month (October 2009, November 2009, December 2009 and January 2010). Four consecutive months of narrative oncology groups were observed.

These groups convened at lunchtime, were one hour in duration and were held in the conference room of each unit. A hot lunch (usually pizza) was served and flyers were posted every month to encourage attendance from all three inpatient oncology units. Each month the group rotated between the three floors to give equal opportunity to professionals on each floor to participate.

On the day of the meeting this researcher sent out emails reminding staff of the meeting. Also, alpha text pages were sent to all of the residents and interns to encourage attendance. This researcher normally conducts the monthly meetings, however, for the purposes of this study, one experienced professional facilitator was recruited to lead the groups in order to minimize bias, as this researcher is a social worker on one of the floors to be studied.

This researcher distributed the in-session packets (Appendix H1-H4) once the attendees entered the room and remained as an observer. They were encouraged to begin eating and reviewing their packets while the facilitator awaited the arrival of oncology professionals. This researcher would often make an overhead announcement that “Narrative Oncology Rounds were about to begin in the conference room.” Once everyone was seated and had their in-session packet in hand, this researcher explained the packet and introduced the facilitator. The packet included the question that each participant was asked to write about and the space for the written narratives. Once the facilitator introduced the group purpose, he proposed the following writing assignment to the group; “Write about an especially stressful or challenging or distressing encounter

with a patient, family member or colleague—or, alternatively, one that was unusually inspiring or uplifting.” This same writing assignment was used each month.

Although left up to the discretion of the trained group leader each typical narrative oncology session proceeded as follows: 1-2 minute introduction (ground rules on narrative sharing, especially confidentiality) by trained group leader (not Principal Investigator), followed by an invitation to write a response to the aforementioned question. The period of writing was followed by a 1-2 minute transition statement by the group facilitator (requesting volunteers to read exactly what they wrote on the paper) and a 40-50 minute group interaction (individual participant volunteers would read their narrative piece and both the facilitator and other group participants commented on the writing). Each session concluded with a 2-3 minute thematic summary by the group facilitator and a request for participants to complete the one-page post-session evaluation (collected prior to leaving the room). The group participants were situated at a table organized in a square to maximize room space and facing one another to facilitate dialogue and to supply a surface for writing. Each participant was given a writing implement if needed.

Facilitator Role in Intervention

The group leader invited participants to share their narratives exactly as written. Once the sharing of narratives began the group leader facilitated the conversation by listening carefully to each narrative, as it is read and taking notes, which he would later use to comment on the participants story. After he made several observations, he invited others to comment on the writing. The group facilitator always honored the text and its

writer, by commenting on its strengths or a unique quality of the writing prior to inviting others to comment on the piece.

The group leader facilitated the flow of conversation, allowing it to develop on its own and if needed through prompts (Appendix F) (Truten, 2008b). The post-session evaluation form was included in the packet distributed upon each participant's arrival (Appendix H4).

Facilitator Training

Although this researcher previously conducted the monthly narrative oncology sessions, she did not facilitate throughout the duration of the study to minimize bias as this researcher works on one of the units to be examined. This expert facilitator is a former nurse and has a doctorate in English from the University affiliated with the hospital. He was recruited to conduct the groups in this study and gave a verbal and electronic agreement. He has been leading narrative groups for the greater portion of five years at the study hospital and several other institutions. He attended Narrative Medicine training at Columbia (with Rita Charon and colleagues), read Charon's book, *Narrative Medicine*, and was invited to participate in the advanced narrative group session in New York. The facilitator is a paid consultant for the hospital and serves on the narrative professionalism committee with this researcher. He is not normally affiliated with the oncology staff on the inpatient units. Additionally, he developed the post-session evaluation used to collect data in this study (Truten, 2008c).

Planning Issues

During the planning of the study this researcher was informed that the medicine interns attend another meeting during the 1pm time slot (when narrative sessions are

conducted). Initially the time of the group was to be at noon; however, it was changed to accommodate attendance from the medicine residents who have daily report meetings (from noon to 1pm daily) to discuss their patients and to receive didactic training from peers. Nurse managers on all three units were aware of the ongoing groups and made it possible for their respective staff to attend by increasing coverage of patients during the time of group meeting. Nurse managers and the clinical nurse specialists on each of the units also played a role in reminding and recruiting staff for each month's group. All staff members were welcomed and no one was turned away from participating in the group.

Precedent

Currently there is no specific illness narrative, narrative medicine or narrative oncology procedure manual, there are however, unpublished, guidelines that have been used during other training sessions at both the hospital to be examined and Columbia University (New York, NY) (Charon, 2006; Truten, 2008a). This researcher relied on the professional judgment and experience of the group leader that conducted the groups throughout the duration of this study.

The narrative approach is partially compatible with quantitative research, for instance Besa (1994) used a single-system research design with a treatment package strategy to apply a set of narrative techniques to six families experiencing parent-child conflicts. Besa (1994) reported that five of the six families reported improved relationships. In a follow-up study of 49 clients discharged from a substance abuse treatment facility (treated with narrative therapy), the clients' created new life narratives which they integrated into their post-discharge lives (Kuehnlein, 1999). More recently Sands, Stanley and Charon (2008), investigated the promotion of empathy, team building and burnout

prevention in pediatric oncology professionals pre and post narrative oncology training. This study utilized the Interpersonal Reactivity Index (IRI) and the Stressor Scale for Pediatric Oncology Nurses (SSPON). These studies yielded seemingly positive results, and the latter used mixed methods which seem most appropriate in investigating the effectiveness of narrative approaches, especially narrative oncology.

Sample, Recruitment, and Setting

Sample

A convenience sample of physicians, nurses and social workers were recruited from three inpatient oncology units at an inner-city academic medical center. The quasi-experimental design used a non-random sample for both the surveys and the process level data or semi-structured interviews. Thus, by definition there was no comparison group. However, the researcher attempted to include every professional from each of the three wards.

Recruitment

Following Institutional Review Board approval and appropriate permissions from Hospital Human Resources, individual unit leadership and administration, the study was advertised for two months through emails, through on unit in-services and information sessions, word of mouth, and posted flyers. The Unit Based Clinical Leadership teams, which consist of nurse managers and physician leaders, as well as Quality Improvement professionals, received detailed information about the study and were asked to bring it back to their respective units and supervisees.

Setting

The study was conducted in a tertiary academic medical center in an inner city. It enlisted participation from professionals on 3 (28-29 bed) inpatient oncology units that treat patients with solid and liquid tumor cancers and blood disorders. The three inpatient units are affiliated with a nationally recognized cancer center that currently sees over 50,000 outpatient visits, 7,400 inpatient discharges, and provides over 24,000 chemotherapy treatments, and more than 66,000 radiation treatments per calendar year (NCI, 2008). Patients are admitted through the emergency department, transferred from other medical centers, and transferred from other units within the hospital. Treatments include chemotherapy, cancer related surgery, cancer related medical complications, hematopoietic stem cell transplants, and radiation therapy. Each unit is staffed with one social worker, 7-8 nurses per shift and 6 teams (2 solid teams, 2 liquid teams and 2 liquid teams with Nurse Practitioners) of physicians (attending, senior resident, junior resident and intern).

Population and Sample

Participants for Narrative Sessions

Narrative session one (NS1) had 15 total participants, Narrative session two (NS2), narrative session three (NS3), and narrative session four (NS4) had 19 total participants 18, and 15 participants, respectively. The researcher did not include any participants that were unable to stay for longer than ten minutes. Although, more participants attended some groups, they may have entered late and left early. Another phenomenon was coming “just to get some pizza” and they would often share their sentiment of regret for being unable to participate.

Table 3.1: Participants that attended each Narrative Session (NS)

	Total # of participants that attended (prior to checking inclusion criteria)	Total # of data packets collected	MD/DO's at NS	RN's at NS	MSW's at NS	Other professionals at NS
NS1-October 2009	15	13	4	5	4	2
NS2-November 2009	13	9	0	7	3	3
NS3-December 2009	19	16	0	14	2	3
NS4-January 2010	18	12	3	10	2	3
Total	65	50	7	36	11	11

Ten participants attended more than one narrative session over the course of the four month study, therefore the total number of unique participants was forty (n=40), while 5 were excluded for not meeting inclusion criteria. Student interns from all disciplines were invited to participate in the group but were excluded from study data (e.g., medical student, social work students, nursing students and pharmacy). If the researcher knew that the member was a student prior to participating they were welcomed to partake in the group but not asked to participate in the study and therefore may not be represented in these numbers.

Inclusion/Exclusion Criteria

Criteria for inclusion for all three disciplines stated (a) they must be a paid employee of the hospital and (b) work on one of the three designated oncology units. Physicians could be at any level in their training including interns, residents, fellows, and attendings, but must be medical or surgical oncologists or doing a rotation on the liquid or solid oncology services on the three designated inpatient oncology units at the time of

the study. Oncologists in other sub-specialties, such as those primarily in oncology research that have patient/ward responsibilities at least twice a year, were invited but did not participate. All Attending Oncologists that have inpatient responsibilities, even if they were on an outpatient rotation were invited but were unable to attend. Several Fellows expressed interest but were unable to attend due to scheduling conflicts. Ultimately, only physicians at an intern and resident level of training actually participated.

The interns and residents often expressed interest in coming to the narrative sessions but shared one of the following reasons; were still rounding with attending on the wards, had to go to “report” (mandatory didactic and patient information sharing session for training physicians held daily), or were caring for an acutely ill patient. Several physicians attended narrative rounds, perhaps initially drawn in by the food but became interested and would attempt to stay and participate, but were paged numerous times resulting in their need to leave the session. One resident wrote most of his narrative, but was unable to finish and requested to “finish [his] narrative” and later handed his packet to the researcher.

Social workers were required to have at least an MSW degree and to be licensed professionals. Each eligible social worker attended 2-3 sessions out of the four. Nurses had an RN license while most had bachelor’s degree, several had master’s degrees. Medical students, nursing students and social work students were excluded.

Each interested oncology professional was asked to participate in all aspects of the study including completion of initial surveys/measures, participation in the narrative oncology group over four months and individual in-depth interviews. However, numerous participants were only able to attend some of the monthly sessions, may have

only completed the survey prior to or post the intervention. Some professionals that attended the group sessions were unable to stay for the entire hour and never completed their in-session narrative or were only able to hear a part of the narrative exchange portion of the session.

Refusal/Dropout Rates

The attrition rate was varied and was usually due to scheduling conflicts, illness/vacation time, and/or an acute patient load. Some stated they would like to attend, however, it depended on the number of patients they were caring for on that day and the acuity of said patients. Despite feeling overwhelmed with patient care issues, approximately three to five professionals “made time” to come to each session. Typically, two to three individuals completed pretest surveys but were unable to participate and their surveys were excluded from the data analysis.

Due to the proximity of the meeting place in relation to their work area, each practitioner had easy access to the meetings. All of the inpatient units in the study are housed in the same building (at the most four flights of steps) or a quick elevator ride. It was noted that as the months progressed staff would agree to cover for those who “really wanted to go,” and made concerted efforts to cover for interested persons that wanted to attend previously but were unable. Managers from each unit actively made arrangements for coverage (of patients) or in two cases assisted in covering for several of the nurses on the floor.

The unit on which the meeting was held had the largest attendance of nurses from its respective floor. However, on average two to three nurses from each floor would make arrangements to come to the sessions even when it was located on a floor different from

their own. Most notable was that over the course of the four sessions, three different nurses that had a vacation day came into the hospital for the express purpose of participating in the narrative oncology sessions.

While four individuals declined to attend over the course of four months, perhaps finding it to be irrelevant or a waste of time others admitted that it was upsetting to discuss emotional content of their work with oncology patients. All of these individuals reflected similar sentiments that “[they] might start to cry and won’t be able to stop...” Two persons shared that they did not feel comfortable sharing their feelings in the group setting. One of the four skeptical or reluctant persons expressed that although she did not find it appealing for her, she felt that it was “helpful” for her colleagues. She ended up attending one of the sessions despite her reservations.

One of these nurses stated in her interview with the researcher, *“I didn’t think I was gonna like it. I was just like, ‘Oh, this is annoying. I got to tell people about my experience.’ But after the first one and hearing everyone’s story, I actually thought it’s a good way to hear about other people’s situations that they’ve been in and things like that...”* When asked about what brought her in from home to come to the narrative session she stated, *“I had class once, so I wasn’t doing anything, but I actually enjoy it. I enjoy hearing about what others have to say and I feel like it’s not just the nurse’s perspectives... you have your social workers, your chaplain and stuff...I like to talk sometimes. Sometimes talking for me helps.”* She went on to say, *“I didn’t even know the question [arrived late]...But I like to write...writing kind of helps me remember, but I feel like when I write more I express more of how I feel, but that’s just me...”*

Approximately ten physicians expressed interest in participating but were unable to do so as their rotation (to another service) conflicted with the group. Four out of the six physicians that attended a narrative session plan to pursue fellowships in oncology when they complete their residency.

Missing Data

Numerous people completed the pre-narrative survey only to be unable to attend the session. These surveys were excluded from analysis. Additionally, a good proportion of persons did not submit their post-session surveys. These persons were also omitted from data analysis. On surveys and post-evaluation data that were submitted, only two had any missing data. Both completed narratives and the excluded or missing information was located on the in-session packet, post-session evaluation. In each case, the person completed filling in their narrative and agreed to have it included but did not complete the Likert scale and open-ended questions, which may indicate that the person left hurriedly prior to finishing the survey to return to their duties, chose not to complete it, or missed seeing it altogether. The narratives were read by the researcher and incorporated into the overarching ideas in the study, but they were not specifically shared in the qualitative portion of the data analysis.

Withdrawing from the Study

Participants could withdraw from the study at any point by calling the designated phone number or communicating in person with the principal investigator and requesting to be withdrawn. However, no one requested that their information be excluded. All persons whose paperwork was eligible for inclusion also circled to “include” their written narrative.

Measures

Sociodemographic Characteristics:

Demographic information were collected through an intake questionnaire (Appendix B, p.2) the following variables were included: race, age, gender, marital/partner status, professional discipline, years in practice and years in oncology practice. To accomplish the study objectives three standardized instruments were given to each participant prior to each narrative session and after each narrative session.

Job Stress and Job Satisfaction:

Hospital Consultants' Job Stress and Satisfaction Questionnaire (HCJSSQ)

The Hospital Consultants' Job Stress and Satisfaction Questionnaire (HCJSSQ) (Teasdale, Drew, Taylor, & Ramirez, 2008) (Appendix C) measured both job stress and satisfaction and was created specifically for healthcare professionals in oncology.

The HCJSSQ is a 42-item self-report questionnaire designed to assess the levels and sources of job stress and satisfaction of consultants. Participants were asked to rate each source of stress / satisfaction according to how much of a source of stress it was in their work on a 4-point scale of 0 (not at all), 1 (a little), 2 (quite a bit), 3 (a lot). Developed at Kings College in the United Kingdom (UK) in 1994, the original questionnaire was modified for use in a further national (UK) survey in 2002 (Teasdale et al., 2008). For use in this study, one question was removed, as it was not applicable to the American healthcare system. Therefore 41-items were used in analysis.

The reliability coefficients reported here are based on data from two national surveys of UK hospital consultants (physicians) (n=1133 in 1994 and n=1308 in 2002). The job stress scale in both 1994 and 2002 HCJSSQ indicates $\alpha=.86$ and $\alpha=.92$.

The job satisfaction scales for 1994 and 2002 indicates $\alpha=.85$ and $\alpha=.87$ (Teasdale et al., 2008). The reliability coefficients reported for this narrative intervention research study are $\alpha=.92$ for job stress and $\alpha = .95$ for job satisfaction.

Compassion Satisfaction, Burnout and Compassion Fatigue/Secondary Traumatic Stress:
ProQOL: Professional Quality of Life Scale: Compassion Satisfaction, Burnout and
Fatigue Scale Version IV (ProQOL – CSF-R-IV)

Compassion satisfaction, burnout and compassion fatigue were operationalized utilizing the Professional Quality of Life Scale Compassion Satisfaction and Compassion Fatigue subscales revised version IV (ProQOL-CSF-R-IV) ((Figley, 1995; Larsen, Stamm, & Davis, 2002; Stamm, 1998, 1999, 2002, 2005) (Appendix D). This scale was originally a 66-item self-report questionnaire called the Compassion Satisfaction/Fatigue Test for Helpers and was developed by Charles R. Figley (1995) and adapted by Stamm (1998, 1999, 2002, 2005, 2008, 2009). In its current form the ProQOL is a 30-item self-report questionnaire. Participants are instructed to indicate on a 6-point Likert scale with endpoints of (0) *never* and (5) *very often*, the characteristics that relate to them and their current work situation.

The research on the scale is ongoing, however, based on 1130 cases of the current version of the scale, the alpha reliabilities are as follows: Compassion Satisfaction (CS) $\alpha=.88$ ($n=1130$), Burnout (BO) $\alpha=.75$ ($n=976$) and Compassion Fatigue/Secondary Traumatic Stress (CF/STS) $\alpha=.81$ ($n=1135$). The standard errors of measure are as follows: CS=.22, BO=.21 and STS=.20 (Stamm, 2009). The alpha reliabilities for this narrative intervention study are CS $\alpha = .91$, BO $\alpha = .61$, and CF/STS $\alpha = .86$.

Burnout: Emotional Exhaustion, Depersonalization and Personal Accomplishment:
Maslach Burnout Inventory-Human Services Survey (MBI-HSS)

Burnout syndrome was operationalized through the Maslach Burnout Inventory-Human Services Survey (MBI-HSS), which assesses three aspects of burnout: emotional exhaustion (EE), depersonalization (DP) and personal accomplishment (PA) (Maslach, Jackson & Leiter, 1996) (Appendix E). The MBI-HSS is a 22-item self-report questionnaire. Participants are instructed to indicate their responses on a 6-point Likert scale the characteristics that relate to how they feel about their job in terms of burnout; (0) *Never*, (1) *A few times a year or less* (2) *Once a month or less* (3) *A few times a month* (4) *Once a week* (5) *A few times a week* (6) *everyday*. This instrument takes approximately 15 minutes to complete and has been used in many studies and has been established as an accepted and reliable instrument. Assessment was focused on the identification of the symptoms associated with each dimension. High scores on the EE and DP subscales and a low score on the PA subscale determines high degrees of burnout. Burnout is conceptualized as a variable, ranging from low to moderate to high degrees of experienced feeling. It is not viewed as a dichotomous variable that is either present or absent (Maslach & Jackson, 1982; 1986). The third edition of the Human Services Survey of the MBI reported reliability coefficients using Chronbach's coefficient alpha ($n=1,316$). The following reliability coefficients for the subscales were reported emotional exhaustion (EE) = .90, depersonalization (DP) = .79 and personal accomplishment (PA) = .71. The reliability coefficients for this narrative oncology research study are EE alpha = .91, DP alpha = .77, and PA alpha = .78.

To establish convergent validity of the MBI-HSS, Maslach and Jackson (1986) first correlated MBI Scores with independent behavioral ratings made by a spouse or coworker. Second, MBI-HSS scores were correlated with the presence of job characteristics that were expected to contribute to burnout. Third, MBI-HSS scores were correlated with measures of various outcomes that had been hypothesized to be related to burnout.

Qualitative Measures

Open-Ended Questions/Process Level Data

Three open-ended questions were collected in post-session evaluation. The survey has been utilized in the same hospital for evaluating other narrative groups that already exist as part of the professionalism curriculum. The survey was originally designed to elicit participant perceptions regarding their experiences in a peer group where they shared their own caregiver/illness narratives. The open-ended questions (Appendix H4) include; Which elements of today's experience, if any, were especially effective; How would you improve this narrative group writing session; and do you have any other comments about today's narrative group session (Truten, 2008c) .

Process Level Data Interviews

Single face-to-face interviews were conducted with ten participants in the researcher's office, which is a central location between the three-oncology floors. The researcher offered to meet with interviewees in any location that they felt would maintain their privacy and comfort. Each interviewee preferred to meet in the researcher's office. The office is quiet when the door is closed. The door has a lock, which prevents persons from entering. On two occasions persons knocked on the door during the interview,

however, when the visitor noticed that the researcher was in-session they decided to return at a later time. The overhead pager was turned down so it would not disturb the interview. Collection of data was collected via digital recorder. These semi-structured process level interviews occurred after the completion of the four-month narrative groups and lasted approximately 45 minutes to one hour. An interview framework was employed (see Appendix G). However, the interviews were not constrained to only answering a rigid set of questions; instead, participants were encouraged to emphasize what is important to them in their experience. This was done in order to elicit rich descriptions of the participants' experiences in the narrative oncology groups as well as in their care for patients and their perceived need for said groups.

The participants' responses shed some light on the impact of their job stressors, their collegial relationships, and their impressions of the narrative groups in dealing with these issues. Additionally, the interviews sought to obtain a description of the research participants' lived experiences of providing care to oncology patients, and their experiences of compassion fatigue, burnout, and job stress or alternatively, compassion satisfaction and job satisfaction. The interviews also delved into detailed impressions of the participants' experiences in the narrative oncology sessions. The interviewees were very forthcoming and shared their thoughts freely about all of the above topics.

Fidelity Assessment

To assess fidelity of the narrative intervention, the following process evaluation plan was implemented that included the following two primary components: 1) written observations of group sessions by researcher and 2). participant evaluations/surveys (See Appendices C, D, E & H4).

Quantitative Analysis

The Statistical Package for Social Sciences Version (SPSS) 17.0 was used to analyze survey data. Descriptive statistics (frequency, means, standard deviations, and range of scores) were computed for each subscale across three study groups (physicians, nurses and social workers). Given the exploratory nature of this research, descriptive statistics served to examine the independent variables of sociodemographic information and intensity of exposure within and across professions. Additionally, descriptive statistics were used to display data from the three likert questions on the post-session evaluation (Appendix H4). The chi-square statistic and cross tabulations were used to determine the difference between the three professionals for nominal-level characteristics. Correlations determined the relationships between two variables at a time. Independent t-tests were used to analyze from pretest to posttest of each of the four monthly narrative sessions individual as well as from pretest of narrative session one to posttest of narrative session four.

Qualitative Analysis

Content Analysis of Process

A content analysis of the open-ended questions on the post session evaluation (Appendix H4) was used. The researcher noted and recorded answers to the questions (Table 4.5), observed themes in the responses and then categorized each response into a theme.

In-depth Interviews

Study participants were asked open-ended process level questions regarding the utility and acceptability of the narrative intervention in achieving its desired goals.

Specifically, the researcher often began with a primer question to relax the interviewee and asked each individual about their years of experience in oncology and years at the study hospital. The interview often continued with a simple question about the participants impressions of the work. If needed a loose interview guide was used to seek additional details or direct the flow of the interview (Appendix G). Most interviewees required few prompts and spoke freely about their stress, experiences in caring for oncology patients and the narrative sessions.

Additionally, participants were asked about their general impressions of the narrative oncology group process, if they felt that narrative oncology rounds should continue, how they felt about the process of writing, if they felt that the implementation of narrative oncology was positive or negative and if positive, what aspects were helpful, and if not, what they found less than helpful. Participants were asked to provide feedback regarding the following: their assessment of the effectiveness and/or limitation of the narrative oncology group, duration, time of day, their perceptions of the facilitator's expertise, whether utilizing a different facilitator would deter from attending future sessions, whether serving food was recommended or desired, and their overall experience of and satisfaction with the intervention itself, the process that surrounded the narrative exchange and the study itself. Finally, they were asked if they had any suggestions for future improvement for the narrative oncology group.

Analysis of Process Level/Qualitative Data

A phenomenological approach was chosen as it is typically used with groups of 5 to 25 participants (Polkinghorne, 1989) that have experienced some type of phenomenon. There is a precedent for phenomenological approaches with healthcare providers,

especially in the nursing and social work literature (Armour, Rivaux & Bell, 2009; Beck, 1992; Bradshaw, Armour, & Roseborough, 2007; Flanagan, 2009; Koch, 1995; Lopez & Willis, 2004; Rather, 1994; Ray & Vanstone, 2009; Rooney, 2009; Svedlund, Danielson & Norberg, 1994).

The phenomenological approach took these lengthy personal accounts from oncology professionals and distilled them into meaning units—taking thematic statements and drawing conclusions about a phenomenon (Riessman, 2008). This researcher looked at the phenomenon of burnout, compassion fatigue/compassion satisfaction and job stress/job satisfaction in oncology professionals that participated in narrative oncology groups where they shared their written stories and engaged in a group dialogue.

Verbatim transcriptions were interpreted and reflective journaling by the primary researcher provided further clarification of the role of oncology professionals and the use of narrative groups. In order to get a better understanding, the researcher attempted to transcend or suspend past knowledge and experience to glean a deeper understanding of a phenomenon (Merleau-Ponty, 1962). This study approached the lived experience of oncology professionals with “fresh eyes” to elicit rich and descriptive data that goes beyond the statistics and the quantitative data.

In contrast with Husserl, who supposed that conscious awareness equated with knowledge, Heidegger was interested in moving from description to interpretation. His focus was on deriving meaning from being. Heidegger vehemently rejected bracketing. In defending his stance against the phenomenological epoche, Heidegger posited that prior understanding, or ‘fore-

structure' augmented interpretation. Therefore, Heidegger saw the researcher as a legitimate part of the research, as *Being-in the world* of the participant (McConnell-Henry, Chapman, & Francis, 2009).

Hermeneutics originated in the theological realm and was used as a method to study scriptures (McConnell-Henry, Chapman, & Francis, 2009), however, Heidegger redefined hermeneutics as a '...way of studying all human activities" (Dreyfus, 1991) Because this study relied on a Heideggerian rather than a Husserlian phenomenological approach (Heidegger, 1962; Husserl, 1964), the prescribed analytic schemes of Giorgi (1985), Colaizzi (1978), and van Manen (1990) were not used in analyzing the data. The goal of the interviewing was to generate detailed accounts rather than brief answers or general statements. All interviewees were given the names of famous writers (all interviewees were female); (Maya Angelou, Jane Austen, Emily Bronte, Emily Dickinson, Anne Frank, Zora Neale Hurston, Sylvia Plath, Ayn Rand, Mary Shelley, Virginia Woolf).

Through an exploration of the personal experiences, this researcher sought to obtain information not previously shared. The interview transcripts were read and re-read and were considered along with process level data to gain insight into the perceived need and preferences of oncology professionals and to take note of recommendations for improving the intervention as well as implications for future research.

Privacy and Protection of Identities of Participants

Data files were stored on an encrypted USB thumbdrive with lock (e.g., Security DR Data Guard USB). Hard copies were stored separately from identifying data in a locked cabinet in the researcher's office. In three instances the researcher was concerned

about protecting the anonymity of the participant. These three participants were interviewees and had shared specific details about their practice. The researcher contacted the individuals and described the quotations that she preferred to document. In each instance the participant stated unequivocally that they were comfortable sharing the information and did not feel the need for special protections. One individual stated, “It does not matter to me. I don’t care if anyone knows who I am. I want to share this information.” Despite this previous sentiment and the verbal encouragement from participants to include all of their shared data in its pure form, this researcher chose to alter some characteristics shared, e.g., gender of patient described, removal of identifying names. Additionally the researcher generalized some quotations to protect the anonymity of the participant as much as possible. Therefore, in three instances, the researcher interchanged quotations between participants without changing the content of the quotation to allow for anonymity of said participants.

The researcher read through all of the transcripts several times to get an overall feeling for them, while, making margin notes and forming initial impressions. Each transcript was examined for significant phrases or sentences that pertained directly to the experiences of oncology professionals in their daily work with patients. The significant phrases and statements were reviewed and meanings were formulated. The formulated meanings were grouped into common categories and themes. This allowed for the emergence of some common themes to all of the participants’ narratives and transcripts. This researcher truly was and continues to be a *Being-in-the-world* examined for this study as the research lens is focused through the eyes of a social worker situated on one of the three oncology units studied.

Reflexivity Statement

One of the most challenging issues the researcher faced throughout this research process was completion of the surveys prior to and after each monthly narrative session. She thought that her colleagues filled them out for her because they wanted to help and were interested in her research, but their hectic days often conflicted with completion of this task.

Additional challenges included, recruiting physicians to join the narrative groups. The nature of their schedules was not always conducive to participation. The researcher felt frustrated at times, because she felt that many of the physicians were interested in attending but were unable to make the time.

This researcher believed that her emotional reactions of frustration with organizational stressors and lack of time for herself and her colleagues partnered with her shared experience of the multiple deaths of patients that occurred throughout the course of this study were difficult to contain at times. Use of journaling, consultation with her colleagues and some diversionary activities helped contain her emotions and increased awareness of her personal and professional biases.

Administrative Arrangements

The proposed study transpired at the hospital described in the study as an inner-city academic medical center. The inpatient oncology units involved in this study consisted of 3 oncology units and are located within the main hospital. All involved parties were approached and formal requests to allow this study to be carried out were made. In order to carry out this study the following arrangements were completed: 1.) IRB approval request was submitted and approved, 2.) Permissions and “buy-in” were

granted by each oncology unit and their respective nurse managers, and 3.) The inpatient oncology, physician, nursing and social work administration and floor staff were aware and in agreement with the study and had no objections to its progression.

Consultants

Verbal agreements were made between this researcher and a narrative medicine trained facilitator/leader that conducted the narrative oncology groups described in this study. The leader received \$25.00 per group hour upon completion of the study.

Human Subjects

A. Risk/Benefit Assessment

1. Risks

The potential risks included disclosure of information on individual subjects. All information was collected under IRB regulations designated by the university and this researcher remained vigilant in preventing accidental disclosure of data. All identifying information was stored separately from the individual data, in locked files and on encrypted thumbdrives, when applicable. The analysis of the outcome measures of stress/distress, coping, empathy, burnout, job satisfaction; compassion fatigue and compassion satisfaction should make a contribution to the knowledge of whether or not narrative group interventions affect these variables in any direction. Since accidental disclosure was very unlikely, the feeling was that the benefits outweigh the risks.

Minimal risk to the participants was expected to occur through the course of study other than the discomfort ordinarily encountered in the hospital work environment daily. The measures used to assess job stress/satisfaction, compassion fatigue/compassion satisfaction, burnout and general distress levels took less than five minutes each to

complete and asked for participant's feelings about their emotions. Participating in groups and sharing can produce anxiety for some; however the overall feeling was that the benefits outweigh the risks. A trained professional conducted the narrative group session with specialized training in this intervention.

Another potential risk was psychological discomfort of participants through their writing about their emotions surrounding end-of-life and oncology care in the narrative group sessions. However, a trained professional facilitated the narrative group sessions; he had specialized experience in this intervention with similar populations, e.g., pediatric oncology professionals. The belief is that despite some initial experience of discomfort for some participants, the overall process of participating in the group session was beneficial, again outweighing the potential risks.

2. Benefits:

Potential benefits for participating in this study included the opportunity to share and find camaraderie with others in the narrative group. Professionals reported that they learned more about themselves and found comfort in knowing how their colleagues experienced caring for those with cancer or a terminal illness.

3. Subject Confidentiality:

All information was kept in a locked file. Each participant was assigned a number and that information was housed in a separate locked location. Also, prior to participating in the group exercise, the facilitator discussed subject confidentiality.

4. Subject Privacy/Protected Health Information:

All data was collected under protocols used by the Office of Regulatory Affairs and Institutional Review Board (IRB), which have full accreditation of the Association

for the Accreditation of Human Research Protection Programs (AAHRPP). IRB approval was obtained from the academic institution affiliated with the study hospital and all participants signed consent forms to participate in the study. This researcher explained the study prior to distributing the informed consent and also explained the research project before each narrative session. Participants had the option to choose whether they felt comfortable sharing their narrative or if they preferred they could circle the option to “exclude” their information from the study.

5. Compensation:

Each participant that attended one or more of the narrative oncology sessions received a hot lunch of pizza, desert and soft drinks. Only the ten participants that completed the interviews in addition to at least one narrative session, including pretest and posttest surveys received a \$25 gift card for coffee and/or the campus bookstore at the completion of the study.

6. Investigator’s Risk/Benefit Assessment:

Minimal risk to the investigator was expected. Due to the investigator being a social worker on one of the oncology units, participants may have experienced the desire to please the investigator when they otherwise would have decided not to participate. The investigator therefore attempted to make it clear to potential participants that there was no pressure for them to participate.

B. Resources Necessary for Human Research Protection

The project staff has members of groups that are traditionally under-represented, including females and ethnic minorities. Due to the location of the hospital in this study, an inner-city institution, that pulls upon the local community for its

employees/professionals there were a number of ethnic minority participants. The overall sample resembled US Census data for the breakdown between Whites, Blacks, and Asians (US Census, 2008).

Chapter IV

Results

“Sometimes if you’re by yourself you have to lock it away somewhere. But in these sessions, you can be weak and be vulnerable and let everything out. It’s a huge catharsis where you can let it out. You still have that with you but you feel like other people are going through it too, so it’s okay, and it’s something to be expected.”—Maya Angelou, Oncology Nurse

Introduction

Oncology professionals had much to say about the rigors of their work and their impressions of narrative oncology rounds. This results chapter is divided into two parts; Quantitative Analysis and Qualitative Analysis. Quantitative results obtained from narrative oncology intervention sessions held once a month over a period of four months (October 2009-January 2010) were derived from a packet of three instruments (i.e., HCJSSQ, ProQOL-R-IV and MBI-HSS) (Appendices B, C, D, & E) given to participants before and after participating in each month’s narrative session. A total of 120 packets were distributed before and after each narrative oncology session with a 44% (n=53) response rate of returned questionnaires over the four-month period. Qualitative results were derived from three open-ended questions on the post-session evaluation (Appendix H4) and ten in-depth interviews with oncology professionals from each of the three-inpatient oncology units.

Quantitative Analysis

Additionally, post intervention evaluations were given to participants as part of the in-session packet (Appendix H1-H4). Only participants that met inclusion criteria (n=50) were used in analysis. Some participants participated in more than one narrative session (n=10). Each post intervention evaluation had three Likert questions producing

quantitative data and three open-ended questions. Tables and Charts/graphs will be used throughout this chapter to assist in visualization of the data.

Participants

Descriptive characteristics and an overview of the sample are presented in Table 4.1. The study participants (n=40; derived from n=50-10 repeat participants) include three primary groups of professionals: physicians (n=6; 15%), nurses (n=27; 67.5%), social workers (n=3; 7.5%) and others (e.g., pastoral care, nurse practitioners) (n=4; 10%). Gender distribution varied significantly over profession ($X^2 = 15.9$; $df = 3$; $p \leq .001$). Physicians were equally male or female (50%; n=3) whereas nurses, social workers, and others were overwhelmingly female (100%; n=27, 67%; n=2, 100%; n=4) respectively. Overall, the respondents were (10%) male and (90%) female and did not vary significantly by marital status across professions with (47.5%) married and/or living with their significant other, (5%) divorced or separated and the other (47.5%) single and/or never married. The mean age of respondents was 32.9 ranging from 23 to 61 years with no significant differences among professional groups. A majority of the sample was Caucasian (77.5%) with minority groups represented as follows: African-American (12.5%) and Asian (10%). Distribution of years of oncology work experience indicated a significant difference between profession ($F = 3.6$, $df = 3$, $p < .05$) with other professionals with about three to four years more than physicians, nurses and social workers. Years of work in oncology were also significant and followed a similar pattern to years employed at study hospital with other professionals ($F = 7.4$, $df = 3$, $p \leq .001$) with about two to three more years than physicians, nurses and social workers.

To determine whether or not study participants level of burnout, compassion fatigue/secondary traumatic stress, job stress, compassion satisfaction and job satisfaction varied from prior to one of the four monthly sessions to after that same monthly session subscales from all three instruments were used. The HCJSSQ measures job stress, job satisfaction through a total overall score and a perceived overall score for each construct. The ProQOL has three subscales, namely, compassion satisfaction, burnout and compassion fatigue/secondary trauma. The MBI-HSS also has three subscales; emotional exhaustion, depersonalization and personal accomplishment.

Table 4.1: Sociodemographics of Sample by Profession

[illegible]

<u>Age</u>	32.9	10.9	27.5	2.3	32.6	10.4	30.0	2.6	44.8	18.8	F=2.3	3	.089
<u>Yrs Employment In Oncology</u>	3.2	1.8	1.5	.84	3.4	1.9	2.7	.58	5.0	2.0	F=7.4	3	.001**
<u>Yrs Employment at Study Hospital</u>	3.0	1.8	2.2	2.0	2.9	1.5	2.0	1.0	6.3	.50	F=3.6	3	.022*

* $p \leq .05$; ** $p \leq .001$

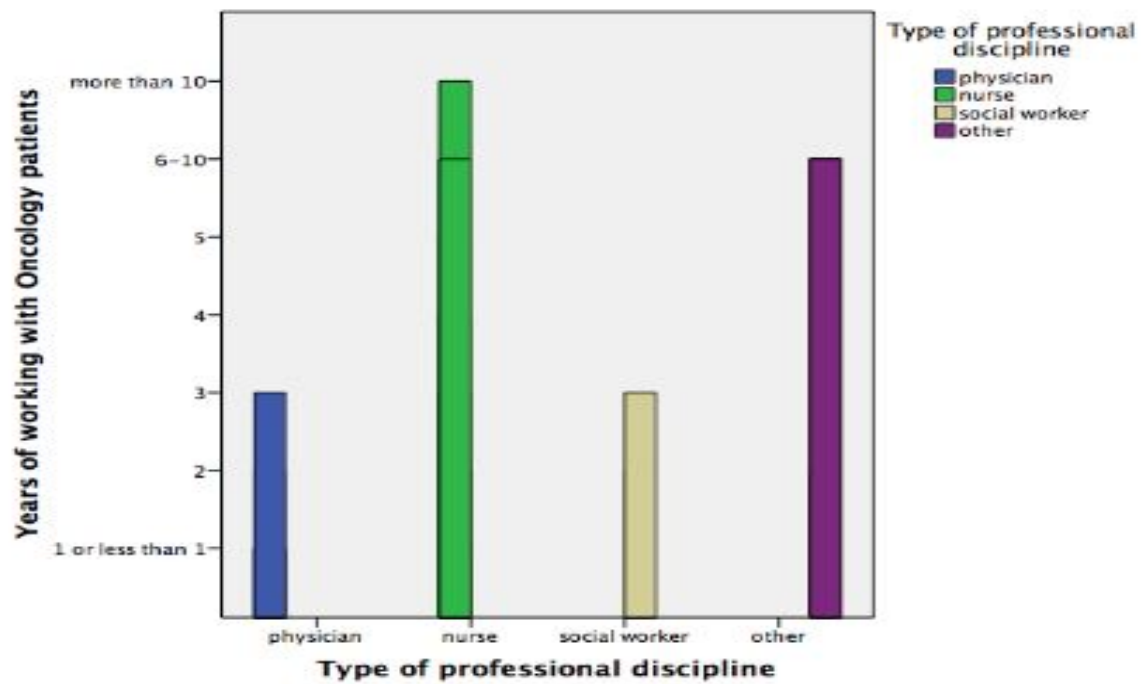


Figure 4.1: Years of Oncology Work by Discipline

To determine whether the sample population experienced the constructs of all three instruments, sample means were compared to normative means for each with the exception of the HCJSSQ, which did not record normative mean data for job stress and job satisfaction. Sample means that increase in relation to the normative mean for items such as burnout (BO), compassion fatigue/secondary traumatic stress (CF/STS), emotional exhaustion (EE), and depersonalization (DP) may suggest that their presence exists in the sample population. A decrease in sample means for scores such as

compassion satisfaction may suggest that compassion satisfaction was lower for the sample population. The higher sample mean score of personal accomplishment (PA) may indicate that sample population had an increased feeling of PA over the normative sample.

To address research question 1a. Does a narrative oncology intervention impact job stress, compassion fatigue, and burnout and/or job satisfaction, compassion satisfaction and personal accomplishment (subscale of MBI-HSS) an independent t-test was used to determine if there was a relationship demonstrated from prior to each narrative session (NS) to after each session (NS1pre-NS1post, NS2pre-NS2post, NS3pre-NS3post, and NS4pre-NS4post).

Table 4.2a: Narrative Session 1 Pretest and Posttest (n=13)

Dependent Variable	Normative Mean	Sample Mean		t	df	Sig (2-tailed)
ProQOL		NS1 pre	NS1 post			
Compassion satisfaction	37.0 (SD=7.0)	34.7 (SD=6.7)	37.5 (SD=6.2)	-.75	16	.467
Burnout	22.0 (SD=6.0)	26.9 (SD=6.1)	19.5 (SD=4.8)	2.2	16	.043*
Compassion fatigue/STS	13.0 (SD=6.0)	19.9 (SD=7.3)	14.8 (SD=5.7)	1.3	16	.210
MBI-HSS						
Emotional exhaustion	21.4 (SD=10.5)	35.4 (SD=7.6)	22.3 (SD=7.5)	3.1	16	.008**
Depersonalization	7.5 (SD=5.1)	12.1 (SD=5.2)	7.8 (SD=5.7)	1.5	16	.164
Personal Accomplishment	32.8 (SD=7.7)	34.7 (SD=5.5)	33.8(SD=6.7)	.30	16	.771
HCJSSQ	Normative Mean					
*** Job stress score calc	NR	39.4 (SD=17.4)	29.5 (SD=7.2)	1.1	16	.289
**** Overall perceived Job stress	NR	3.3 (SD=.83)	2.5 (1.3)	.23	16	.156
*** Job satisfaction calc	NR	38.0 (SD=8.5)	36.5 (SD=18.2)	.06	16	.813
****Overall perceived job satisfaction	NR	2.9 (SD=.83)	2.8 (SD=1.5)	.05	16	.754

* $p \leq .05$; ** $p < .01$

*** Scores calculated by summing ratings given to each item

**** Scores recorded by participants as overall rating

NR- scores not recorded in manual

Pre and post-narrative session one questionnaire responses (n=13) were analyzed using an independent t-test and indicated that participants reported significant decreases in emotional exhaustion and burnout ($t = 2.2$, $df = 16$, $p < .05$) and ($t = 3.1$, $df = 16$, $p < .01$) respectively. This difference included professionals of all disciplines. Although,

scores for compassion satisfaction increased and scores for compassion fatigue and depersonalization decreased they were not significant changes.

Table 4.2b: Narrative Session 2 Pretest and Posttest (n=9)

Dependent Variable	Normative Mean	Sample Mean		t	df	Sig (2-tailed)
ProQOL		NS2 pre	NS2 post			
Compassion satisfaction	37.0 (SD=7.0)	33.8 (SD=7.6)	38.3 (SD=3.8)	-.95	7	.376
Burnout	22.0 (SD=6.0)	25.3 (SD=7.3)	19.3 (SD=3.2)	1.3	7	.225
Compassion fatigue/STS	13.0 (SD=6.0)	17.2 (SD=9.2)	9.7 (SD=4.0)	1.8	7	.115
MBI-HSS						
Emotional exhaustion	21.4 (SD=10.5)	28.2 (SD=9.2)	29.0 (SD=4.9)	-.15	7	.889
Depersonalization	7.5 (SD=5.1)	10.3 (SD=5.6)	13.3 (SD=4.7)	-.79	7	.453
Personal accomplishment	32.8 (SD=7.7)	31.3 (SD=4.6)	38.3 (SD=4.0)	-2.2	7	.061
HCISSQ	Normative Mean					
* Job stress score calc	NR	37.3 (SD=16.8)	28.0 (SD=1.7)	.93	7	.383
** Overall perceived job stress	NR	2.8 (SD=1.2)	2.3 (SD=1.2)	.61	7	.563
* Job satisfaction calc	NR	43.8 (SD=20.9)	31.3 (SD=14.6)	.92	7	.390
** Overall perceived job satisfaction	NR	2.8 (SD=.98)	2.7 (SD=.58)	.27	7	.798

* Scores calculated by summing ratings given to each item

** Scores recorded by participants as overall rating

NR- scores not recorded in manual

Table 4.2c: Narrative Session 3 Pretest and Posttest (n=16)

Dependent Variable	Normative Mean	Sample Mean		t	df	Sig (2-tailed)
ProQOL		NS3 pre	NS3 post			
Compassion satisfaction	37.0 (SD=7.0)	39.0 (SD=6.2)	40.6 (SD=5.9)	-.44	13	.665
Burnout	22.0 (SD=6.0)	20.5 (SD=6.8)	17.7 (SD=5.3)	.84	13	.416
Compassion fatigue/STS	13.0 (SD=6.0)	20.8 (SD=14.8)	12.2 (SD=6.9)	1.6	13	.140
MBI-HSS						
Emotional exhaustion	21.4 (SD=10.5)	26.3 (SD=13.5)	20.0 (SD=10.1)	.97	13	.348
Depersonalization	7.5 (SD=5.1)	7.5 (SD=7.6)	5.2 (SD=3.9)	.80	13	.440
Personal accomplishment	32.8 (SD=7.7)	38.3 (SD=4.5)	37.6 (SD=5.4)	.202	13	.843
HCJSSQ	Normative Mean					
* Job stress score calc	NR	38.8 (SD=30.3)	29.6 (SD=13.5)	.84	13	.416
** Overall perceived job stress	NR	3.5 (SD=1.9)	2.7 (SD=.65)	1.2	13	.242
* Job satisfaction calc	NR	47.0 (SD=16.3)	39.3 (SD=17.4)	.77	13	.454
** Overall perceived job satisfaction	NR	3.8 (SD=.96)	3.6 (SD=.51)	.31	13	.765

* Scores calculated by summing ratings given to each item

** Scores recorded by participants as overall rating

NR- scores not recorded in manual

Pre and post-narrative session questionnaire responses were analyzed using an independent t-test for all four narrative sessions, however, none of the scores for narrative session two and three showed significant changes despite some trends in a desirable direction (e.g., compassion satisfaction in NS2pre to NS2post increased from 33.8

(SD=7.6) to 38.3 (SD=3.8)). In narrative session four there was a significant change in compassion fatigue or secondary traumatic stress ($t = 2.3$, $df = 9$, $p < .05$).

Table 4.2d: Narrative Session 4 Pretest and Posttest (n=12)

Dependent Variable	Normative Mean	Sample Mean		t	df	Sig (2-tailed)
ProQOL		NS4 pre	NS4 post			
Compassion satisfaction	37.0 (SD=7.0)	39.0 (SD=6.5)	40.3 (SD=8.9)	-.25	9	.808
Burnout	22.0 (SD=6.0)	22.3 (SD=3.2)	21.0 (SD=4.9)	.45	9	.662
Compassion fatigue/STS	13.0 (SD=6.0)	18.5 (SD=4.7)	12.1 (SD=4.2)	2.3	9	.045*
MBI-HSS						
Emotional exhaustion	21.4 (SD=10.5)	26.0 (SD=7.5)	21.6 (SD=8.1)	.89	9	.397
Depersonalization	7.5 (SD=5.1)	11.8 (SD=6.1)	7.1 (SD=5.3)	1.3	9	.223
Personal accomplishment	32.8 (SD=7.7)	37.0 (SD=2.9)	37.0 (SD=9.5)	.000	9	1.00
HCJSSQ	Normative Mean					
** Job stress score calc	NR	36.0 (SD=10.8)	28.0 (SD=6.6)	1.5	9	.156
*** Overall perceived job stress	NR	2.8 (SD=1.3)	2.7 (SD=.95)	.05	9	.958
** Job satisfaction calc	NR	42.3 (SD=9.2)	42.7 (SD=13.0)	-.06	9	.952
*** Overall perceived job satisfaction	NR	3.0 (SD=1.2)	3.7 (SD=.49)	-1.5	9	.176

* $p \leq .05$

** Scores calculated by summing ratings given to each item

*** Scores recorded by participants as overall rating

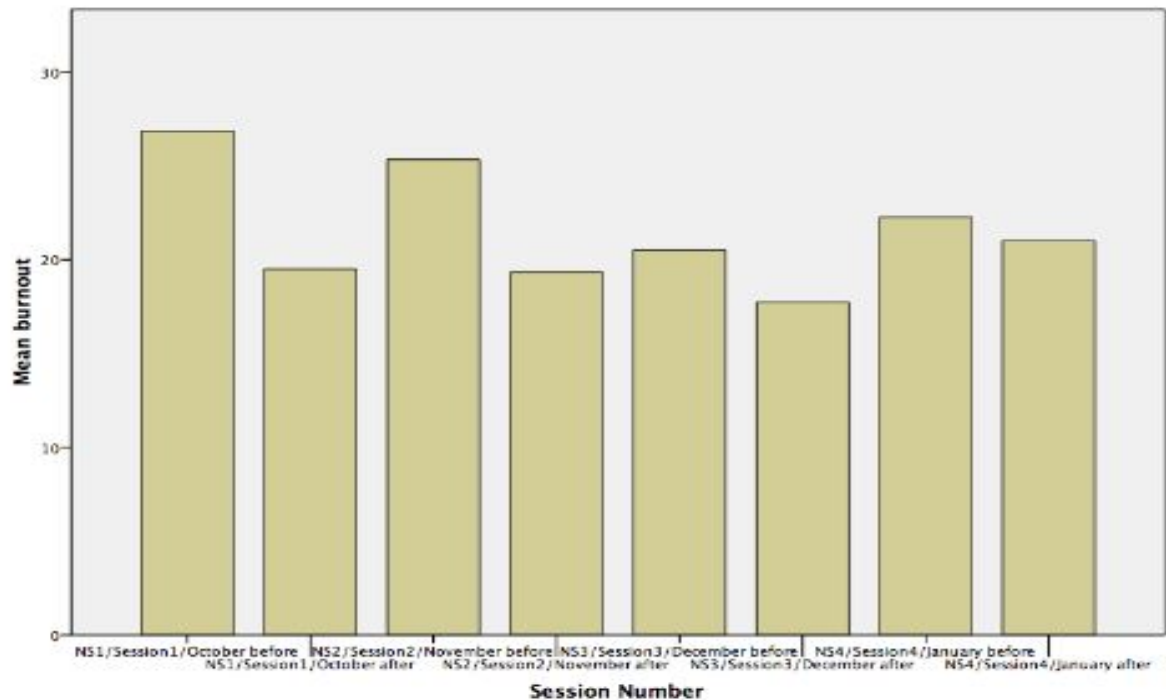
NR- scores not recorded in manual

An independent t-test was also used to analyze narrative session one pretest to narrative session four posttest. Although, all of the scores seemed to show a desired change, significance was shown when equal variances were assumed for burnout ($t = 2.2$,

$df = 19, p < .05$), compassion fatigue/STS ($t = 2.6, df = 19, p < .05$), emotional exhaustion ($t = 3.8, df = 19, p = .001$), depersonalization ($t = 2.1, df = 19, p \leq .05$) and overall perceived job satisfaction ($t = -2.3, df = 19, p < .05$).

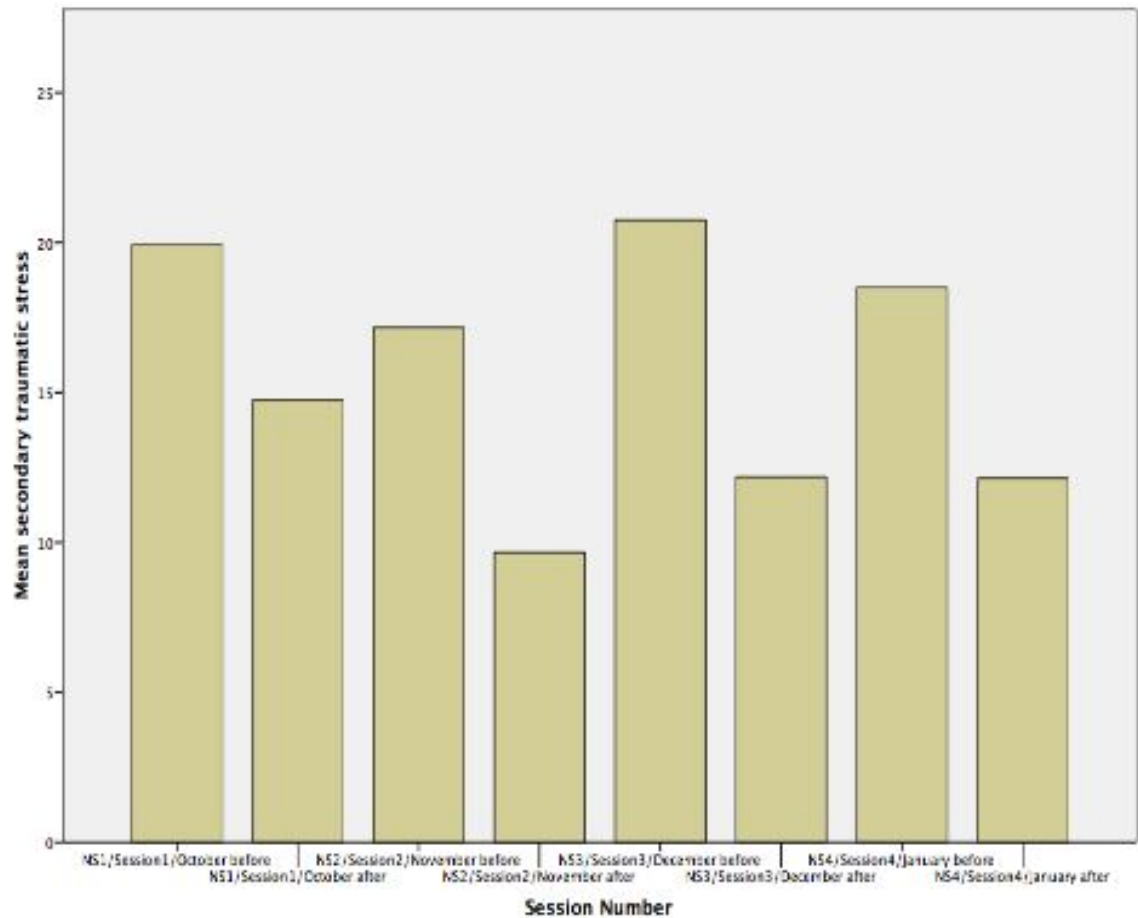
Additionally, mean scores reported prior to NS1 were compared to mean scores from after NS4. Scores for compassion satisfaction, summed job satisfaction score and overall perceived job satisfaction score all increased, but only the latter was statistically significant ($t = -2.3, df = 19, p < .05$) when variances of dependent variable across groups were assumed to be equal.

Figure 4.2: Measure of Burnout



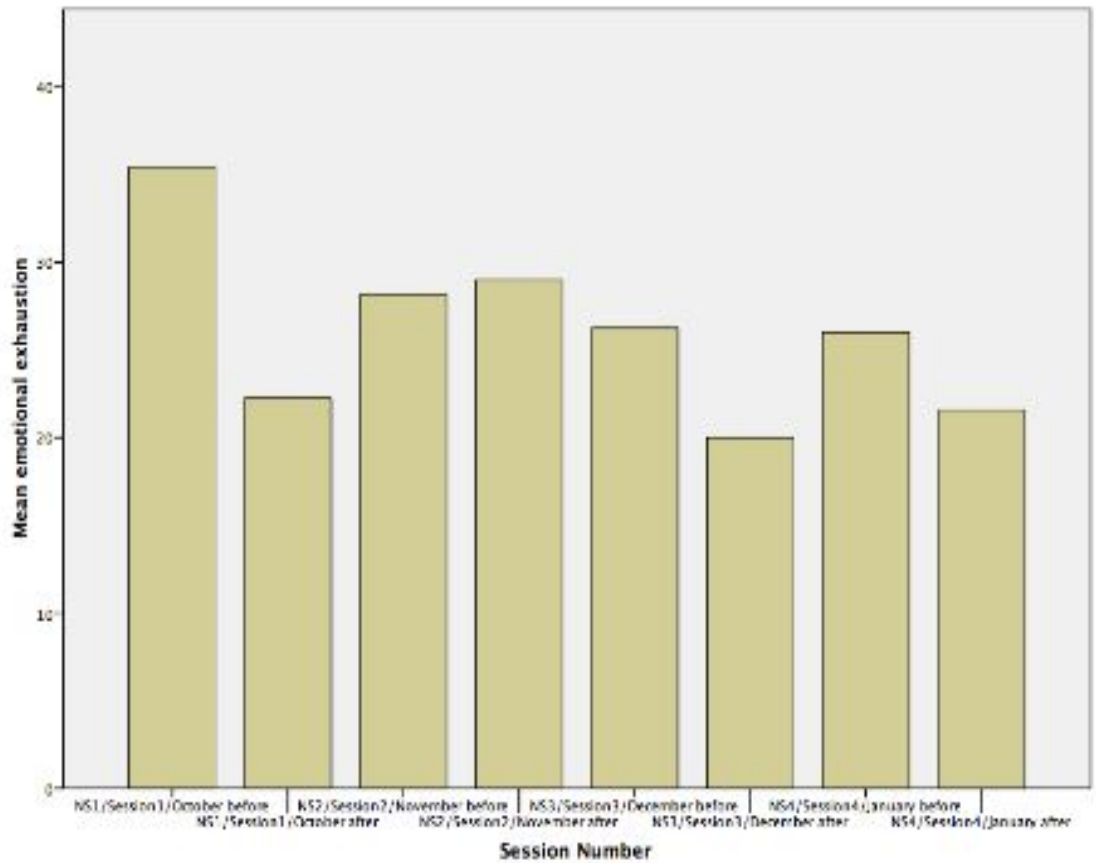
The measure of burnout decreased in each session; NS1pre 26.9 (SD=6.1) to NS1post 19.5 (SD=4.8), NS2pre to NS2post 25.3 (SD=7.3) to 19.3 (SD=3.2), NS3pre 20.5 (SD=6.8) to NS3post 17.7 (SD=5.3), NS4pre 22.3 (SD=3.2) to NS4post 21.0 (SD=4.9) and was statistically significant in narrative session 1 ($t = 2.2, df = 16, p < .05$).

Figure 4.3: Measure of Compassion Fatigue/STS



Compassion Fatigue/Secondary Traumatic Stress decreased in each of the four narrative sessions; NS1pre 19.9 (SD=7.3) to NS1post 14.8 (SD=5.7), NS2pre 17.2 (SD=9.2) to NS2post 9.7 (SD=4.0), NS3pre 20.8 (SD=14.8) to NS3post 12.2 (SD=6.9), and NS4pre 18.5 (SD=4.7) to NS4post 12.1 (SD=4.2) and was statistically significant in NS4 ($t = 2.3$, $df = 9$, $p < .05$). STS was nearly significant in narrative session 2 ($p = .115$) and in narrative session 3 ($p = .140$).

Figure 4.4: Measure of Emotional Exhaustion



Emotional exhaustion decreased in three of the four narrative sessions, NS1pre 35.4 (SD=7.6) to NS1post 22.3 (SD=7.5), NS3pre 26.3 (SD=13.5) to NS3post 20.0 (SD=10.1), NS4pre 26.0 (SD=7.5) to NS4post 21.6 (SD=8.1) with statistical significance noted in Narrative session one ($t = 3.1$, $df = 16$, $p \leq .01$).

Table 4.3a: Narrative Session One pretest and Follow-up Narrative Session Four (n=)

Dependent Variable	Normative Mean	Sample Mean	
ProQOL		NS1 pre	NS4 post
Compassion satisfaction	37.0 (SD=7.0)	34.7 (SD=6.7)	40.3 (SD=8.9)
Burnout	22.0 (SD=6.0)	26.9 (SD=6.1)	21.0 (SD=4.9)
Compassion fatigue/STS	13.0 (SD=6.0)	19.9 (SD=7.3)	12.1 (SD=4.2)
MBI-HSS			
Emotional exhaustion	21.4 (SD=10.5)	35.4 (SD=7.6)	21.6 (SD=8.1)
Depersonalization	7.5 (SD=5.1)	12.1 (SD=5.2)	7.1 (SD=5.3)

Personal accomplishment	32.8 (SD=7.7)		34.7 (SD=5.5)	37.0 (SD=9.5)
HCISSQ	Normative Mean	Possible Range		
* Job stress score calc	NR	(0-105)	39.4 (SD=17.4)	28.0 (SD=6.6)
** Overall perceived job stress	NR	(0-4)	3.3 (SD=.83)	2.7 (SD=.95)
* Job satisfaction calc	NR	(0-66)	38.0 (SD=8.5)	42.7 (SD=13.0)
** Overall perceived job satisfaction	NR	(0-4)	2.9 (SD=.83)	3.7 (SD=.49)

* Scores calculated by summing ratings given to each item

** Scores recorded by participants as overall rating

NR- scores not recorded in manual

Figure 4.5: Measure of Depersonalization

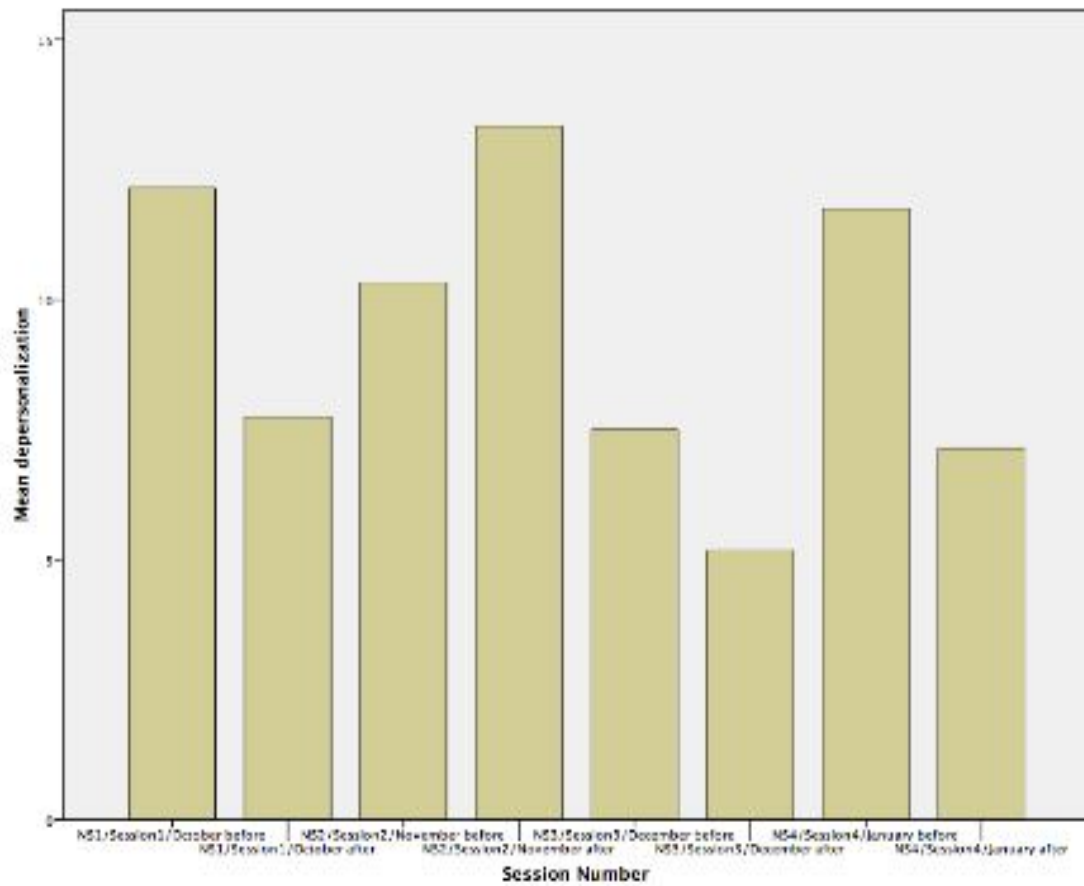


Table 4.3b: Independent t-test comparison of NS1pre to NS4post

Dependent Variable	Variances	t	df	Sig. (2-tailed)
ProQOL				
Compassion Satisfaction	Equal variances assumed	-1.6	19	.124
	Equal variances not assumed	-1.5	9.5	.177
Burnout	Equal variances assumed	2.2	19	.041*
	Equal variances not assumed	2.4	14.9	.032*
Compassion Fatigue/STS	Equal variances assumed	2.6	19	.017*
	Equal variances not assumed	3.1	18.3	.006**
MBI-HSS				
Emotional Exhaustion	Equal variances assumed	3.8	19	.001***
	Equal variances not assumed	3.8	11.4	.003**
Depersonalization	Equal variances assumed	2.1	19	.054*
	Equal variances not assumed	2.0	11.9	.064
Personal Accomplishment	Equal variances assumed	-.70	19	.491
	Equal variances not assumed	-.59	8.1	.573
HCJSSQ				
***** Overall perceived Job stress	Equal variances assumed	1.4	19	.171
	Equal variances not assumed	1.4	10.7	.203
**** Job stress score calc	Equal variances assumed	1.7	19	.113
	Equal variances not assumed	2.2	18.3	.044*
***** Overall perceived Job satisfaction	Equal variances assumed	-2.3	19	.033*
	Equal variances not assumed	-2.7	18.3	.014**
**** Job satisfaction calc	Equal variances assumed	1.7	19	.113
	Equal variances not assumed	2.2	18.3	.044*

* $p \leq .05$; ** $p \leq .01$; *** $p \leq .001$

***** Scores calculated by summing ratings given to each item

***** Scores recorded by participants as overall rating

NR- scores not recorded in manual

Descriptive statistics were used to calculate the mean score for each of the post-session evaluation questions that utilized a likert scale. Scores could potentially range from (0) *Definitely disagree* to (5) *Definitely agree* (See Table 4.4a, 4.4b, 4.4c, & 4.4d)

The mean scores for questions one, two and three were 4.74, 4.56, and 4.52 respectively. These scores indicate that most participants felt that the narrative exchange was beneficial to their well-being/resilience; the narrative experience helped ease their mind and allowed them to feel better equipped to face whatever they filled in the “blank” with. Tables 4.4a through 4.4d summarize the answers to the post-session evaluations.

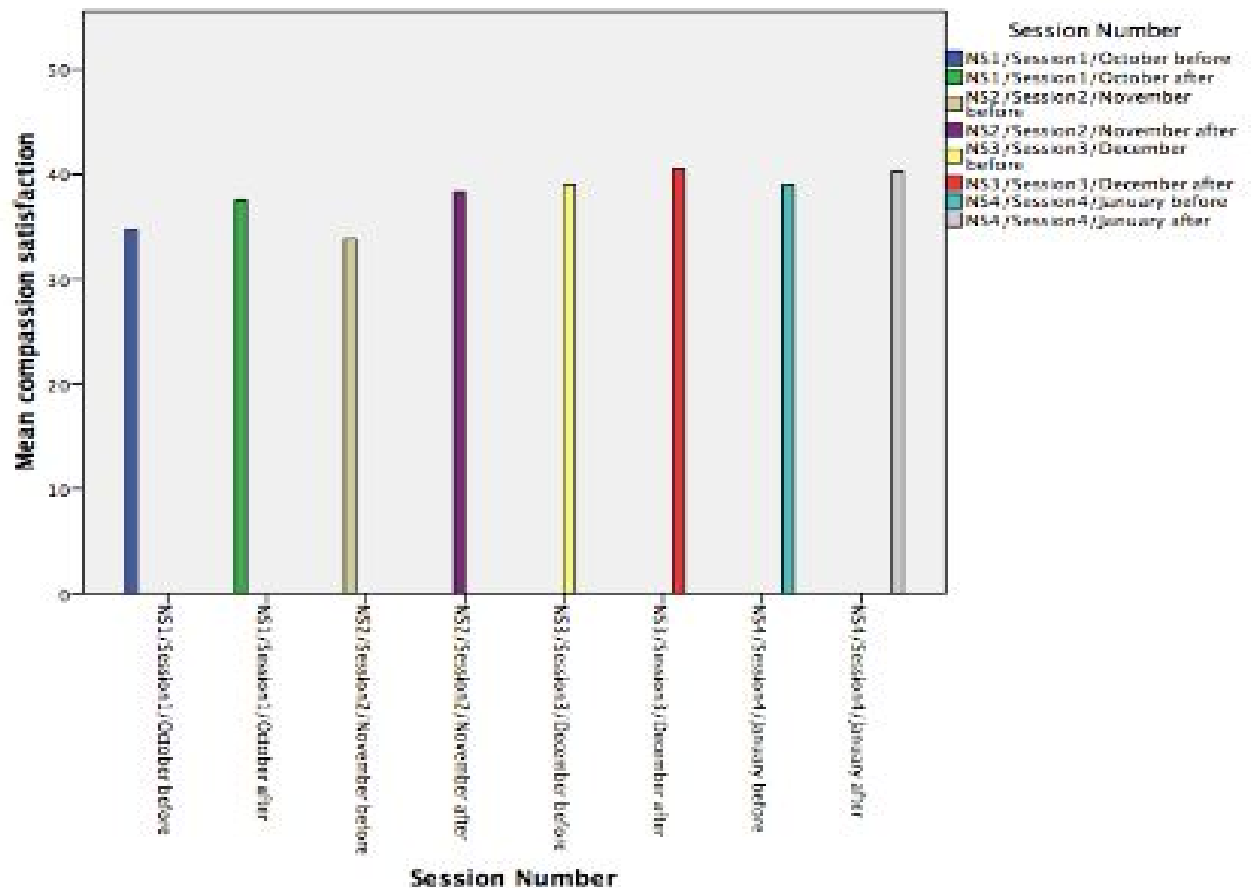


Figure 4.6: Measure of Compassion Satisfaction

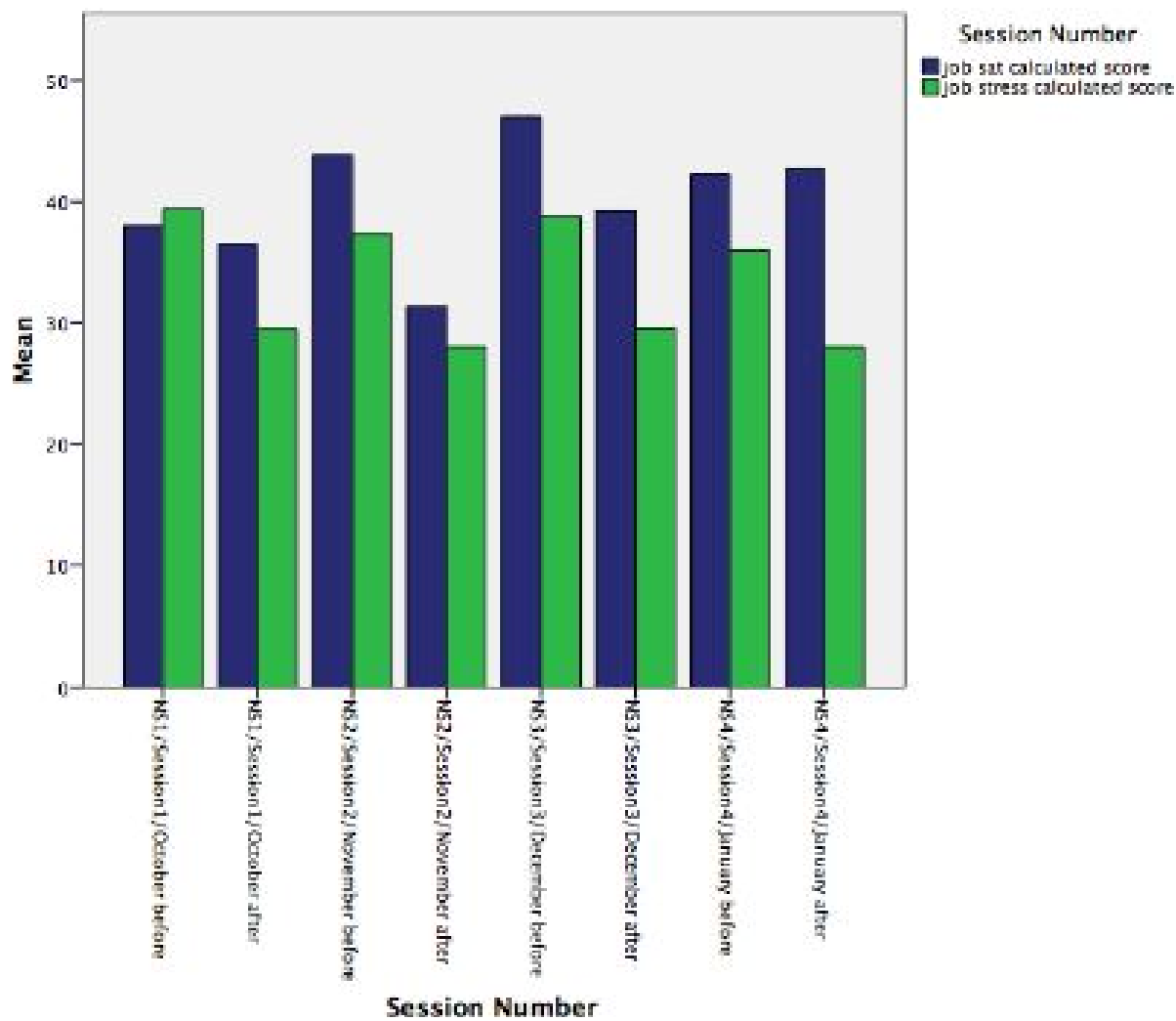


Figure 4.7: Measure of Job Stress and Job Satisfaction

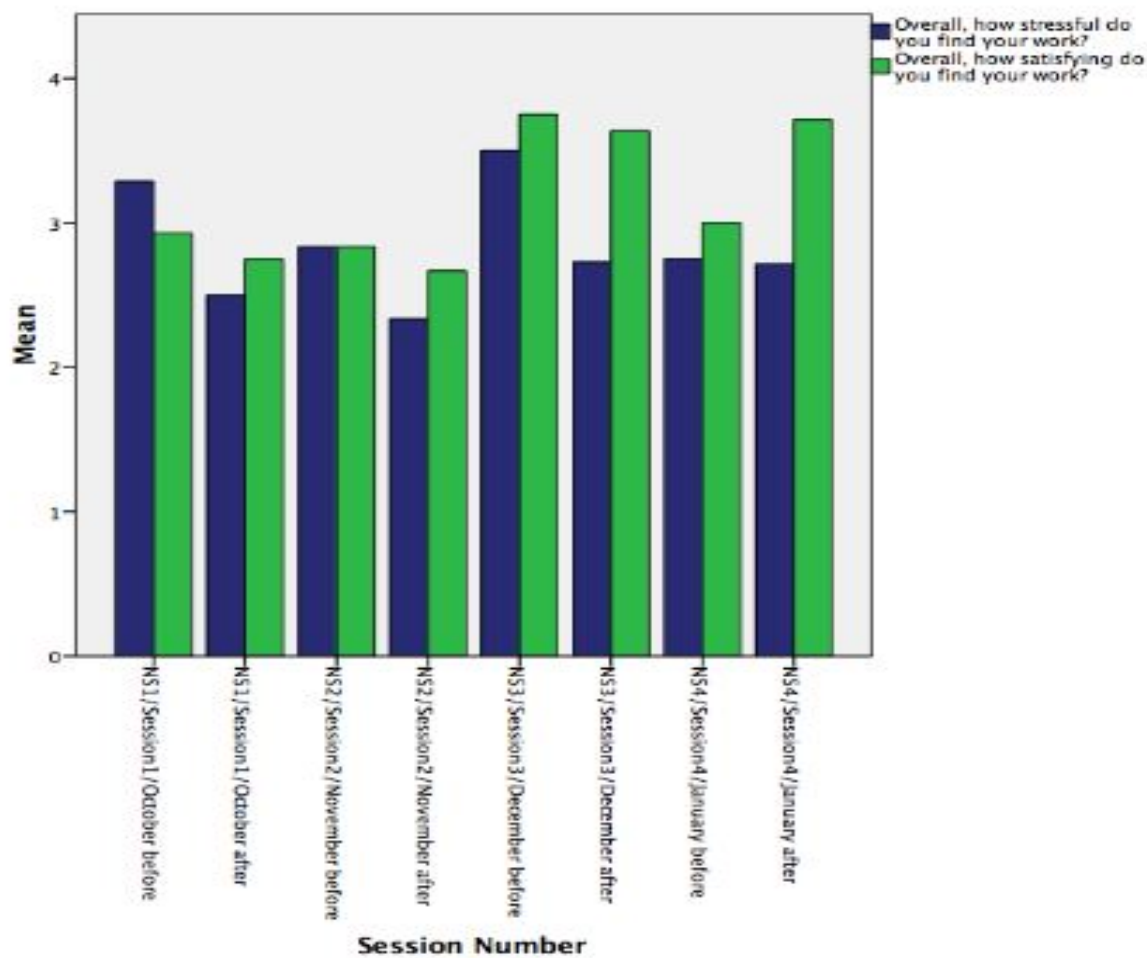


Figure 4.8: Measure of Perceived Job Stress and Job Satisfaction

Table 4.4a: Narrative Post-Session Evaluation Data

	N	Minimum	Maximum	Mean	Std. Deviation
Narrative Session Participant Survey question#1	50	2	5	4.74	.600
Narrative Session Participant Survey question#2	50	1	5	4.56	.760
Narrative Session Participant Survey question#3	50	3	5	4.52	.614

Table 4.4b: Data from Post-Session Evaluation--Question One

Post Narrative Question1- "Today's narrative exchange experience was beneficial to my well-being/resiliency."

Narrative Session Participant Survey question#1	Session Number				
	NS1- October2009	NS2- November2009	NS3- December2009	NS4- January2010	Total
Definitely Disagree	0	0	0	0	0
Probably Disagree	1	0	0	0	1
Not sure	1	0	0	0	1
Probably Agree	4	1	2	1	8
Definitely Agree	7	8	14	11	40
Total	13	9	16	12	50

Table 4.4c: Data from Post-Session Evaluation--Question Two

Post Narrative Question2- "Today's narrative experience has helped ease my mind."

Narrative Session Participant Survey question#2	Session Number				
	NS1- October2009	NS2- November2009	NS3- December2009	NS4- January2010	Total
Definitely Disagree	1	0	0	0	1
Probably Disagree	0	0	0	0	0
Not sure	1	0	1	0	2
Probably Agree	4	4	2	4	14
Definitely Agree	7	5	13	8	33
Total	13	9	16	12	50

Table 4.4d: Data from Post-Session Evaluation--Question Three

Post Narrative Question3- "After today's narrative group I feel better equipped to face..."

Narrative Session Participant Survey question#3	Session Number				
	NS1- October2009	NS2- November2009	NS3- December2009	NS4- January2010	Total
Definitely Disagree	0	0	0	0	0
Probably Disagree	0	0	0	0	0
Not sure	1	0	1	1	3
Probably Agree	7	6	1	4	18
Definitely Agree	5	3	14	7	29
Total	13	9	16	12	50

Qualitative Analysis:

Content Analysis of Process

A content analysis of the open-ended questions on the post session evaluation (Appendix H4) assessed several features of the narrative oncology intervention and provided richness to the overall data. Each answer to the three questions was recorded and when the participant expressed more than one thought or response to an item, the researcher broke up the comments into meaningful segments and each segment was considered individually. The three questions assessing intervention efficacy and comments are as follows:

- Which elements of today's experience, if any, were especially effective?

The majority of participants shared that they appreciated the ability to share and witness perspectives of their colleagues. Many of the professionals shared that they felt validated in their emotional struggles through this sharing within the narrative exchange. *Theme(s): Shared Perspectives, Validation and Closure*

- How would you improve this narrative group writing session? Most of the comments for this section were left blank; however, when recommendations were listed they fell primarily into three categories: 1.) went well/no recommendations and 2.) more time to both write and share 3.) less traffic in and out of the room. *Theme(s): Satisfaction, Request for more time and Less Traffic*

- Do you have any other comments about today's narrative group session? Most of the comments in this section were also left blank. Some of the

shared comments included positive commentary about how the participant felt the session benefited them. Additionally, some participants communicated their appreciation with “thank you!” While others stated that they were hoping that the sessions would continue. One person shared that they worried about coming to the narrative session because the stories move them to tears, but they appreciated on this occasion that there was shared laughter. *Theme(s): Anecdotes and Appreciation*

- Extras: The first three of the six questions on the post-session evaluation (Appendix H4) were somewhat open-ended but asked participants to fill in the answer on a Likert scale. Several individuals completed the thought and filled in the Likert scale.
 - Today’s narrative exchange experience was beneficial to my well-being/resiliency
 - *self-learning*
 - Today’s narrative experience has helped ease my mind...
 - *regarding my perceived inadequacies*
 - After today’s narrative group I feel better equipped to face...
 - *to face each day’s stresses*
 - *everyday*
 - *a difficult situation*

Table 4.5: Answers/Comments to Open-Ended Post-Session Evaluation Questions

Which elements of today's experience, if any, were especially effective?	How would you improve this narrative group writing session?	Do you have any other comments about today's narrative group session?
THEMES		
<i>Shared Perspectives, Validation and Closure</i>	<i>Satisfaction, Request for more time and Less Traffic</i>	<i>Anecdotes and Appreciation</i>
being able to share similar experiences with others who care	not when I am actively taking care of patients so I can concentrate on this	liked it
sharing stories builds connection between us all so that we get multiple perspectives on what we are experiencing here	To stop the coming in and out. I realize it's difficult but it's very disruptive	wish that this was not the end of this group session
sharing stories about the same patients	more time to write (I came late)	it was very beneficial
Feeling comfortable expressing myself and my feelings in front of others. Knowing that my co-workers whom I respect also have doubts about themselves	not being called out of room	It was so nice to sit down and hear how everyone is doing. So many times a patient will die and then we literally need to get ready for the next admission! It is just so beneficial to have time to talk about this!
openness and honesty; sharing	More time to write or allow to write/complete at the end	interns/nurse leader need to be able to pass pager to someone
multidisciplinary approach—the openness and honesty with which the participants shared their experiences	more time	great experience
Being able to listen to others and their experiences helps me to see that my feelings towards certain situations are valid.	more time to think about and write narrative	I think it was extremely beneficial!
the sharing	Less leaving and coming back in.	Wonderful!
to hear from new people	more time	I am really enjoying hearing how honest everyone is!!
Learning my feelings of inadequacy or short-comings are “healthy” and common.	nothing I would change	group leader was very effective and brought great insight
the discussion	Allow enough time for everyone to share (less people?)	Great!

I like the humor	more time	Sometimes I worry about coming to these narratives because the stories can move me to tears and it is stressful to cry in oncology as a caregiver. This time we were laughing.
the element of discussing the narratives with colleagues who can all relate on the same level	I would leave it the same, it is just the starting point	Thank you
very insightful to why I do what I do, why I feel things I feel and how to improve my practice	would have had another hour	Disappointed that MD didn't come. They miss out
very beneficial to all involved and opens people to view the opinions/etc. of all people involved in patient care		Very good—thanks!
I enjoyed hearing perspectives from other medical professionals. The person leading the discussion was very effective.		please have more
Hearing stories of other people other disciplines about same patient I take care of as a resident listening to RN stories		sorry it's the last one
realizing I am not alone in my stress and my struggle		went well
To hear, first-hand, that others around me are as conflicted about the same things		Nothing—please keep this going! We need your help!
Sharing experiences with other professionals and getting multiple perspectives in various situations.		wish physicians would come
the ease of sharing/relaxed atmosphere		allow everyone to speak
sharing		not to focus on the same people (presenter of narrative)
hearing everyone's story, knowing that we all have the same sort of stories		thought it was great
allowing everyone to comment on each other's stories		the leader posed great questions and assisted with the groups' fear
to hear everyone's perspectives		the narrative facilitator's style

on the suffering they have endured while caring for patients with cancer		of affirmation of practice
hearing the struggles with similar patients		
Hearing similar stories help to lift off some of the weight you carry as a care provider. Thank you.		
discussion about narratives		
sharing positive experiences was effective in releasing stress		
nice to hear other's stories, let's you know you're not alone		
honesty of participants		
I really enjoyed hearing the different realms of practice talk about their different experiences		
all discussion		
As always the openness and honesty that everyone displayed.		
the sharing of narratives and getting to know how others feel and deal with situations that arise		
hearing stories from others—validating some things you would experience on your own		
multidisciplinary approach—the openness and honesty with which the participants shared their experiences		
the closure I had for [patient's name]		
the hearing narratives of other staff member and how they have encountered stressful situations and dealt with it		
all		
hearing different perspectives from different professionals		
the guy running it going over		

the narratives		
being able to talk about positive things for someone who died		

In-depth Interviews

Two main categories existed within the context of the interviews, patient care and impressions of the narrative exchange. Professionals shared rich descriptions of their experiences of their perceived job stress, compassion fatigue and burnout. Within each of the categories, quotes, post-session evaluation open-ended answers and excerpts of narratives were condensed into meaning units which were clustered into subthemes, and were then condensed into themes.

Common to Heideggerian phenomenology, quotes illustrating each of the thematic categories will be provided and then are followed by an interpretive paragraph. Typical to this method, quotes often illustrate more than one thematic category. Interviewees are given the name of famous writers to distinguish them throughout the analysis. All interviewees were female (Maya Angelou, Jane Austen, Emily Bronte, Emily Dickinson, Anne Frank, Zora Neale Hurston, Sylvia Plath, Ayn Rand, Mary Shelley, Virginia Woolf).

Process level analyses about logistics of narrative oncology were derived from both interviews and answers to post-session evaluations. These themes triangulated with the process level questions in the interviews. The following are the categories and themes that emerged from the interviews with 10 oncology professionals:

Category I: Patient Care

***Theme 1: The Balancing Process:
Emotional Proximity- Distance, Self-Protection, and Closure
Gallows Humor***

Exhaustion
Need for Closure

Theme 2: Stressors and Laborious Work:
Desire for Intimate Emotional Connections and Guilt
Organizational Stressors

Theme 3: Burden and Privilege of Care
Reality of Mortality

Category II: Impressions of Narrative Exchange

Theme 4: Standing on Common Ground and Meaning Making:
Shared Perspectives and Bearing Witness within Narrative Exchange
Eulogizing

Theme 5: Comfort in Confidentiality and a Safe-Space within Narrative Exchange

Theme 6: Group-Care becomes Self-Care

Process Level Analysis:
Writing Gives Structure
Facilitator
Participation
Not therapy but supportive
Addressing Criticism

Table 4.6: Meaning Unit conversion to Subthemes

Quotes	Condensation/Meaning Unit	Subthemes
You see [the patients] start from this cheery, bright-eyed, “we can beat this, I’m not gonna let this disease get me”—and it’s kind of like you as a nurse—a care provider—see yourself in them. We’re fighting like you are fighting cancer—together. Then you see a failure of the treatment and then you see it again and then you see it again. Then they come back and then there’s a transplant and then there’s all these complications and then you see their quality of life go down. Almost every time that person comes in it’s a huge drain on you because we’re human beings, too.	<ul style="list-style-type: none"> • Pride in Fighting Cancer • The seeming futility of the process • Stays with you • The gravity of dealing with the constant reminder of life and death 	<ul style="list-style-type: none"> • Witness to suffering-optimism replaced by rigors of disease • Professional seeks distance from emotional suffering and the constant reminder of mortality • Perception of work changes over time

When we go home it's not like the kind of job where you can swipe out and leave it here. It kind of comes with you because it is such an emotional thing. You're dealing with lives and hope and just wanting to live and beat it.		
"In the beginning I never used to feel like that ...it has gotten to the point where I have been really stressed out. Not so much to the point where I don't care anymore, but to the point where I feel like I'm kind of neglecting them because I feel like I'm just going in, doing my assessment, doing the tasks I need to do, but not really getting time to actually sit down and talk to them to figure out how they're feeling."	<ul style="list-style-type: none"> Finding Balance between tasks of work, protecting self and emotionally connecting with patients. 	<ul style="list-style-type: none"> Balancing Process between self-protection and emotional connection.
After [<i>Sarah</i> (made up name)] passed away, I had a few weeks where I was <i>that</i> nurse—when you come to work, you have two choices. You can be yourself and make a connection and do your job how you are. But you have a choice to be [compassionate] or the choice to be like, "I just have certain tasks to do. It's such a busy day. Let me just do my tasks and get through it." I don't have to take that extra five minutes and make a connection at the beginning of the shift. After [<i>Sarah</i>], I was doing that. The day I found out about her it was so shocking for me that that day even, I think there was a change. I kind of just went in, dropped the pills, "here, can I get you anything? Okay, bye." That kind of in-and-out—I was guilty about it—but I definitely did that a few days in a row when I was just done with it and I didn't want to let myself go there."	<ul style="list-style-type: none"> Through traumatic loss of patients, professional finds the need to emotionally disconnect and becomes focused on tasks. Professional's perception and worldview change over time. 	<ul style="list-style-type: none"> The load and burden of caring for persons that are dying.
"I still feel like there are people that are stressed out and think that no one is going through what they're going through. I think people think it's just them going through this and hearing others	<ul style="list-style-type: none"> Professional feels isolated in their emotions and finds comfort in sharing and hearing colleague's stories 	<ul style="list-style-type: none"> Emotional isolation creates need for finding common ground Sharing stories with colleagues is helpful

<p>talk about it... ‘Yeah, I had that happen to me once. This is how I dealt with the situation.’ I feel like it does help, hearing others—people’s stories and even telling your story might help...”</p>	<ul style="list-style-type: none"> • Environment is stressful 	
<p>“Even as I am speaking now, it’s very disjointed and my emotions come in. But the writing was neat because we had a time limit and you had to make it concise. I think literally, nurses could probably speak for hours on this subject if we were together. But writing it makes you really reach down, pick a few key things, get them out and then you’re able to deal with those things as opposed to this overwhelming—right now even, there are so many things I could say that overwhelm me emotionally, but when you write, I think in a short time it’s the most effective way because when you have to read it you’re only dealing with those specific things in that one narrative.”</p>	<ul style="list-style-type: none"> • Writing gave clarity to expression of emotions • Professional practice is emotionally overwhelming and writing helps narrow the focus and multiple emotions 	<ul style="list-style-type: none"> • Narrative exchange is a safe space to share perspectives.
<p>“I didn’t realize how much I repressed, or held back what I was feeling. So you think of who I am as a person, and how I’ve always been considered super-sensitive. And when I started working here, everyone in my family was like, ‘How are you gonna handle this? How can you do this? Laura, of all people how are you gonna do this job?’ And then I’ve completely stopped—not stopped feeling—I feel and I care about people, but I don’t realize how it affects me. And that’s why with the narratives, it’s sort of—everything is blocked off, and I can’t even know where to begin writing. It’s because everything is so hidden. And it really gets me thinking, and it makes me realize how much of my feelings I’m not even understanding, as it relates to the job...once I start writing, then it brings up feelings...because then it makes me feel things that I didn’t address, that were hidden,</p>	<ul style="list-style-type: none"> • The narrative groups allow for introspection and the realization of how much emotion has been hidden. 	<ul style="list-style-type: none"> • Through the group narrative exchange the professional learns to care for self.

and now I feel them. And then I'm feeling like I've been hit by a bus."		
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Table 4.7: Conversion of Subthemes to Themes

Subthemes	Experiences of Working with Oncology Patients Themes	Narrative Oncology Themes
<ul style="list-style-type: none"> • Witness to suffering-optimism replaced by rigors of disease • Professional seeks distance from emotional suffering and the constant reminder of mortality • Perception of work changes over time 	<i>Emotional Distance and Self-Protection</i>	
<ul style="list-style-type: none"> • Balancing Process between self-protection and emotional connection. 	<i>Desire for Intimate Emotional Connections and Guilt</i>	
<ul style="list-style-type: none"> • The load and burden of caring for persons that are dying. 	<i>Burden and Privilege of Care</i>	
<ul style="list-style-type: none"> • Emotional feelings of isolation create a need for finding common ground with colleagues • Sharing stories with colleagues is helpful 		<i>Shared Perspectives and Bearing Witness within Narrative Exchange</i>
<ul style="list-style-type: none"> • Narrative exchange is a safe space to share perspectives 		<i>Comfort in Confidentiality and a Safe-Space within Narrative Exchange</i>
<ul style="list-style-type: none"> • Through the group narrative exchange the professional learns to care for self. 		<i>Group-Care becomes Self-Care</i>

Category 1—Patient Care:***Theme 1: The Balancing Process:
Emotional Proximity- Distance, Self-Protection and Closure***

All ten of the interviewees described a self-protective emotional distance that they created at one time or another in their practice with oncology patients. One seasoned

nurse, Sylvia Plath shared, “I guess a long time ago I found myself building a wall up that I don’t get emotionally attached to anyone...anyone in—as far as patients are concerned.” She went on to say, “I just don’t get—I don’t engage in personal information. So there is no exchange of that—as little as possible.” She admitted that she knew about patients but that she invested less of herself than she used to,

I don’t stop the patients from talking about their personal lives...as far as patient safety is concerned and their well being is concerned, I’m always gonna advocate for my patients. I don’t want anything to go wrong for them when they are leaving or—that they get the best care that they can while they are here. But I don’t form an emotional attachment. Sylvia Plath

Jane Austen,

We have primary nursing and from that experience I learned how it’s dangerous to get that close to a patient because you kind give a part of yourself...A week ago, I had another primary [patient]. I learned all about her...I knew I was feeling stressed was because since my first primary’s death, I didn’t sign up for another primary [patient]. I felt like I was becoming—not cold to it, but kind of protecting myself a little bit.

Gallows Humor

Jane Austen also discussed how she was surprised by the gallows humor of one of her colleagues, but over time understood this type of coping,

But I think the more seasoned nurses have a different way of handling it—I don’t know if it’s good or bad—but I do see not necessarily that they’re always more cold about it but they can take it in better stride...for example, one of the nurses—is so funny, but I remember at my six-month mark here and he was joking about a patient while giving report. He was like, “so-and-so, 80 years old getting chemo, “and then he made a snide comment, “oh he’s probably gonna die,” before we even started the chemo. He said things like that. At that point, I was like, “oh my God. Why would you even joke about that?” but now, having been here I totally see where he’s coming from.

Maya Angelou,

I think over time, I think it will affect your ability to do – because then it becomes – you have to cope with it somehow. So it's either you avoid the situation altogether, you avoid patients, you avoid families, you dread coming to work – all of those things that for sure don't lend to a healthy relationship with your patients.

Emily Dickinson,

Sometimes you joke or make light—not really make light, but accepting a reality—it's easier than always having that bright-eyed, cheery, hopeful aspect where you get shot down so many times.

These oncology professionals shared that sometimes they use dark humor to cope with the constant feeling of loss. Some try not to form attachments and create distance so that they do not have to feel the combined weight of this collective pain that surrounds their days. They find a way to cope in the midst of stress. This not only speaks to their depersonalization and emotional exhaustion, but it also speaks to their resiliency.

Exhaustion

Anne Frank,

I think I'm so tired and so exhausted and so overwhelmed that if I truly – I worry that if I truly sat down to talk or to think about it that I would just crack. And I wouldn't be able to come in the next day and do my job. I mean, I – I think you just get to a level when you keep shoving it in that you just keep – you've seen on traumatic experience after the other, one death after the other, one person suffering. We see the worst of the worst complications because we're in-patient.

An outpatient oncologist was just saying that – she actually said that to the house staff on rounds today. She said, "I wanna have a teaching moment. If you're interested in oncology, what you see on the floor is not really what oncology does. She said here is the sickest of the sick where everything went wrong."

And I was shocked. I was like, oh, my god. And it made me think. I was like, but this is – these nurses, we are in-patient nurses. We are here 24/7 year round. And she literally just said that we are seeing the worst of the worst. This is when therapy unfortunately doesn't work, where cancer is so advanced or it's not responding to treatment. So you're seeing the

worst of the worst of the worst of the worst all the time...and it's just—it's exhausting. And I think sometimes when I get to that point where I'm like, oh, I can't even think about this, I think it's because literally I know that I have to get up and be here at 7:00 a.m. the next morning. And if I really stop to think about it, I wouldn't be able to go on. I think I would just get so tired. And I think it's because I have no voice, per se, because I'm always like, okay, well, shove it down because here comes the next admission. Literally, somebody dies and you literally – from the admissions department, it's sick, but they're like – we'll get phone calls and they'll – admissions will literally be like, "You need to get that body to the morgue because we have another admission we need to put in there. And we'll be like, oh, my god, but this family needs time and the nurses need time...I mean, that's how bad it gets. So I think that's why we shove it in."

Anne's very honest discussion of her daily exhaustion and feelings of being overwhelmed convey the needs of the clinician and how they are not being attended to while at the same time recognizing the need to allow patients and their loved ones time to mourn. The vision of the need to fill the bed immediately after someone dies shows the lack of time that professionals have to digest the loss of their patients. There is no closure and there is no time and Anne imagines that if she had these luxuries that she feels she would "crack."

Need for Closure

Virginia Woolf spoke about how thoughts of patients will invade her thoughts randomly,

I thought a lot about a particular patient who's like 23, when I was at mass on Christmas Eve, and then that following Sunday, just thinking, I hope she didn't end up here. Because we do make a really strong effort to get everyone who can walk and talk and has a good reason to be at home – that's young, or doesn't have many more Christmases, or has kids – we make every effort to get them home. So I thought about her, not purposefully – she just sort of came into my head and stuck with me. And I just had hoped that she didn't end up back in, and that she felt well enough to enjoy Christmas, because I don't know that she'll have another one.

Virginia discussed that a colleague called her at home on Christmas Eve to tell her that her patient had died,

...I would have come back to work and said, ‘How’d that end?’ I know that I need that closure. I know that – that sort of thing where, “Once, at band camp,” – I need to know that story, not that she died on the 24th. That wouldn’t be enough for me. I’d be like, well, who was here? When did it happen? How did she change? I need to know those things.

The following narrative was written by a nurse who came to the group on her day off,

We practice primary nursing on our floor. The first patient I ever signed up for was [Patient’s Initials]—a 45-year-old female. Personally, I’m not particularly good with names—but, to give you a sense of how well I knew this patient, I can tell you I not only knew her, but her children’s names, her daughter’s boyfriend’s name, best friends’ names, her favorite color, what she thought of her husband, etc. etc. [Patient name] was being treated for ALL. She had not achieved remission and the last time I saw her—she was receiving MOAD chemo regimen. During our last encounter, she was not my assigned patient for the day. I found that I was avoiding going to visit her, because I knew I would cry in front of and with her. Her last bone marrow biopsy showed 70% blasts—this was her last ditch effort chemo—it had to work...or else. I finally made myself go to her that day—she was sleeping—just had IV benadryl. I gave her a hug, she smiled, I left. About a week later, I was working and overheard someone mentioning her name. I inquired about it and heard she passed away in the MICU. I was in disbelief. I could not conceive of what had happened.

Professionals like the nurse who shared this narrative often create physical distance between themselves and their patients. They admit that they do not visit with the patient if they are not actively caring for them, but as this narrative indicates their thoughts are still very connected to these patients. There seems to be a feeling of guilt in the lack of closure, the fact that there were no goodbyes, that one moment the person is alive and the next moment they are not.

***Theme 2: Stressors and Laborious Work:
Desire for Intimate Emotional Connections and Guilt***

Maya Angelou discussed how she has been altered by working in oncology,

at baseline, I am somebody who's very in touch with her feelings, who doesn't hide feeling, who can cry very easily. But all of that's not there anymore. I don't cry even with my [parent] being sick. It was a couple of tears. But I intentionally fought back and hid it, hid those feelings...even looking at poor [patient name] crying—it hurt me because I'm like, why didn't I feel any of that that he's feeling? Where is that? Where is that part of me? Where has it gone? And it's just—I know I just—it's sort of like you are numb. And I think it's just stress. And then you're numb to even being happy when you get home. It's like okay, we laugh, we joke, but am I feeling overall happy? It's like when you go home to deal with your family and you can't even hear them...I can't take in any more information...What's left? You go home. You don't wanna deal. People, don't talk about your problems to me. I can't hear it. I don't care...And I think to know that other people are feeling that way—because you feel like a pretty crappy [mother, sister, wife] because I don't wanna deal with that. So to know other people are going through it and that it's not unusual or abnormal—and it's sort of like that guilt of not—guilt also causes you to go into the—well me—to do-nothing mode because I'm feeling guilty. So instead of dealing with what I'm feeling guilty about I feel more guilty and depressed and you just sit some more.

Maya continued later,

I don't know exactly the turning point, but I think it was a year because I think I felt a lot more stressed about—but maybe it was getting used to the job...it's always been—the whole time I've been here it's been a countdown to three more months. Okay, I'll do it for six months. Okay, I'll do it for nine months. Okay, I'll do it for a year. I'll do it for a year and a half. It's always constantly counting down how much longer I can do it...My friends are here and the people I work with. I do like the patients—I do like what I do, so it's not that I hate it, but it just takes a lot out of you. So it's not like I hate the job, I like it, which is the weird thing, but you just feel so drained and it's just so tiring. And then you go in days and it's really rewarding and you're like, "Okay. Why do I want to leave?" And it's hard to understand and to explain it.

Organizational Stressors

Emily Dickinson,

I think this environment is cut throat. I think this environment is toxic, and this environment is exhausting. This environment – you can't even

eat lunch. You know what I mean? We have nurses that it's 2:00. They haven't even gone to the bathroom, not to be disgusting. But seriously, you can't eat lunch. When you are—we've promoted this culture where I think it's acceptable to do five things at once, meaning I might be in a room with sterile gloves on doing a sterile dressing change, and the secretary will be overhead paging me...and an administrator will be looking for me... "but I was in that room." It's just – it's constant. What's happening is if I'm the nurse caring for four patients and all four call bells are on, there's only one of me. There's four of them. So then, we push our stress to the nursing assistants and we say, "You guys split the floor. You have 16 patients. You have 16 patients." They can't possibly answer all those bells. They can't possibly. So then, what you see is tension arise between the RNs and the CNAs... So it's just – that's just one example to me of how we ask ridiculous things of our nurses. They cannot possibly be drawing up beds and doing math in their head at the same time that they're answering a phone or some thing, we want the nurses on rounds with the physicians. Well, there's six medical teams. They don't know when they're always rounding. How the heck are they supposed to be there? Plus, they're trying to hang meds or whatever. It's just – it's a crazy environment. It's crazy.

One of the physician narratives discussed subtle surprise that the usual nightly chaos of a nightfloat admissions and the fact that this one had gone smoothly,

This week one of our "nightfloat" patients was a gentleman with metastatic bladder cancer. He was not known to myself or my co-residents, but was coming in for fatigue and little known to him had a recent outpatient scan which was just read as progression of disease on treatment. I felt like this could be a recipe for disaster. Not knowing the patient since he was admitted overnight, not being the primary team, having this horrible information...in actuality it ended up being a good situation for everyone involved. The primary team was called immediately and agreed to come by and talk about the results/hospice. Us, as the covering team, spoke to him about the scans, as withholding information would have also felt wrong to me. The family was so appreciative to us as the covering team, the primary team and subsequently to nursing and hospice.

Anne Frank, a nurse discussed how the acuity of her patients causes her to have less time to spend "getting to know" her patients,

I think nurses do not care for one another...I don't think we even recognize it...I think we're so focused on the acuity...so I think people get

so caught up—a lot of stress comes from trying to clinically manage these patients, but then there's a tremendous frustration that comes behind it because...they delivered all the drugs, they gave all the drugs, they gave all the blood transfusions, but nowhere in there did they really get to actually sit with that patient and talk about, like what does the cancer mean to them? And how they are managing emotionally

Zora Neale Hurston says,

In the beginning I never used to feel like that ...it has gotten to the point where I have been really stressed out. Not so much to the point where I don't care anymore, but to the point where I feel like I'm kind of neglecting them because I feel like I'm just going in, doing my assessment, doing the tasks I need to do, but not really getting time to actually sit down and talk to them to figure out how they're feeling.

Virginia Woolf,

I can have a day off and someone can be on my mind intermittently through the whole day. And I think when that happens I'm probably not as productive as I should have been on my day off. But I could be off days – I was wondering that the other day, thinking about this research project, and is that why I can be off for three days and I've barely gotten two loads of wash done. And I think that that's just me, and procrastinating, and not being motivated at home. And I need to work through that... But I was looking at it like, is this really an effect of work? I don't know that answer. Maybe it is. I don't know. I don't feel like I'm thinking about work all day, but that doesn't necessarily mean that that wasn't the thing that sapped me of all motivation. Because I could come here and be moving all day long, and get hundreds of tasks done in 12 hours or eight hours. And somehow at home I can barely get the dishes done before the end of the day. So I don't know.

Zora Neale Hurston,

I feel like when [the patients] are emotional, you get maybe, five, ten minutes to spend with them but you still don't feel like that's enough so that kind of stresses you out also because in your mind you're thinking I have to get this, this and this done.

Themes One and Two overlap in their discussion of intense personal involvement with patients, insufficient preparation to meet emotional needs of patients, staffing, heavy workload, organizational stressors and caring for patients that are suffering. Each

professional interviewed described the need to detach emotionally at various times. One nurse even described the “danger” of becoming “close” to patients. The professionals described both the challenges and the need to both connect and detach thus maintaining a balance. Most interviewees reported that when they experienced a traumatic loss they would more often detach. Professionals felt that over time they were more in need of remaining distant and that if they did not care for themselves that they would “crack.” They spoke about the lack of time for emotional processing in their day. Some described, “dreading” coming to work in an environment that they found simultaneously toxic and rewarding and the need to have closure in these intimate relationships with patients and families.

Theme 3: Burden and Privilege of Care

Jane Austen shared both the privilege of caring for oncology patients and the load and burden of caring for this population,

You see [the patients] start from this cheery, bright-eyed, “we can beat this, I’m not gonna let this disease get me”—and it’s kind of like you as a nurse—a care provider—see yourself in them. We’re fighting like you are fighting cancer—together. Then you see a failure of the treatment and then you see it again and then you see it again. Then they come back and then there’s a transplant and then there’s all these complications and then you see their quality of life go down. Almost every time that person comes in it’s a huge drain on you because we’re human beings, too. When we go home it’s not like the kind of job where you can swipe out and leave it here. It kind of comes with you because it is such an emotional thing. You’re dealing with lives and hope and just wanting to live and beat it... I think the most exciting part for me was that I got to work on a cancer floor. That part of it’s really cool. I get to see people fighting for their lives everyday, which is really an amazing experience. But I think the stressful part...you don’t want to make a mistake...you want to make sure everyone’s safe. You’re really busy and you want to make sure you get to all the details, but I think another part—which is even more stressful—is the emotional aspect of taking care of these patients because when you go

home and have three days off—I think the actual stress of work in terms of medications and stuff can be left because you feel like you were able to rest and sleep—but I think the emotional part stays with you. For me, since I’ve only been working for a year and four months, I think it’s been cumulative. It feels like a load that you carry with you...It’s all these silly thoughts on a day coming home from work. Then, all of a sudden I took a step back and said, ‘God, it’s not fair to work in a job where I feel like if I don’t stay extra and visit someone they could die and I would have that regret.’ It was really a silly dramatic moment but it was true that she could’ve died.

There is a sense of pride and personal accomplishment in the war against cancer, but the description from Jane about watching patients’ hope diminish over time creates feelings of helplessness in the care provider. She sees herself in those she cares for and attempts to heal. The pressures the professional places on herself to be perfect and not make a mistake so that each patient served is given the optimum chance of survival combined with her realization of the futility of this work is emotionally exhausting. There is a constant tug of war going on in her thoughts—she’s angry that she feels like she has to stay longer at work and cannot just go home like other jobs, but in the same sentence states the reality that the patient could die and that she would have longstanding regret. Ayn Rand, a leader on one of the floors shared,

...I have hardly focused on just having a conversation with somebody, like on emotional – like the impact of this. You know what I mean? And as we see nurses start to leave and turnover and everything, it’s just sad that they’re burned out and I haven’t really done anything about it...I think a lot of nurses – a lot of nurses will say to me, a lot of staff nurses, particularly when they’re having a bad day, they’ll say, “I can’t – I’m gonna be a primary care nurse practitioner so I don’t have to deal with this anymore, and I can just work with healthier patients and treat people that have sinus infections and more primary care issues and not these issues.” And in particular, when they feel stressed out – particularly if they have a patient that’s dying and maybe they have another patient that gets kind of busy, we try so hard to even out the assignments. But you never know who’s gonna spike a fever or require blood transfusions or something. And those are the days when people will say the most that they don’t feel like they have the time even to do this job

because they don't have the time to sit with patients. And that's, I think, sometimes when you hear them say the most.

Emily Dickinson,

I was trying to talk to other friends on another floor—they're on a more trauma—like gunshot-type floor. Their experiences are different than ours because it's almost like our story is the story of fighting cancer. You see someone—you see completely different people—people with no support system, people of all ages, people with huge families and huge reasons to want to live.

Emily Bronte,

I feel [the work] is pretty satisfying. I mean like I said before there are some days where it's just like, 'man everybody's dying.' 'why do I do this?' It's just sometimes it seems like we are creating more medicines that don't necessarily cure cancer and maybe they just keep people alive longer and maybe they suffer more because they are living with cancer for longer, but I just really try to find something that I may think is really little for somebody could be extremely meaningful for them and just kind of keeping in mind. No matter whether it was giving someone a taxi voucher to get home cause they didn't have another ride home and they didn't have money to get home or something as big as having somebody cry and express their feelings. That knowledge that I am helping somebody in someway even if it's just a little piece...

Reality of Mortality

Maya Angelou,

...you give so much of yourself to your job and your patients, and it's because you know a lot of them are going to die, and you know. So then you have nothing left to give to yourself or your family or your friends or your – no social life. You become so into your job, and I think it's because of the patient population. It's not like you can say, 'Well, I'll deal with that tomorrow.' There's always this feeling like, 'Well, maybe they won't be here tomorrow. And this is their – this is important to them. And they may not be here for much longer.' So you have all of that you have to carry. So it's sort of – you push – what your own needs are go unmet. You'd really like to get home to your family, but you're like, 'Okay, I'll just have this last conversation with this person,' or 'I'll just see this last person,' or 'I'll make sure this is handled.' Or the nurses don't take lunch because they wanna make sure everything's okay with their patients. And it's sort of like this guilt, like, okay, I should be happy I'm healthy. I'm

alive. You give so much to the patients to try to make up for what they're going to be losing, and what they've lost.

Mary Shelley, a social worker, gives her opinion about the challenges nurses face in caring for their patients and the fact that each individual is faced with the reality of mortality on a daily basis,

It's a very different type of relationship that nurses have with their patients. So I think they get stressed about the amount of work they do, the acuity of the patients and to watch someone that you have a relationship with especially since we have repeat offenders to watch them get sick and die. Because eventually it's gonna happen to everybody you work with since death is inevitable for all of us.

Ayn Rand, describe the huge emotional burden and potential futility of treatment,

The emotional part of it gets to me all the time. It does. I mean, especially, like we're bringing in these patients for a high dose IL2 therapy. And these patients would have less than a year to live. We're hope – but this is only a 16 percent shot at a – at like maybe like five years, giving them five years...this has been a huge source of stress for me...we're increasing our acuity, we're delivering two pressers that we normally don't give... But then, one of [the nurses] just came to me the other day and said to me, '*We've only had – we're on our fourth patient.*' And she actually said this, and it hit me like a ton of bricks. She said, '*You know, the other three have all progressed and one of them has died.*' And she's like, '*And this therapy is so hard to run, like it's just so hard.*' And so it makes me think ... And here I am going gung ho...I'm realizing, oh, my god, she's absolutely right. The other three people died and we never really talked about it. We never really sat down and talked about how much training we've had to do for this protocol and how we're not even seeing – we don't even have this tangible evidence yet that we're seeing people survive...And I – and I think about that now. I was thinking about it all last night. I really was because I knew I had to get here really early this morning to be here for that next dose. But I thought about it, and it's funny because I ...that [patient], I've gotten to hang out in his room for sometimes 20 minutes at a time...he's telling me how, "I don't wanna die, and I'm so afraid. Do you think this is gonna work? Have you seen this work in patients?" And I'm sitting there, like, oh, my god. Like we have to be honest with him but I half wanna lie to him. But so yeah, that's hard because I'm getting attached to him and I really wanna see him come back, but I don't know that he will."

The following narrative excerpt reinforced the knowledge of one's mortality and both the burden and privilege of care,

I think it's hard when in the end, the effects of our chemo end up hurting the patient. He was so positive, so optimistic and I knew the first hour of my first shift caring for him that he'd be a patient that I'd never forget with a passion for the Phillies and college football, we immediately hit it off. I was his RN the day of his day 14 bone marrow biopsy and you could just see the hope in him and his wife. As days and weeks went by those results meant little. Persistently febrile, fungal pneumonia, we just couldn't win. Even days I was not caring for him, at least 5 minutes of my day included a quick chat with him and his wife—pitching debates, or a “it's fine, I'll get through it.” Ultimately, the time came that we couldn't handle his care here [on a regular medical oncology floor]. It felt like such a defeat. When I finally got the gut to see him in the MICU, he wasn't the man we all got to know and love anymore. Sitting in my car unable to stop crying. What's the point of working here? I just can't imagine how his family is dealing without such an amazing man until last week when he was in my dream—I'm still unsure where we were, but we were walking together. I kept saying, “No you're dead, how are you here? And all he could say is—“Sally (name changed), I'm fine, it's ok now. “ And all I can hope is his family knows too.

Themes One through Three dealt with the balancing process and emotional proximity and acuity, change in worldview and changed perceptions of the work with oncology patients. Category two consists of the interviewees impressions of narrative oncology, including process level content about the groups.

Category 2--Impressions of Narrative Groups:

These narrative sessions are so amazing because you hear from people who are doing the same thing you are doing and you see that you're all human, of course we would react like this. Jane Austen

Theme 4: Standing on Common Ground and Meaning Making: Shared Perspectives and Bearing Witness within Narrative Exchange

Emily Bronte,

I feel like it humanizes people and it's not just somebody in a white coat it's somebody who...has these fears about death and dying and I guess it's finding a common ground... There's some, at least for me, there's some feeling of, 'oh well they're going through it too,' at least a commonality. It's also a way of finding meaning because of what we do and hearing why other people do it despite the fact that you know, 'yeah this person will probably die of cancer whether it's now or 5 years or whenever.'

Zora Neale Hurston,

I think other people wanted to say probably what those others were thinking, but didn't, and yesterday proved you had one person that did something and another nurse was doing the same thing, but in their head they're thinking the same way. So you never know what another person's thinking until you hear.

Zora continues and addresses desire to have other disciplines, especially physicians present,

I think it is. I feel like they get to see our point of view, we get to see what they're thinking. We never know what others have or what they're thinking unless we see – we hear it from them. We don't know certain things unless they [share]...it gives me a little bit of comfort knowing that I'm not the only one going through that, or I'm not the only one that feels [that way]."

Mary Shelley,

I like hearing other people's stories like their stories – of the stories that we all know like how they're dealing with it. How do you deal with this kind of stressful job?

Anne Frank,

No, but like I – I don't know. I've been a nurse now for ten years, and I think it's amazing to me, but just now I'm starting – I think after these narratives have made me think about this, like how burnt out I actually am, to the point where, like for the past couple days I haven't gotten home until 8:30 at night. And for – this has been going on for – I've been doing this job for five years.

And just really kinda after the narratives have started, I've been realizing it's 8:30 at night and I haven't even eaten dinner. This isn't even a normal time to eat dinner. So just now, I'm starting to recognize this. So honestly, I don't really think I am taking care of myself at all, quite frankly. I think I think about it all the time...

Jane Austen,

Sometimes if you're by yourself you have to lock it away somewhere. But in these sessions, you can be weak and be vulnerable and let everything out. It's almost a huge catharsis...you still have that with you but you feel like other people are going through it too, so it's okay, and it's something to be expected. Everyone says when you're a new nurse you should expect to feel it but it's different when you hear them share their stories.

Ayn Rand shared a profound statement about how the narrative exchanges got her thinking about this work. Her statement includes ideas that are relevant to, themes one through four,

it's so funny because somebody actually asked me today, 'Well, what is oncology nursing?' And it cracked me up because after doing these narratives...I was like here we go...If you would have asked me what oncology nursing was so many years ago, I would have said it was—I would have come back with something very clinical. It's chemotherapy, supported bone marrow transplant. Now, I say it is a willingness to be present in tragedy...Well, I've been thinking about it, but I think it evolved more with the narratives...I was really thinking...what we really do—it's so funny because—since I've been doing more of these narratives, it makes me think that despite all the clinical stuff—that's all great and everything. But sometimes I think what these patients need the most is just somebody to be there, be present with them, just sit there with them. An in their uncertainty, in their anxiety...That's what I think I arrived at that because the more I think about the trauma that I think I've been through with this profession, I'm like well, what was it that I've been doing? Well, I've been witnessing tragedy...and I've been willing to come back to it. I think we're all willing to come back to it because I think we care. Because we wanna be compassionate people. We wanna care about people. We wanna help them...Even when there is no cure, we wanna be there, know at least that we can be there. If I can't—can't fix it, but I can there. I can acknowledge what happened to you...but yeah, it's painful"

Eulogizing

Much of the sharing in the narrative sessions was about patients and their families. The following narrative shows the complex relationships that exist with patients on an oncology floor, but ultimately honors the individual's suffering,

He was 40ish, he had a long history of physical disability, he was maybe a chronic liar, he definitely told big stories. Suffice to say he'd been through it before his diagnosis of leukemia, but last night he died. This morning and part of the afternoon was marked by staff story telling "oh he lied all the time," "when you turned him he farted on purpose," despite being paralyzed from the chest—down he had this control Amazing!! (Do you know that corpses can also do this?) So anyway you get it. Just all these stories about how difficult and challenging he was but not much about what he'd been through or any attempt to see how it might be to be in his shoes/wheelchair. Let me tell you he suffered. He had bad disease and never stood a chance. Whatever the other stuff he was young. His mother lost numerous children before him to accidents, disease and cancer. She didn't need to lose a physically crippled son to cancer at age 40ish. Thank you for listening about him.

This narrative was a tribute to a patient, but also described feelings of conflict about concern for the end of the patient's suffering,

I am writing about my experience working on a very poignant case. I first met this patient a year ago when she was first diagnosed with acute lymphocytic leukemia. She was 36-years old and also 21 weeks pregnant at the time of diagnosis. She had to terminate the pregnancy at that time with minimal family support. The patient was a single mother to a 3-year-old girl. I got to know this patient very well, as she was initially admitted for a month and she had several other admissions for more chemo for a period of several months. This patient received a BMT in February and since she was discharged from HUP in March, she suffered several complications, forcing her to be hospitalized multiple times, with several admissions being very lengthy. She has not been home since May, going between HUP and a nursing facility. The patient is now in the MICU on a ventilator, dialysis and several pressers. Her heart is so weak and she will most likely die very soon, despite the fact that she remains a full code, per her family's request. I've seen her in the MICU. Her body looks like it is rotting. After all the suffering that this woman has endured, I just want for her suffering to end.

This social worker's story continued the next month,

The last time I wrote for the narrative oncology group, I described my experiences working with one of my transplant patients. She was a 37-year-old woman with a three-year-old daughter who was diagnosed with acute leukemia in October 2008. The patient was also 21-weeks pregnant at the time. Between the time of her diagnosis and this fall (over the course of a year), this patient has spent much of that time [in the hospital]

with various medical complications. In early October, the patient went to the MICU and she spent about a month and a half in the unit on incubated mechanical respirator and pressers with multi-organ failure. Her family chose throughout the ordeal to continue aggressive measures to keep the patient alive. However, she died this past weekend after almost two hours of on-and-off coding [procedure when a patient needs to be revived or is pulseless, in cardiac arrest or not breathing]. I was at home on Monday night and I started sobbing in my bathroom, finally allowing myself to grieve the death of this woman who has impacted me both professionally and personally in a profound manner. Professionally, she was the first patient I worked with since time of diagnosis, saw through transplant and then watched slowly die. Personally, my mother had breast cancer when I was six she fought to live in order to raise me. I saw that love, devotion and fierce loyalty in this patient as well. Everything she did was for her daughter.

The theme of feeling that benefit was gained for the professional social worker, nurse, chaplain, physician, and so forth was shared in both the written data collected in the post-session evaluation (n=50) and in the in-depth interviews (n=10). It was probably the strongest theme to emerge and was consistently shared by every interviewee on every evaluation. The first open question posed (#5; Appendix H4), *Which elements of today's experience, if any were especially effective*, was answered by each professional that filled out the evaluation and every answer included some version of this theme.

The strength of the theme and the comfort reported from hearing other's stories seemed to be rooted in the reported emotional isolation felt by many of the oncology professionals.

I still feel like there are people that are stressed out and think that no one is going through what they're going through. I think people think it's just them going through this and hearing others talk about it... 'Yeah, I had that happen to me once. This is how I dealt with the situation.' I feel like it does help, hearing others—people's stories and even telling your story might help..." inpatient oncology nurse

Sylvia Plath attended one of the narrative groups, admitted that she might attend future sessions, but was unsure whether or not it would be helpful for her. She did however, feel that despite her reservations that the groups were of benefit to her colleagues and wanted to see them continue.

Well, it's their feelings about whatever their situation is at that time...I mean, maybe not for me but other people because a lot of people found—they were talking about it, and they found that to be very useful...I see how they can find it useful because that's just the type of person that they are—they need that. They need that connection. I, myself? I don't think so—only because I'm not a talker about those types of things. I don't have a lot of insights...people are talking about feelings regarding other—their patients—situations with their patients—family situations with their patients, and how it's affecting them; and how it's stressing them out; and how they feel about it. So, yeah, it's productive for people.

Anne Frank, a nurse enjoyed hearing from other professional disciplines, “I enjoy hearing what others have to say and I like that it's not just the nurse's perspectives.”

Anne elaborated on sharing in the narrative oncology group,

But the nice thing about it is that people will start telling their stories and you learn so much from one another. You'll be like, oh, my god, look how that affected this person or I had something similar or wow, I knew that patient. Or you can relate to it so much where – because it's such pure emotion. It's just so good to know. It makes you think, wow – I think sometimes in nursing, we're just taught – we're constantly taught, well, you have to adapt. You have to constantly deal with – because you never know what's gonna happen. Somebody's stable one minute. They're bleeding out the next minute. And so, it's just kinda like you have to be able to flip gears and move from emergency nursing to palliative care nursing or whatever. So we don't take time, I think, sometimes. This is nice because you don't – you get to hear people's raw emotion. And you realize, wow, that person's been thinking about this, too, or whatever. So I like it because everybody gets to – different – all different themes emerge. You walk away from that meeting hearing so many different people's viewpoints.”

Jane Austen discussed how writing and sharing helped her to see that she was not alone in her struggle and that her fellow professionals had similar relationships with patients,

“The narratives that we go to made me realize that we all kind of have that patient that really hits home and we all carry these similar stories.”

Emily Bronte,

I think its useful for myself because it makes me sit down and do something you know to process it written and it really is interesting hearing other people’s perspectives and experiences and finding similarities and being able to say wow that person feels that way too they look like they are always so capable and so strong and that was just a front or that was just or I don’t know maybe I don’t sometimes look as frazzled as I sometimes feel or you know its just kind of interesting to hear what people are feeling and experiencing when you kind of have your own impressions of how you think this person never does anything wrong and they are feeling insecure about this

Emily Bronte went onto discuss her sharing,

...I think it probably had more of an impact to have people hear it because it’s kind of like somebody’s witnessing what I have experienced... it was easier for me to read what I had written as opposed to if I just had to speak I don’t think I would have volunteered necessarily just to speak and so it was nice to be able to write it out and read it from the writing.

Virginia Woolf shared what initially drew her to participate in the narrative oncology groups,

That whole story, that – “Once, at band camp,” – there’s this whole back story. I once had this woman who was just a really difficult wife, and she questioned everything you did, she wanted to write it down. She’d be like, ‘Now, what time is it that you’re doing these vital signs?’ And you’d say, ‘2:30,’ and she’d look at the clock and be like, ‘2:32. Okay,’ and write that down. And when he was getting ready to go home the next day, I said – we got into a conversation about his other hospital stays. And she said, ‘Well, we were in the semi-private, and the other patient coded.’ She saw it coming. She couldn’t get anyone to do anything. Then the wife got there, she went to the lounge with the wife, and ended up seeing this patient code. Then another patient became very unstable who she could clearly see something was going wrong, and no one was listening, which was her perception. And I just – one of the things I said to her was, ‘You don’t wear this sign that goes, there’s this whole back story. It’s why I’m this anxious.’ And nobody knows that when they meet you. And I don’t know how you convey that to them.” But it’s that whole – all that story that brings them to this point today.

***Theme 5: Lack of Voice and Emotional Isolation:
Comfort in Confidentiality and a Safe-Space within Narrative Exchange***

Zora Neale Hurston, stated, “I feel like it’s a way for others to get things out that maybe they aren’t able to say or because we know that’s not really gonna leave the group.” Zora also shared that she felt soothed to be able to talk to others and there is no judgment by others,

I think for me, it releases some of my stress level that I have. I feel like it calms me down a little bit just to be able to sit for an hour and talk. I know that nobody’s gonna judge me for what I say or how I felt at that moment. Nobody’s like, “Oh my God. I can’t believe she thought like that.

Emily Bronte, a social worker, described the need for a safe space to discuss issues related to one’s job,

I think it’s really good and I have been just surprised at how open people are and I mean we know each other and especially kind of among the floor divisions and you don’t really know some people and for not really knowing people, people are open and honest and I think they are a really good tool for people to be able to talk about these important issues you know because some people can’t really go home and talk to their partner or spouse about what’s happening because they don’t necessarily get what’s happening in a way that people that work in the same atmosphere get it...I feel like it’s a safe space.

Theme 6: Group-Care becomes Self-Care within Narrative Exchange

Maya Angelou, a nurse in a discharge planning role admitted that she, a normally sensitive person, found that she had shut her emotions off so effectively that when she sat down to write about an issue in the narrative session that she had difficulty,

I didn’t realize how much I repressed, or held back what I was feeling. So you think of who I am as a person, and how I’ve always been considered super-sensitive. And when I started working here, everyone in my family was like, ‘How are you gonna handle this? How can you do this? Maya, of all people how are you gonna do this job?’ And then I’ve completely

stopped—not stopped feeling—I feel and I care about people, but I don’t realize how it affects me. And that’s why with the narratives, it’s sort of—everything is blocked off, and I can’t even know where to begin writing. It’s because everything is so hidden. And it really gets me thinking, and it makes me realize how much of my feelings I’m not even understanding, as it relates to the job...once I start writing, then it brings up feelings...because then it makes me feel things that I didn’t address, that were hidden, and now I feel them. And then I’m feeling like I’ve been hit by a bus.

Maya used some vivid language to talk about her emotions once she began to unlock them. She shared that she valued the sessions because she realized that she needed to process all of her emotions.

And I guess if I did it all the time I wouldn’t be such a—like you’ve been vomiting, and it’s just all of this stuff that comes up that you held down and packed in...and maybe if I just addressed it all along, if I dealt with it, then it wouldn’t be so like this projectile thing coming up...I guess it’s just your place in that interaction how you fit in with what you’ve seen and what you’ve witnessed. You witness so many things that are so heartbreaking. And to be a witness to that, and how that feels and what that means—so it’s sort of digesting that...So I think initially, for an individual, [the narrative groups] would have to be more frequent, until you sort of get to some type of normalcy with your feelings, because it’s a lot to come up in one session once a month. And I think if I were to do it more frequently then things could be addressed, and it would sort of get through the patchy spot.

Mary Shelley, a social worker, shared,

I really like that the nurses and doctors are coming...it’s nice to see people that don’t think about the psychosocial piece...getting excited about it and wanting to participate...I enjoy doing it and got something out of it...it was exciting for me as a professional.

Emily Bronte knew that the upcoming narrative session would be a place where she could discuss her emotions about the death of her patient,

I remember I was like oh this patient just died and narrative oncology is next week that’ll be an outlet or one way to express and to process what I just experienced...I did more as it went along not in the first session we

did do I think that I necessarily had that in mind but I kind of started to think of it as a way to use it to process it.

Emily Dickinson, participated in three of the four narrative sessions,

I remember after two of the sessions especially after writing it and then sharing it—it felt just good to have it out and it was a way of processing it where if I hadn't necessarily processed it would kind of just be festering inside of me.

Virginia Woolf,

I really like it. I like to hear what other people say. I like to just be there to practice being a good listener and not top their story. And I hope that I'm successful at that, because it's important that this not be a competition of – well I had this patient, or that same patient I had this relationship with them. And I like to give a voice to the patients' story, and to tell what they've struggled through. And it's somewhere to vent a little bit about my peers when they're acting 12. And it's a safe place to do that. I feel safe to say that there. And it might be a way to convey that to some other 12-year-old in the room. That probably sounds disparaging, but I'm 44, and I work with people half my age, and they're sometimes about themselves. And they're not always focused on what they need to be. And I'm not by any means perfect. I goofed off a little bit today because I had a lighter assignment, and then paid for it later when I had to really buckle down. And I know that eight-hour days are tough to get through, so I shouldn't have even done that. It should've been a cake day. But it's a safe place for me to express that frustration and not have any backlash, especially when it's on a different floor and there's maybe no one from my floor there, so there's no repercussion. I already feel a little bit isolated from my peers. Having been in the manager role and then being twice their age, it feels uncomfortable sometimes in my role in my unit. But when I come to this there's a better span of ages. My experience is valued. And the people in the room are there because they care about patients and want to share a story.

Virginia talks about how she would like the narrative oncology groups to continue,

I would miss them. I'm glad that on the days that I work that we have them and I can get there. It's an outlet for me. I have others, in terms of peers and friends, who will let me tell the story of a patient without being like, oh that's – even if it's a family member – that's too sad, or gory...all day. I have a family member that knows I wanna tell her the whole story, and gets me. But I would miss it, because it's a good outlet for me, and I like the creative part of it. I like the writing of it. And I always come away from that feeling like I've unburdened something, or celebrated some

patient who's been really courageous, or a family member who's been so selfless.

Mary Shelley spoke about one of the nurses she works with on her floor,

I know the nurses that have been there have liked it and wanted to go back. One of my nurses in particular, she's actually very quiet and I'm surprised spoke at all was actually really excited about it because she really enjoyed doing it. She felt like she got a lot out of it. She wanted to be able to go again.

Process Level Analysis
Writing gives Structure

Mary Shelley,

It's really hard to talk on your own to have it be very thoughtful versus off the cuff. It gives you a little more structure to your thoughtfulness.

Ayn Rand stated,

Even as I am speaking now, it's very disjointed and my emotions come in. But the writing was neat because we had a time limit and you had to make it concise. I think literally, nurses could probably speak for hours on this subject if we were together. But writing it makes you really reach down, pick a few key things, get them out and then you're able to deal with those things as opposed to this overwhelming—right now even, there are so many things I could say that overwhelm me emotionally, but when you write, I think in a short time it's the most effective way because when you have to read it you're only dealing with those specific things in that one narrative.

Emily Bronte,

I feel like the writing is good because it gives 10- 15 minutes to just internally figure out what you want to say and how you want to say it and then you just write and then you just read what you say whereas if you don't have a narrative and people just have to come and talk I feel like that's harder to get people to open up... I feel like maybe it's almost easier to write something and read it out loud than it is to just say it out loud and it gives people. I feel like it would be more useful to keep the narrative then if you just had people getting together over lunch and sharing cause I think it gives you a way to organize your thoughts and people may be more willing to read if they have had time to write something down and then read it.

Anne Frank,

I love the writing piece. I really do because I'll be honest with you. On the very few occasions where I think – in my career as a staff nurse over the ten years that I've been nursing, I can think of just a handful – like if I exclude your narratives, I can think of maybe just a couple in-services or debriefings that I've been to where the chaplain will come and talk to the nurses or whatever. And what happens with those meetings is sometimes they get off course. Or sometimes you wind up only talking about one particular patient that really, maybe not everybody took care of. And so, the nice thing about the narrative to me is that things – the fact that you don't necessarily know what's gonna come up, like we have an idea – like you tell us write about something that was really difficult or something – I think you can write more positively, too.

Maya Angelou,

...it's not as cathartic as writing it down, and seeing it. It's just different. Because I talk about it and I sort of – especially when I get home, everything becomes a joke, and you laugh it off, and that's like a defense, just joking and talking about these horrible things and trying to make light of it so you can cope. But when you write it sort of brings up the real feelings.

Ayn Rand,

And what was so interesting with the narrative group, for me, was for me to be able to sit down and write about my own – the things that have gone on here, and it's amazing. When – to be honest with you, when you started telling me about it, I was like, well, I'm gonna have trouble writing stuff down. When I got in there, I couldn't get the pen in my hand fast enough to start writing this stuff down, to be like, oh, my god, all this happened and all this happened and whatever. But what was so amazing to me about the narrative, is that what got me a lot, too, was the – the stress and the emotion of the other nurses and hearing them talk about so many stories and just realizing – especially some of the newer nurses. And again, with these newer nurses, the focus always seems to be on trying to help them with their skills, that again, sometimes I forget, oh, my god, that person just died. You know what I mean? Did anybody go and really debrief them formally, like sit them down and talk to them?

... But we don't necessarily sit them down and be like, 'Hey, that patient that you cared for the past two months died. How are you doing?' But that – that broke my heart. That got me. I was like, oh, my god, look at – look at how they're suffering. And we haven't really done a whole lot for them. It just – it just made me think, yeah, they need a lot of support clinically, but they need so much support from an emotional perspective, too, that we just have ignored.

Facilitator

Mary Shelley,

So I think it's interesting to have an outsider because he's a person who's not connected ... I'm pretty impressed with that. And at first I thought it was kinda funny how he takes notes and goes back to his notes, but there are just times that he really wants to be able to go deeper into what people are saying and trying to get people to be engaged or to engage people that don't usually speak up or would be happy just quietly sitting there but without putting anyone on the spot or really making people feel uncomfortable which can happen when you're dealing with that stuff.

Participation

Mary Shelley:

I think it's the same reason why they don't come to any other... touchie feelie groups that we offer because they don't have time, it's not important to them, their higher ups, their attendings don't think anything of it so they don't say "Hey you should go do this." I think more would, especially ones that you have relationships would be interested in it. I just don't think they have a lot of time especially ones that aren't interested in oncology. They just kind of do this rotation, just the bare minimum and just get out without killing anybody and not take advantage of the other pieces to take here.

Interviewer:

And you think if they had more time like if the ones that at least were going into oncology that they may come?

Mary Shelley:

Yeah, I think so. Yeah, especially if you personally have relationships with these doctors and be like, "You're coming." And I think once they came they would enjoy it and wanna go. Plus, at also – just the attending level too; get the attendings there.

Emily Bronte,

It just sounded interesting because you know we're driven by the medical model ... there really isn't a place that we can talk about our emotions and feelings about working with people who cope with death and dying as regularly as we do. So I was like wow you know this is happening it sounds interesting and the free food was nice too.

Ayn Rand,

And a lot of people get to participate versus if you just do it as, okay, we're gonna sit down and talk about Mr. Jones today. I don't think you hit nearly the amount of issues that you do with the narrative. So I love the narrative. I think it's fabulous.

Anne Frank,

I love it. I love it because we're all kind of one – it's nice to be one oncology program, but it's so nice to walk in the room and you have the nurse practitioner there or there's a physician there, to hear different perspectives. And then, you've got a nurse from [the three inpatient oncology floors] and there was one patient that we discussed that hit all of our floors that's been a patient here for like two years or so. And so, some of the same struggles that we had, they had. And it was – and it was also interesting to hear the nurses' points of view, from we took care of that patient a lot when he first got diagnosed. Rhoads 7 had this particular patient a lot when he was dying. And so, it was so interesting to hear the comments from the nurses, like at the different stages in the layers of grief and frustration. And it's just so neat to hear what they were frustrated about or what upset them the most at different phases in somebody's treatment course because it's different.

Emily Dickinson,

Yes. I wish [the narrative oncology groups were] more frequent and on a like on a timed schedule and everything. And I really do. And I also wish that we had more support from administration to – for instance, send us a staff for all seasons nurse that we could almost get the nurses in there so they're not interrupted. You know what I mean? Because it's just – it's just hard, unfortunately, sometimes in the middle of the day to cover assignments and things like that. I wish I had more time to cover. I wish I had more time to be there.

I think it would be awesome to offer nurses on their day off. I think a lot of them would come because I think – again, I think they're starving for this attention. They have a lot of stories to tell that they wanna tell and they need a forum to do it in. And that is such a great safe forum to do it in. It just is. So I would love to see it continue.

I'd love to see it with the physicians because I sense sometimes a lot of tension between the physicians and the nurses. And I think what happens particularly with the experienced nurses is they get furious with these newer doctors and they're like, "I've been doing this for ten years. What the hell do you know?" You're gonna write me orders?

And then – but the physicians, I think, need a lot of guidance from the nurses. But they don't need that attitude. They need teaching. They need help. I think if they had better relationships with the nurses, they might be more upfront about that. You know what I mean? I mean, there's attitude issues on their part, too. It's not just us. But I'd love to see some more – I think it would foster team collaboration. I'd love to see us work more as a team. I'd love for the physicians to get there.

But these residents and interns are so stressed out, I've seen them go down to tears in the middle of their day. And I get it. I mean, I understand. They're getting five million phone calls. They can't even process. They can't even think. They can't complete one order before the next phone call is ringing, "I need you. Come down here. See this patient. Do this. Reorder this," whatever. They're exhausted.

Not Therapy but Supportive

Mary Shelley, discusses how she would invite someone to the group who states that they do not desire "group therapy" or "talking about feelings,"

I would acknowledge that it's difficult to talk about feelings especially with coworkers. But I would say it's not so much therapy as it is support because in my head the therapy is much more ongoing, you're delving into past issues versus this is more of a supportive approach. And yes, it can be scary. You can just say as little or as much and just try it a while and see what you think.

Addressing Criticism

Interviewer:

There has been criticism of the narrative group approach and they say, 'well, you have this group in the middle of the day and you go in there, you churn up all of these emotions, then you send the people back out to the units. How would you respond to that?

Anne Frank:

You know what? I gotta be honest with you. I could see how you'd be thinking that it would be concerning. But I still think it's a great thing to do because even though you do churn up a lot of emotion, better you churn up that emotion than you burn – I think people burn out when they don't have any voice.

And so, at least if you go – I've walked away from the narrative having two different emotions. I've walked away from one feeling very sad and just kinda really thinking about it, but I was still able to do my job. And

quite frankly, as painful as that was to hear some of the stories, it felt good to have a voice. It felt good to hear other people discuss the problems that they were having. And I did think about it a little bit when I got home, but in a sense, I think when you – you almost get to do a little bit more healing.

Zora Neale Hurston,

I think [not writing] might actually work, too. I feel like that ten minutes—I won't even say we waste, I just feel like it could have been ten minutes we could have heard two other stories about—we could have gotten around to everyone. Sometimes people are not writers, and sometimes just telling their story is good...[when came to one session late] I didn't even know the question. But I'm a write—I like to write. So and then writing kind of helps me remember, but I feel like when I write more I express more of how I feel, but that's just me. I feel like some people aren't the same way."

In this section, the interviewee discusses her impressions of Schwartz rounds at the study hospital, compared to narrative oncology. She concludes that much of the helpfulness of narrative oncology was in its specificity to her practice.

Emily Bronte,

I don't know if it really changed I guess just personally sharing and that some of my colleagues knew a little bit more about me than before but it didn't make me uncomfortable sharing...it was intense hearing about other people's experiences and even if I didn't know them or I'd never heard anything they'd said before it was very impacting...[regarding Schwartz rounds] well I think they are related and then they aren't related its just a narrower and more specific topic whereas with narrative oncology you are specifically talking about oncology patients...

[narrative oncology] I think it's related I think there are probably some people who are going to get burned out no matter what but I feel like for me it could be something that I use and hopefully reduce stress so that I am not as fatigued and it's a way to cope and it's a way to process experiences and emotions and hopefully it, I think it lowers stress...It's one piece in a number of things you have to do to take care of yourself to keep yourself from getting stressed or burned out or decrease it or to keep it as low as you can...

Interviewer:

Did you feel pressured to attend narrative oncology because it was my project?

Emily Bronte:

No no it's interesting to me because it's my field too and I didn't feel any pressure from you I felt if I really wanted to I could say no and you would be ok but it's something that I am interested in and is applicable to what I do...It just sounded interesting because you know we're driven by the medical model where we work and there really isn't a place we can talk about our emotions and feelings about working with people who cope with death and dying as regularly as we do. So I was like wow you know this is happening it sounds interesting and the free food was nice too."

Interviewer:

Do you think that if a person was really uncomfortable that they would be forced to share?

Emily Bronte:

No, I don't. I think [the facilitator] would be able to sense you know you can call on somebody I think he would sense it and not push...and he's a great facilitator too...

Emily answered the question posed by the researcher about whether or not she felt pressured to participate and she stated that she felt that she could decline if she did not desire to attend. She also shared that she thought narrative oncology helped reduce her stress, but admitted that there should be additional outlets for oncology professionals. She discussed that Schwartz rounds at the study hospital are not always focused on oncology and that she appreciated the specificity of narrative oncology. She described one motivator to attend the narrative oncology sessions was that it was a change from the medical model and that it seemed like a place to talk about the challenging issues she faces on working with patients who are terminally ill.

Process level analysis from Interviews

Interviewees answered specific questions about group logistics; a.) how they felt facilitator performed, b.) opinion on need for food and type of food served, and c.) suggestions for improving the group. Themes and/or discussion that emerged for these logistical narrative group issues overwhelmingly recognized that the facilitator was an integral part of the experience and that he was incredibly effective in eliciting discussion and extracting narrative sharing from group members. Participants also stated that they liked his overall demeanor and the tone of the group. Participants agreed that food was an asset and in most cases a must-have.

I think [the narrative exchange] would still be as helpful but I don't know if the incentive would be there. I know as shallow as it sounds you come to this for free lunch. It might get somebody in the door and they might say this is kind of cool maybe I will come to another free lunch...I think it's nice to have hot warm food and then you write and share something...I think it's a comfort. Emily Bronte

Several interviewees stated that they thought some people would come even without food, but that food served to pull in participants that may not have otherwise attended. These persons went on to state that they felt that even if a participant was drawn to the group for food that they would find some benefit in the exchange of narratives and the subsequent discussion.

Suggestions for improving the group were often left blank or had comments such as "like it," and "nothing." When a more specific comment was shared the topic included two ideas, "would love to have another hour" or "less leaving and coming back in." The first recommendation came from numerous persons who felt that they needed more time to write or preferred to have additional time to process each of the narratives. The latter comment was mentioned as several participants would often be paged and leave to return

the call. The first session in particular seemed to have more of the “coming and going” than others.

Chapter V

Summary and Discussion

...[narrative sessions] would have to be more frequent, because it takes so much out of you to bring up so much stuff...until you sort of get to some type of normalcy with your feelings, because it's a lot to come up in one session once a month. And I think if I were to do it more frequently then things could be addressed, and it would sort of get me through the patchy spot. —Zora Neale Hurston, *Oncology Nurse*

Summary

The data in this study tells its own story of the daily rigors of its protagonists. The participants in this study gave us a glimpse into their professional reality reiterating the literature that job stress, compassion fatigue, secondary traumatic stress and burnout exist as a result of their work with cancer patients in an inpatient hospital setting. The story includes the vivid descriptions from participants about their need for an outlet such as narrative oncology to share perspectives with other colleagues. This story is only the beginning and there are many other chapters to be written about how to assist oncology healthcare providers in alleviation of job stress, prevention of burnout and compassion fatigue and to increase their job satisfaction and compassion satisfaction.

Allegra, Hall and Yothers (2003) found that the rate of burnout in oncology physicians exceeded 60%. Their survey, although primarily with physicians, seems indicative of the whole oncology community. According to their study the top three signs of burnout were frustration (78%), emotional exhaustion (69%) and lack of satisfaction with their work (50%). According to the literature, burnout and other components of job stress may often go unrecognized or ignored (Chamberlain, 1999; Cordes & Dougherty, 1993; Felton, 1998; Figley, 1995; Maslach, 1976; Maslach, Schaufeli, & Leiter, 2001; Penson et al., 2000; Radey & Figley, 2007; Rohan, 2009) and when this occurs, the literature while offering some solutions has not studied the potential interventions as

much as the phenomenon themselves. Also, if interventions exist they may be poorly attended due to many of the same issues that were present in this study, lack of time, lack of buy-in from leadership and decreased interest of institutions to begin to change the overall mindset—that investment in healthcare professionals is an investment in patient care.

This research narrative about oncology health care providers confirms through mixed methods that these 40 participants (n=50-10 repeat participants) experience job stress, compassion fatigue, emotional exhaustion, depersonalization, and burnout in addition to having moments of job satisfaction and personal accomplishment. For example, from the pretest of NS1 to the post test of NS4 burnout decreased from 26.9 to 21.0 ($p<.05$), compassion fatigue went from 19.9 to 12.1 ($p<.05$), emotional exhaustion went from 35.4 to 21.6 ($p=.001$) while overall perceived job satisfaction increased at NS4 (3.7) NS1pre (2.9) ($p<.05$). Additionally, the data including the interviews provided detailed insight into the impressions of ten of these professionals about narrative oncology.

Pretest and posttest data from NS1 showed no statistically significant increases in compassion satisfaction, and decreases in compassion fatigue/STS, depersonalization, job stress, overall perceived job stress. Furthermore the data also show statistically significant decreases in burnout and emotional exhaustion. All scores went in the desired direction with the exception of three out of ten measures; personal accomplishment, job satisfaction and overall perceived job satisfaction, which decreased. NS2 showed no statistically significant scores although six out of the ten concepts went in the desired direction, namely burnout, compassion fatigue/STS, personal accomplishment,

compassion, job stress, and overall perceived job stress, whereas emotional exhaustion, depersonalization and job satisfaction both total and overall perceived. NS3 also showed no statistically significant changes in scores although seven out of the ten concepts moved in the correct direction; increase in compassion satisfaction, decreases in burnout, compassion fatigue/STS, emotional exhaustion, depersonalization, job stress and overall perceived job stress went in the desired direction whereas personal accomplishment, job satisfaction and overall perceived job satisfaction decreased. Narrative Session Four (NS4) showed all concepts went in the desired direction with the exception of personal accomplishment, which stayed the same. Additionally, compassion fatigue/STS showed a statistically significant decrease.

Despite the overall lack of statistically significant changes in each individual month (e.g., NS1pre to NS1post, NS2 pre to NS2 post), there were numerous and notable changes from month one to month four (NS1pre to NS4 post) and although all were not statistically significant, all of the ten concepts went in the desired direction. The significant changes occurred in, burnout, compassion fatigue/STS, emotional exhaustion, and depersonalization.

After four months of narrative sessions oncology professionals reported significantly less burnout, compassion fatigue, emotional exhaustion, depersonalization (when variances were assumed to be equal) and job stress . Participants reported a significant increase in both measures of job satisfaction; the overall perceived job satisfaction of professions and job satisfaction when variances were not assumed to be equal. Increased feelings of compassion satisfaction and personal accomplishment were reported from month one to month four, but the changes were not statistically significant.

The findings suggest that although there were limited statistically significant changes from month to month (pretest to posttest), the changes from month one to month four may indicate that the narrative oncology groups raised awareness and that they opened discussion on each of the units. It is likely that discussions about the narrative oncology meeting and content spilled over to the units throughout the month and the impact is not only from the monthly meetings but also of in-between interactions.

According to post-session evaluations for each month, the results showed that the overwhelming majority of participants agreed that 1.) the narrative exchanges contributed to their well-being and resiliency 2.) helped eased their minds and 3.) allowed them to feel better equipped to...where some participants “filled in the blank” statement (Appendix H4, question 1-3). Additionally, the researcher’s notes reveal that as the fourth month approached many individuals would approach this researcher and give verbal feedback. Individuals reported and the *talk* or *buzz* on the units echoed the following sentiment; “when’s the next narrative session. I need a narrative after...happened...”

Therefore, Hypothesis 1a, which stated a narrative oncology intervention has an impact on compassion satisfaction, burnout, compassion fatigue/STS, emotional exhaustion, depersonalization, personal accomplishment and job stress and job satisfaction from pretest to posttest of each monthly session over a four month period was partially supported. While Hypothesis 1b stated professionals would report decreased job stress, BO, CF/STS as well as increased reports of job satisfaction from pretest NS1 to posttest NS4 was mostly supported. The small sample size in each monthly group and the fact that most participants attended only one narrative session also impacted the quantitative analyses and the partial support of the hypotheses. However, the fact that

despite the small size of the sample the data tended to trend in the right direction while not significant was still meaningful. This meaningful trending of the data over four months combined with the qualitative data help to validate the need to continue and expand narrative oncology rounds.

Hypothesis 2 indicated that oncology health professionals that partook in the intervention would report a desire to have access to ongoing monthly interdisciplinary narrative oncology groups was supported by much of the themes that emerged in the qualitative analysis. The qualitative analysis was divided into two parts 1: Content analysis of process and 2. in-depth interviews. One theme that was strongly supported in both the written open-ended process questions and the in-depth interviews (at least 43 out of 50 post-session evaluations along with all ten interviewees) was the idea of *Shared Perspectives or Bearing Witness* to the stories of others—especially other colleagues.

The oncology professionals that participated in the study described in vivid detail their overwhelming job stress and exhaustion and their perceived need for a *safe space* to be *validated*, gain *closure*, *eulogize* and to stand on common ground with like-minded professionals. These professionals described finding solace and meaning in the narrative exchange and a metaphoric generalizability (Furman, 2006; Furman, 2007) that developed in the thematic content of each month's shared narratives.

While all of the hypotheses are not fully supported there are some other indications that narrative oncology is an asset to inpatient oncology practice. The use of narrative oncology rounds on these three units has had some changes in the culture of the floors even since the close of data collection that seem to validate the importance of such a group. The three oncology units are now all included in the same rounds whereas prior

to this there was a separation. There is an increased recognition of the need to process information and traumatic incidents on the unit. On one occasion the nurse manager asked the researcher to speak with the night shift staff that had witnessed a traumatic death. One intern physician stated, “what happened to the group where we had yummy pizza and spoke about challenging issues?” One of the social workers created a support group/debriefing session for her individual floor in addition to narrative oncology which is once a month. The overwhelming “buzz” is that there is a need and professionals are hungry to process this information so that they can provide better care to their patients. This realization was heartening and profound to several individuals that have approached this researcher to discuss the research project. This combined with the other data both qualitative and quantitative shows that after the novelty wears off people still desire to attend.

These findings reinforced the *attention, representation and affiliation* described by Charon (2006). It supports the theoretical orientation of these practices that *narrating* is an avenue toward consciousness, engagement, responsibility and ethicality.

It is through writing that we can *know*, most fundamentally, what might be the case with a patient and our relationship with the patient. If we can understand clearly the passages that link the confrontation with a suffering person with the representation of that experience and the subsequent reflection on the meaning of it, we can conceptualize roads toward the eventual goals of narrative medicine—extending empathy and effective care toward the patients we serve and building community with colleagues with whom we do our work (Charon, 2006, p.131).

Attention, Representation and Affiliation

Attention

The professionals in this study reported the daily need to attend to multiple issues and requests at once. These health care providers attend to numerous patients at once, attempt to advocate for said patients, and negotiate the rigors of working in a large teaching institution. The conflict reported by participants about how much and when to visit patients, the need to *not* attend sometimes by emotionally detaching themselves, opposes the paradoxical need to both connect and engage with patients. The professionals described feeling responsible for their patients while experiencing simultaneous guilt for what they considered to be lacking. One notable area where many of the participants shared their perceived shortcomings was in caring for themselves and in “not having anything left” for family and friends in their personal lives.

Representation

The writing that was shared by oncology professionals and represented in the narrative sessions was done without extensive training or practice and yet moving and profound stories were shared about their work with patients and families. The narratives shared by participants as well as the narrative exchange triggered by the read narratives touched upon the full range of human emotion. They represented the fears of inadequacy of the oncology professionals, their anger and frustration with patients, their sadness and overwhelming loss of the singular and unique persons they had the privilege to meet and care for and together they reached out to one another, validated the time spent with a patient and in some cases touched the arm of their coworker or handed them a tissue. The narratives themselves are profound representations of the internalization of daily practice

and the subsequent verbal exchange is the externalization of the restoried or reconstructed group narrative.

Building Community and Affiliation

The narrative intervention groups became a collection of voices speaking what was once unspoken, making public what was once private. Ultimately it showed that the professionals' writing, telling and subsequent hearing of one another's oncology narratives put their experiences into personal and social contexts, gave coherence, structure, symbolism, and meaning to what was an otherwise chaotic and *distressing* experience. Charon (2006) acknowledged that the process of bearing witness requires a community and that through shared suffering healing can begin to occur,

If narrative medicine includes the duty to bear witness to individual patients' suffering, we may find ourselves naturally drawn to identify and join with the communities in which the suffering and potential healing may occur. The turn toward oral history and trauma studies for inspiration gives us the dividend of focusing on the communities that nourish our patients' sense of self, of belonging, and of future, for it is in these communities that a return to wholeness or health happens. (Charon, 2006, p.197)

The "shared perspectives" described by the narrative oncology professionals in this study seem to have served as a jumping off point for community building and affiliation with fellow oncology caregivers. Through shared suffering and experience the potential for healing seemed to begin. Many of the professionals commented that they

had increased awareness of their own emotions regarding patient care and some for the first time began to introspect. The practice of narrative oncology not only helped these practitioners have a “safe-space” to share perspectives and bear witness to one another but also prepared them to practice patient care narratively—honoring the stories of their patients moment to moment. One nurse discussed that she realizes that some patient interactions that may seem odd or neurotic to staff have “back stories” that explain the origin of this behavior.

Information gathered within this study suggests practitioners should be exposed to narrative rounds on a regular basis or some other *community-building* group that supports the physicians, nurses and social workers providing care to cancer patients on a monthly basis. Based on previous research and the reports of helpfulness of the groups by participants in this study, the implementation of narrative sessions in an oncology setting could impact patient care and outcomes. Thus, an investment of this nature in employees could be an investment in patient care, however, future research is needed as is discussed below.

Also present within the context of this study were the five features of narrative medicine both as Charon (2006) describes them, but with additional meanings as well.

Temporality

For healthcare professionals, especially those practicing with terminally ill patients, time is a particularly vivid concept. They struggle to find more of it for their patients. When there are no treatment options left physicians may recommend administering salvage chemo treatments. Nurses and social workers may advocate to maintain a patients comfort and recommend transitioning their suffering patients to

hospice care, which supports quality of life rather than an extension of it at the cost of maintaining comfort. Sometimes the entire medical team sees the futility of treatment, but cannot imagine “not fighting” or “giving up” on the young mother who had to terminate her pregnancy when diagnosed with leukemia, but who has other young children at home. No matter what struggle presents itself daily there is the irrefutable fact that time is precious and that it is fleeting. They grapple with the fairness of their jobs and the fact that they feel obligated to see each of their critically ill patients before they leave for the day because they may not be there tomorrow. They listen to the stories told by their newly diagnosed patients, who prior to lying in their hospital bed were working in healthcare themselves.

The saying “tempus fugit” rings especially true in oncology work. This study gave professionals time together to process their caregiving stories and to connect with one another.

By respecting the beginnings, middles, and ends of human events, narratives require, from each reader and writer, adherence to human’s obligatory existence within the flow of—and the buoyancy of—time. Narrative might be the most important discovery humans have made in order to deal with the problem of time, (Charon, 2006, p. 42).

Singularity

The singular experience of each individual participant demonstrated that the majority desire to utilize reflective practice and writing to help make sense of their own caregiving journeys in order to better equipped to work with their patients. Through

acknowledging their own singularity they recognize the singularity of their patients and are better able to bear witness and accompany patients on their respective journeys. The sentiment shared by participants in this study is akin to Charon's previous assertions,

The reflective writing that is growing in medicine for students and for professionals testifies to professionals' willingness and skill to examine their own experiences and to make sense of their own journeys, not for solipsistic reasons but for the sake of improving the care they deliver.

(Charon, 2006, p.47)

Ayn Rand, a participant in this study shared the following also located in Chapter 4 of this document,

...but I think it evolved more with the narratives...I was really thinking...but sometimes I think what these patients need the most is just somebody to be there, be present with them, just sit there with them in their uncertainty, in their anxiety...because we wanna be compassionate people. We wanna care about people. We wanna help them...

Causality/Contingency

Narratives have plots and announce a series of events. Narratives attempt to make sense of why things happen, connect thoughts through motive or cause (Charon, 2006).

There are a lot of unknowns in caring for the terminally ill. Why do some persons respond to treatment and others do not? What causes leukemia? How long can I continue to work in this environment?

The plots that we encounter and create in medical practice are very practically and irrevocably about their endings. They point to human ends, using their geometries to understand or to imagine the vectors of life, the

plottedness of life, the inevitability of death, and the narrative connections among us all (Charon, 2006, p.51).

Intersubjectivity

“The subject is the self-who-knows, the self-who-acts, and the self-who-observes,” (Charon, 2006, p.51). Just as it was important for this researcher to be self-aware, it was significant that emotional proximity was examined in themes one and two deal with the issue of emotional distance and closeness and the fact that professionals shared that they both need to put emotional distance between them and their patients and that they also wish that they had more time to spend with their patients. These seemingly conflicting ideas demonstrate one of the major challenges and risks involved in oncology work. The professionals struggle with how to connect and at the same time self-protect.

Ethicality

How do oncology physicians, nurses and social workers sustain themselves in oncology work? How do these professionals make meaning in their work? By sharing narratives in the hospital setting, the receiver owes something to the teller by virtue of knowing it (Charon, 2006). The stories told within conference rooms on the hospital wards and their tellers expect confidentiality and the receivers of this knowledge do as well. The comfort found in the “safe-space” is both literal and allegorical.

Recommendations and Implications

Policy Implications

The cost of healthcare is well-known and has been the subject of much recent national debate. Included in the overall cost of healthcare is the cost of caring for employees and the results that job stress and all its permutations can have on productivity

and outcomes. A landmark study of 600 American workers indicated that burnout resulted in lowered production, increases in absenteeism, health care costs, and personnel turnover (Northwestern National Life, 1991), which all seem to affect patient care. According to Felton (1998), “burnout is a health care professional’s occupational disease,” and early identification is needed to prevent depersonalization of the provider-patient relationship. Felton’s study also stated that prevention and treatment are essentially parallel efforts and should include all of the following; greater job control by individual workers, group meetings like narrative oncology, better up-and-down communication, and more recognition of individual worth to name a few. The findings in this study echo the sentiment of the aforementioned studies, by caring for our healthcare professionals and giving them access to groups such as narrative oncology there is more of a chance that they will build a community of shared grief and joys, feel validated, feel that they have a voice and ultimately feel empowered because it while helping to alleviate job stress and prevent burnout and compassion fatigue. If employees are given something as simple as a monthly meeting with a paid lunch the money spent in food and paying the facilitator will easily be saved in retention of one employee and preventing, “turnover costs.” According to PriceWaterHouseCoopers (PWC) Saratoga Institute (2010),

Organizations that overlook the proven advantages of detailed and frequent measurement around the cost of retaining, and losing valuable employees...are allowing dollars to slip away instead of adding them to the bottom line... Some of the costs of turnover include:

- Lost productivity during a vacancy
- Diminished productivity of the team and managers

who are covering for a vacant position

- Diminished productivity of the team and managers

who are training the new hire

- Increased labor costs due to overtime or contractors needs

- Hiring and onboarding costs

- More difficult to quantify impacts may include

decreased customer satisfaction, increased future

turnover and loss of institutional knowledge (PWC, 2006, p.1).

Oncology professionals in this study all shared their concern for providing the best possible patient care. However, due to reports of exhaustion and lack of time, oncology professionals in this study admitted that they were “counting down” the time until they move on to another job, participant Maya Angelou stated, “the whole time I have been here it’s a countdown to three more months...” and one participant, Emily Dickinson stated, “I think this environment is toxic, and this environment is exhausting—you can’t even eat lunch.” If a group such as narrative oncology was provided employees may be more inclined to stay in their positions and team affiliation may be stronger as it was reported by the participants in this study. Policies on inpatient oncology floors should include regular groups for professionals that encourage them to socialize. Narrative is one vehicle that can work in real-time hospital setting as was demonstrated in this study. Policies should be written that discuss protections and preventative strategies to help promote wellness in employees and prevent burnout. In order to take good care of our patients, we need to take good care of their healthcare providers, especially those “on the line.”

Educational Implications

Much of the literature that investigated burnout, compassion fatigue and secondary traumatic stress in oncology professionals recommended interventions that included on-site professional resources, specialized retreats, educational programs, and relevant education. This research confirms how important such interventions are for employees. The findings in this study along with the literature indicate that future health care providers, especially social workers, nurses and physicians should be given formal training that includes both prevention and management of job stress and all that accompanies it. There seems to be no way to avoid some of the emotional stressors that accompany this work, especially on the inpatient wards and therefore preventive strategies should be taught early on in their oncology work.

One cost-effective method that can easily be implemented into social work, nursing and medical school curriculums is the use of autoethnographies, including such things as poems and narrative reflections (Furman, 2006; Furman, 2007) in addition to parallel charts and conducting narrative groups with students.

Since this study began the narrative medicine program at Columbia, has again set the standard on how practitioners practice with patients narratively, through the emergence of the first Master's degree in Narrative Medicine, the curriculum and its syllabi should be considered by other institutions in consultation with Columbia University and with appropriate permissions.

Additionally, social work educational programs may incorporate more literature into the curriculum to assist in close reading, utilizing the identification of form, time and plot, all of which would prove helpful in taking patient biopsychosocial histories and in

prioritizing the plan of advocacy for a patient and/or client in addition to observing and appreciating the uniqueness and importance of the story. In the past, social work programs have incorporated coursework such as social policy through literature. The literature and the reading of stories (e.g. *My Own Country* by Abraham Verghese, *Wit*, a play by Margaret Edson, or the *Death of Ivan Illych* by Leo Tolstoy) provide a rich example of illness narratives and would allow students the freedom to exchange commentary, debate and ideas. This type of narrative exchange is a great teaching point on the beginnings of conducting a narrative oncology or narrative medicine group. Furman (2006) also provides an excellent example of the use of an autoethnographic poetry and narrative reflections, which can easily be incorporated into human behavior in the social environment syllabi or even into research coursework on qualitative analyses.

Limitations of Study

As with any quasi-experimental study, there are limitations to the study design which lead to caveats on conclusions drawn from the findings. First, study participants are not randomly selected which limits generalization beyond this study. Additionally, participants were not randomly assigned to the narrative groups, and despite some individuals that attended multiple monthly session, most participants varied from month to month which presents limitations to internal validity. The small sample pool was primarily female and from the nursing profession and thus the generalizability to males and those of the other professions may be different. The participant pool was drawn from oncology units in one large university teaching hospital and in one city again limiting the generalizability to any oncology units in any other hospital (teaching or community) and in any other city.

While the participant pool was relatively limited, another limitation stems from the questionnaires used in the study. Because there is no single compassion fatigue measure that assesses all aspects of the concept of compassion fatigue, the researcher chose three instruments that seemed to provide the fullest picture. However, there were numerous other scales that could have been included. Some instruments that may have been more beneficial to use include the Secondary Traumatic Stress Scale (STSS), the Impact of Event Scale (IES or IES-R), the Trauma and Attachment Belief Scale (TABS), the World Assumptions Scale (WAS) (Bride, Radey & Figley, 2007) and/or the Interpersonal Reactivity Index (IRI). Additionally, updated versions of one of the tests that was used became available during the study, however, the researcher continued to utilize the manual and the data from the ProQOL-IV-R rather than the updated ProQOL-V.

Validity, random sampling, reliability and generalizability are necessary to increase rigor in quantitative research, trustworthiness standards were developed to evaluate validity of qualitative study findings and how they are reported. Threats to both credibility and trustworthiness are often grouped under three broad headings: reactivity, research bias and respondent bias (Padgett, 1998). Methodologically, the qualitative measures used are not designed to get the full lived experience of oncology professionals. Open-ended questions from the post-session evaluation allow only an initial exploration of meaning and context and depth. The interviews helped to enhance the understanding of the oncology professionals' experiences. Through the use of excerpts from the narrative oncology sessions, interviews and open-ended questions while the use of mixed methods helps in analytic triangulation, an audit trail including descriptions of the iterative process

of data collection and interpretation (often using tables) was provided. Another methodological issue in the survey is that the qualitative questions follow the quantitative scales. This ordering may have impacted the responses.

Interpretation and analysis of data, especially qualitative data require that the researcher continually question their interpretations. Within qualitative research, reflexivity, the ability to examine oneself, is an important method of addressing the impact social factors can impose on a study (Adamson and Donovan, 2002). In this study, it was particularly important to consider through the reflexive process the impact of this researcher's professional experience on one of the oncology floors in this study and the bias that may result. This researcher needed to be able to identify her taken-for-granted knowledge, and be open to what she is no longer aware of. For example, this researcher was initially surprised by the importance of participants to have others shared perspective, partially because the researcher personally felt that it was implied.

Although, the quality of qualitative studies not necessarily determined by the size or randomness of the sample, which were not present in this small (n=40) non-random sample, the goal was to go in-depth with a small number (n=10) people. This study sought to compose a group of people who were "information-rich" (Kreuger & Casey, 2000), but lacked the in-depth insight from one core contingent—the physicians, none of whom were able to participate in the interviews citing reasons such as logistical issues of being off the oncology service and time limitations. In all cases, each physician expressed their sincere regret. One colleague of this research communicated that one of the narrative oncology physician (male) participants came to the researcher's office to "discuss" the study, but the researcher was away from the hospital on that occasion. This

leaves an obvious gap in the interview data collected and is an implication for future research. It also speaks to the overwhelming commentary identified in this study about time constraints and the need for hospital policy to include time for professionals to decompress or just have some *true* free time during the day to socialize with colleagues.

There are arguments both for and against interpretation and the fact that there is always more than one way of understanding a text. However, this does not mean that all interpretations are of equal value (Ricoeur, 1976). Although, one may consider the fact that this researcher is a social worker on one of the oncology floors a limitation, it may also be considered strength as the interpretation and discernment of the meanings of the quotes from fellow colleagues may have been to please the researcher. Perhaps those with opposing opinions chose not to discuss these with the researcher. However, on the other hand professionals seemed at ease and were willing to openly discuss their opinions and experiences.

Some of the participants engaged in narrative oncology groups that were held intermittently and irregularly by the researcher leading up to the study which may impact their view of the narrative oncology sessions. The sessions were not conducted in the five months prior to the beginning of the study due to scheduling conflicts and lack of funding.

Another significant change occurred in the rounding of professionals on the three oncology units. Prior to July 2009, two of the floors met together daily for discharge rounds, while the other oncology floor had independent rounds. It is important to note that all of the same physician teams service all three floors were expected to be in two locations nearly simultaneously. The residents would stop in during their ward rounds to

report on any issues on their patients and leave to resume rounding with their attending physician. Present in the room at this time were two to three nurse discharge planners, two social workers, one chaplain and the charge nurse from the two floors. It is important to note that the focus of daily rounds was discharge planning and utilization review and held a very different focus than narrative oncology.

The other unit had the same key players awaiting physician input, charge nurse, social worker and chaplain. A decision was made that the nurse discharge planners would become embedded in the medical team and would complete walking rounds with the physicians and pharmacist. Social work and pastoral care were expected to meet twice a week for a half an hour for psychosocial rounds. The general feeling from the floor staff was that this new model challenged communication. Staff shared frustration on numerous occasions and in numerous forums, which was later replaced with resignation to the “new rounding model.” The purpose of the new twice-weekly rounds was different from the previous rounding as the focus was to be on discussion of challenging psychosocial issues and “difficult cases.” Initially, attendance was poor to these psychosocial rounds and may have served to fuel animosity between disciplines. One person shared,

I think its an institutional thing I don't think the whole change was done in any way to slight social work or pastoral care I just think we just kind of fell by the wayside with this new model and I don't think they really thought about how we were going to be incorporated.

This individual goes on to share that she thought that narrative oncology may have served to fill some of the newly found communication gap,

In some ways the narrative oncology rounds allows for collaboration and we used to have daily collaboration and ways of getting information. I guess especially in light of how everything's changed I really like them as

well because they give me another...this is a place where you can say what you think.

Another oncology professional shared,

I have never rounded with the doctors since they have done that. I have to chase the doctors down to find out what's happening with a patient...you have to hunt that—you have to go to all the nurses and find out if they know anything. And if they don't know it, then you have to hunt down the doctors...[In the old rounding model] I don't know if people discussed things that bothered them, but you got the information that you needed on your patients and that was important.

These two quotes reiterate the fact that the strength of the *Shared perspective and Bearing Witness theme* could have been impacted by this turn of events. Additionally, numerous comments were made in the interviews and post-session evaluations about desiring for an increased presence of physicians. One comment read, “disappointed MDs didn't come they miss out.” For the most part the physicians who did attend reported finding the narrative sessions helpful and wished they had been able to attend more.

After the study concluded, psychosocial rounds, although one a half an hour in length and do not utilize the narrative model slowly evolved into a “processing session.” Despite the change in rounds, professionals continue to ask for narrative oncology and expressed their desire for it to continue, “wish this was not the end,” “please have more,” and “very beneficial to all involved and opens people to view the opinions/etc. of all people involved in patient care,” “very insightful to why I do what I do, why I feel things I feel and how to improve my practice,” and “It was so nice to sit down and hear how everyone is doing. So many times a patient will die and then we literally need to get ready for the next admission! It is just so beneficial to have time to talk about this!”

Narrative oncology rounds resumed three months after this new rounding model went into effect. Several interviewees mentioned on more than one occasion that they

would like to have physicians present in the narrative meetings. This researcher believes this to be true, but also frustration and job stress may have been elevated past their normal point, which accounted for much of the changes in scores or lack of changes in scores in each month and over the course of the four months of the study.

Those who agreed to participate may be a self-selecting group. However there were individuals who admitted they did not want to attend the sessions and did not think they would like it, yet they came because a coworker encouraged them to do so. Additionally, others came out of their curiosity or because they might have felt allegiance to the researcher. Despite the initial hesitation or motivation for narrative oncology attendance, interviewees or persons who commented on the post-session evaluation admitted, they found it beneficial.

The study began in the month of October and therefore took place over the holiday season. This time of year can often be more difficult for healthcare professionals. The study hospital saw an increase in number of deaths on the oncology units. This coupled with the increased acuity and filling beds to capacity forces staff to be challenged in both their work and home environments at this time of year. This latter point is consistent with literature on compassion fatigue and healthcare (Meadors & Lamson, 2008).

Future Research

Due to exploratory nature of this study, the researcher is left with more questions than answers. There are many suggestions for future research beginning with the need to research with a control group and a comparison group. Ideally this research would occur at multiple institutions by field personnel that are not active members of the medical team

as this researcher was, but it would be beneficial to have data collectors and field interviewers that understand the nuances of inpatient hospital work. It was clear that the oncology professionals desire to discuss their experiences. This researcher found the interview data to be so rich that it was a challenge to choose just some of the quotes to incorporate in the data.

Specific to the limitations of this study it would be beneficial to address the changes in discharge planning rounds and communication in general. The perceived lack of communication by several of the interviewees could have contributed greatly to the findings in this study.

There are numerous other professionals and non-professionals caring for oncology patients that are impacted by this work and it seems logical that they should also be included in future studies. For instance, physical and occupational therapists, pharmacists, and certified nursing assistants. Some of these professionals attended the narrative oncology sessions in this study, but they were not included in the data. It was clear on one occasion that writing might not be as easy for some as it is for others and thus other types of supports for these professionals should be explored.

The data in this study also lacked insight and opinions from patients and families. Future studies may simultaneously examine patient satisfaction to see whether or not it correlates with the experience of oncology professionals.

Additionally, future research would benefit from measures that are specific to oncology work. It may be beneficial to design and test an evaluation tool for group supports such as narrative oncology, Schwartz rounds, Reiki groups and the like.

Also, it is a well known fact that healthcare facilities and institutions, including the federal government are interested in cost containment, increased quality of patient care and more institutionally specific, employee retention and therefore future research should invest in studying the cost of providing supports for its employees. Research should include additional groups such as narrative oncology and utilization by employees of some already offered supports, e.g., employee assistance programs. Finally, it would be beneficial to study professionals who left oncology practice and what, if anything may have deterred them from pursuing other professional endeavors.

Summary

Oncology professionals are challenged daily by the emotional rigors of their work and the seeming contradictions that it poses—the need to depersonalize, but to maintain emotional connections to patients. It seems clear that these individuals experience job stress, burnout and its components of emotional exhaustion and depersonalization, and compassion fatigue or secondary traumatic stress. However, it is also evident that along with these challenges there are rewards such as feelings of personal accomplishment and job satisfaction. Because there are many more questions than answers the need for future research is clear. Ultimately, this study demonstrated one of the inherent paradoxes in oncologic healthcare: dealing with death and dying causes great stress while simultaneously enriching the lives of the healthcare professional. Finally, these professionals would benefit from having an outlet, such as narrative oncology to share and bear witness to their multi-layered perspectives.

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Appendix A: Consent Form

University of Pennsylvania Informed Consent Form

Title of the Research Study: Narrative Intervention with Oncology Professionals

Principal Investigator: Nicole Saint-Louis, MSW, LSW
School of Social Policy and Practice/Oncology SW at HUP
Tel: 215.662.2695
Email: Nicole.saint.louis@uphs.upenn.edu

Emergency Contact: see above

You are being asked to take part in a research study. This is not a form of treatment or therapy. It is not supposed to detect a disease or find something wrong. Your participation is voluntary which means you can choose whether or not to participate. If you decide to participate or not to participate there will be no loss of benefits to which you are otherwise entitled. Before you make a decision you will need to know the purpose of the study, the possible risks and benefits of being in the study and what you will have to do if decide to participate. The research team is going to talk with you about the study and give you this consent document to read. You do not have to make a decision now; you can take the consent document home and share it with friends, family doctor and family.

If you do not understand what you are reading, do not sign it. Please ask the researcher to explain anything you do not understand, including any language contained in this form. If you decide to participate, you will be asked to sign this form and a copy will be given to you. Keep this form, in it you will find contact information and answers to questions about the study. You may ask to have this form read to you.

What is the purpose of the study?

The purpose of the study is to learn more about the experiences of oncology professionals, namely, physicians, nurses and social workers that care for cancer patients on the following inpatient oncology units; Rhoads 3, Rhoads 6, or Rhoads 7. This study is being conducted as part of a doctoral dissertation and it will measure the amount, if any, of job stress, burnout and compassion fatigue or alternatively job satisfaction, and compassion satisfaction that you and your colleagues experience. It will also provide a group called narrative oncology that is designed to support healthcare professionals that care for oncology patients. This study seeks to see if the groups are helping support professionals in any way and if they affect the experience of stress related to your job, burnout and compassion fatigue.

Why was I asked to participate in the study?

You are being asked to join this study because you are a physician, nurse or social worker that works on one of the designated inpatient oncology units and your opinions, feelings and experiences are important to know and understand as part of this study and may influence future research and programs.

How long will I be in the study? How many other people will be in the study?

The complete study will take place over a period of 5 months. This means for the next 4 months we will ask you to spend one day a month participating in a narrative oncology session. Each session will last approximately 1 hour. Additional time will be asked of you to fill out surveys prior to attending the first group and after you finish the last group. You will also be asked to participate in a one-on-one interview at the end of the four month period. The interview would be approximately an hour and will be held at your convenience.

You will be one of numerous people in the study. The study will attempt to recruit physicians, nurses and social workers from Rhoads 3, 6, and 7. In total it is estimated that you will be giving 5.5 hours of your time over 5 months.

Where will the study take place?

The study will take place at the Hospital of the University of Pennsylvania on one of 3 inpatient units. The narrative oncology groups will rotate floors, e.g., first month will be held on Rhoads 6, next month on Rhoads 7. The groups will be held in the conference rooms on each respective floor and lunch will be served.

What will I be asked to do?

You will be asked to come to fill out a packet of information prior to attending the first narrative oncology session. The sessions will go on for four months. It is ok if you are unable to participate in all of the groups and if you can only attend one group. You will be asked to complete the same survey packet at the end of the four months. You will also be asked to participate in a one-on-one recorded interview with the Principal Investigator. The interview will be to get your opinions and thoughts about your overall experience and should last approximately one hour. The interviews will be conducted at the end of the four months. The narrative oncology groups will be held every 3rd Wednesday of every month from 12:30:1:30pm.

What are the risks?

It is believed that the risks to you are minimal. You might experience some emotional discomfort in writing and or sharing your thoughts in a group setting, but the groups are designed to be supportive and will be sensitive to your concerns. Risks to your confidentiality will be limited by keeping your name and demographic information separate and in a locked cabinet away from any other information about you. You will only be identified by a number that will be assigned to you. Your fellow group participants will be asked to keep all information discussed in the group private and confidential.

How will I benefit from the study?

There is no apparent benefit to you. However, we believe that your participation in the group may help you feel supported and may help you identify with your colleagues. Additionally your participation could help give insight on how to provide for the needs of oncology professionals that care for such a difficult population (dealing with death and dying), which can benefit you indirectly. In the future, this may help other people to see how to reduce job stress, burnout and compassion fatigue.

What other choices do I have?

Your alternative to being in the study is to not be in the study.

If you choose not to be in the study the following are other treatment choices that you may want to consider attending the narrative oncology groups as a participant even though you are not in the research study. Your participation will be welcomed as it is beneficial to all participants to have others present in the group.

What happens if I do not choose to join the research study?

You may choose to join the study or you may choose not to join the study. Your participation is voluntary.

There is no penalty if you choose not to join the research study. You will lose no benefits or advantages that are now coming to you, or would come to you in the future.

If you are currently participating in the narrative oncology groups and you choose not to volunteer in the research study, you may continue as desired in participation of the group. This group is conducted for the benefit of all staff that attend and if you are uncomfortable participating in the research this will in no way impact your ability to participate and be included in the group.

When is the study over? Can I leave the study before it ends?

The study is expected to end after all participants have completed all visits and all the information has been collected. The study may be stopped without your consent for the following reasons:

- The PI feels it is best for your safety and/or health-you will be informed of the reasons why.
- You have not followed the study instructions
- The PI, the sponsor or the Office of Regulatory Affairs at the University of Pennsylvania can stop the study anytime

You have the right to drop out of the research study at anytime during your participation. There is no penalty or loss of benefits to which you are otherwise entitled if you decide to do so. Withdrawal will not interfere with your future care.

If you no longer wish to be in the research study, please contact Nicole Saint-Louis, at 215.662.2695 or Nicole.saint.louis@uphs.upenn.edu and take the following steps:

- Request that you be withdrawn from the study. State your name and any collected information will be destroyed and not included in the study.

How will confidentiality be maintained and my privacy be protected?

The research team will make every effort to keep all the information you tell us during the study strictly confidential, as required by law. The Institutional Review Board (IRB) at the University of Pennsylvania is responsible for protecting the rights and welfare of research volunteers like you. The IRB has access to study information. Any documents you sign, where you can be identified by name will be kept in a locked drawer in the PI's locked office. These documents will be kept confidential. All the documents will be destroyed when the study is over.

What happens if I am injured from being in the study?

If you are injured and/or feel upset and emotional discomfort while participating in the study you may contact the PI or the emergency contact name on the first page of this form. Also, you may contact your own doctor, counselor or seek treatment outside of the University of Pennsylvania. Bring this document, and tell your doctor/counselor or his/her staff that you are in a research study being conducted at the University of Pennsylvania. Ask them to call the numbers on the first page of this form for information.

If you are injured and/or feel emotional discomfort from being in the study, the appropriate care will be provided without cost to you, but financial compensation is not otherwise available from the University of Pennsylvania. If you are injured and/or feel emotional discomfort while in the study but it is not related to the study, you and your insurance company will be responsible for the costs of that care.

You can seek help through the Employee Assistance Program at Penn Medicine also known as Penn Behavioral Health. The Employee Assistance Program (EAP) provides assistance with issues and challenges that may arise in your personal or professional life. EAP services are available 24 hours a day, 7 days a week by phone at 1-888-321-4433 or online at www.pennbehavioralhealth.org.

Will I have to pay for anything?

There is no monetary cost to you during this study. The only contribution that will be asked of you is your time.

Will I be compensated for participating in the study?

To show our appreciation for your time, we will give you a \$25.00 gift card to the University of Pennsylvania Bookstore upon completion of the study. If you decide to

withdraw from the study before the study is over, your compensation will not be distributed.

Who can I call with questions, complaints or if I'm concerned about my rights as a research subject?

If you have questions, concerns or complaints regarding your participation in this research study or if you have any questions about your rights as a research subject, you should speak with the Principal Investigator listed on page one of this form. If a member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the Office of Regulatory Affairs with any question, concerns or complaints at the University of Pennsylvania by calling (215) 898-2614.

When you sign this document, you are agreeing to take part in this research study. If you have any questions or there is something you do not understand, please ask. You will receive a copy of this consent document.

Signature of Subject _____

Print Name of Subject _____

Date _____

Appendix B: Pre and Post Session Packet

1

Participant Code #: _____

Name: _____

Demographic Information:

2

Participant Code #: _____

About You

.Please provide the following information:

1. Gender: M F

2. Age:

3. Ethnicity:

a.) Caucasian

b.) African-American

c.) Hispanic

d.) Asian

e.) Other

4. Marital/Partner Status:

a.) Married

b.) Living with

c.) Divorced/Separated

d.) Single/Never Married

5. Type of Professional Discipline:

a.) Physician

b.) Nurse

c.) Social Worker

d.) Other

6. Years of employment at Penn:

1

2

3

4

5

6 -10

more than 10

7. Years of working with Oncology patients:

1

2

3

4

5

6-10

more than 10

8. Highest level of education:

a.) Associates Degree

b.) Bachelor's degree

c.) Masters degree

d.) doctoral degree/MD./D.O

Appendix C: Health Consultants' Job Stress and Satisfaction Questionnaire

(HCJJSQ)

4. The Consultants' Job Stress & Job Satisfaction Questionnaire (2002)

Stressful aspects of your work

To what extent have the following factors contributed to any stress you have experienced in your job in the past few months? Please rate each factor by circling the relevant number on the 0 to 3 scale. If not applicable, please rate '0'.

		Extent contributes to stress			
		Not at all	A Little	Quite A bit	A Lot
1	Being involved with the physical suffering of patients	0	1	2	3
2	Encountering difficulties in relationships with junior medical staff	0	1	2	3
3	Feeling you have insufficient input into the management of your unit or institution	0	1	2	3
4	Disruption of your home life through spending long hours at work	0	1	2	3
5	Having inadequate facilities (e.g. equipment, space) to do your job properly	0	1	2	3
6	Having to deal with distressed, angry or blaming relatives	0	1	2	3
7	Keeping up to date with current clinical and research practices	0	1	2	3
8	Having to take on more managerial responsibilities	0	1	2	3
9	Encountering difficulties in relationships with consultant colleagues	0	1	2	3
10	Feeling under pressure to meet deadlines	0	1	2	3
11	Being responsible for the quality of the work of other staff	0	1	2	3
12	Being involved with the emotional distress of patients	0	1	2	3
13	Encountering difficulties in relationships with administrative staff, e.g. secretaries	0	1	2	3
14	Having too great an overall volume of work	0	1	2	3
15	Feeling you are poorly paid for the job you do	0	1	2	3
16	Encountering difficulties in relationships with managers	0	1	2	3
17	Having conflicting demands on your time (e.g. patient care/management/research/College)	0	1	2	3

		Extent contributes to stress			
		Not at all	A Little	Quite A bit	A Lot
18	Having inadequate staff to do your job properly	0	1	2	3
19	Dealing with the threat of being sued for malpractice	0	1	2	3
20	Disruption of your home life as a result of taking paperwork home	0	1	2	3
21	Feeling that your accumulated skills and expertise are not being put to their best use	0	1	2	3
22	Disruption of your home life as a result of being on call	0	1	2	3
23	Having a conflict of responsibilities (e.g. clinical vs. managerial; clinical vs. research)	0	1	2	3
24	Uncertainty over the future funding of your unit/institution	0	1	2	3
25	Being responsible for the welfare of other staff	0	1	2	3
26	Having performance targets which are unrealistic or unattainable (e.g. due to lack of resources)	0	1	2	3
27	Dealing with patients or relatives having expectations of care that cannot be met	0	1	2	3
28	Having to comply with increasing bureaucratic and regulatory procedures	0	1	2	3
29	Feeling concerned about keeping your skills up to date due to your Trust not investing in new technologies	0	1	2	3
30	Providing patient care within multi-disciplinary teams	0	1	2	3
31	Feeling that you are losing generalist skills as your job becomes more specialised	0	1	2	3
32	Having difficulties recruiting high calibre staff	0	1	2	3
33	Having insufficient formalised time for teaching, training and research	0	1	2	3
34	Having inadequate administration systems (e.g. IT, filing procedures for notes)	0	1	2	3
35	Having to submit a job plan and undergo performance appraisal	0	1	2	3
36	Being required to provide routine NHS clinical services (e.g. outpatient clinics) outside normal working hours	0	1	2	3

Satisfying aspects of your work

To what extent have the following factors contributed to the satisfaction you have derived from your job in the past few months? Please rate each factor by circling the relevant number on the 0 to 3 scale. If not applicable, please rate '0'.

		Extent contributes to satisfaction			
		Not at all	A little	Quite a bit	A Lot
1	Having a high level of responsibility	0	1	2	3
2	Being perceived to do the job well by your colleagues	0	1	2	3
3	Being able to bring about positive change in your unit/institution	0	1	2	3
4	Having good relationships with patients	0	1	2	3
5	Feeling you have the staff necessary to do a good job	0	1	2	3
6	Deriving intellectual stimulation from research	0	1	2	3
7	Having a high level of autonomy	0	1	2	3
8	Having opportunities for personal learning (developing clinical/research/management skills)	0	1	2	3
9	Having good relationships with other staff members	0	1	2	3
10	Having variety in your job	0	1	2	3
11	Feeling you have adequate financial resources to do a good job	0	1	2	3
12	Being involved in activities that contribute to the development of your profession	0	1	2	3
13	Feeling you have a high level of job security	0	1	2	3
14	Deriving intellectual stimulation from teaching	0	1	2	3
15	Feeling you have adequate facilities to do a good job	0	1	2	3
16	Feeling your clinical experience is used to the full in the job you do	0	1	2	3
17	Feeling you deal well with relatives	0	1	2	3
18	Being an expert in a specialist area	0	1	2	3
19	Being perceived to do the job well by patients	0	1	2	3
20	Having the opportunity to practice medicine privately	0	1	2	3
21	Providing patient care within multi-disciplinary teams	0	1	2	3
22	Being able to complete a difficult clinical procedure successfully	0	1	2	3

4.1 Global Ratings of Job Stress and Job Satisfaction

In both the 1994 and 2002 questionnaires the following two questions were asked to ascertain a 'global measure' of stress and satisfaction for each individual consultant.

a) Overall, how stressful do you find your work?

Not at all stressful 0 1 2 3 4 Extremely stressful

b) Overall, how satisfying do you find your work?

Not at all satisfying 0 1 2 3 4 Extremely satisfying

Appendix D:**ProQOL: Professional Quality of Life Scale: Compassion Satisfaction, Burnout and****Fatigue Scale Version IV (ProQOL – CSF-R-IV)****ProQOL R-IV****PROFESSIONAL QUALITY OF LIFE SCALE****Compassion Satisfaction and Fatigue Subscales—Revision IV**

[Helping] people puts you in direct contact with their lives. As you probably have experienced, your compassion for those you *[help]* has both positive and negative aspects. We would like to ask you questions about your experiences, both positive and negative, as a *[helper]*. Consider each of the following questions about you and your current situation. Select the number that honestly reflects how frequently you experienced these characteristics in the last 30 days.

0=Never 1=Rarely 2=A Few Times 3=Somewhat Often 4=Often 5=Very Often

- _____ 1. I am happy.
- _____ 2. I am preoccupied with more than one person I *[help]*.
- _____ 3. I get satisfaction from being able to *[help]* people.
- _____ 4. I feel connected to others.
- _____ 5. I jump or am startled by unexpected sounds.
- _____ 6. I feel invigorated after working with those I *[help]*.
- _____ 7. I find it difficult to separate my personal life from my life as a *[helper]*.
- _____ 8. I am losing sleep over traumatic experiences of a person I *[help]*.
- _____ 9. I think that I might have been “infected” by the traumatic stress of those I *[help]*.
- _____ 10. I feel trapped by my work as a *[helper]*.
- _____ 11. Because of my *[helping]*, I have felt “on edge” about various things.
- _____ 12. I like my work as a *[helper]*.
- _____ 13. I feel depressed as a result of my work as a *[helper]*.
- _____ 14. I feel as though I am experiencing the trauma of someone I have *[helped]*.
- _____ 15. I have beliefs that sustain me.
- _____ 16. I am pleased with how I am able to keep up with *[helping]* techniques and protocols.
- _____ 17. I am the person I always wanted to be.
- _____ 18. My work makes me feel satisfied.
- _____ 19. Because of my work as a *[helper]*, I feel exhausted.
- _____ 20. I have happy thoughts and feelings about those I *[help]* and how I could help them.
- _____ 21. I feel overwhelmed by the amount of work or the size of my case[work]load I have to deal with.
- _____ 22. I believe I can make a difference through my work.
- _____ 23. I avoid certain activities or situations because they remind me of frightening experiences of the people I *[help]*.
- _____ 24. I am proud of what I can do to *[help]*.
- _____ 25. As a result of my *[helping]*, I have intrusive, frightening thoughts.
- _____ 26. I feel “bogged down” by the system.
- _____ 27. I have thoughts that I am a “success” as a *[helper]*.
- _____ 28. I can't recall important parts of my work with trauma victims.
- _____ 29. I am a very sensitive person.
- _____ 30. I am happy that I chose to do this work.

Appendix E:**Maslach Burnout Inventory (MBI) 3rd edition****MBI–Human Services Survey**

How often:	0	1	2	3	4	5	6
	Never	A few times a year or less	Once a month or less	A few times a month	Once a week	A few times a week	Every day

How Often 0–6	Statements:
1. _____	I feel emotionally drained from my work.
2. _____	I feel used up at the end of the workday.
3. _____	I feel fatigued when I get up in the morning and have to face another day on the job.
4. _____	I can easily understand how my recipients feel about things.
5. _____	I feel I treat some recipients as if they were impersonal objects.
6. _____	Working with people all day is really a strain for me.
7. _____	I deal very effectively with the problems of my recipients.
8. _____	I feel burned out from my work.
9. _____	I feel I'm positively influencing other people's lives through my work.
10. _____	I've become more callous toward people since I took this job.
11. _____	I worry that this job is hardening me emotionally.
12. _____	I feel very energetic.
13. _____	I feel frustrated by my job.
14. _____	I feel I'm working too hard on my job.
15. _____	I don't really care what happens to some recipients.
16. _____	Working with people directly puts too much stress on me.
17. _____	I can easily create a relaxed atmosphere with my recipients.
18. _____	I feel exhilarated after working closely with my recipients.
19. _____	I have accomplished many worthwhile things in this job.
20. _____	I feel like I'm at the end of my rope.
21. _____	In my work, I deal with emotional problems very calmly.
22. _____	I feel recipients blame me for some of their problems.

(Administrative use only)

	cat.		cat.		cat.
EE: _____	_____	DP: _____	_____	PA: _____	_____

Appendix F:**Narrative Medicine Group Facilitators' Guidelines (Truten, 2008b)**

PURPOSE: Participants are able to witness, interpret, and translate their own and each others' experiences to gain a better understanding of themselves and, in turn, of their colleagues and, ultimately, their patients.

Facilitator's Role:

Listen carefully to each narrative as it is read, taking notes throughout.

Honor that text and its writer, first by praising something about the writing (there's always something skilled there—accuracy, detail, passion, integrity, focus...)

Voice: was the story told in the first person singular—the “I” voice?
 --or the first person plural—the “We” voice?
 --or the third person omniscient—no identifiable narrator?

Style: --a formal style of telling?
 --or an informal, colloquial style of telling?

Structure: --clear and logical plot or account of events?
 --or a broken, chaotic plot or account of events?

Themes: --e.g., the nearness of death
 --e.g., the cost of caring
 --e.g., the value or privilege of work

Mood: what is the dominant mood in the story?
 --anger?
 --sadness?
 --regret?
 --fear?
 --equanimity?
 --dissociation? (absence of mood—distance)

Desire: what does the writer most seem to want, seek, crave in this story?
 --control?
 --recognition?
 --understanding?
 --validation?
 --relief?

There is no single “right” reading or interpretation—all participants’ possible interpretation add to the overall “truth” of the work.

Appendix G:**Appendix G: Interview Guide:**

Introduction: [speaking to tape recorder] This is Nicole Saint-Louis on (date) with participant (alias). I am going to ask about your experiences as a healthcare professional dealing with terminally ill patients. There are no right or wrong answers and I am interested in your honest opinions and thoughts.

I. Orientation to the Interview—Your information will be kept confidential. After listening to the tape, transcribing the conversation the tape will be destroyed and you will be deidentified in the written transcription.

II. In-depth Interview

BACKGROUND

Identity

- How long have you been working in this position?

TIME & REFLECTION

HEALTH CARE TEAMS

Relationships with Colleagues

- How would you describe the atmosphere you work in? (friendly, hostile, busy, calm, crazy)
- How would you describe your colleagues?
- Do you think they feel the same about the work environment?
- Is this environment supportive? (do colleagues support one another, perpetuate angst)

Narrative Oncology Groups

- What were your experiences in the narrative groups?
- General impressions?
- How did you feel the facilitator performed?
- How do you feel about the time of day?
- How about the length of the session?
- Did you feel that they were helpful? If so, in what way?

Relationships with Patients

Interactions

- Where do you put those emotions?

Boundaries and Coping

- How do you think your coworkers' feelings are similar or different?
- How do you take care of yourself?
- Do you think it would be beneficial for the healthcare providers to have a forum to discuss the day-to-day care of the dying patient population?
- What would you envision to be a supportive environment for you and your coworkers?

CLOSING

- Thank you for taking time out of your busy schedule to talk with me. Do you have any questions? Is there anything you would like to add?

Appendix H1: In-Session Packet **1**

Wednesday

Month Day, Year

NS#

This page is just for the researcher and your name will be kept separate from all

other information. Your identity and the fact that you chose to participate or not to

participate will be kept confidential. Thank you.

Participant Code #: _____

Name: _____

Appendix H2: In-Session Packet:

Principal Investigator: Nicole Saint-Louis, MSW, LSW

School of Social Policy and Practice/Oncology SW at HUP

HUP Tel: 215.662.2695

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2

Narrative Medicine Groups: _____ Participant Code #: _____

Date:

Theme question: “Write about an especially stressful or challenging or distressing encounter with a patient, family member or colleague—or, alternatively, one that was unusually inspiring or uplifting.”

Please indicate the number of narrative small groups you previously attended:

_____ or this is my first.

Thank you for participating in today's narrative oncology session. Due to your signing of the informed consent document at the beginning of the study you have given permission to record today's session and to use your written narrative for research purposes. As you may recall, we are conducting a study that looks at what oncology professionals write about their experiences. Participation in this study is entirely voluntary. If you decline to participate you will still be able to participate in the narrative medicine session, but your written narrative and your surveys will not be included in the corpus of research data. Your written material will be kept confidential and deidentified from you as the recorder. Your identity and the fact that you chose to participate or not to participate will be kept confidential. Thank you.

[illegible]

3

Appendix H4: In-Session Packet (Post-Session Evaluation)**4**

Participant Survey _____ Participant Code #: _____

Narrative Oncology Group (Truten, 2008c)

The purpose of this survey is to determine participant perceptions about their experiences with a narrative group approach to facilitating illness narrative groups. Please take a few minutes to fill out this survey and hand it in before you leave. We appreciate your feedback about these narrative sessions. Thank you.

Date:**Type of Professional:**

For questions 1 through 3, please circle whichever of the five answers best describes your opinion about this narrative oncology group session.

	Definitely Agree	Probably Agree	Not Sure	Probably Agree	Definitely Disagree
1. Today's narrative exchange Experience was beneficial To my well-being/resiliency... 5		4	3	2	1
2. Today's narrative experience Has helped ease my mind... 5		4	3	2	1
3. After today's narrative group I feel better equipped to face... 5		4	3	2	1

Please answer the questions below:

5. Which elements of today's experience, if any, were especially effective?
6. How would you improve this narrative group writing session?
7. Do you have any other comments about today's narrative group session?

THANK YOU