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Changing Landscapes: End-of-Life Care & Communication at a Zen Hospice

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Changing Landscapes: End-of-Life Care & Communication at a Zen Hospice

by

Ellen W. Klein

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
Department of Communication
College of Arts & Sciences
University of South Florida

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Keywords: Health, Community, Spirituality, Ethics, Caregiving, Dying

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Dedication

For Ann and Avigayil.

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Abstract

This dissertation examines end-of-life experiences at a small Zen hospice in the Pacific Northwest region of the United States. Through an exploration of how end-of-life communication, sense-making, decision-making, and care in this setting differ from that of typical clinical settings, this project highlights and interrogates the experiences of dying as spiritually, rhetorically, narratively, relationally, and communally bound events.

Keywords: Zen hospice, end of life, narrative sensemaking, medical-ethical decision making, spirituality, healing rhetoric, communities of practice

Chapter One: Entering the Landscape



Figure 1: Summer, Primrose

One lesson, Nature, let me learn of thee,
One lesson, that in every wind is blown
Matthew Arnold

Bright green shoots push their way up through the soil bringing spring's first tight buds of crocus, daffodil, and primrose. Soft showers and cool winds give way to summer's warmth, wild roadside cornflowers, and trees full with ripening fruit. Then, just when every green and flowered thing has reached its profuse bloom, early morning and afternoon breezes turn cool. Once vibrant, verdant leaves begin to yellow and crisp at their edges only to overnight, it seems, give way to flaming oranges and reds. As quickly as leaves fall to blanket the ground, once only

chilly nights have become bitter cold. Sharp morning winds accompany bright winter days and I look to bare branches and frozen soil for signs that spring comes again.

Seasons change and the landscape of nature transforms from one glorious and sometimes terrible state to the next. Flora and fauna come and go in the natural course of a year; new animals are born, fruit and flowers bloom, and, eventually, with the passage of time, they all die. Through observation of nature, we are reminded that nothing stays the same and yet everything is the same; dying is like this too. It is dynamic, though, like the seasons, predictable in many ways. Dying is an experience, our own or those of others, with which we must at some time all contend. It spares no one. Yet, it is felt each time as a distinct, discrete event. Like a birth, a death is the same as and different from any other death. Comfort may be found in the knowledge that death is nothing new, our bodies inherently know how to do it, and, unencumbered by an excess of interventions, it is a relatively simple and predictable physical process. At the same time, our dying presents us with the challenges that make each death unique. For instance, each experience of dying may be complicated by emotional and/or spiritual suffering that comes as a consequence of unmet expectations, loss of hope, or fear of the unknown. Each death may also be complicated by the prospect of very real physical suffering. Understanding the dying trajectory as a transforming landscape offers us the opportunity to notice the changes underway, to realize the dynamic nature of dying, and to see how emotional, physical, and/or spiritual needs emerge, dissipate, and emerge again. So too, we are afforded the chance to participate in attentive and mindful care of the dying as they transition to, and through, each new stage of the process. This metaphor of dying as a transforming landscape reminds us that the passing of time does not allow any of us to remain steadfast in a moment. As the landscape changes, it will surely also fade.

A. Attending to the Landscape

For as long as I can remember, I have been an avid observer. I am keenly attuned to pattern and aberration. This general sensibility later translated well into clinical skill in which attention to change and deviation from the “norm” is paramount to assessing a patient’s status. I did not begin with a clinical context, however. I began with nature. As a child, I spent long hours outside in the yard, garden, and neighborhood of my grandparents’ home. Blackberry brambles engulfed the back fence, long neat rows of vegetables grew each season, violets flowered the ground beneath the pussy willow tree, and, each spring, tiger lilies made their appearance. Nightly, generations of birds flocked outside the back door where Nana, my grandmother, prepared their ritual feeding of stale cornbread and biscuits. Hot pink azalea bushes gave colorful contrast with the pale green of my grandparents’ clapboard house while quince, peonies, and forsythia made bright yellow and pink contributions of their own. I came to anticipate all of this with each new season. Images such as these act as visual reminders of the importance of attending to the often-unnoticed change around us. These changes are vital communications, ones that, were we less attentive, we might otherwise miss. Authors and poets of great renown have always drawn our attention to the importance of attending to nature’s landscape (Thoreau, 1904; Oliver, 2003; Dickinson, 1961; Bishop, 1983; Plath, 1992; Emerson, 1995; Whitman, 1999; Carson, 2002). Calling her readers to mindful attention in her poem “Swan,” Oliver (2003) asks, “Did you see it? [...] And did you feel it in your heart, how it pertained to everything? And have you changed your life?” (p.15). The beauty of the swan, she seems to say, is both a source of sensual pleasure and potential transformation. Through our mindful attention to the swan, to nature, we may awaken ourselves to what is right before us, to look, listen, and feel our way to understanding. For as Oliver (1994) reminds us, “to pay

attention, this is our endless and proper work” (p. 8). Ultimately, we may move through life and through dying oblivious to the subtle yet significant changes taking place, or we may make ourselves consciously aware of, and attend to the landscape as it alters before our very eyes.

B. Getting Acquainted & Exploring the Hospice Landscape

Every summer we come to the island for my daughter to go to camp, and, over the years we have befriended people who live on the island and others who, like us, come to the island during school breaks and holidays. A few summers ago, a woman whose children attend the same camp as my daughter, and with whom I have become friends, lost her ailing father. In early August that year, while we were still together on the island, she shared with me the warm, loving experience that she had with the people to whom she entrusted her father’s care in his final days. My friend described the long and difficult trajectory of her father’s dying and the incredible care he received at the Zen hospice facility where he lived during that time.

At that same time, I was looking for a place to conduct my dissertation research. I had already learned a great deal and had been teaching college students about the unique approach to working with the dying that is employed at the San Francisco Zen Hospice Project¹. Drawn to their particular kind of end-of-life care, I wanted to see who else was infusing care of the dying with similar Buddhist sensibilities and practices. When my friend described her experience with the hospice, I knew it was a place about which I needed to learn more. My friend strongly recommended that I visit the hospice and she was kind enough to connect me with the director and physician, Ann. Shortly thereafter, during a phone conversation with Ann, she and I

¹ The Zen Hospice Project in San Francisco California began in 1987 under the direction of Frank Ostaseski and in response to the dire need for compassionate twenty-four hour care for those suffering and dying from AIDS (Varvaloucas, 2012). The Zen Hospice Project has since facilitated the care of over three thousand patients, trained roughly eight-hundred hospice volunteers, and provided educational services to the public (Heilig, 2003).

arranged my initial visit. A ferry ride and beautiful drive through Pacific Northwest forests later, I arrived at the hospice house to meet Ann.

The hospice landscape may be viewed from many perspectives: the literal space and place of it, the people involved, and the kinds of physical, emotional, spiritual, and ethical work that is undertaken by the community. The space and place are quite simple, serene, and in keeping with Buddhist sensibilities. The hospice is located on an island and is situated amidst a great field surrounded by a coniferous forest. Patients receive their care in the main house which is much more spacious on the inside than it might appear from outside. The atmosphere of the place is calm, quiet, and welcoming. Large, comfortably furnished living spaces connect to an open area kitchen where meals for patients, families², friends, and caregivers are prepared. The patients' rooms are cozy and offer beautiful, scenic views of the surrounding fields and forest. Beside the hospice house is a small yellow cottage in which Ann, the physician and director of the hospice, lives. Overall, the site is pleasing, even reassuring. It welcomes and comforts.

Sitting at a small kitchen table, Ann and I drink strong, dark coffee that she made for us while we talk. Ann wants to know how I came to be interested in the hospice, what my research focuses on, and why I am studying death and dying. I tell Ann about my daughter's decade of serious illness and about my work with medically fragile children and women experiencing perinatal loss. I tell her that I am bruised by inadequacies in the system of care for the seriously ill and dying, and that I want to contribute to improving our practices. Ann and I speak at length about our lives, families, and work. She is generous with her time, and she listens deeply with a comforting stillness. Ann nods, gently bobbing her head in affirmation, as she takes in my story

² I employ this term "family" in the broadest possible sense to include loved ones, partners, and significant people in the lives of the dying that may not be represented or acknowledged by a definition of family limited to laws of kinship. Instead, I draw upon the concept of "families of choice" to include anyone of importance to the dying person (Weston, 1991; Weeks, Heaphy & Donovan, 2001; Oswald, 2002; McCarthy & Edwards, 2011; Treas, Scott, & Richards, Eds. 2014).

and considers my questions. She laughs easily and smiles readily. Ann tells me briefly about the hospice house, how they work in conjunction with the local hospital, island hospice services, and the monastery to which they are connected, and by whom they are supported. When I begin to sense that I have answered her questions, I ask for her permission to conduct my research at the hospice house. Ann agrees and then invites me to have lunch with her at the monastery.

After a quick call to the Vice Abbot, we are on our way. Ann and I walk between a small barn and covered garage and pass a little garden enclosed by fencing erected to keep out the deer. We continue on a dirt path running through tall, sweet meadow grass that covers the field to the edge of the woods where the path narrows and darkens under the pine canopy. Taking up slow passage across the soft, dark earth, giant yellow and black spotted banana slugs leave shiny, silver trails over leaves and moss. I watch my footing so as not to step on them as we make our way. Ann describes the path connecting the hospice and the monastery as their “umbilicus.” I think to myself that this is an interesting and intimate, maternal metaphor for their relationship.

Once we clear the woods, I see that the monastery is comprised of a collection of modest yet visually pleasing wood buildings. The Vice Abbot who heads the monastery, visiting monks, and practitioners live, pray, eat, and work here. There is a lovely, full garden in which they grow most of their food and a spacious, high-ceilinged kitchen that benefits from the natural light permitted by many windows. This is the place in which meals are prepared for members and guests of the monastery and where Ann and I will share lunch on stools around the tall butcher-block table. A young, quiet, smiling female initiate has prepared our lunch using what she picked from the garden. She places rice, vegetables, soup, and a hearty-grained bread on the table for us. Ann introduces me to the Abbot; he smiles and nods his head towards me but does not speak. Turning to Ann, he speaks briefly with her about matters at the hospice and about an

upcoming community event. With eyes still downcast, the Abbot turns back to the table and, with the corners of his mouth hinting at a smile, he says, “you’ll just follow along and try to keep up.” His smile broadens and lunch begins. I come to understand what he means when he tells me to try to keep up. Our lunch is a practice in mindful eating as we participate in the Japanese ritual of oryoki³, often translated as “just the right amount.” As is the custom, ours is a silent lunch except for when meal sutras are chanted. We eat from small bowls and food is served from the right, passed to the left, and goes around again as we move through each phase of the meal. Chanting, eating, and stacking bowls happens quickly, and I work to keep up with the fast pace as well as the words chanted before, between, and after courses. When it is over, having moved so quickly and without opportunity to ask questions, I am both confused and exhilarated by the process. I think to myself that I have done well not to audibly sigh, “Whew!” when the ritual is complete. Having rinsed and stacked my bowls, as the others did, I look up to find the Vice Abbot meeting my gaze for the first time. With his head still slightly bowed, he says, “Well, I guess you’ll fit right in then.” I took this to mean that I had passed some quiet test and that he had given his permission for me to return. I was relieved and excited to begin my work with Ann and the Vice Abbot. Reflecting on the day sometime later, I realized that this visit not only began the relationship that ultimately led to this dissertation project, but also, in many ways, changed my life.

³ For a simple, yet thorough explanation of the oryoki ritual please see Kay, L. & the Sangha of Kannon Do Zen Meditation Center. (n.d.). A manual for the construction and use of eating bowls. Mountainview, CA: kannondo.org. To view a video showing the ritual in action see Oryoki Basic Instructions With A Zen Master Chozen Bays Roshi - Mindful Eating Workshop at Great Vow. Retrieved May 25, 2014 from <https://www.youtube.com/watch?v=QdZk2IGVUPE>.

C. Thinking Narratively

Although I secured permission to conduct my research with the hospice, it would not be until the following summer that I returned to the island to begin observing and participating in the care of patients. In the interim months before my return, I considered at length what I hoped to learn from the people at the hospice. Every quest to make end-of-life care better seemed to have one thing in common: an interest in helping patients find as peaceful, pain- and suffering-free ends to their lives as possible. Because this aim cannot be reduced to mere pain-management, this led me to think about how vital it is to consider the stories we tell about end of life and to wonder what kind of stories a Zen hospice might help dying patients tell. Giving serious consideration to the individual and collective narratives in which we envision ourselves living, and through which we make sense of the world, is not new, however. We are, as Fisher (1985b) reminds us, “[...] storytellers-authors and co-authors who creatively read and evaluate the texts of life [...]” (p. 86). More so, Frank (1995) says that often we are not only storytellers, but also “wounded storytellers.” The “person who turns illness [and dying] into story transforms fate into experience; the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability” (Frank, 1995, p. xi). The act of storytelling, Frank (1995) argues, not only joins us in the shared experience of suffering, but gives voice to the voiceless. “Telling stories of illness [and dying] is the attempt [...] to give a voice to an experience that medicine cannot describe, [...] wherein] the storyteller seeks to reclaim her [or his] own experience of suffering” (p.18). These authors are not alone, however, in their shared sense that the narrative endeavor is a vital one.

A wealth of scholarship is dedicated to defining and highlighting the importance of narrative in the fields of communication (Fisher, 1984; Fisher, 1985a; Fisher, 1985b; Book,

1996; Bochner, 2002; Harter, Japp & Beck, 2005; Bochner, 2009; Ellis, Adams & Bochner, 2011), medicine (Kleinman, 1998; Mattingly & Garro, 2000; Brody, 2003; Charon, 2006; Apostelaris, 2012; Roscoe, 2012; Roscoe, 2009; Hurwitz & Charon, 2013; Vanatta & Vanatta, 2013; Rian & Hammer, 2013), ethics (MacIntyre, 1984; Lothe & Hawthorn, 2013; Brody & Clark, 2014; Montello, 2014; Hoffmaster, 2014), religious ethics (Fasching, deChant, Lantigua, 2011; Goldberg, 1991; Stroup, 1991; Fasching, 1992; Fasching, 1998; Fasching, 1990), to name only a few. In their respective fields, scholars and writers teach us a great deal about the power of narrative to shape and inform our understanding of the world around us, of our place in it, and how we make sense of and manage our most difficult and deeply consequential experiences. Certainly our dying is one such experience and, because dying is not so much a problem to be solved as a story to be told, the transforming landscape of the dying trajectory is also and always a narrative.

So too, dying is an ongoing, emerging story composed by and with patients, practitioners, loved ones, and caregivers. As Frank (1995) and others have argued, dying is certainly often, but not merely, a clinical story. At best, it may be understood as co-constructed and emerging across the evolving landscape of end-of-life trajectories. When patients and caregivers co-create the dying experience in this shared landscape they collectively engage in what I have come to understand as and call, “composing a death.” I lovingly borrow inspiration for this frame of dying from Mary Catherine Bateson’s (1989) work, *Composing a Life*, wherein she writes about “that act of creation that engages us all—the composition of our lives” (p. 1). As in life, we compose the story of our dying and death. When we do so, we engage, as Bateson (1989) describes, in an “improvisatory art [...] combin[ing] familiar and unfamiliar components in

response to new situations,” with patients, practitioners, caregivers, and families composing together as the story emerges and changes over time (p. 3).

Conceiving of dying as a story we compose together, an approach fundamentally different from that of the traditional clinical model, also helps us understand dying as a relational experience. As such, this frame invites us to enter into the narratives of others. Furthermore, in the end-of-life context, thinking of dying as a story we compose together calls upon us to entertain narratives that are different from our own, perhaps even narratives that we might never have imagined. And, even though these narratives will be in many ways unique in that the manner of our dying may reflect our individual lives, what we certainly share is a desire to make the dying process for ourselves, and those for whom we care as good as it can possibly be. In this way, it may be said that we keep company with those who wish to narrate, or compose a “good death.”

D. Narrating a “Good Death”

A great deal of scholarship has been dedicated to improving the end-of-life experience, to defining what it means to have a “good death,” and to devising the best possible means of creating a “good death” for patients and ourselves. This notion is readily traced back to the work of Ariès (1974) and the much celebrated, as well as critiqued, work of Elizabeth Kubler-Ross (1970, 1997). A preponderance of scholars over the last several decades have reached for a thorough and inclusive definition of what it means to have or provide a “good death” (Emanuel & Emanuel, 1998; Hart, Sainsbury & Short, 1998; Smith, 2000; Steinhauser, Christakis, Clipp, McNeilly, McIntyre, & Tulskey, 2000; Sandman, 2004; Izumi, Nagae, Sakurai & Imamura, 2012; Scarre, 2012; Sherwen, 2014). Understandably, scholarship relies on practitioners, family

members, and patients for contributions to defining a “good death” (Steinhauser, Clipp, McNeilly, Christakis, McIntyre & Tulsky, 2000; Pierson, Curtis & Patrick, 2002; Balducci, 2008; Miyashita, Morita, Sato, Hirai, Shima & Uchitomi, 2008; Andersson, Ekwall, Hallberg & Edberg, 2010; Horne, Seymour & Payne, 2012; Courtemanche & Grady, 2012) while some scholarship focuses more specifically on the disparities in these perspectives (Payne, Langley-Evans, Hillier, 1996; Copp, 1997; Costello, 2006). A number of themes emerged over the years as important to practitioners, patients, and families alike. These themes are not limited to but include concerns about pain management (Lynch & Abrahm, 2002; Wilkie & Ezenwa, 2012), what quality of life may mean for patients and practitioners (Byock & Merriman, 1998), the importance of place of dying and death (Yao, Hu, Lai, Cheng, Chen, & Chiu, 2007; Paddy, 2011; Hales, Chiu, Husain, Braun, Rydall, Gagliese & Rodin, 2014), decision-making (Parks & Winter, 2009; Huang, Chiu, Lee, Yao, Chen & Hu, 2012; Tan & Manca, 2013), spirituality (Schenck & Roscoe, 2009; Stajduhar & Coward, 2012; Wynne, 2013; Will III, 2013) and relationships (Tan, Zimmermann & Rodin, 2005; Zerwekh, 2006; Foster, 2007; Prince-Paul, 2008; Prince-Paul & Exline, 2010). Input from patients, practitioners, caregivers, and families has certainly developed our understanding of what it may mean to die well, and yet our end-of-life care still seems lacking. Each new experience of dying asks something of us, asks us to consider how we might better story dying and yet, Schenck and Roscoe (2009) rightly caution us that, “care should be taken not to impose on dying persons the obligation to die a good death [...] or] insist that all who are approaching the end of life use the time remaining to craft a good story” (p.68-69). And so, those of us wishing to better end-of-life care through scholarship or participation in the care of the dying must continue to examine the stories we tell about dying and the roles we play or may play in co-constructing end-of-life narratives with patients and families.

E. Aims of the Project

As someone engaging in that effort, I came to see this dissertation as a means of examining end-of-life experiences at this small Zen hospice to explore how end-of-life communication, sense- and decision- making, and care in this setting might differ from the typical clinical setting in which most Americans die. I hope to show how the spiritual, communal, relational and ethical practices at this Zen hospice can inform and enlighten our understanding of caring for the dying. Rather than treat the spiritual and relational as secondary or adjunct concerns for patients and practitioners who are involved in the care of the dying, this project aims to highlight and interrogate the experience of dying as spiritual and relational in nature. Furthermore, through this project, I seek to better understand death and dying as narratively, relationally, and communally bound events that, as a consequence of individual and collective spiritual narratives, may prove to be sources of resilience, comfort, and/or distress for patients and caregivers alike.

Through this research I hope to concurrently identify ways that communication may be enriched and complicated by the stories in which we see ourselves and others living, especially in deeply intimate and consequential moments like those at the end of life. In my work with the members of the hospice, I seek to understand how Zen narratives inform the practices of care I have found there with patients, practitioners, caregivers, and families. This endeavor is generated by my interests in how Zen spiritual practices influence the patient-practitioner relationship, the ways in which spiritual narratives inform end-of-life decision-making, and patient and practitioners' engagements in such decision-making in relationship with one another. Unlike the traditional hospice approach that relies on an overtly clinical model for dying, Zen

hospice philosophy and practice make center stage the spiritual nature of dying. I hope to learn from this project how this approach works in the microcosm of the hospice house, in the local monastic community, and how its practices might translate into other end-of-life contexts.

F. Research Almanac

As a means of compassionately and ethically achieving these research goals, this dissertation uses a feminist ethics of care approach to conducting ongoing participant observation with patients, families, practitioners, and members of the hospice house and local community. In the course of several hundred hours of participant observation I worked along side the hospice physician, nurse, and caregivers taking care of patients and their loved ones. I amassed copious field and interview notes and participated in numerous communal and organizational events. Using these notes, I coded my data and identified major emerging themes that I address in the analyses that follow. Interwoven with my analyses are accompanying narratives of events that took place when I was at the hospice. I present the major themes of my research in the form of seasons: autumn, winter, spring, and summer, the periods during which I cared for the patients whose stories I share. In keeping with the theme of changing landscapes at the end of life and as part of engaging in the practice of mindfulness, I also recorded images, a few of which I have included here, of the literal changes in landscapes at the hospice house and around my own island home during the course of my research through drawings and paintings.

This dissertation is organized into seven major chapters, throughout which the communal, relational, ethical, narrative, spiritual, and rhetorical themes carry and interweave. Following this introduction, chapter two presents theoretical perspectives on the end of life as spiritually, rhetorically, and communally situated experiences while chapter three covers my methodological

approach and includes an at length discussion of the ethics of care. Subsequently, chapters four through six offer analyses of the major emerging themes of my research and correspond with seasons of the year. Chapter four details the nature of what Ann calls “[island hospice] Energy”. It includes a discussion about managing certainty and uncertainty, doing and non-doing (wu-wei), the role and importance of intention as well as the five precepts adopted from Frank Ostaseski, the former director of the San Francisco Zen Hospice. This section shows the island hospice approach to helping patients and families decide if the hospice is a “right fit” for them and to selecting, training, and assigning tasks for volunteers and initiates who come to participate in the care of patients. This chapter also highlights some of the surprises they experienced working with patients, families, and volunteers that the physician and nurse/nun shared as examples of the importance of “don’t know” attitude that embraces rather than avoids relational uncertainty. Additionally in this section, I address “inhaling” as a receptive communication practice and a form of communication described as “tending” in conversation. This chapter further shows how choice, safety, privacy and independence are navigated.

Chapter five addresses the ways in which ritual and improvisation are enacted in end-of-life care. I discuss the fluid nature of these two aspects, how they work in tandem, and how they communicate and employ deep ethical “know-how” along with clinical and/or relational prowess without engaging in radical autonomy or paternalism. I also show how some improvisations might be understood as “play” at the end of life and how ritual performance may act as a communicator of clinical and/or relational know-how and may also, therefore, be interpreted as a sign of trustworthiness. This section also discusses sensemaking and decision-making as co-constructions and relational accomplishments with practitioners, patients, families, and

caregivers by, as Ann explains “following not leading” patients via the practice of mindfulness in which “you attend to what is happening in front of you in as clear a way as you can manage.”

Chapter six addresses a notion with which we are all well acquainted, that death often constitutes a clinical and/or even personal failure for practitioners and caregivers and that spiritual narratives are often cited as sources of comfort for patients, families, caregivers and practitioners in the face of this failure. This chapter also highlights the ways in which personal and spiritual narratives may act instead as a source of constraint or failure for practitioners, patients, families, and caregivers. As a consequence these narratives may then produce more suffering than relief. This section also examines the tension(s) that can result when personal narratives that call for opposing actions come in conflict with one another and how these are suppressed, acted upon, or dissolved at the island hospice.

Finally, the last chapter and final season of this dissertation is a reflective and reflexive discussion of my time spent at the hospice. In this concluding section, I present my final thoughts on the potential implications for end-of-life care and communication beyond the context of the small hospice setting and what the practitioners, patients, families, caregivers, and member of the monastic community have so graciously taught me.

Given what I learned over the course of the year at the hospice house, major themes that emerged made it evident that I would not only benefit from attuning to the changing landscape and thinking narratively, but also come to see the great importance of attending to the spiritual, rhetorical, and communal aspects of end-of-life care. Specifically, I became more finely attuned to how spirituality at the end of life is communicated with patients in their dying as well as among practitioners and caregivers in their care of dying patients. Consequently, I argue for treating the spiritual and relational components in end-of-life experiences as deeply meaningful

and worthy of equal consideration along side physical and/or clinical concerns. Furthermore, because we make sense of our experience through our personal and communal narratives, those narratives often come in conflict with one another, especially in the sometimes highly charged and always deeply consequential context of end-of-life sense-and decision-making. Navigating these narrative tensions can be fraught with difficulty, but it is not impossible, and this research seeks to also acknowledge the comforts as well as expose the tensions created by the narratives in which we live and through which we make sense of illness, dying, and loss.

For these reasons, the following chapter serves as a brief foray into scholarship dedicated to spirituality at end of life, the work and significance of healing rhetoric, and aspects of key Buddhist principles that situate death in the context of community. It is within this body of scholarship and theoretical perspectives that I believe what I have learned from the people at the hospice and monastery will most likely fit as well as offer significant contribution to our understanding of composing, together, narratives of end of life.

Chapter Two: Dying as Spiritual, Rhetorical, and Communal Landscapes

End-of-life experiences can be the most difficult experiences we individually and collectively face. Technology often outpaces our ethics and, as such, technological advances have made it possible to extend life well beyond what we seem prepared to grapple with ethically. We find ourselves confronted with clinical interventions that are often futile (Ferrell, 2006) and potential sources of discontent for patients, practitioners, families, and caregivers. As a result, when we are, or someone we know is dying, we face an array of complicated and difficult issues. Practitioners have the added problem of having to make and implement clinical decisions that further challenge who we are and what we think we know about the world as we have come to understand it, one another, and ourselves. Furthermore, death and dying bring about ruptures in the fabric of our lives that often cannot be easily made sense of or mended.

Thus, end-of-life situations are worthy of not only medical and ethical but also relational consideration. With autonomy as the reigning paradigm in medical ethics for roughly the past sixty years, this limited focus is evidenced in instances in which we concern ourselves with aspects of individual agency. We fail to grant equal consideration to our responsibilities to and for one another. In so doing, we risk deemphasizing or even ignoring the relational nature of these experiences; this can only ever grant us partial understanding of situations at the end of life. Comfort for the dying or for those participating in their care can be understood as a relational accomplishment as within our relationships is from where we must seek to best care for the dying, their families, and their caregivers.

This chapter offers an overview of pertinent scholarship related to aspects of the spiritual, rhetorical, and communal natures of end-of-life care and communication. While these perspectives may, at first, seem unrelated, my experiences at the island hospice converge at the intersections of these theoretical perspectives and as a whole a common thread among these perspectives is relationality. I begin my discussion by introducing theoretical perspectives on spirituality, specifically highlighting the moral distress, spiritual distress, and suffering that patients, practitioners, families, and caregivers may experience. Next, I discuss common healing rhetoric and metaphors that are employed in consoling and compensating (Payne, 1989) for loss and end of life. I conclude this chapter by exploring the relational and communal landscape by surveying literature that examines patient-practitioner and patient-caregiver relationships and discussing communities of practice and, more specifically, Buddhist community.

A. Exploring the Spiritual Landscape

Death and dying have long been storied as clinical and spiritual experiences, and medical ethical literature abounds with case studies framing and reinforcing end of life as a clinical event complicated by uncertainty and the difficulty of ethical decision-making. Whether emphasizing autonomy or paternalism in end-of-life care, much of this scholarship concerns itself with what should or should not be clinically done in the care of the dying. Chief concerns include implementing or withholding life-prolonging clinical interventions and, for example, consequences of using medical technologies to extend life and cease or prolong suffering. Focusing on the clinical aspects of dying such as these has arguably taken precedence over other concerns in recent history, particularly in the West.

Ironically, an even greater body of literature exists that explores death and dying as a spiritual experience. One need only turn to such timeless stories as *The Epic of Gilgamesh* (Anonymous & George, 1999), St. Augustine's *Confessions* (Augustine & Pine-Coffin, 1961), *The Life of the Buddha* (Saddhatissa, 1976), or even more recent accounts such as those in *Tuesdays With Morrie* (Albom, 1997), *The Last Lecture* (Pausch & Zaslow, 2008), or *My Stroke of Insight* (Taylor, 2008) to find how encounters with illness and death have been described and understood as opportunities for spiritual transformation. These disparate ways of making sense of death and dying as clinical and spiritual, however, are not often put in conversation with one another. Namely, equal consideration to the clinical and spiritual aspects of end of life is rarely given. This is not to say that spirituality is not considered in the clinical model of end-of-life care; on the contrary, it is. Though, spirituality is relegated to some lesser component of the larger clinical picture of a patient's dying and is frequently considered as adjunct spiritual care offered at will or request by nurses or members of pastoral care teams. As such, spirituality at end of life is not often granted equally great importance in the care of the dying.

Some organizations, such as traditional hospices, employed in end-of-life care concern themselves more with the spiritual nature of dying than do others. Ultimately, however, most hospices do not typically stray far from the biomedical script, leaving spirituality at end of life as a luxury at best and as an afterthought at worst. Research has been dedicated to understanding and improving communication about spirituality in healthcare (Miller & Knapp, 1986; Lo, Quill & Tulsky, 1999; Long, 2001; MacLean, Susi, Phifer, Schultz, Bynum, Franco, Klioze, Monroe, Garrett & Cykert, 2003; Egbert, Mickley, & Coeling, 2004; Keeley & Yingling, 2007; Marr, Billings & Weissman, 2007). Healthcare practitioners may feel uncomfortable or unqualified to address spiritual matters (Ellis, Campbell, Detwiler-Breidenbach & Hubbard, 2002; Saguil,

Fitzpatrick & Clark, 2011; Abbas & Dein, 2011; Biro, 2012; King, Dimmers, Langer & Murphy, 2013; Wynne, 2013). So, too, ambiguous understandings of spirituality and religious beliefs may further complicate efforts to identify and address patients', family members', and practitioners' spiritual concerns. Offering some definition of spirituality that functions inclusively may be helpful. Such a definition serves as a loose framework for thinking about how people use their religious and spiritual narratives in the sense-making effort, thereby making it easier, for instance, for practitioners and patients to have the kinds of vital communication they need to have in the course of the end-of-life trajectory. To this end, we may say that while religion may incorporate the spiritual, it cannot be said that spirituality must incorporate the religious as the two are neither wholly reliant upon nor necessarily mutually exclusive from one another.

Spirituality and/or spiritual narratives may offer a source for meaning and decision-making as well as a resource for comfort and resilience (Daaleman & VandeCreek, 2000; Levin, 2001; McClain, Rosenfeld, & Breitbart, 2003; Rousseau, 2003; Robinson, Thiel, Backus & Meyer, 2006; Steinhauser, Voils, Clipp, Bosworth, Christakis, & Tulskey, 2006). While expressions of individual spirituality may be diverse, they "can influence how patients and healthcare professionals perceive health and illness and how they interact with one another" (Pulchalski, 2002, p. 291). Spirituality, then, may also be related more to aspects of relationship in which care is given and personal connection achieved rather than limited to efforts of meaning making (Edwards, Pang, Shiu, & Chan, 2010). Findings by Edwards et al. (2010) that support this notion echo many of Pulchalski's (2002, 2006) findings that showed listening, caring and sharing were primary spiritual and relational concerns for patients. Understandably, Steinhauser et. al (2007) further argued that "acknowledging these needs constitutes compassionate,

comprehensive palliative care” (p. 101). We are then compelled to consider carefully the role of spirituality and the relationships among patients, families, and caregivers.

Spirituality is frequently discussed as a protective measure for patients, practitioners, and caregivers. Studies suggest patients or caregivers who employ some kind of spiritual or religious practice note a more positive affect (if not at least a less bleak one) than those who do not (Chang & Tennstedt 1998; Holt-Ashley, 2000; Oman, Hedberg, Downs, & Parsons, 2003; Holland & Neimeyer, 2005; Marsh, Beard, & Adams, 1999; Duggleby, Cooper, & Penz, 2009; Vitale, 2009; Richards, Oman, Hedberg, Thoresen, & Bowden, 2006; Oman, Richards, Hedberg & Thoresen, 2008; Ekedahl & Wengström, 2010). Professional caregivers may also have some sense of greater job satisfaction or fewer incidences of burnout than those who do not engage in a spiritual practice.

Spiritual beliefs are, however, rarely problematized as potential sources of distress. The complicated and often difficult aspects of spiritual narratives are given less consideration in end-of-life care and scholarship. Because, as I previously noted, spiritual narratives are often the source from which patients, practitioners, families, and caregivers make their end-of-life decisions, there is always the potential for those individual narratives to come into conflict. The narratives of practitioners, patients, and families will not always complement one another. These narratives inform our sense of what should or ought to happen and there is significant potential for disagreement about how the end of life should be navigated. Spirituality thus serves as much more than a source of comfort as spiritual narratives can also function as a source of distress, especially in situations in which individual or organizational narratives come in conflict with one another. The clinical and spiritual event that is end of life – an event of both body and spirit – provides therefore a unique, rich moment to consider.

A constellation of factors such as family dysfunction and communication patterns may provoke distress from caregivers who participate in the trajectory of end-of-life experiences including the months, weeks, or days leading up to a death and the days following it. It is important, therefore, to place a parenthesis around the time before and the time after dying so as to not disregard the equally significant experiences of practitioners and caregivers as well as family members following a death.⁴ It goes almost without saying that death and dying are stressful events for families and healthcare providers and that stress does not dissipate simply because the one for whom they cared has died. Frustration, loss, and grief are ongoing; we do not require research to tell us this, and this is true as much for practitioners and caregivers as it is for families. We must then carefully consider, in particular, the kinds of distress or even despair that dying may present to those who survive.

a. Spiritual distress. Spirituality is one contributing factor to the distress that arises in end-of-life care. Existing scholarship on healthcare providers' spiritual concerns is often focused on how the ritual or spiritual practices of these care providers, such as prayer, may act as protective measures against burnout (Meltzer & Huckabay, 2004). In this literature, a great deal of attention is given to managing the spiritual concerns of patients (Levin, 2001; Koenig 2001; Koenig 2002; Koenig 2009; Richardson, 2012). The scholarship often refers to this as "spiritual care" work (Kristeller, Zumbrum & Schilling, 1999; Highfield, 2000; Carroll, 2001; VanDover & Bacon, 2001; Van Leeuwen & Kusveller, 2004; Tanyi, 2006). While these aspects of spirituality at the end of life continue to be a concern, even in the project in which I engaged, I argue that we may find through careful consideration and observation that there is another

⁴ I borrow this bracketing from Mary Catherine Bateson's (1980) account of her father's dying in which she includes both the days preceding and the days following his death at the Zen hospice in San Francisco.

manner in which we should consider the role of spirituality: considering how care providers' spiritual practices and narratives may contribute to their own distress.

Spiritual distress may be specifically tied to theological beliefs or values, and likely includes existential ones. The spiritual aspect of the distress has to do with the "why me" questions, the "what is the meaning of this" contemplations, and the grief that we experience when something feels meaning-less. We call on our spiritual narratives, for example, to help us make sense of what is going on, and, to our chagrin, our narratives sometimes fall short. These narratives sometimes betray us with a meaning that causes even greater, deeper despair and, when our theistic or secular narratives fail to help us make sense of the experiences of death and dying or create friction with others' narratives, we find ourselves in conflict. As such, this conflict is a source of potential distress and this is particularly so in the context of complex end-of-life situations. Spiritual distress then may be understood as pertaining to either theistic or secular matters that call into question such things as the meaning of life, what happens after death, what are the regrets and accomplishments of a life, etc. for patients, practitioners, families, and caregivers. As I have suggested, this becomes especially tricky when the beliefs that are underpinning what healthcare providers, patients, and families think should be done or avoided come into conflict with one another. Be it spiritual, theological, and/or existential, beliefs or values seem to get at the heart of meaning-, sense-, and decision-making.

We may assume that the abundance of scholarly interest concerning spiritual distress is reason enough for ongoing attention, though this same body of research offers equally ample evidence that practitioners and caregivers are vested in the good outcomes of their patients. Were they not vested, engaging in practices with which they did not agree and/or deemed futile would not be problematic for them. As such, healthcare providers may be understood to feel a

great deal of responsibility for their dying patients, wish to relieve suffering, and avoid using interventions that may only prolong it.

b. Moral distress. A significant body of literature documents and explores what has been called, at least since the mid 1980s and beginning with Jameton's work, "moral distress" (1984) wherein Jameton describes the conflict that nurses experience when they believe they know the proper course of action and yet are unable to respond accordingly due to institutional constraints that include, but are not limited to lack of power, time, and institutional support. Nurses, for example, face both initial distress, caused by the frustration and anxiety that these constraints and cultural and personal value conflicts produce, and reactive distress that results when nurses cannot or do not act on their initial distress (Jameton, 1993). It is not that nurses do not know what to do and how to intervene clinically. Rather, nurses struggle with what they believe they ought to do in a given circumstance. Jameton (1984) differentiates this moral distress from what he calls moral uncertainty that is experienced when the ethical course of action is unclear and moral dilemma that is experienced when multiple courses of action seem appropriate or plausible.

Hamric (2000) identifies these concerns in the context of what she calls "everyday ethics." Hamric notes the often rapid progression from uncertainty to distress that nurses experience on a regular basis and she describes the high frequency with which these experiences are not fully understood by the nurses themselves nor adequately discussed or processed. She positions these concerns in the realm of the everyday since the kinds of situations that nurses face that may prove distressing are not cases worked out in the abstract. In contrast, they are situations that occur frequently and are rarely revisited.

As Rushton (2006) points out, distress of this kind can have either positive or negative effects; distress may produce feelings of compassion or acceptance and/or loss and despair.

Copious research has, in fact, been dedicated to the negative impact that moral distress has on clinicians, and especially nurses (Wilkinson, 1987; Sundine-Huard & Fahy, 1999; Hamric, Davis, & Childress, 2006; Pendry, 2007; Hamric & Blackhall, 2007; McCarthy & Deady, 2008; Morgan, 2009; Pauly, Varcoe, Storch, & Newton, 2009). In particular, research on nurses who experience moral distress indicates significant decreases in job satisfaction, high turnover rates, and even departure from the profession altogether (Decker, 1985; Erlen, Frost, 1991; Millette, 1994; Corley, 1995; Hamric, 2000; Elpern, Covert, & Kleinpell, 2005; Corley, Minick, Elswick, & Jacobs, 2005). It is easy to see how healthcare providers working with patients at the end of life would readily be included in the category of those experiencing the kind of distress Jameton (1984) and Hamric (2000) describe. We may infer from this that healthcare providers would certainly benefit from interventions crafted to ameliorate moral distress.

A number of interventions have been suggested to address moral distress. The American Association for Critical Care Nurses (AACN) developed what they call the “4 A’s Model to Rise Above Moral Distress” (Rushton, 2006). The model seeks to engage nurses in a process that will help them identify and validate the distress they are experiencing and determine possible courses of action to alleviate the distress (Rushton, 2006). The intent seems to be that nurses should have a responsibility to and for themselves as much as to and for their patients. Responsiveness to their own needs that stem from elements of moral distress may speak to the “emotional exhaustion” that Meltzer and Huckabay (2004) describe in their study of critical care nurses. They make the connection between moral distress and “emotional exhaustion” that they define as “occur[ing] when a person’s appraisal of occupational stressors exceeds his or her coping

capabilities or they conflict with the person's values and belief system so that he or she cannot cognitively reconcile with the stressors and cope" (Meltzer & Huckabay, 2004, p. 7). Their findings suggest that the emotional exhaustion that leads to burnout results primarily from clinicians' involvement in life-sustaining care that they feel is futile or in conflict with their own values (Meltzer & Huckabay, 2004).

Additionally, Meltzer & Huckabay (2004) note outcomes that result in high absenteeism, interpersonal conflict, decreased morale, and, among other things, potentially compromised patient care. Circumstances of moral distress are also instances of heightened uncertainty that should be addressed through interventions that emphasize "ethical principles such as respect for others (autonomy), helping others in their best interest (beneficence), avoiding harm (nonmaleficence), and fairness (justice) [as] major components of decision making" (Meltzer & Huckabay, 2004, p. 7).

While closely linked, and often experienced in tandem, spiritual and moral distress have clear distinctions: spiritual distress is about why we believe we should or should not implement or avoid certain interventions; moral distress is about what we must or must not do developing as a consequence of either a restriction from intervention or a requirement to intervene in the care of a patient particularly when deemed futile. As not only a potential component of moral distress, spiritual distress may also include or exacerbate theological distress. At the heart of moral distress, I contend, are the theistic or secular spiritual narratives that inform our sense of what ought to happen since, consciously or unconsciously, we turn to our narratives for direction and meaning.

c. Suffering. Spiritual narratives can produce such differences between individuals involved in end-of-life care that they find themselves in conflict with one another about decisions. Those conflicts produce distress that may even manifest in suffering for patients, providers, and/or family members. This seems especially so for healthcare providers who are regularly confronted with situations that put their beliefs in conflict with those of patients, colleagues, or administrators, thereby producing moral and spiritual distress. Undoubtedly, ongoing or unresolved distress manifested within the end-of-life experience may produce very real suffering. Our inability to do for the dying what we believe would be in their best interest, or the requirement that we intervene in ways that we believe are not in their best interest, may produce such distress, for example, that we are haunted by our powerlessness in the situation.

I recall the case, from a number of years ago, of a patient who was in her mid-forties. She was in the end stages of a terminal disease but might have had her life extended through certain clinical interventions. She had, however, requested a “Do Not Resuscitate” (DNR) order as an expression of her wish to end her considerable physical pain and emotional suffering. Her physician, who was a friend of mine as well as an orthodox Jew, did not want to grant her request. By his own account, his religious beliefs concerning the sanctity of life prevented him from readily accepting her request. She was young and also had fairly young children that she would be leaving behind when she died. He tried, in fact, to dissuade her. Ultimately, he signed the DNR, but not without a great deal of reservation. When she later coded and was not resuscitated per the order, he was devastated. He was kept awake some nights as he replayed the events in his head and wondered how much time with her family she might have had if the DNR had not been in place and if the clinical team had been able to successfully revive her. Many months after, he asked that I have an ethicist come to our monthly ethics committee meeting to

work the case with us. What he wanted, needed to hear was a validation, for his actions (permitting the DNR), for his initial feelings of reticence, and for his ongoing feelings about the outcome that he described as “plaguing” him. Long after his patient died he was clearly suffering, by his own admission, over his patient’s decision and his own. He acknowledged some sense of relief in finding that the committee supported both the patient’s autonomous action as well as his sense of frustration and loss.

This brief narrative exemplifies the distress and suffering which clinicians may face when they are confronted with circumstances of dying wherein the spiritual or religious narratives that inform their sense of what is right or ethical are in conflict with patients’ narratives. Specifically, this conflict acts as a challenge to clinicians’ role as healers as well as to the sense of duty that their role requires. This narrative is not only an example of patients’ and practitioners’ spiritual narratives being in tension with one another. It is also an example of the kind of strain that is created for the practitioners between who they are as individuals and what is required of them as clinicians, and this strain causes suffering. While I see fairly clear distinctions between experiences of moral and spiritual distress (which can be theological or secular) and suffering, I also see them as working with one another; spiritual and/or moral distress produces suffering, and, in turn, suffering exacerbates distress.

We thus approach, consciously or unconsciously, as the case may be, end-of-life circumstances as patients, practitioners, family members, or caregivers and from our various religious or secular narrative perspectives. The story in which we see ourselves living and dying becomes the place from which we make our decisions about how to do or aid others in that dying. These narratives inform our sense of what is right and wrong and, therefore, so too our beliefs about what we ought or ought not do in the care of those who are dying. For healthcare

providers, patients, and families alike, this becomes complicated when the narratives that tell us what we ought to do conflict or put us in opposition with what others' narratives prescribe. The friction created by opposing narratives creates moral and spiritual distress for patients, practitioners, families, and caregivers as they seek to make decisions together that will honor the desires of the dying as well and who care for them to the greatest degree possible in a given circumstance. Navigating the complex landscape in which conflicts inevitably arise can be difficult and may certainly be considered a relational accomplishment when it occurs. The often-complex circumstances in which conflicts arise and end-of-life decisions must be made are negotiated and manifested through discourse. As such, these situations must be examined not only as clinical and spiritual events but also as communicative, or rhetorical, ones.

B. Exploring the Rhetorical Landscape

Another source of potential distress between patients and physicians is that the experience of dying is, unfortunately, complicated by the shared sentiment that death is a failure. The traditional western framing of death posits that such a failure is typically one either of medicine or of will. We long for the cures promised by science while we preference individual autonomy and self-determination. Because medicine cannot stave off death forever, and because we cannot simply will ourselves well, we are left with the failure of both. Under these conditions, medicine fails us and we fail ourselves. As a consequence of this, patients and physicians are often left bereft as to make sense of the end-of-life experience. While there are certainly other scholars who concern themselves with health communication and rhetoric (Segal, 2005; Radley & Billig, 1996; Frank, 1993; Harter, Japp, & Beck, Eds., 2005; Gwyn, 2002; Sharf,

1990), two complementary approaches are particularly helpful for thinking about and understanding the kinds of communicative healing efforts we make regarding end of life.

a. Appraisals & reappraisals. One way to redefine death as failure is to explore the potential of therapeutic communication. Burleson and Goldsmith (1998) articulate the importance of exploring the sense of failure with which we all struggle at the end of life. Surely scholars, healthcare providers, and patients alike may agree upon a shared goal that examines our end-of-life communication (despite the sometimes problematic nature of spirituality at end of life), mines it for ways to make meaning of circumstances that can sometimes seem meaningless, and seeks to improve end-of-life experiences through healing discourses. Burleson and Goldsmith (1998) contribute to this endeavor by assessing effective and ineffective messages that are used as comforting communications. Significantly, their work emphasizes the ways in which, “understanding how certain message forms reduce distress [and how they] would have obvious practical value for all those who provide emotional support, both professionally and informally” (Burleson & Goldsmith, 1998, p. 246). For Burleson and Goldsmith (1998), comforting messages are verbal and nonverbal “communicative attempts” to “alleviate the distress of another [... by] work[ing] through emotions and attempting to change another’s emotional state” (p. 247). Their understanding extends beyond mere sympathizing, agreeing with someone, or more clinical or long-term concerns addressed through psychotherapeutic interventions and represent what they consider to be indicative of “social supports” (Burleson & Goldsmith, 1998). To engage most effectively, Burleson and Goldsmith (1998) stress the importance of messages that “focus on emotional states [rather] than focusing on solutions to the problem, or attempting to deny, minimize, or avoid talking about the emotions” (p. 252).

Perhaps most importantly, Burleson and Goldsmith (1998) note the function of appraisals and reappraisals in communicative attempts at comforting. This is key since they explain how our appraisals of difficult situations, such as those at end of life, affect our emotional reactions and thus our responses (1998). Appraising death as an “uncertain, existential threat,” for instance, may produce anxiety while appraising death as an “irrevocable loss” may produce sadness (Burleson & Goldsmith, 1998, p. 254). Specifically as a failure of will for patients or as a failure of clinical prowess for practitioners, either may experience shame or guilt. It is not difficult to imagine how appraisals of this nature would contribute to distress in patients or healthcare providers, particularly when those appraisals are informed by narratives that define our senses of right and wrong in decision- and sense-making.

Coping efforts must be employed to manage the demands placed on and the conflicts that arise for healthcare providers, patients, and families in end-of-life decision- and sense-making. In situations in which moral or spiritual distress feature prominently, the coping process is crucial. Burleson and Goldsmith (1998) note, “coping efforts influence subsequent appraisals (i.e., reappraisals) of events and, thus, emotional reactions to them” (p. 257). If, as they suggest, comforting is a “process of facilitating reappraisal” of a circumstance for a distressed person, then both patients and caregivers may benefit from messages that help them reappraise the distressing situation (Burleson & Goldsmith, 1998, p. 274). I am specifically reminded here of Payne’s (1989) work wherein he describes what Burleson and Goldsmith call reappraisals as rhetorical acts of healing.

b. Rhetorical acts of healing. Payne (1989) shows how we engage in rhetorical constructions in which metaphors play a primary role and such rhetorical constructions lead us to

experience “the transformation of self from a failed condition to one that offers success” (p.12). By engaging in these constructions we seek to persuade others and ourselves that, when we are confronted with the disruption created by failure, reconciliation of “self-in-relation-to-world” is possible (Payne, 1989, p. 144). With failure, clinical or otherwise, comes loss, and both of these must be managed rhetorically. This is accomplished through the logic of certain themes or *topoi* that inform our understanding of how failure and loss are “culturally and symbolically observed and how failure is defined in such ways that cooperative resolutions via discourse are possible” (Payne, 1989, p.44). We employ these discourses in efforts to console and compensate for failure and loss as well as to transform and transcend them. In order to engage in this rhetorical work, our identities must be constructed with a measure of plasticity and must be subject to change as they are “formed, sustained, and reformed through communication” (Payne, 1989, p.18). Furthermore, we must be persuaded to make changes that are “gratifying and uplifting for selves and society” (Payne, 1989, p.19). Payne (1989) additionally notes the importance of finding the context in which to order (in two senses, sequencing as well as structuring chaos) these disruptions.

One such context is exemplified when we come to decide that family members must come together “because of” a death, or, “because of a death,” another life has been made richer or more appreciated. Another instance of context emerges in the case of suffering. “Because of” our own or someone else’s suffering, we come to believe that we have learned some great lesson, have been made more aware of our own mortality, and have, therefore, understood that we should enjoy the time that we have.

The healing rhetoric, albeit some more healing than others, that we employ helps us make sense of and heal “failures” such as death and illness. For patients, physicians, and caregivers

alike, healing occurs through the writing and rewriting of these failures through new stories of those experiences that, if unaided, would seem inconsolable. These examples of healing rhetoric taken from both eastern and western traditions show how they may be used to console and/or compensate for the failures that death presents. Furthermore, these examples illustrate how we might utilize rhetorical therapeutics to transform and transcend such failures.

Blessing & curse. To begin, I offer two relatively simple statements that represent the power and great consequence of the words we choose to help others and us make sense of grave illness and end of life. I distinctly remember when my daughter's first experience with illness (from which she was not expected to recover) was framed as both a blessing and a curse. These memories show how one situation interpreted through two different religious narratives produced diametrically opposing messages, though both were intended to offer comfort. Although the narratives employed frame the events in radically different ways, what is most notable are the ways in which they align. Both narratives seek to offer some consolation and spiritual compensation for the physical and spiritual failures that resulted when my daughter was unable to be restored to her former health.

On the third day of her dying, the pediatric intensivist came to my daughter's bedside where I had sat awake and fearful since her admission from the emergency room to the medical intensive care unit. "Well..." he said, "we didn't think she would live, but she did...but she'll probably be a complete vegetable. You'll need to get yourself ready for that." Turning on his heels, he walked away. I was stunned, not because I couldn't imagine that possibility as a potential clinical outcome of a traumatic brain injury, but because I

couldn't imagine it for my daughter. I didn't have any idea what to do with that, how to "get myself ready." I was going to need some help with this, so I called one of my oldest and dearest friends who is a Protestant preacher's wife and my rabbi. "I need help," I said.

At different times, my friend, the preacher's wife, and my rabbi arrived with radically different responses. My friend told me:

When I look at her, I see your sin. She's sick because you have sinned. If you want her to get well, you need to ask for forgiveness. You need to repent and hope God will heal her.

But what was my sin? What had I done that was so horrible that God would punish me like this, that God would punish my daughter?

When my rabbi arrived later, I told him, "I'm not sure what to do with this... I can't think straight..." I asked him, "Remind me, please, what do we [Jews] believe about this?" Sitting next to me, the rabbi was calm and said:

We believe that special needs children are old souls. They come into our lives to teach more than they do to learn. This is why the greatest, most learned rabbis, in whose presence we would stand, stand up when a special needs person enters the room. They recognize them as the old soul that they are, for their wisdom, and for what they have to teach. It is a blessing, because she has come to be your teacher....to be our teacher.

The larger religious narratives inform the consolations that I received from my friend, the preacher's wife, and also from my rabbi for my daughter's near death and permanent injury. My friend's consolation stresses a "because of" context; my

daughter's circumstance is a consequence of my unidentified sin. Consolation and compensation are spiritual and material in that the corporeal loss results from a spiritual failure, or sin. As compensation, if I perform the appropriate ritual – sufficiently penitent and seeking forgiveness in an effort of surrender and mortification – then spiritual restitution is certain while physical healing becomes an additional possibility.

In the second situation, because of my daughter's injury, I, as her parent and as a "self," and our community, our "society," lose the child that she was and the person she may have come to be. In their stead, we gain a teacher, an older wiser soul from whom we will learn. In this way, the rabbi's account consoles us with a spiritual gain that compensates for that loss by "erase[ing] the loss and transform[ing] it into an opportunity for gain" (p. 45). As compensation, my daughter's loss becomes my personal and our communal gain.

Our lives consist of a larger story in which we see ourselves living and the multitude of stories that we construct and reconstruct along the way. The stories that we form and reform help us understand and make sense of our experiences, though not all of the stories we construct are as helpful or comforting as the one the rabbi offered me. The spiritual narratives that we often turn to are limited or limiting in their ability to serve us well at the end of life. For example, my friend's series of statements frames my daughter's near death and subsequent grave illness as a curse, or, the "sins of the mothers visited upon the daughters." In contrast, the rabbi's statements frame her experience as a blessing. In the rabbi's framing, my daughter is not a sign of my sin; rather, she is a gift from God. While one of these frames may be more palatable to one belief system than the other, they both do the same work. In the context of their respective

religious narratives, both offer some kind of consolation and compensation for the failure that occurred.

Fight & dance. Death represents the most significant rupture in the life story, so, too, the greatest therapeutic challenge. Constructed in this way, death is a failure from which neither patient nor practitioner may recover. To help us manage the failures of science and will, we grasp for narratives that will rally, if not save us. Death and illness become enemies against which we may come to believe we must fight.

The fight metaphor is employed in countless examples of illness and dying as it functions as an “in-order-to” motive that directs the individual towards a goal of survival. By engaging in a fight with and/or against disease or death, a patient may achieve survival, if not restoration of health. Examples of the frequent adoption of this metaphor can be seen on the television at pink ribbon events hosted in benefit of the “fight” against breast cancer, and in our daily newspapers’ obituaries that detail someone’s valiant struggle to the end. I am not suggesting the will to fight for one’s life is something to be discouraged or that the fight itself doesn’t have a place in the trajectory of illness. Rather, I am suggesting that this narrative, like any other, has its limitations. Certainly, we may need to draw on the strength of “the good fight” in order to make it through treatment that is painful or difficult, or to muster the courage to face long or even uncertain recovery. However, at some point in the trajectory of illness and dying, the metaphor fails us because it positions us for failure. The metaphor puts patient and practitioner in opposition to the body instead of in concert with it. No matter how good the fight, it cannot always be sustained as treatment eventually becomes futile. Sooner or later, patients die, and practitioners are invariably helpless to stop it. When we fight illness we do not always win, and when we

fight death, we never win. Since death comes to us all, even when we are not ready for it, both patient and practitioner share this failure. Unable to sustain the fight, the dying patient surrenders while the practitioner, incapable of staving off death any longer, fails the patient in the curative endeavor. And so, having lost the fight, both of their failures destroy the hope for survival that our efforts intended to produce. Despite every valiant effort, once death wins we must go about the business of repairing the breach it created. We must subsequently “assess the meaning of our failure” and seek consolation for it (Payne, 1989, p.94). This is not new. However, to those of us who have concerned ourselves with illness and the end of life, we have long felt the repercussions of our failure. Perhaps what we have not considered is how we may be better served by a change in metaphor.

This understanding of therapeutic rhetoric helps us see the implications of the fight and failure metaphor, and, through it, we are able to imagine how an alternative metaphor may offer something more beneficial to the end-of-life scenario. While understanding dying as a fight to the end may give courageous meaning to patient and practitioner, dying as a fight to the end is clearly limited in its ability to provide therapeutic relief. In its place, an alternative construction may provide even greater consolation and/or compensation for the failure we experience in death. One such example is the Taoist metaphor of dance that offers consolation of a different kind. With possibilities for facilitating acceptance of, and peace with death rather than opposition to death given way to reluctant submission to it, the Taoist metaphor of dance, life, or, in this case, dying is like dancing: fluid, seamless, rhythmic, and something with which we meld and go along. Dying, then, is not something against which we fight. Like the fight metaphor, this dancing with death interpretive framework employs the past-future *topos*; the “in-order-to” context, however, requires a different sequence of action and seeks a different goal. Instead of

engaging in combative action against disease and death, the Taoist metaphor of dance asks for movement with it. The goal is not to struggle; the goal is to embrace.

I do not suggest here that the western rhetorical approaches are wrong and that the eastern ones are right. Rather, I argue that, when they are employed in end-of-life sensemaking, the western narratives of fight and failure are limiting in troubling ways. The therapeutic benefits of the western narratives of fight and failure are confined to the context of struggle against death; this is limited to that which is combative and oppositional. The dance metaphor offers the possibility for making sense at end of life that is simply not typically emphasized and seldom embraced in western religious or spiritual narratives. While there is certainly a place for struggle in the trajectory of serious illness, once we recognize that the fight cannot be won, we need not encourage patients to continue the fight against themselves and against death. In contrast, embracing death can potentially lead to more peaceful end-of-life experiences. In this metaphorical shift, we see the implications for what understanding the rhetoric of failure can do for us even in the most difficult and complex circumstances. Payne's work (1989) exemplifies that we have the power to make sense of the disruptions in our lives, especially those that we have come to see as our failures. This eastern perspective may help us think differently about how we may come to understand and manage the end-of-life scenario with our patients and for ourselves. More importantly, through thoughtful exploration and rhetorical construction of these failures, we may come to find some small relief even at the end of life.

As pleasant as this alternative metaphor may seem, particularly in comparison to the fight metaphor, I wonder if we are still left without any real restitution. We busy ourselves with discourses meant to, as Payne (1989) notes, console or compensate for failure. I, too, have engaged in precisely what I have pointed to in the pink ribbon efforts to fight breast cancer, for

instance. Even through my proposing the eastern metaphor of dancing with death rather than raging against it, I am engaging in my own healing rhetoric, readily enamored by a more soothing metaphor. My consolation, however, is short lived since I am as troubled by the ease with which a new metaphor seemed to offer comfort as I am by the one that I argue disserves us. This is the point that concerns me most: our narrative and rhetorical constructions are lacking, and will forever remain so, since no story exists that makes restitution for the failure that is death. As well intentioned as they might be, all attempts seem insufficient. While some are more helpful in ways that others are not, all are still ultimately lacking. And this is also true of death. It is not repairable.

What, then, can we do? The narratives we turn to are both potentially helpful and limiting in their ability to serve us well at the end of life. These narratives, however, do not prevent or heal death. I return to the therapeutics we employ to ease the despair of our loss: if we cannot construct a story that is perfect, and one that perfectly heals, can we not at least make sure we examine the stories that we do tell? Can we not at least concern ourselves with the great consequence of these narratives and of the nature of what heals and what only seems to heal?

Both approaches, those by Payne (1989) and by Burleson and Goldsmith (1998), help us better understand instances wherein we experience failure, or death as failure. These approaches show how we can reconstruct failure through our healing rhetoric by using reappraisals, or consolations and compensations, to alleviate distress through what may become, in this process, comforting messages. Perhaps, then, we may begin to conceive of ways to ameliorate that distress through reappraisals of spiritual narratives as they are employed in appraisals of distressing situations. In other words, what may be called for are the kinds of healing discourses

that facilitate narrative reappraisals that would thus disarm potentially distressing end-of-life situations and give way to comfort for patients and caregivers.

By examining the ways in which we co-construct the narrative settings of end of life and work together to make sense of end-of-life experiences through our employment of spiritual and/or religious narratives, the intersection of spirituality, rhetoric, and medicine becomes clearer. Understanding these dynamics is key to the concerns of bioethics in that these dynamics speak directly to how individuals and families engage in decision and sense making about their health care, and, even more crucially, in illness and end-of-life situations. If we are to continue to speak meaningfully to the medical and ethical questions that arise out of end-of-life situations facing people today, we must put ourselves in dialogue with the clinical, spiritual, and rhetorical.

C. Exploring the Relational & Communal Landscape

We must further attend to the landscapes of patients, practitioners, caregivers, and families, and recognize end-of-life trajectories as not only spiritually and rhetorically, but also relationally and communally situated. Because patients, practitioners, families, and caregivers are all, to varying degrees, necessarily in relationship with one another, it is not difficult to imagine the importance of the relational context. With this relational context in mind, we may turn to the great wealth of scholarly interest in the relational aspects of clinical care.

a. Relational landscapes. A large body of scholarship rightly concerns itself, primarily, with aspects of the patient-practitioner or the patient-caregiver relationship. The distinction between these two relationships is in the more broad definition of a caregiver that includes non-professionals who are often also family members. Research explores the quality, therapeutic

value, and importance of the patient-practitioner relationship examining these relationships from both the perspectives of patients and providers (Matthias, Parpart, Nyland, Huffman, Stubbs, Sargent & Bair, 2010; Halpert & Godena, 2011; Ratanawongsa, Wright, Vargo & Carrese, 2011; Phillips-Salimi, Haase & Kookan, 2012; McCarthy, Buckley, Engel, Forth, Adams, Cameron & Ufberg, 2013; Davis, 2013). A wealth of research gives equal consideration to the patient-caregiver relationship and the impact these relationships have on both patients and caregivers (Sharpe, Butow, Smith, McConnell & Clarke, 2005; Fleming, Sheppard, Mangan, Taylor, Tallarico, Adams & Ingham, 2006; Miller, Bishop, Herman & Stein, 2007; Tang, 2009; Mancini, Baumstark-Barrau, Simeoni, Brob, Michel, Tarpin & Auquier, 2011; Mori, Fukada, Hayashi, Yamamoto, Misago & Nakayama, 2012; Williams & Bakitas, 2012; Goetzmann, Scholz, Dux, Roellin, Boehler, Muellhaupt & Klaghofer, 2012; Cramm, Strating & Nieboer, 2012; Boerner & Mock, 2012; Williams & Bakitas, 2012; Douglas & Daly, 2013). Significant scholarship also addresses the patient-provider relationship in the context of dying and the end-of-life trajectory (Curtis, Wenrich, Carline, Shannon, Ambrozy, & Ramsey, 2001; Wright, Braijtmann, & Macdonald, 2014; Brion, 2014) and often focuses on the communication within these relationships (Callanan & Kelley 1992; Foster, 2007; Rodriguez, Bayliss, Alexander, Jeffreys, Olsen, Pollak & Arnold, 2011; Hsu, Saha, Korthuis, Sharp, Cohn, Moore & Beach, 2012; Mikesell, 2013; Price & Lau, 2013; Skea, MacLennan, Entwistle & N'Dow, 2014).

In the Zen hospice context, however, relational boundaries extend beyond the immediate patient-practitioner and patient-caregiver relationships. These relationships are vital and deserve special and careful attention, to be sure. In this island hospice context, the importance of communal relationships, how end of life is communally situated and, therefore, how care of the dying is a concern of all become readily apparent. As such, care of dying patients and their

family members presents opportunities for the whole community in which community members may participate to varying degrees and from which each member may learn. Block (2008) teaches us the importance of community as a source of belonging. Block diagnoses the fragmentation that we experience from a fixation on personal interests. This overemphasis on our independence leads to our isolation from one another. Block sees the experience of community as an opportunity for personal and communal transformation. Choosing to be accountable to and for one another, he says, transforms us and has the power to reduce our and others' suffering.

I return briefly to the situation of my daughter's hospitalization recounted in the previous section of this chapter to highlight the connection between individual and communal experiences of illness and dying. We see in this example how the rabbi responds to my daughter's near fatal injury by framing her new status as teacher for the community, someone from whom we may all learn. Her illness is then relationally and communally bound. Her need for care becomes her contribution to the community, and the care the community may give her becomes equally significant.

To understand how this may work for the island hospice community, we must first investigate more broadly what it means for a community to function as a community of practice and then, more specifically, how the hospice functions as a Buddhist community of practice.

b. Communities of practice. Expanding our notion of relationship to the communal, we may begin to better understand what it means to die and be cared for in community by exploring the concept of communities of practice. As Eckert (2006) explains, "communities of practice emerge in response to common interest or position, and play an important role in forming their

members' participation in, and orientation to, the world around them" (p.3). Wenger (1998) defines the nature of a community of practice as a joint relational endeavor (Lave & Wenger, 1991) in which members of a group of people engage and negotiate together. Their mutual engagement and purpose are supported by and enacted through shared sensibilities, activities, vocabularies, and routines (Wenger, 1999). We see this clearly in the words of a founding member, when he says that the island hospice has "two purposes: to serve the needs of families seeking help caring for their loved ones as they approached the end of life, and to provide a training ground for Zen students who wanted to experience the dying process up close" (Trowbridge, 2013, p. xi). Although Wenger and Lave (1991) developed their ideas within and for a learning context, it is not difficult to imagine how a Buddhist community might also be understood as a community of practice, especially in the unique circumstance in which the community is organized around care of and for the dying as well as the context in which learning from the dying also takes place. To varying degrees, the members of the Zen hospice and monastery, in cooperation with one another, function together as a community of practice organized around the shared desire to support those at end of life. For this reason, understanding the ways that a hospice founded on and organized around Buddhist principles and practice affords us, also, a systemic appreciation of dying as a communally situated experience.

c. Buddhist community. Exploring the communally constructed, negotiated, and shared sensibilities and practices of this hospice may offer us insight into how the particular community in this study functions together. As Meadows (2008) tells us, there is a relationship between structure and behavior, in that systems are "interconnected in such a way that they produce their own pattern of behavior over time" (p. 19). While Meadows cautions us that the behavior of a

system cannot be reduced to its mere elements (p. 29), I begin here with a few simple explanations so that we may return to them in later chapters in order to see how they work together in the care of the dying at the island hospice. While there are many components to a Zen approach that may or even should be mentioned, two are particularly worthy of our immediate attention. First is the narrative of the Buddha, and the second is comprised of three fundamental Buddhist concepts: interdependence, contemplation or the importance of the contemplative mind/practice, and *sanga* (community). I offer a few brief, rudimentary explanations of these concepts that serve as foundations upon which this island hospice community is built. These concepts also serve as the basis for understanding the communal system of care at the hospice that I describe throughout the course of my discussion in subsequent chapters.

I present this brief narrative of the Buddha's life⁵ to illustrate what this story teaches us about the transformative power of interacting with death and the significance of human impermanence and interdependence. As a young prince of privileged birth, Siddhartha Gautama (563-483 B.C.E.) wanted for nothing and knew no suffering for the first twenty-nine years of his life. Having never left his palace, as his father forbade him to do so, he longed to learn of life outside the palace gates. Four times, however, Siddhartha traveled beyond the gates in secret.

The first three times he left the palace, he discovered an old man, a sick man, and a dead man. So troubled was he by these encounters that he no longer felt the security and happiness that he had once known for he recognized that, at some point, we all have our own encounters with aging, sickness, and death (Fasching, deChant, & Lantigua, 2011). These encounters taught him of life's impermanence. Traveling beyond the palace gates a fourth time Siddhartha met a monk who was living as a forest dweller. He was so moved by the simple lifestyle that the monk

⁵ I offer this brief narrative of the Buddha's life as cited in Thomas (1927).

was leading that he abandoned his former life of luxury and set out on his own quest as a forest dweller to seek answer to the problems presented by aging, sickness, and death. Renouncing the world and taking up the life of the sannyasi, a Hindu Brahman ascetic, Siddhartha came to understand that desire is what creates suffering and, because of the impermanence of all things, we can never satisfy our desires. We can only create more suffering. In taking up the life of the ascetic, he sought to extinguish the desires that he believed produce suffering. He came to find, however, that all the years of self-denial and austerity did not lead him to the liberation that he sought:

Although he fasted and starved himself until you could see his backbone through his ribcage, the only thing he achieved was dizziness and headaches. He began to realize that this was not the path to liberation either, for just as the attempt to fulfill our desires only makes us desire even more, so the attempt to deny our desires only makes us more obsessed with the absence of that which we desire. In both cases the self and its selfish desires are only reinforced. (Fasching, deChant, & Lantigua, 2011, p. 170)

It was only when he sat in prolonged meditation beneath a fig tree that he experienced enlightenment. He realized the path of liberation cannot be found through the extremes of excess or deprivation. Instead, the path to liberation is found in the middle way, the way of the four noble truths: life is suffering, desire is the cause of suffering, the way to end suffering is to extinguish desire, and adhering to the eight-fold path extinguishes desire. The eight-fold path involves: right understanding, right thought, right speech, right action, right livelihood, right effort, right mindfulness, and right meditation. Moreover, “it is only in the Buddhist community, led by those who have trod the middle path and so can show the way, that the novice or new seeker can learn the meaning of the eight-fold path as an actual set of practices” (Fasching &

deChant, 2001, p. 142). Teaching the nature of impermanence and the importance of encounters with old age, sickness, and death, the story of the Buddha functions as a foundational narrative in which we find key aspects of Buddhist philosophy that are critical to understanding Buddhist practice and community.

The first of three Buddhist concepts deserving special consideration is the notion of interdependence. Interdependence places us not only squarely within the realm of systems, but specifically in the relational. Our sense of relationship between patient and provider or caregiver is informed by our interdependence and, so, we must consider the whole of a dying experience within the context or narrative setting of the relational experience. For a Buddhist, a separate self does not exist and is considered to be an illusion. To understand what this illusion means, it is helpful to imagine ourselves as icebergs floating in the ocean⁶, the tips of which protrude above the surface of the water. Each of us may, as an iceberg, look across the ocean to another iceberg and think to ourselves that we are all separate from one another. We may even imagine ourselves as merely the tips that float above the water. But, in fact, icebergs are more than that; the whole of an iceberg is that which is both above and below the water's surface. More importantly, what is the ice but frozen water? The icebergs that we imagine ourselves to be, the same ones that float apart from one another, are not separate. We are not separate from one another. We are all water, all a part of the same ocean. It is fruitless to think of ourselves as disconnected. A sense of interdependence with one another may radically alter not only our understanding of death but also our understanding of how to manage death together. When we labor under the illusion of separate or individual autonomous selves, we story life as a limited, finite experience that ends with our death. From a Buddhist perspective, however, since we are not independent, finite beings, death is not a failure or an experience against which we must

⁶ I borrow this helpful metaphor from one of my mentors, Dr. Darrell Fasching.

fight; it is an opportunity for transformation. When we die we are returned to nature and the cosmos. We thus transform from one state to another. Furthermore, understanding the interdependent nature of all beings requires us to treat one another as intimately connected to us. This has exciting possibilities for end of life because, in attending the dying, we attend, also, to ourselves. We are intimately connected to every dying patient and, as a result, our care and communications become even more deeply consequential.

Contemplation, as part of Zen practices, affords a mindset that is uniquely equipped to reflect on our interdependence as well as to engage one another as intimate others. The contemplative mind in Buddhist tradition allows for and encourages ethical engagement in that the practice of contemplation is fundamentally self-reflective. It provides opportunities to thoughtfully examine who, what, and how we are in the world as well as in relationship to one another. The contemplative mind has the power to remind us of our responsibilities to and for one another as it concurrently reveals the nature of our existence and experiences as collective, not individual.

This collective framework is embodied in the Buddhist *sanga*, or community. *Sanga* acts as refuge and support, practices right or ethical action through its engagement with members and non-members alike, and may be expanded to include a global community. The communal concern is for the good of oneself but also and equally for the good of others. The shared goals of the *sanga* seek to assure and improve, through thoughtful contemplation and practice, the good and peaceful welfare of all beings and the earth.

A Buddhist framework's acknowledgement of interdependence, contemplative practice, and participation in the *sanga*, even through my limited discussions of them here, may offer the optimal environment from which to explore end-of-life circumstances at the island hospice. The

idea of a community engaged in ethical practices, and one that seeks the best interests and welfare of itself and others, will undoubtedly offer not a perfect place (as no place can be perfect) but one that is sufficiently fertile, where the needs of dying patients and the community of healthcare providers and caregivers can be met.

This chapter has shown that dying and end-of-life care may be situated in spiritual, rhetorical, relational, and communal contexts that, like all others, can be comforting and complicating. Such contexts and narratives that shape them offer us sources of meaning- and sense-making; also, they guide us in decision-making and have the potential to offer us comfort through the consolations and compensations that we construct. As Payne (1989) tells us, though, they may fail at this. Considering the great consequence of our healing rhetoric, we may be compelled to co-construct with one another re-appraisals (Burlison & Goldsmith, 1998) of end-of-life experiences that narrate them in as comforting a way as may be possible. Examining these spiritual, rhetorical, relational, and communal narrative settings helps us better understand end-of-life care in this Zen hospice context. At the same time, exploring these settings may also give us an opportunity to critically consider how these contexts are interconnected with one another as well as how they may influence or even determine the nature of our dying and end-of-life care. Having explored the theoretical and philosophical narrative landscapes most useful for understanding end-of-life care at the island hospice, I turn to this study's other narrative settings, namely, the methodologies and methods that establish this research.

Chapter Three: Methodologies & Methods

A. Methodology: Ethics of Care

Guiding my research with dying patients, families, and those responsible for the patients' care is a methodology of a feminist ethic of care. This methodology can be understood as a relational care-focused ethic that preferences "interdependence, community, connection, sharing, emotion, [and] trust..." (Tong, 2009, p. 163). These traits have been typically associated with women and have been contrasted with "independence, autonomy, intellect, [and] will" typically associated with men: (Tong, 2009, p. 163). It is important to note that many of the latter so-called "masculine" aspects are also important and are certainly not absent from an ethic of care; it would be an oversimplification to suggest, for example, that autonomy is not a concern of either feminism or ethics of care. In the clinical setting, this may evidence itself in how a patient's wishes are honored in their end-of-life care and decision-making. For instance, through the implementation of advanced directives a patient may wish to cease interventions such as radiation or chemotherapy or decline extraordinary life saving measures. In many instances of this sort, preferencing patients' wishes upholds patient autonomy and suppresses paternalistic inclinations or interventions. Upholding autonomy is an expression of feminist ethics in that patients' wishes are respected and their agency intact. Supporting patient autonomy is one expression of an ethic of care embodied in the care of the dying.

Despite the tendency to relegate care- or relation-centered ethics to a feminine, or even "morally weak" ethic, care-focused feminists "regard women's capacities for care as a human strength rather than a human weakness [and] expend considerable energy developing a feminist

ethic of care as a complement of, or even a substitute for, a traditional ethics of justice” (Tong, 2009, p. 163). Critics argue, however, that a feminist ethic of care risks an association between women, care, and nature that might reinforce biological essentialism (Tong, 2009, p. 174). Like Gilligan (1982)⁷, I maintain the position that an ethic of care is not merely a female capacity. Rather, it is a human one. I claim this position in an effort to avoid reinforcing any divisive perception that fosters a gendered dualistic approach to understanding or applying ethics in sense- and decision-making. Furthermore, moral individuals, regardless of gender, would ideally be able to express aspects of an ethic of care and an ethic of justice, as these are complementary to one another (Tong, 2009). Practitioners and caregivers capable of employing both ethical aspects offer patients and their family members the best possible assistance in end-of-life decision-making.

Perhaps of equal importance is what care-centered feminists have to say about engaging in ethics as a moral act. According to Tong (2009), morality is not about affirming others’ needs through the process of denying one’s own interests. Instead, Tong (2009) argues that morality is about affirming one’s own interests through the process of affirming others’ needs since, “when we act morally (engage in ethical caring), we act to fulfill our ‘fundamental and natural desire to be and remain related’” (p. 196). Tong (2009) explains here that we meet one another’s needs because we reflectively choose to do so. Rather than claiming that acting ethically means that we do things because we ought to do them, i.e., out of a sense of duty, Noddings (2003) argues that the opposite is true as she explains that our “oughts” or “musts” are built upon our “wants” (p. 82-83). Thus, doing something because we “ought to” is not morally superior to doing

⁷ Carol Gilligan is a seminal scholar in the area of feminist ethics. Challenging male-centered theories of moral development that hinge on aspects of justice and fairness and that typically render females as less ethically mature than males, Gilligan (1982) argues that females, who typically engage in relational and care centered ethics, are not less mature but orient to the world differently. She argues that these two ethical orientations need not compete with one another. Instead, they should compliment each another.

something because we “want to” (Tong, 2009). The two are interrelated. We want to do a thing particularly because we desire to remain in and foster relationship (Tong, 2009). We connect to and long for our feelings of having been cared for, and we long to care for others as a way to replicate that relationship of care (Noddings, 2003). According to Noddings, “the impulse to act on behalf of the present other is itself innate. It lies latent in each of us, awaiting gradual development in a succession of caring relationships” (2003, p. 83). Noddings (2003) speaks here of the desire to behave ethically that is born out of relationships of caring. It isn’t that we do not experience the “I must” or “I ought” in response to the need of another. Rather, “I am obliged, then, to accept the initial ‘I must’ when it occurs and even to fetch it out of recalcitrant slumber when it fails to awake spontaneously, and the source of my obligation is the value I place on the relatedness of caring [...] aris[ing] as a product of actual caring and being cared-for” (Noddings, 2003, p. 84). In the end-of-life scenario, the importance of these aspects of an ethic of care is in how we care for others as part of a relationship rather than as a transaction.

When we consider how this theory may be an embodied ethic, and therefore a sound method for engaging in research, what may begin to sound more like feminist ethical theory than practice becomes ethics in action. Such ethics in action are particularly relevant in the complex situations involved in end-of-life care and decision-making. In line Hamric (2000), Varela (1999) grounds ethics in action when he explains that ethics is more than mere rational judgment. Rather than abstract knowledge, ethics may be understood as “primarily concrete, embodied, incorporated, lived. [...] The concrete is not a step toward something else: it is both where we are and how we get to where we will be” (Varela, p. 7). For Varela (1999), and for our purposes here, ethics is more than, “ethical reasoning consist[ing] mainly in the application of rules or principles” (p. 28). Ethics is a matter of ethical action that arises spontaneously and through

“intelligent awareness [...] in harmony with the texture of the situation at hand” (Varela, 1999, p. 31). Because of its relational emphasis, an ethic of care employed as embodied ethical enactment, as Varela (1999) describes, has powerful implications for interacting and researching with patients, families, practitioners, and caregivers.

Considered together, the scholarship of Varela (1999), Reinharz (1992), Gilligan (1982), and Noddings (2003) provides a theoretical and methodological framework for engaging in research with the dying that is relationally situated and ethically sound. Specifically, my methodological approach based on the work of these scholars occurs within relationships of care. I share the following story to show the situatedness of ethics, how ethics function in action, and the ways in which care-centered ethics emerge from relationships of care.

a. Care-centered relationship: my “ethics of care” story. There are always reasons why researchers choose one method and methodology over another, and my experiences having been cared for in a care-focused relationship by a woman who understood what it meant to care for and communicate love to an “Other” (de Beauvoir, 1949) taught me the value of caring for others, as patients and as research participants. In my life, the origins of a care-centered relational ethic extend to my early childhood. The “memory of caring and being cared for,” as Noddings (2003) says, “form the foundation of ethical response” (p. 1). I chose to conduct research in the ways that I did because of my experiences with, and of, an ethic of care. These experiences connect to my earliest memories of having been cared for, and, thus, my methodology in this research is care-centered and relational. The very place where I learned the ethical importance of care was my care-centered relationship with the woman who mothered me.

Any subsequent ethical action in my adult life has been built upon these experiences, and all credit for having planted the seeds for ethical action in me belongs to...

Lorraine. My earliest memories are of her. My small hands hold her face; I want to see and be seen by her. She smiles at me and I feel loved. Her strong hands, rough and calloused from work, smooth the hair on my forehead that is wet from the heat of the day. When I need to, I can conjure the feel of her cool cheek against mine, feel my arm wrapped around her solid leg, or hear her tell me, "Hush, baby." When I need to, I can see her in my grandmother's kitchen, or back yard, teaching me to do the work she does every day- the cooking and cleaning, hanging clothes on the line, the ironing...

The starch smells like lemons, steamy lemons, and so now do Papaw's undershorts. Wiggling the hot iron down the legs and along the seams I press and starch, and press and starch again. "Careful," he warns as he passes by, "those shorts are going to stand up on their own...a fellow needs to be able to sit down," he says, smiling at me. I am learning to iron and Lorraine, the woman who has kept my grandmother's house and cared for her children and grandchildren, the woman who cares for me, says men's shorts and handkerchiefs are the best place to start. Secretly I wonder if she just doesn't want me working on more precious linen or if maybe she is just tickled by the idea of Papaw trying to sit down in his shorts or blow his nose in a handkerchief when I'm finished with them. The latter seems more likely. But this doesn't stop me.

I keep spraying that starch, thick coats soaking through the material making the iron hiss and spit. Moving on to the stack of handkerchiefs, I lean into the point of the iron pressing from the center and out into each of the four corners. Finding my rhythm, I flip the hanky over and repeat the motion, ironing a sharp crease with each fold until it is small enough to fit neatly into

Papaw's pocket. Satisfaction and disappointment mingle when I realize that the basket of crumpled clean laundry has already been transformed into stiff neat stacks. I look around for something else to starch. Lorraine has been watching me out of the corner of her eye. She intervenes, "Come on in the kitchen and eat something, baby," she says to me. I am easily distracted. A moment in the kitchen with Lorraine is better than just about anything. Even ironing.

My grandmother and Lorraine did the better part of the mothering that I experienced when I was a small child. While my mother worked during the day, Lorraine took care of me. Although having a nanny or housekeeper was certainly not uncommon for white families where I grew up in Tennessee, what strikes me as remarkable is the care she gave me in the context of the social and political circumstances at that time in our nation's history. Lorraine dressed and fed me. She tended to my small child needs. She redirected me when necessary. She talked with and listened to me. Lorraine did not just teach me how to work, how to cook, or how to iron. While these things are important, what she taught me, that no one else did, was how to embody, and put into practice, an ethic of care. What I learned from Lorraine was that social constructions of race, intolerance, and hate can be relationally transcended through loving peaceful action.

Lorraine was more than a nanny or housekeeper; she was a mother to me, a mother who left her own daughter each day to take care of someone else's. She was a black woman who took care of a small white child in the Deep South at a time when abject racism was unapologetically a cultural norm. Through "Other Mothering" (Hill-Collins, 2000), Lorraine embodied Dr. Martin Luther King, Jr.'s proclamation, "Darkness cannot drive out darkness; only light can do that. Hate cannot drive out hate; only love can do that" (King, 1963). Dr. King was assassinated

one year before I was born only a handful of miles from where Lorraine mothered me every day. On April 4, 1968, sixteen months before my birth, and without warning, a .30-caliber rifle bullet entered Dr. King's right cheek. He had been on the balcony in his room at the Lorraine Motel in Memphis, Tennessee. At that hostile time in our country's racial history, in the same place where countless hateful, violent acts of bigotry and hate occurred for centuries, Lorraine's mothering, her love, taught me how to embody and practice an ethic of care.

Fasching, deChant, and Lantigua (2011) show us how King's commitment to, "win hearts and minds through a willingness to turn the other cheek while never backing away from the demands for justice" represent the power of ethical action as "a way of life" (p. 255). The goal for King was, "to love one's enemy, not in the sentimental sense of affection (eros), nor in the reciprocal sense of friendship (philia), but in the constructive sense of seeking their well-being (agape) (Fasching, deChant, and Lantigua, 2011, p. 255-256). While my relationship with Lorraine was how and when I first learned what it means to engage in an ethic of care, I hesitate to tell this story for I recognize how easily it may be misunderstood and its message lost. Even though I may readily and rightly credit scholars like Gilligan and Noddings for naming and explaining ethics of care, for me it is necessary to publically acknowledge and credit Lorraine and the countless other women who, through other mothering, embodied and practiced an ethic of care long before it was even named and entered academic conversations. Lorraine's mothering me at that time, in that place, when I was a small child was not only a job. To me, it was a deeply ethical act. She took care of me, and my grandmother's house, not because it was a job that she wanted; Lorraine did it because it was a job she no doubt needed. She needed to work to take care of her own family, and caring for children and caring for homes were among the few jobs a Southern white supremacist society permitted Black women to have in the 1960s

and 1970s in the U.S. At that time in U.S. history and in Tennessee, as a black woman, Lorraine's employment possibilities were few and I suspect that she took care of my grandmother's children and grandchildren because it was one of the few jobs available to her. As I consider the environment in which Lorraine lived and worked, I presume that she loved and cared for me, a privileged white child, not because the social conditions made it easy for her to do so. She did it in spite of, and yet lovingly in the midst of those conditions. Through an ethic of care, Lorraine transcended the racial divide. I represented her oppression, and yet, she loved me. She did what Dr. King preached: to drive out hate, she loved (King, 1963).

Decades later I cannot offer my relationship with Lorraine as narrative context for who and what I am as a researcher without acknowledging the deeply complicated social and racial contexts in which our relationship took place. As Wallace-Sanders (2011) explains, "it is impossible for anyone to truly know how African Americans felt about white southerners" (p. 31). Raines (1991) states that because of racial inequality, "the dishonesty upon which such a [southern] society is founded makes every emotion suspect, makes it impossible to know whether what flowed between two people was honest feeling or pity or pragmatism" (p. 90). The limits of what I, a then small, white girl, could understand prevent me from ever really knowing how Lorraine felt about me, or the cost to her of engaging in our relationship. To me, Lorraine embodied deeply ethical actions. As a woman who, under the oppressive social conditions created by deep-seated racism, Lorraine chose to communicate love and acceptance to a child who was not her own.⁸ Lorraine taught me how to love and be loved, and to hold in trust the

⁸ Most importantly, I do not wish through the above recounting of my attachment to Lorraine to perpetuate the stereotype of a Black woman as "Mammy" as the Mammy stereotype continues to do catastrophic damage to Black women and Black womanhood (Wallace-Sanders, 2011, p. 7). Because "the mammy image is central to intersecting oppressions of race, gender, sexuality, and class" (Hill Collins, 2000, p. 73), I do not seek to participate in or reify this controlling image applied to Black women. My experiences with Lorraine taught me that love is greater and more powerful than hate, and one of the most transformative experiences of all is transcending established boundaries between two people, even more so when those boundaries are socially constructed.

good of (an)other. Upon reflection, I realize that, like most of us, I have learned about caring for others through my experiences of being cared for by others. Over the years, this understanding has translated into the ways in which I engage others in relationship and specifically, here, the ways in which I came to conduct this research. In my work I aim to honor what Lorraine taught me about caring for (an)other; my argument here is for the deeply consequential and lasting effects of embodying an ethic of care and for how it may serve as a framework for conducting compassionate, caring, and ethical research. Like Lorraine, countless women live such an ethic of care every day. These individuals practice care-centered ethics and yet, unlike many academics who write about it, they are rarely credited for their contributions to understandings of what it really means to engage in an ethic of care. In this project, I draw on my experiences with Lorraine to exemplify an ethic of care learned through personal, daily, lived experience. My memories of Lorraine are snapshots representing the relationship I still have with her. These memories remind me of what Lorraine taught me: the capacity love has to blur the lines between self and other. These memories also continue to teach me how to ethically care in my work, in my life, in my research.

b. Reciprocity & relationship building: setting the scene at the hospice house. Two summers ago, when I was given the go ahead to conduct research with the island hospice, I initially thought that I would come to the island for six weeks or so like I have every summer for years. I imagined staying at the hospice for several days at a time while my daughter was in overnight camp. There was a possibility that we might not have a patient at the hospice during the time I would be there, but I was aware that I would likely need to return the following summer in order to spend more time researching and wrapping things up, at which time I might

have another opportunity to participate in the care of a patient. Because I could not, at the time, imagine how to stay on the island for a whole year to complete my research, when I left my final meeting with Ann the summer before I began, my plan was to return for a second year of data collection. In the fall and spring as I finished my course work and began writing my dissertation proposal, I felt as though staying for such a short period of time would give me merely a glimpse of the goings-on at the hospice and would likely provide me with an incomplete, if not false, sense of the place. Most importantly, I had a growing concern that conducting my research like this would be violating principles that I considered paramount. I worried that I would be sweeping in just to “get the story,” rather than taking the time necessary to understand and become a part of the hospice community.

I also worried that I would not be able to sufficiently reciprocate with the people at the hospice if I gathered my data in such a short period of time. I would not have the time to give as much (if not more) to the community as I received in my relationships with those at the hospice. Essentially, I felt as though my connection with the hospice community would be contractual and transactional rather than truly relational. I expressed these concerns to my committee members and to Ann in the early spring of 2012 and Ann agreed that staying longer would allow me to enter into the flow of things at the hospice and that this would be a choice “more in keeping with the way things happen here.” I felt relieved and concerned to hear that: I was relieved because staying longer resonated with my sense of how good qualitative and feminist research is a relational accomplishment, though I was concerned about how to finance a year of research when I was so far away from my university where I taught. My committee was incredibly supportive of my request to research on site for a year and, somewhat magically, funds to support my work appeared from anonymous donors.

In any given research endeavor it is necessary to not only understand the methodologies that serve as frameworks for approaching our research, but we must also give an accounting of the methods that we employ. For this particular project I am to claim unambiguously feminist methodology and methods, and in the following subsection I explain my positionality, interpretation of the goals of feminist research, and justification for employing these methods.

B. Methods

a. Feminist research. Naming my research “qualitative” and “feminist” is insufficient. As Reinharz points out, there is “no single ‘feminist way’ to do research” (1992, p. 243). Like other feminist researchers, I value working across multiple disciplines, and I describe my research as existing at the intersections of communication studies, medical and religious ethics, and feminist scholarship. This interdisciplinary emphasis begins to qualify my work as feminist, but as Reinharz (1992) explains, in addition to the multiplicity in feminist research methods and perspectives, the “emphasis on inclusiveness in feminist research methods allows us to study the greatest possible range of subject matters and reach a broad set of goals” (pp. 244-245). My research on and writing about relationships, interactions, and communication in the Zen hospice context is informed by a feminist ethic of care that make central that which occurs, exists, and transforms in the “private” realm: including, illness, dying, caretaking, and death. Alison Jagger (1992) describes this feminist ethics approach as one that prioritizes what are commonly characterized as “feminine” qualities: connection, community, sharing, and interdependence. As I have observed and participated in these aspects throughout the course of my research, I have come to learn that these are among the most essential in end-of-life care and decision-making, particularly in this hospice community.

I further qualify my project as feminist because my research is relational. Quite early on in the research process I learned that the kind of research in which I wished to engage could only happen as a relational accomplishment. My research occurred within the relationships with my committee, the practitioners, volunteers, members of the monastic community, patients, families, and even the physical landscapes. Engaging in and examining these relationships required me to take into account aspects such as power, vulnerability, and positionality. Also in line with feminist methods, I approach my research with awareness of and responses to roles, and particularly of how these are experienced and interpreted by participants and researchers, and, through this research I aim to respond to power differentials in the participant/researcher relationship while highlighting the ways in which any knowledge gained through this project was co-created. Stemming from this is how I contend with such power differentials by ensuring that all participating in this project have voice; by this I mean that all involved have the opportunity to share input about scholarship that results from my data collection efforts. I seek, through my work, to engage in ways of knowing that are not patriarchal and I do so to honor the voices, experiences, and stories of those with whom I study, particularly the dying who often have little or no voice and whose experiences may be marginalized through forms of silencing such as exclusion, bastardization, or misappropriation.

My project is interdisciplinary as my scholarship draws on and contributes to multiple academic disciplines and fields of study including communication, medicine, spirituality, religion, and ethics. In addition to my research's interdisciplinary and egalitarian foci, I qualify my research as feminist because I identify as a feminist researcher, and the researcher and research in which a researcher engages can never be analyzed separately

Working to understand the conditions of the dying and those of their caregivers has meant identifying the contexts in which we collectively experience failures, conflicts, and shortcomings as well as successes at the end of life, and recognizing, and articulating how those experiences might help create better end-of-life experiences for others. I continue to seek to understand end-of-life experiences by conducting this research and engaging in caregiving to more thoroughly comprehend these crucial aspects of end-of-life experiences, to make sense of the experiences of the dying, and to improve the conditions of the dying and their caregivers. Our discomfort with dying and death (our own and that of others) often leads to our engaging in practices that marginalize those who are dying. For example, we resort to radical interventions to stave off death and, once those interventions no longer offer hope of recovery, we do things like put dying patients at the end of the hallway, out of our sight, as if the extent of our capacity for clinical intervention constitutes the extent of our capacity for care of the dying. Researching in order to enhance existing practices, relationships, and conditions of marginalized populations, such as the dying, further identifies my research as feminist. Such a social justice focus is key in feminist scholarship.

Since it was and remains important for me to be able to give something back to the people with whom I research, my choice to continue my research over the course of a year was intended to build relationships and contribute to those relationships. I wanted to participate in the care of patients and their family members as well as in the daily routine of the hospice as much as possible. When I was at the hospice I cooked, cleaned, did laundry, watered the plants and flower garden, and tended to the physical and emotional needs of patients and their family members. This kind of participation was, I believe, the best possible way to engage in care-centered research. My role as a caregiver allowed me to foster relationships with participants

while above all, “valu[ing] openness to intimacy and striving for empathy, which should not be confused with superficial friendliness” (Reinharz, 1992, p. 68). The context in which participant observation occurred was relational rather than individualistic since the autonomy of the researcher is not an assumption in feminist research.

Furthermore, I neither assumed it possible for me to completely “get” the full story at the research site nor conducted my research in order to merely consume the experiences of others. As a feminist researcher I recognize that I can only ever hope to come to understand part of the story and partially experience the stories that belong to others. I can only experience the parts that my participants choose to share with me or allow me to witness. Therefore, I can only ever experience what participants are willing for me to “know,” and, because we can never fully know the experiences of others, that knowledge is always incomplete because each of us experiences a moment or event differently, and through our own personal histories and positionalities, multiple truths of any given moment or experience exist. Since there can only ever be multiple realities, we are not individuals in these experiences so much as we are collective participants in an experience we have together. I conduct my work with the intent to enhance the relationships of all parties involved in the processes of death and dying, and my hope is to contribute to scholarship on death and dying to help create systems and practices that more effectively and compassionately address difficulties that arise for dying patients, their families, caregivers, and practitioners.

Research methods such as feminist participant observation encourage the researcher to place her or himself in relationship with participants, allowing a “feminist ethic of commitment and egalitarianism in contrast with the scientific ethic of detachment and role differentiation between researcher and subject” to guide the research process (Reinharz, 1992, p. 27). This

commitment requires that I considered the roles I played in my relationship with participants. I recognized that how I see myself as researcher may not be how my participants see me and my dual role as researcher and caregiver further complicates this dynamic. Since no matter how I may see or present myself as researcher and caregiver in relationship with my participants, my participants may understand my roles quite differently, I recognized that it was necessary for me to always be reflexive about how I was understanding and presenting myself in relationship and how others may have been understanding and relating to me in relationship. In light of this, recognizing imbalances of power in relationships with participants and working to equalize them was vital, and, in order to do this, I considered transparency in my interactions with my research participants extremely important. I accomplished this during my data collection by adhering to strict informed consent procedures and offered my participants my work so that they would have a chance to review and critique it throughout the writing process.

I did my best to be aware of and reflexive about situations in which I may have, “listened with at least part of my attention focused on producing potential material” and about how that may have affected my ability to be fully present for those around me as well as how that may have altered what I said or did in a given moment (Anderson and Jack, 1991, p. 13). Anderson and Jack (1991) promote learning to “listen in stereo, receiving the dominant and muted channels clearly and tuning into them carefully to understand the relationship between them” (p. 11). Like Anderson says of her own research experience, I too faced the challenge of trying to make sense of what I was hearing while I was hearing it and needed to have “the process of analysis [...] suspended or at least subordinated to the process of listening” (Anderson and Jack, 1991, p. 15). As part of listening with people as they tell their stories, it is important to ensure that I create

environments in which participants feel comfortable enough to share difficult stories without feeling forced to do so.

I not only followed steps to carefully protect every participant's identity, but I also ensured that all participating in my project were given voice by giving them opportunities to offer their input about my scholarship. Concurrently, I found my own voice through my interactions with my research participants. I also frequently communicated with my participants to make sure that I was accurately reflecting what I experienced during my interactions with them. Reinharz (1992) articulates her hopes for what may be accomplished as scholars find their own voice when she explains that finding, claiming, becoming comfortable using one's own voice leads the researcher to a place of understanding, a moment in which the researcher comprehends a phenomenon and "finds a way of communicating that understanding" (p. 16). As researchers, Reinharz explains, we cannot speak for others, but we can, and "must speak out for others" (Klein in Reinhartz, 1992, p. 14). Just as Reinharz does not wish to speak for the feminist researchers about whom she writes, and, instead, she presents their voices alongside her own, I seek to present in my scholarship the voices of those with whom I have studied and learned. I aim to do this while acknowledging the ways in which my voice frames the arguments I make and acknowledging that my personal experience cannot and should not be overlooked.

b. Framing the research through inquiry. One of the primary ways in which the voice of the researcher is evident is in the formulation of guiding questions. As researchers, we make choices about what we study, what gets included, and what finds its way to the cutting room floor (Lofland & Lofland, 1995; Jorgensen, 1989; Taylor & White, 2000; Silverman, 2011). We use the questions we develop to frame our research and because framing is seeing, we determine

by our questions what we are likely to find. This is not to say that in the course of researching we are not met with some surprise, but rather that we often find that for which we look. It is vital, therefore, to be reflexive about how we frame our research and how it is that we come to find what we do. This means understanding the research process as a co-creation with participants and acknowledging our contribution to the data we collect (Jorgenson, 2011). Who I think I am, who my participants think I am, how I conduct myself with participants, and what expectations I carry with me all influence what I come to learn or know. Both participants and researchers are active interpreters; our interpretations of one another influence how we come to understand and respond to one another in the research setting (Jorgenson, 2011). In particular, I am guided by my personal and professional experiences with patients at end of life, my daughter's lengthy and grave illness, the scholarship and mentorship afforded me in my studies, and my keen desire to improve the experiences of the dying and those who care for them. It is impossible for me to approach my research as a *tabula rasa*; I do not come to a site as a blank slate upon which the stories of the patients, families, practitioners, caregivers and members of the monastic community are written. What these individuals are willing to reveal to me is indelibly marked by the frame of reference I bring with me and by what we create together in the research process. Therefore, I cannot begin to present what it is I think I have come to know through my relationships with these individuals without first defining what it is I hoped to learn. The following guiding questions, developed long before I came to learn and work with the hospice community, have acted as the frame for my research throughout my time there.

- What is the “sense of place,” or “landscape,” that I may find, describe, and come to make sense of at the Zen hospice, and what are the common stories, sets of beliefs, goals, or activities enacted by members of the Zen hospice community?

- How do caregivers utilize the common stories, sets of beliefs, goals, and activities enacted by members of the Zen hospice community in a setting in which many patients and even some caregivers are not Buddhist practitioners?
- What rhetorical “work” is getting done through the Zen hospice narrative of dying (as opposed to traditional – hospice/medical – narratives of dying)?
- Furthermore, what rhetorical work is being employed when spiritual narratives informing medical-ethical decision-making come in conflict with one another, and what are the potential consequences of failing to cooperate for mutual benefit in the dying experience?
- What is the nature of the Zen communal practice? How is it engaged and explicitly and implicitly enacted through ritual, improvisation, and communication (shared goals, conditions, parts, and participation)?
- How does the Zen idea of “mindfulness,” or “co-presence,” relate to end-of-life communication and what does the Zen hospice teach about being fully present with the dying?
- How is “meaning” negotiated (participation and reification), and how much ambiguity and improvisation are present/fostered/resisted/tolerated within the Zen hospice community as a part of the community’s history of negotiation?
- How might ritual function as a source of coherence for the community in end-of-life care?
- What is the Zen hospice frame for end-of-life care? How much flexibility does the frame have; in other words, how does it ritually and philosophically encourage (or inhibit) flexibility and structure?

- Through conversation, how might the Zen hospice facilitate “tending” to one another in death and dying experiences and facilitating a patient’s “turning toward death”? How might the Zen hospice end-of-life experience be understood as “composing a death”?

c. Informed consent. Few are offered the precious opportunity to work with patients who are dying and with their caregivers, and, with this great privilege comes even greater responsibility. Dealing appropriately with this potentially vulnerable population has meant being extremely careful with and respectful of my participants and their information.

To maintain transparency, equalize power imbalances, and ensure confidentiality and full disclosure of all research activities, I consistently and carefully made sure that all twenty-one⁹ study participants, including four patients, three practitioners, ten volunteers, and four family members, who ultimately agreed to have their stories included were properly consented per University of South Florida Institutional Review Board requirements.¹⁰ Obtaining consent was not at all a difficult or cumbersome process with the hospice staff or volunteers. With patients and their family members, however, obtaining informed consent was a bit more complicated because determining when and how to approach each potential participant took time and careful consideration. Consenting patients required me to consider a number of important factors. One of the most important was determining if and when each patient was capable of giving informed consent. This can be tricky with patients receiving medication for pain management. To effectively navigate these moments I sought the help of Ann by asking her, before proceeding each time, if she felt that the patient was sufficiently mentally intact to give legal informed

⁹ These categories of participants are not exclusive as some individuals were members of multiple categories. For example, several participants were both volunteers and members of the monastic community.

¹⁰ Please see Appendices A and B for copies of USF IRB consent form.

consent. The necessity of this practice is readily evident in the situation of one patient who was, in fact, not capable of consenting to participation as his cognitive ability deteriorated rapidly due in part to the administration of high doses of narcotics. This patient's wife, however, participated enthusiastically and she specifically asked that his story be included in this research.

Sometimes I was asked to wait until another time or time of day to explain both my dual role at the hospice as caregiver and researcher and the research that I was doing. For example, patients were often at their best early in the morning before the first dose of medications was administered. This meant that there would be a small window of time between when the patients woke up and when they received their doses of medication that might alter or impair their judgment. During this window of time, with the patients' informed consent, I had the opportunity to discuss the project, their potential involvement in the research, and the details of the consent form. Before our interviews, in order to avoid potentially making patients or their family members feel pressured or coerced into participating in the research, I always asked potential participants to take time to think about it before they signed the informed consent forms; some participants took an evening to consider whether or not they would participate while others only seemed to want one or two hours to make their decision. I also gave potential participants opportunities to ask me questions about the nature and goals of, and future plans for the project as well as what I hoped to learn.

All individuals recruited were voluntary participants. Interestingly, several participants articulated that they felt there was something about their experience from which others could learn and this seemed to be a motivating factor for participating. These individuals explained that, if something good might come to others from the suffering that they experienced or were experiencing, then the suffering accompanying their dying or the dying of their loved one would

in some way be more valuable. Many participants expressed that making a contribution through their suffering for the good of others was important since it was something they could actively “do” in the midst of an experience that was largely out of their control.

In addition to obtaining proper informed consent, I assured participants that all of their information would be kept confidential; I accomplished this during the consent process by explaining to participants how I would mask their identities (I also offered participants the opportunity to have their names included in the research if they so desired). One of the hospice’s confidentiality procedures requires all staff and volunteers to use the initials of its patients in communications other than those in the patient’s chart or in conversation with authorized caregivers, family, and friends. I also used initials in my field notes to identify participants, though in my data analysis I abandon these initials for pseudonyms to obscure identities when writing about participants. With the exception of the physician, nurse/Buddhist nun, Abbot, Roshi, and the Roshi’s interpreter (who all chose to be identified in my research by their legal names), the use of pseudonyms was crucial in my study. Though including such description is characteristic of qualitative research, in order to ensure participants’ anonymity I opted to not include information about their potentially identifiable descriptors and, in another effort to maintain confidentiality, I avoid using thick, rich description of participants.

d. Data collection. Once my committee gave me permission to conduct my research, I completed the University of South Florida’s Institutional Review Board certification procedure and Ann gave me permission to proceed. An interim year had passed since my last meeting with Ann and, in that time, state requirements for working with patients at the hospice changed. Staying for the year to work at the hospice meant that I needed to be trained as a volunteer

caregiver for the hospice and I needed to complete a new state mandated seventy-five hour “Fundamentals of Care Giving” course. The law that had been enacted earlier in the year was ambiguously written, so how this change would impact the hospice volunteer staff in the long term was unknown. Many were concerned that new volunteers might not be willing to take a seventy-five hour course (even in one not involving direct patient care) before being allowed to work in any capacity. While Ann, the board members, and I worked to obtain clarification of the ruling as the law applied to the hospice volunteers, I completed a background check, took a TB test, obtained CPR, First Aid, and Food Handler’s certifications, and took one of the few available caregiving courses at a local home health facility recently certified to provide the training.

The caregiving course that I took met several days a week and was taught by a former nurse. It became immediately clear that the training was intended for home health aides who had already been providing care in the local community for some time. The content was basic and the course teacher, who was still working to assemble and determine how best to teach the curriculum, asked me to teach the few units related to hospice and end of life. The women taking the course were a delight, and it was a joy to contribute to their new program. I helped teach the course as a thank you to the home health facility for having allowed me to join them in their training. By the time I completed the training, we were well into the fall and the hospice was awaiting the next patient’s arrival. Months later, the hospice was able to determine via repeated requests for clarification of the law that its workers would not be required to complete the seventy-five hour course since they are unpaid volunteers. This was a relief to everyone involved.

e. Participant observation. Since my research aim is to use my data and analysis to improve the systems, practices, and communications related to death and dying, and, given the nature of the research site, I decided to use participant observation as my primary and interviewing as my secondary research method.

I spent several hundred hours engaged in participant observation at the hospice as I worked along side the hospice physician, nurse, and caregivers taking care of patients and their families. During this time, I amassed copious field and interview notes and I participated in numerous communal and organizational events. Doing participant observation gave me, as researcher, opportunities to see, hear, and experience the happenings at the research sites and to witness the care of and communication with patients and families and between caregivers. Even more, participant observation allowed me to engage and participate in care and communication as a member of the caregiving team.

The ways in which I participated, observed, and conducted my interviews stemmed from my recognition of each person I encountered as a “master,” as a valuable voice, and as an agent whose narratives and experiences are deserving of inclusion and close intellectual consideration and examination. In my research I aimed to equalize power differentials and actively created spaces where all perspectives were heard, appreciated, respected, and included. The framework from which my scholarship stemmed is egalitarianism: I treated each person’s narrative voice and contributions as equally valuable.

Being aware of power differentials between me, dying patients, and their loved ones was compulsory as doing so compelled me to recognize when I needed to alter my behavior and choices in order to create more balance in particular situations. Working with the dying is an intimate affair, both physically and emotionally, for the patients, caregivers, and family members.

The hospice environment puts individuals in close physical and emotional proximity with one another though my role as researcher, at the same time, created an unavoidable distance between the dying patients, their family members, and me. To mediate this distance and power differential, I engaged in a willingness to be mutually vulnerable, a key goal in feminist interviewing. I shared, for example, my experiences with a dying child, caring for my grandmother as she dealt with and ultimately died from complications related to Alzheimer's disease, and my own experiences of significant illness. Through these instances, I sought to become less of an "observer" and more of a "participant" in the care and in the sense of loss that accompanies it. Giving my participants access to moments in my personal life – without inappropriately shifting the focus from their experience to my own – was intended to position me as less of a voyeur or audience member in the storying of their lives, and more as a companion or partner in experiences of loss. In these moments the participants and I shared ground and this helped us come to understand one another more fully and sensitively.

In further effort to engage in care-centered research, I made sure that all of my data collection methods occurred within the context of my relationships with participants. I made my research decisions as, first and foremost, relational choices. The contexts in which I interviewed or had conversations with participants included but was not limited to: bedsides, formal meetings/retreats, coordinating care moments, and informal moments over meals or cups of tea. Recognizing the richness and complexity of the situations at end of life, I came to each bedside without research tools that would typically be utilized for interviewing or taking field notes; I did not use tape recorders, surveys, or video cameras and I did not take notes when I was with a patient or family member. Instead, I made notes after I spoke with the participants and sometimes stopped between the daily tasks in which I participated to quickly jot down something

someone said or note a significant detail. I purposely completed the majority of my note taking when I was not with a patient or when there was little or no chance that a patient's family might see me writing my notes; I took notes in privacy to avoid potentially making patients or their family members feel uncomfortable. Although all involved were made aware of my dual role as researcher and care provider, I did my best to avoid making participants feel studied by quietly observing so as not to disturb or intrude on the caregiving or dying process. I made every effort to downplay my data collection in that I did whatever I could to not shift the focus away from the dying process of the patient.

f. Interviews. My secondary, supplementary research method was conducting interviews. I used interviews primarily in cases in which I needed to ask specific questions about what I had seen or participated in as a participant observer. These interviews gave me the chance to get clarification, find and fill gaps in my understanding of the hospice goings on, and be externally reflexive and reflective with Ann and MyoO (resident nurse and Buddhist nun). Such moments allowed me to come back to Ann and MyoO after I had taken time to think about what I had seen, heard, observed and participated in and discuss with them what I was experiencing as a participant observer at the hospice.

Fluid, semi-structured interviewing that I did mirrored the complex and fluid nature of end of life care. "Fieldwork relationships are fluid over time" (Reinharz, 1992, p. 68) as they invite "transformation-or consciousness raising-lay the groundwork for friendship, shared struggle, and identity change" (Reinharz, 1992, p. 68). Since participant observation functions as a more natural form of "knowing" and learning with people, at the hospice I used conversational interviews only when necessary. These instances arose when I needed to ask specific questions

and get clarification on matters that did not come up in the course of our work together or when evoked by reflection on certain moments or interactions with particular participants. These reflective inquiries were layered and circular; I returned to certain ideas or experiences on multiple occasions as I thought more about them, and I came to understand them differently through subsequent experiences.

g. Data analysis. For me to begin analysis of the data that I collected over the course of the year, I first needed to consider what Schön (1983) and Steier & Ostrenko (2000) call the “problem setting.” These authors highlight our tendency as researchers to concern ourselves primarily with a given problem we wish to solve. We do this “at the expense of considering more fully the assumptions embedded in ‘problem setting’-how we construct our ‘problems’ in the first place” (Steier & Ostrenko, 2000). As I suggested earlier, death is not so much a problem to be solved as a story to be told. Working with this orientation to understanding and exploring end-of-life experiences, it stands to reason that I should make a small adjustment from “problem setting” to narrative setting. And so, like data collection, analysis of the data was “done not in the frame of [...] ‘extracting’ information from the other, but to develop an understanding [...], to explore assumptions and to generate ideas about how to proceed (Steier & Ostrenko, 2000, p.50). Along with this notion of setting, I found what Weick (1995) reminds us about context helpful for understanding the scope of any given setting and for recognizing the contribution context makes to the sense-making effort. Weick (1995) says that sense-making is about context and while our tendency may be to pay less attention to what lies in the periphery (of our narrative setting) so that more attention may be paid to what we determine to be central concerns, we lose the bigger picture, the context in which these occasions occur. Through our

hyper focus on the center we lose both the context for the center as well as the center itself (Weick, 1995). In other words, our sense-making suffers when we fail to take seriously the context or narrative setting in which we are making sense of end-of-life circumstances. I have said that it has been important for me to consider and incorporate aspects of narrative setting that includes peripheral as well as central aspects of the setting or context. While I have even identified some of these aspects as they relate to guiding questions as a frame for research, there are, however, other key aspects of the setting or context in which this research occurred that also required identification and consideration. By this I mean to point to not only particular personal assumptions that I brought to the research, but also to some larger elements. For example, I could not discount the impact of coming to study from a primarily western perspective a hospice influenced by and grounded in eastern Zen practices and worldview. Furthermore, I needed to seriously consider my Western clinical training when studying a site where a clinical approach to dying is superseded by a more spiritual approach and clinical interventions are few.

With this in mind, the next step in my data analysis process was to thematically code my field notes. After having made careful note of people, events, and circumstances at the hospice when I was doing my participant observation, I decided to wait a period of time in order to give myself space that helped me recognize the themes that emerged from my data and to consider the narrative setting. By the middle of the year during which I was collecting data, I was able to clearly envision the themes that were most representative of end-of-life care and communication with and between patients, family members, caregivers, volunteers, and members of the monastic community at the hospice. These themes revealed themselves sometimes subtly, needing to be teased out over several interactions or events. At other times, the themes were glaring and impossible to miss. The most obvious one that emerged from my data now functions as the

overarching metaphor and primary theme for the project: the changing landscape. Not only did I experience the changing physical, emotional, and spiritual landscapes at end of life with our patients, but I also witnessed the marvelous literal change of the island landscape throughout the year, and thus this theme manifested as paramount. A series of thematic segments in this project supplement and enhance this seasonal theme while illustrative narratives, theoretical analyses, and corresponding drawings or paintings of the local flora and fauna accompany each of these sections.

h. Transitioning to seasonal landscapes. Drawing on our personal stories, we each bring to any moment our own set of feelings, prejudices, desires, beliefs, and hopes that help us make sense of our surrounding world. As Fasching, deChant, & Lantigua (2011) state, one of the primary ways in which our ethical selves are shaped is through story, particularly spiritual stories and “our understanding of good and evil is primarily shaped by the kind of story we think we are in and the role we see ourselves playing in that story” (p. 6). From our own stories, and the larger narrative(s) into which we see them nestled, we develop a narrative ethic that helps us determine what we believe, for example, is right or wrong. This narrative ethic informs our decision-making and that of others since we look to these stories to help us in the sensemaking endeavor. This is evident, for example, in my story about Lorraine. Both how I see myself in relationship with her and how I make sense of her caregiving in a white supremacist south guide how I make sense of the world around me, and, ultimately, how in the context of this research project I come to engage in the relationships with my participants. Like Noddings (2003) argues, an early experience having been cared for lays the foundation for building the ethical capacity to care for others. Because experiences at the end of life can be particularly challenging, they try

and stretch our abilities to make sense of and understand the losses at hand. Through this research I seek to comprehend and articulate the ways in which patients, family members, practitioners, and caregivers make sense of dying through their personal narratives and how those narratives both complicate and enrich their sense and decision-making at end of life.

Chapter Four: Autumn



Figure 2: Autumn, Blackberries

In the morning breeze
a riverbank willow
scatters its leaves
into the flowing waters—
so autumn begins...
Rengetsu¹¹

¹¹ After the loss of almost all of her close family including two husbands and at least four children, Buddhist nun Otagaki Rengetsu (1791-1875) became famous for her poetry and pottery. In spite of her great personal losses, her

The cornflowers are in bloom, their bright, blue petals dotting tall, dry grasses that line the lane and stretch out in front of great blackberry brambles taller than I am even when I reach up on my toes. Hard, green berries have been slowly replacing the pink and white blooms. Vines, long thick tendrils, with terrible thorns reach out for the late August sun with new leaves and tender shoots.

Every year I have watched the blackberries blossom and begin to grow and every year I have had to leave the island just before they have come into season. This is the first year I am here in autumn to see them, full, fat and ripe, ready to be picked.

When the time came, I wanted to gather them all in my basket. I stretched and reached for every berry, eating one for every two that made it in. They were warm from the day's sun and melted in my mouth. As my basket filled, I made mental note of how many I had, one quart, two, and then easily three and four. I counted them as I planned for the jam I would make and plucked an extra handful just for the yogurt I would eat before I began mashing and boiling the berries.

Down in the meadow the fruit on the orchard trees has almost disappeared. The last few pears hang heavily where only the birds will enjoy them and one last shriveled fig dangles from a branch high above my reach. Two trees still bear small, sweet rose-colored sugarplums that I will gather for winter preserves. Owls return to our ridge, their calls to one another echo through cool, night breezes; autumn arrives.

A. Who We Are, Where We Are

This chapter offers an expanded description of the hospice landscape to help paint a clearer picture of the island hospice. To tell the story in which the members of the hospice care team see themselves living, I detail in this chapter the setting in which care for and of the dying occurs. Stegner (2002) reminds us that, to know who we are, we must know where we are. Extending this to the hospice, in order for us to know who the hospice members are as a community, we must know something more, both literally and figuratively, about where they are. This literal and figurative setting involves the people who engage in caring for patients and families, those supporting that care work, the manner in which that caring takes place, as well as the community of practice in which the caring occurs. I begin this discussion with a brief look at how the hospice community defines itself.

a. What's in a name? Part of the story we tell about ourselves is inherent in the names we are given or the names we choose for ourselves. Sometimes these are names given to us by our parents, ones we are given in memory of someone else, names that we take or choose not to take by legal means, or terms of endearment or ridicule. Other times these are names that resonate with us, and sometimes they are not. The naming we do, however, matters.

I began my research, and, indeed, this dissertation referring to the island hospice as a Zen hospice. As summer waned and the first signs of the coming fall season emerged I made my way to the hospice. In my first visit to the site and after talking at length with Ann, the project I hoped to do with the people there, our own lives, and our experiences with dying patients, I was invited to have lunch with her and the Abbot in the monastery kitchen. Following the lunch, during which we did not speak, the Abbot asked me why I had come. When I respond that I was

interested in how a Zen hospice takes care of and engages in end-of-life decision- and sense-making with patients and families, turning to face Ann, he smiled and asked, “Is that what we are, Ann, a Zen hospice?” Ann laughed and replied, “I don’t know; is it?” Admittedly, I was not sure what to make of this exchange and wondered if it was just playfulness on their part, or, if, in fact, their status as a hospice was in some way contested. I waited to see what more I might learn.

When I returned the following summer to begin my actual research, I continued to think of and refer to the hospice as a Zen hospice. I was influenced by my familiarity with the San Francisco Zen Hospice, admittedly, by the general Zen environment there, and by their connection to the monastery. When I learned of the hospice’s official categorization as an adult family home, I understood it as a legal categorization for state certification purposes. While attending a board meeting early on in the research process, I came to see referring to the place as a Zen hospice indicated significant misunderstanding on my part. This was made evident when board members were looking over the IRB consent forms. One board member voiced what came to be a shared concern of a number of board members. In the title of and throughout the IRB consent form, I referred to the hospice as a Zen hospice. “We are not a Zen hospice,” said one member. “We have been very careful about not using that term so that we don’t alienate people in the community who aren’t Buddhist.” At first, the board members seemed to want me to change the title of the project and the IRB consent forms before we went any further. Though, once I explained that this was just a working and not final title of the project, they consented to leaving it the way it was in the form. They did, however, insist upon a clarification in the dissertation that did not formally identify them as a Zen hospice. I asked the board to help me understand their thinking on this. As it was explained to me, they had been very careful in the

formalization of their name. To the community at large, they wanted to present themselves as a non-denominational entity open to all kinds of patients from any belief systems.

This was curious to me since it seemed evident from even one visit to the site that there is a Buddhist connection. Even someone unable to distinguish between the many types of Buddhism would recognize the island hospice as relating to Buddhist practice of some sort. As an organization, they construct a Zen and, at the same time, not-Zen hospice and not-hospice; in so doing, they retain the membership in Zen community (*sangha*) while also retaining membership in the larger non-Zen local community. They are, for all intents and purposes, a hospice in that they care for the dying. Yet, they choose to define themselves as not-hospice by claiming the title, adult family home.

Borrowing from the ethnomethodological framework of membership categorization of analysis (Bartesaghi & Bowen-Perlmutter, 2009), we may understand this as a contested moral account because the categories, “Zen” and “not-Zen,” or, “hospice” and “not-hospice,” are morally laden. Membership categories are the building blocks of our social order in that they organize our accounting of identities and activities. These identities and activities are prescribed for those who are bound to the categories. That is to say that the members of the hospice staff are not entirely comfortable with the Zen identity to the extent that it may exclusively bind them to the identity and activities prescribed for a Zen Buddhist community. So, too, the category of, “hospice” identifies them potentially with what traditional hospice has come to be defined. To free themselves of the exclusive association with Zen or traditional hospice practices, they choose to sublimate or loosen their connections to either in name. Doing so similarly liberates them from the expectations these names would entail. In this way, a Buddhist foundation and

connection are retained without necessarily alienating anyone who may be put-off by the categorization.

One of the major ways in which the island hospice distinguishes itself from traditional hospices is through its “adult family home” designation. Additionally, the island hospice differentiates itself from traditional hospices through the kinds of care that it provides; as Ann explains, “we are not a palliative care hospice environment. Comfort and support are what we do best. Aggressive interventions will not happen. We do not transport patients to the hospital if their condition worsens. All of the decisions about that have already been made before a patient comes here.” In more traditional hospice settings, a patient may receive, for example, chemotherapy to shrink an encroaching tumor or antibiotics to resolve an infection. A traditional hospice might choose to engage in this kind of intervention in order to either prolong someone’s life, even if only temporarily, or as a comfort measure to reduce pain or symptoms associated with a tumor or infection, in these examples. At the island hospice, however, these kinds of interventions would not be employed. As Ann reminds me, they do not do anything that prolongs the dying trajectory, and patients and families must be very clear on this before being admitted. While the island hospice board and staff would not define themselves as overtly Zen, they readily define themselves as a community of care.

b. The island hospice community of care. Understanding how the island hospice defines its role is important, though how they are organized as a community of care is of equal significance. Like any community of practice (Wenger, 1998; Wenger & Lave, 1991), the hospice community is organized around shared concerns, goals, and activities and, in this context, related to the care of the dying. Because community is rooted in activities performed together,

we may come to understand how the community builds and maintains cohesion through, for example, mindfulness practice in the form of the “five precepts” (Ostaseski, 2009). In this way, the hospice community members’ communal knowledge may be understood as a kind of situated knowledge (Haraway, 1988) that includes not only communal and specifically Zen Buddhist ritual practices, but also the very intimate care of the dying. The community’s mutual engagement in supporting the care of the dying through the hospice house and practices of negotiation, like those previously discussed (safety, privacy etc.), foster community relationships and clearly impact end-of-life care. Together these communal practices constitute a form of wisdom capital (Gaudiani, 1998) that helps us understand how this community may “live in ways that sustain well-being for others” (p. 60). These practices are articulated in volunteer trainings, modeled by Ann and MyoO in their patient care, as well as supported by the members of the board and monastery. Volunteers and family members carry this communal wisdom with them when they come and go and this wisdom is similarly transmitted to the community at large through interaction during community events. This wisdom functions as a knowledge source for caregivers who must also make sense of the dying experience. So, too, this wisdom informs both communal belief about end-of-life care and is embodied in the physical and spiritual care of patients and families.

The island hospice is structurally organized and supported as a community, and engages in end-of-life care as a communal act. They work closely with and accept patients from the local island physicians, hospital, and traditional hospice facility. With the local hospice nurses, the hospice also provides coordinated care throughout the course of a patient’s stay. This somewhat unique care relationship with local providers greatly enhances patient care and benefits patients because the transition of care from hospital, home, or traditional hospice environment is made

smoother. A continuity of care is maintained. Such an arrangement allows patients to receive the benefits of pain management ordered by their regular or former hospice physician while facilitating their move from the end-of-life experience involving clinical interventions to the low-tech approach to end of life at the island hospice. This is not to say that patients are not provided clinical care, but rather that curative or life-prolonging interventions are not employed in the care of patients while all other measures of comfort and pain management are made readily available.

The hospice house is connected to and supported by the local monastery. The Roshi oversees the monastery and the hospice house. While the Roshi quite frequently visits from Japan and meets with the hospice board in communal collaboration, his involvement is from afar. It is not on a day-to-day basis. Another key individual at the hospice is the Abbot of the local monastery who manages the affairs of the monastery and participates with the hospice house. Like the Roshi, the Abbot is not involved in the on-going management of the hospice house or the care of patients.

The hospice house has its own volunteer board comprised of ten original and founding members including the Roshi, the Abbot, Chisan (the Roshi's translator), Ann (the physician), and MyoO (the nun and nurse). Not all members of the board are from a clinical or monastic background. An attorney, philanthropist, and physicist are members, for example. The board meets once a month, beginning and ending their meeting with a short meditation. Ann offers a brief up date regarding patients cared for, status of the hospice finances, needs of the hospice house, and any matter of potential concern. Any decisions needing to be made are collaboratively discussed and determined.

Disagreements rarely occur, and when they do, they are managed with deep listening, mutual respect, and patience. When I attended the regular meetings, I never witnessed displays

of anger, irritation, passive aggression, or disrespect among board members. Having served on numbers non-profit boards over the years, I found this remarkable. When I asked how board members managed this cohesiveness, they told me that their abiding respect for one another and commitment to the shared aim of caring for patients at end of life, their families, the community, and each other direct them in their work together.

Volunteers who participate at the hospice also come from various walks of life: some are former healthcare providers, some are members of the extended monastic community, but most are local people who have been drawn to the work that the hospice does. A few volunteers have become associated with the hospice through the death of a loved one. Others simply want to support the work being done there. Not all volunteers give direct patient care as some prepare meals, work in the garden, play music for patients and families, read to patients, offer home repair services, or use specialized training to give, for example, massages or Reiki to patients, families, or caregivers alike. A special few of the volunteers come to the hospice from the monastery in Japan. These volunteers come by invitation only and are chosen by Chisan, the Roshi's interpreter. One at a time, these people come usually for a period of three to six months as a special part of their monastic training. They come to learn, at the bedside, what it is that the dying may have to teach them.

Interestingly enough, Ann and MyoO say that they rarely have to direct people to or dissuade them from participation to which they do not feel them suited. This came up in a conversation following a volunteer training in which I noted the presence of two people who might have been of concern in positions involving direct patient contact. During this caregiver training, one of these individuals tended to make herself the focus of discussion while the other person seemed easily agitated. In my conversation with Ann and MyoO that followed this

training, I asked Ann and MyoO how they planned to manage a circumstance of this nature. While they are particular about who is allowed direct contact with patients, Ann and MyoO assured me that volunteers tend to appropriately self-select the majority of the time. Rather than actively directing the process, Ann and MyoO allow it to unfold, waiting to see what potential volunteers will choose for themselves.

All volunteers undergo special training before being allowed to participate in the caring work of the hospice. Several times a year, trainings are organized for those who want to learn more about end-of-life care as it is practiced at the hospice or those who think they may want to be involved in some way. Ann and MyoO typically lead these training events, but I was graciously allowed to participate in the process alongside them on several occasions. During these trainings I learned a great deal about the expectations of what caregiving at the island hospice should be. Participants learn the fundamentals of assisting and caring for dying patients, through, for example, instruction on proper hand washing technique, maneuvering a wheel chair, repositioning a patient in bed, etc. They also learn the particular philosophical approach to care of patients and family members, how to “maintain the [island hospice] energy.” Contributing heavily to this “energy” are the “five precepts” (Ostaseski, 2009) coupled with the island hospice’s way of navigating privacy and independence as well as choice and safety.

c. Five precepts. The island hospice borrows from Frank Ostaseski (2009) (former San Francisco Zen Hospice director) the following “five precepts” that serve as a shared philosophical position from which all volunteers are encouraged to function. They are taught that in order for these precepts to “be understood and realized, they have to be lived into and

communicated through action” (Ostaseski, 2009). In other words, these precepts must be taken up as a practice of doing rather than as an exercise in thought.

The first precept asks that we “welcome everything. Push nothing away” (Ostaseski, 2009). Ann explained that as part of the practice of care, we must accept whatever is before us in the moment and that while we “must use good judgment, we must not be judgmental.” This asks us not to be frightened or put off by what is unfamiliar to us, to ways of being and dying that may be different from what we have seen or known before.

The second precept requires us to “bring [our] whole self to the experience” (Ostaseski, 2009). But, as Ann warns, “be careful what self you are bringing to the bedside.” The Roshi expands on this when he says that there is a “relational exchange with the dying person. You radiate to a guest whatever you bring with you. It is a spiritual experience for you, too, to live in the moment.” Bringing our whole and wholly present selves to our caring, Ostaseski (2009) says “enables us to form an empathic bridge to the other person.”

The third precept asks us to “[not] wait” (Ostaseski, 2009). Here, Ostaseski differentiates patience and waiting, in that waiting implies expectation and missed opportunity. This is future-focused in that it keeps us from being fully present in a moment.

The fourth precept is “find a place of rest in the middle of things” (Ostaseski, 2009). We do this, Ostaseski (2009) says, when we “bring our full attention, without distraction, to this moment, to this activity.”

The final precept, “cultivate don’t-know mind” asks us to leave our certainty behind and open ourselves up to myriad possibilities. Relationally speaking, the effect of our certainties is that they blind us to the processes of others. We fail, then, to see that the certainty of another is “as valid and legitimate as our own [...] however undesirable it may seem to us” (Maturana &

Varela, 1987, p. 245-246). As Maturana and Varela (1987) tell us, we must opt for a broader perspective, a domain of existence in which both parties fit in the bringing forth of a common world” (p. 246). We only ever have, as they explain, “the world which we create with others—whether we like them or not” (p.246). When we lock ourselves, and others, in with our certainties, we create a kind of loneliness, a gulf between us that Maturana and Varela (1987) say can only be transcended by our interaction with others. “Don’t-know mind” (Ostaseski, 2009) asks us to suspend our certainty, or, as Ann suggests, our judgment in order for us to be open to the conditions and experiences of someone else. In this end-of-life context, giving up certainty may mean that dying patients are not left alone, lonely, and separated by a chasm that our certainties may create between us.

The notion of remaining in a “don’t-know mind” (Ostaseski, 2009) may be expanded upon when we consider how this might be enacted. For Ann, this means that she “follows, not leads” a patient in their dying. This exemplifies attending to the landscape, allowing it to emerge and change before our eyes without becoming stuck at a certain point as the landscape passes us by. Ann says that we must, “read the body and notice the subtle changes physically and emotionally – the sights, sounds, smells, touch –we have to listen to what they are saying.” Doing this, she says, “is the practice of mindfulness, that you attend to what is happening in front of you in as clear a way as you can manage.” Attending to a changing landscape in this context also means that one cannot rigidly stick to set rules.

d. Negotiations. Flexible parameters must exist, and we must negotiate these as we navigate a dynamic trajectory. Two of the most common negotiations that come up in the course

of volunteer training and in actual care of patients has to do with the often-competing needs for confidentiality, privacy, safety, and independence.

Maintaining patient and family confidentiality is a must. This almost goes without saying in patient care, but given the small community in which the hospice is located, and the number of local volunteers participating in the goings-on, the value and importance of having and discussing guidelines concerning privacy cannot be underestimated. During the training, Ann tells volunteers that maintaining confidentiality “in our small community will be a challenge to your ingenuity and your ego. She articulates that maintaining confidentiality “requires personal strength and confidence to remain silent.” Volunteers are given a number of suggestions for how they might redirect inquiries for information about patients and are permitted to participate in caring with the condition that they maintain “kindly silence regarding the stay of our guests.”

Privacy also extends to actual care of patients. This requires its own kind of ongoing negotiation. Patients, even dying and fragile ones need privacy at times. Caring for these patients means that we are present for and participate in tasks that are normally done in private. Adult diapers are changed, trips to the toilet are made, bodies are washed, etcetera. As Ann reminds us, “we don’t necessarily know what people want to do alone.”

While privacy is of great importance, there are also significant safety concerns. Patients may be unsteady on their feet but still wish to walk themselves to the bathroom rather than use the bedside commode. Or, patients may wish to shower off rather than be washed with a cloth by hand. This can be potentially dangerous for patients who are weak or otherwise physically frail. Concerns for safety in this way challenge a patient’s independence and ability to choose what they feel is best for them.

At the island hospice, every effort is made to yield to the needs for independence and privacy, even when there is a safety concern. This may mean, for example, having more than one person assist in getting a patient to a bathroom or placing a patient on the bedside commode or bathroom toilet, but step out of the room while the patient uses the restroom.

The tension between patient's privacy, safety, and independence can be a challenge to caregivers, but it is one that, in this context, requires less attention to the concerns of the caregiver and more attention to the concerns of the patient. Caregivers must face such challenges with patients, and, as Ann instructs, "we work together to solve problems." Ann explains that caregivers' placing the patient in the position of expert "allows patients to tell us [caregivers] how they move best" or what is of most importance to them. What is "best" for a patient is determined by the situation at hand and constantly negotiated as the status of a patient changes over time. Negotiations are thus patient-centered, co-inspired, and co-constructed. Such co-inspired and co-constructed care calls for a special kind of communication.

e. Special communication. While the hospice is an especially quiet place, one in which little actual talk occurs, there is still a great deal that is communicated and from which we can learn. Such communication requires the mindset generated by the practice of the "five precepts" (Ostaseski, 2009), to be sure, and is maintained through the practice of mindfulness in whatever is happening in the moment, as Ann describes. However, there is more going on here than even these two powerful practices.

Over time, observing Ann and MyoO in their communication with patients, families, and caregivers, I realized that how they communicate can be explained with two simple, yet powerful

ideas: the first is what Frye (1983) calls the “loving eye” and, the second, placing parentheses before and after a death.

Frye (1983) distinguishes the “loving eye” from the “arrogant eye” that, as she explains, absorbs the identities of others, claiming them as their own. As Epston (2009) so beautifully explains in his discussion of Frye’s work (1983), “the ‘loving eye’ knows the independence of the other. It is an eye of one who knows that to see the seen, one must consult something other than one’s own will and interests” (Epston 2009, p. 76). He goes on to explain that, under the “loving eye,” people “who lay claim to certain kinds of knowledges aren’t unauthorized or delegitimated because they are not regarded to be in a position to know. The ‘loving eye’ confers social standing on those who have been dismissed and degraded by the ‘arrogant eye’” (Epston, 2009, p.76). Ann and Myoo, in particular, have a gift for this. They do not impose their will upon others, or assert their positions as doctor and nurse over patients and families. Instead, Ann and Myoo extend to patients and families the position of experts of their own situation, deferring to a patient’s or family member’s knowledge of their own needs and desires. In circumstances in which Ann and Myoo’s expertise is valuable, however, it is incorporated. Their particular kind of know-how does not diminish or cripple the knowledge of the other. Ann and Myoo’s ability to look upon others with the “loving eye” (Frye, 1983) is what makes it possible, I believe, for them to engage in the constant negotiation that is required in the mindful attention to and care in the end-of-life trajectory.

This embodiment of the “loving eye” (Frye, 1983) may be further characterized by what Turkle (2012) calls “tend[ing]” in conversation (p. 2). The mindfulness of Zen practice, of which Ann speaks and practices, is a call to be fully present with one another. In a New York Times piece dedicated to a social commentary on our cultural obsession with technology, Turkle

(2012) argues for being fully present with one another as well. She explains, “in conversation we tend to one another. (The word itself is kinetic; it’s derived from words that mean to move, together.) We can attend to tone and nuance” (Turkle, 2012, p. 2). She goes on, “In conversation, we are called upon to see things from another’s point of view. FACE-TO-FACE [*sic*] conversation unfolds slowly. It teaches patience” (Turkle, 2012, p. 2). We are, Turkle (2012) explains, getting “shortchanged. As we get used to being shortchanged on conversation and to getting by with less, we seem almost willing to dispense with people altogether” (p. 3). In the end-of-life context, what Ann does when she “reads the body” or “follows the lead of a patient” is tending. Turkle (2012) describes what may be lost when we are not tending in conversation. We risk “shortchanging” (Turkle, 2012) ourselves and those for whom we care when we are unwilling to give our full attention to those who are right in front of us. Turkle (2012) tells us something more about what may be lost or gained in our communication when she reminds us that, “most of all, we need to remember [...] to listen to one another, even to the boring bits, because it is often in unedited moments, moments in which we hesitate and stutter and go silent, that we reveal ourselves to one another” (Turkle, 2012, p. 4). In care of the dying, what may be revealed to us, by a patient or family member with whom we are “tending” (Turkle, 2012) in conversation, has the power to radically impact the situation and those involved. It is how we know what is going on and, therefore, what to do next. Looking upon each other with the “loving eye” (Frye, 1983) is part of this vital activity of caring for dying patients and their families through the practice of mindfully tending (Turkle, 2012) in conversation as it is practiced and modeled by the staff at the hospice. These practices further extend to care of and communication with families, caregivers, the local community at large, and one another.

Another way in which the island hospice engages in end-of-life care as a communal act is through the extension of care that goes beyond the parameters of death as a discrete event. One way we may conceive of this extended care is as a bracketing of the dying process that includes the death and the days and events preceding and following it as well as the people in relationship to, or involved in the care of the dying; I call this bracketing of dying, placing parentheses.

f. Placing parentheses. Bateson (1980) offers us insight into how we may think differently about the context of a death when she recounts her experience of her father's last days at the Zen Hospice in San Francisco. Bateson's article title, "Six Days of Dying" (1980) leads us to believe that the six days about which she tells us in her article are the days preceding her father's death. Instead, and of great relational importance, Bateson counts the days of dying as the three preceding his death and the three following. The parenthesis that she places around her father's dying to include what follows his physical death encourages us to give the days after a death the same attention as we give the days preceding it. The experience, then, is not only about the last days *of* the patient, but rather the last days *with* the patient. This is in addition to the days that follow for the families, caregivers, and practitioners after the patient's death.

Using this notion of an extended parenthesis, we may further explore the manner and kinds of caring that go on for and with patients, families, and those involved in patient care at the island hospice, and those particularly following a death. Looking to these practices, I found some of the clearest examples of how the island hospice continues the communal care after a person has died. This begins with the care of the patient's body once death has occurred. In the same manner that other decisions are made, patients and families decide what to do with the body. Some patients and families with whom I worked chose to have quiet, reflective moments

or perform rituals to honor the death. Other patients' families told stories of their lives together, made toasts to the deceased, or sat with the body until more family and friends arrived. Not all moments following a death were subdued, however. One family drank to excess and put considerable effort into dressing the patient's body in a flashy outfit and pointy-toed cowboy boots.

After a patient dies, staff members assist as needed with washing the body and preparing it for burial or cremation. The water that was used to bathe the body is then ceremonially poured on the ground in the garden around a small statue of the Bodhisattva Jizo¹², the guardian of physical and spiritual travelers. They often make a toast to the dead with a small glass of scotch or wine reserved for this special purpose and gather around the kitchen table to tell stories of their own as a way to process the events in which they participated. The Abbot comes from the monastery to lead them and anyone else interested in chanting the Hakuin Zenji's Song of Zazen¹³ and the Heart Sutra¹⁴ as part of the ritual after a death. If family members do not wish to have this done for them, the sutras are chanted in the empty room after the body and family members have left for the benefit of the staff and caregivers. Staff members continue their care of families until they are ready to leave. Some leave right away, wanting to be alone or back in their own homes while others choose to stay at the hospice for hours or days after the death. They spend this time mourning the loss and celebrating the life of their loved one.

¹² Jizo is the guide to travelers, pregnant women, and parents of children who have died. To learn more about Jizo, please see the following: <http://www.dharmacrafts.com/2ITM015/DharmaCrafts-Meditation-Supplies.html#sthash.YFw3n6DU.dpuf>

¹³ For a copy of Hakuin Zenji's Song of Zazen please refer to Levy, D.A. (1967) Hakuin zenji: Song of zazen. Cleveland, OH: [s.n.].

¹⁴ For an English translation and commentary on the Heart Sutra please see Pine, R. (2004) The heart sutra: The womb of Buddhas. Berkley, CA: Counterpoint Press.

Continuing the care of patients' families does not always end with this period of time. One of the most revealing things about how families respond to their care is that so many family members return to the hospice and monastery community long after their loved one has died. The experience of care leads some to return to participate in caregiver retreats or other community events at the hospice and or monastery. Some even work as volunteers in the care of other patients and families. From this, we see how, as Morrie tells Mitch in *Tuesdays With Morrie* (Albom, 1997), death ends a life but it does not necessarily end a relationship. Placing the parenthesis around what follows a death, as well as around what precedes it, allows the opportunity to more fully explore the loss in the context of the relationship. Death ending a life but not a relationship is meaningful when understood in Buddhist traditions that teach that a patient's death is not indicative of the end of existence, but rather a transformation of it. Such ongoing relationships with families and the island hospice function as ways to maintain and enhance the island hospice caring community.

This chapter has painted with a broad stroke the island hospice landscape through illustrations of the ways in which the hospice functions as a community of care, through explanations of how the community is organized, and through descriptions of the fundamental principles on which the hospice community is founded and from which the members draw when caring for the dying, their families, and one another. The following two chapters investigate in further detail aspects of care and communication at the island hospice that present the most significant contributions to end-of-life care as I learned them from patients, families, and community members.

Chapter Five: Winter



Figure 3: Winter, Snowdrops

Also overtaken by cold
the dew
left behind as a memento of autumn
turns to frost this morning
here at my reed-bound hut.
Rengetsu

As the crisp autumn days have turned cold, each new day begins and ends with the starting and stoking of a fire. Stepping out into the cold air each morning, I make my way to the woodpile for kindling and logs where nearby blue jays scratch the bare ground in search of seeds and squawk impatiently for me to give them more. The last of the Canadian geese that will remain on island fly overhead, their discordant honks heralding the coming winter. Tender white snowdrops and wild violets decorate the yard and hillside peeking out from between the rocks and dotting the meadow.

As winter settles in, a December afternoon brings clear, blue skies and fat snowflakes that blanket the lane and laden heavily the forest's boughs. Shiny-eyed crows chase the tiny nuthatches and juncos from the holly trees and the small, white and black winter berries that dot the hedgerows. Once brown moss covering the hillside's rocks and barren oaks glows grey-green in early evening's light. As evening falls, winter's bright stars illuminate the sky and the full moon throws long shadows from the great firs.

Having worked in the care of the dying for many years, I am interested in new ways of thinking about how, with our patients, we make sense of the things that happen at the end of life. I have come to see these occasioned events in terms of rituals and improvisation in end-of-life care.

A. Ritual & Improvisation

Weick, Sutcliffe and Obstfeld (2005) rightfully observe that, “to ‘violate’ something is to interrupt an ongoing flow” (p. 100). Illness and dying represent these violations; they are significant ruptures in the continuity of the life story and are arguably some of our most difficult and complex experiences. The challenge we all face is to make both our living *and* our dying

meaningful. But how that gets defined and how we go about manifesting it is complex, decidedly individual, and deeply personal. When these experiences occur in the clinical context, they may instead become subject to the institutional and, therefore, impersonal. This meaning making is further complicated by the competing needs of patients, practitioners and family members, and these in turn play out in the narratives in which we each see ourselves living as well as those narratives that story our dying. This is especially so where our narratives of the “good death” are concerned.

Unfortunately, the ways in which we seek to create a good death for patients – and ourselves – is most often through and confined by medical ethical decision-making. One consequence of employing this particular language of decision-making is that it fetters us to the realm of autonomy and paternalism wherein the good death becomes the product of right and/or wrong choices, ever and always a series of morally laden either/or propositions. As such, those making the decisions are then perceived as either good or bad for having made the choices that they did. This good/bad, right/wrong framing of end-of-life choices is, therefore, deeply consequential for if the patient or practitioner makes the “wrong” choice, the finality of death also conveys finality to the choices made in dying.

When we focus our attention on decision-making and who has the power to make the decisions, we are invariably drawn into a double bind: the well-known polarity between patient autonomy and practitioner paternalism. This focus takes center stage, rendering other possible narrative contributions peripheral, or downright ignored. Because “sensemaking is about the interplay of action and interpretation rather than the influence of evaluation on choice,” Weick, Sutcliffe, and Obstfeld (2005) ask us to consider framing experiences instead as “good people struggling to make sense, rather than as [potentially] bad [people] making poor decisions” (p.

409-410). That is what patients and practitioners are, good people trying to make sense *of*, and *in* the complex end-of-life situation that is “an ongoing, unknowable, unpredictable streaming of experience in search of answers to the question, ‘what’s the story?’” (Weick, Sutcliffe, & Obstfeld, 2005, p. 410).

If, instead of asking “what is the right choice or decision, medically, ethically, personally?” we could ask “what’s the story and what can I do next?” my sense is that we will find in the mixture of what Weick, Sutcliffe, and Obstfeld (2005) call retrospect and prospect the cues to thoughtfully guide our actions with and for one another. In other words, in order to make sense of a given situation we must refer and make connections to previous experiences while acknowledging “that ignorance and knowledge coexist, which means that adaptive sensemaking both honors and rejects the past” (Weick, Sutcliffe, & Obstfeld, 2005, p. 412). Past experiences inform future actions, but only in that the truth of a given situation evolves, changing and taking shape over time (Weick, Sutcliffe, & Obstfeld, 2005). Imagining a changing end-of-life story is not difficult, especially for anyone who has witnessed someone’s dying. Instead, the difficulty is in actively, thoughtfully engaging in the process as it unfolds.

The Zen hospice physician, Ann, refers to certain periods in patients’ end-of-life trajectories as being “in the river.” A patient experiences the rapids, the gentle slow moving flow, and even the swirling eddies. Like a river, the patient moves their way through sometimes swiftly, sometimes slowly, sometimes with turbulence and other times with ease to the mouth of the great ocean, death. As practitioners, caregivers, and loved ones, we may stand on the shores busying ourselves with observations and interventions as the patient floats in front of and then past us, or we may enter into the river with them, allowing ourselves to also be carried along by the water. In so doing we situate ourselves such that we may attend to what we only really ever

have available to us: what is before us at the moment. As Ann instructs, this is how, at any given moment, we “attend to what is happening in front of us in as clear a way as we can manage.”

If we extract ourselves from well-intentioned, but confining language of medical ethical decision-making that may in fact limit our ability to manage end-of-life experiences meaningfully, we find through Weick’s (2005) concept of sensemaking a new more flexible language for thinking about and acting in the end-of-life scenario. “Sensemaking is not about truth and getting it right. Instead, it is about continued redrafting of an emerging story so that it becomes more comprehensive, incorporates more of the observed data, and is more resilient in the face of criticism” (Weick, Sutcliffe, & Obstfeld, 2005). Perhaps this is a framework for the end of life that, like the experience itself, will unfold over the trajectory of an illness or the experience of dying in such a way as to make sense of the experience as it unfolds.

One way in which we may begin sensemaking at the end of life is by exploring “what’s the story?” by means of ongoing reflection about our routine activities. Hansen (1989) points out, repetitive acts (...) are ritual-like in the sense that they not only help focus attention, but also evoke and display meanings and attitudes surrounding their purposes” (p. 276). This seems a particularly relevant place to begin sensemaking. As Hansen (1989) notes, “who and what we repeatedly attend to in the commonplace, everyday contexts in which we find ourselves can have enduring consequences for the kind of person we become” (p. 269). Arguably, the end-of-life experience is very much a commonplace event despite our efforts to characterize it through medicalization as “a decision rather than something that happens to us” (Schenck & Roscoe, 2008, p. 63). And, Hansen points out, that to which we attend, especially through ritualized acts, has consequences. In the end-of-life situation those consequences extend to patient and practitioner, and carry a measure of “moral significance” in that the rituals serve a deeper

purpose than we might realize, signaling a shared sense of purpose and responsibility (Hansen, 1989).

Identifying the kinds of ritualized activity found in end-of-life care helps us understand the possibilities and limitations created by those rituals as well as the impact they have on patients and practitioners. Whether in the hospital, home, or hospice setting, care of the dying is orchestrated through a series of ritual actions. Patients are assessed, diagnosed, and monitored through a repetition of temperature, blood pressure, cognitive function, input, output, and pain/comfort checks, to name only a few. Interventions are prescribed and carried out, adjusted and readjusted to accommodate the changing condition of the patient. Each setting has a certain readily identifiable repertoire that is appropriate for its care of patients at the end of life, and, while the kinds of interventions may vary somewhat in the different settings, the methods for determining and employing them are much the same. For example, when a cancer patient is seen at a cancer center, the expectation is that the patient has come to be treated with the kinds of interventions a cancer center makes, chemotherapy, radiation therapy, etc. A patient at this hospital would not expect to be offered or expect to receive primarily palliative care as this is not the type of treatment that this kind of facility typically employs. For the patient in hospice, chemotherapy or radiation therapy may still be a component in their care, but only as palliative measures. The difference between them, then, is the focus of care: either curative or palliative. Nonetheless, both are enacted through a similar repetition of seemingly mundane and often unacknowledged rituals.

These clinical rituals, curative or palliative in nature, are, however, vital. Through locating them we have access to what these rituals can reveal about the status of a patient and, for that matter, about practitioners. So, out of our ritualized activities, we are able to accomplish

many positive things for patients and for ourselves. We are likely to accurately assess a patient's clinical status and, as a result of our efforts, discover a significant portion of "what's the story?" Many of the rituals in which we engage in the care of the dying are constituted as efforts to "do no harm." Like the placement of catheters or the administrations of medication, some are relegated to the realm of the professional while most are taken up by anyone participating in the caregiving. Hands are washed, meals are prepared, garments are changed and ablutions are seen to all in the ongoing routine of caring for the individual. Many of our communications are also ritualized when we take the temperature, so to speak, of the person for whom we care. We see this in the questions we routinely ask: "How are you feeling today? Are you having any pain? Where does it hurt? Would you like something to eat? And so on. The ritualization of care does something more for us, as well, in that it acts as a communication of our knowledge and competence in care for both practitioners and loved ones. Knowing how to properly perform the rituals indicates to other practitioners that you can be trusted, that you know what you are doing, that I know what I am doing. Correct, and, even more so, masterful performance of the ritual communicates rightful membership in the cult of clinical practice. On some level, this is true for non-professional caregivers as well. Through correct ritual performance, they may or may not communicate their level of competence in caregiving. In either case, this performance signals the degree to which they may be entrusted with participating in the care of a patient.

As relevant and enlightening as they may be, these ritual activities in which we engage at the end of life are also limited in what they can establish about the emergent story. They are indeed meaningful acts that help us focus our attention on the situation at hand, but, through their very repetitive ritualistic nature, they tend to discourage the kind of flexibility in approach and response that may reveal significantly more of the end-of-life story (Hansen, 1989). The ritual

acts keep us focused on the most immediate physical and emotional concerns of patient care, however, a focus that is too narrow fails to take context into the patients' life contexts (Weick, Sutcliffe, & Obstfeld, 2005). As Weick, Sutcliffe, and Obstfeld note (2005), "to lose the periphery is to lose the context for the center, which means the center vanishes" (p. 104-105). This is perhaps the greatest risk inherent in a strictly clinical approach to end of life. Through rigid ritualization of the end-of-life experience, we may lose the most important aspects of aiding someone in their dying; we may lose the very meaning that the dying experience has to offer us.

What we may need, then, is not to end the rituals we employ in care of the dying. Rather, we may need a complement to those rituals. Nachmanovich (2009) offers us something useful in his work on play, "play is not the name of an act or action; it is the name of the frame for an action" (p. 2). Though invoking the notion of play in the end-of-life scenario may seem irreverent or even macabre, it is not literal play that I refer to here – although perhaps there is room for that as well – but rather play as Nachmanovich offers it, in the form of improvisation. He suggests, "our task here, if you will, is de-reifying: loosening the grip of literalism" (Nachmanovich, 2009, p. 13) or, as I suggest, the grip of ritualism. To improvise is not to behave so radically as to wreak havoc or create chaos. Even improvisation requires some form, a loose framework to which one must adhere. Not anyone, for example, may simply act at will within the situation. To improvise as a practitioner is still to call upon one's training, experience and expertise, to act within certain given parameters. As such, we do not need to dismantle the order and predictability that ritual brings to the experiences of dying; instead, we need to combat its potential rigidity. "Playing can propel us right out of the limiting mindset of things-and-forces" (Nachmanovich, 2009, p. 14). We must still adhere to the demands of legal, ethical, and

prudent practice, though, through improvisation, we may also expand our notions of what that may include.

a. Going to grandma's. Nachmanovitch (2009) further describes how “improvisation/playing with other people is a practice based on listening and responding in real time, and the more we do so, the more we are able to soften our edges, to turn stone into lava” (p. 14). This lovely articulation of improvisation reminds me of an experience I had some years ago, a moment with a young patient of mine in which I think we may see exemplified what it might mean to yield to improvisation in an end-of-life scenario.

Before today, the last time I saw Emily was several weeks ago at her school. She was tired. Cancer does that to a body... dying does that. Because Emily still wanted to be with friends and teachers and to maintain some semblance of normalcy, her mother had reluctantly agreed to let her spend days, or parts of days when she felt up to it, at school with her kindergarten class. Her teachers had placed a mat, the blue plastic folding kind, on the floor in the napping room. When I came to see her that day, that is where I found her, laying on her side, her head haloed by downy blonde fuzz and resting on a tiny pillow that somehow managed to look large beneath her even smaller head. Her eyes were closed and her respirations came in slight shallow breaths. I pulled another mat from nearby and lay down beside her. When she opened her eyes, face to face, we smiled at one another and I knew her time would be soon.

Today she seems even smaller. I don't know how that can be, but her tiny frame is swallowed in her mother's embrace. I think to myself that perhaps it should be. I know when I see them there, in each other's arms, nestled in a chair, that she is nearly ready to die. This ordinary scene of maternal comfort is shrouded in their shared lingering and longing, and I wait.

Speaking for the first time since I arrived, Emily asks her mother, “Mommy, will you help me pack my bag? ...I need to pack my bag.” Fat tears spill from her mother’s eyes and fall on Emily’s yellow flowered pajamas. Unsure of what it means, her mother looks over at me and I smile a little, silently nodding my head urging her to follow along. She carries Emily into her room to pack her pink suitcase with the words “Going to Grandma’s” in big bubble letters. Her mother puts her favorite books and pajamas in and tucks the blanket Emily holds out on top. Scooping Emily up, her mother carries her back to the overstuffed chair, dragging the case behind her. Settled once again, with her mother stroking the fine wisps of her hair, Emily says, “Ok, Mommy ...I’m ready to go now.” Fresh tears well in her mother’s eyes, “Go? ...Go where, sweetheart?” she replies. “On my trip ...keep this for me, Mommy,” Emily says taking her stuffed bunny from her chest and pressing it to her mother’s. Closing her eyes, still holding her bunny to her mother’s heart, Emily took her final breath.¹⁵

This narrative shows how Emily’s having had those around her listen and attend to the cues she was giving (i.e., that Emily had been ready to “go”) resulted in Emily receiving permission from her mother to prepare herself and us for the moment she knew was upon her. In my former work I reflect on this encounter and “see how a narrative with which this patient [Emily] was familiar (‘going to grandma’s house’) helped her and helped us find meaning in what she was experiencing in her dying” (Klein, 2010, p. 40-41). Unfettered by any specific expectation of what she should do or by responses to what she was doing that might have invalidated her requests to pack a bag, Emily was able to make sense of what was happening to her and communicate it with those of us around her in those moments. We improvised in our care of her and that made it possible for Emily to accomplish this and show us how she needed

¹⁵ An earlier version of this narrative was published in 2010 in my Religious Studies Master’s thesis entitled, “Shamanism, Spiritual Transformation and the Ethical Obligations of the Dying Person: A Narrative Approach.”

us to support her in her journey.

This story of Emily helps us imagine the indispensability of even the mundane rituals in which we engage in end-of-life care, such as pain or comfort management, for example. This encounter also helps us understand how improvising in care through recognizable but perhaps difficult to define (Hansen, 1989) adaptations to the emerging story of a patient's dying has the power to radically alter the experience for both patient and practitioner. As Nachmanovitch (2009) says, there is a "complex relationship between play and purpose" that gives rise to a complexity that is in our best communication interests (p. 17). He goes on to explain that we need not hide from the complexity or paradox that is created by this relationship as these constitute a kind of "vital activity" (Nachmanovitch, 2009, p. 19). In this regard, we may see how, just as it did for my young patient, improvisation in the care of the dying opens up spaces for new sensemaking without necessarily requiring foreclosure on rituals designed to manage care through competent assessment, diagnosis, and intervention.¹⁶

Contemplating these possibilities, I wondered when I first came to the island hospice if I would find evidence of ritual, play, and improvisation as I have described it here. I thought the likelihood was indeed quite great because the complementary interplay between ritual and improvisation seems to be a natural part of practicing patient care as an art.

Certainly, Ann, MyoO, and other caregivers made regular displays of flexibility in their care routines. For instance, mealtimes were impromptu affairs. Meals or snacks for patients and their friends and loved ones were prepared at all hours and on the basis of need or desire rather than routine. Similarly, visitations for patients occurred when they best fit the wishes and physical states of patients. No pre-determined visitation hours schedule existed, so family,

¹⁶ A version of the section beginning at the beginning of the chapter through this point was published in April 2014 in the *Journal of Medicine and the Person* as an article entitled, "Making sense, ritual, and improvisation at the end of life."

friends, and loved ones had the freedom to come and stay when they could and when it best suited the condition of the patient; visitations had nothing to do with the preferences of the hospice house caregivers. These kinds of improvisations are not, however, foreign to patient care in other settings, particularly in the care of the dying.

b. Ringing the inkin. Other instances of the interplay between ritual and improvisation represent the general spirit of the hospice's approach to end-of-life care. For example, in coordination with the monastery, the hospice offers caregiver retreats several times a year for local community members who are or have been involved in the care of someone who is dying. These retreats are designed to give care to the carers and are a way for the hospice house and monastery to provide solace and comfort to members of the local community who may be struggling with or negotiating the recent or ongoing care of someone significant to them. Some who attend are actively caring while others have experienced a not too distant loss of the person for whom they cared. The retreats last the better part of a day and include time to talk, share, meditate, rest, and enjoy a delicious meal. They typically take place at the monastery where there is ample room for the dozen or so people to gather around tables or on cushions in the large, long, Japanese style rooms.

Because Ann wanted me to have the opportunity to experience the retreats firsthand, she asked me to participate the first time as a caregiver rather than as someone serving the participants. The retreats began socially through introductions during which time each person may share a bit about themselves and the circumstances of caregiving in which they were involved. They then shifted into group discussion and conversations between participants. Many of the participants knew each other from the local community or from having met at

previous caregiver retreats. They took this time to catch each other up on their situations and offer words of comfort to those who had experienced a recent loss. I was regarded with some curiosity since I was not an active caregiver at that moment (other than in my role as volunteer caregiver at the hospice). During the group introductions I briefly shared my experiences of caring for my daughter through a decade of illness and my grandmother throughout the long trajectory of her struggle with Alzheimer's disease, and that led the participant caregivers to accept me as someone both in and outside of the circle of caregivers, as participant and observer.

Ann and the Abbot gently guided the retreat, allowing participants to take the discussion where they wished it to go and helped to transition between activities or bring closure when needed. MyoO and some of the hospice volunteers prepared and served a delicious lunch of soup and lasagna with fresh vegetables from the garden. We ate and talked quietly with one another before going on a walking meditation through the forest and around a small pond before beginning the afternoon's meditation with the Abbot. After our walk we congregated in the room in which the community of Zen practitioners typically meditate, or, as it is called, sit zazen. The Abbot led us in some gentle movement to stretch and relax our bodies after which we settled on cushions and mats on the floor for a short meditation. As part of the ritual, each session of meditation was punctuated by the high, clear ringing of a small bell called an inkin. The inkin is struck three times to begin a session and twice to bring it to a close. Some caregivers took up the lotus pose, while others sat in chairs or stretched out on mats. As is traditionally done, the Abbot rang the bell to begin our first of several short periods of meditation and relaxation. Most of the participants were silent, one fell asleep and snored softly, and another wept quietly throughout. When the Abbot rang the bell bringing the session to a close, one woman spoke up and inquired sharply, "Can you not do that please? Can you just not ring that bell every time? It agitates me."

Unfazed and with the soft expression typically characterizing his face, the Abbot replied, “Yes, yes, of course.” And so, the next session began and ended without the bell.

Like Hansen’s (1989) classroom rituals, the inkin functions as a marker for the beginning and ending of the meditation. It is meaningful in that it garners attention to and brackets the experience. The ritual is intended to offer a comfort to the participants, but the ritual cannot serve its purpose if, instead, it becomes a hindrance. The Abbot was able to make sense of the caregiver’s agitation in light of the weariness she experienced as one caring for a dying family member. He did not hold fast to a rigid form. Rather, the Abbot took his cue from the caregiver in order to know what to do next. He has attended to what is right before him in the moment: a woman stressed by the constant pressure of caregiving.

c. Red Ducatis. This kind of in the moment improvisation with caregivers is also evident with patients and families at the island hospice. As autumn faded and winter began to set in, I was called to participate in the care of our newly admitted patient, Saul. An encounter with him is one of the most delightful, albeit painful in the context of his physical suffering, examples to which I readily return.

Saul can no longer get up from the bed. Multiple fractures from metastasized bone cancer make him too fragile to even turn without risking more fractures. He has not opened his eyes yet today and seems to drift in and out of a light consciousness. This is a significant change from the Saul of only a few days ago, the fellow who smiled and flirted with caregivers. When we speak to him, he responds intermittently with soft guttural sounds that let us know he hears us. His friend since childhood has come to visit him. They have enjoyed a lifetime of friendship and many years as fellow motorcycle riders. Together they cruised on their matching red Ducati

bikes and today Saul cannot lift his head to even look out of the window as his friend arrives. His wife wonders aloud if there is a way we could move him to the window to look down into the parking lot at his friend's shiny red bike, but he is too frail and weak to even entertain this idea. Seeing the disappointment in her face, a caregiver tells her to call down to his friend to ask him to drive around the hospice house and underneath Saul's bedroom window where he can rev the engine loud enough for Saul to hear. Saul's wife's face lights up at this idea, and within moments, the Ducati is snarling and growling to everyone's delight. Hearing the noise, Ann and MyoO come to an adjacent window to watch and cheer "Bravo! Bravo!" as the engine revs again and again. I look back to Saul and see his eyebrows raise and the smile appear on his face. He has heard and recognized his friend's arrival. One last connection to their shared history has been made.

This experience with Saul and his wife is an important one, in that it represents a moment wherein a caregiver allowed the situation at hand to tell her what it is that both Saul and his wife need. She responds to his need to connect meaningfully with his friend. Once quiet has been restored, and Saul's friend has joined him at the bedside, I ask Ann what she thinks of the roaring engine in the usually quiet house. "It was great, just what he needed," she says. Ann and MyoO set the tone by creating an environment in which everyone bends to the particular needs of patients and families, an environment in which such flexibility makes sense and is natural.

Another way in which practitioners and caregivers yield to the changing needs of patients and families is exemplified in the following narrative about the hospice nurse, MyoO, and a hospice patient's wife.

d. Taking advice. MyoO is very particular about not using anything toxic in the hospice house and, in keeping with her Buddhist sensibilities, she strives to do no harm. She prefers vinegar for cleaning in the house, and insects found inside the house are caught and released outside. On one of my first days at the hospice, MyoO was especially pleased when I caught a moth drawn to an inside light and I returned it to a leaf in the garden. A smile lit up her face, and she told me, “This is good, Ellen. Thank you.”

Looking through the kitchen window into the solarium one morning, I see Saul’s wife in conversation with MyoO. Saul is sleeping in the next room and they are talking about the geraniums and palms that grow in raised planters along the length of the room. Like all of the plants in and around the hospice house, they are beautiful as MyoO tends them well. Like MyoO, Saul’s wife loves to garden and MyoO listens intently as Saul’s wife explains how to kill the aphids without using toxic chemicals. From that point forward, at various moments throughout their time at the hospice we saw Saul’s wife water the plants, wipe the leaves individually with a wet cloth, or share some bit of gardening advice with MyoO. When I ask Ann and MyoO about these interactions with Saul’s wife or her work with the plants, they point to her need to be busy, to work, and to contribute. Caring for plants is something with which she is familiar, on which she can speak knowledgeably, Ann and MyoO explained. Saul has been brought to the hospice house because she could no longer care for him on her own at home. She cannot turn him or change his linens without assistance. Alone, she cannot do for him what he needs. Because Saul is so fragile, every movement painful, even Saul’s wife’s most gentle ministrations are fraught with difficulty. Each day, and increasingly so as his death neared, Saul’s status and needs changed. Teaching MyoO how to care for the plants and caring for them when she was at the hospice gave Saul’s wife familiar ground; she participating in the care of her husband and

contributing to the goings-on in ways that she found meaningful. As such, doing this provided her a small comfort.

Particularly where decision-making with patients was concerned, these three brief accounts of simple improvisations do not quite capture the full depth and breath of flexibility I experienced and witnessed at the hospice house. In my experience, these kinds of gentle improvisations often occur in other relaxed patient-centered care environments. Allowing a family member to be the expert or water the plants, the Abbot not ringing the bell, or allowing the friend of a patient to rev the engine of his motorcycle are examples of simple accommodations to the needs of patients, families, and caregivers. Some circumstances, however, ask for more ongoing attention to the changes, needs, and statuses of dying patients and of those involved in their care. As circumstances evolve, navigating them can become tricky. Another situation with a patient stands out and, lest my former examples suggest that these are static in nature, highlight the dynamicity of these improvisations.

e. Birth & death plans. Many years ago, when I worked in obstetrics and taught Lamaze classes to expectant mothers and their partners, the most frequently discussed concern was how to write a birth plan. No matter how much I encouraged students in my classes or patients that I saw to not become too attached to the birth going a particular way, invariably, hopes translated into plans and plans often translated into disappointments. Women frequently had very specific ideas about how the baby would be born, what interventions would or would not be permissible during labor, whether or not breastfeeding was important and so on. It was not uncommon for some to be incredibly rigid about how the process should unfold and to be hard on themselves when it did not go as planned. Many who have worked in obstetrics are

familiar with this dynamic, and it is entirely understandable since women are bound by the beliefs they have about what it means to be a good mother and connected to this is what it means for them to have a good birth. Nurses and doctors working in labor and delivery can sometimes be less than enthusiastic, often dismissive, and even unkind about a woman's birth plan. Ideally, these things are discussed during routine visits throughout the course of a pregnancy, but it is not uncommon for the nurses and doctors actually participating in labor and post-partum care to be encountering a patient's wishes for the first time, and, coupled with the fact that births rarely unfold exactly as planned, this can lead to situations in which patients feel they have not been listened to or their wishes honored.

I recall a situation I encountered when I was a young nurse. A student from one of my birthing classes had asked me to accompany her to her delivery. So, I was there when she was admitted to the labor and delivery floor when she reaching into her purse and took out and unfolded a lengthy description of how she thought the birth of her daughter should go. "Here's my birth plan," she said to the nurse. "I don't want to be on the fetal monitor. I prefer to be up walking around while I labor. I don't want any drugs for pain. I don't want an episiotomy and I want to breast feed the minute my baby is born." The nurse looked up from the chart and over her reading glasses at her as she took it from her hand. Rolling her eyes and without even giving it a glance, she turned it face down in the chart and declared, "Well, that's never gonna happen." The patient and I were both horrified. The patient immediately began to cry. "Don't cry now," the nurse said, softening a little. "It isn't that I won't try to give you what you want, it's just that it isn't likely to go that way. Things happen that you can't control."

Birthing bodies have a trajectory of their own, so, too, dying bodies. Because our death denying culture has in many ways conspired to allow the topic of dying to be avoided entirely,

some patients do not know what they want their dying to be. Others, however, like expectant mothers have plans for how they want to die. Unfortunately, the best-laid and intended plans cannot always be manifested. Patients at end of life come to their dying with strong feelings about how it should go. Like many patients, one patient at the hospice house was insistent that she wanted to remain clear-headed and conscious throughout the course of her final days. She came to the hospice with a great deal of certainty about this and did not, therefore, want to receive any narcotics that might cloud her judgment or thinking. When she first arrived, this seemed a reasonable expectation and one, in fact, that the hospice readily supports. As time passed, however, and pain caused by an encroaching abdominal tumor increased, this stance became more difficult for her to maintain. This meant that decisions about pain management had to be handled on an ongoing basis. Her degree of pain, her willingness to receive medication, and her desire to be clear-headed changed over time, often several times a day. At some points the patient welcomed pain- or even anxiety-reducing medication, at others it seemed important to her to resist. Ann took each moment as it came, responsive to the patient in front of her at the moment, encouraging but not pushing. That is not to say that Ann left behind the vision of how to die that the patient brought with her but rather that Ann was able to adjust and respond to the changes in the vision as they took place. In this case, Ann exemplified what it means to engage with a patient in an ongoing clinical improvisation that honors the changing physical and emotional landscape of a patient's dying trajectory.

f. “Do you meditate?” There is another way in which we may think of, as Nachmanovitch (2009) warns, not becoming too literal-minded that has to do with the nature of our rituals and what we might come to understand as a kind of insight available to us in our care

of the dying. Over the course of my time at the island hospice and in my many interactions with community members, volunteer caregivers, and people participating in the monastic rituals, a question I was frequently asked was, “Do you meditate?” Interestingly, I was never asked this by staff of the hospice or by leaders of the monastery, but I was asked often enough that I could not ignore the possible significance of it. The question was often accompanied by knowing looks that seemed to say, “I think not!” and were likely generated early on by my obvious lack of familiarity with the zazen rituals and the fact that I was unknown to many of the regular participants. I usually responded with a smile and, “sometimes.” This was an obviously unsatisfying answer to most. Like the clinical practitioner, the religious practitioner also communicates skill through performance of the rituals. What they wanted to know was if I were one of them. My clinical skill permits me enter into the confidence and community of other health care providers. In similar fashion, my religious skill, or lack there of, has the power to do the same. Sensing that I was not one of them (someone who sits zazen as they do), disapproving looks were frequently followed by advice on what it was like and how to do it. As one community member advised me shortly before a meditation began, “It’s going to be hard for you, really hard, especially when you first start doing it. Your body will be really uncomfortable and you won’t be able to sit still for very long. You just have to wait for it to pass though. It will take a long time, a *really* long time.” Satisfied with her own advice, she left me to it.

I have meditated before, in a yoga class or religious service, but, given her warnings, I prepared myself to be uncomfortable. I stacked mats on which to sit, wedged pillows under my middle-aged knees, closed my eyes, and waited for the discomfort to begin. But then it didn’t happen. I felt just fine. I was relaxed and quiet, and even the hamster on my mental wheel took a break. Naturally, I thought I must be doing it wrong or that I hadn’t been sitting there long

enough. So, I waited. The discomfort never came. I wasn't agitated or resistant. In fact, the feeling I was experiencing was not foreign at all. I felt exactly the way I always felt when I was sat at the bedside of a patient. At first, I sat long hours with women in labor, and then later, I sat long hours with the dying. But the feeling was the same. The quiet and stillness were familiar to me and I was comforted by it as I had been so many times before.

Assuming that my meditation experience was only of personal significance, I kept it to myself until some months later when I noticed one of the new caregivers sent by the monastery doing his best to avoid sitting with the patient we had at the time. Coming into the kitchen where MyoO and I make breakfast and where the young male initiate sits having tea, Ann offered the caregiver the chance to take her place at the bedside. "I think this might be a good opportunity for you to sit with him. He is so quiet, for you to feel what that is like." He said, "Maybe I should eat breakfast first and I should rest a little before I go in, I think, but maybe I could do it then." Ann replied, "sure, when you are ready" and as Ann turned to go back to the patient's room, I offered to go instead.

Looking a bit confused, the young caregiver told me that the patient is sleeping and does not seem to need someone there. He wanted to know why we were sitting with the patient when he was sleeping. "Ann is offering you a gift. She wants you to have the experience for yourself of sitting in meditation with someone at the bedside." "Oh!" he said, quickly putting down his cup and heading into the patient's room. MyoO had been watching and listening from where she washed dishes at the kitchen sink. "This is good," she said with her brow furrowed slightly the way it does when she is thinking seriously about something. Explaining what it means to sit zazen she says, "If it is a little bit noisy, then that is the practice. That is what you are learning. If it is quiet then that is your practice. That is what you are learning." Sensing that the

connection I made some time earlier between sitting zazen and sitting at the bedside, I tell MyoO about my meditation experience at the monastery and even about the ringing of the inkin during the caregiver retreat. “This is what it is, she says, you just take what is coming to you, whatever it is, in that moment, that is your practice, that is your meditation.”

g. Meeting with the Roshi. After these experiences and after having had some time to reflect on them, I came to feel that I had a fair grip on how, under Ann and MyoO’s guidance, the island hospice managed the changing landscapes with patients, families, caregivers, and one another. I had been interested in the aspects of ritual and improvisation in care of the dying and felt that I had found evidence of both. I wanted to better understand how these practices might be grounded in Buddhist philosophy, so asked to speak with the Roshi when he visited from Japan.

On the morning we were to meet, a thick fog blanketed the water. As the boat that took me to the hospice pulled away from the ferry landing, the island on which I lived and those surrounding it were quickly obscured. I was unable to orient myself as we headed out into the sound, but the ferry moved on as if our direction was clear. I had been awake most of the night. Curiously, I felt too anxious to sleep well. I was not sure why, as I do not typically feel anxious about these things. The Roshi and I met before, but we had never spoken directly with one another. I had a small concern that I was going to have wasted his time. I had been present in meetings with him and the board members of the hospice, and I watched as he inhaled what they had to say to him, communicating with their words and bodies. He was quick to smile, a smile that he makes with the whole of his face, eyes, cheeks, creases of his skin all in concert with one another. He laughs easily, quiet laughs that do not erupt but seem instead as if they reside

current-like always just below the surface. Ann and Chisan, the Roshi's translator, joined me in the meeting, and a monk served us tea while we spoke. I had prepared questions for the Roshi about the connections between the hospice house and the monastery, the value he sees in the hospice house for not only the patients and families, but for the community, and how Zen practices and philosophy contribute to how the hospice functions.

When I finally sat before him, he asked me to tell him something about my project and myself. I shared briefly about wanting to better understand how the hospice cares for patients at end of life and how we might improve care of the dying. As soon as he began to speak I realized that my questions would not guide this interview; the Roshi will tell me what he wants me to know, what, in the moment, he feels I need to hear. The first thing that he told me is, "in Buddhism it is not a question of how we care for people. How do we see them? What do we see there? More than care, how do we see? There is only one way to look at this from the Zen view. In the words of the first patient ever at [the hospice], 'it's only dying.'" When we are looking at the person, he told me we mustn't make a big deal about their physical state. Their dying is not the central issue. We may "bring it to their attention, but don't emphasize it." We must, he said, realize how we make a person feel because of how we see them. With the wrong view of the patient, we could produce the "wrong energy." "Any preconceived notion can make someone sad," he tells me. We must not, therefore, enter into the situation with a dying person with a plan or assuming that we know what is best. How the patient perceives their situation must be taken into account and there are many different possibilities for how that may be. It was at this point in our conversation that I felt we had arrived at a point of connection. Feeling that he validated my sense that we must learn to improvise in our care based on what we see before us at the moment,

I said, “Yes, I would call this improvisation.” “No,” he was quick to respond. “This is not improvisation.” Once again, my ferry was in a fog.

I was perplexed by this response and, when the meeting was over, I asked Ann and the Abbot about it. Ann explained, “If you are in the now, you don’t need to improvise. You know what to do and it is, therefore, not an improvisation.” She went on, “in Japan, improvisation doesn’t happen until you are a master.” The Abbot spoke with me at great length about both ritual and improvisation. He reminded me that ritual is the “form of Zen.” There is a certain way to hold the hands, bow, walk, sit, eat lunch and that these rituals, “focus [one] in a certain mindful way [such that one is] centered then more in a confident simple spontaneous way.” This, he says, exemplifies the Zen term, *kufu*. Through ritual practice, a skill is perfectly learned and, as a result, no thought need arise or exist. This is not to say that one becomes thoughtless. Rather, one becomes thought-less, free of thought. In this state, one may clearly perceive and respond in spontaneous right action.

Varela’s (1999) notion of embodied ethics may be very helpful to us in understanding what Ann said here about knowing what to do and what the Abbot taught me about the mastery of *kufu*. Varela (1999) describes ethics not as something occurring in the abstract, but rather as embodied and enacted. He, too, turns to the eastern traditions of right action in order to argue for ethics as a doing and not merely rational judgment or reasoning, as enacted and not merely abstracted. As Varela says, “A wise (or virtuous) person is one who knows what is good and spontaneously does it” (1999, p. 4). Then, paradoxically, the concept of *wu-wei* (often translated as “non-doing”), “points to a [ethical] journey of experience and learning, not to a mere intellectual puzzle that one solves,” (Varela, 1999, p. 33). Varela incorporates in the concept of

embodied ethics the Buddhist notion of “skillful means,” which can be understood as compassionate action. Such compassionate ethical action:

...must be developed and embodied through disciplines that facilitate the letting-go of ego-centered habits and enable compassion to become spontaneous and self-sustaining. It is not that there is no need for normative rules in the relative world – clearly such rules are a necessity in any society. It is that unless such rules are informed by the wisdom that enables them to be dissolved in the demands of responsiveness to the particularity and immediacy of lived situations. The rules will become sterile, scholastic hindrances to compassionate action rather than conduits for its manifestation. (p.73-74)

Equally important, in an embodied ethic, a feminist ethic of care, and the Buddhist notion of interdependence is how we may come to understand ethics, and specifically medical ethical sense and decision-making, in the context of the relational. Each of these complementary ideas offers a key insight in that those involved in sense and decision-making are positioned as something more than those acting and those acted upon. In other words, neither decision-making nor sense making is a transactional event. Employing second-order cybernetics, von Foerster (1992) illustrates this by using the formulation, “A implies B, B implies C, and—O! Horror!—C implies A or A implies B, and—O! Shock! –B implies A!” (p. 4). This circular formulation might be applied to the relational model for which I argue wherein caregiver (C) is in relationship with, responsible for, and obligated to patient (P). Likewise, P is in relationship with, responsible for, and obligated to C. Utilizing this circular model illustrates interdependence – not disconnection – between caregiver and patient. It thus becomes what might be termed a formulation of interdependence.

This is important if we are to expand the ethical implications of the relational end-of-life experience. As an example of independence, von Foerster (1992) explains how one, in this clinical context a practitioner or caregiver, may say, “I can tell others how to think and act” (p. 4). In contrast, he offers an example of interdependence in which the individual may say, “I can only tell myself how to think and act” (p. 4). In the first case, statements made in the position of independence translate as “thou shalt” or “thou shalt not,” whereas in the second instance, statements made from interdependence articulate, “I shall,” or “I shall not.” While the former may be moral, it may not be necessarily ethical. That is the distinction. And so, in von Foerster’s (1992) words, “...ethical reward and punishment [...] must reside in the action itself” (p. 6). We must, therefore, “let language and action ride on an underground river of ethics, and to see to it that one is not thrown off, so that ethics does not become explicit, and so that language does not degenerate into moralization” (p. 6). Through circular relational formulations of this kind, we see how second-order cybernetics exemplifies the model of interdependence and creates conditions conducive to the kind of ethical action described by Varela (1999) or the Abbot.

It is possible that the use of metaphor further helps us understand the relational setting in which we do medical ethical sense- and decision-making with patients and families. Perhaps through taking up a metaphor of dancing, we may abandon assumptions that, like the Roshi says, may make us think we know what is best, and instead allow us to not only see the patient as he says we must, but also envision patient, caregiver, and death as partners in the dance. Just like dance partners who know the ritual of the steps and can therefore move fluidly and improvise as they go, those taking up this metaphor in their care of patients may move together with their patients and their patients’ families rather than work in opposition to them. In this frame,

practitioner and patient are placed on even ground; all parties are equally intelligent and competent, for this experience of dying is indeed new terrain, a valuable place of “not-knowing” (Schön, 1983) for everyone involved. Perhaps, here we may find the “value of a willingness to approach learning from the vantage point of the amateur [dancer, in you will]- a willingness to challenge assumptions in a spirited way, and to convey the joyfulness of learning [the dancing steps] by surprise rather than solely deductive reasoning and technical rationality [even at the end of life]” (Schön 1983, p. 63). Furthermore, the willingness that Schön (1983) articulates about here might lead us to a place where we may be, as the Roshi has suggested, “open to learning about what [dying] might mean to others (even the possibility of its being heard initially as negative)” (p. 64). This has the potential to encourage us to be more receptive and responsive to others. The relational may then take precedence over the individual. Our willingness positions us in such a way as to create mutual vulnerability. The benefit of this vulnerability is that as we do sense- and decision-making, we do it together as a relational accomplishment.

Further informing our sense of knowing what to do, we may return to von Foerster (1992) who posits that, in the context of the relationship that is circularly formulated, “undecidable” questions emerge. This is not to say that they cannot be decided, but rather that there are so many possible ways in which they may be decided. End-of-life decisions are precisely such undecidables. In the landscape of dying a number of ways in which to approach and manage that dying may emerge. As the Roshi has said, we must see the patient that is before us, as they are in that moment. von Foerster states, “tell me how the universe came about and I will tell you who you are” (p. 8). Or, in an alternate formulation suited to the context of dying, “tell me how one should die, what is life prolonging, and what prolongs suffering and I will tell you who you

are.” Here we see, like the Roshi says, how many possible permutations exist in a given end-of-life situation: an infinite number.

Approaching end-of life experiences as part of a relational interdependent and therefore co-constructed landscape, we have the capacity to honor the various physical, emotional, and spiritual aspects of dying. Whether we rely upon the western notion of improvisation or play, as I did when first making sense of my experiences with the island hospice, or come to fully understand and take up the eastern notion of *kufu*, the work that is getting done is much the same. In so doing, we are finding a way to flex, to bend in our care in order to allow a softening of the rituals we employ so as to not break others and ourselves. Furthermore, the ways in which we come to see and respond in spontaneous right action to the situation at hand are not disparate considerations belonging to individuals who are separated from one another; rather, they are brought together in the course and composition of an end-of-life trajectory. In response to this approach as I have seen it modeled at the island hospice, patients may come to recognize the change in their own landscape when they need no longer use their energy to struggle with practitioners, caregivers, or interventions. So, too, practitioners and caregivers may find that they are no longer in a struggle for control over the process of the patient’s dying. As such, ethical sense- and decision-making may become, in such a situation, embodied in the conversation between patient and practitioner through acts of flexibility and co-inspiration brought about by having come to understand themselves, the situation, and each other differently. In this shared landscape, patients and caregivers participate in the co-creation of the dying experience and may be understood to have collectively engaged in composing a death.

Chapter Six: Spring



Figure 4: Spring, Foxgloves

From a spring brocade
woven
of willows and cherries
colors bloom
in the voice of a warbler.
Rengetsu

As spring arrives, I watch from the window where small, brown bunnies hop from their cozy warren beneath the stump of a once great fir to nibble the lettuces near my door. Barn swallows return to build their nests with bits of hay and horse's mane or tail. Even the occasional chicken feather makes a soft addition and colorful appearance. I await the first small chirps and the sight of their tiny heads peeking from their nests with great anticipation. High on a branch a baby squirrel yips and barks at Mabel, our dog, who watches curiously from below. To my delight, twin fawn are born in the meadow, resting and grazing alongside their mother in the tall grasses. The great, twisting vines of wisteria covering the front porch have begun to bloom and will soon be thick with purple flowers and buzzing bees.

Early in the morning on my way to the ferry that will take me once again to the hospice, I pass the Warm Valley farm where newly born lambs nurse from their mothers on wobbly legs. I cannot help but stop to watch them for a while taking in the little lambs' antics and the island's state of profuse bloom. Cherry trees boast pale pink and white blossoms that are as lovely on the ground as they are in their branches. As their petals fade, lush clusters of peonies and irises adorn local gardens and mid-spring's flowering red currents bring the return of my beloved hummingbirds. With the appearance of speckled foxgloves, unfurling trumpet blooms welcoming fat honeybees that come to call, I know that, before long, summer will arrive.

Characterizing death as a failure is not difficult. As I noted in an earlier chapter, our modern clinical prowess and emphasis on often radical, curative, life-saving efforts has made giving-in to the dying process akin to the greatest possible failure. In this regard, we want our narratives, particularly our spiritual narratives, to offer comfort to us or to others. This is no doubt why we draw so heavily upon them and find such scholarly interest in examining their positive effects for patients and practitioners. Even when we employ the kind of improvisation

that Nachmanovitch (2009) speaks of or the mastery that is the Zen kufu, difficulties may arise. In circumstances in which we use our most flexible of frames, asking, “what’s the story?” (Weick, 1995), there are still times when the story that unfolds is deeply problematic for patients, families, caregivers, and practitioners.

It can be painful when narratives no longer serve patients well. The same narratives that heal or comfort can also become problematic. This is true for patients who no longer derive comfort from the narrative in which they have seen themselves living. This can also be true when the stories of patients come into conflict with those of practitioners and caregivers; such tension can become a source of stress for those involved in the care of the patient. To some degree, it may seem disconcerting to challenge the therapeutic value of our spiritual narratives when they, so often, offer comfort and support, though, they are also undoubtedly a source of great conflict. Because of this, it is imperative that we give thoughtful consideration to the rhetorical work that these narratives do and to their consequential nature.

As is evidenced in the argument about the complicating as well as comforting nature of spiritual narratives that I introduce in chapter two, I came to the hospice environment already attuned to how narratives meant to provide comfort can function as sources of suffering. I want to clarify here that I do not oppose spiritual or religious narratives; on the contrary, over the years, I have witnessed patients, families, and practitioners draw on their spiritual narratives and use them as powerful sources of deep meaning and comfort. I have also experienced moments in which spiritual narratives became sources of profound bewilderment and despair for individuals. I must acknowledge that I brought to the research a desire to find a new way of understanding and possibly responding to this narrative potential. My intent has not been to insensitively deconstruct narratives that may bring some hope or comfort. Rather, my goal has been to

explore the shadow side of these narratives so that we may better understand what they communicate in the context of end of life and how we might ameliorate the suffering that these narratives may unintentionally cause.

In the course of my time at the island hospice, two patients in particular stood out as having experiences in which their narratives were more problematic than comforting. The first involved a patient who suffered terribly when she became trapped by the very narrative that, up to that point, had empowered and soothed her. The second patient and her partner suffered as a consequence of clinging to a narrative that was incapable of providing the comfort they sought and led to a succession of therapeutic narrative attempts that proved painful for them and similarly distressing to those involved in their care.

A. The Guru

In the early spring when the daffodils in my yard were in full and vibrant bloom, Hanna, a teacher of Transcendental Meditation and western mysteries, as well as a Reiki Master, came to stay at the hospice house. When Hanna arrived, she came with her own following of students still looking to her for instruction and guidance. She had not yet passed on her mantle, as guru, and she seemed to draw strength from her position even as she moved through her final stages. Four students, in particular, regularly visited and attended to her. Before coming, Hanna had created a ritual that was to be performed when she was actively dying, and she intended for all four of her students to participate. When I asked Hanna why she wanted to come to the island hospice to do her dying, she explained, “as a spiritual leader, this was the place that made the most sense for someone like [me] to come.” Hanna told Ann that she wanted, “quiet, to meditate, to cry and not be smothered.” Hanna made it very clear to me that she felt her spiritual training

and prowess had prepared her for “dying well.” To her, as she explained, “dying well” was dying consciously, serenely, and with all of her faculties.

Most importantly, her dying would be her final great spiritual act and lesson to her students. She would remain their teacher throughout her dying, showing them how it should be done, how she had envisioned herself dying. In this effort, Hanna continued to offer her student spiritual guidance when she had her meetings with them. Hanna read (or others read to her) books in which she found spiritual meaning and encouragement, she meditated, she received blessings of various sorts from her visitors, and she participated in an assortment of rituals that had spiritual significance to her and her students. As Hanna’s stamina deteriorated, and as the pain from her tumor increased, these spiritual interventions no longer afforded Hanna the same comfort that they previously had. Hanna’s anxiety increased significantly as her desire to remain “fully present and clear-headed” came in conflict with her need for anxiety and pain management. It was important to Hanna, as the spiritual teacher, to avoid medications that would interrupt her clear state, and she did not believe she should need or take such medicines.

For Hanna, the conflict between the person she thought she must be in her dying (the person her narrative told her she should be) and what the dying process was demanding of her became too great. Hanna’s intermittent resistance to offers of pain and anxiety medication unfortunately meant that she was not given good or consistent control of her pain or anxiety. Instead, Hanna’s pain and anxiety ebbed and flowed with increasing angst and tension, producing crescendos in both. Ann, MyoO, and I were concerned that Hanna would experience a psychotic break as a result of these peaks and troughs, and, ultimately, as a result of the kind of distress she experienced as a consequence of the disparity between how she believed her dying ought to go and the experiences she was actually having. Those who have frequently

participated in the care of the dying know that this sometimes occurs. In this circumstance, Hanna had a narrative about herself that had helped her make sense and meaning of her experiences in life. At the hospice, her experience of dying, however, challenged this narrative and the narrative no longer functioned well for her as a guide for sense- and meaning-making. Hanna's narrative of spiritual teacher and guru placed too great a demand upon her dying body and vulnerable emotional state. She could not reconcile her roles and beliefs about what her death should be to the dying process as she was experiencing it.

Hanna responded to this tension with more healing rituals. Having decided the day on which she would die, Hanna insisted that her students perform the dying ritual with her even when it was evident to all that she would not, in fact, die on that particular day. After eight long weeks of the dying trajectory, Hanna's body finally gave out. In the end, she died quietly. Though her journey to that point was fraught with suffering, suffering caused by a narrative from which she was unable to release herself, Hanna held fast to a story of the person she was and the person she should be, trapping herself in a narrative that was not sufficient for the experience at hand.

Hanna was not the only patient who suffered as a consequence of narratives that could not soothe the rigors of a dying trajectory. With the spring return of the hummingbirds and the reappearance of foxgloves on the ridge where my island house is built, came the season's second patient, Jean. The narratives from which Jean and her partner made decisions and sense of her dying experience were not only difficult for her; these narratives created a great deal of concern and tension for all involved in Jane's care.

B. “No stone unturned”

As Ann describes, “Jean and her partner left no stone unturned in their effort to affect the trajectory of, and give meaning to her dying.” The patient and her partner had an intense desire to have Jean’s death be a “good” one. They tried anything either of them could think of in order to make Jean’s death exceptional. Feeling as though Jean was capable of having the “best of deaths,” her partner was determined that Jean would be enlightened on her deathbed. The first disappointment that Jean’s partner had was that Jean was not ready to die. Before coming to the hospice, Jean’s partner knew that Jean was dying and wanted her to accept it so that she could “be clear and conscious in her dying.” Ann explains that, “the second, third, fourth, fifth, sixth, and seventh disappointments for Jean and her partner all followed in sequence.

When one thing did not work to help bring about, or make more meaningful, the end of Jean’s life, another thing was tried. Jean’s partner tried a brain training routine, Wiccan prayers, and Aryurvedic oil dripping. Ann recalled, “even a Hindu incantation group [...] came and sat around the bed giving ‘oneness blessings.’ Then a Christian priest, I think, although I’m not sure. Christ was in the picture, aromatherapy, and Kiertan.” The list of rituals invoked went on. With each new ritual, Jean became more and more anxious. On the final day of dying, Ann explained, Jean’s poor partner “was so exhausted with all of the effort. She drank a bottle of scotch, played Motown *really* loud, and got drunk. A pressured need was what it was.”

The “pressured need” to force a good death, to find a way to bring the death on more quickly and in a spiritual or enlightened way, that Ann referenced was a source of suffering and distress for Jean, Jean’s partner, Ann, MyoO, and the hospice caregivers. As MyoO told me, “there was just so much pushing and pushing to die, for it to be good, and it was really hard on everybody.” Ann echoes this sentiment, “[Jean] came by her own account, ready to die and both

she and her partner did everything they could imagine to quicken her death. This was distressing to the [island hospice] caregivers as they felt bruised, I think, by all of the ‘pushing’ to die.” But the discomfort for Ann, MyoO, and the caregivers did not end with the myriad attempts to bring about her death or make it meaningful with every possible spiritual ritual they could imagine. The physical process of Jean’s dying brought its own tensions to be managed. “The literal dying was the most gruesome we have had here, absolutely horrific for all of the trying to make it beautiful.” The force of her breathing near the end was so great that she coughed and choked and even though Ann was able to give her the maximum amount of Dilaudid permissible, [Jean] continued to gasp and struggle for a breath. [Jean’s partner] said, “just lay her flat on her back. She’ll die this way.” This was terribly disconcerting for those who were there and attending to her care. Ann responded, “[You] can’t do that, but what way? The body was in agonal- I don’t know what you would call it. Primary agony.” The young monastic initiate who participated in her care was, as Ann put it, “just sort of stunned.”

We see here the kind of moral uncertainty described by Jameton (1984) and discussed at length in chapter two wherein care providers are faced with a situation in which they are uncertain how to respond. That uncertainty, as a consequence of the manner in which the dying trajectory unfolded, developed into significant distress for those involved. By their own accounts, Ann and the caregivers were clearly distressed by the “pushing” to speed up the dying process and to force it to occur on the patient’s and her partner’s own terms. They were further distressed by the patient’s partner’s request to hasten her death by laying her body flat, a position in which she would certainly have been unable to continue breathing, and yet, Ann and the caregivers were faced with the patient’s and the partner’s abject suffering. Suffering that was not

only physical, but also emotional and spiritual. The desire to alleviate that suffering was great, though the manner in which the partner wished to have it relieved caused understandable concern.

In a later communication between the staff, Ann remarked on how even in this very difficult case, the island hospice “supported the safe and open space for all of it to happen, and [Jean’s] dying unfolded in both remarkably wholesome and profoundly disconcerting ways. Everyone here was again shown the benefit of patience, and the necessity of letting go of expectation and control.” This was a circumstance in which, I believe, any practitioner or caregiver may have struggled. For even the most seasoned, the challenges presented by this situation would have been great and it is not difficult to imagine how tempting it would be to intervene at various points along the way. This is, perhaps, one of the greatest examples of the approach to dying that this island hospice has embraced. We see how Ann and MyoO have drawn upon four of the five precepts: welcome everything, push nothing away, bring your whole self to the experience, find a place of rest in the middle of things, and cultivate don’t-know mind described in chapter four. We also find evidence of the kind of on-going improvisation or *kufu*, and ethical know-how discussed in chapter five.

When I later asked Ann to discuss both Hanna’s and Jean’s experiences with me, we returned to the notion of a good death and to the (often spiritual) narratives that people draw on for meaning and sensemaking at end of life. Ann told me that the island hospice is a place that is “ripe ground for the tendency to try and create a good death.” She returned to Hanna’s experience to explain how Hanna’s expectations of herself as a spiritual leader created the conditions for her suffering. Hanna believed, Ann said, that “if I can come to [island hospice] it will be where a teacher like me belongs at a time like this when, in fact, all of the scaffolding collapses.” The western notion of the good death, Ann described, is the “initial desire, but it

takes on a life of its own.” Pointing to the experience with Jean and her partner, Ann referred to the obvious “undercurrent of wanting it to be over. It was an exhausting experience but what I hadn’t seen in such relief before was this intentional making it happen in such a way.”

Ultimately, Hanna, Jean, and Jean’s partner had expectation of and longed for a good death. They sought and defined it in their own ways by drawing on the spiritual narratives from which they had in the past been able to find meaning and comfort. Hanna wanted to die as she had lived, a spiritual master and teacher. Jean and Jean’s partner wanted Jean’s dying to be a clear conscious enlightened spiritual event. Both experiences evidenced a deep desire for personal transformation and transcendence in dying through religious or spiritual practices that were connected to the narratives in which they saw themselves living and dying. The notion of dying and death as opportunities for transformation and transcendence is one not only shared by these patients but also present in western and eastern spiritual narratives. As such, they heavily influence our understanding of end of life and are worthy of further discussion.

C. Resurrection & Enlightenment

With this desire for transformation and transcendence in mind, I return to Payne’s (1989) conception of consolation and compensation to help us better understand the work our narratives do for us in situations like dying that place the greatest stress upon our rhetorical healing efforts. I first offer a narrative of resurrection to explore western narrative possibilities for transformation and transcendence. Then I turn to an eastern narrative of enlightenment to think about its potential value, especially for patients, practitioners, families, and caregivers at the island hospice. Western resurrection and eastern enlightenment narratives help us understand how the failure of death may be both transformed and transcended. They call for the

implementation of all three *topoi* in that they rely on past-future context, for instance when past actions may be interpreted as causes for future outcomes; self-social context, for example when the disruption of failure may be overcome by a sacrifice of self for a connection to a greater good or larger scheme of things; and spiritual-material context, an example of which would be past failures being reconstructed to provide a kind of compensatory order beyond the linear.

One western version of transformation and transcendence from which I most readily draw is the story of the Israelites being cast out of Jerusalem and enslaved in the diaspora. This narrative originates in the Torah but is familiar to most people through one biblical interpretation or another. In essence, the narrative recounts not only the sacking of the Israelite nation, but perhaps, more importantly, the prophetic response by Ezekiel. Having been expelled from Jerusalem with no hope of returning, and forced into slavery outside the land, the Israelites express their great distress at the knowledge that they and their subsequent generations will likely never see a return to the land and will surely die as slaves. They experience what is arguably a deep sense of theological despair as a consequence of having failed to hold onto the land that HaShem (the translation being “the Name”) has granted them. They do not see a way of repairing that loss until the prophet Ezekiel reveals, in what is clearly shamanic language of individual and collective dismemberment and remembering, a vision of resurrection of the dead. What this means for the Israelites is that even though they will never again return to Jerusalem and even though their children and their children’s children will die enslaved and outside the promised land, their bodies will one day rise from the grave and sinew will be put back onto bone, and they will in spiritual body be returned to Jerusalem. Ezekiel’s message is a well-known narrative and one that I believe to be among the best of examples of therapeutic

rhetoric; it is constructed expressly for the purposes of repairing the failure and loss of the nation while imparting hope to the hopeless.

Ezekiel's prophetic vision offers not only the consolation of the Israelites' loss of the Promised Land and a spiritual compensation, albeit in some distant, unspecified future, but also individual and collective reparation and restitution. Through this narrative, each Israelite may hope for the resurrection promised to the whole nation; the very personal experience of failure, loss, and enslavement are taken up and incorporated by the collective loss. So, too, we see the compensatory action of the narrative when the past failings for which the Israelites experience suffering in the diaspora are overshadowed by the future hope of resurrection. As Payne indicates (1989), "the ultimate compensation for suffering and loss is the divine transfiguration; the soul is being fitted for its place in heaven. Spiritual development is created by pains and failings that defy our normal understanding and seem incalculable" (p. 124). Failure and suffering are, like the dead bodies of the Israelites, transformed. The corporeal loss becomes a spiritual gain and the Israelites' spiritual failing, thus transformed, makes way for the spiritual body to transcend even death. It seems that this narrative offers a prime example of how the problems of failure, extreme circumstances of destruction and enslavement, and even death itself may be rhetorically reconstructed so as to speak meaningfully to intense theological despair. Ezekiel's promise seeks to heal the individual and collective loss of freedom, homeland, and national unity experienced in the material world but reconciled at some future time in the spiritual realm.

Eastern enlightenment narratives offer another way to manage the fear and loss that death brings. If we experience liberation through enlightenment from the fiction of a separate self, then, too, we experience liberation from death, which becomes only a myth. As understood in the

Taoist as well as Zen traditions, if each of us imagines ourselves as only a wave in the ocean, then, crashing upon the shore, we cease to exist. Our wave is gone. When we think of ourselves as the ocean, our crashing upon the shore means our death is not, in fact, a death; we have not ceased to exist. We have only been transformed from one wave to another. It is not, therefore, that in physical death we no longer exist, but rather that we exist differently. This is not as foreign to the western thinker as we might expect as we need only think of who we were at five or ten or even fifteen years old to recognize that we are not the same self that we were then. Our identities have been transformed by the course of natural development as well as by our life experiences. In essence, that self has died and yet continues on in the new form in which we now find ourselves. Therefore, death is not something to be feared because there is no self to lose to death. There is only a self to be transformed by it and this transformation also acts as a form of transcendence of death. Death no longer has the power to permanently destroy, thus it becomes something that we need not fear. This dissolution of fear that the eastern account can accomplish is a kind of healing in itself, as, in this perspective, through death we are transformed into the vastness of nature and we also transcend death. The eastern enlightenment narrative asks us to consider ourselves as more than purely biological beings, for, if that is all we are, then death consumes us.

Both the resurrection narrative and the eastern enlightenment narrative require a spiritual component for transformation and transcendence to occur. When we do not reduce ourselves to the physical and succumb to the illusion of the dualistic mindset that separates us from everyone and everything else, we come to understand that we are at one with all that appears to be apart from us. Furthermore, as part of this larger whole, we cannot be lost or separated even by death. Payne's (1989) work offers us the clearest understanding of how we come through narratives

such as these to find relief from the disruption brought by death, however we may come to make sense of our dying. We aim to use our rhetorical narrative constructions to lessen the sting of death and to restore narrative continuity to our life stories, something that does not come with ease and is often, as we have seen exemplified here, accompanied by great suffering and struggle.

Through the *topoi*, we see the patterns evident in the ways in which we accomplish this. Understanding these patterns is, therefore, crucial to the study of end of life. While the eastern understanding of death I have suggested here does offer a story in which we experience death as a transformation rather than as a loss, we must ask if it is only possible for us to be truly comforted by this narrative if and when we are able to transcend our western dualistic (self and other, life and death, etc.) thinking? If so, this requires a transformative experience that might not appeal to, or be available to all patients, families, or caregivers even at the island hospice. While the hospice is clearly founded on and operates as part of a Zen system of belief and practice, there was not any evidence that all caregivers embraced a narrative of this nature or that even those who did ever offered it as an alternative frame for dying. That is to say that the success of care at the island hospice cannot be located in the application of an eastern narrative of transformation and transcendence to individual patient experiences. Nor can I say that I believe that patients, like Hanna and Jean, who struggled within their own narratives and found them wanting would have had a better experience if only they had adopted another more suitable narrative. Jean and her partner tried all manner of spiritual resources from Hindu to Buddhist to Christian and beyond to create the best possible death that they could imagine and were still unable to transform the dying experience into the one for which they strived and hoped.

D. “Whatever walks in our door”

After all of my time at the hospice, it was during a follow-up interview with Ann that I came to truly understand what it is that the island hospice community has to teach us about the care of the dying. What I discovered is that the lesson would not come in the form of an alternative narrative that they employed, an eastern over a western. It was even that they crafted better or more comforting consolations and compensations. I listened for them. I came ready and open to hearing and adopting them. The most important thing I learned, the thing we may take away from this study, was surprisingly simple. While the communication I observed was always gentle and kind, I did not find it in what was communicated through talk, rather it was in what wasn't said. It was nestled in silence. As Ann reminds me, they say very little because there is very little to be said. Ultimately, the approach of the island hospice is one that does not try and alleviate suffering, pain yes, but not suffering. Ann and the caregivers at the island hospice do not try to talk or story it away. Pain can be managed with relative ease. “Managing suffering, Ann says, is a whole other day.” Suffering is “what is happening. I try not to compound it, try not to compound emotional and spiritual angst. People are going to suffer. No one can take that away. This is the irony. We talk about the good death with no suffering but it is going to happen. We learn to turn towards suffering and not away from it.” Ann explains to me that making a space for suffering is different than working to alleviate it. In other end-of-life contexts, everyone, she says, is “trying to make it different or better. What I want to have here is-you don't make-you allow things to become revealed, reveal themselves. It is a very tricky line-area-how you deal with that point of view. People suffer regardless. You can't make it perfect.” She went on to say that all we can do, what she does there at the island hospice, is

“keep an environment as clear, clean, and unobstructed as possible, allowing it [suffering] to be expressed in a safe environment.”

When I asked Ann to tell me how she manages this when the desire to heal, to prevent pain and suffering can be so strong, she admitted that this is part of a constant process of personal development. There is she explains, “no one answer to that. It happens daily, moment by moment. It is a great place of growth for me here, more than anything else because the whole spirit world thing, I really don’t know, but I can become aware of me, in the tension, what’s happening for me. It is easier here to not fall back on stock phrases and answers. They can really deaden my openness to trying to dance with the whole thing. Stock answers are a real red alert to me. If I find I am going in that direction, I need to pay more attention.” In response, I explain to her the concept of “undecideables” that I have been working with as I try to understand what goes on at the hospice. “Yes, exactly,” she replies. “Swimming in that territory is really challenging and interesting-its jazz.” This leads her to talk a bit about uncertainty and how the response to it is often one of fear. This, she tells me, is how people “end up with stock responses, out of fear of living with uncertainty.” When I ask her how she manages uncertainty she tells me that the “only way out of that is to spend time settling yourself with yourself, somehow finding a way to be comfortable in your own skin.”

Those who are familiar with Buddhist teaching will likely wonder, as I did, how the hospice’s approach to suffering for their patients at end of life can be reconciled to the Buddhist principles that seek to eliminate suffering. After all, the Buddha not only established the nature of human existence as suffering and identified the sources of that suffering, but then brought the hope of liberation from that suffering. As is expressed in the Four Noble Truths, life is suffering; inevitably we all experience physical, emotional, existential pain (Barrett, 1996). Our suffering

is caused by our attachment as we cling to a false sense of permanence and a desire for certainty. “Because we attach to things, we constantly suffer, since despite however much we love things they must always change and disappear and return to emptiness” (Sahn, 1997, p. 97). Freedom from this attachment, the Buddha taught, is the only way to alleviate our suffering (Barrett, 1996).

Simply put, suffering is of our own making, and if we can “make this suffering, we can also take it away” (Sahn, 1997, p. 98). The final Noble Truth, as taught by the Buddha, teaches how through practicing the Eightfold Path we might put an end to our suffering (Sahn, 1997). Given this understanding of the nature of suffering it would seem unusual that a hospice founded on Buddhist principles would not offer some prescriptive for alleviating suffering at end of life. Perhaps the Eightfold Path would be the narrative that we need, the story most suited for dying. And yet, Ann is very clear in her assertion that suffering is part of the dying experience and that it cannot be eliminated.

Wanting to understand what seemed like a tension between the Buddhist principles and the actual hospice practice, I turned to a conversation with the Roshi in which he explained quite simply how it was possible to comfortably hold both of these perspectives at once. Dying, he said, is not a “time to learn something new.” We should not, he went on to say, “treat someone’s dying as a time to teach them something. This is a time for us to learn something from them. Each person’s death is their own. We must be able to understand this from their point of view.” This ultimately, as the Roshi has said, what it means to “see” the patient as they really are or as Ann describes to be as clear and present in the moment as we can be. We cannot, they say, alleviate the suffering of others but we can through mindful attention not add to the suffering of a dying patient. Ultimately, we can only create a safe and supported space for that suffering.

I began this chapter and indeed my experience with the island hospice much like the people I have written about here. Like them, I was looking for a way to story dying. I was looking for a way to co-create end-of-life experiences that would alleviate suffering, making things better for those at end of life. I wanted explore the narratives that we see ourselves living and dying in so that I could understand how and why our narratives fail us when they do. In the end, Ann taught me something different and yet vital about care of the dying. We don't suffer because we are doing it wrong, because our narratives are wrong. No matter how well constructed our narrative compensations or consolations we cannot guarantee escape from suffering. For many it is an inevitable part of the process of dying. To wrestle and fight against it cannot do us or our patients any good. We must instead turn our attention to creating safe spaces for patients and families wherein they may have whatever experience of dying it is that they are going to have. We must as Ann says, "be open to whatever walks in our door."

Chapter Seven: Summer



Figure 5: Summer, Morning Glory

From a spring brocade
woven of willows and cherries
colors bloom in the voice of a warbler.
Rengetsu

Daily spring rains yield to long, warm dry spells. Here on the island and around the hospice house the air is thick with the scent of freshly cut sweet meadow grass and wild rose. Local roadside farm stands boast freshly cut sunflowers and bright pink and red zinneas, displaying and selling farmers' summer harvests. Baskets are filled with hearty kale, rainbow chard, onions, beets and carrots. Delicious organic blueberries, strawberries, and raspberries are sold as quickly as they are picked and fresh brown eggs are gifted from free roaming hens. Along the roads daisies spring up and blooms from morning glory and sweet pea vines make their first appearances. In the mornings, the pines are alive with small bird song and soft summer winds. Tourists flock to the islands as they have every summer, combing the shops, slowing the travel to and from the islands, and enjoying the beautiful forests and beaches. Warm afternoons and long summer days are met with cool nights and bright skies and, more quickly than it seems it should, summer begins to slip away.

A. Reflection & Discussion

This project examined end-of-life experiences at this small, island hospice and explored how end-of-life communication, sense- and decision-making, and care in this setting differ from that in typical clinical settings in which most Americans die. This dissertation narrated the literal landscapes as they transformed throughout the seasons of my year of research beginning from my first late summer arrival to the island and throughout the subsequent year. I have shown in these pages how the spiritual, communal, relational, and ethical practices at this island hospice might inform and enlighten our understanding of caring for the dying.

As part of this endeavor I interrogated how spirituality enriches and complicates the dying experience. Most scholarship concerning spirituality and end of life has been dedicated to the protective nature of spiritual narratives. Those of us who have worked with patients struggling with illness or at end of life are familiar with the ways in which our narratives can create tensions for ourselves and with others. As comforting as our narratives can be for us in their constructions as consolations and compensations for the loss we are experiencing, when they are no longer sufficient for the loss at hand, they may instead be a source of, or exacerbate suffering. I have also shown how sensemaking in the dying experience is narratively bound and how the narratives in which we see ourselves living and in which we do our sensemaking are also sources of comfort and potential distress. Our healing rhetoric, often in the form of spiritual narratives, allows us to construct consolations and compensations for our senses of loss, or failure; though, those constructions are not, however, capable of fully repairing the rupture that a death creates.

Through this research, in many ways I found what I thought I would find. This is inevitable since research questions always frame what researchers find through their scholarship. I wanted to learn how the island hospice cared for patients, incorporated spirituality, managed narrative tensions, and functioned as a community of practice. I learned something about all of these aspects of end of life care at the island hospice, however, what I did not anticipate, was finding that an approach to managing the suffering of patients and their families that does not orient around how to alleviate that suffering. Instead, I learned that the key was to permit and embrace that suffering. I learned what it means to create a space for suffering rather than resist or story it away.

In the time I spent observing and participating in the care of dying patients and their families within the island hospice community, I recognized that the island hospice approach to dying differs from most. Much of the time dying is framed and treated as a clinical problem, and, subsequently, a failure, and technological advances and interventions have clinically and ethically complicated end-of-life experiences. As I have shown in this research, the island hospice does not approach dying as a clinical problem or failure. Rather, the hospice prunes dying down to the fundamental process that it has always been. As Ann says, “we have been doing this [care for the dying] for thousands of years. It’s simple, really.” Despite its small size, the hospice manages to accomplish what many larger, better-funded organizations may not: the alternative approach to dying that the island hospice community and staff have taken is one that does not struggle against death as the island hospice treats dying as a source of potential transformation for patients, families, caregivers, and all involved in the process. As part of the hospice’s alternative approach to caring for the dying, the staff and caregivers at the hospice understand end of life as a spiritual event as well as a clinical one. The hospice incorporates the care of the dying into, and treats it as, an essential part of the communal practice.

As unique and mindful as the island hospice approach to end of life may seem, as Ann reminds us, “we can’t make it [the dying experience] perfect.” It might be tempting to say that we can control, create, narrate, or facilitate a good death for a patient. However, we can never compose a singular definition of what it means to have a good death or to die well. What we can do is be mindful in our practices and in our communication; we can create environments in which dying patients and their families can be well cared for and supported. The kind of end-of-life care found at the island hospice is thus neither prescriptive nor formulaic. Rather, it is rooted in very simple Zen practices that call for mindful, attentive ethical knowhow (Varela, 1999).

a. Limitations. I had the benefit of being in this island hospice community for an extended period of time, and this was a privilege many researchers would not be granted. Additionally, because of the hospice staff's small size, I had the opportunity to build relationships with people in the hospice care community as I served as a caregiver for patients alongside the staff and other caregivers at the facility. Despite the intimacy and extended amount of time I had at the site, the scope of this study necessarily remains quite small. In retrospect, much about my experience with the island hospice – what they taught me about end-of-life care – is not readily applicable in other end-of-life contexts.

The island hospice is a small in size and scope, much smaller than most end-of-life care facilities. This hospice is exclusive in many ways, though not financially since they even welcome patients who cannot afford to pay. The hospice takes in very few patients in a given year, and, typically, the hospice only takes in two patients at the most at one time. Accepting so few patients in a given year is hardly replicable for most organizations that care for dying patients. Another way this island hospice differs from most end-of-life care facilities is that their staff members have opportunities to recuperate with often long reprieves between patients. Such flexibility is not common or possible in many care contexts. The island hospice has a host of refreshed volunteers, people who are there of their own accord because they want to be. These caregivers step in and help with patient care, cooking, cleaning, etcetera. Because of this, the incidence of burnout at the island hospice will likely never match that of a typical end-of-life care facility.

Another aspect of this research that is worthy of consideration involves the feminist practice of bringing one's research back to participants for them to review. Admittedly, I was

enamored with the idea of this practice because I felt that doing this would be one way to honor the stories that participants share with us. Giving participants opportunities to correct misunderstanding, make clarifications, or otherwise alter researcher's representations of what they have shared reveals research as being co-constructed, as being co-created by participants and researchers. With this in mind, during the dissertation writing process I sent what I had written to Ann to give her an opportunity to review my work. I also conducted a number of follow up interviews with participants in order to gain insight into or further explanation of my observations. What I did not anticipate was how much work this would be for my participants, and Ann, in particular. What was initially crafted as an opportunity for participants became, in many ways, an obligation. While I made it clear that I did not believe that anyone should feel that they must read and respond to what I had written, it would be foolish to think that – when presented with my work and a request to review it – participants would not feel obligated, on some level, to read it.

I return to another aspect of what it means to research with others, one that I initially touched upon in chapter three regarding what can be known by a researcher and what might be the most ethical approaches to engaging in research with and of others. The hospice environment is warm and welcoming and, as such, I was embraced quickly as a member of the caregiving team. I had the benefit of an extended period of time with my subjects, days or weeks with some patients and families, and almost two years with members of the staff and hospice and monastic community. The sense of belonging to that the environment, time that I spent, and relationships that I developed as a consequence of both does not, however, mitigate the fact that those with whom I worked and for whom I cared were under my surveillance. Knowing that they were being watched and that what they said or did was may have been recorded in writing,

and at some point analyzed and written about, undoubtedly changed how we interacted with one another and what they were willing to say or do in my presence.

There are a number of aspects about researching with others that I continue to think about and believe deserve mentioning. I have encountered researchers who talk about how they have “become friends with” their subjects, and, while I certainly understand the affection that a researcher can come to feel for the people with whom she researches, I do not believe that, while research is ongoing, researchers can actually “become friends with” their subjects. Becoming friends with subjects seems to be a position that does not fully account for the relationship between the researcher and the researched, namely that even in the best possible circumstances, and no matter how much effort is made to mitigate the power differentials between subjects and researchers, the relationship between the two parties remains one in which there is an inherent power imbalance. This is especially the case when considering dying patients and their families.

This is not to suggest that I did not come to feel quite close to and fond of those with whom I researched. On the contrary, I hope and anticipate that some of those relationships will over time develop into friendships. I also do not wish to suggest that there is some distant and objective place from which a researcher engages in her research. A position of neutrality or objectivity does not exist and thinking that it does would mean suffering under the illusion of magical thinking. It is not possible to know everything, and certainly not possible by simple observation and/or even participation. And, while I do not believe that the researcher-researched relationship is one best characterized by friendship, I have come to understand more intimately that the observer and the observed are parts of the same whole. My subjects and I are not separate from one another and we are changed by one another’s presence, and we benefit from the understanding that both researcher and researched are changed by the experience.

I am reminded in this reflection of an old Sesame Street cartoon. A little girl stands poised pin in hand ready to pop the balloon she holds in the other. Played out in captions above her head she imagines what will happen if she pops the balloon; the balloon will make a loud pop, the loud pop will wake the baby, the baby will begin to cry, mother will... and so on. In that moment of reflection, the girl realizes that her actions are not without consequences, that she does not stand alone. She is connected to the balloon, the baby, her mother, etcetera. So too, I am connected: to the patients, families, staff, and community members. My actions are not without consequence.

b. From theory to practice. For these reasons, in future research of this qualitative nature, I will undoubtedly carry with me the people with whom I have worked and those for whom I have cared. Their stories and my experiences with them have altered my own story, certainly for the better. Their memory will remind me of the great consequence of caring for and researching with others and will no doubt positively influence the research I undertake in the future. I will not, for example, abandon the feminist practice of offering my work to participants. However, now that I recognize the energy, time, and sense of obligation this practice can place on participants, I aim in future studies to be much more sensitive to what it means to ask people to participate in the review of my research during the data collection and writing processes. Instead of telling participants that I will send them my work for them to review (which puts the participants in positions of obligation once they have received my work), I will ask participants if they would like for me to send them my work. If they desire this, I will ask them to tell me when and how they would like to go about that process: When would they prefer I send them the

work? At what stage in the writing process would they like to see my writing? How would they like or prefer to respond to my writing, if at all?

Considering the limitations of this study, particularly those related to size and scope that I explained, I hope to extend this research by engaging in follow up research with other Zen hospice facilities, particularly the Zen Hospice in San Francisco, as well as other end-of-life or palliative care facilities that incorporate mindfulness, contemplative, or communal practices similar to those employed at the island hospice. Because the island hospice is such a small community environment, looking to other hospice and palliative care environments would allow me to see what particular practices in end-of-life care have been most helpful elsewhere and by and with whom.

Another way I would attempt to enhance a project of this nature would be to add audio recordings of interviews that are done as follow ups. While I would not feel comfortable conducting formal, audio-recorded interviews with dying patients and their families, my research would significantly benefit from transcripts of follow up interviews with staff-only participants (this excludes patients and patient's family members) because, regardless of how skilled a researcher may be in note taking, one can never capture as much. While the same is true for audio- and video-recordings, the benefit with those is that a researcher can capture every word as well as metacommunications such as voice inflection, tone, pauses and hesitations, body language, etcetera.

The island hospice teaches those who engage in end-of-life care and scholarship a great deal about what it can mean to care for the dying. The hospice community members reveal to us what is possible in smaller, more intimate environments. They show us what we can do when we are not burned out, when we know a reprieve (either between patients or in the form of rested,

recuperated volunteers) will come. The island hospice teaches us something that we, as academics in particular, can learn: there is merit in the doing and not just in the theoretical. We cannot substitute our thoughts for our actions, as these must be wedded. We must engage fully, mindfully, and wholeheartedly in the care of the dying to the point that our thought does not override our action. We must engage in caring for the dying through, as Varela (1999) teaches us, spontaneous enaction (an embodied ethic).

The next logical step for my research would be to explore another aspect of what I learned at the island hospice that received very little attention in this dissertation. One of the defining elements of the hospice house approach to end-of-life-care is that the staff members at the hospice employ a minimal amount of technology in the clinical care of dying patients. This is unusual in end-of-life care. In fact, this approach is quite the opposite of that typically taken in the care of dying patients. Going forward, it would be of great value to further develop a discussion on this low-tech island hospice approach as a poetic corrective to our cultural obsession with technological interventions employed to stave off death at any cost.

c. Final thoughts. Life is experienced, as Bateson (1989) reminds us, as a series of discontinuities and continuities. Reflecting on the course of the year I spent researching and writing, some of these discontinuities and continuities stand out readily while others revealed themselves over time. Death certainly presents the greatest discontinuity, and yet, as part of the ongoing cycle of death and birth is also a continuity on which we may count. The change of seasons also represents this connection between discontinuity and continuity. The flowers of spring bloom and fade and yet return again the following year. Cool breezes melt into hot summer days and flocks of birds arrive and depart with the change of season. These ongoing

transformations were evidenced in the changing landscapes of the islands on which I lived and worked. There was another, more subtle example of these discontinuities and continuities that was quite a pleasant surprise.

When I was a young girl around the age of ten I remember seeing a book laying face down on the table of my mother's friend. Not typically drawn to the books my mother and her friends read, had I not noticed the picture of the author on the back cover I likely would not have looked inside. However, the picture drew me in. The photo of the author, Edith Holden, is of a girl not much older, I thought, than I was at the time. She sits with her hands folded in her lap, brows furrowed, and without a smile. I remember thinking to myself that she wasn't smiling because she didn't want to wear that velvet dress. My mother and I had argued recently over a dress; I wanted to wear a pants suit but she wouldn't permit it and it caused me no end of unhappiness at the time. Feeling myself connected to this girl, I opened her book, *The country diary of an Edwardian lady* (1977). I began to read. I loved her drawings of English flora and fauna, her accounts of the changing seasons. Over the years she had faded from my memory. It wasn't until well into the process of writing this dissertation, and after all of the drawings I made throughout the year had been completed, that I saw her work (1977, 1989) again. Shopping for a calendar for the coming academic year, I saw and bought one with a reprinting of her drawings. Flipping through the pages I remembered her. I remembered her drawings, finding my own curiously in the style of hers. Here I was, some thirty-five years later, still carrying her with me in my own work. What seemed like a series of discontinuities between an English girl of the early nineteen hundreds, a Southern girl in the nineteen-seventies, and an adult making my own observations of changing island landscapes was actually a connection that remained unbroken over time.

Ultimately, death is inescapable. We cannot hope to change this outcome for any of us. Inevitably, to resist this is futile. While we cannot eliminate dying or suffering, we are not without the ability to improve our care of the dying, to enhance the environments we create for patients and families going through the processes of a death. Through mindful attention to the landscapes in which we find ourselves, and those into which we enter with others, we have the ability, as the Roshi has said, to “see” the dying as they are. In so doing, we may create a space for suffering rather than try to alleviate it. Fully present and aware, we are sensitive to the changing needs of dying patients and their families, we are able to view them with “the loving eye” (Frye, 1983), and we are able to tend to their arising needs in unfolding receptive and responsive communication. With this in mind, we work to enhance our end-of-life care and communication, acknowledging how it is that we come to make sense of, and rhetorically manage the disruptions created by death and dying experiences.

By looking to the stories we tell ourselves about dying, we may come to understand how these narratives give us courage when it is difficult to physically, emotionally, or spiritually go on. Although these stories may call us to embrace our loss, to move with and within it, or even against it, ultimately, death comes whether we go down fighting or sigh into its waiting arms. What matters for those of us who wish to improve the care of the dying is how we care, the spaces we create for those who are dying and their loved ones, and the kind of communication in which we engage in those moments.

Summer has gone now, long warm days replaced with short afternoons and cooler evening breezes. Petals from summer's wild roses make a lovely pink carpet alongside the lane, their full blooms replaced along thorny branches with deep red rosehips. A flicker bird rests high in a pine reminding me of his frequent visits to the feeder outside Saul's window. Saul is gone now,

all of our former patients are, but I am comforted by the calls of the great horned owls that echo once again in the autumn night sky.



Figure 6: Autumn Again, Rose Hips

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Appendices

Appendix A: IRB Approved Informed Consent to Participate in Research - Non-Staff Member



I. Informed Consent to Participate in Research – NON-STAFF MEMBER Information to Consider Before Taking Part in this Research Study

IRB Study # 00009099

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below. Please tell the study staff if you are taking part in another research study.

I am asking you to take part in a research study called: “Composing a Death: End of Life Conversations at a Zen Hospice” and the person who is in charge of this research study is Ellen Klein. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. Lori Roscoe, Ph.D., is guiding Ellen Klein in this research project. The research will be conducted at Enso House hospice and One Drop Zen Monastery on Whidbey Island in Washington State, and the researcher is gathering data for this qualitative study between 2012 and 2013. She will collect data in the form of field notes; the primary data collection methods will be participant observation and interviewing. With your consent, the researcher will observe and take notes about what she empirically experiences while she works as a volunteer caregiver during your stay at the Enso House. If you choose to participate in this study, please know that you will experience no risks, inconveniences, or discomforts. You reserve the right to end your participation at any point in the data collection and interviewing process.

II. Purpose of the study

The purpose of this study is to gather data about how the Zen hospice approach works in the microcosm of the hospice house and local monastic community, how its practices might translate into other end of life circumstances, and how spirituality in end of life is communicated with patients in their dying as well as among practitioners in their care of the dying.

You are being asked to participate in this study because you are a patient, a caregiver, a member of the monastic community, a family member or a friend of someone who is receiving care at the Enso House Hospice. You are being asked to participate in this study by being interviewed about end of life communication and your personal experiences. The researcher who is the PI of this study is gathering data from this research project to complete her dissertation in the field of Health Communication. The researcher is in the process of earning her doctorate from the University of South Florida.

III. Study Procedures

To participate in this study, you might be asked to partake in an interview. With your permission, the researcher might make field notes during her participation in and observation of patient care and the goings on at Enso House Hospice and One Drop Zen Monastery.

All interviewing will occur on the premises of the Enso House/Monastery. Each interviewee will be asked to relay their own experiences in their own words, at their convenience, and for the length and frequency of their choice. None of the interviews will be audio or video recorded, unless requested by the participant. The researcher will take her own personal notes during her participant observation and during the interviews that will be conducted. The interviews will include questions related to your experiences with end of life at Enso House Hospice/Monastery. We may discuss topics such as end of life communication, decision-making, ethics, and care and these conversations will center on your personal experiences and perspectives. The interviews should last between 30 minutes and an hour and a half, unless you wish it to be longer. The interviews that I will conduct will be singular interviews. If at any time you wish to discontinue an interview, you may stop and recommence at a later time or discontinue the interview all together.

My participant observation data gathering at the Enso House/Monastery entail participation as a certified volunteer caregiver as determined by Washington State Fundamentals of Care Practice, Washington State Department of Health, Adult Family Living, and Enso House/Monastery regulations. The tasks vary, and I will spend approximately one to three days per week at the Enso House/Monastery gathering data. I am requesting permission to include you in my research observations and/or in my interviews.

Procedures for Exclusion & Discontinuation

The care procedures that I will be observing will include interactions between caregivers and patients, interactions between caregivers and patients' friends and family members, interactions between caregivers, interactions between patients and their families and friends, and interactions between patients, families and friends, or caregivers and members of the monastic community and/or volunteers of the hospice house.

In addition to observing interactions, I will be observing mealtime rituals, individual bodily care for patients that may include, but not be limited to, administration of medication, positioning of bodies, changing of clothing, etc. Any direct care that I will participate in will be limited to "the fundamentals of care" as determined by the restrictions of Washington state law.

Individuals excluded from observation might include any individual unable and/or unwilling to give legal informed consent and/or individuals deemed inappropriate for this study – for any reason (physical, mental, etc.) – by the licensed physician in charge, Dr. Ann Cutcher, MD. If at any point a patient is unable to speak for themselves the director and/or family members, significant other, or anyone else accompanying the patient may determine that observations for this study will be terminated from that point forward. Furthermore, I will utilize my experience as a former hospice nurse to guide me in determining how to respond sensitively to the changing status of a patient and discontinue my participant observation for my study (should continued note-taking become inappropriate or insensitive).

Details Regarding Length of Time that My Observations Will Cover

These observations will occur during my shifts as a volunteer at the Zen Hospice/Monastery that might continue until Dec. 2013. The number of days per week between now and that time will vary since the goings on, the numbers of patients, and the needs of those patients at the site will influence the frequency of my visitations.

IV. Total Number of Participants

About 50 individuals will take part in this study. The only site where data will be gathered will be the Enso House/Monastery (unless participants choose alternative locations for the interviews).

V. Alternatives

You do not have to participate in this research study. Your participation is completely voluntary and you reserve the right to end your participation at any time without penalty.

VI. Benefits

It is unknown if you will receive any benefits by taking part in this research study.

VII. Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day and there are no known additional risks to those who take part in this study.

VIII. Compensation

You will receive no payment or other compensation for taking part in this study.

IX. Cost

There will be no additional costs to you as a result of being in this study.

How Do I Withdraw Permission to Use My Information?

You can revoke this form at any time by sending a letter clearly stating that you wish to withdraw your authorization to use your information in the research. If you revoke your permission:

- You will no longer be a participant in this research study;
- We will stop collecting new information about you;
- We will use the information collected prior to the revocation of your authorization. This information may already have been used or shared with other, or we may need it to complete and protect the validity of the research; and
- Staff may need to follow-up with you if there is reason to do so.

To revoke this form, please write to:

Principal Investigator, “Composing a Death: End of Life Conversations at a Zen Hospice”

For IRB Study # 00009099

Email: ewklein@mail.usf.edu

While we are conducting the research study, we cannot let you see or copy the research information we have about you. After the research is completed, you have a right to see the information about you, as allowed by USF policies.

X.

XI. Privacy and Confidentiality

We will keep your study records private and confidential, and only she will have access to these notes. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator and her academic, dissertation advisor, Dr. Lori Roscoe.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
- Any agency of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).
- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

I may publish what I learn from this study. If I do, I will not include your name (unless you give your permission to allow this). I will not publish anything that would let people know who you are (unless you give your permission to allow this).

I will use pseudonyms and not use subjects' identifiable information when disseminating results unless otherwise requested from the subject. Only with participants' consent, will I include identifiable information in my dissertation; that information will never violate HIPPA laws concerning confidentiality and privacy. All data collected will be stored on a password-protected computer.

XII. Voluntary Participation / Withdrawal

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study. Your decision to participate or not to participate will not affect any of your student, volunteer, or employment statuses.

XIII. New information about the study

During the course of this study, we may find more information that could be important to you. This includes information that, once learned, might cause you to change your mind about being in the study. We will notify you as soon as possible if such information becomes available.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, contact Ellen Klein at ewklein@mail.usf.edu.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638.

XIV. Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study and I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

XV. Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/ she understands:

- What the study is about;
- What the potential benefits might be; and
- What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization

Date

Printed Name of Person Obtaining Informed Consent / Research Authorization

Appendix B: IRB Approved Informed Consent to Participate in Research - Staff Member**XVI. Informed Consent to Participate in Research – STAFF MEMBER
Information to Consider Before Taking Part in this Research Study****IRB Study # 00009099**

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below. Please tell the study staff if you are taking part in another research study.

I am asking you to take part in a research study called: “Composing a Death: End of Life Conversations at a Zen Hospice” and the person who is in charge of this research study is Ellen Klein. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. Lori Roscoe, Ph.D., is guiding Ellen Klein in this research project. The research will be conducted at Enso House hospice and One Drop Zen Monastery on Whidbey Island in Washington State, and the researcher is gathering data for this qualitative study between 2012 and 2013. She will collect data in the form of field notes; the primary data collection methods will be participant observation and interviewing. With your consent, the researcher will observe and take notes about what she empirically experiences while she works as a volunteer caregiver during your stay at the Enso House. If you choose to participate in this study, please know that you will experience no risks, inconveniences, or discomforts. You reserve the right to end your participation at any point in the data collection and interviewing process.

XVII. Purpose of the study

The purpose of this study is to gather data about how the Zen hospice approach works in the microcosm of the hospice house and local monastic community, how its practices might translate into other end of life circumstances, and how spirituality in end of life is communicated with patients in their dying as well as among practitioners in their care of the dying.

You are being asked to participate in this study because you are a caregiver, member of the monastic community, or other volunteer staff member at the Enso House Hospice. You are being asked to participate in this study by being interviewed about end of life communication and your personal experiences. The researcher who is the PI of this study is gathering data from this research project to complete her dissertation in the field of Health Communication. The researcher is in the process of earning her doctorate from the University of South Florida.

XVIII. Study Procedures

To participate in this study, you might be asked to partake in an interview. With your permission, the researcher might make field notes during her participation in and observation of patient care and the goings on at Enso House Hospice and One Drop Zen Monastery.

All interviewing will occur on the premises of the Enso House/Monastery. Each interviewee will be asked to relay their own experiences in their own words, at their convenience, and for the length and frequency of their choice. None of the interviews will be audio or video recorded, unless requested by the participant. The researcher will take her own personal notes during her participant observation and during the interviews that will be conducted. The interviews will include questions related to your experiences with end of life at Enso House Hospice/Monastery. We may discuss topics such as end of life communication, decision-making, ethics, and care and these conversations will center on your personal experiences and perspectives. The interviews should last between 30 minutes and an hour and a half, unless you wish it to be longer. The interviews that I will conduct will be singular interviews. If at any time you wish to discontinue an interview, you may stop and recommence at a later time or discontinue the interview all together.

My participant observation data gathering at the Enso House/Monastery entail participation as a certified volunteer caregiver as determined by Washington State Fundamentals of Care Practice, Washington State Department of Health, Adult Family Living, and Enso House/Monastery regulations. The tasks vary, and I will spend approximately one to three days per week at the Enso House/Monastery gathering data. I am requesting permission to include you in my research observations and/or in my interviews.

Procedures for Exclusion & Discontinuation

The care procedures that I will be observing will include interactions between caregivers and patients, interactions between caregivers and patients' friends and family members, interactions between caregivers, interactions between patients and their families and friends, and interactions between patients, families and friends, or caregivers and members of the monastic community and/or volunteers of the hospice house.

In addition to observing interactions, I will be observing mealtime rituals, individual bodily care for patients that may include, but not be limited to, administration of medication, positioning of bodies, changing of clothing, etc. Any direct care that I will participate in will be limited to "the fundamentals of care" as determined by the restrictions of Washington state law.

Individuals excluded from observation might include any individual unable and/or unwilling to give legal informed consent and/or individuals deemed inappropriate for this study – for any

reason (physical, mental, etc.) – by the licensed physician in charge, Dr. Ann Cutcher, MD. If at any point a patient is unable to speak for themselves the director and/or family members, significant other, or anyone else accompanying the patient may determine that observations for this study will be terminated from that point forward. Furthermore, I will utilize my experience as a former hospice nurse to guide me in determining how to respond sensitively to the changing status of a patient and discontinue my participant observation for my study (should continued note-taking become inappropriate or insensitive).

Details Regarding Length of Time that My Observations Will Cover

These observations will occur during my shifts as a volunteer at the Zen Hospice/Monastery that might continue until Dec. 2013. The number of days per week between now and that time will vary since the goings on, the numbers of patients, and the needs of those patients at the site will influence the frequency of my visitations.

XIX. Total Number of Participants

About 50 individuals will take part in this study. The only site where data will be gathered will be the Enso House/Monastery (unless participants choose alternative locations for the interviews).

XX. Alternatives

You do not have to participate in this research study. Your participation is completely voluntary and you reserve the right to end your participation at any time without penalty.

XXI. Benefits

It is unknown if you will receive any benefits by taking part in this research study.

XXII. Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day and there are no known additional risks to those who take part in this study.

XXIII. Compensation

You will receive no payment or other compensation for taking part in this study.

XXIV. Cost

There will be no additional costs to you as a result of being in this study.

How Do I Withdraw Permission to Use My Information?

You can revoke this form at any time by sending a letter clearly stating that you wish to withdraw your authorization to use your information in the research. If you revoke your permission:

- You will no longer be a participant in this research study;
- We will stop collecting new information about you;
- We will use the information collected prior to the revocation of your authorization. This information may already have been used or shared with other, or we may need it to complete and protect the validity of the research; and
- Staff may need to follow-up with you if there is reason to do so.

To revoke this form, please write to:

Principal Investigator, “Composing a Death: End of Life Conversations at a Zen Hospice”

For IRB Study # 00009099

Email: ewklein@mail.usf.edu

While we are conducting the research study, we cannot let you see or copy the research information we have about you. After the research is completed, you have a right to see the information about you, as allowed by USF policies.

XXV.

XXVI. Privacy and Confidentiality

We will keep your study records private and confidential, and only she will have access to these notes. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

- The research team, including the Principal Investigator and her academic, dissertation advisor, Dr. Lori Roscoe.
- Certain government and university people who need to know more about the study. For example, individuals who provide oversight on this study may need to look at your records. This is done to make sure that we are doing the study in the right way. They also need to make sure that we are protecting your rights and your safety.
- Any agency of the federal, state, or local government that regulates this research. This includes the Department of Health and Human Services (DHHS) and the Office for Human Research Protection (OHRP).
- The USF Institutional Review Board (IRB) and its related staff who have oversight responsibilities for this study, staff in the USF Office of Research and Innovation, USF Division of Research Integrity and Compliance, and other USF offices who oversee this research.

I may publish what I learn from this study. If I do, I will not include your name (unless you give

your permission to allow this). I will not publish anything that would let people know who you are (unless you give your permission to allow this).

I will use pseudonyms and not use subjects' identifiable information when disseminating results unless otherwise requested from the subject. Only with participants' consent, will I include identifiable information in my dissertation; that information will never violate HIPPA laws concerning confidentiality and privacy. All data collected will be stored on a password-protected computer.

XXVII. Voluntary Participation / Withdrawal

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study. Your decision to participate or not to participate will not affect any of your student, volunteer, or employment statuses.

XXVIII. New information about the study

During the course of this study, we may find more information that could be important to you. This includes information that, once learned, might cause you to change your mind about being in the study. We will notify you as soon as possible if such information becomes available.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, contact Ellen Klein at ewklein@mail.usf.edu.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638.

Appendix C: IRB Approved Verbal Script for Recruiting Patients, Patients' Family Members, and Friends

Study Name: "Composing a Death"

Study ID Number: Pro00009099

P.I.: Ellen Klein

Verbal Script for Recruiting Patients, Patients' Family Members, and Friends

My name is Ellen Klein, and I am a doctoral candidate in the department of Communication at the University of South Florida. While I volunteer as a caregiver at the Enso House hospice and monastery, I am engaging in participant observation in a research study entitled "Composing a Death." My study's identification number is Pro00009099. My participation in your care or the care of your loved one does not, in any way, obligate you to participate in my study. Should you agree to participate, I will provide you with an informed consent document and my contact information. Through the process of an interview – that should last between 30 minutes and an hour and a half – I am interested in having you share your experiences with end of life here at the Zen hospice and monastery.

Appendix D: IRB Approved Guiding Questions

IRB Approved Guiding Questions

P.I.: Ellen Klein

Study Number: Pro00009099

A. Guiding Questions

The following are my initial guiding research questions:

- What is the “sense of place,” or “landscape,” that I may find, describe, and come to make sense of at the Zen hospice, and what are the common stories, sets of beliefs, goals, or activities enacted by members of the Zen hospice community?
- How do caregivers utilize the common stories, sets of beliefs, goals, and activities enacted by members of the Zen hospice community in a setting in which many patients and even some caregivers are *not* Buddhist practitioners?
- What rhetorical “work” is getting done through the Zen hospice narrative of dying (as opposed to traditional – hospice/medical – narratives of dying)?
- Furthermore, what rhetorical work is being employed when spiritual narratives informing medical-ethical decision-making come in conflict with one another, and what are the potential consequences of failing to cooperate for mutual benefit in the dying experience?
- What is the nature of the Zen communal practice? How is it engaged and explicitly and implicitly enacted through ritual, improvisation, and communication (shared goals, conditions, parts, and participation)?
- How does the Zen idea of “mindfulness,” or “co-presence,” relate to end of life communication and what does the Zen hospice teach about being fully present with the dying?
- How is “meaning” negotiated (participation and reification), and how much ambiguity and improvisation are present/fostered/resisted/tolerated within the Zen hospice community as a part of the community’s history of negotiation?
- How might ritual function as a source of coherence for the community in end of life care?
- What’s the Zen hospice frame for end-of life care? How much flexibility does the frame have; in other words, how does it ritually and philosophically encourage (or inhibit) flexibility and structure?
- Through conversation, how might the Zen hospice facilitate “tending” to one another in death and dying experiences and facilitating a patient’s “turning toward death”? How might the Zen hospice end of life experience be understood as “composing a death”?

Appendix E: IRB Approved Consent Form

Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

I freely give my consent to take part in this study and I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

XXIX. Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/ she understands:

- What the study is about;
- What the potential benefits might be; and
- What the known risks might be.

I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization

Date

Printed Name of Person Obtaining Informed Consent / Research Authorization

Appendix F: IRB Letter of Approval

IRB Letter of Approval

October 17, 2012

Ellen Klein
Communication
5055 Cypress Trace Drive
Tampa, FL 33624

RE: Expedited Approval for Initial Review

IRB#: Pro00009099

Title: Composing a Death: End of Life Conversations at a Zen Hospice

Dear Ms. Klein:

On 10/16/2012 the Institutional Review Board (IRB) reviewed and APPROVED the above referenced protocol. Please note that your approval for this study will expire on 10/16/2013.

Approved Items:

Protocol Document:

IRB-Protocol.14 Oct. 2012.edited3.docx

Consent Documents:

Composing a Death.Non Staff Member.Informed Consent.15 Oct. 2012.docx.pdf

Composing a Death.Staff.Informed Consent.15 Oct. 2012.docx.pdf

Please use only the official, IRB- stamped consent document(s) found under the "Attachment Tab" in the recruitment of participants. Please note that these documents are only valid during the approval period indicated on the stamped document.

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the

approved research must be submitted to the IRB for review and approval by an amendment. We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John A. Schinka, Ph.D., Chairperson

USF Institutional Review Board

Appendix G: Springer Letter of Publication Permission




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<p>Title: Making sense, ritual, and improvisation at the end of life</p> <p>Author: Ellen Klein</p> <p>Publication: Journal of Medicine and the Person</p> <p>Publisher: Springer</p> <p>Date: Jan 1, 2014</p> <p>Copyright © 2014, Springer-Verlag Italia</p>	<p>Logged in as: Ellen Klein</p> <p style="text-align: center;">LOGOUT</p>
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Issue number	1
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Portion	Full text
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Expected completion date	Dec 2014
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