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Nicole Saint-Louis

CUNY Guttman Community College

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Writing to Cope: Meaning Making for Professionals Caring for the Cancer Patient

Nicole Saint-Louis

Abstract: This paper will focus on the use of narrative or writing as an opportunity to bear witness, honor and work through the grief and loss professional caregivers experience in their oncology practice. The discussion includes, meaning making, narrative theory, narrative therapy and the growing literature of narrative medicine. Sample narratives will be shared to elucidate how writing can assist with the pain, loss and grief professional caregivers experience in the care of those coping with death and dying.

Keywords: meaning-making, narrative oncology, cancer, theory

During my tenure as an inpatient oncology social worker, I spent much of my time supporting patients and families. At one point, I noticed that I was spending nearly as much time providing support for my colleagues. I worked in a nationally recognized cancer center that was a preferred treatment facility for a number of different types of cancer. Over the course of one particular month, the nurses, physicians, social workers, and other professionals that I worked with on one of the three-inpatient acute care oncology units, experienced fifteen patient deaths. The stories of sorrow, pain, and despair felt by patients and families were palpable and were worn on the faces of my professional caregiving colleagues. In order to cope with my own emotions, I began to write. I integrate parts of my own caregiving narrative into the discussion.

In this paper, I briefly reflect on the emotional manifestation and observation of grief and loss in the professionals that care for cancer patients. Then, I provide a theoretical framework for the use of narratives in coping with suffering, grief and loss in professional caregivers in oncology practice. I mention Frankl and meaning making in the midst of suffering and the parallels to the daily practice of oncology professional caregivers. Additionally, the theoretical discussion includes narrative theory, narrative therapy and the burgeoning literature of narrative medicine. Nearly fifteen years of inpatient hospital social work and oncology experience inform this discussion. Sample narratives are shared to elucidate how writing can assist with the pain, loss and grief professional caregivers experience in the care of those coping with death and dying.

Observation and Manifestation of Grief through Narrative

Many emotions accompany a cancer diagnosis, which the patient expresses through patterns of gestures, expressions, sounds or words, and which the oncology healthcare professional observes and

internalizes. Anxiety, hope, and distress manifest when a patient and his or her health caregiving team embark on the beginning of treatment (NCCN, 2008). Patients and the medical providers accept the risky side effects of the treatment with the anticipatory knowledge that the cure will be worthwhile. In those instances when the treatment does not go as expected, or all treatments have been exhausted and death is imminent, patients and the professionals that care for them are confronted with the reality of their own mortality. The need to deal with multiple losses simultaneously is the foremost coping task faced by a dying patient, their loved ones and the health care workers (Block, 2001). Writing in the form of personal journaling and/or blogging (an illness narrative) is one medium that helps individuals cope with the distress, grief, and loss associated with a cancer diagnosis.

As a social worker and mental health professional, the impact of the suffering of the patients and families we work with can be especially intense. We are taught to empathize with our clients and to forge strong alliances with those we serve, especially during times of suffering. This prolonged contact with patients in emotional distress can be painful. Brown (2006) discussed that vulnerability is at the heart of a lot of emotions, especially empathy and shame. Empathizing with our patients requires the professional caregiver to be vulnerable. We share their emotional journeys, we grieve and we mourn the loss of patients with whom we have developed close relationships. I began to write down thoughts about my experiences and the pain I was witnessing.

One nurse became tearful in a corner of the nurse's station while organizing her medications to give to her next patient. I went over to speak with her. She strained to speak through a cracking voice and she looked at me through her tear-filled eyes saying, "it's just so hard...I just came back from maternity leave and [the patient] has young kids..."

One of the patients that we had worked with for years

died unexpectedly. The nurse taking care of him exited the room and collapsed as she let out guttural sobs...

I frequently held back tears welling in my eyes so as to be present with patients and families. I never wanted them to feel like they had to take care of me, but the constant dissociation of feeling takes an emotional toll. In the next section, I share a narrative of my work with Ms. F and her family.

Narrative: Ms. F and Family

While in rounds this morning, I observed the beleaguered nursing staff listen closely while the inpatient oncology attending, Dr. T, explained that all efforts to help Ms. F, a 40-something mother of four, were in vain. Ms. F was a full-code and the physician stated solemnly, "I do not know if we can keep her alive through the night. She has mets pervading every portion of her lungs, along with multiple PEs and is on a 50% nonrebreather..." While Dr. T rattled off the multiple comorbidities everyone in the room gasped and the air we began to breathe seemed somehow thicker. We were all still reeling from the numerous deaths that had occurred over the past few weeks.

I met with Mr. F, the patient's husband regularly since Ms. F was admitted and he was struggling. It was only 3 days ago that she came to our floor, but it seemed like weeks. His wife's turn for the worse happened so suddenly. Mr. F was unsure if he should tell his four children about her condition and if so how to tell them. He hoped that Dr. G, the outpatient oncology attending that had been treating his wife for months would bring better news.

Before Dr. G met with the family, he came to my office. He did not have anything hopeful to share with Mr. F and he looked so defeated. Ms. F's rapidly declining health also hit him hard. He had given her excellent care and at one point, she seemed like she might go into remission. I listened intently to Dr. G as he recalled getting to know this patient and family and his recommended course of treatment. I knew that he kept searching his mind for something else he could give her, some therapy, some medicine. He was questioning his abilities as a healer. What happened? How come it didn't work? I always knew him as someone who cared for all of his patients and I reassured him that it sounded like he had done everything he could do to help Ms. F. At the end of our lengthy conversation, he thanked me for working with the family. As he was leaving

he turned and asked, "Do you think he [the husband] should tell the kids?"

I responded that I thought it was best to give the kids the option; three of their children were young adults and should have the opportunity to decide if they wanted to see, and very likely say goodbye, to their mother. I acknowledged that the youngest child was probably too young to understand, but that the patient might want to see her baby. Dr. G lowered his head and said, "I will talk to him too...this is so hard." I could see and feel the weight of this situation on his shoulders. I walked him out to the nurses' station, where he leaned on the counter, to balance himself and took a deep breath. "Dr. G, this family is so blessed to have such a caring doctor. You have done everything you could for her," I said quietly. He looked at me, let out another deep breath and said, "It's just so hard." I knew what he meant. The nurse standing nearby had a similar posture and listened intently. We shared a knowing glance as Dr. G readied himself to enter the room. "Would you like me to go with you?" "Yes, that would be great."

Initially, the patient's husband and father of their children thought it would be better if the children did not miss school and did not have to deal with witnessing their mother dying. Over the three days we met, I provided emotional support in all of our interactions and acknowledged his ambivalence about telling his children. It was clear, he was having difficulty coping and he wanted to protect his children from the pain he was feeling. He was also holding out hope that Ms. F would improve.

Ultimately, when it was apparent that his beloved wife was going to die, he told me that he thought about it and he felt that giving their children the opportunity to make a decision was what he wanted to do. He asked if I would be there when he called his children...at the close of the phone call, he told me they would be at the hospital in about two hours. He asked if I would meet with them when they came to the hospital...

I sat with him in the corner of the oncology unit, near the elevators as we waited for two of his four children (ages 18 and 16) to arrive. His eldest child, age 20, was away at college and was coming in after classes that evening. As we sat on the bench, the father said with his voice shaking and head to his chest, "I do not think I can be here when they come." He looked up at me and his eyes pleaded, "Please help." I encouraged him to take some time for himself. He had been there from the moment his wife was admitted with no time to truly grieve. He checked to make sure I was willing

to stay, he thanked me, and then he politely and quietly excused himself.

As I waited for the kids to arrive, I thought, “tissues, I need tissues...” I grabbed a bunch of boxes of the cheap hospital tissues, wishing I had some nice soft brand-named ones, and placed them in various strategic locations. I decided I would also carry three boxes with me. I paced back and forth in front of the elevator waiting for the doors to open. I watched the elevator doors open and I saw two teenagers and Ms. F’s sister-in-law. Ms. F’s sister-in-law had been at the hospital and she went to pick the children up from school.

Both of the children were so poised, however, their breathing was rapid and the sadness and fear flickered in their wide-eyed expressions. I introduced myself to them and asked if they would be willing to talk for a minute before they went into the room to see their mother. They both nodded affirmatively seeming relieved to catch their breath. I took them to a quiet conference room on the unit that the clinical nurse specialist had reserved for us. Once they sat down, I let them know my role and that I had been talking with their dad since their mom was admitted to the hospital. I told them their dad would be back soon and that he had just taken a walk. I then asked them what they knew so far. They both looked at me and the eldest began pausing in between words to catch his breath, “We know our mom has cancer and she is really sick. We know it’s bad.” I responded, “yes, your mom is quite sick... When you go in the room your mom will look very different than the last time you saw her...”

They looked at me as I spoke to them and I knew they were listening intently. I felt as though I could hear their hearts beating loudly. I admired their courage. I could tell the brother, who was older, was trying to be strong for his sister and he rubbed her head as she leaned into him. I tried to calm them, and myself, through soft tones attempting to model relaxed breathing. I asked them if they had any questions. The daughter was kneading her hands and she looked at her brother who asked, “Is this it? Should we say goodbye?” It was here that I almost lost it. I slowly inhaled and did not speak until I knew my voice would be steady. I let them know that the doctors said that their mother has been fighting hard to get well, but that despite her strength and determination, her body was giving out. After I finished answering all their questions and we sat for a moment, I asked them if they were ready to go see their mom. I let them both know that

“whatever you are feeling is normal and okay.”

I encouraged them to talk to their mother and tell her whatever they wanted her to know. We all left the conference room together. I led the way with their aunt walking behind them. It was a long walk in short hallway. We walked quietly and slowly together. I stopped to wait for them periodically, checking to see how they were doing and then I would turn towards the room. It felt as though we were in a silent film walking in slow motion. I could not hear the noise of the unit and it seemed eerily quiet for the afternoon. As we walked by the nurses’ station, one nurse turned away as if she was looking at the screen, but I could see that she was wiping tears from her eyes. As we got just outside of Ms. F’s room, the 16-year-old daughter collapsed onto the floor with her head in her hands and began to sob. Her aunt was nearest and reached down and plucked her from the floor embracing her with tears streaming down her face. I fought tears with all my might and I could see a number of my colleagues had tears running down their cheeks. I waited for Ms. F’s daughter and her aunt until they indicated silently that I could continue to lead them to the room.

As we approached the door, Ms. F’s 18-year-old son put on his bravest posture attempting to hold back tears and as he did this his thin frame convulsed with no sound. The patient’s daughter entered the room after her brother and both children embraced and began to sob. They held each other for a couple of minutes and I stood next to them with eyes full of water as their aunt embraced them. I was still holding the tissue boxes as a stray tear escaped and trickled down my cheek. Once they had released all of the initial tension, both teens and their aunt faced me and took a tissue as I offered it to them. I reassured them. “Tell your mother whatever you want her to know.” I told them that I was going to give them time as a family and I would be just outside if they needed anything or had any questions. I watched as they approached their mother’s bed so gingerly and then they began to hug her, laying their bodies across hers as they cried. As I walked out of the room, the patient’s husband approached and we shared a look. He braced himself as he walked into the room.

Reflections

I began to question the meaning of this work. How do we prevent emotional exhaustion and stay fully present and empathic in the midst of such suffering? How can we find meaning of the seemingly senseless death of this young mother? How do we witness suffering day after day without losing empathy? How do we stay

focused and attentive to the needs of our patients? 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... (p. 263).

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). Over the past several years, there has been an explosion of illness narratives published by patients. Concomitantly, there has been an increase in the production of narratives in healthcare professionals (Charon, 2006; Frank, 1995, Kleinman, 1988). Charon (2006) who coined the term *Narrative Medicine*, and later, *Narrative Oncology* commented:

By telling of what we undergo...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).

Professionals experience both the pain and the privilege of caring for the sick. We also attempt to recognize each patient’s individual and unique narratives. Accordingly, we healthcare professionals need to have a forum to share their own caregiving illness narratives reflecting upon the “layered consequences” of helping and healing the sick person.

When the professional caregiver listens to the patient tell his or her story, he or she encourages the patient to give voice to their pain. The professional *bears witness* to the suffering that their patients experience, thus informing their own caregiving narrative. Telling and subsequently hearing the illness stories or caregiving stories of others puts the experience into personal and social contexts, gives coherence, structure, symbolism, and meaning to

what may be an otherwise chaotic and *distressing* experience.

Several studies in a variety of populations have shown that the ability to make sense of loss (in personal, spiritual or philosophical terms) alleviates disabling grief symptomatology (Coleman & Neimeyer, 2010; Currier, Holland, & Neimeyer, 2006; Davis, Wohl, & Verberg, 2007; Niemeier, Torres, & Smith, 2011) and that writing is one way to make sense and meaning in the midst of loss. The use of narrative helps the professional caregiver alleviate grief the same as it does for patients.

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). As more health professionals share their caregiving experiences, their experiences and indirect suffering are given a language so that other professionals understand. There is a therapeutic component to the combination of reading, writing and sharing – healing.

Through identifying their own strengths and weaknesses in caregiving, and the sharing of one’s oral narrative, the health professional “bears witness” to the distress, grief, loss, and suffering of illness and is better able to attend to the needs of their patients. Additionally, 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 (Saint-Louis & Bourjolly, n.d.).

Meaning Making

Narrative theorists study how stories help make sense of the world and phenomenon while also studying how people make sense and meaning of the stories. In Frankl (1959/2006), 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 these death camps and brutal human loss. Along the way Frankl discovered that human beings’ ultimate drive is to find meaning and purpose for existence. He asserted that 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 ... we are challenged to change ourselves” (Frankl, p. 112).

The professional caregiver has the opportunity to assist a dying patient’s attempt to find meaning, while also

finding his or her own meaning in providing this care. Additionally, through participation in reflective writing, or writing groups such as narrative oncology or narrative medicine, the professional finds a way of avoiding depersonalization, demoralization and meaninglessness during suffering. The narratives or stories help transcend the suffering and restore meaning to chaos, and rejuvenate workers to deal with the rigors of their work. Grieving among the professional caregivers should be encouraged rather than stifled. It is in the safety of a room of colleagues, which allows for the vulnerability necessary to restore empathy (Brown, 2006). 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, one reasons 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.

Narrative Theory and Narrative Therapy

The theoretical foundations for narrative medicine or narrative oncology come from a number of clinical fields whose practitioners are committed to hearing patients out and acting as active receptacle for their patients' stories of suffering (Charon, 2006).

Narratology is the structuralist study of narrative or of stories. Traditionally, narratologists have concentrated on the criticisms of the narrative plot. Culler (1983) discussed how the contemporary narratologists emphasize story presentation or the narrative act as a key component of the meaning of the story. The shaping of the human experience is initialized and continued through stories. The structuralist analysis of narrative attempts to comprehend how the recurrent themes and patterns yield a set of universals that determine the makeup of a story. Moving from taxonomy of elements to how the elements are arranged in the actual narratives is the ultimate goal (Pradl, 1984), as also noted by White (1980, p. 5):

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* (p. 5).

The French philosopher, historian and sociologist Michel Foucault whose thoughts and work heavily influenced the development of narrative therapy, noted:

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).

Narrative theory is actualized when it is applied to therapeutic situations. 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 Foucault, 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 (Bruner, 1986; Freedman & Combs, 1996).

When both narrative and social constructionism are used as guiding metaphors for one's work, one sees how the stories that permeate our society constitute our lives and the people we work with (Freedman & Combs, 1996). 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.

In narrative therapy, White and Epston (1990) wanted *the clients* 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 illness event, interaction with a patient or related emotions are identified, one wants to link those events, interactions or emotions that occur over time in order to make sense or meaning from them. Thus, once a preferred illness 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 and Epston (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 (p. 9).

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 he or she were an outsider and to think about alternative outcomes for the protagonist in the story.

Thus, the use written narratives about illness as the "preferred event" or "problem saturated story" helps the writer to make meaning, to deconstruct and then externalize the issue. The reconstruction or co-construction of stories occurs in the verbal discourse of the narrative oncology sessions – the verbatim oral recitation of the written narratives and the subsequent exchange between the healthcare professionals and the facilitator.

Narrative Oncology a form of Narrative Medicine

Narrative Oncology is a type of narrative medicine practiced by oncology professionals. This type of *Narrative Medicine* uses writing as a co-creation of meaning between the patient and the professional or brings a more relational stance to medical practice through writing. Charon defines narrative medicine as medicine practiced with narrative competence or as "fortifying clinical practice with narrative competence to recognize, absorb, metabolize, interpret, and be moved by the stories of illness" (Charon, n.d.). Charon identified five narrative features of medicine – temporality, singularity,

causality/contingency, intersubjectivity and ethicality:

[Medical] 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).

Medicine practiced narratively was initially intended as a clinical writing discipline for physicians. However, it now includes a broad range of professionals and refers to "theory and practice of reading, writing, telling and receiving stories" (Charon, 2006, p. viii).

An important component of narrative medicine or narrative oncology is the act of telling one's story in the presence of another. The other bears witness and helps mitigate existential fears of loneliness, suffering, physical harm, loss and death. Both the practitioner and patient, or in the case of narrative oncology rounds described below, practitioner and practitioner, witness the unfolding of a life story in the former or the observing of a professional caregiving narrative in the latter. In narrative oncology rounds or sessions, the professionals share their narratives and comment on the writing of the other.

Narrative oncology sessions typically occur in the healthcare facility where the professionals are situated. The rounds or sessions can last anywhere from forty-five minutes to an hour-and-a-half. There is usually a facilitator that helps to keep the discussion moving and pulls out themes in the writing and sharing of colleagues. These meetings can occur monthly or bi-weekly. The oncology professional caregivers are urged to write to a prompt or questions posed by the facilitator. Alternatively, they can bring something they wrote outside of the session.

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 maintaining a patient's comfort and recommending 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 Latin saying “tempus fugit” rings especially true in oncology work.

Singularity

Through acknowledging their own singularity, oncology professionals recognize the singularity of their patients and are better able to bear witness and accompany patients on their respective journeys. The sentiment shared in the narrative excerpts below 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).

Although, all of the patients that oncology professionals care for have cancer, many with the similar diagnoses, they are each unique. Ms. F had children like many of our patients, and by writing about and recognizing the singular experience of the F family, it helped me to continue to hear each individual patient voice. Singularity in the narrative realm means that each patient is no longer reducible to a number and his/her individual situation is recognized and appreciated.

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 and there are many questions that consume the thoughts of professional caregivers. Why do some persons respond to treatment and others do not? What causes leukemia

or lymphoma? 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).

The patient was diagnosed with cancer is a story. The patient was diagnosed with cancer, was working full-time until she was admitted, and her husband was not coping well is a plot (Forster, 1927). The effort to find causes and make sense of why things happen is the engine that propels narrative (Charon, 2006). In the case of Ms. F, I had to uncover Mr. F’s reasoning for not wanting to tell his children about his wife’s illness. Part of the plot was his fear of losing his wife and the great pain and suffering that would come in having to tell his children they were losing their mother.

Intersubjectivity

“The subject is the self-who-knows, the self-who-acts, and the self-who-observes,” (Charon, 2006, p.51). As healthcare professionals, we often struggle with emotional proximity to our patients and their stories. We simultaneously strive to have empathy and emotional closeness and to be present and care for them while also maintaining enough emotional distance to continue our work. 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. The intimacy between patient and healthcare professional occurs through our interactions with them, especially through listening to what they tell us (Charon, 2006). We become receptacles for patient stories and join with them to create meaning. Additionally, we learn from one another when we share our caregiving narratives. The intersubjective exchange with patients or with colleagues allows for each individual professional to make personal discoveries.

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.

Three Movements of Narrative Medicine

In addition to the five features of *Narrative Medicine*, there are also three movements of narrative medicine are *attention, representation and affiliation* (Charon, 2006). The three movements support the theoretical orientation that *narrating* is an avenue toward consciousness, engagement, responsibility and ethicality.

Healthcare professionals *attend* to the multiple issues, requests, and patients at once. In the context of dealing with a terminally ill patient, *attending* to a patient’s needs change from the hope and optimism of treatment to dealing with the emotions of death and dying. These feelings are often intensified in inpatient settings as the healthcare providers deal with the most acutely ill patients. The use of narrative helps the professional to refocus on the story of a unique patient.

Through the story the healthcare professionals are *representing* what they have witnessed. Additionally, by sharing the writing verbatim in a group setting colleagues from the same or other disciplines share or *affiliate* in and learn from the story. In a recent study, professionals expressed comfort in these shared perspectives (Saint-Louis & Bourjolly, n.d.). The *affiliation* through the attention and representation occurs not only among clinicians themselves, but also includes an affiliation with the patient – a greater understanding of the patient’s journey.

This reflective and/or creative writing is not confined by or bound to the limits and conventions of the medical chart or the electronic medical record. Narrative medicine and its relatives, i.e., literature-and-medicine, relationship-centered care, patient-centered care and others, encourage healthcare professionals to *represent* more completely what they learn about patients and themselves (Charon, 2006).

Bearing Witness-Sample Narratives

Sample Narrative A

The following narrative written by an oncology nurse demonstrates the emotional journey of this one

professional.

Zora (Oncology Nurse) narrative:

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 guts 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... 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 – ‘Zora (name changed), I’m fine, it’s ok now.’ And all I can hope is his family knows too. Zora spoke of the hope in the beginning of treatment and the subsequent disappointments, loss and pain encountered through her interactions while caring for this patient. Zora had been carrying the grief of the loss of this patient with her so that it manifested in her dreams where she was searching for peace. Through her writing she shares her grief and her story closes and cycles back to hope again. She was able to use the supportive environment of narrative oncology rounds to confront her emotions. By writing down her story, she was able to come full circle from hope to hope and she found meaning in her knowledge of and relationship with this patient. Other narratives might appear cold to an outside reader, however, fellow healthcare professionals can relate to the reality and the emotional toll of this narrative within the group setting.

Sample Narrative B

A nurse, who came to the narrative oncology session on her day off, wrote the following narrative,

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, and 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. The nurse admits how well she knew this patient, which indicates the emotional bond forged between this professional caregiver and this patient and her family. 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.

Sample Narrative C

The following narrative by an inpatient oncology social worker expresses deeply complex emotions experienced while caring for a young mother. She wrote about the conflict of the wishes of the patient's family for prolonged hospitalization and "extraordinary medical care" or measures taken to extend the patient's life and her ultimate desire for the pain and suffering of this young patient to end:

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 [the Hospital] 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 [the Hospital] 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.

Sometimes the narratives resemble the bluntness and lack of emotion of chart writing. However, there is so much emotion and pain in the last sentence and the desire to have her suffering end. Here the clinician's wishes for the patients suffering to end are based on her experience and the knowledge of probable outcomes, which ran contrary to the desire of the family. The social worker seeks release from her pain as well.

This type of conflict would rarely manifest in a setting other than the supportive context of a narrative oncology session. Here the facilitator can lead the discussion of the narrative and colleagues support this professional in her emotional conflict and turmoil because they too have had similar experiences. In traditional daily medical rounds, the professional might simply express that the patient and/or family have "unreasonable expectations," but he/she would not elaborate on the feelings underlying this statement. Through the use of narrative medicine rounds, this writing in the group setting and verbally sharing what was written offers support to the writer that might not have otherwise been available. Additionally, it helps others in the group affiliate with the writer's experience thus building community. Through these moments of reflection, professionals described feeling better equipped to deal with similar situations and to cope with the rigors of their work (Saint-Louis & Bourjolly, n.d.). The clinical detachment or emotional numbing exhibited in Sample Narrative C is also a part of the meaning making that occurs within the group setting and for the writer of the narrative.

Sample Narrative D

Below is another sample narrative shared in a narrative oncology group setting. The following is an excerpt of James' (name changed) story, which highlights the last meeting of this clinician, and this patient, who presented to the emergency department for leg pain. The leg pain and wound that accompanied the pain would later be diagnosed as a pathologic fracture due to Stage IV lung cancer. James' initial admission lasted three months (Late February to April) and three months later (July), upon readmission to the hospital he died on inpatient hospice.

We then began to communicate nonverbally. I rolled up a pillow and put it under his head and we moved in this silent way both of us trying to alleviate his apparent discomfort and air hunger. In the midst of this awkward dance, he made us both chuckle when he stated with a delivery that was quintessentially his, "I'm going for the 'L' shape." Ironically, I immediately understood what he meant because it helped maximize the flow of oxygen to his labored lungs. After we managed to make him less uncomfortable, I sat in the chair next to the bed. I knew he was tired, not just physically tired, but emotionally. He was ready to go soon. "James, it's ok if you want to go to sleep." He replied, "you ain't gonna leave me is you." "No, I'm right here. I will sit with you for awhile." I thought I would try to stay until Kendra came back so that he wouldn't be alone. I was hoping she wouldn't be too late as I thought about all that I had to do before days end, but I chose not to worry, and to sit and absorb this moment. I sat still somewhere between tears and stoicism. I sat in the nondescript concave blue chair next to a sleeping Jake as a swirl of emotions rushed over my person. I thought about my first interaction with Jake who was admitted through the emergency room for an orthopedic issue, only to find that it was caused by metastasized tumor from his stage IV lung cancer. Jake pulled me out of my thoughts with a whisper, "I feel like the devil is on top of me..."

My heart sank and I felt a chill in my spine. "What makes you feel like that?" "I've done a lot of bad stuff in my life." I chose to comfort him and to engage in a discussion about his spiritual beliefs. Later I would ask the Chaplain to stop in and see him as well. He stated that he talked to God all of the time and that his ultimate comfort came through his redemptive relationship with his Creator. Silence fell upon us once again with only the sound of the oxygen flowing through his mask. "Are you

scared?" "Sometimes." I just rubbed his hand and my heart ached inside my chest. We sat like this for several moments and I said; "we knew it was going to happen, we just didn't know it would be this soon." He shook his head as a tear trickled down his cheek, "I wish I had more time." I fought back the tears welling in my eyes.

This particular narrative highlights the author's coping with her own grief rather than the detailed clinical interactions she had with the patient in previous meetings. This narrative focuses on what was important to her at the moment of the meeting and compelled her to write. She was in pain and grieving and as she was writing about him tears began to stream down her cheeks. Writing this narrative allowed the author to bear witness to the suffering of the patient and his family as well as to grieve for and eulogize the patient. It also allowed for the revisiting of tender moments and memories of a patient that she came to admire and adore.

Additionally, the memorializing and reflection through the narrative and subsequent sharing with colleagues of the patient and the moment allows for learning to occur. Through sharing this story with other colleagues in narrative oncology rounds, the professional found comfort in the similar stories of colleagues – thereby affiliating and building community. Professionals have little time to process their own emotions, however, through the writing of the narrative she gave form to her pain and she was then able to work through the emotions. She was also able to share this story with her colleagues who processed the story of the patient and shared similar emotions. In the next section, I share a narrative of my practice with Mr. A:

Narrative: Mr. A

One evening around 7pm, I was finishing up some documentation when there was a knock on the door. It was the Clinical Nurse Specialist. Her eyes showed a glimmer of hope mixed with relief that I was still in the office, "I know it is late and you are trying to get out of here, but we have a situation."

"Of course, what is going on?"

"We have a patient in Room 21, that is end stage. He is mostly unresponsive and he is actively dying. We do not have a single contact. We do not know what to do and we don't want him to die alone. We have made him comfortable..." She trailed off, "would you?"

Before she finished her sentence, I started to get up from my chair.

She looked at me with such appreciation and thanked me. I walked to the back nurses' station and I opened the paper portion of the chart to see what information might identify the patient. There was nothing. I searched every computer database we used, also nothing. According to the chart and the nursing staff, the patient's primary language was Japanese. However, he was fluent in English. I then gowned and gloved and went into the patient's room. He was in and out of consciousness. I touched his hand and introduced myself. "Mr. A, is there anyone I can contact to tell them you are here?" He opened his eyes, pulled on my hand, and began to speak, but his words were garbled. He closed his eyes and returned to his agitated slumber. He did not look completely comfortable so I spoke with the nurse.

Then, I sat with him for a couple of minutes, thinking about how I was going to find someone that knows this man and cares for him. The nursing staff knew that he had some children, but that was all of the information they had. I could see the collective concern of the faces of my colleagues and their trust and hope that I could help. I knew finding family was as important for the staff as it was for the patient. We all hated the thought of someone dying alone in a cold, sterile, hospital environment.

As I was thinking, I began to speak to Mr. A. "Is it alright if I look through your bags to see if I can find any information?" I did not know if he truly understood or heard my questions, but he seemed to assent. Subsequently, I began to search respectfully through the pockets of two bags that he had with him when admitted. I did not find much and I was about to give up the search when I realized I missed a pocket. I reached in and I found a basic (non-smart) cell phone with duct tape around the battery. I searched through the phone directory and was relieved to see that there were a number of contacts. I went to the Nurses' station across from the patient's room and began to dial the first number on the list. I reached a voice message. Hi "this is ... a social worker at ... calling to speak with Mr. V. I found your number in Mr. A's cell phone and it is really urgent that I speak with you. I was hoping to get in contact with his family." I methodically made my way through the alphabet of contacts in his phone. Somewhere around the middle of the alphabet, someone answered the phone. I began my introduction, "Hi this is... Do you know Mr. A?"

He spoke English with a thick accent, "Yes, I know A. I am his neighbor." I asked if the neighbor knew Mr. A's family and if he would be able to help me get in contact with them. I sensed some hesitation, perhaps skepticism, which I understood. I acknowledged his concern and I told Mr. A's neighbor that I would not be asking if it were not an emergency situation. He seemed to soften. He told me that Mr. A had two children and that they were hanging out with his children. The neighbor indicated that Mr. A mostly kept to himself and that he was estranged from his wife. He told me he would try to get in touch with family, especially, his children and call me back. I returned to Mr. A's room and let him know that I reached out and tried to find his children.

I tried to encourage him that we were doing everything possible to get his family there. As I sat with Mr. A, I noted the change in the hospital surroundings, the normally well-lit hallway was dark now as it was nearing 9pm and a quiet came over the unit. In spite of Mr. A's deteriorating condition, I thought it was best to give him verbal updates. I sat and spoke to him for quite awhile. Finally, one of the nurses came to the room and stated the phone was for me. The neighbor told me he tried to get the children to call me, but they were busy. I now felt a greater sense of urgency. I thanked him for his efforts to this point and I pleaded with him to please have his children call me as soon as they can. I had not disclosed any details to the neighbor at that point, but I felt I needed to share how dire the situation was with Mr. A.

"Mr. A is very sick. He is probably not going to make it through the night. I know this must be a shock, but we want his family, especially his children, to come and be able to say goodbye to him..." As soon as I said this, the neighbor said, "I will get in touch with them right now. They went to get some food and they are coming back to my house. I promise I will call you right back." I imagined the previous conversation between the neighbor and Mr. A's children. The teenagers probably did not want to be bothered as they were hanging out with friends. Perhaps, they did not have a strong relationship with their father. Also, I had not heard back from anyone else on the list. This time the neighbor called me right back. He indicated that the children were on their way and they should arrive at the hospital in 30 minutes. The neighbor told me he would call some other family and they would come a little bit later.

I shared the news with the clinical nurse specialist, the charge nurse and the other nurses and CNAs caring for Mr. A. They all seemed relieved that some family

were on their way, but uneasy with the fact that two children would be coming. Sensing their discomfort, I reassured my colleagues that I would stay until the children arrived and talk with them before I left for the evening. We spoke about how hard it had been on the unit lately. One nurse shared, "I don't think I could handle it without your help tonight." I knew what she meant. We talked through how we were feeling and we supported one another as we waited for the children. I felt incredibly lucky to work with such compassionate colleagues.

I re-gowned and gloved and went into the room to speak with Mr. A who seemed to be resting more comfortably. I spoke to him and told him his children were on their way. I touched the top of his hand, but he seemed to be slipping further away. I whispered again, "I am trying to get your family here. Your children are on their way." I hoped that he would hold on and wait for them to arrive. I knew the look and smell of impending death and I knew it would not be long. I stayed with him for a bit and realized I had not called my own loved ones. I realized how tired I was and I went out to the desk to make a phone call. Just as I finished the call, two children came around the corner and appeared at the nurses' station.

They looked around the same age, approximately, 11 and 12 years old. Later, I found out they were 14 and 12. They had terrified looks on their faces and seemed apprehensive to approach Mr. A's room. They were dressed casually and each had a fast food container in their hand. The nurses looked at me with an expression that pleaded, *please don't leave yet. Please help us with the kids.*

I introduced myself and Mr. A's primary nurse to the children. As I gowned and gloved, I spoke to them and two nurses helped both children gown and glove. We walked into the room together. I reintroduced myself to them and explained my role. However, they did not respond. Their eyes were wide open and they were staring at their father in the bed. They looked like they were in shock. Both teenagers had been out having fun with friends and now they were thrust into the harsh realities of life. I pulled some chairs near the bed as both children watched my every move. I encouraged them to sit and I pulled up a chair next to them. Both teens sat facing the bed with their chin to the chests with their backs rounded hunching over their laps. They seemed to be avoiding looking at their father. The eldest put his head in his hands. As we sat there, I began to try to engage them in conversation. They

looked at their father but quickly averted their eyes and then they looked at me.

I realized I had introduced myself, but I did not know their names. The older child was more communicative so I asked, "What is your name sweetheart?"

"Jay."

"And what is your name?" directed at the younger of the two. He did not answer. Jay responded, "His name is Matt." I asked about their mother. Jay indicated that she was working and the neighbor would tell her where they were. He indicated that his parents did not really talk to one another. I asked if they had any questions about what was going on with their father, but they did not respond immediately. I explained as sensitively as I could what was happening. They remained quiet and polite. I noticed that Jay wanted to say something, but he seemed stuck. He would mouth words, look at his father, then at me. I let Jay know that it was okay if he wanted to talk to his father. I modeled this by talking with Mr. A and touching his hand.

After I did this, Jay dropped his head to his chest and took a labored breath. I wondered if I had done something disrespectful or culturally inappropriate. I asked the children, what I could do to help them right now. Once I said this, they both relaxed a bit. Jay fixed his eyes on me and I knew he wanted to tell me something. I began to think that I should give them time to themselves and that my presence might have been impairing their communication. I also did not want to leave them alone if they were scared. I started to mention that if they would like I could give them some time alone with their father. They nodded their heads affirmatively. However, I did not feel convinced they wanted to be alone. I acknowledged how difficult this must be for both of them and how they had been having a relaxed night with friends and all of a sudden, they were thrust into a very serious and shocking situation. As I was about to inquire further, Jay seemingly mustered all his strength to say, "We were fighting. We did not have a good relationship."

I thanked him for sharing this information with me and acknowledged again how hard this must be. I shared that "relationships can be complicated, and sometimes even difficult..." They both remained quiet so I continued. "There must be so much going through your minds right now...no matter what happened between you I can see that you care for your father... right now you have the opportunity to talk to him..." I reiterated that I would give them some time alone with

Mr. A. After we sat in silence for a minute or two, I slowly began to move.

Jay grabbed my hand, "Will you stay for a minute?"

"Sure. Of course." I sat next to Jay as he began to cry and squeeze my hand and his father's hand. He did not let go of either as he spoke in both Japanese and English. Every once in awhile, he said, "Why?" through his tears.

The younger child, Matt hesitated, but seeing his brother reach out gave him the courage to do the same. He also held his father's hand. Then Matt looked at me and innocently stated, "Will he be alright?"

I acknowledged that this is a lot to take in right now, but that their father was quite ill. I told them that in a little bit the doctor would be up to see them and they could ask any questions they might have of both the physicians and the nurses. In the meantime, I let Jay and Matt know that the doctors were keeping Mr. A comfortable. I answered their questions and I indicated that the medical team felt that Mr. A had probably a couple of days. However, I knew based on how Mr. A looked that it was probably more like hours. I reiterated that we could call the doctors to come and answer any questions they might have right now, but they seemed to be okay for the moment. I let them know again that the nurses could also answer any medical questions they have about how their father was doing. I sat with them for a bit and I let them know I would give them some time with their father. This time they both seemed to calm down and were more comfortable. I thought this might be a good time to allow them to be alone with their father. After leaving the room, I debriefed the nurses all of whom were nearby at the RN station. As we talked, we could hear the children crying in the room. We paused our conversation and all took a deep breath fighting back our own tears. One nurse looked at me and said, "This is so hard. I do not know how you do it all of the time... Thank you." I agreed that this was difficult and that it impacts us all in different ways. I thanked her for taking such good care of Mr. A..."

Conclusion

Narratives or writing about clinical practice provide oncology caregiving professionals an opportunity to bear witness, honor and work through the grief and loss they experience in their daily work. As we take care of people in healthcare settings, we become a

part of their lives. We are immersed in their stories and simultaneously our own caregiving stories emerge. These experiential stories or narratives incorporate patient suffering, pain, grief and loss as well as the emotions of the individual professional and are an integral part of the practice of narrative oncology.

Narratives help make sense of conflicting or confusing emotions and allow the individual author to reflect on each situation, mourn and tap into the pain of others. By finding meaning in the suffering of one's patients' or colleague's stories, we can find significance in providing care in the midst of overwhelming sorrow.

Using writing or narrative is a strength-based exercise and can be personally empowering. Each participant shares their own unique phenomenological experience and its specific meaning to them. They bring emotions, which may otherwise be repressed or forbidden, to a safe discussion among colleagues. The condition created is relational and emotionally validates each member.

Numerous schools of thought influence narrative medicine/oncology and narrative methods in medical and psychotherapeutic practice.

Writing is one medium that helps individuals cope with the distress, grief, and loss associated with caring for individuals with cancer diagnoses. The use of these narrative methods and narrative medicine rounds in healthcare practice 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.

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- About the Author:** Nicole Saint-Louis, D.S.W, LCSW is Assistant Professor of Human Services, Stella & Charles Guttman Community College at the City University of New York (CUNY) (646-313-8045; nicole.saint-louis@guttman.cuny.edu).