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Making Space for Dying: Portraits of Living with Dying

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MAKING SPACE FOR DYING:
PORTRAITS OF LIVING WITH DYING

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A DISSERTATION

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This is to certify that the dissertation entitled:

MAKING SPACE FOR DYING: PORTRAITS OF LIVING WITH DYING

prepared by

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is approved in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Leadership and Change.

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For my mother, who is my first home;
for Will, who is my present home;
for my first daughter, Jemma, who also helps others in need of a good home;
for Selena, my second daughter, whose birth-death was my initiation.

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Abstract

In *Making Space for Dying: Portraits of Living with Dying,* I describe the everyday lived experience of dying and the care culture within freestanding, community-based, end-of-life residences (CBEOLR) utilizing portraiture and arts-based research. I craft four case studies into "portraits," based on interviews, on-site visits, up-close observation, and field notes. In the person-centered portraits, I reveal the inner landscape of two terminally ill women, with data represented in poetry. In the place-centered portraits, I "map" the social topography of two CBEOLRs to illustrate how lives and care of the dying are *emplaced,* from the perspectives of community leaders, residence staff, volunteers, family members, and residents, with data presented as aesthetic (storied) narrative. Collage and photographs further enhance the text. Little has been written about the meaning of home and the centrality of a home-like environment in the healthcare milieu, specifically in the context of the end-of-life care setting. My research helps to fill a gap in understanding care culture in the freestanding CBEOLR, a care-setting genre rarely examined in the literature. Additionally, my study develops the notion of a "good place to die" and introduces the Home for the Dying, a CBEOLR model unique to New York State. Lastly, building on the literature on liminality, and informed by clinical practice as an oncology social worker, my study specifically highlights the terminal stage of cancer and introduces the concept terminal liminality*,* characterized by descent. Two broad dimensions emerged: Nesting-in-Being and Nesting-in-Place*.* Together, these dimensions created a framework for exploring care culture and ways of working with existential suffering. The bird's nest, as a utilitarian though temporal structure, provided an elegant metaphor for the special end-of-life residence. Three linked sub-themes related to care culture emerged, Nest of Simple Things (meaning making), Nest of Belonging (community making)*,* and Nest of Everydayness (home making). Implications for leading change in end-of-life care highlight an initiative to establish and maintain a CBEOLR in my own community. This dissertation contains embedded jpg images and two supplemental files [MP4 video, MP3 audio]. The electronic version of this Dissertation is at AURA, http://aura.antioch.edu/etds/ and OhioLink ETD Center, www.ohiolink.edu/etd

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Prologue: Mwezi’s Plea

I met Mwezi at the Omega Institute Wellness Center where we worked summer seasons, she as an astrologer, and me as a massage therapist. Although we only greeted each other in passing, I reached out to Mwezi in my year-round role as a social worker at the Oncology Support Program (OSP) of HealthAlliance Hospital, when it was shared among Wellness Center staff that she was diagnosed with cancer of the uterus and cervix. I stayed in touch intermittently, mostly to connect her to OSP and community resources. Later the cancer metastasized to her brain, followed by a downturn in prognosis from advanced to terminal. Being a single person living with a terminal prognosis poses additional challenges, as well as barriers to care. Mwezi maintained her wit while sharing serious concerns about how she could continue to manage to live alone, who would take care of her, and how she would be able to afford to remain in her apartment. We were both painfully aware of her limited options. One day, over the phone, Mwezi asked me point blank, “Can I come live with you?” My heart in my throat, I told her I was unable to fulfill her request. Synchronistically, I had recently launched a research project investigating community-based residences for the dying and discovered a care model I strongly resonated with, called Homes for the Dying. I shared my dream with Mwezi of establishing a place in our community— a surrogate home complete with surrogate “family” caregivers—in the event a person wished to remain in their own home to die but lacked the human and financial resources to do so. We both knew it would not arrive in time for her death. Mwezi wound up being forced to leave her apartment and community, and to move out of state to live with her daughter who lacked the physical space and emotional capacity to provide the care she needed. Mwezi died shortly after, on November 15, 2010, in an institutional setting while receiving post-surgical rehabilitation. She was 57. Mwezi’s question continues to live in me.

Borders are set up to define the places that are safe and unsafe,
to distinguish ***us*** *from* ***them****.*
A border is a dividing line,
a narrow strip
along a steep edge.
A borderland is a vague and underdetermined place
created by the emotional residue of an unnatural boundary.
It is in a constant state of transition.
The prohibited and forbidden are its inhabitants…
[The **crossed***] live here…the half dead:*
in short, those who cross over, pass over,
or go through the confines of the 'normal'.
(Anzaldua, 1987, p. 25)

Places that separate people can never be safe enough...
[O]ur only refuge is in the goodness in each other.
(Remen, 2000, p. 10)

The birds are above,
the fish are below,
and we are betwixt and between.
(van Sandwyk, 1995/2005)

Chapter I: Introduction

Human beings are “homebound” creatures. We are home makers, home dwellers, and home seekers throughout life. Home is the universal symbol of care, comfort, safety, and belonging. It is a visceral sense of “I belong to you, and you belong to me” (P. Bojarsky, personal communication, January, 12, 2013). The meaning and function of home evolves as we move through the life cycle. Like the chambered nautilus, we outgrow our early family home and begin the spiral journey, expanding outward, as we migrate to new places often far from our home of origin. Throughout life, we cast new chambers, incorporating new understandings of life and self, as old ones die. Foremost, home is the mortal casing of the body, our original home. Inevitably, the body retires. We shed our temporal shells, emptying their mysterious content some call the soul. People nearing death oftentimes speak in metaphor; some say they are going “home.” Hence, the dying process can be seen as both a home-leaving and a home-coming. We come full circle. Our final home becomes a transitional space (Winnicott, 1965) and the vehicle in which we make safe passage. Upon arrival at death’s doorstep, our life journey ends.

Only less than one hundred years ago in America, people died at home and communities mourned publicly: “It was not only an individual who was disappearing, but society itself that had been wounded and that had to be healed” (Aries, 1982, p. 559). Influenced by professional and institutional interests, the meaning and boundaries of the hospital space has shifted over the ages from their traditional function as houses of “soul care” in the Middle Ages, to “houses of cure” during the Renaissance (Risse & Balboni, 2012, p. 326), and “houses of high technology” since the twentieth century (p. 327). Also altered are the meaning and boundaries of death (Hockey, Komaromy, & Woodthorpe, 2010a,b; Komaromy, 2010; Sudnow,1967). By the 1950s, hospitals were popularized as being the safest, most appropriate place for patients, and the most convenient place for professionals in which to manage the modern death. In the decades following, the hospital death became increasingly characterized as technological, heroic, and prolonged—not the kind of death most people say they prefer (Dartmouth Atlas Working Group, 2010). By the 80s, the hospital death peaked; a new trend, dissociating mortality from medicine and warehousing those deemed incurable in nursing homes rose, further sequestering the dying from the living (Risse & Balboni, 2012).

Aries (1982) called this Western social trend the "Invisible Death." In effect, death, and its companion bereavement, are cloaked, shunned, isolated, sanitized, euphemized, and swept from our daily life and view (Aries, 1982). From a historical perspective, this alteration in where and how people die is a relatively new phenomenon. Representative of our zealous faith in science, this development also signifies a decline in human consciousness, which transforms the ordinary into something alien. The first hospice facility in the United States opened its doors in the thick of this trend, in 1974, on the heels of other social movements. As an alternative medical entity, hospice represents a humanistic counter-culture to biomedicine and the "bad" hospital death, returning death back "home".

Making Space for Dying

Nearly every day in my hospital-based clinical practice, I am made poignantly aware of the needs of terminally ill individuals and their loved ones for more, better, and accessible end-of-life care, care setting choices, and care systems. Patients deemed no longer hospital "appropriate," falling outside the borders of medical cure and disease management, and those who are unable to safely remain in their own residence, yet prefer not to die in an institutional setting, are left in a quandary. Most communities have sparse, if any, alternatives. Through my personal and professional life, the organization Circle of Friends for the Dying (CFD) I recently co-founded, and with this dissertation, I endeavor to shorten this gap of unmet needs by "making space”—and, literally, making home—for the ineffable phenomena of dying. An earlier, unpublished investigation, *Dreaming Out Loud: Initiating Plans for a Community-based Home for the Dying* (Lark, 2011), serves as a foundation for this study. It included on-site visits, interviews, and focus group discussions, whereby I begin to share my vision of a “good place to die” with others in my community (see Appendix A for map of past and current site visits and Appendix B for comparison of the hospice residence and home for the dying models).

Americans are already steeped in a public health and end-of-life (EOL) care crisis (Byock, 2012; Meier, Isaacs, & Hughes, 2010). Without significant public discourse and systemic change in how we conceptualize and deliver care, for the living and the dying, rapidly changing demographics toward a top-heavy senior population will result in a full-blown “social catastrophe” (Byock, 2012, p. 5). A stark imbalance between those in need of care and those positioned to care will result in a caregiver crisis. High cost will drive the responsibility of care into the hands of unprepared communities.

A significant underlying problem is our pervasive culture of denial (Becker, 1973). As Byock (2012), a physician-leader in palliative care, reckoned, Americans have never seriously “grappled with the fundamental fact of our mortality” (p. 2). Transforming how we care for the dying will require transforming our relationship to death (Wright, 2003). We can begin to normalize death by re-membering and re-storing the place of dying within communities. Awareness and exposure to dying can be gained through sharing stories, engaging in public discussion, training of lay-caregivers, and the development of community-based care settings. In these ways, we can help to improve quality of care and quality of life for the dying, stimulate creative ways of caring, and perhaps reduce death anxiety.

“Making space for dying” is about opening our minds, our hearts, our conversations, and our communities to the experience of dying. Space or place-making means stretching our inner and outer boundaries. This involves exploring a constellation of sociocultural, psychological, and existential dimensions which shape how and where we die, and who provides care for the dying. We can “make space” through modifications in our interpersonal relational space, and by “advocat[ing for] adjustments to the geography of the ‘normal’ world” (Stanley, 2004, p. 361). In this way, we soften borders and bridge gaps to “welcome home” whoever has been made to feel unwelcome (Stanley, 2004). Implicit in the notion of space and place-making is learning to embrace suffering, loss, and death inherent to being human. In essence, making space for dying means, as Fabian (1973) instructs, “striv[ing] toward a realistic consciousness of death—ours” (p. 198). Through this process of reshaping ourselves, we can expand the space we call life.

Place: The Missing Link

Hospice is not a place. Rather it is a philosophy of care dedicated to the alleviation of pain and suffering and the optimization of quality of life for terminally ill persons. Theoretically, hospice care in America is a nomadic entity traveling to multiple sites, including private residences; adapted hospital beds or hospital-based hospice units; and contracted nursing homes. Aside from sporadic outcroppings of freestanding community-based end-of-life residences (CBEOLRs), hospice lacks a visible, recognizable, and distinct home of its own in the social topography (Worpole, 2010). M. Brown (2003) conceptualizes hospice as a holistic, triangular model consisting of philosophy, policy, and place. Moore, Carter, Hunt, and Sheikh (2013) insist hospice care always be contextualized as hospice-in-place. Thus, place is the missing anchor and link in the hospice care “package.”

According to Kammen (2008), the word “hospice,” first used in 1842, connotes both a safe physical space and a quality of relationship—a safe harbor and a sacred, human-to-human, space. Derived from the Latin, *hospis,* it refers to an interpersonal interstice, a “place of interchange between host and guest” (Kammen, 2008, p. 3). This is reminiscent of the traditional meaning of the word hospital, from *hospitalitas,* signifying a “gift-relationship” (Risse & Balboni, 2012, p. 328). As a distinctly relational practice (Halifax, 2009), hospice opens up space and possibilities for what it means to care for another person, expanding medicalized notions of care (Manzo, 2003). Relationship is understood as the matrix for meaningful “engagement with the things that matter” (Gadamer, 1993, p. 144), whereby humanness is galvanized. At its finest, caregiving becomes “an occasion when people discover what each can be in relationship with the other” (Frank, 2004, p. 4). In retrospect, I realize this was Mwezi’s invitation.

From its original inception, Cicely Saunders, considered the mother of the modern hospice movement, envisioned St. Christopher’s (SC), the first modern hospice facility, as *more* than a place (D. Clark, 1998). Her broader thrust was the origination of a movement (D. Clark, 1998). Opened in 1967, in London, SC was conceived of as a place second-best to one’s own home, if circumstances did not allow a person to remain there. This innovative model was intended to provide the best in clinical care without sacrificing the most vital human needs for comfort, kindness, and respect (Shur Bilchik, 1999). Unlike the care settings in this study, SC was designed as a hybrid model—in-between a home and a hospital—for those with terminal and chronic illness, the latter to be discharged to their primary residence, some to return later (Special Correspondent, 1967).

The Hidden and the Between

American researchers and clinicians have been reluctant to delve into the non-physical, more nuanced realms of the human experience of dying less readily understood or amenable to scientific measurement (Arnold, 2011). Competency in the existential domain has gained recognition as critical only recently, particularly for professionals engaged in death-related work (Chi Ho Chan & Fong Tin, 2012). Decades prior, Saunders (1998a) identified clinician awareness and coping with one's own existential anxiety as a hospice precept, requisite for providing quality end-of-life care. The literature suggests existential anxiety, embedded in the denial of death (Becker, 1973) and ubiquitous across modern cultures, may be at the root of difficulty in providing quality care to the dying (Boston, Bruce, & Schreiber, 2011; C. Thomas, Reeve, Bingley, Brown, Payne, & Lynch, 2009). The dying person's negotiation of existential suffering hinges, at least in part, upon their caregiver's capacity to recognize the source of distress and to be available and open to the person's meanings (Friberg & Ohlen, 2007), requiring considerable awareness and skill. In this way, health care providers have the capacity to ease or exacerbate existential suffering (Friberg & Ohlen, 2007). My scholarly endeavors are, among many things, a personal inquiry to deepen awareness of my own existential anxiety.

The existentialists argued that the liminal life is indeed the ordinary life; therefore, the "liminal view has to be included in any satisfactory account of the experience of life" (Little, Jordens, Paul, Montgomery, and Philipson, 1998, p. 1491). Liminality is also a relevant framework for understanding the lived experience of life-threatening illness (Little et al., 1998). The word *liminal*, meaning "limit," translates from the Latin (*limin, limen)* as "threshold" or "margin" (Foster & Little, 1987, p. 94). Van Gennep (1960) introduced the term "rites of passage" to describe cross-cultural categories and patterns of ritual behavior, also described as "life crisis ceremonies" (p. vii). Consisting of a three-phase structure, the rites constitute the "constants of social life" (p. 189). Sandwiched between an initial stage of separation and a final stage of incorporation, with the term *liminaire* applied to the middle, transitional phase, together marking the completion of a cycle of social metamorphosis (van Gennep, 1960). To be a being-in-transition, is to be in a chrysalis-like state of suspended identity and social status (V. Turner, 1987). As described by V. Turner (1987), van Gennep's successor, the "initiate" is neither one's former or transformed self (p. 6), but rather a structureless inter-being:

> The essential feature…is that the neophytes are neither living nor dead…and both living and dead…Their condition is one of ambiguity and paradox….Liminality may perhaps be regarded as the…realm of pure possibility….Transitional beings are…neither one thing nor another, or may be both; or neither here nor there; or may even be nowhere (in terms of any recognized cultural topography), and are at the very least "betwixt and between" all the recognized fixed points in space–time of structural classification. (p. 7)

This is an apropos description of the lived experience of the terminally ill patient or dying person.

Importantly, van Gennep (1960) understood the transitional phase as both "symbolic and spatial," suggesting a ritual space is essentially a holding environment (Winnicott, 1965, 1980) for the initiate as s/he "wavers between two worlds" (van Gennep, 1960, p. 18). Based on these observations, he surmised, the nature of human life and relationship is "to separate and to be reunited, to change form and condition" (p. 189). Thus, van Gennep viewed periods of social separation, enacted through spatial separation, including "change of residence," as a normative means for symbolically demarcating transition (p. 192). Places designed for dying are such liminal spaces, within which the border between life and death is crossed (Froggatt, 1997).

Care Setting and Care Culture

While health care ethnographers observe care setting from a sociological or anthropological perspective (Barnard, Towers, Boston, & Lambrinidou, 2000; Mattingly, 2010), the route taken by health care geographers is rooted in an existential perspective (Moore et al., 2013). According to Seamon and Sowers (2009), existential geography, which emerged in the 1970s, “insist[s] human experience, awareness, and meaning must be incorporated into any study of peoples’ relationship with space, place, and environment” (p. 666). Informed by Heidegger (1962), geographers recognize our fundamental not-at-home-ness in the world (p. 188), hence our need for human sheltering (Moore et al., 2013; Sifton, 2000) and for physical shelters that evoke a sense of home and everydayness (Svenaeus, 2001). This basic sense of un-ease or “homesickness,” kept in check in times of health, is unleashed when confronted with life-threatening and terminal illness (Svenaeus, 2001, p. 104).

Place is “culture manifest” (Poland, Lehoux, Holmes, & Andrews, 2005, p. 172). Care setting is a complex interplay of culture. How persons conceptualize their EOL experience is influenced and constrained by the care setting culture, including the meanings attributed to suffering and death by others in the environment (C. Thomas et al., 2009). I will use the term “care culture” to amplify the relevance of place in practice and for highlighting the cultural underpinnings of everyday social enactments within care settings. The notion of care culture is referred to sporadically in the literature as culture of place (Poland et al., 2005), atmosphere (Edvardsson, 2005; Rasmussen, 1999; Rasmussen & Edvardsson, 2007), place-based model (Briller & Calkins, 2000), and people-in-place model (Moore et al., 2013).

Culture of place locates care within an interlocking grid comprised of power, technology, culture, and place (Poland et al., 2005). Influenced by Rasmussen (1999), Edvardsson (2005) chose the word atmosphere to bridge two interlinked, reciprocal dimensions: environment and people-in-environment. Suggesting a link between quality of care, quality of life, and qualities of a care setting, based on their small pilot study, Briller and Calkins' (2000), place-based model of care:

> uses the concept of place…as the organizing principle for understanding multiple dimensions of a setting including organizational, social, operational, and physical elements…. Place provides…conceptual clarity for how different sets of care practices, environmental features, and interpersonal interactions…[are] structured. (pp. 17-18)

Another component of care culture is care philosophy. A care setting regarded as "best" is one with a comprehensive and consistent care philosophy (Briller & Calkins, 2000; Realdania Fund, 2006) that is complementary to its atmosphere (Edvardsson, 2005). Rasmussen, Jansson, and Norberg (2000) indicate a good atmosphere and good care are inseparable in the perception of hospice patients.

Place implies a peopled or communal enterprise (Moore et al., 2013). In a people-in-place model, relational dynamics are "always emplaced" (Moore et al, 2013, p. 155). Similarly, a person-action-environment framework provides a holistic sociocultural perspective for understanding human action and interaction as "situated" within place (Faber, de Castell, & Bryson, 2003, p. 143). Place is the stage upon which actors make meaning through action, without which action is rendered meaningless (Moore et al., 2013). Care culture provides the script. Thus a place-story—comparable to portraiture, can reveal everyday social processes and care practices at play, serving as a tool for comparing and assessing care models (Weber, 2000). Understanding form (design) and function (operations) of a place can lead to actualizing better, more inclusive places (Seamon & Sowers, 2009).

Place or care environment, another dimension deemed elusive by researchers and clinicians, is "possibly the least explored and understood" dimension in end-of-life care (Rasmussen & Edvardsson, 2007, p. 120). Adapting a place-sensitive orientation represents a paradigm shift to one that is "more qualitative, postmodern and 'postmedical,'" hence more spacious and capable of holding diverse and divergent views from multiple stakeholders (Poland et al., 2005, p. 172). It re-positions place, invariably obscured in the background, to the forefront for re-examining how the human experience of illness (Poland et al., 2005; Rasmussen, 1999) and death are emplaced (Moore et al., 2013; Rasmussen & Edvardsson, 2007). Promoting a restoration of the humanities—and the human—in medicine, physician Rita Charon (2010) affirms the significance of this re-orientation to EOL care:

> The entire biomedical enterprise seems obsessively focused on time. Adding three weeks to a cancer patient's lifespan constitutes success. Maybe a shift to a commitment to space and all it entails will challenge this hegemony and madness and will bring some element of meaning and beauty back into the care of the seriously ill.
>
> So think, now, of the magnitude of the question of where is my home when I am dying….We all owe attention to these spaces as…we consider how best to care for the dying….[For w]herever persons arrive at their last days constitutes their final and perhaps, most urgently needed home. (n.p.)

Returning Death Back Home: Communal Solutions

An essential task to improve quality of EOL care is to recast care of the dying as a human rather than medical enterprise, invoking communal rather than medical solutions (Economist Intelligence Unit, 2010). To this end, Byock (1997) insists systemic barriers in EOL care need a holistic, grassroots approach to change—or what I conceive of as a resurgence of hospice's grassroots origin. Byock (1997) identifies the collective imagination, especially summoned through shared stories, as the necessary stimulus to action: "Only imagination, working on the level of shared values and expectations, has the power to effect the required transformation in end-of-life care" (p. 247). Community and public awareness and education are also vital change ingredients, enabling a transfer of power from macro to local levels and from professional caregivers in institutional settings back to families and volunteer caregivers in community settings (Byock, 1997, 2012). Breines (1989) defines community as:

> A network of relationships more direct, more total and more personal than the formal, abstract and instrumental relationships characterizing state and society….The desire for connectedness, meaningful personal relationships and direct participation and control over…social institutions on the basis of needs of the individual and community takes on radical meaning. (pp. 6-7)

In these ways, "the engaged audience becomes a community of learners, hopefully better prepared to think about and act upon similar episodes in their own lives," and in the lives of their neighbors (Sharf & Vanderford, 2009, p. 28).

Research Purpose, Questions, and Gaps in the Literature

The purpose of this dissertation is to describe the everyday lived experience of dying and the care culture within community-based end-of-life residences, and to do so in an artful and compelling manner to engage a diverse audience. To this end, my research questions are: What is the lived experience of dying? What is the nature of a good place to die? How do we live with dying?

This study builds on a small body of research focusing on the meaning of home and the centrality of a home-like environment across various health care milieus (Calkins & Marsden, 2000; Edvardsson, 2005; Manzo, 2003). However, few studies focus on these themes exclusively in the context of the end-of-life care setting (Moore et al., 2013; Rasmussen & Edvardsson, 2007; Rasmussen et al., 2000). My research helps to fill a gap in understanding care culture in the freestanding community-based end-of-life residence (CBEOLR), a care setting genre rarely examined in the literature. While the notion of a good death, promoted by the hospice movement, has a strong presence in the literature, this study develops the notion of a good place to die. In addition, this study introduces the 2-bed Home for the Dying, a model unique to New York State, though potentially adaptable. Lastly, building on the literature on liminality (Blows, Bird, Seymour, & Cox, 2012; Little et al., 1998; McKenzie & Crouch, 2004, 2006; Thompson, 2007) and informed by my clinical practice, this study specifically highlights the terminal stage of cancer and introduces the concept terminal liminality. Addressing these gaps will contribute toward understanding the lived experience of dying and the possibility of a more holistic place-based, dying person-in-place, and peopled community-in-place-centered hospice practice, fulfilling a need in communities.

Overview of Methodology

Qualitative methodologies serve to shed light on the human experience of dying for which there is little known (Ryan, 2005) and that may not be easy to know (Kuhl, 1999). Four conditions are necessary for determining the quality of text: 1) orientation toward a specific phenomenology, 2) strength (i.e., "perceptive, insightful and discerning"), 3) richness (detail, nuance); and, 4) depth (layers of meaning and mystery) (Kuhl, 1999, p. 57). Kuhl asserts phenomenological narratives fit with palliative and hospice care research and practice which necessitate understanding dying from the inside, as only the dying person can know it. Making the case for a narrative-based ethnographic approach, Ellis (2008) insists that homogenized data, obtained from questionnaires or even extracted from interviews and thereby stripped of context, is only relevant if "turned back into stories" which accurately reflect and are meaningful to patients' lives: "Staying with the stories…keep[s] us closer to the questions, 'what should we do?' and 'how should we live?'" (p. 105). This points to Husserl's (2010) decree: back to the things themselves for directing attention back to the stories themselves*,* unimpeded by theoretical knowledge and interpretations (cited in Svenaeus, 2001). This view appreciates patients as being the experts of their own experience.

Qualitative ways of knowing, centered on narratives, have social and political implications. They serve to heighten the postmodern recognition of disease, suffering, and death as social constructs (Boston et al., 2011; Kleinman, 1988) to be probed and pierced rather than realities to be accepted. In effect, narratives effectively demonstrate that reality is no more than a set of conditioned assumptions (Williams, 2004). “Medical hegemony,” Payne and Turner (2008) argue, “fails to acknowledge the value of diversity and the potential enrichment of our understanding derived from different disciplinary and methodological perspectives” (p. 337). To do so poses a threat to positivism’s “privileged” association with medical science as the “gold-standard” for research (Payne & Turner, 2008, p. 337). Despite the wrench of convention, by the late 1990s, qualitative research emerged as the “methodology of choice to better understand subjective experience relating to meanings, patterns, and relationships” (Boston et al., 2011, p. 609) of individuals living with life-threatening and advanced illness (Mount, Boston, & Cohen, 2007; Polkinghorne, 1988).

The methodology chapter elucidates my rationale for choosing portraiture (Lawrence-Lightfoot & Davis, 1997) and arts-based research (ABR) for achieving the objectives above. It details additional criteria to ascertain best methodological fit for my research topic, purpose, questions, and voice. As a style of social inquiry, Lawrence-Lightfoot and Davis (1997) conceive portraiture as an aesthetic science, whereby the researcher, as artist, skillfully crafts impressionistic narratives or portraits. Portraitists are like alchemists; they work to convert raw data into gold, conveying essences rather than likenesses of human and organizational phenomena (Lawrence-Lightfoot & Davis, 1997). Like a painting or a photograph, portraits make the lives of people facing dying and the care culture within the end-of-life care setting palpable.

Voice—my personal style and means of expression—is a vehicle for transmitting my particular ways of learning, being in the world, and connecting with others as an artist-scholar-practitioner. Portraiture and ABR mesh with my identification as a social change artist, a term I resonate with rather than the conventional term leader. Cole and Knowles (2008) describe a confluence of three elements that endow the artist-researcher with good methodological fit. These are: 1) the phenomena under investigation, 2) the arts-medium(s) utilized and, 3) artistic skill. I believe these approaches, especially the incorporation of poetry and collage, authenticate and give sustenance to my voice. They are appropriate instruments of ineffable experience.

Behar (1996) notes, “Writing about death can be an especially powerful way to approach reflexivity” (p. 84). What’s more, she claims, how one writes about death matters. We need research tools that can deftly infiltrate guardrails of resistance, to skillfully provoke laypersons (Barone & Eisner, 2012) and strategically jolt scholars (and clinicians) from their mutual comfort zones (Behar, 1996). In this manner, audience members can become co-participants, permitting socially constructed sanctions between self and Other—especially dying Other—to relax, at least temporarily (Behar, 1996). I regard portraiture and ABR as such tools, mediating the border between what can and cannot be articulated.

Unconventional, poetic, and non-verbal presentations of data remind us of the limitations of language, especially under conditions of pain and suffering (Frank, 1998; Kirmayer, 2000). Portraiture’s “painted” prose (Lawrence-Lightfoot & Davis, 1997, p. 4) and allowance for adaptive renderings of data in poetry and collage were chosen for their rich capacities. Foremost in my mind, these include: 1) to illuminate our fundamental aesthetic nature (S. Brown & Dissanayake, 2009); 2) to render more immediate, intimate, nuanced, and holistic representations of lived experience (Borrof, 1993) to make and communicate meaning; 4) to captivate and move a diverse audience toward reflection; and 5) to enlist social action (Barone & Eisner, 2012). In these ways, portraiture and ABR invite audiences to move closer to the subject at hand (especially useful when presenting a topic preconceived as unpleasant).

Furthermore, as a methodology that recognizes the sacredness, interdependence, and co-creative potential of relationship (Lawrence-Lightfoot & Davis, 1997), portraiture matches my personal and professional values. Attention to goodness, a noteworthy and refreshing core tenet of portraiture (Lawrence-Lightfoot & Davis, 1997), concurs with social work's strengths-based code of ethics and my quest for good places to die. Moreover, the ideological frameworks of ABR and portraiture correspond with the feminist (Westmarland, 2001) epistemology I identify with, concerning knowledge production, contextualization of phenomena, and the obligation of the researcher to positively affect real lives.

Chapter Summaries

A review of the literature, in the following chapter, explores six interwoven domains. How and where we die in America provides an overview of how and where we die, thus situating this study within a particular place and time for elucidating the current and projected state of affairs concerning my topic. The sociocultural construction of illness and dying explores culture as the primary mechanism for shaping perception and structuring our inner and social worlds. Illness and end-of-life narratives, examines narrative as a primary vehicle for social meaning construction. Next discussed is the role of meaning-making as a fundamental way of coping with the unknown. The hidden dimensions: existential suffering and liminality sheds light on the largely unseen existential dimension of human experience and examines liminality as a framework for understanding the lived experience of illness. The last domain, making space for dying, returns to the discussion initiated here on the roles of care setting and care culture in EOL care. Together, these domains offer windows into the subjective and collective experience of living with dying. The methodology chapter discusses portraiture and arts-based research in depth, with a focus on poetry and collage, identifying key characteristics of each approach to data collection and aesthetic presentation. Here, I also explain research design, scope and limitations of this study, and learning from a pilot portrait, *Illuminations: Portrait of Diana,* in preparation for this research. The latter is one of four portraits constituting my research findings—the main course of this dissertation. Person-centered portraits include a collage, adding a visual layer to enrich the poetic text, in addition to photographs; place-based portraits contain photos, to enhance the aesthetic narrative. In a reflective, auto-ethnographic piece, designed as a prelude to my discussion chapter, I integrate salient personal experiences and images from dreams. I also introduce collage work from which the metaphor of nest/nesting and the dual framework for my discussion, nesting in being and nesting in place, emerges. In the discussion chapter, I elaborate on the portraits in response to my research questions and emergent themes, drawing on relevant previous research and clinical experience in relationship to the literature, and highlight key points of my learning. I conclude with implications for leading change in end-of-life care . Here I encapsulate current issues and anticipate future trends concerning my topic, highlighting Circle of Friends for the Dying, a not-for-profit organization established in 2012, birthed from my earlier research, whose mission is to establish and maintain a Home for the Dying in my own community—a goal preceding, and continuing throughout and beyond, the life of this dissertation. I also provide recommendations to the novice end-of-life researcher.

These pages represent my “scholarly home” (C. Kenny, personal communication, January, 4, 2013). I welcome the reader inside.

Chapter II: Literature Review

To orient the reader, I will briefly map out this chapter. I will cover six interwoven domains relevant to my study: 1) How and where we die: an overview of death in America; 2) the sociocultural construction of illness and dying; 3) illness and end-of-life narratives; 4) the role of meaning–making; 5) the hidden dimensions: existential suffering and liminality; and 6) making space for dying: the role of care-setting and care-culture. The ordering is intentional. The outer, first and last, sections focus on care setting, reflecting the theme and central function of place as a holding environment. The middle sections, focusing on the inner dimensions of experience, draw solely or primarily on the narratives of terminally ill and dying individuals to illustrate the lived contexts in which perceptions, meanings, behaviors, and choices are shaped and enacted (C. Thomas et al., 2009).

How and Where We Die: An Overview of Death in America

Death is a constant. Historically, aversion to death and associations of death with morality and punishment, have also been consistent (Brendel, 2005; Meier et al., 2010). However, patterns of dying and death as a social process change (Reith & Payne, 2009). Contemporary disease outcomes, related to advances in public health and medicine, have impacted longevity and mortality rates, re-shaping when we die and cause of death. Only a century ago, acute infections resulted in a quick death, with children being the most frequent to succumb. Also largely forgotten, a fledgling medical profession was struggling for social and economic survival (Starr, 1982). In contrast, modern death is most often the result of a chronic disease associated with old age, with periods of management and decline often spanning many years, sometimes decades.

As life expectancy in the United States has steadily increased, expectations of longevity have become normalized. Death, especially untimely ones, is perceived as deviant and unjust. As childbirth-related, childhood, and early adult deaths have declined, death has advanced further along an expanded life cycle, and farther away from everyday life. Changes in cultural values and viewpoints are accompanied by changes in how society manages illness, suffering, and death. Scientific explanations espoused by the medical establishment have largely displaced religious and moral explanations. Physicians have become the priests of American society, defining, regulating, and ministering—hence, medicalizing—these social processes. In a parallel process, funeral and bereavement rituals have also become more secularized (Reith & Payne, 2009), and more private.

In the last century, medical advances have dramatically extended the average American lifespan from 47 to nearly 78 years, significantly changing the way people die (Kiernan, 2010; Miniño, Xu, Kochanek, & Tejada-Vera, 2009). We live longer lives and die slower, (Kiernan, 2010) considerably 'harder,' deaths (Byock, 2012). The shadow side of medical progress has brought patients and families unforeseen hardships and needless suffering. Moreover, "for the first time in human history, we can anticipate our mortality" (Kiernan, 2010, p. 164). Yet, despite the gift of more time, most individuals, families, and society-at-large remain unprepared for death.

We live in rapidly changing times. Projections of changing demographics will result in a larger and sicker cohort of chronically ill and disabled adults, increased healthcare costs, and a shortage of lay caregivers (Economic Intelligence Unit, 2010). By the year 2030, the proportion of seniors will increase to 25%, a jump from 16% in 1999 (Jennings, Ryndes, D'Onofrio, & Baily, 2003), while the number of adults over 85 is expected to double (Center to Advance

Palliative Care, 2009). By 2050, 1 in 5 Americans are expected to be over 65 (Economic Intelligence Unit, 2010). Feeding the anticipated elder-boom is a ballooning cohort of aging Baby Boomers. These Americans, born between 1946 and 1964, constitute 26% of the total U.S. population (Cohn & Taylor, 2010). Now facing the challenges and bureaucratic obstacles of caring for their own aging and dying parents, Boomers are anticipated to demand more humanistic and affordable alternatives for themselves. Pioneers in palliative care agree: America is unprepared to meet these historically unprecedented changes (Byock, 2012; Meier et al., 2010).

Also on the rise, in 2009, nearly 66 million Americans, 29% of the U.S. population, were lay caregivers to a disabled, ill, or aged person; most were women (The National Alliance for Caregiving & AARP, 2009). Another 400,000 Americans are hospice volunteers—a remnant of the origins of the hospice movement in America, seeded by volunteers—fulfilling the 5% volunteer quota hospice agencies are mandated to meet to qualify for Medicare and Medicaid reimbursement (Hospice Foundation of America, 2013). Gravely deficient is end-of-life education, support, and respite for family caregivers.

Leaders in health and end-of-life care espouse hospice and palliative medical specialties are an essential part of the solution, providing significant social as well as economic benefits. Currently, just 10% of patients, representing the most seriously ill segment of the population, accounts for two-thirds of national health care spending (Meier et al., 2010). In 2010, Medicare enrollment numbers climbed toward 50 million, with costs exceeding $500 billion (Center to Advance Palliative Care, 2009). One quarter of Medicare spending covers costly and futile treatment for people in their final year of life (Smith & Long, 2012).

Inappropriate Spaces for the Dying

According to Meier et al. (2010), “battling death is the raison d’être of modern medicine,” with physicians as leaders in combat (p. 13). Hospitals are the battleground; they are also symbols of public safety. At best, the hospital is a place of healing, with doctors serving as compassionate agents in the face of human limitations and suffering. At worst, it is a fortress of denial, whereby physician-technicians regard death as an “aberration to be engineered out of existence” (Little et al., 1998, p. 1492). Declaring war on cancer, and disease in general, promotes scientific progress and intensifies a focus on cure while withdrawing attention to care*,* especially to those deemed uncurable (Reith & Payne, 2009). Thus medical science instills the impression that death can actually be prevented, as opposed to postponed (Reith & Payne, 2009). While reliance on physicians may temporarily anesthetize the realities of living with serious illness and death, it tends to breed fear and denial (Kubler-Ross as cited in Brendel, 2005). These emotions promote dependence and compliance with medical authority, signifying a “surrender of private judgment,” compromising personal medical decision-making (Starr, 1982, p. 10). And so it is a longer—not necessarily better—life for which the profession has garnered cultural status and ample reward (Starr, 1982).

Table 2.1

How and Where Most Americans Die

- more than 70% die in an institutional facility;
- depending on region, 50 to 60% die in a hospital;
- half of those hospitalized die in moderate to severe pain;
- 38% spend 10 or more days in an intensive care unit (ICU) (where the average baseline cost per day is $2000) or on a ventilator;
- nearly 45% of ICU stays end with family's deciding to withdraw or withhold life support;
- most do not have advanced directives; for those who do, these documents are routinely ignored and overridden by health care professionals (HCPs);
- over 30% of families exhaust most or all of their savings on hospital care, making medical bills the leading cause of bankruptcy;
- nursing homes (NHs) are the primary residence for 20% of the population; most (76%) will die there, constituting 25% of the total deaths;
- 75% of NH occupants are women; 50% are 85 or older; only 1 to 5% are hospice enrolled;
- 1/3 to half of NH occupants die within the first year;
- many are transferred to the hospital as the final place of death or die en route; and, last but not least;
- 35,000 people across the nation are being medically-maintained in a persistent vegetative state.

Note. Source of data: Bern-Klug & Ellis, 2004; Kiernan, 2010; Meier et al., 2010.

Hospitals and nursing homes. Hospitals and nursing homes are ill-suited to the needs of those approaching the end of life, as illustrated in Table 2.1. Nor were they designed with that function in mind. Promoting cure—the province of Western biomedicine, hospitals were designed to provide routinized aggressive, critical, curative, and restorative care (Kiernan, 2010). Nursing homes were designed primarily for short-term skilled rehabilitation or for long-term maintenance-type care aimed at the elderly, chronically-ill, and disabled (Bern-Klug & Ellis, 2004). Hospitals and nursing homes are the wrong kind of places for the terminally ill, delivering the wrong kind of care, resulting in what most Americans view as the wrong kind of death. They provide the wrong care culture. Hospital care, which became the norm in the 1950s (Aries, 1982), is well suited to the sudden, critical-response-related, death from swift-killing heart disease and stroke, or serious injury. Nevertheless, it is ill suited for the incremental, chronic disease-related death, which is on the rise and expected to increase. The focus of care in the hospital setting is well suited for the critically ill person, expected to return to a functional life, rather than the terminally ill person, expected to continue on a trajectory of decline until death (Kiernan, 2010). In effect, high tech care-cultures, which promote life prolongation, dislocate the dying person and further confound the murky boundary between life and death (Callahan, 2012). Nursing homes are similarly ill suited for the dying and their families. These homes (surely a euphemism) are strongly associated with suboptimal or negligent care largely due to high resident to staff ratios, high staff turn-over, and lack of staff training in end-of-life care (Bern-Klug & Ellis, 2004). For these reasons, most patients and families are heavily vested in preventing or prolonging nursing home placement. Placement is by default—a last resort—due to the inability to maintain independent living, and insufficient or exhausted resources.

A report spanning 50 academic medical centers across the nation, *Quality End of Life Cancer Care for Medicare Beneficiaries,* concludes: how people die in America is a matter of place (where one lives and receives care) and organizational care practice, rather than patient preference (Dartmouth Atlas Working Group, 2010). The care that elderly cancer patients with a terminal prognosis receive is not the care they say they want:

- most patients preferred doctor-patient ‘partnerships’ and honest conversations regarding prognosis and treatment options, including expected efficacy of treatment and impact on quality of life (QOL);
- instead, a polarized discourse prevailed, pitting cure against care, quantity of life against quality, hospital care (*hope*) against hospice care (*giving up* hope), and life against death;
- the above resulted in uninformed decisions, underutilization of comfort care, and needless suffering;

- an institutional culture and pattern of practice, favoring the latest aggressive treatment and technology, prevailed;
- across regions and medical centers, over 1/3 of all patients in the study died in hospitals and ICU’s; in most cases, care practice was not aligned with patient preferences for less aggressive care;
- amongst patients who indicated a preference to die at home, more than half died in the hospital; and,
- less than 50% of patients received hospice, some with referrals routinely close to death, virtually cancelling potential benefits to patients and their loved ones (Dartmouth Atlas Working Group, 2010).

Hospice in America

The American hospice movement migrated from its starting point in London to Connecticut, in 1974, under the leadership of Florence Wald, Cicely Saunders’ protégé. Noteworthy, prior to the professionalization and bureaucratization of hospice services, volunteers were the attributed founders and disseminators of the early grassroots hospice movement across America (National Hospice and Palliative Care Association, 2013). In translating hospice from Saunders’ philosophy (see Table 2.2) to American policy, as a qualified Medicare benefit in 1982, Congress limited the terms of its delivery and accessibility. Two qualifications were instituted, the discontinuation of curative and life-prolonging medical interventions, and a prognosis of six months or less to live. According to attorney Judy Citko (2009), the six-month benchmark, chosen at random, was an agreement predicated on the assumption of a predictable illness trajectory, permitting legislation to be pushed through. These defining parameters are hospice cares confining barriers, placing reluctant physicians as the gatekeepers of hospice referrals. Policy designed to quantify boundaries between chronic and terminal illness, and life and death have resulted in significant underutilization of services and lack of timely referrals, compromising its benefits to patients and families (Hospice, Inc., n.d.; Reith & Payne, 2009).

Table 2.2

Saunders' Principles of Hospice and Palliative Care

Support individuals’ potential “to live until they die”:

- enable a sense of control and independence;
- recognize the patient’s personhood as intrinsically embedded in a social network;
- learn what is meaningful to the patient in order to promote a sense of meaning and completion;
- encourage patient and family awareness of the seriousness of the patient’s condition;
- facilitate realistic end-of-life decisions, tasks, and personal growth in the patient and their significant others; and
- cultivate caregiving skills necessary for discovering one’s own meanings in the face of adversity, and for taking responsibility for awareness of one’s own anxiety in order to be present for others in distress.

Note. Source of data: Saunders, 1998a.

The hospice Medicare provision makes several other flawed assumptions: adult patients and families will opt to forego or discontinue life-sustaining/death-prolonging measures, a criteria for admission; and the terminally ill person has an accessible primary care provider able to manage and sustain care at home under the medical oversight of hospice, though in reality, largely alone.

The most insidious barriers to palliative and hospice care (as well as the use of advance directives to promote patient voice and choice for refusing, limiting, or withdrawing EOL medical interventions) are physician and public unfamiliarity and misconceptions, physician reluctance, and associations of hospice with imminent death (Jennings et al., 2003). While the archaic standard practice of withholding a cancer diagnosis from beginning to end of illness is defunct in America, the withholding of a terminal prognosis persists. These withholding practices “converge to a single major goal: maintenance of hope…. The modal policy is to tell as little as possible [as late as possible] in the most general terms consistent with maintaining cooperation in treatment" (Oken, 1961, p. 1123). For the vast majority of doctors and patients, hospice signals the end of hope.

"Too little, too late," was the crisp analysis made by a professor in social work school, encapsulating Americans' (and American physicians') relationship to hospice and reluctance to utilize services in a timely manner, if at all. In 2011, about 40% of all deaths in the United States occurred under the care of hospice services; however, a trend of shorter length of stay persists, and utilization of the full six-month benefit, at about 11%, remains the exception (National Hospice and Palliative Care Organization, 2012, 2013). The median length of stay continues to hover at approximately 19 days, with death or discharge occurring for about 50% of patients within 14 days, and about 35% within one week (National Hospice and Palliative Care Association, 2013). These numbers have remained largely unchanged for the past several years (National Hospice and Palliative Care Association, 2013).

Timely utilization of hospice services optimizes the social benefit for patients and their kin, along with the economic benefit to society by lowering EOL-related medical costs. Social benefits include: better EOL symptom and pain management resulting in higher quality of life and, sometimes, longer life for patients (Temel et al., 2010); reduced hospital utilization (including emergency and intensive care); less use of futile treatments and life-sustaining interventions; and less traumatic deaths, paired with less complicated bereavement for loved ones. They amount to less suffering.

The wish to die at home. Consistently, 80-90% of Americans say they wish to die in their own home. Yet fewer than 25% do (Byock, 2012). According to the 2013 National Hospice and Palliative Care Association annual report, while most (66%) hospice care in 2012 was provided in the patients primary residence—the place the person calls "home"—only 41.5% was in a private residence (41.5%). The other 24.5% was either in a contracted nursing home (17.2%) or a freestanding hospice residence (7.3%). The remaining 34% of hospice services was inpatient, in a hospital-based hospice unit (27.4%) or acute care hospital unit (6.6%) (National Hospice and Palliative Care Association, 2013, p. 6).

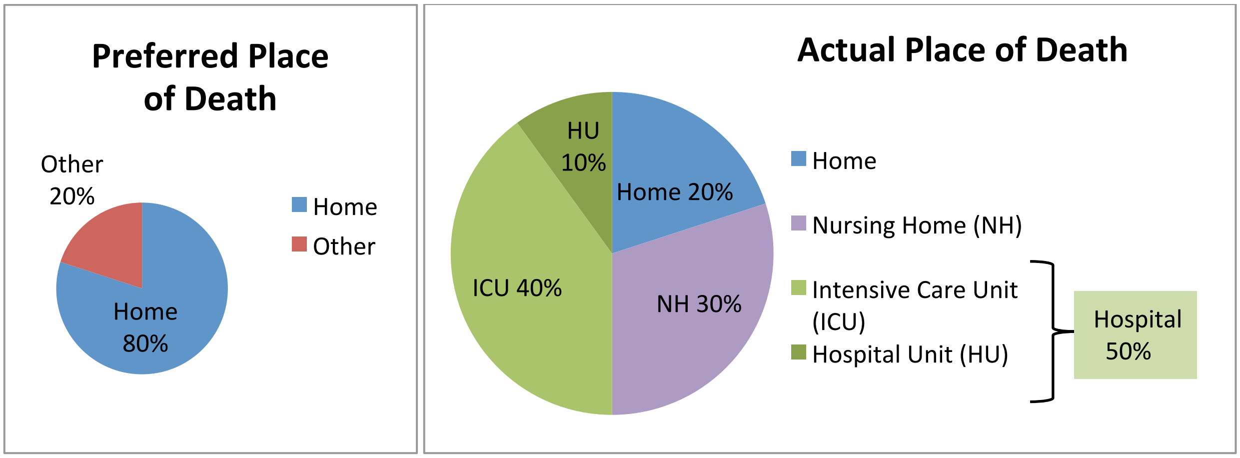


Figure 2.1. Preferred Versus Actual Place of Death in the United States. “Home” refers to a private residence; statistics represent approximations. Source of data: Byock, 2012.

Ideals regarding a home death and the reality of caring for a dying person are often incongruous. The demands of everyday caregiving tasks, often the role of a solitary primary caregiver (PCG), may lead to caregiver burnout and erode the quality of relationship with the dying person. Gravely deficient is end-of-life education, support, and respite for family caregivers. These points are illustrated by Cannuscio (2010) a researcher in the area of family caregiving. After participating in the unskillful and uneasy family caregiving of her dying father in his own home, she ponders: “So how can we reasonably expect families…to manage death at home? I [now] understand why many families couldn’t even try” (p. 2453). Typical of Americans, this family enrolled on hospice too late, after fatigue and desperation set in. Cannuscio (2010) elaborates:

> My mother [the PCG] would have rather spent my father's last days as his friend rather than his primary nurse; he would have valued professional care to calm his tremendous anxiety; and our family would have welcomed death education…We needed more comfort than our family home…could provide. (p. 2453)

Removing barriers to hospice services, developing strategies to enable people to remain in their own homes, creating alternative home-like care settings, and bringing a sense of home and the familiar to institutional facilities are all important for improving end of life care. More difficult to change is our pervasive culture of denial, discussed next. The denial of death, rooted in existential anxiety, may be the underlying culprit explaining the gulf between what Americans say—regarding the wish to die at home—and where they actually die (see Figure 2.1).

The Sociocultural Construction of Illness and Dying

Le soleil ni la mort ne se peuvent regarder en face.
(You cannot stare straight into the face of the sun, or death.)
(F. De La Rochefoucauld, Maxim 26)

The central function of culture: Alleviation of death anxiety.

Heidegger (1962) conceives of human beings as beings-in-the-world and, simultaneously, beings-in-death. We are also beings-in-culture. Culture encompasses the vast ways in which social beings negotiate and engage in social processes, including the inevitable experiences of illness and dying. The experience of dying is shaped by cultural, social, and medical beliefs; the nature of the specific disease process; the culture of care; and the nature of the dying person (McKechnie, MacLeod, & Keeling, 2007). Pickering (2010) defines culture in the context of healthcare as "behavioral and attitudinal norms in addition to systems of meaning [that] shape…behavior, belief, resilience, and consequently pain expression and management" (p. 343). These norms and meanings are transmitted, and operate, unconsciously (Del Rio, 2004).

Moreover, humans are beings-in-denial. Becker (1973) situates our innate death anxiety in the center of all human and cultural activity. Culture, as a complex death-denying "enterprise," serves as a central "line of defense" against this primal anxiety (Becker, 1973, p. xiii), that Law (2006) describes as a seemingly sourceless "inward uneasiness" (p. 140). The chief project of culture is to obscure overt bodily evidence and implicit knowledge pertaining to our mortality, thus mitigating existential anxiety (Little et al., 1998). From a psychological and ontological perspective, culture provides adaptive strategies for living reasonably well while minimizing existential anxiety; it attempts to apply these strategies to dying. As central arms of culture, religion and medicine play a significant role in this effort.

Social constructionism. "Truth" and meaning—"what people understand, believe, and do"—are a history and culture-bound dialectic (Hockey et al., 2010a, p. 2). Influenced by sociologists Berger and Luckman (1966), Sharf and Vanderford (2009) describe social constructionism (SC) as a "symbolically-based tension between commonly accepted knowledge and personal understanding," whereby lived meanings are made subordinate to dominant meanings, and subsumed into "reality" (p. 10). A dynamic interplay between subject/object and perceived/received truths, disseminated through language, is reinforced by way of everyday communication (Sharf & Vanderford, 2009). Applying SC concepts to the health care arena, Mishler (1981) argues, "The world is a meaningful reality…constructed through human interpretative activity," whereby illness is mediated by "cultural values, social norms, and culturally shared rules of interpretation" (p. 141). SC emerged as a way to contest medical meanings of illness and:

> to unpack sources of symbolic usage…[that] people often accept…as natural and inevitable without considering how meanings emerge from contextual and political sources in ways that mold health belief and behaviors, clinical judgments, and organizational routines. (Sharf & Vanderford, 2009, p. 12)

Specific to end-of-life care, a social constructivist perspective "identifies the models, paradigms or classificatory frameworks which operate as organizing principles when human beings encounter death" (Hockey et al., 2010a, p. 2). Indeed, van Gennep's (1960) rites of passage was such a categorizing schema, attempting to outline the markers and borders of human behavior and experience (Hockey et al., 2010a). Dying and death, however, resist such positivist ordering. Human beings and bodies are not predictable:

> It is this gap between the intricacies of the human body….[and] the available knowledge and skills of multiple providers….complicated by factors such as individual differences among stakeholders, organizational beliefs and culture, differences in….diseases and… economics…[that] makes it difficult, if not impossible to plan and standardize the health care interventions processes. (Tan, Wen, & Awad, 2005, pp. 39-40)

This is especially the case when providing care for people living with terminal illness and those nearing death.

The meaning of suffering. The experience of suffering is situated in subjective perception and in the nature of whole persons, which extends beyond the physical domain typically associated with pain, to include psychological, social, and existential origins (Cassell, 1982; Kleinman, 1988). As a signature of human experience, suffering and its associated emotions are embodied expressions, influenced by culture (Seale, 1998). Fear of annihilation lurks in the cracks of suffering and pain; they are symbolically bound up with death, especially when intractable (Morris, 1993). Cassell (1982) makes a subtle through important distinction between suffering and pain: while suffering always accompanies some dimension of pain (i.e., physical, psychosocial, existential, spiritual), pain may not always invoke suffering. He defines suffering as "the state of severe distress associated with events that threaten the intactness of the person" (Cassell, 1982, p. 128). It is a felt assault on personhood (Kleinman, Brodwin, Good, & Good, 1992). It is the recognition of personhood, or the lack thereof, which gives the alleviation of suffering its moral imperative.

Fundamental to a sense of personhood is individuals' meaning attributed to the experience of suffering, which may collide with dominant cultural and medical meanings (Fadiman, 1997). Pain and suffering cannot be neatly packaged into medical jargon nor can they be branded into private pathologies (Kleinman et al., 1992). Rather, they are complex sociosomatic and intersubjective processes acting to "inscribe history and social relations onto the body" (Kleinman et al., 1992, p. 9). Yet the ill and dying body insists on an account of reality and meaning that coheres with its own experience (Kirmayer, 1992).

The undervaluation of personhood, along with subjective experience and meaning, are rooted in Cartesian dualism. The latter causes an "anachronistic division" in perception, separating subject/object, body/mind (Cassell, 1982, p. 128), and living/dying, suggesting, by its very nature, a more insidious "recursive trap" (W. Weber, personal communication, March 20, 2013). This conflict imposed on consciousness, and further reinforced by conventional medical culture (Cassell, 1982), renders communication and understanding pain and suffering inept (Cassell, 1982; Kirmayer, 1992; Kleinman et al., 1992). To some degree, sufferers hurdle this socially-imposed divide through the dual expression of pain using both words and the symbolic language of body symptoms (Kleinman et al., 1992). A language of authority and rationality constricts words and subjective meanings. As a primal language, the eloquence of body symptoms functions as an adaptive mechanism employed to articulate meaning. Kirmayer (1992) eloquently remarks, "Through pain and suffering that foreshadows its own mortality, the body drives us to seek meaning, to take our words as seriously as our deeds" (p. 325). When words fail, the body speaks.

Resilience in the face of suffering is described by Cassel (1982) as an individual's capacity to re-construct meaning, re-direct life energy, and experience transcendence. This coincides with Egnew's (2005) definition of healing as the capacity to transcend suffering. While suffering is associated with a loss of meaning, healing connotes a reconciliation of meaning (Egnew, 2005). Transcendence ushers a renewed sense of continuity and belonging to something "larger and more enduring" (Cassell, 1982, p. 133).

Social death, the dying self, and the dying body. The experience of dying is best understood within a sociocultural context (Faber et al., 2003; McKechnie et al., 2007; Williams, 2004; Wright, 2003). Humans are social creatures and death, as well as care of the dying, is primarily a social enterprise (Aries, 1982; Jennings et al., 2003). This being the case, EOL care requires a comprehensive coordinated care system inclusive of the community at large (Jennings et al., 2003). Recognition of the centrality of relationships and motivation for belonging are prolific in the psychology literature (Prince-Paul, 2008), and represent core ethical tenets (Jennings et al., 2003). Sulmasy (2003) insists end-of-life care justice must reflect the human realm; accordingly, all humans—including dying humans—are innately social and have "radically equal intrinsic worth or dignity" (p. S14). Informed by Sulmasy (2006), Prince-Paul (2008) emphasizes that human beings are, essentially, "beings in relationship" (p. 366). Similarly, Vanderpool (1978) suggests humans are beings in community. Byock (2003) refers to the communal social bond as a "covenant" of mutual reliance, more fundamental and secure than a contract (p. S40). Working against these notions, is the perception of death as a breech—a rupture—in the social contract of the living (Williams, 2004); the dying are therefore transgressors.

From a sociologic and symbolic interactionist framework, the notion of social death conceptualizes dying as social and relational constructs (Williams, 2004). This framework speaks to the social nature of suffering induced by the withdrawal or severing of human contact from those approaching death. The dying self is also a social construction, orchestrated within relational and environmental contexts (Williams, 2004). It is the experience of a changing self on a trajectory of permanent physical and cognitive decline as the person approaches death (Williams, 2004). Dying under conditions of poverty and systemic discrimination, as well as dying young or “off time,” exacerbates social isolation and existential suffering (Williams, 2004). *Sociomas,* a term coined by Abraham (1993), refers to the total, cumulative impact of social-related problems, causing or exacerbating suffering, on health and the experiences of illness and dying.

While many factors mediate the experience of living with terminal illness, fundamentally, it is the immediate day-to-day embodied experience of living with a dying body which most noticeably circumscribes perception of quality of life and of dying (McKechnie et al., 2007). The dying body is the body-self (Kleinman & Kleinman, 1994) threatened by the impending loss of everything. K. Richardson, MacLead, and Kent (2010) describe the “lived bod[il]y” experience of dying persons as one of “contracting worlds” operating within the constraints of “lived spaces” and “lived time” (p. 132). Dying narrows and closes our ways of being in a body and being in the world (K. Richardson et al., 2010).

Situating human experience in human bodies, phenomenologists define embodiment as “The sense of being in a body…[and] how that body occupies its social space” (McKechnie et al., 2007, p. 258). Embodiment materializes and anchors otherwise abstracted dimensions (Hockey et al., 2010a) of a conceptualized self moving through psychological space and time. Scheper-Hughes and Lock (1987) identify three domains of the body—or texts about the body, and how bodies negotiate social worlds, including disembodying systems of knowledge and power (Kirmayer, 1992). These are: 1) phenomenology’s “individual body-self of lived experience”; 2) Douglas’ (1973) “social body of symbolic representation”; and 3) B.S. Turner’s (1984) “body-politic of power, domination, and control” (Kirmayer, 1992, p. 324). Kirmayer (1992) suggests a fourth arena: the body of medical science. The quest of the suffering body, working against cultural processes of “unmaking,” is to find itself a home, reflected and reconstituted in the human realm (Kirmayer, 1992, p. 324). Thus, Kirmayer suggests, a “turn toward the body represents a longing for community, for bodily connection and participation in a habitable world of substance and feeling” (p. 324).

Dying as hard work. Dying as hard work was a repetitive theme found in the EOL literature, related to quality of life. While hard work comes with the territory of a gradual death for anyone living with a chronic or terminal illness, it is exacerbated by psychosocial stressors, including low socioeconomic status (SES) and social/healthcare discrimination, which further diminish QOL. Social ills of racial and ethnic discrimination make both living and dying harder. For dying poor and minority persons, the hard death is often experienced as the continuum and conclusion of a hard life (Williams, 2004).

The hard work of low socioeconomic status. The hard work of dying, intersecting with low SES and discrimination, is illustrated in Williams’ (2004) unique, phenomenological study of mostly female, black, poor, young, separated or divorced, dying persons. This study validates her findings in the literature, which suggest SES is the *most* important determinant of coping with illness, suffering, and death, exacerbating all other psychosocial ills and illness-related factors. The virtual absence of this significant demographic factor from the literature I reviewed may be attributed to the fact that the overwhelming majority of EOL research is based on white, middle-class participants. In fact, in 2012, racial minorities (non-Caucasians) accounted for less than one-fifth of Americans utilizing hospice services; over 80% were Caucasian (National

Hospice and Palliative Care Association, 2013). This is due, in part, to systemic barriers to accessing these services, including the way in which hospice is defined in the United States as an age-qualifying Medicare benefit. It fails to consider the reality of poor minorities who suffer an increased risk of “off-time” terminal illness and death, outside of the expected social order of the dominant group (Williams, 2004). Hence, social death is sometimes associated with premature physical death (Williams, 2004).

Distrust is a more pervasive barrier. Perceptions of trustworthiness toward the healthcare system and its professionals are shaped by cultural perceptions (Blacker & Jordan, 2004) embedded in the context of historical oppression (Del Rio, 2004). The legacy of Tuskegee and other historical incidents of racial bias-influenced medical neglect tinge the collective memory and perceptions of African Americans under the care of predominantly Caucasian physicians. Distrust of physicians is more prevalent amongst African Americans compared to European Americans (Kagawa-Singer & Blackhall, 2001). Moreover, the object of distrust differs. While European Americans may fear too much treatment at the end-of-life, African Americans rightly fear too little (Kagawa-Singer & Blackhall, 2001). Therefore, the idea of opting for comfort measures only—the hospice way, may be reassuring to Caucasians but threatening to African Americans like other racial groups who experience health care disparities (Kagawa-Singer & Blackhall, 2001).

Poverty and racial/ethnic discrimination hinder access to healthcare. Cultural competency, typically prescribed in the literature, will not in itself suffice to address systemic problems attributed to diminished QOL, throughout the life cycle, in poor and racial minority populations. Rather, policies promoting a more equitable society and healthcare justice (i.e., universal access) are necessary to equalize the disproportionately higher probability of middle-age death and shorter lifespan in racial minorities, as compared to Caucasians (Williams, 2004).

Two major themes Williams (2004) identifies are "terminal illness career" and "emotional labor" (p. 31). The former term suggests a permanent, downward-spiraling trend in social status along with an affixed terminal role/identity, eroding one's sense of personhood. The word "career" is apropos to the full-time job of managing terminal illness which overshadows, inevitably displacing, employment and job roles. As death approaches, the person is progressively robbed of roles integral to identity and sense of social worth. This was experienced as particularly destabilizing to an already vulnerable population (Williams, 2004).

The hard work of relinquishment. The hard work of relinquishment, portraying dying as hard work, was an overarching theme in the EOL literature, regardless of SES (Coyle, 2006; Faber et al., 2003). McKechnie et al. (2007) focus on the daily physical labor involved in negotiating progressive loss of bodily function. This "project" includes maintaining a "veneer of wellness" for as long as the ailing body permits and, ultimately, the work of "shedding" a body (p. 256). Thus, the activity of physically managing a dying body is a seeming strategy for curtailing social death and a dying self. Characteristic of the work of dying is living with the day-to-day experience of "protracted uncertainty," for which the only certainty is increased physical decline and death (McKenchnie et al., 2007, p. 258). Coyle (2006) also speaks of the work of negotiating uncertainty and fluid needs within a burdened, bureaucraticized health care system, as patients competed to be recognized and heard.

Four meta-themes, synthesized within the context of relationship, were identified in Coyle's (2006) study of persons with advanced cancer using phenomenology: relationship to the health care system, to a changing self (cf., C. Thomas, et al.'s, 2009, concept of identity), to pain and other symptoms, and to imminent death (cf., Wright's, 2003, concept of relationship to dying). Three sub-themes contributed to the overarching notion that dying with advanced cancer is hard work: maintaining control of the disease, searching for a support system, and struggling to find meaning (Coyle, 2006). In essence, Coyle (2006) suggests hard work is the psychospiritual labor of living with "existential paradox," described as a readiness or desire for death while continuing the struggle to survive (p. 267).

Contesting end-stage illness as a manageable problem. The construct of disease "management" is antithetical to the lived experience of end-stage disease as hard work and hardship, as illustrated by Faber et al.'s (2003) sociocultural multiple case study. Using an ethnographic approach, the researchers effectively portray the permanently transformed bodies, compromised activities, and daily suffering endured by persons living with end-stage renal disease (ESRD). In doing so, the investigators de-construct the self-management (SM) model (N.M. Clark & Zimmerman, 1990) prevalent in conventional health care settings, which construes advanced disease as a "manageable problem" solved through strict compliance to medical protocol (Faber et al., 2003, p. 144). SM operates to medicalize, euphemize, and minimalize the day-to-day burden and suffering of living with advanced illness experienced by patients and their loved ones. Furthermore, it promotes the illusion of autonomy, which belies the reality of persons with fragile bodies who are completely dependent on medical technology and the concerted efforts of professional and familial caregivers for survival. More accurately, the investigators apply the term "work" to all dimensions of patient care, operating conjointly within and outside medical settings, to capture daily life consequential to living with ESRD. The data illustrate the double-speak quality of concepts of manageability and autonomy in regard to persons living with any type of end-stage illness. Rather, always a relative term when applied to human lives, autonomy tends to dwindle in direct correlation to proximity to death. Finally, the study makes explicit the situated (in this case, institutional) context within which social experience, illness, and EOL-related meanings are constructed; what constitutes a medically legitimate concern (Faber et al., 2003) or protocol; and traits of an acceptable death.

The ideas brought forth in this section suggest that attunement to subjective, embodied meanings, including individual and culturally distinct symbolic and linguistic expressions, are central to effective care of suffering individuals (Stella & Schofield, 2010). These lived meanings are the crux of the illness and EOL narrative, discussed in the next section. Additionally, the influence of care setting and care culture, exemplified in the previous segment, will be expounded upon in the final section of this chapter.

Illness and End-of-Life Narratives

We tell ourselves stories in order to live.
(Didion, 1990, p. 11)

Stories are not material to be analyzed; they are relationships to be entered.
(Frank, 1998, p. 200)

Narratives and the production of culture and medical subculture. Like culture, narrative is a fundamental organizing structure central to social life, informing how we live. Narrative also shapes how we die and how we cope with serious illness, suffering, and death (Gelfand, Rapspa, Briller, & Schim, 2005). Culture produces an interlocking grid of narrative templates (Frank, 2010) acting as the legos with which we construct *logos* (meaning) and experience. Homo sapiens are indeed *homo narrans*, meaning we are “narrating being[s]” (Gelfand et al., 2005, p. 4). The word “narrative” (from the Latin, *noscere*) translates as “to know” (Gelfand et al., 2005, p. 3). In addition to offering a way of knowing, Broyard (1992) remarks, “Making narratives…rescues me from the unknown” (p. 21). Stories make the incomprehensible occurrences of life habitable and human (Frank, 2012). Didion’s (1990) epitaph, above, enfolds the universal imperative to tell stories within the mortal flesh of life. It also seems to foreshadow the untimely and unexpected deaths of her husband followed by her daughter (written about in her memoirs), which reminds us: We also tell ourselves stories in order to live with death and dying.

Sharf and Vanderford (2009) identify five functions of narratives in the health care setting: “sense-making, asserting control , transforming identity, warranting decisions, and building community” (p. 10). Narratives distinguish our humanness, recognizing the complexities and idiosyncrasies of our storied lives and deaths as central to our being. End-of-life stories illustrate how illness and dying are fundamentally biographical rather than biological experiences (Barnard et al., 2000). Our lived stories—like our lived spaces—are biographical markers (Charon, 2010), establishing our place in a storied universe. While serious illness acts as a biographical disruptor (Bury, 1982), narrative acts as a bonding agent for salvaging ruptured bodies, identities, and lives. The narrative exchange of meanings between patient and clinician, is a vehicle for patients to retain their human status, as opposed to silence which can threaten “to close down the shop of one’s humanity” (Broyard, 1992, p. 20).

The narrative impulse is a way to negotiate the unexpected. *Peripeteia,* a dramatic element in stories, makes use of the unexpected fateful twists and turns in human lives throughout the life cycle (Bruner, 2002). Broyard (1992) observes, “Always in emergencies we invent narratives….Storytelling seems to be a natural reaction to illness….Stories are antibodies against illness and pain” (p. xiii). Moreover, stories are restorative in the face of traumatic and dehumanizing side effects of medical treatment and practice.

Culture is a tapestry of competing narratives, whereby select texts are endorsed while others are marginalized. Dominant texts can serve either to stabilize or to transform systems. Social stability and psychological security rely on (and are conditioned by) homogenous and repetitious structures. The danger of stories lays in their ability to over-stabilize systems to the point of calcification through propagating a one-dimensional, slanted view (Frank, 2009). Such is the case with the canonical narrative of biomedicine, which can collide with (Fadiman, (1997) and conceal lived narratives that may threaten to impinge upon clinical hope and the myth of medical cure (Mattingly, 2010). Scrutiny of grand narratives, Mattingly (2010) stresses, can serve to expose power structures and to reveal complexity, "demand[ing]" a shift in attention toward the "existential, practical, political, economic, and ethical" quandaries that accompany living with illness (p. 73). Based on drama theory (Burke, 1945), she describes the influence of culturally manufactured scripts on social life:

> As everyday actors, we locate ourselves in unfolding stories that inform our commitments about what is possible and desirable, our narrative anticipations and judgments about how things should and will unfold, and an understanding of the motives and actions of our interlocutors….we enter situations armed with narrative resources that prepare us to find our way in them.
>
> These are not emotionally neutral or merely cognitive cultural schemas…but politically charged dramas that shape the rhythms of activity and the experiences and expectations of participants….They are very often conflict driven, providing anticipatory understanding of who has power and legitimacy to act in certain ways and under what circumstances, who are the keepers of truth, knowledge, and expertise, where risks lie, [and] what is worth taking risks for. (Mattingly, 2010, p. 43)

Moreover, Mattingly (2010) emphasizes, just as culturally received stories are not the only story, subjectivity does operate in a vacuum but within a constellation of contexts. Lives are indeed influenced by cultural scripts and contexts, but these are *not* sole determinants for how we live (Frank, 2004, 2010). Human unpredictability steps in to offer its share of mutability and dramatic flair. Thus, stories, like people and other animate systems, have the capacity to move (Mattingly, 2010) and to breathe (Frank, 2010).

The capacities of stories. Storying has intentionality. It energizes and synergizes narrative. Tellers tailor word and voice to fit their audience. A story is a collage of select words, meanings, and imagery, assembled to work on listeners: to evoke or provoke (Garro & Mattingly, 2000; Paley, 2009). Storying involves crafting. It is the tale (Frank, 1995) or "yarn" one weaves from narrative threads into evocative and evolving character and plot. Familiar elements of drama, including scene, plot, character, and motive, are used to fabricate a story (Mattingly, 2010). These token markers make for a familiar and enticing vernacular that allows others to venture into unfamiliar and anxiety-provoking territory (Sharf & Vanderford, 2009).

Socio-narratology: What stories do. While narratology concerns the study of "how stories are told," socio-narratology, a term coined by Frank (2010), has to do with "what stories do": how they act on people, individually and collectively; how people interact with them; and their intended and unintended consequences (p. 1). Stories mesh with the everyday fabric of social life, shaping our sense of reality and possibility. They are circulate and reinforced through communication and socialization. We breathe in stories and we become, through identification, the stories that we believe in. Throughout our life course, we exchange old stories for new ones that better fit our evolving storied selves (Frank, 2010).

That our choices for stories can lead us to better or worse choices for living—and for dying—implicates their moral capacity, potential danger, and the ethical responsibility of both storyteller and receiver. The basis of a story's goodness is its capacity to promote beneficent rather than harmful decisions and actions. Good stories are good friends; they offer their "*good* companionship" and counsel (Frank, 2010, p. 19). Emphasizing the ethical dimension of stories, Frank (2010) declared the scholar/practitioner's responsibility is not merely to help people understand how to live, but how one "*ought*" to live (Frank, 2010, p. 19). The capacity of stories to transmit the good is also practiced in portraiture.

Stories from the borderlands. The people-based portraits in my study fall into the narrative genre that Mattingly (2010) refers to as transformative journey or travel stories concerning those "dwelling-in-travel" (Clifford, 1997, p. 2) toward the unknown. Mattingly (2010) also refers to these narratives as border stories and the places where they are lived as borderlands. "Border story" is an apropos term to describe the accounts in Mattingly's (2010) longitudinal narrative phenomenological study of African American families living with chronically ill and disabled children within an institutional care-setting. Likewise, the stories shared in my dissertation are border stories.

Similarly, Frank (1995) identifies the genre of quest stories. Both journey and quest stories promise those facing terminal illness a final destination, bounded by death; neither offer reassurance of a clear path or resolution (Frank, 1998). The roles of traveler and their travel companions involve living in-between, the art of learning how to live with ambiguity (Bruce, Schreiber, Petrovskaya, & Boston, 2011). Death is the ultimate travel story journeying toward the ultimate border crossing.

Community and communitas. A community is an enclave of co-produced meaning (Gelfand et al., 2005). It is the petri dish of culture in which meaning begets meaning. Based on the Latin, the translation of the word community is fellowship (V. Turner, 1969). Community members belong to a fellowship of meaning. Community is defined as "a group of people who are socially interdependent, who participate in discussion and decision making, and who share *practices*…that both define the community and are nurtured by it (Bellah, Madsen, Sullivan, Swidler, & Tipton, 1985, p. 333). Buber's (1961) poetic definition captures the essence of community:

> Community is the being no longer side-by-side…but *with* one another of a multitude of persons. And this multitude…moves towards one goal, yet experiences everywhere a turning to, a dynamic facing of, the others, a flowing from *I* to *Thou*. Community is where community happens. (p. 51)

During periods of shared adversity and chaos, liminality can knit disparate individuals and groups into communitas. Communitas mitigates and converts existential anxiety through acts of social solidarity, restoring social equilibrium and delivering new meaning (V. Turner, 1969). While society can act as a structure of separation and marginalization, pitting one group against another, communitas works to bypass borders and to shore up tears in the social fabric (Gelfand et al., 2005). Similarly, Moss (1985) makes note of how "as a rule, society organizes into energetic wholeness in times of crisis" (p. 153).

Collective narratives for community-building and social change. Collective narratives have the capacity to heighten group awareness; stimulate imagination and discourse; coalesce and reinforce group or organization identity; and mobilize a shared commitment to action (Sharf & Vanderford, 2009). Collectively produced narratives serve as symbolic strategies that can build, strengthen, and sustain bonds (Sharf & Vanderford, 2009), generating a symbolic convergence of shared values and meaning (Bormann, 1985). The families of children living with chronic illness and disability in Mattingly's (2010) study, noted above, provide a good example. These families met in a collective narrative group several times a year for the duration of the study and continued to meet annually, beyond the borders of the 13-year research project. The fact that these collective interviewing groups yielded some of the richest, most intimate data, compared to individual family member interviews (Mattingly, 2010), speaks to the significance of forming and sustaining surrogate families during critical times. Individuals and families drawn together by the blood-bonds of circumstance, cemented by collective storytelling, can be considered “border families.”

A primary goal of Barnard et al.’s. (2000) ethnographic study was to include a multitude of voices and perspectives, including the palliative care team members and the researchers as participant observers, while highlighting patient and family member voices. The challenge was to strike a balance between staying true to participants’ voices and making a scholarly contribution by, for example, imposing themes on the flow of lived experience. (Portraitists, working solo or in collective groups, act similarly). A key objective was the production of practical findings applicable to improving the quality of palliative and EOL care, regarded as the true measure and merit of narratives (Barnard et al., 2000). Thus, the pragmatic truth (Lawrence-Lightfoot & Davis, 1997) rings true to the reader and possesses clinical and educative utility (Barnard et al., 2000). Driving home the arbitrariness and partiality of claimed facts in narrative accounts (Frank, 2012), Barnard et al. (2000) regard the EOL narratives they produce as fiction. They also underscore the researchers’ handiwork in story making, describing their collective narrative as the “result of creative, selective, shaping processes” (Barnard et al., p. 404), akin to portraiture.

To speak or not to speak: Narratives in the clinical setting and beyond. Recognizing the challenges and constraints of clinical dynamics, Kirmayer (2000) inquires, “How can we know what stories are *not* told (p. 175)?” Following this line of inquiry, Gunaratnam and Oliviere (2009) ask, “[W]hat lies outside of narrative at such times, what emerges from its incapacity,” and what are the implications for care (p. 7)? Narratives give voice to the “mysterious bod[y]…the often unnoticed source of life” (Frank, 2009, p. 167). A turn from the incubation of bodily expression through word, toward a “bod[y that] suddenly require[s] speech," signals a turn toward life and healing (Frank, 2009, p. 165). While dying is a normative process of physical and physic "withdrawal from word and world" (Gunaratnam & Oliviere, 2009, p. 7), there remain other bewildering experiences which render the body silent. Harrison (2007) refers to the "nonrelational," liminal zone on the brinks of human experience as the "blank cry" (p. 593), a description that conjures Edvard Munch's anxiety-provoking image of the reverberating screamless scream.

Kirmayer (2000) portrays the clinical encounter as a contest of meaning and narrative authority between "the voice of the body, the voice of medical authority….and muffled voices of the family," prone to resistance and misunderstanding (p. 169). He describes metaphor-rich illness narratives as poetic truth grounded in lived sensorial, bodily experience, in contrast to disembodied, scientific or clinical truth (Kirmayer, 2000)*,* based on rational, causal "bio-explanations" (W. Weber, personal communication, March 20, 2013). Patient narratives, regarded by health professionals as clinical material, are turned to influence patients to adopt a more realistic or rational view (i.e., the clinicians') rather than as seeds for sowing and tending relationship (Frank, 1998; Moore & Hallenbeck, 2010). Nearly all patient-talk simulates doctor-talk (Frank, 2002), whereby individual expression and sense of personhood are virtually flattened (Broyard, 1992).

Moore and Hallenbeck (2010) claim physicians do listen to patients. However, many fail to understand, relate to, or think with patient storylines, or to consider such stories within a larger whole-life context (Frank, 2004). Each party is merely making decisions based on their own familiar storyline. In other words, doctor-patient miscommunication is more a matter of crossed meanings and intentions than failed listening (Moore & Hallenbeck, 2010). Narrative competence involves cultural brokering (Moore & Hallenbeck, 2010), a competency valued by social workers. Cultural brokers link and equalize divergent voices, translating foreign clinical language into local meanings that align with the patient's story and personhood (Moore & Hallenbeck, 2010). This requires the capacity to extract intended meanings and connect discordant storylines (Friberg & Ohlen, 2007; Moore & Hallenbeck, 2010).

Reflecting on his own illness, Broyard (1992) believes that suffering predisposes a person to metaphor and poetry, defining the latter as "language writing itself out of a difficult situation" (p. 21). "Inside every patient there's a poet trying to get out….Dying or illness is a kind of poetry" (Broyard, 1992, p. 41). Furthermore, metaphoric expressions of the dying can point to something beyond our ordinary fields of vision and meaning. Embracing the dying person's poetic meanings provides clinicians a way to join with and companion the dying, to the degree possible, as they approach the border between life and death. In this manner, illness stories can be mutually therapeutic. Their therapeutic value rests on compassion, defined as the capacities for deep listening and to suffer with another (Frank, 1998; Moore & Hallenbeck, 2010). Presence and "just listening" create a space for change through the "nonelicitation of change" (Frank, 1998, p. 208).

Some stories implore repetition (Frank, 2010) while others remain shackled to ankle of the throat. The stories that break free are not random. I concur with Frank's (1998) assertion that "people tell the stories they need to tell in order to work through the situations they are in" (p. 206). Similarly, Shapiro (2011) maintains that narratives represent dynamic and complex negotiations, each iteration presenting the best possible story—and best possible self—one can tell, or bear telling. However proximal to fact a story may be, personal accounts represent personal truth. Holding to a story—or being held by a story—serves as a life preserver and psychic anchor, enabling persons to "hold their own" (Frank, 2012, p. 6).

At the heart of illness and EOL narratives is the quest for meaning and the need for sense-making, the subject of the next section.

The Role of Meaning-Making

Fundamental to understanding what is meaningful to a person at the end of life, is understanding how they lived (Masson, 2002), their life story. Ways of being and coping in dying—one's deathstyle—are generally consistent with one's lifestyle (Yedidia & McGregor, 2001). A wholistic perspective means a whole-person/whole-life context (Yedidia & McGregor, 2001) consisting of the individual's cultural milieu, social network, religious/spiritual and medical beliefs, and prior experience with loss (Gruenewald & White, 2006; McKechnie et al., 2007; Wright, 2003).

Terminal illness precipitates a crisis of meaning. Meaning-making represents an overarching developmental task centered on how to live with the fact of existence, concluding in non-existence, a venture encompassing personal and transpersonal dimensions (Arnold, 2011; Gruenewald & White, 2006; Wright, 2003). Meaning mitigates death anxiety (Yang, Staps, & Hikmans, 2010) and despair, making the reality of death plausible, if not less intolerable (Lethborg, Aranda, Bloch, & Kissane, 2006). According to Blumer's (1969) concept of situational or symbolic interactionism, people relate to things based on the meaning they ascribe. Thus, meaningless suffering can be rendered meaningful and, thereby, endurable (Ardelt, Ai, & Eichenberger, 2008). A case in point, the notion of aggressively fighting to the very end to prolong life may be perceived as meaningless to Caucasians, but quite meaningful to racial minorities.

As a central task of both living and dying, meaning-making is a coping mechanism for:

1) optimizing well-being; 2) alleviating existential anxiety and suffering; and 3) maintaining a sense of psychological coherence, stability (Bruce et al., 2011; Lethborg et al., 2006; Mount et al., 2007), and normalcy (Vig & Pearlman, 2003). Additionally, it is a mechanism for adopting a new normal in the face of mounting loss (Vig & Pearlman, 2003). Coping offers a dimmer-switch for regulating levels of death awareness and anxiety. The goal of coping is not to deny death but to "keep it in check," implying the need to "restrain" death anxiety to a functional level, enabling the person to focus on living (Sand, Olsson, & Strang, 2009, p. 19). Living with dying is achieved by "taking charge," alternately "pacing" and "pushing" oneself to engage in the normative activities of living (Carter, MacLeod, Brander, & McPherson, 2004), thus keeping the balance of awareness focused on living rather than on dying (Sand et al., 2009). More than a sense of maintaining personal control and staving off loss of function, taking charge represents the capacity to actualize one's needs and to adopt a life philosophy compatible with death (Carter et al., 2004). Existential despair, then, is the inability to mobilize needs and an adequate meaning system (Carter et al., 2004).

Illness as a crisis of meaning. A crisis of meaning can threaten to rock—or sink—the tenuous boat of psychic equilibrium. Lethborg et al.'s (2006) narrative analysis uses a theoretical framework based on three concepts to develop a model for understanding how meaning is experienced and applied when a person is confronted with advanced cancer. These concepts are: assumptive world (Janoff-Bulman, 1989), sense of coherence (Antonovsky, 1987), and meaning-based coping (Folkman, 1997). The researchers describe a dynamic adaptive process linking three domains: experiencing the reality of advanced cancer, responding to its impact, and living life out fully with continued meaning (Lethborg et al., 2006, p. 40), thereby suggesting crises of meaning are resolvable. During a crisis, a person's assumptive world, the conditioned lens of perception through which a person understands self and world, comes under siege (Bruce et al., 2011; Lethborg et al., 2006; Yang et al., 2010). Suffering is inversely relative to the degree of consonance, or sense of coherence*,* achieved between the person's assumptive world and their lived experience. Meaning-based coping requires the activation of a person's cognitive apparatus when their familiar meaning system is found to be inadequate to the task (i.e., there is a sense of dissonance between one's assumptive world and lived experience). Suffering becomes the catalyst and meaning the gird-like net, able to stretch, reshape, and hold the person in crisis and restore them to a life worth living (Lethborg et al., 2006).

Yedidia and McGregor's (2001) ethnographic study found comparable motifs**:** "struggle (living and dying are difficult); dissonance (dying is not living); endurance (triumph of inner strength); coping (finding a new balance); incorporation (belief system accommodates death); quest (seeking meaning in death); and volatility (unresolved and unresigned)" (p. 807) . This final motif challenges Lethborg et al.'s (2006) last domain, "living life fully with continued meaning," suggesting that some crises of meaning are not soluble (p. 34).

Meaning–making as a social and existential process. To make meaning at the end of life is to beckon light in the midst of darkness. Bruce et al. (2011) conceptualize the quest for meaning as a "basic social process" (p.3) compelled by a crisis of existential "groundlessness" and the need for anchoring (p. 4). Similarly, Mount et al. (2007) assign meaning-based coping as the basis for quality of life, specifically, the capacity to form meaningful bonds. Meaning is actualized in the crucible of relationship through "healing connections" to self, others, the phenomenal/sensorial world (e.g., nature), and to "Ultimate meaning," however that may be conceived by the individual (Mount et al., 2007, p. 372). Suffering then, is an absence of meaning, a sense of dis-connection. In accordance with Heidegger (1962), Boston et al. (2011)

assert that making meaning is a solitary endeavor; therefore, only relationship to self matters and is substantive in the face of death. Similarly, Wright (2003) describes coming to terms with death as an inner-evolutionary process, a dialectic between the dying person and their relationship to death, along a continuum of meanings. Motifs include: “imprisoned by death, *carpe diem* (seize the day), *carpe mortem* (seize thy death), life and death transformed, silenced by death, and waiting for death” (Wright 2003, p. 441).

Empowerment versus diminishment. Meaning-making is a fundamental human motivation (Frankl, 1992). Underlying this motivation is a primal need for control (Sand et al., 2009). While autonomy is each individual’s freedom and responsibility (Frankl, 1992; Kant, 1985), with illness and age this responsibility is inevitably transferred to society, primarily to the hands of medical professionals (K. Richardson et al., 2010). Empowerment of vulnerable and dependent persons is an affirmation of our innate interdependence, which becomes increasingly apparent as death approaches (K. Richardson et al., 2010). In this manner, supporting a dying person’s felt sense of autonomy, to the degree possible, can be a power-equalizing and restorative intervention, having political and moral implications (K. Richardson et al., 2010). Hence, a respectful death hinges on respectful care (Farber, Egnew, & Farber, 2004). Respect pivots on the quality of relationship between the individual in need of care and her/his carers, thus placing respect as a guiding principle for meaningful communication and sound decision-making, whereby the dying person’s meanings, values, and goals are honored (Farber et al., 2004).

A sense of meaning and dignity can be enhanced or eroded by care providers (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002). Persons receiving (institutionalized) inpatient EOL care are more susceptible to loss of dignity than those receiving outpatient EOL care (Chochinov et al., 2002). Non-medical interactions (i.e., comfort measures) can offer effective ways for caregivers to empower dying persons (K. Richardson et al., 2010; Wright, 2003), providing an enhanced sense of belonging and security (Ryan, 2005), thus preserving social dignity (Chochinov et al., 2002). When authentically delivered (K. Richardson, et al., 2010), these more subtle, difficult to measure, humanistic interventions (Arnold, 2011) are central to meaning-making and thus, quality of life.

The meaning of time. Recognition of life's finiteness is experienced as an assault to "ontological security" (Arnold, 2011, p. 8). Death symbolizes the end of "lived time" (capitulation) as it encroaches upon the "lived body" (contracting world) (K. Richardson et al., 2010, p. 132). While still possible, setting meaningful and realistic goals serves as time's anchor and ford. Vig and Pearlman (2003) refers to remaining involved with life and engaging in meaningful activities as "living while dying," ensures persons nearing the end, and those around them, that they are still living and therefore still have social worth (p. 1597). In this sense, meaning is derived from practical and purposeful, at best enjoyable, use of time, especially as it involves and impacts significant relationships.

Terminal illness foreshortens and terminates an imagined productive and fruitful future, threatening generativity (Erikson, 1994). In her raw end-of-life journal, laced with poetry, Philip's (1995) refers to this loss of time-to-come as a "planting problem": to stop planting is to stop living and learning (p. 272). To be generative in the face of dying is to continue to sow seeds and tend one's garden despite the certainty of missing its eventual flowering; it is pure generosity.

Adaptability. Park and Folkman (1997) refer to meaning as personal "perceptions of significance," requiring reassessment at critical points in the life cycle (p. 116). Response shift

(RS), a fundamental coping principle based on Folkman's (1997) adaptation theory, normalizes and makes salient perceptual changes in response to changing situations throughout the illness trajectory, and as death becomes more evident. This concept aligns with Sarte's notion that meaning is not static, rather it evolves throughout the course of living (Boston et al., 2011). RS organizes and integrates a person's perceptions, concerns about illness and dying, and contextual factors into a tenable story (Gruenewald & White, 2006). As a psychological and existential reaction, RS activates a psychic alarm which, in turn, stimulates a repertoire of adaptive strategies (Gruenewald & White, 2006) conducive to psychospiritual healing (Mount et al., 2007). RS is a response based on the need to re-vision (Mount et al., 2007) positivity of meaning (Romanoff & Thompson, 2006): to make lemonade from lemons. This proclivity for adaptability complexifies human beings, as well as EOL research and practice. It also offers clinicians an instructive, strengths-based framework for understanding alternating, ambiguous, and contradictory meanings of patients and their close relations (Wright, 2003) as each person searches for a meaning they can live with, and as new meanings emerge.

Masson's (2002) synonymous term, flexible realism, equally appreciates and accounts for the raw, oftentimes messy experience of being human, whereby ideals and desired goals fail to hold up to the crucible of real life situations. Flexible realism describes the way in which "people strive together to get as near as possible to a death which positively coheres with, or positively contradicts, the life of the dying person" (p. 208). Notions of what is good are relinquished to what may be considered good enough in the face of presenting contingencies, limitations, or conflicting realities. A pertinent example: Masson (2002) observes, when remaining in one's own home at the end-of-life is no longer an option, patients and their families redirect efforts toward finding an alternative setting that resembles home and home life, to the degree possible.

The next section puts two hidden or elusive domains on the map of the human experience of dying, the existential dimension and its counterpart, liminality.

The Hidden Dimensions: Existential Suffering and Liminality

In the first half of this section, I will review the literature on existential suffering and well-being, followed by the literature on liminality.

Existential suffering and well-being. The hidden, existential domain has only become of interest to researchers over the last decade, mostly from outside the United States (Boston et al., 2011), despite its heightened prominence and significance proximal to death (Cohen & Leis, 2002). In a 2011 review of the literature, based predominantly on palliative care provider perspectives, existential suffering was conceived of as a "condition for which there is no consensus on treatment" (Boston et al., 2011, p. 605), rather than as a natural and expected part of the human condition. Indeed, medicalization may be a strategy to avoid inexplicable suffering, reflective of intolerance for areas of human experience impervious to biomedical knowledge and traditional forms of medical intervention. Contributing to its neglect are the raw, elusive, and threatening qualities associated with the existential realm, experienced by patients and professionals (Bruce et al., 2011), each of whom may be ambivalent to reveal their vulnerability (Yang et al., 2010). Patient expression of vulnerability may trigger clinician insecurities and existential anxiety (Boston et al., 2011). Professional vulnerability, typically construed as a weakness, may actually be an asset for fostering compassionate communication and response toward dying patients as well as fellow clinicians who may be experiencing existential distress (Boston et al., 2011). Mount et al. (2007) bypass the lack of consensus in the literature on the meanings of the terms "existential" and "spiritual" by using "inner life," an alternate term suggested by participants early in their research, to span interwoven existential, spiritual, and psychological domains of experience (p. 374).

Psychic rupture: The existential ordeal. Existential anxiety is like a splinter, at times residing closer or receding farther from the surface of awareness, evading strategies for removal. Not readily visible, though acutely felt, Williams (2004) describes existential suffering as a state in which existence itself becomes unbearable. Forcing a confrontation with one's mortality, it can trigger a disconcerting sense of discontinuity (Yang et al., 2010), or of being less than human (Williams, 2004). Coyle (2006) sums up the felt experience of death's imminence as the "existential slap" (p. 267). A hallmark flagging this unchartered territory is the daunting "Why me?" question (Bruce et al., 2011) commonly posed by those diagnosed with a life-threatening illness. This may invariably lead to the equally unanswerable "What is the meaning of life—and death?" question that permeates existential crises. Existential suffering is primary grist for the meaning-making mill.

Dying and death remain the ultimate separation, the "ultimate unknown" (Kearney, 2007, p. 1). Faced with these ultimate's and a sense of groundlessness, the reflex is to cling to old structures of meaning or, if they fail to appease anxiety, to make new meaning (Bruce et al., 2011; Lethborg et al., 2006; Yang et al., 2010). Yalom (1980) identifies four "ultimate concerns" or "'border' situations": death, isolation, meaning in life, and freedom (p. 1). Similarly, Yang et al.'s (2010) grounded theory study identifies characteristics of existential crisis as: awareness of finitude; dissolution of the future; loss of meaning; fear, anxiety, panic, and despair; loneliness; powerlessness; and identity crisis. Existential crises tended to flare at critical junctures along the illness trajectory, preceded by death awareness, including a downslide in physical deterioration (Yang et al., 2010).

The psychospiritual mechanics of coping and meaning-making. Awareness of death carries a burden. In the classic, *Man's Search for Meaning*, Frankl (1992) asserted that while human beings do not have a choice in the matter of whether we will suffer and die, we have the power and responsibility to choose how we relate to suffering and death. Similarly, Heidegger espouses life's certain ending serves as the "fundamental confirmation of our existence in the world," bringing into stark relief our innate freedom and responsibility for how we live (Little et al., 1998, p. 1490). According to Bruce et al. (2011), based on their grounded theory analysis, a confrontation with existential suffering leads to a dynamic process in which people position themselves in one of three ways: 1) turning toward discomfort ("engaging groundlessness"); 2) turning away from discomfort ("taking refuge in the habitual"); or 3) learning to live with discomfort and ambiguity ("living in-between") (p.1).

Yang et al. (2010) uses three sensitizing concepts, a template of select ideas to guide theory development, to explain how meaning is made when faced with an existential crisis: "meaning as interpretation", "meaning as experience", and "spirituality" (p. 56). Each is congruent with Bruce et al.'s (2011) terms, above. First, meaning as interpretation**,** congruent with taking refuge in the habitual (Bruce et al., 2011), refers to pre-existing structures of meaning deployed to ward off existential anxiety. Denial of death remains intact as the old order and meaning of life continues (Yang et al., 2010). Similarly, Lethborg et al. (2006), based on Janoff-Bulman (1989), uses the term "assumptive world" to describe the conditioned lens of beliefs and meanings through which people interpret their experience.

Second*,* meaning as experience*,* congruent with engaging groundlessness*,* (Bruce et al., 2011) refers to new meaning, characterized by a sense of connection to something larger than oneself, as an adaptive or compensatory function in response to failure of the old framework to provide adequate relief from existential suffering. In this case, death can no longer be denied (Yang et al., 2010). Prince-Paul (2008) calls this phase transcendence: a "sense of being part of a greater whole, going beyond the self, the body, and the physical world" (p. 366). Similarly, Sand et al. (2009) describe Lifton's (1976) term "experiential transcendence" as a state in which the usual psychic "borders between life and death disappear" (p. 19).

Third, spirituality*,* congruent with living in-between (Bruce et al., 2011), refers to a dismantling and restructuring of the old meaning system as the result of an intense archetypal struggle with a numinous "Other" (i.e., Death or God). The result is a fundamental transformation of one's meaning system. The person is no longer fighting reality—nor fighting death. In effect, death becomes conscious. Together, these concepts suggest a hierarchy of meaning-making, consisting of three levels, as shown in Table 2.3.

Table 2.3

Levels of Meaning in Response to Existential Crisis

First order meaning: "Meaning as Interpretation"	Second order meaning: "Meaning as Experience"	Third order meaning: "Spirituality"
Actively defended ego	Receptive ego	Transpersonal ego
Meaning is the product of a pre-existing framework	Meaning serves an adaptive, compensatory function	Meaning is an inductive, transpersonal experience
Sociocultural (i.e., conditioned) meaning	Personal meaning	Transpersonal meaning
Crisis is thwarted	Crisis is acknowledged	Direct encounter with the perceived source of crisis
Death denial remains intact	Death can no longer be denied	Death becomes conscious

Note. Source of data: Yang et al., 2010.

Later, I discover a table constructed by Friberg and Ohlen (2007) with parallel constructs, respectively: "the stable path, the turning point and the waiting" (p. 221).

What is spirituality? In response to this question, I reflected on Frankl (1992) who refers to spirituality as the human-making dimension. I also focused on Yang et al.'s (2010) distinction between the "active attribution of meaning [the second level] and the experience of meaning" (the third level), which cannot be willed (p. 66). In the second level, the person makes meaning; in the third, the person is forged by meaning. It is the third phase by which spirituality is defined and distinguished from religion (first phase). As Yang et al. (2010) reasons, in the second level the person is "passively embedded" in a higher reality whereas, in the third level, they partake in a direct encounter described as an "intense active-passive process of relating to, and often wrestling with, 'reality-as-it-is'" (p. 57). It is this dynamic encounter with "life-as-it-is," and the resulting personal transformation, which authenticates spirituality (Yang et al., 2010, p. 62). Altered at the ground level of being, the person's sense of life and self must be fundamentally relearned (Yang et al., 2010). Notably, preconceived religious notions generally were not found to play a part in the transformative process (Yang et al., 2010). However, when used intuitively and symbolically, religious symbols or imagery may serve as a transitional object (Winnicott, 1971, 1980) to facilitate spiritual growth and awakening (Moss, 2007). Existential crisis, precipitating symbolic death and rebirth, is a portal to higher-order meaning (Yang et al., 2010).

Embracing paradox. The experience of living with dying represents a paradox. Persons living with terminal illness exist in a precarious state of "living with dying" (Carter et al., 2004, p. 612). The tail end of terminality entails a "particular way of being in the world" that is "dying, yet living or living, yet dying" (Kuhl, 1999, p. 4)—or living dying, the two being "recursively connected" (Wright, 2003, p. 452). The literature consistently describes living with the reality of dying as a developmental task that requires learning how to hold and negotiate the tension of opposites (Bruce et al., 2011; Carter et al., 2004; Yang et al., 2010). Implicit is the capacity to embrace existential suffering and uncertainty. Stroebe and Schut (2001) describe the existential crisis as a discursive, potentially highly vacillating, process of swinging—or being swung—between poles.

In their existential hermeneutic analysis, Sand et al. (2009) conceptualize the activity of coping as a dynamic psychic pendulum "counterbalancing death with symbolic manifestations of life," or a symbolic afterlife (p. 19). In this manner, when self-continuity can no longer be achieved literally, it is secured symbolically (Sand et al., 2009). Bruce et al. (2011) describe "living–in-between" as engaging in a "paradoxical and recursive process" by which a liminal groundspace is cultivated, in effect depolarizing knowing/unknowing and ground/groundlessness (p. 6) through the practice of death awareness. *Bardo,* a Tibetan term, symbolizes a psychospiritual border zone, experienced as a "continuous, unnerving oscillation between clarity and confusion, bewilderment and insight, certainty and uncertainty," through which personal development is potentiated (Sogyal Rinpoche, 1993, p. 105). Thus, embracing paradox implies learning to embrace mortality, our temporal flesh and bone existence (Frank, 1995; Little et al., 1998).

Liminality: Land of the Lost

I am a lost cartographer with no maps.
(Varela, 2001, p. 246)

Liminality sheds light on the existential dimension of the human experience of dying, otherwise prone to shadow and silence. Commonly considered the province of philosophers, mystics, and poets, the concept of liminality has been of interest to anthropologists, sociologists, and psycho-oncologists rather than health care researchers and clinicians, perhaps due to its mystical intonations (Little et al., 1998). The existentialists embraced liminality as a "philosophy of life" (Little et al., 1998, p. 1491). They insisted that illness, suffering, death, and their accompanying anxiety, be fully cognizant and in plain view as the normative state of human affairs (Little et al., 1998). The disorientation of deep illness and suffering can mute one's sense of humanness and eclipse language (Frank, 1998).Those able to break the spell of silence speak in a "twilight language," rich in metaphor and imagery (Varela, 2001, p. 254). Francisco Varela's (2001) words, written in the wake of an unexpected liver transplant eventually leading to his demise, illuminate liminality:

> Never have I felt more acutely my fragile ontology, the impossibility of grasping onto anything, a living dot suspended in space….The utter loneliness for which there is no utterance….It's death's trace...a feeling of recognition of its presence, of an inevitable guest, whose movements go beyond anything within my reach. From then on the trace of death has set its own agenda, its own rhythm to my life. I have, in fact, become another. (pp. 251-252)

Little et al.'s (1998) grounded theory study of colon cancer survivors, 3 months to 12 years post-treatment, establishes liminality as the overarching category for understanding the lived, embodied experience of cancer and for elucidating illness narratives. Furthermore, they conceptualize liminality as a subjective, intrapsychic process versus a social process, distinguishing their theory from their anthropologic predecessors. Echoing the previous literature on the existential realm, liminality is described as a two-fold "dynamic" process of "accommodation and adaptation" within an "oscillating trajectory" of illness (Little et al., 1998, p. 1493). The acute phase is activated by a confrontation with mortality at the point of life-threatening diagnosis, while the sustained phase is experienced for the duration of the illness trajectory or the person's life (Little et al., 1998).

Acute liminality is entry to the void. Little et al. (1998) draws on the metaphor of a black hole to signify "a discontinuity of subjective time, in which powerful forces operate to change perceptions in time, space, and personal values" (p. 1492). For the duration of this phase, the person's social status remains on the border. Sustained liminality is defined as "a prolonged dialectic between body and self, in which a narrative is constructed to give meaning to the challenging and changing biographical, physical, and existential phenomena in which illness and aging evolve in the locus of the body" (Little et al., 1998, p. 1493). Three patterns are noted: persistent identification with "cancer patientness," "communicative alienation" from the larger social world about the cancer experience, and "boundedness," an ongoing sense of constricted time, space, and power (p. 1486).

Similar to Little et al. (1998), McKenzie and Crouch's (2004) participants, living with cancer for two or more years, perceived cancer as a permanent stigma causing "interpersonal emotional dissonance," a split between their inner experience and maintenance of an exterior façade of normalcy and positivity (p. 139). Participant suffering remained a private preoccupation, along with masking anxiety (Crouch & McKenzie, 2006). In a later study, Crouch and McKenzie (2006) expand on Little et al.'s (1998) two-stage theory, adding a third stage: "transcending" liminality (p. 495). In this stage, beginning five years post-diagnosis, representing a benchmark of cancer survivorship associated with medical cure, a sense of security is reestablished (Crouch & McKenzie, 2006).

In her study of women living with ovarian cancer, Thompson (2007) claims liminality is a permanent state lasting until death, comparable to Little et al.'s (1998) concept of sustained liminality. However, Thompson (2007) departs from or elaborates on Little et al.'s (1998) constructs in other areas. First, her participants put a positive spin on boundedness, often perceiving it as a meaning-making catalyst for generativity rather than a barrier to growth. Second, although participants generally experience communicative alienation, this is not the case with fellow ovarian cancer survivors (Thompson, 2007). Peers also serve as the "life thread" for the participant in Friberg and Ohlen's (2007) study, providing a profound source of comfort and practical information sorely lacking in encounters with medical providers (p. 223).

Friberg and Ohlen's (2007) single phenomenological case study follows a patient with advanced cancer through the maze of existential meaning-making in the health care setting. They conceptualize a three-fold path, consisting of "managing," "confronting," and "living" existential uncertainty (Friberg & Ohlen, 2007, p. 221), a schema consistent with the processes previously described related to the existential domain. Their findings entail the plight for meaning, whereby sense making is constrained by medical professionals' controlled dispensation of information (communication) and the patient's assimilation of reality (learning). Essentially, meaning remains caught in an impasse of mutual reluctance, by which each party asks "hidden" questions and offer "neutral" responses (p. 221). Learning is contingent upon the patient's capacity to "discern the existential in the experiential" (p. 225). It is the ability to decipher the codified and encrypted behaviors and messages of HCPs relative to one's own bodily experience in "search for a unifying picture" (p. 222). This view, however, puts the burden of 'learning' (or sense making) on the terminally ill patient. In the case illustrated, communication remains thwarted by a pervasive culture of silence. Despite the participant's arduous quest for a candid picture, HCPs, including hospice providers, evade existential issues, and thereby fail to support the patient's experience of dying (Friberg & Ohlen, 2007).

A profusion of loss and "lostness" are signposts of liminality. Kelly (2008) describes the inner landscape of people with AIDS as an "emotional discourse" (p. 337) of living "not with loss but 'in' loss" (p. 335). To be living is to be "living loss" (Kelly, 2008, p. 336). Lostness undercuts humanness. The dying person becomes a castaway, not merely of society, but of one's own body and being. Varela (2001) describes himself as "a lost cartographer" within the alienating landscape of his own body; he has become “another” (p. 246). Friberg and Ohlen’s (2007) participant suffers from a sense of disorientation, whittled down by fruitless attempts to locate himself within the illness trajectory—or within himself. They are the living lost. Those related to the chronically ill and dying person are also sucked into the void. Mattingly (2010) uses the term borderland*,* discussed earlier, to depict both a place (the hospital) and the familial experience of lostness, an ordeal traversed by hope and anchored by community.

Blows et al.’s (2012) review of the literature utilizing liminality as a platform for understanding the experience of cancer survivorship concludes there is a need for future research in applying the concept to long-term survivors (beyond the five-year benchmark) and for understanding the psychosocial implications of living a “liminal life” throughout the cancer trajectory (p. 2155). My study helps fill these gaps, highlighting the liminal life of the terminally ill—or terminal liminality—a demographic not explicitly addressed in the literature on this topic.

The final section locates the experience of living with dying within care settings and their specific care cultures, acting to allow or obfuscate expressions of liminality, and to further orient or disorient the dying person and their significant others.

Making Space for Dying: The Role of Care Setting and Care Culture

A death outside the home can be likened to a death outside society.
(Degrémont, 1998, p. 127)

Care setting and care culture inform and support how we dwell with illness and dying, and how well. Attention to care setting and care culture reveal how the experience of illness, dying, and death are choreographed and orchestrated social phenomena, influenced by how a space is articulated (Realdania Fund, 2006; Verderber & Refuerzo, 2006) and how care is conceptualized (Goffman, 1961; Komaromy, 2010; Rasmussen & Edvardsson, 2007; Sudnow, 1967). Most important, is how the dying person and their kin perceive the care environment and the quality of care provided.

Care culture shapes the kind of spaces, the kind of care, and the kind of relationships within a given care setting (Edvardsson, 2005; Komaromy, 2010; Rasmussen & Edvardsson, 2007). Care setting and care culture are like Siamese twins; they are mutually bound (Poland et al., 2005). Place materializes care philosophy, linking place with practice (Edvardsson, 2005; Hockey et al., 2010a; Poland et al., 2005). Thus, care setting, care culture, and care philosophy are inextricably connected (Rasmussen & Edvardsson, 2007; Rasmussen et al., 2000), suggesting a fundamental relationship between where we die and how we die, or quality of death.

Poland et al. (2005) distinguish the terms space and place, describing the former as an abstract variable and the latter as a container (p. 171). Edvardsson (2005) builds on meanings attributed to place, space, and environment, often used interchangeably, instead choosing the word atmosphere. Renowned architect, Frank Lloyd Wright, comments, while people are generally not cognizant of such things, we can actually "derive countenance and sustenance from the 'atmosphere'" of the places we live and the things we live with (as cited in Lawlor, 1994, p. 135). The more generalized words spatiality and materiality refer to our lived, orientated, and culturally synthesized spaces across the social landscape (Hockey et al., 2010b; Verderber & Refuerzo, 2006; Worpole, 2010). Place concretizes and anchors otherwise abstracted healthcare-related meanings, such as care, safety, comfort, and healing (Rasmussen & Edvardsson, 2007).

Meaning emplaced. The meanings attributed to illness, pain and suffering; knowledge; care; and dying and death are emplaced. Boundaries and meanings are imposed upon the continuum of experience via care setting and culture. According to Murray et al. (2007), how care is conceptualized within a care setting defines and constrains meanings attributed to experience and the ways in which people understand and express pain and illness. People living with advanced illness have unique multidimensional needs that are not easily distinguished. Distress perceived in one dimension may mask or exacerbate symptoms in another. Cultural norms and meanings embodied (Kleinman, 1988) and embedded in perception are difficult to untangle, and tightly interwoven dimensions of the illness experience are hard, if not impossible, to isolate (Murray et al., 2007).

Total pain, a hospice concept Saunders promoted as early as 1964, encompasses total persons and the physical, psychosocial, and spiritual problems associated with living with terminal illness (Saunders, 1998a). In a similar manner, Dyck, Kontos, Angus, & McKeever (2005) understand the provision of care to mean more than the "material care of bodies," problematizing biomedical meanings of care (p. 173). According to Moore et al. (2013), perceptions of care are strongly associated with accessibility; a felt sense of care is a matter of close-at-handness and whole-hearted action-in-deed by caregivers. These ideas suggest the meaning of care is also emplaced.

Arnold (2011) found hospice-enrolled patients, whose multi-dimensional needs do tend to be recognized, expressed physiological needs less often than other needs, likely due to effective total pain management. But what actually accounts for this finding? Is it aggressive pain management or a care-culture that legitimizes and attends to non-physical dimensions of suffering? Perhaps it is both. Murray et al.'s (2007) findings suggest non-physical dimensions of quality of life outweigh physical concerns toward life's end. Charon (2010) emphasizes, pain management, while paramount, is not an end in itself. While it is understood that aggressive management of physical pain is requisite to freeing energy and attention for meaning-making, less understood is how attention to meaning-making may in turn reduce pain and suffering in myriad dimensions (Charon, 2010). I will revisit this phenomenon in the later discussion chapter.

The meaning of knowledge, and who holds knowledge, is emplaced. Poland et al.'s (2005) framework culture of place offers a mechanism for unpacking the "complex interrelationship between power, technology, culture, and place" (p. 170). Its aim is to expose social constructs and power relations embedded in place, which act to secure social hierarchies and boundaries between knowledge/power holders and receivers. Institutional care culture is maintained by a wider interlocking, (though often fragmented), grid of systems that, together, turn the wheel of the biomedical industrial complex (Poland et al., 2005).

Also emplaced is the meaning of death. Sudnow (1967) asserts that the terms dying and death lack *a priori* meaning; rather, meaning is always contextualized based on organizational setting, practice, and protocols produced by its authorized knowledge holders. Similarly, Komaromy (2010) contends that standardized definitions of death are arbitrary and changeable, as are the delineation of boundaries charting transitions between disease or prognostic stages, or states of being, ranging from living-dying-dead. Rather, boundaries and meanings adapt to changing historical, social, political, technological, and environmental contexts (Hockey et al., 2010a). Competing medical, sociological, and existential theoretical frameworks for the dying process are subjective. Giddens (1991) suggests a link between three social phenomena associated with modern dying: 1) the sequestration and privatization of dying; 2) crises of meaning; and 3) existential anxiety, arguing that meaning is not made, nor is existential anxiety appeased, in a vacuum. Rather, they require social and environmental context. Hockey et al. (2010a) pose the rhetorical chicken and egg conundrum, debating, which comes first: existential anxiety or biomedical culture? Regardless, they are mutually reinforcing.

Institutional care setting culture. Illness is an initiation into medical culture by which vulnerable persons, excised from their everyday identities and habitats, and transformed into dependent patients, must adapt (Williams, 2004). Through socialization processes embedded in institutional care settings, social beings and bodies are converted into institutionalized beings and bodies (Wiersma & Dupius, 2009). Goffman (1961) coined the term total institution, apropos to hospitals and nursing facilities, as "a place of residence…where a large number of like situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered way of life" (p. xiii).

Sudnow's (1967) term social death, illustrated by his ethnographic study of hospitals, refers to the meanings, behaviors, and organizational activities of hospital staff in response to the anticipated death of patients, in effect, treating them as if they were *already* dead. In a similar manner, Douglas (1966) uses the term matter out of place to describe those experiences that symbolically fall—or thrust a person outside the bounds of orderly social categories. Douglas' concept is reminiscent of van Gennep's (1960) description of territorial practices as a means to keep matter in its "proper" place. Spatial divides are a means to organize and maintain social life and groups (van Gennep, 1960). A territorial passage, from one place to another, signifies a "crossing of borders," distinguishing those undergoing a transition in social status (van Gennep, 1960, p. 192).

Komaromy's (2010) ethnographic study of nursing homes frames dying as a spatial, functional, and social divide, making evident the social construction of dying. In short, institutional living is "loosely defined as not dying" (Komaromy, 2010, p. 60). Communal spaces within the nursing home are reserved for social activities symbolically associated with living. Absence symbolizes dying or death. Staff acts as a type of border patrol, performing the duty of removing residents who cross (or threaten to cross) the line between living and dying (Komaromy, 2010). Unanticipated deaths in communal spaces are regarded by staff as "transgressions," erasing abstract boundaries and exposing the fragility of life, along with the futility of trying to control death (Komaromy, 2010, p. 63). In the eyes of the researcher, care is reduced to social artifice, whereby everyday residential life is no more than a routine/ritual "performance fulfilling the appearance of social connection, rather than a form of meaningful care in which the residents feel sustained and valued" (Komaromy, 2010, pp. 60-61). Hence care in the nursing facility is a matter of doing something to someone to make them look and act like a 'normal' person (Komaromy, 2010) rather than a way of being in authentic relationship. This depiction of social investment in simulated living reminds me of Marge Piercy's (2010) *End of Days,* a poem of protest against the kind of medicine, society, and care setting which keeps human bodies "sort of, kind of alive or sort of undead" (p. 319). She concludes: "Death is not the worst thing; denying it can be" (Piercy, 2010, p. 319).

The liminal, the sacred, and the everyday: **Hospice emplaced.** *Ars sacra moriendi, ars sacra vivendi.* Translated as "The sacred art of dying is the sacred art of living," these words are inscribed on the walls of Hospice de Beaune, at l'Hotel-Dieu (Groves & Klauser, 2005, p. 16). A remnant of the "ancient hospice movement" in 15th-century France and elsewhere in Europe, it reminds us that special care of the dying and places designated for their care are not new, rather they are part of our social heritage (Groves & Klauser, 2005, p. 14). Historically, hospice served the poorest and neediest (Groves & Klauser, 2005), in keeping with the early role of hospitals (Risse & Balboni, 2012).

Optimally, the specialized end-of-life care setting is where the work of dying is allowed to unfold and living is encouraged. They are places of liminality and gestation. Dying persons feel most welcome and at-home in spaces designed for dying (McKechnie et al., 2007). These environments are not hospitals where “fixable” bodies are expected to recover or private residences where “normal” bodies continue the work of living (McKechnie et al., 2007). The specialized palliative and hospice care setting serves a two-fold function, providing a refuge for the dying and a buffer of protection for the living; death is made “safe” for all (McKechnie et al., 2007). These less medicalized environments, “where time stands still,” provide an incubator-like “space for the sequestration of the body as it decays, thus setting it apart from mainstream society, enabling accepted ideas about living to be maintained” (McKechnie et al., 2007, p. 261). As described by McKechnie et al., the specialized hospice setting remains a structure of separation and discontinuity, disconnected from community and everyday life.

Kearney’s (2009) first impression of St. Christopher’s Hospice in London was that it is “place of healing,” wherein hospice care, as a soulful kind of medicine, attends to restoration of the soul rather than soma (p. xviiii). He likens places designed for living with dying to temples, “where what is most fundamental, natural, and indigenous to the human psyche can most easily do its own work of bringing about integration, balance, and wholeness” (Kearney, 2009, pp. xxii-xxiii). In contrast to Komaromy’s (2010) description of caregiving in the nursing home, above, the central role of hospice caregivers, as Kearney (2009) describes, is to create an environment conducive to healing; essentially, to support or make space for living.

The meaning of healing, distinct from medical cure, signifies a state of subjective well-being or wholeness independent of cure, physical health, or even the continuity of life (Egnew, 2005). Meza (2011) pairs the word healing, typically associated with the word cure and ‘power,’ with the word relationship to promote the restoration of healing to mainstream medicine and medical settings as a social practice. Healing is evidenced by the restoration of patient back to their full person status, whereby social ties can be resumed or newly made, as enabled by their care providers (Seale, 1998).

Kearney (2009), an end-of-life care physician, and Worpole (2009), a professor of architecture and landscape design, each use the word “sacred”—usually anathema in conventional medical spheres—to describe the specialized end-of-life care setting. Another architect, Lawlor (1994), dovetails the sacred with the everyday. He describes sacredness as “an experience of the radiance of life, the unseen force that transforms and nourishes the physical world….There is always something more (p. xi). While the sacred continues to be integrated into contemporary hospice design, its appearance has changed. The chapel, traditionally associated with the sacred, a mainstay in the design of St. Christopher’s in the 60s (reflective of Saunders, who was a highly religious person), is a relic. A sign of changing times and increasing secularization, the hearth displaces the chapel as a symbolic focal point for contemplation and gathering (Worpole, 2009).

Curiously, the meaning of the word ‘sacred’ implies to “set apart” in place and function from everyday life (Sacred, n.d., para. 1a). This meaning corresponds with the spatial/behavioral observations of van Gennep (1960) and Douglas (1966), and my own perception, which suggests that the human inclination to set the liminal apart from the everyday may be an innate response, albeit distinctly packaged according to cultural/ethnic group. (Non-human animals appear to exhibit such behavioral patterns, too, as I recall my cats that gave birth or died.) This perspective seems complementary rather than oppositional to Becker (1973), Sudnow (1967), and Komaromy (2010), who conceptualize sequestration as a cultural tactic to obscure our existential frailty, though this, too, may be true.

Hospice emplaced globally. Byock (2010) reminds us, there may be no better measure of civility than how a society or community cares for its dying. Across the globe, individuals from diverse fields are coming together to translate hospice philosophy into living space (Charon, 2010), making the hospice of the future a tenable place with a recognizably human face (Worpole, 2009). One exemplar are the hospice residences and adaptive design principles featured in the "Programme for the Good Hospice in Denmark" (Realdania Fund, 2006), in response to a 2004 law requiring a 12-bed hospice facility in every county. The venture, marking a momentous collaborative effort "to create a synthesis of form, content, and needs, which support the users of a hospice, from the human, professional, and architectural angle," resulted in a rapid proliferation of accessible hospice beds (p. 5). The project, serving as a blueprint for other countries, demonstrates how public will and policy can change the shape of how people die.

While the essence of hospice care culture continues to bear Cicely Saunders' stamp, globally, her vision of care setting, manifest in St. Christopher's , a 48-bed hybrid model, bridging hospital and home in design and function, has been pared down considerably in contemporary hospice design to human-scale reflective of home. Verderber and Refuerzo's (2006) worldwide architectural study of hospice residences, ranging from eight to fifty-two beds, includes a few smaller, independent models. The largest and oldest hospice residence in the United States (and featured in this volume), established by Saunders' protégé, Florence Wald, bears resemblance in scale to Saunders' model. Verderber and Refuerzo (2006) identify three salient features distinguishing hospice from institutional settings: optimization of "person-nature transactions" (p. 33); human-scale; and incorporation of "transitional amenities," described as 'in-between' or 'transitional' spaces, such as "alcoves and vestibules—areas for people to pause and reflect, to retreat to temporality" (p. 16). Hence, hospice design recognizes and makes space for liminality.

Constructive associations of transitional spaces, conceived as an essential feature of the hospice setting in Verderber and Refuerzo's (2006) exposé, are consistent with the hospice design principles outlined by the Realdania Fund (2006), calling for a balance of accessible private and communal hidden spaces and enclosed niches, both indoors and out. However, temporal spaces have less soothing connotations in other studies. Both Worpole (2009) and Mattingly (2010) refer to spatial liminal zones as places for unsettled waiting; the former, within the hospice setting, and the latter, in the institutional lobby (for which she applies the term borderland). This view corresponds with patients in an outpatient hospice day care setting, in another study, who regarded the stairway between floors, separating the outpatient from the inpatient hospice floor—where people actually die—as a forbidden zone (Moore et al., 2013).

Home-like care settings. Degr*é*mont (1998), the architect whose epigraph opens this section, suggests the most humane environment for dying people is the most human and familiar one: home. In recent years, a trend toward a more home-like atmosphere in care settings has emerged, anticipated to spread across the health care spectrum (Dyck et al., 2005). Importantly, home-model care-settings are not places that call themselves homes, yet look, operate, and feel like an institution or resort (Briller & Calkins, 2000). Rather, a "homespace" setting (Dyck et al., 2005, p. 173) is one in which "spatial frames" of connection, "commonplaceness" (Friberg & Ohlen, 2007, p. 224), and an ambiance of "everydayness" can be seen and felt (Briller & Calkins, 2000; Rasmussen & Edvardsson, 2007).

The primary intention of the home setting model and its staff is to provide a place with a warm, informal, lived in feeling reminiscent of home, wherein patients feel sheltered (Moore et al., 2013), thus engendering a felt sense of ontological security (Giddens, 1990). “Sheltering” (a sense of home and safety) is the opposite of groundless “drifting” (disorientation, dislocation), and encourages “venturing” (exploration, learning) (Moore et al., p. 151). The concept of venturing at the end of life reminds me of Mahler’s concept of rapprochement in the early developmental stage of life, whereby the child is enabled to wander from the perceived source of security toward discovery of the world before returning to home base (Mahler, Pine, & Bergman, 1975/2000). In sum, environments patients can identify with foster a sense of existential ease or at-homeness (Seamon, 1979). This suggests a good physical dwelling is one that promotes existential dwelling.

Place in conjunction with notions of home have been investigated in a handful of studies, such as: the hospice outpatient day care setting (Moore et al., 2013); freestanding community-based AIDS (Vreeland, 2012) and Alzheimer’s residences (Briller & Calkins, 2000; Calkins & Marsden, 2000); long-term private residential setting for the chronically ill (Dyck et al., 2005); and the freestanding hospice residence (Rasmussen & Edvardsson, 2007; Rasmussen et al. 2000).

Discussions on the deeper, lived meanings of home (Calkins & Marsden, 2000) and Briller and Calkins (2000) working definition of home, both addressing the needs of people living with Alzheimer’s, appear transferable to those living with dying (albeit the capacity to participate in activities of daily living would be more limited). The latter is adaptable for establishing the nature of a good place to die (Briller & Calkins, 2000). As such, a home setting is one in which the physical space and specific characteristics of the care culture support a flow of activity coherent with, and conducive to, the everyday lives and specific physical and psychosocial needs of its residents, and are evocative of home, family, and community life (Briller & Calkins, 2000).

The function of a special home at the end of life is consistent with an ordinary home throughout life: to engage in the activities of daily living, to provide comfort and safety, to participate in social and reflective activities, and to invoke memory, meaning, and a sense of belonging (Charon, 2010). Physical spaces that evoke delight and are favorable to socialization, reflection, and ritual can also serve as experiential landmarks for exploring the nature of a good place to die, in addition to exposure to nature, art, and music, all of which provide a healing function at the end-of-life (Charon, 2010; Verderber & Refuerzo, 2006).

Above all else, a good care culture, across care settings, is decisively non-institutional, making space for an aesthetic of homelikeness in environment and caregiver style (Briller & Calkins, 2000; Edvardsson, 2005; Moore et al., 2013; Respeirda Fund, 2006). The hospice care setting provides the "right kind of bed" in the right kind of environment, staffed by the right kind of individuals, that is, people who are servant-oriented and perceive their work as a vocation (Saunders, 1964, p. 3). "Good culture" in the hospice care setting is associated with soft (i.e., humanistic) values and a care philosophy that "permeates" the premises, whereby policy and practice are adaptive to residents' changing circumstances and needs (Respeirda Fund, 2006, p. 68). It also sets the pace for relational time, amenable to relationship-building, reflection, and meaning-making, hence, breaking from 'institutional time' centered on efficiency. A good care setting is associated with good care (Rasmussen et al., 2000); however, while good design and aesthetics are vehicles for transmitting and supporting a good care culture, the former alone is no guarantee of the latter (Edvardsson, 2005; Respeirda Fund, 2006)

In the final section of this literature review, I explored care setting as an aesthetic of place and care culture as an aesthetic of care. In the following chapter, I will discuss portraiture and arts-based research, methodological approaches employed to explore my research topic and to describe my findings through aesthetic narrative.

Chapter III: Methodology

The research self is not separable from the lived self.
(L. Richardson, 2002, p. 887)

This chapter will explore portraiture and arts-based research (ABR), continuing the previous introductory discussion on my rationale for employing these approaches for this study. The body of this chapter has four broad sections. First, I describe the personal and universal significance of the arts. Second, I describe ABR, and then speak specifically about poetry and collage. Third, I discuss portraiture, capped by a summation of common attributes of these complementary approaches to research. The chapter ends with a description of research design and co/searcher selection, including limitations of this study and, lastly, learning from a pilot study to be considered as I approach the remainder of my data collection.

Who Am I?

Prior to any labels describing my worldly roles and identities, I am an artist. More accurately, I am art. Art is a way of being and relating, prior to thought and constructs. Art is a practice for exploring meaning-making and an instrument for self-expression. Coming home to the arts and an aesthetic way of knowing is, fundamentally, a return to the senses and basic sensibility. Personally and professionally, I have utilized the arts as a psychospiritual tool for transformation and healing. Art is a way to identify and befriend feeling, to bring order and meaning from chaos, to touch suffering with awareness, to decipher dreams and body symptoms, to come home to the body, to ritually mark inner and outer transitions, to reclaim and reframe experience, and to discover new ways of being. Art is a means to amplify the voice of the unconscious, ushering *prima materia* to the surface of awareness, where it can more effectively direct change. Thus through activating and bringing forth the whole self, the arts engender a felt sense of wholeness.

Knowing that I am art relaxes the (American) culturally prescribed mandate to actively produce and sell art requisite to identifying and measuring oneself as an artist. While practicing art-making is important and soul-nourishing, cultivating an artistic life is equally important. Poetic living is a way of seeing, sensing, engaging, and experiencing the world (Leggo, 2008). With this more expansive and inclusive sensibility, everything I engage in, and all whom I engage with, is potentially art-full.

True to my own explorations, I integrate the expressive arts with bodywork and body-centered psychotherapy in my private practice, utilizing drawing, poetry, journaling, collage-making, and creative/authentic movement. The expressive arts are also an integral to our philosophy at the Oncology Support Program (OSP). We recognize the arts as a therapeutic medium for self-expression/learning/healing, and for socialization and community-building. Perhaps best of all, they are a way to celebrate and enhance life. Moreover, OSP has sponsored art exhibits featuring work by those inflicted by cancer as a means to engage and educate the public about the impact of cancer on real lives. It also sends an important message, demonstrating that, while cancer diminishes the body, the spirit survives and can even thrive, as readily expressed through the arts. Through including an interactive area for visitors to post their thoughts, stories, and photos of loved ones who died from cancer, a larger social message is conveyed: cancer is not only a private crisis, it is a public, national, and growing global crisis. We are all affected.

What Is Art?

Creative acts circumscribe a felt experience of I amness: I create, therefore, I am. At the same time, art and the creative function are universal, intrinsic to the human experience: We are, therefore, we create. The universe is suffused with creativity. Life, in all its manifestations, is a work of art. As a re/source of life, art is also a re/source for healing. According to Halifax (1982), “Th[e] special and sacred awareness of the universe is codified in song and chant, poetry and tale, carving and painting. This art is not art for art, rather it is art for survival, for it gives structure and coherence to the unfathomable and intangible” (p. 11). Thus, the arts have functional, psychosocial, spiritual, existential, and humanizing relevance. Art-making is unique to the human species (though Nature itself is indeed artful and deliberate in its creations), distinguishing us most noticeably from all others. As a staple of culture, art fosters and nourishes creativity, the very foundation of problem solving; thus, it is crucial to social betterment through meaningful change (W. Weber, personal communication, March 20, 2013).

Art is a way of seeing, a way of being, a way of learning and knowing, a way of (re)connecting with our intuition, and a way of communicating. It is original language. Before words, there was art to communicate and tell stories, to describe the human experience, and to punctuate the seasons of life. A world of images precedes and informs speech. Images are the matrix of the unconscious, shaping our imagination and dreams, the foundation of “higher” faculties of reason. Artists are personal and social diary-keepers. They record who we are—for better and for worse—and remind us who we are capable of becoming. They are both her/storians and visionaries.

S. Brown and Dissanayake (2009) assisted me in bypassing the mental banter of whether I am a ‘real’ artist and poet. Derived from the Greek *aiesthesis,* they note, the word aesthetic is wedded to the senses. As a universal social activity, influenced by cultural values and styles of expression, the aesthetic and artistic reflect the human condition. The social function of art is strongly tied to individual and group livelihood and survival, as shown in Table 3.1. As *homo aestheticus*, art is not only something we humans have a tendency to do, it is what we inherently are. Prior to the elevation of the terms “art” and “aesthetics” to elitist notions and standards in the last two centuries, the arts were viewed, across time and place, as embedded in the everyday rhythms, routines, and rituals of human *artified* behavior. We are *artifiers*. *Artification* refers to the act of transforming the everyday ordinary into the everyday sacred through artistic/ritualistic engagement. It is not merely about making objects appealing but distinguishing and imbuing them with symbolic meaning (S. Brown & Dissanayake, 2009).

Table 3.1

The Social Function of Art

The arts serve to:

- reinforce collective identity and belonging;
- mark time and ritualize the life-cycle;
- communicate with the divine and, thereby,
- alleviate uncertainty and existential anxiety; and
- foster community and a spirit of cooperation for the common good.

Note. Source of data: S. Brown & Dissanayake, 2009.

What Is Creativity?

Creativity operates as the transcendent function of the psyche. It is an alchemical process of converting raw material into tangible gold. The creative impulse is the instinct for self-awareness and the urge for self-expression. Creative engagement allows the soul to play; it *is* soulful play. Kenny (1989) defines the creative process as an inter-play:

> of forms, gestures, and relationships, which as a whole constitute the context for a movement toward wholeness. It is an existential being and acting which is not product-oriented and which appreciates each emerging moment as the only moment in time…It is informed by love, the intelligence of the heart, and thus the knowledge of the self-organizing system. (p. 89)

Gadamer (1998) describes play as a dynamic exchange and intermingling of subject and object, allowing what may otherwise remain unformed or hidden to come into view. This idea is portrayed in “The Creation of Adam,” Michelangelo’s masterpiece, painted on the ceiling of the Sistine Chapel. Here, creativity is symbolized as a dynamic tension and holding of paradox between two opposing phenomena, portrayed as God and Adam. It is also a symbol of liminality or transitional space. The hairsbreadth-gap between outstretched hands and fingertips represents infinite space and infinite possibility: the Creative Void. The void is the creative field of play, from which creative works emerge. In the timeless, spacious zone of creative activity, ego and Otherness dissolve, birthing new possibilities. The creative process involves cycles of indwelling (gestation) and out-dwelling (invention), a reaching inward toward self/soul and a reaching outward toward Life, in its infinite capacity for expression.

Moreover, as Gardner (2002) suggests, the dynamic exchange between researcher and audience, made accessible through aesthetic expression, is also a form of creative inter-play. In this manner, portraiture and ABR are not only intersubjective, they are what I would call interessential, as the researcher’s essence intermingles with that of her co/searchers and audience. Thus, portraiture and ABR are humanizing, relational, and emergent modes of inquiry, as well as interventions (Lawrence-Lightfoot & Davis, 1997).

Principles and Attributes of ABR

In their review of ABR dissertations in the field of education, where arts-based inquiry began in the 1970s, Sinner, Leggo, Irwin, Gouzouasis, and Grauer (2006) identify four attributes, also applicable to healthcare research: “[1] a commitment to aesthetic…practice, [2] inquiry-laden processes, [3] searching for meaning, and [4] interpreting for understanding” (p. 1223). ABR later expanded to include a wide range of creative practices (Sinner et al., 2006) and disciplines of inquiry in the human and social sciences (Cole & Knowles, 2008). ABR is relatively new to the field of health and medicine, where a positivist paradigm continues to reign and unscientific qualitative methods are resisted (Boydell, Gladstone, Volpe, Allemang, & Stasiulis, 2012). While some studies in Boydell et al.'s review of ABR research in health care address life-threatening illnesses, none focused specifically on the end-phase of life. ABR has many notable capacities suitable to healthcare research, as shown in Table 3.2; most cited is the ability to elucidate the subjective experience of illness (Boydell et al., 2012). "Reflexivity, metaphor, and generativity" contribute to making ABR a prime candidate for translating the "highly subjective" (Higgs, 2008, p. 551) and sensitive aspects of human experience associated with EOL research. These features underscore the artist-researchers significant use of self in the process of inventing artful research and representations (Higgs, 2008).

Research that is relevant, accessible, engaging, and holistic, integrating body, mind, heart, and soul, are cardinal goals of ABR (Cole & Knowles, 2008). Transcending constraints of conventional language through symbol and metaphor, ABR provides appropriate apparatus for investigating the ineffable matters of the human condition (Cole & Knowles, 2008; Eisner, 2008). As "expressions of meaning" (Eisner, 2008, p. 8), the arts are the manifestation or "structural equivalent of emotions" (p. 7). The aesthetic medium is the message (Eisner, 2008).

Table 3.2

The Capacities of Arts-based Research

Arts-based research has the capacity to:

- capture and amplify nuance;
- shift perception, making "the familiar strange and…the strange familiar" (p. 11);
- generate empathy and potentiate action;
- cultivate social and emotional intelligence;
- deepen humanistic sensibilities and understanding; and
- produce practical knowledge relevant to real lives.

Note. Source of data: Eisner, 2008.

A more radical view of the “aesthetic utility” of ABR, offered by Barone and Eisner (2012), emphasizes the capacity for “luring” its audience to “vicariously reexperience the world” (p. 20). A measured dose of perceptual “disequilibrium” can instigate reevaluation of preconceived or implausible worlds and meanings (Barone & Eisner, 2012, p. 16). Intent on exposing blind spots, artists shine a spotlight on negated social experience and voices by shifting our gaze to the “negative” (Higgs, 2008, p. 553), in-between, spaces of society. Thus, working for social change, the artist researcher humanizes the unseen and unseemly, and softens fear, all of which reinforce Otherness. Importantly, as Barone and Eisner (2012) astutely recognize, a paradigm centered on the quest for absolute truth and knowledge (that which drives the medical industrial complex) is a defense strategy, masking uncertainty and unknowingness inherent to living. ABR offers an antidote to what Caputo (1987) refers to as the “metaphysical desire for safety” (p. 7) by offering a refreshing, albeit sobering, return to the “original difficulty of things” (p. 6). In sum, by striving to unearth uncomfortable issues and unpleasant truths, (Barone & Eisner, 2012) ABR fosters our capacity to embrace uncertainty and the unknown.

Poetry as a way of knowing and expression.

Poetry is the shortest emotional path between two people.

(Robert Frost, as cited in L. Richardson, 2002, p. 879)

A poem is clay in my hands. It gives me something moist to hold and to mold, something I can work with, and a means for working through. Poetry is a way to understand my personal her/story and larger soul/story. Introduced in a high school creative writing class, what served as a lifesaver during turbulent teenage years has evolved into a life-enriching practice. Throughout, it has served as sense-maker and integrator, bringing structure and form to feeling, and offering a canvas to paint the changing landscapes of life, the natural world, and within.

In my Women's Cancer Support Group, How to Live discussion groups, and focus groups for earlier research on the topic of this dissertation, I have used poetry as an icebreaker; as a stimulus for group member reflection, expressive writing, and dialogue; and as a way to punctuate and bring closure to a meeting. Rotating facilitators open monthly Circle of Friends for the Dying board meetings with a selected poem, as a way to presence and come together as one heart, one mind. Poetry is woven into collages on cards and scrapbook covers I have made for friends and program members facing dying, and into eulogies delivered at memorial services. An original poem framing the world outside my window served as a prelude for monthly letters to the pen pal on death row who I never met, as a way to send beauty and acknowledge our common humanity. In a similar manner, Lusseyran (1959) recited poems to his bereft companions in Buchenwald as a means to offer respite, revitalize the soul, and to hold and re-member their place in the world. I believe the personal poems recited during my first residency at Antioch was the most authentic, and perhaps most vulnerable, way to introduce myself to my cohort. In the Research Redesign learning achievement, I imagined participants' original poetry as a source of data and as an aesthetic/expressive/therapeutic medium for making sense of serious illness. Collage has been used in similar ways throughout my adult life. If the "research self is not separable from the lived self," as L. Richardson (2002) proposes is true (p. 887) then, based on these examples, I am indeed an artist-researcher.

The literature validates my lived experience as a poet, and provides insight into my relationship with prose. For me, prose requires forced induction and forceps, while poetic language is more naturally birthed. L. Richardson's (2002) assertion, "Nobody talks in prose" (p. 879), may explain why I find thinking and writing in prose so challenging. By contrast, the language and shape of poetry more accurately reflects speech—and the natural movement of the breath (Tedlock, 1983). In this manner, it more accurately reflects and makes space for embodiment, and for feeling. Contrary to Descartes' influential mantra, "I think, therefore I am," my experience of the world proclaims "I feel, therefore I am." Returning to my native tongue, poetry has allowed me to integrate my artistic and scholarly selves (L. Richardson, 2002).

The poetic impulse originates in the feeling body, residing close to the bone of sensation, emotion, image, and intuition. Kenny defines intuition as a deeply integrative form of tacit knowledge: "a highly sophisticated form of logic that integrates…body, heart, mind, and soul experience and gives you an immediate response" (Antioch class presentation, January 15, 2011). Poets have a knack for intuiting and harvesting the words in-between words (Higgs, 2008). Rooted in the Greek *poiein*, means "to make" (Leggo, 2008, p. 166). According to L. Richardson (2002), the function of poetry "is to re-present actual experiences—episodes, epiphanies, misfortunes, pleasures; to retell those experiences in such a way as that others can experience and feel them" (p. 887). It is an aesthetic re-casting, transmitting the essence of an experience. Griffin (1995) presses the point further, insisting poetic expression "does not [merely] describe. It *is* the thing. It is an experience, not the secondhand record of an experience, but the experience itself" (p. 191). These perceptions are evidenced in poetic passages and renditions of life-threatening illness.

A compelling example is the poetry illuminating the dark corridors of Claire Philip's (1995) intimate cancer journals. *Lifelines* was written in the 1980s (and published posthumously) when the word cancer was rarely spoken in public or privately, whether in a doctor's office or amongst significant others. Spanning the last three years of her life, the journals were indeed her lifeline, a way to contain, anchor, companion, witness, and, perhaps above all, learn from suffering. Philip mixed metaphor-packed poetry into her prose to articulate and highlight meaning. In exchange for a lifelong pattern of privacy and anonymity, the poetic form casts a silk casing for raw feeling to be met and attended. Poetry as revealment counters the culture and psychology of concealment that reigned over, and would have otherwise silenced, her illness experience. Here, the presence of poetry is symbolic of the tender urgency for authentic expression when facing further suffering and death (Philip, 1995).

Drawing from the creative well of original, *a priori* knowing, the poet opens up “textual spaces,” promoting non-discursive ways of experiencing and interpreting the world (Leggo, 2008, p. 167). Art-making and audience receptivity require and stimulate embodied thinking, metabolized cellularly and experientially rather than analytically, carving out subtle vistas of understanding (L. Richardson, 2002). L. Richardson suggests we are physiologically predisposed to respond to poetry, stating, “Even if the prosodic mind resists, the body responds to poetry. It is *felt*” (p. 879). Thus the poet has the capacity to “‘show’…another person how it is to feel something,” inviting empathy and compassion in her audience (L. Richardson, 2002, p. 880). The poetic form offers audiences “a site for dwelling, for holding up, [and] for stopping” (Leggo, 2008, p. 166). It makes space to listen, reflect, and feel. The qualities discussed lend authority to the poetic voice as it reaches into and touches audiences, making poetry a compelling choice for social science research (Leggo, 2008; L. Richardson, 2002) and, specifically, end-of-life research.

Collage as a way of knowing and expression. I have also been a collage-maker since my teenage years: a searcher, discoverer, collector, and meticulous arranger of findings. Collaging has been a means for bringing beauty and some semblance of order and coherence to my experience of the world. The phenomenon of finding feels as though I am being found, as life and nature present me with fresh surprises. Best finds manifest not as the result of seeking but rather through deeply participating in the present moment.

Artists are drawn to the unconventional. A strong penchant for curiosity, observation, and improvisation, predispose them to discovery. As vessels for creativity, their receptacles are attuned, open to the sentient and material relics of their environment. Artist-researcher Lou Horner (as cited in Higgs, 2008) describes herself as being in a continual state of search—of hunt—for artifacts of meaning. The artist, she concurs, “is always researching, collecting artifacts, observing the world and conditions and emotions to use in their portrayal of the meaningful” (p. 550).

I find Butler-Kisher’s (2008) definition for collage rather limiting: “the process of cutting and sticking found images and image fragments from popular print/magazines onto cardstock” (p. 265). More broadly, I conceive of collage as the activity of blending previously disparate materials of any sort into a synergistic, aesthetic, relational whole. This involves precise scissoring (or careful tearing), positioning, and pasting or other method of bonding things together. Apropos is the term assemblage, alternately used. My collage work has evolved over the years from being single to three-dimensional, and from largely paper to mixed ingredient compositions, predominantly contributed by nature.

The term collage, popularized by Picasso and Braque in the early twentieth century, is derived from the word *coller,* meaning glue or to stick (Butler-Kisher, 2008). Yet the practice of collage-making began as early as 200 BC in China, alongside the invention of paper, long before it was popularized by Cubists as a means to illustrate the multidimensional nature of reality (Butler-Kisher, 2008). As a form of “visual inquiry,” the “partial, embodied, multivocal, and nonlinear representational potential" of collage is to evoke fresh ways of seeing, knowing, and revealing (Butler-Kisher, 2008, p. 265).

A collage is a visual poem. Like poetry, collage-making fits a poststructuralist agenda (L. Richardson, 2002) to short-circuit and disentangle our conditioned perceptual apparatus, cultivating what I refer to as perceptual dexterity both in maker and viewer. Insightful meanings linger around borders, between the hidden cracks and crevices of everyday "language, images, materials, situations, [and social] space" (Irwin & Springgay, 2007, p. 6). In the same manner in which linguistic devices are employed in poetry, visual devices are applied in collage to disrupt predictable interpretations (Butler-Kisher, 2008). Moreover, just as poetry opposes conventional writing practices, collage collapses prescribed visual routines, each working to dismantle oppressive power structures and redress divergent worldviews. In sum, ABR envisions and endeavors toward social transformation.

Principles and Attributes of Portraiture

At the end of the day, what matters is a good story.
(A. Guskin, personal communication, January 10, 2012)

Described by its creatress, Sarah Lawrence-Lightfoot, as a border methodology, portraiture intersects social science disciplines of anthropology, psychology, and sociology (her province) with the arts (Lawrence-Lightfoot & Davis, 1997). Portraiture also artfully borders several qualitative methodologies, including case study, narrative, phenomenology, ethnography, and arts-based research (Carroll, 2007; Lawrence-Lightfoot & Davis, 1997). While malleable, it is also a rigorous and systematic style of studying "human experience and organizational life" (Lawrence-Lightfoot & Davis, 1997, p. xv). By purposefully shaping an aesthetic narrative, portraiture attempts to come "as close as possible to painting with words" (Lawrence-Lightfoot, 2005, p. 6). In particular, portraiture relies on the fundamentals of ethnography: "talking, listening, transcribing, translating, and interpreting," as well as "bearing testimony and witnessing" (Behar, 1996, p. 163). Central to all qualitative methodologies, these exploratory skills, Behar (1996) insists, "offer the only, and still slippery, hold on truth" (p. 163). Portraiture fulfills Behar's (2008) appeal for an ethnography merged with the creative dimension into a genre of *creative non-fiction,* in effect, expanding the scope and reach of ethnographic scholarship toward a broader audience. Together, these elements weave a storied narrative ideal for capturing the subtle, interior dimensions of people and the culture of places: how they operate, and what they look and feel like, from the outside-in, and from the inside-out (Lawrence-Lightfoot, 2005).

Goodness. Based on on-site visits, up-close observation, in-depth interviews, and field notes, the goal of Lawrence-Lightfoot's (1983) portraits of high schools was "capturing their institutional character and culture and documenting the mix of ingredients that made them good" (Lawrence-Lightfoot, 2005, p. 5). Similarly, Davis, Soep, Maira, Remba, and Putnor's (1993) collective, "group voice" portraits of community-based arts-centers, "trac[ed] the structural, ideological, relational, and cultural themes that have made them resilient and creative organizations" (Lawrence-Lightfoot & Davis, 1997, p. 15). In this dissertation, I will create portraits of community-based end-of-life residences (CBEOLRs), illustrating what makes them good. Attention to goodness, central to portraiture, offers a perceptual lens to discern and illuminate the features, everyday activities, and voices which qualify a residence as a 'good place to die,' for residents and their loved ones, as well as for residence staff and volunteer community members supporting, and affected by, the dying process.

Intimacy. Integrating empathy and introspection, Cooley (1909/1956) refers to intimacy as a "method" for seeing another person's "human nature [as] not wholly alien to…[one's] own"

(p. 7). Intimacy implies a mutual recognition of wholeness between researcher and co/searcher (Witz, 2006). Lawrence-Lightfoot and Davis (1997) are intent on having their respective subjects feel thoroughly “attended to, recognized, appreciated, respected, [as well as] scrutinized” (p. 5). The existentialist psychologist van Kaam (1959) uses the term experiential communion to describe intimacy:

> The experience of ‘really feeling understood’ is a perceptual-emotional Gestalt: A subject, perceiving that a person co-experiences what things mean to the subject and accepts him, feels, initially, relief from experiential loneliness, and, gradually, safe…with that person. (p. 69)

The authenticity of the portrait rests upon this capacity: to be wholly in touch with, and touched by, the Other, who is perceived “as sacrosanct, part of the mystery of existence” (Witz, 2006, p. 266). As described by Lawrence-Lightfoot and Davis (1997), the multi-faceted and fluid roles the portraitist plays in creative relationship to her co/searcher supports the cultivation of intimacy:

> As I listen to…life stories, I play many roles. I am a mirror that reflects back their pain, their fears, and their victories, I am also the inquirer who asks the sometimes difficult questions, who searches for evidence and patterns. I am the companion on the journey, bringing my story to the encounter, making possible an interpretive collaboration. I am the audience who listens, laughs, weeps, and applauds. I am the spider woman spinning their tales…I am a therapist who offers catharsis, support, and challenge, and who keeps track of emotional mine fields…[and] the human archeologist who uncovers the layers of mask and inhibition in search of a more authentic representation of life experience. (p. 12)

Foremost, I hope to be the trusted “companion on the journey.”

Resonance. The artful portraitist executes her craft with intentionality and intuition, selecting resonant detail with which to embroider a meaningful and cohesive story (Lawrence-Lightfoot & Davis, 1997). Listening for resonance implies attunement to the participant’s voice, words, and deeper meanings. Conventional meanings of the word resonance suggest qualities of richness: “being deep, full, and reverberating; the ability to evoke or suggest images, memories, and emotions" (Resonance, n.d., para. 1). These connotations are fitting to the portraitists' purpose. Witz (2006) translates Lawrence-Lightfoot and Davis' (1997) use of the term to mean "clear flows of feeling," whereby participants' core psychological structures and ways of being are revealed (p. 250). Lawrence-Lightfoot and Davis (1997) use the metaphor of quilt-making to describe an iterative process of placing and piecing together resonant swatches of research material. I naturally gravitate toward the metaphor of collage-making. Portraitists and poets weave a quilt of resonant words to evoke images; collagists weave a quilt of resonant images and visual patterns (sometimes laced with words) to evoke ideas. Resonance sparks identification. Like a good book, a good portrait has a transporting effect, bridging distance and difference. It moves the audience closer to the subject at hand. Thus, portraiture promotes a felt sense of participation.

A people's scholarship. Absent of academic and medical jargon, portraits have all the artifacts of a good story, offering a refreshing contrast to conventional textbook-style knowledge and writing. Portraiture's aesthetic features are what make it approachable and accessible to diverse audiences. Lawrence-Lightfoot and Davis (1997) understand, "If we want to broaden the audience for our work, then we must begin to speak in a language that is understandable, not exclusive and esoteric . . .a language that encourages identification, provokes debate, and invites reflection and action" (p. 9). Linking scholarship with solidarity, Featherstone (1989) brands portraiture as an on-the-ground people's scholarship, rooted in real lives rather than abstract knowledge. In this way, portraiture produces intimate stories that speak to the heart of what really matters to people, serving as a catalyst for rich dialogue critical to community-building and right action (see Chapter VII for an elaboration).

Common attributes of portraiture and ABR. Through reviewing the literature on portraiture and ABR and highlighting salient features in this chapter, in addition to practicing their dual implementation in my pilot study, I discovered their common adaptability, attributes, and complementariness (Carroll, 2007; Hill, 2005; Newton, 2005; Swamy, 2011). They are found to be mutually enhancing and synergistic. In many respects, ABR's conceptual framework and rationale for providing a good methodological fit mirrored that of portraiture. The following table summarizes common attributes.

Table 3.3

Common Attributes of Portraiture and Arts-Based Research

- Research is construed as an aesthetic practice & the researcher is perceived as an *artist;*
- The artist's *signature* on the research canvas is made overt (Cole & Knowles, 2008);
- Creative representation of data is *impressionistic* rather than factual;
- ABR *paints* with images; portraiture "paint[s] with words" (Lawrence-Lightfoot, 2005, p. 6) (poetry also paints with words, especially metaphor);
- Portrayal of *psychological truth* (Higgs, 2008, p. 550), depicting nuanced inner-states of being;
- Respect for *uncertainty*;
- Meticulous attention to and rendering of *detail* (detail carries essence);
- Researcher, co/searcher, & audience are viewed as co-investigators and *co-producers of meaning*;
- Meaning-making is construed as a complex, *intersubjective*, and emergent process;
- *Wholistic* orientation, connects body/mind/heart of researcher and audience;
- The *aesthetic* dimension is conceived of as an active, catalytic agent, enabling "vicarious participation" (Eisner, 2008, p. 6);
- Promotes *evocation:* the capacity to rouse empathy, emotion, action, deep conversation, and to raise fresh, complex questions (Eisner, 2008);
- *Empathy, emotion, and imagination* are perceived as both researcher skill and audience resources to promote social awareness, community-building, and change;
- A central goal is to expand/transform audience perception;
- Generates practical knowledge applicable to real lives & accessible to diverse audiences;
- Invokes "universal humanist thinking" and feeling (Behar, 1996, p. 169);
- Amplifies and generates goodness; and
- Shifts the positivist standard of validity to a standard of *authenticity* (Lawrence-Lightfoot & Davis, 1997).

Research Design

The purpose of this study is to describe the everyday lived experience of dying and the care culture within freestanding, community-based end-of-life residences, and to do so in an artful and compelling manner in order to engage a diverse audience. To this end, a series of case studies were crafted into two genres of portraiture: people portraits are based on interviews of individuals living with terminal illness; place portraits are based on interviews of a diverse group of individuals centered on the care of terminally ill residents situated in a CBEOLR.

Person-centered portraiture, referred to by Lawrence-Lightfoot as “human archeology,” is described as a respectful probing of a person’s layered complexities, to reveal character and essence (Lawrence-Lightfoot & Davis, 1997, p. 15). This term aptly “convey[s] the depth and penetration of the inquiry, the richness of the layers of human experience, the search for…[meaningful] artifacts, and the careful labor that the metaphorical dig requires” (p.15). It is an excavation of the psyche. In this manner, the human archeologist studying the end-phase of life breaks ground to unearth and examine the internal landscape of living with dying (Lawrence-Lightfoot & Davis, 1997). Similarly, Mount et al. (2007) use a phenomenological approach to delve into individuals’ “existential/spiritual/inner life” in order to comprehend their particular experience of life-threatening illness (p. 376). As a pilot project, in preparation for this study, I blended this genre of portraiture with arts-based research to produce “Illuminations: Portrait of Diana” (see Chapter IV).

Moreover, Lawrence-Lightfoot (2005) refers to place-based portraiture as “life drawings” (p. 5). Life drawings are not merely about place. Rather they illustrate how lives are emplaced: how “actions and interactions are experienced, perceived, and negotiated in the setting” (Lawrence-Lightfoot & Davis, 1997, p. 15). As applied to my research, a portraitist rendering of an end-of-life care setting draws a highly detailed, though surface-level, map of the social topography and peopled ecology of a place (Lawrence-Lightfoot & Davis, 1997) to describe how care is also emplaced (i.e., care culture). This suggests a person-action-environment framework akin to the health/social care geographer's trade (Moore et al., 2013; Poland et al., 2005) and a sociocultural perspective for understanding human action and interaction as situated within place (Faber et al., 2003; Rasmussen & Edvardsson, 2007).

My portrait construction was based primarily on semi-structured, conversational-style interviews. In this manner, I encourage, rather than guide, participants to address and reflect on certain areas of experience while encouraging free and nuanced expression. Witz (2006) distinguished between interviewing for information versus for feeling*,* as practiced by portraitists, to reveal "deeper aspects" of the individual (p. 246). It is interviewing for essence.

Participant and site selection. Person-centered portraits was based on a purposive sample of two adults who were members of the HealthAlliance Hospital Oncology Support Program (OSP), where I am a staff social worker. OSP is a community-based program, offering free supportive and educational services to people living with, or affected by, cancer, in the home-like setting of the Cancer Support House or in the hospital. Criteria for inclusion included: awareness of a terminal prognosis; sufficient cognitive capacity and physical stamina to partake in one or more in-depth, 60- to 90-minute interviews; enrollment on hospice services; and willingness to speak about terminal illness and dying. Interviews were conducted in the participant's private residence. I previously interacted with participants in a variety of capacities at OSP, including my role as support group facilitator. Both participants were female, over the age of 60, and living with terminal cancer; one was Caucasian and the other (still living as of May 2014), was part Native American. The latter was selected as representative of a candidate for a (hypothetical) community-based residence, *if* such an option were available (i.e., she lived alone and lacked a primary caregiver).

For the place-based portraits, a purposive sample of two different models were selected to highlight the care culture and distinguishing characteristics of the CBEOLR, and for light comparison. Both sites were visited prior to this study, and some staff were previously interviewed, either formally (for earlier research) or informally. Site selection was based on several criteria, including: first or representative model in a region; innovative organizational and care practices; community orientation; and home-likeness in scale and features. Participants included residence staff, community leaders, volunteer caregivers, residents' kin and friends, and terminally ill residents. (I was unable to highlight the latter, as I had initially intended, due to lack of accessibility of residents, unable or willing to participate; also see Chapter VII). Most interviews were conducted in the CBEOLR. Similar criteria and procedures as in the first participant set were used to select and interview a few residents. Prospective participants (and their relations) were identified and approached by staff. Depending on capacity, a 30- to 90-minute interview was conducted. All interviews were audio taped, with the *option* of supplemental video recording. (I decided not to use any video clips in the final document, as I initially planned, but rather to rely on other media). Additionally, I observed everyday caregiving practices of residents up-close. (While I was unable to engage in direct, hands-on care for this research, as initially planned, I was able to do so as a volunteer at a home prior to embarking on this project).

Furthermore, field notes were used in interviews and on-site visits to capture foreground interpersonal (including non-verbal) interactions, as well as background environmental observations (supplemented by photographs), which might have otherwise gone unnoticed

(Mount et al., 2007). Understanding was an emergent process, whereby field notes were used to record, reflect on, and refine data, serving to ground and contextualize the interview material (Mount et al., 2007). Following interview transcription and integration of field notes, and other supportive data, the first set of interviews were transposed into an arts-based, poetic and visual (via collage) narrative; the second set were transposed into an aesthetic, story-like, narrative, based on standard portraiture style. Data collected from earlier research is integrated into the final text and document as a whole, demonstrating "sustained thinking" on my topic (C. Kenny, personal communication, January 4, 2013).

Importantly, due to the personal nature of patient and family interviews and inclusion of photos, along with other supportive autobiographical material, participation was contingent upon the verbal and signed agreement that the person's identity and identifying information would not be confidential. One resident, Deidra, who initially spoke with me at length but did not wish to sign a consent, is fictionalized. When possible participants (or their appointed research agents,) had the opportunity to edit and delete any part of the draft in which they appeared. The Antioch University Institutional Review Board approved the previous and present research. In addition, consent was obtained from the director of respective residences.

Scope and limitations. This study was limited in scope in several areas. It is hoped that strengths will compensate for their impact. First, the research methodologies, research design, and small sample size were chosen to emphasize depth rather than breadth, and to yield rich description rather than facts (Crouch & McKenzie, 2006). I realize that qualitative and arts-based research may not speak to those who equate real research with numbers and hard facts. So-called soft research, outside the borders of convention, invoking vulnerability, may prove to be foreign or uncomfortable to some researchers and clinicians (Behar, 1996). Some, however, may regard my use of unconventional methodologies and representation of data in addressing the subject, employing art as an interpretive and integrative tool, as a strength.

Second, the nature of the phenomenon and population studied, in addition to the nature of the care-settings studied (having few beds), limited access to residents whom I originally planned to highlight in the place-based portraits. While findings for the uncommon care-setting genre I chose to study may not be considered directly transferable to other care-settings, they are intended to promote new understandings and meanings that may indeed prove valuable to people in diverse contexts (Edvardsson, 2005). Moreover, they may provide stimulation and guidance to clinicians and leaders to envisage new possibilities for care and places of care, such as adopting a more home-like environment, as intended.

Furthermore, the subjective nature of engaging in qualitative research involves significant interpretive filtering of data through a personal and biased lens. Readers oriented to quantitative research may also be critical of my previous relationships with participants in the person-based portraits, citing lack of objectivity. I believe the privilege and benefit of my longer-term relationships served to heighten trust, which facilitated intersubjectivity, meaning-making, and nuance, whereby a sense of being understood was optimized. This was confirmed by family members who reviewed and commented on one portrait, and by the second participant who reviewed her own portrait. In the case of one Diana, for instance, having had a long-term relationship opened the invitation by her family to be present as she was nearing death, a ‘private’ experience that may otherwise have been off-bounds. Thus, relational depth can substantiate data and foster authenticity, improving credibility.

Lastly, my own selection bias for participants in the person-based portraits and imposed by the care-setting, as far as who chooses or is chosen to be a resident at a CBEOLR, and who consents to be a research participant, may also limit the credibility of findings and their transferability to other terminally ill people. In the final analysis, credibility of narrative research lies within readers' perception. This is based on a number of factors, including whether the study has: 1) resonance, "the click of recognition" (Lawrence-Lightfoot & Davis, 1997, p. 247), similar to verisimilitude, meaning the interpretations are true to life and lived experience (Polkinghorne, 1988); 2) a sense of an "aesthetic whole" (Lawrence-Lightfoot & Davis, 1997, p. 243), in essence, "the story holds up, the pieces fit, [and] it makes sense" (Eisner, 1985, p. 241); and 3) whether the research has relevance to, and the capacity to positively affect, real lives (Westmarland, 2001).

Prior learning: Observing essence. I got a taste of the complexity and challenges of conducting end-of-life research through conducting a few interviews for pilot studies and constructing a portrait based on one participant, Diana, in the following chapter. I learned, as conditions change, often rapidly, how one searches must change. Witz (2006) is particularly instructive in his distinction between interviewing for information versus interviewing for feeling and essence, as practiced by portraitists, to reveal "deeper aspects" of the individual (p. 246). In the same manner, the researcher observes for feeling and essence, revealing new data and interpretive insight. I discovered, while opportunities for verbal exchange are extinguished, new possibilities for connecting and making meaning can come forth. Observation proved to be a critical tool for researching (and being with) the dying, particularly for people who were non-verbal due to illness or nearing death. This shift in researcher roles (from interviewer to observer,) directed by the participant's transition in being, is conveyed in the poems by a shift in voice. As Diana's voice gradually dissipates, my voice becomes the vehicle to carry and express essence as I endeavor to transmit the ineffable. While there are indeed limits for understanding the subjective experience of dying, it seems that learning to be with the phenomenon of dying is limitless. In one of the last poems for Diana's portrait I wrote: "with one foot/in the twilight zone,/it is impossible to know/if what Diana says is true./Being here, now, with Diana,/'truth'/no longer matters." A different kind of truth emerges. As anticipated, I had ample opportunity to practice being adaptable and open to what is possible to learn about researching people who are nearing death, which I elaborate on, retrospectively, in the final chapter.

Chapter IV: Portraits

Illuminations: Portrait of Diana

Figure 4.1. Detail of "Tribute to Diana."

It is remarkable how much consolation and hope
we can receive from [those]…who, while offering no answers
to life's questions,
have the courage to articulate the situation of their lives
in all honesty and directness.
(Nouwen, 1974, p. 39).

In my heart, I have had a good life….
I have learned to love.
(Diana Edelman, 2011)

Figure 4.2. Diana (with her Beloved Orange Cat, Jinglebell, who predeceased her on July 4, 2011).

In the eulogy I shared at Diana Edelman's memorial, I refer to her as the "Central Spoke—if not the Hub—in the wheel of our weekly women's cancer support group." Prior to interviewing her for a pilot research project, I knew Diana for five years through my work at the Oncology Support Program (OSP). She also participated in a yearlong, monthly study and discussion group on issues related to dying and death that I facilitated. The poems that follow were constructed from excerpts of the first of two interviews (the second included her family) conducted on August 21, 2011, as well as research journal notes based on phone calls, home visits, and email correspondence maintained over the last months before Diana died. Her spoken and written words are italicized. The data spans the time-period from her enrollment on hospice in July 2011, until her death five months later. The collage was assembled after the poems were composed, representing a further layering and way of being with the data—and Diana. Diana died at home on December 3, 2011, at the age 73. Through this portrait, I hope to illustrate and honor the tribute written in Diana's obituary: "She lived her dying generously."

Figure 4.3. Going to Hidden Lake Camp Lake Placid, August 1950.

I Lived with Fear

I remember sweating bullets
every time I went for blood tests
and CT scans and PET scans, worrying
that the cancer would come back.

That cancer, when I was first diagnosed
in December of 1986, had a whole lot of fear
attached to it. I was 48 years old, living in Woodstock
with 3 kids in junior and high school. I was married then.

I picked up
from the doctors
that my prognosis wasn't good. I had
twenty-two positive lymph nodes—
all that you could have—
all matted together.

A prime candidate,
I lived with fear of recurrence.
I lived with recurrent fear.

I had a mastectomy
and 6 months of pretty serious chemo
prescribed by Sloan Kettering.

I had little scares
from little lumps.

But it all turned out okay!
It all turned out great—20 or 21 years cancer-free!

Until
the
other
shoe

dropped.

The other shoe

drops.

Breast cancer again, in 2007.
But a new one.
A different one. Lobular.
An unfortunate one.

Diagnosed at stage IV.

So I understood right off the bat
that was not good news.

There is no stage V
There is no cure.

Those years,
living between cancers,
were good years—I got back
into teaching, I got a degree
in teaching English as a Second Language at SUNY Albany;
I got a divorce, and I did a lot of hiking in the Catskills.

When she describes Suzy, and Benji, and Maudie,
her three adult children,
as being open and honest, Diana is also characterizing herself:

> *None of this denial stuff*
> *they want to know*
> *what is going on*
> *and they want to help—*

She was open and honest.

> (This might be her epitaph,
> had she chosen
> a tombstone burial
> rather than a whole-body donation
> to Albany Medical Center.)

But the breast specialist consulted at Sloan Kettering was not.

I asked how long
but he wouldn't give a prognosis.
He adamantly refused.

More forthcoming, her oncologist told her two to four years.

Four and a half years later,
she outlived the prognosis.

I'm Okay with Dying

The Great Regret,
is how I was with my children when they were young,
and I was drinking.
I wasn't the mother I wished I had been
and I'm still sorry about how that hurt them. And I know
I can't go back
and redo it
in any way.

But I feel now,
from the lessons learned being in recovery
and seeing what wonderful parents they are,

it's about learning how to love—

how to be less self-centered, less afraid,
more there for the other person—
even if you learn that the day before you die
or the day you do die,
it's still of value.

The Twelve-step program really helped me with the cancer.
Like really taking a look—
a Real
Serious,
Honest
Look—
at myself and my own shortcomings.
Painful and hard to do,
but a huge payoff
in the end.

Really coming to a sense of awareness
and being able to accept
these aspects of myself,
see how I've hurt people, in particular my children
through some of my own shortcomings
and then making amends.

That whole process,
which goes on and on,
has been tremendously helpful.

I'm so grateful for that now, because facing the end of my life,
having felt the Change—
that very, very Serious Change—years-long,
has made such a difference.

It has given me
a Sense of Completeness,
*of **Mission Accomplished**—*
or still accomplishing.

It's never finished.

What would it be like
to be facing the end of my life
without that Sense?

I've been trying to write my obituary
and I'm thinking,
What the heck am I going to put in there?
There's not a lot
and there's nothing
spectacular,
but in my heart,
I've had a good life.

You can't really put it on paper—
you can't put ***anything*** *on paper,*
but it feels—
            it feels like
            I've learned
            to love.

I grew up in a lot of fear,
                        a lot of fear*, and fear has been a big part of my life,*
and I think, with the help of some of the programs—
Twelve-step and Oncology Support—
I've been able to Transcend—not all,
definitely not all,
but ***some*** *of the fear,*
and learn more about love.

And that's enough!
And that's enough right there!
To make a life
Worthwhile.

Figure 4.4. Another Last Hoorah 10/2/2011. A day of family horseback riding, just two months before Diana died. Left cluster: Diana, Suzanne holding Nikko, with Benji in the rear. Right cluster: Samira in stroller, next to Liam and Alana; Patrick, Susie, and Nina "Maudie" in the rear.

Lessons

I've lost my hair three times—once,
from treatment of the first cancer,
twice from the second—
but not entirely.

I never lost
        every
        single
        sprig.

But close to it!

Life is an accumulation of lessons.
        The Worst Things
that happen can become
        the Best Things.

I really believe
that thing about pain
is the best teacher.

Living with stage IV cancer is bittersweet.

For every loss
there is some kind
of compensation.

Loss and gain
          are two sides
                    of the same coin. If you let the losses in,
                    the gains are there, they are absolutely there.

I learned
how different something can look
          when you look
                    from a different
                                        angle
          or position.

So it isn't all about loss.
It's about something I had!

          A Richness.
                    A Goodness.

When I gently remind Diana that her discomfort
is temporary,
she
quickly
reminds me:
It's ***all*** *temporary!*

Her words
          hang
on my bathroom mirror,
and in my mind.

Diana's favorite words were Roethke's:
"In a dark time
the eye begins to see."
And some anonymous ones:
"Experience is a comb life gives you
                              after you lose your hair."

These words, Diana understands,
spoken in different ways and languages,

have the same meaning across cultures.
They express a very basic truth
about the human condition.

Another thing that makes me feel
Complete,
            makes me feel
                                    okay with dying—a recent Illumination—
is that I keep having this Feeling:
that I've learned this
            and I've learned that—
                                    and I'm so grateful—
but I've learned these things   *too late.*

I've learned a lot of stuff in my life, but always,
it's just
            a little bit
                                    too late.

Yet, I've recently come to the Feeling,
probably having to do with the fact
that I'm coming closer
to death,

***I don't think it's too late**,*
not at all!

It is never too late!

Figure 4.5. “Tribute to Diana.” Ingredients: bamboo chair seat, driftwood, fabric from Diana’s pillow, bark, shells, lichen, fungus, seedpod, leaf, moth, comb, feather, beads, mirror, sequin, garlic top, paper, paint, and string.

Figure 4.6. Detail: "Eye of Illumination."

Figure 4.7. Detail: "Experience is a Comb."

Figure 4.8. Detail: "Who am I? (The 'I' Begins to See").

Commentary on Diana’s Portrait and Collage

Through collage, I weave myself into Diana’s lifeworld, using pieces of fabric from her home and some of her favorite words as thread. A small forest of eyes quest inward and outward. They represent the desire for intimacy: to know and be known, to see and be seen in wholeness, the yearning for self-awareness and completion, and a sense of playful curiosity and wonder—all of which I associate with Diana.

The perennial question, “Who am I?” (see Figure 4.8), which we circle around but can never completely answer, embroiders an eye (the eye-shaped tree bark) embedded with a sliver of mirror, its pupil. This is my eye/my question, too, related to the imperative for conscious use of self in research, clinical practice, and in being with dying. The mirrored eye is self-reflective; it looks within. It also the eye of the observer and witness. In the context of this portrait, the witness includes, potentially, the dying-person-as-witness (Diana), scholar-practitioner-as-witness (me), and the audience-as-witness (you, the reader). Diana’s favorite words, by poet Theodore Roethke (with a play on the words eye/I), hold the possibility of growth and transformation through embracing existential suffering: “In a dark time the eye begins to see.” For Diana, these words speak to every persons’ life journey toward becoming human.

Diana’s children were earnest witnesses throughout Diana’s dying process. The comments of Benji and Susie, Diana’s children, convey a recognition of the individual experience of dying (capturing the essence of their mother) *and* the universal. When Benji reads the poems, he is “brought back to her voice, her image, and her way of being in the World”. He also writes: “A particular poem, ‘It's all downhill from here’... especially conveys to me the broken reality that death intrudes upon us all.” Benji describes the collage as “earthy and chaotic - and therefore 'creaturely' and closer to the truth of the human situation” (personal communications, October 2, 2012).

Susie writes:

> You captured the very essence of her and the experience of her life and death….
>
> There is a clarity and richness here that very accurately conveys what the living and dying experience is for one person, and those that loved her….I think she would be both flattered by the accuracy of her experience and pleased that you are sharing this with others. She would feel satisfied that you understood her, that you took the meat of her essence and got it down on paper (personal communication, September 26, 2012).

Regarding the collage, she observes:

> I see the collage as [a] response to Diana and the impact she had on others in the OSP. It has both depth and darkness, but light and with movement...like my mother…. I can't help but feel turquoise is missing….she *was* turquoise, not earth tones. There is a buoyancy and hope in turquoise and I don't feel those qualities in the collage. But again, the collage isn't Diana, it's how she impacted others

The portrait also provides comfort, as Susie shares:

> I have not tucked her death into a far corner of my mind that got uncovered by reading and experiencing these words and images….So this is not a reminder, so much as a reinforcement of the feelings and thoughts I've experienced since her dying began….When her dying room was created, an incubator, a chamber, it was with purpose of warmth and acceptance. No façade of a get-well room. Truth and awareness were all there was. And it was wrapped in love…. I will always remember this feeling. And I relive it reading your/her words and pictures (personal communication, September, 26, 2012).

October 2011: Last hoorah's.

I did it!

Overlook Mountain yesterday.
It took me 2 hours; twice
as long
as usual,
but I got
to the summit.

Legs so weak, I pleaded
with my hiking buddies to go on ahead,
but they insisted
on walking with me.

We picnicked
in the bright sunshine at the top,
enjoyed magnificent views
from the Fire Tower,
and even the Great View
from the backside of the summit.

On the way up, one of us almost stepped on a black snake, about 4 feet long.

Crossing its path
it saw us and froze
before continuing
on its journey.

We took pictures of it
with its narrow tongue, darting in and out.

Now we have a little plan
to try Huckleberry Point on Monday.

These brilliant sunshine days are incredible!

Hospice Hike #2

When I told a few casual friends
at my line dance class
I'm on Hospice,
    they looked a little stunned.

Yesterday,

I hiked to Huckleberry Point with a friend.
Again, twice the time as usual,
but I got there!

We soaked in the sun on the ledges
like happy lizards
and watched the turkey vultures soar.

I'm going to try to hike a few more—
Giant Ledges,
Magical Quarry,
Twin Mountain.

I'd like to get a small list of Hospice Hikes accomplished
to share
as evidence
for others considering going on Hospice.

Even if they worsen my symptoms
or shorten
my days
I won't regret them one bit.

They feel like
my Last Hoorahs!

Hospice doesn't mean
you die in two days.
It doesn't necessarily mean
you're in bed all the time.

You could be on a mountain!

Figure 4.9. Giant Ledges: Diana Standing on Top of Her World.

11/21/11 It's all Downhill from Here…

She tells me she is fading
away
day
by
day.

Still
able
to crawl
up
stairs
to take the showers that she loves,

she is able to do
more and more
less and less.

A vacant hospital bed,
like a polite guest,
waits
in the living room,
while she continues to sleep in her upstairs bedroom.

We plan

a final interview,
both wondering aloud
how much longer
before death
calls.

Days?
A week?

Or maybe death
will crawl, too,

and she will linger
                    longer…

11/25/11 Sooner than Later

The Edward Gorey poster
previously hung
on the living room wall
                    perches
by the front door.

A yellow sticky note,
tagged by Diana some time ago,
bears my name,
though I am not anxious to claim it.

Bequeathed
years before, when “A Year to Live”
was only a notion,
it features *The Gashlycrumb Tinies*—a recitation
of unimaginably horrific fates.

Its quirky humor
reminds me of Diana.
                    I smile.

Now, death is sooner
rather than later.

Much sooner.

Diana’s voice late last night
is muffled by medication. Wishing to remain

lucid, she still tries
to stave off
opioids.

Within 24 hours,
Susie, her daughter, changes
the *Lotsa Helping Hands* community website posting
from “Need for overnight care”
to “Need for round-the-clock care.”

My goal of being with Diana for a third interview
shifts, too,
to just being with Diana,
and to relieving her son, Benji, of the overnight shift.

He tells me she is sad and scared.

I cry,
though not with her. And ache
the simple ache
of the heart.

Figure 4.10. Diana and I at the Annual OSP Holiday Celebration, 2007.

11/25/11 What Really Matters

Overnight at Diana’s,
the living room
transformed; now Death
has moved in.

The living room
is a living/dying room.

I come bearing a futon to roll out
on the floor next to Diana's hospital bed
to sleep on,
and empty
my small bagful of offerings:
fruit cake, tea light votives, and a cow bell
to hang at Diana's bedside
for the nights Benji or others sleep upstairs.

The hospital bed is strategically positioned
in the left corner of the room.
This visit
Diana occupies it. She faces
the sliding glass door of her tree-filled backyard.
                    To her far right, a fire blazes in the fireplace.

The room feels like an incubator.

The "hibernation," as Diana had anticipated calling it,
has officially begun.
I quickly realize I am overdressed
and remove my tie-dyed fleece pullover, wishing
I had another layer
to peel.

Benji has lovingly crafted a vibrant cocoon.
Family photos, previously distributed
among the downstairs rooms, now hover over
Diana's bedside cubby,
and concentrate on her.

Across the room, hangs a large sketchpad on the wall
with encouraging notes
for Diana to read, if she cares to.
In large letters, it lists the basics:
***Susie arriving (from Alaska) on Wednesday**
***Bowel movement needed, today!**

Benji plays back messages on the answering machine for Diana to hear.
Well wishes from family and friends.
She asks him to playback the saved message from Andrea,
a younger woman from the Women's Cancer Support Group
who died a few years ago,

just after her 50th birthday.

At the time the message was left,
Andrea, too, was at home on hospice.

Though familiar,
I can barely
          connect
                    the dots
between the Andrea I Knew,
                              the Andrea Who is No More,
                                                            and the Disembodied Voice
that rewinds time
and whispers the same words
over
          and
                    over.

Singing Goodbye

I visit Diana.
Robin, a member of the Women's Cancer Support Group, visits too,
and the three of us have some fun together
looking through scrapbooks assembled by the women's group
and singing familiar tunes…
This Little Light of Mine…

Then, seemingly, from out of nowhere,
with whatever gusto
she can still muster,
Diana breaks out
into a solo
drug-slurred rendition
of *Toot Toot Tootsie Goodbye.*

She is stellar!

Botching up the words
whole-heartedly, she leaves out some
and repeats
the chorus line…

We are all cracked up.

She tells us that a family member used to be in Vaudeville.

But with one foot
in the twilight zone,
it is impossible to know
if what Diana says is true.

Being here, now, with Diana,
“truth”
no longer matters.

The Sounds & Movements of Dying

This is the sound and movement
of lorazepam
and oxycodone

names of palliating drugs
though pansy-like

induce
a potent
vacancy

a rhythmic drifting
and dozing
like birds
swimming laps

or a cat
lapping water
from a metallic silver bowl.

You are a swimmer
breathing underwater
slipping
into vastnesses;

you sleep
like the slip
of a finger
that falls
asleep on a piano key.

You embody sea and ether;
you are fish and sky ocean and bird—

flow of the rivers
salt of the earth—

mountain and tree
rising in mid-air.

This is the movement, the sound of dying:

water flashes a silver tongue,
peals liquid bells—

and I remember how
we never got
to float you
in the pool
this past August,
circled and cradled
by family and friends,

or to visit Andrea's memorial bench at Poet's Walk,
or to conduct our final interview,
as planned.

And I remember how we practiced
saying farewell in October
not knowing
if it was real
or only rehearsal.

Now, at the Threshold,
holed-up,
as if a permanent resident
of a sense-less and sensory-drenching

flotation tank,

you are the singing and the far-flying echo
reverberating
within the chambered cave
of your dying.

12/1/11 - A Final Lesson

Last night's visit
you part the waves
of your resting place
to acknowledge my name when I arrive
but little else.

It is clear
you are preparing to leave.
But where will you be going?

Agitation
in your movement,
your furled brow; you want to sit up
climb out of bed
go for another eight-mile hike at Minnewaska. Now!

You still have the will,
you only lack the energy. You want to break free
of your confined Existence—
but not
quite yet.

Do you speak with clarity or metaphor when you say
they will be coming for you in the morning?
Or that soon you will board a plane—
as you work your way
inward and outward,
onward and onward,
through the luminous layers
of somnambulant waking
and drug-laced sleep?

I ask about your pain, where you are going, if there is anything you need…
You only manage to say:

Stop asking so many questions!

Diana Squires Edelman

Diana Squires Edelman WOODSTOCK- Diana Squires Edelman, died on Dec. 3, 2011, at 73, of metastatic breast cancer. She lived her dying generously, with grace, sorrow and humor. She showed those who loved her how to do it. Diana was born in Syracuse, June 23, 1938. She and her parents, Enoch and Florence Goulet Squires, and her brother, Mark, moved to Tigard, Oregon, then back east, to Lake Placid and Columbia County, N.Y. In 1956, Diana graduated from high school in Hillsdale, N.Y. She earned her B.A. (1960) from Cornell and later completed graduate work there and at SUNY, Albany. She married Robert Edelman in 1965. They had three children. The couple later divorced. From 1966 to 1972, Diana lived with her growing family in Boeblingen, Germany, where her husband worked for IBM. While there, she taught in an American Army school. Favorite among her European travels was a ten-day backpacking trek with her husband on the Hardangervidda in Norway: "We happened into the sunniest weather they had had there in decades. The following summer we went back to Norway for more backpacking and it rained every day for three weeks." Back home in America, the family moved to the Woodstock area, where while raising her children and participating in the peace movement, Diana volunteered and subsequently worked for Family of Woodstock (1980-90). Her most recent employment was teaching E.S.L. to adults at the Educational Opportunity Center, Albany, N.Y. (1994-2007). "Over the years," she said, "I met and learned from hundreds of students from all over the world. Each one brought their uniqueness and culture into my classroom. They made the planet seem a friendly place." She loved hiking, biking, cross country skiing, line dancing, writing and sewing. She was a member of the Catskill 3500 Club, having successfully climbed all 35 peaks over 3500', in summer and winter: "The challenge, the camaraderie, the wildflowers, the summit views, the sweaty, prickly bushwhacks, the balsam boughs bent low with snow, even the nettles and bugs are among my fondest memories ever." The watershed event of her life was becoming a Friend of Bill. She was thrilled to witness her children as parents: "They do it so much better than I did." She is survived by three children, Benjamin Edelman and his wife Suzanne, of Ghent, N.Y.; Susan Houlihan and her husband Patrick, of Homer, AK.; Nina "Maudie" Edelman of Boiceville, N.Y.; four grandchildren, Liam Patrick and Alana Iris Houlihan, Samira Diana and Nikko Talal Edelman; a brother, Mark Squires; a half-sister, Storey Squires; a half-brother, Jared Squires; and by many dear friends. Her beloved orange cat, Jinglebell, predeceased her on July 4, 2011. Donations in memory of Diana may be made to the Oncology Support Program of Benedictine Hospital. Make checks out to Benedictine Health Foundation and mail to Oncology Support Program, 105 Mary's Avenue, Kingston, N.Y. 12401. According to Diana, "The O.S.P. provides an extraordinary opportunity for people in our area who are living or have lived with cancer to bond with others and learn and grow from the experience, even while sustaining losses. It has opened my eyes and heart, given me dear friends, and seen me and many others through the toughest of times, always in a spirit of love, honesty, and gratitude. As the poet Theodore Roethke wrote, 'In a dark time the eye begins to see.'" Diana's favorite saying was: "Experience is a comb life gives you after you lose your hair." An informal memorial gathering will be held at 35 Forestwood Drive, Woodstock, N.Y., on Tuesday, Dec. 6, from 4 to 7 p.m.

Figure 4.11. Diana With Her Children, 2011. Left to right: Nina “Maudie”, Susie, & Benji.

I am grateful to Diana’s children for generously allowing me into their intimate circle of exquisite care for their mother during the final weeks and days of her life, and for sharing their hearts with me.

The Long Dark Tunnel of Living & Dying: Portrait of Grace

Figure 4.12. Detail of “Searching for Home: Tribute to Grace.”

November 13, 2012 (Extract from email)

Hi Grace,

Little may you know, you have had a strong impact on my life and my learning. I have journaled about our encounters for my own personal process and for a school assignment in my effort to understand my role as an oncology social worker, our social world and systems, as well as the nature and experience of being human, which includes illness, suffering, and death.

I believe the dilemmas you now face exemplify the need in our community for a ‘good’ place to live out the final phase of life until death. For someone who would prefer to die at home but cannot, an alternative place could be made accessible to anyone interested, including those with limited financial and/or social resources. I conceive of a ‘good place to die’ as a care-setting that looks and feels like home, reflects the special needs of the dying, where every effort is made to understand and respect the needs of each individual resident. I believe your story could serve others who are facing the end of life, and help mobilize awareness and a community effort to create such a special place.

Warm regards,
Elise

Figure 4.13. Grace, 2012. "I would know that I was not alone," Grace says, with the patchwork quilt, handmade by friends, wrapped around her. HealthAlliance Infusion Center, June 15, 2012.

Grace replied to my note, "I will do my best to shed light on the long dark tunnel of dying."

My impromptu invitation is precipitated by a phone call to Grace earlier that day. After a month of receiving hospice services at her private residence, she is feeling pressured by the agency to develop a contingency plan required by "live alones," hospice patients lacking the necessary means to remain in their own home once it is deemed unsafe to do so. Based on her financial and insurance situation, Grace is told that her only option is Rosary Hill, a 72-bed nursing facility, staffed by nuns, close to two hours away from her home. It is one of the few places, in New York State, where indigent, terminally ill cancer patients can receive free room and board. Grace concedes that, at some point, she will need more help and will be required to go somewhere—"But not yet!" She is adamant. Grace thinks it is too soon and too far away.

Based on what she tells me, I agree. In the months following, Grace frequently battles with bouts of serious ailments and to remain on hospice services on her own terms—at home— for as long as possible.

I receive Grace's story piece-meal over the course of a few years, beginning with her utilization of Oncology Support Program (OSP) services, including peer support, financial assistance and, for a brief period, membership in the Women's Cancer Support Group. I also encourage her to submit one of her poems to *Celebrate Life!*, the OSP newsletter. Grace presents as a resilient woman who handles hardship with good humor. Months prior to the interviews, we meet individually a few times to discuss and explore her increasingly severe pain in her chest area. She finally relents to consult her physician. It is then Grace discovers that her breast cancer has metastasized to her lungs, as I had suspected.

The following poems are constructed from a series of increasingly informal interviews and email exchanges, from November 2012 through January 2014, spanning Grace's experience as a hospice patient (which extends beyond this writing, in May 2014). Additionally, in April 2013, Grace lends me her unpublished manuscript of poems, *On the Wings of Angels*. Two pieces, "The Care Package" and "Gear Jamming Double Clutch Diesel Demon," are Grace's originals, included by permission. Staying true to her words and meaning, with Grace's approval, only minor changes were made to the two original poems and to excerpts included in the collage. This was done for clarity and flow or to maintain confidentiality regarding sensitive material, as requested. Italicized words represent Grace's spoken or written words.

Grace's Place

The bedless one-bedroom apartment
is sparsely furnished, well organized,
and neat.

Nearly everything in it belongs
to someone
else.

Grace has written careful instructions to have things
returned to their proper owners
after she dies.

A directive to euthanize Noel,
her beloved orange cat, is included,
so we can be in Heaven together, she explains.

This, she believes, is the Compassionate Thing to do.

Noel, like Grace, has multiple medical conditions, requiring Costly Care.
Grace has no accessible family and doesn't wish to burden friends,
most working two jobs and occupied with family responsibilities.

She sleeps in one of two recliners:
the first, in the bedless-bedroom,
the other where she perches for visits,
planted in the Sunny Spot of the living room.

Seated here, in her personal Command Center, near to a large window overlooking
other buildings from the low-income housing development for seniors,
she can glimpse the tree-studded mountains far beyond.

Communication tools strategically placed—within arm's reach,
Grace is at the center of her universe, as she conducts
the everyday affairs of her world.

Survival

I don't have a clue
of what heaven's like,
but its gotta be better than
down here.

Life
down here on Earth
has been very hard.

My life has been a constant battle to survive.

Heaven is
some place beautiful
where there is no pain and suffering.

I am not anxious
to leave this place
but I am not afraid to leave it either.

I have eighteen medical conditions,
including cancer and MS.
I was born with disabilities,
including vocal cord and eye deterioration.

By the time I was ten years old I had been through hell.

I have been Homeless four times;
once when I had a good job.

I lived
in a storage shed.

The longest and hardest was six months through the winter.
I lived in a VW bug
with no heat.

That was Hard.

You do
what you have to do
to survive.

Life is a matter of survival.

You either survive   or you float away
and die.

I have always had a strong survival instinct.
My brain is very strong;
my will power is very strong.
I don't like when someone says I can't do something.
Right away, I get bristles!

I think I am going to go
quick, because I don't see myself getting to a point
where I am
                    lingering around.

I asked the doctor for a ball-park figure
but he wouldn't say. Instead, he told me
I always Beat the Odds.

It doesn't matter.

It's up to God any way.
I am very spiritual.
I believe in God
and the Great Spirit.

Home is Just a Place

On her orderly work table, beneath framed puzzles,
sits a puzzle she is currently assembling,
titled: *There is No Place like Home*.

I ask Grace what makes this apartment—or any place—"home".

She hesitates and stares at me blankly.

I have Moved Around all my life, she responds. *This place,*
which I have been in since February,
is like all the others.

It is just a place.

Home, I guess,
is the framed puzzles.
It's the things I create;
the memories on the walls—my 'Inspiration Wall,'
with my plaques; my poems; my pictures of friends,
and the one of the baby from St. Jude's Hospital.

No matter how bad I am feeling,
I look at that picture of the baby
and then I am not feeling too bad.

Because my life—I am 62 years old—
it's been a hard life
but a wonderful life.

That baby hasn't even started a life and has brain cancer.
The children at St. Jude's have hardly lived

and they are already Struggling.

I sent St. Jude's my poems and children's stories.
They sent me a card with a picture
of a laughing baby.

The Realization

In 2010, the oncologist told me
I had a spot on my lung. He told me
I was on borrowed time.

I told him: "We are all on borrowed time!"

Now, I have been on hospice one month.
The last chemo was hell.
                Hope—
that the doctors were right,
that is was going to make a difference—made me continue.

But I figured it out
when I was getting chemo,
that this ***wasn't*** *going to help.*

                The Realization
hit me like a ton of bricks:

I am not going to be the person who says,'I have two more sessions,' or
'My treatment is done and I have no more infusions after this one,'
like the people sitting on either side of me in the Infusion Room.

It hit me like a ton of bricks—

For me, there is no stopping
these infusions, because once they stop
the tumors are going to continue to grow.

I realized this right then and there,
and then I had a clot in my lung
and when they did the scan for the clot
it showed the tumors on my lungs **were** *still growing,*
and there were new tumors on my lungs, too. I said,

          "That's it!"

I have done everything!
It's not their fault. My body's
screwed up. Doctors can't heal everyone.

When I went for the follow-up appointment, the oncologist
recommended another treatment.
I said, ***"NO.***
I want quality of life.
I gotta have my quality of life!"

I don't look at myself as curable.
Maybe making me more comfortable
is a sense of healing.

The Motivator

I really don't see a difference in my life
since the cancer got so bad.

I have no regrets.

I have met some incredible people by having cancer and hopefully
I have done something for others.
I motivate people not to give up.

Hospice is going to use my poem, "On the Wings of Angels"
set to music, to bring to nursing homes and to share
with other individuals who have cancer and are terminal.

So that's a legacy right there.

If I was to go tomorrow, at least I know
I have done something positive with my life while I was here.

I am not really preparing to die. I am just continuing
my projects working with the homeless.
I am going to do what I can
to make somebody else's life a little bit better.

While I am here,
I am going to continue
to Instigate and Coordinate and to Push
all the members of my "Angels Without Wings Network" with my ideas.

While I am Here,

I have got to get my two cents in!

I would tell others:
'Never give up the fight*.*
Your life is worth fighting for,
but don't be afraid to die,
because everyone is going to die.

You just have to live your life.'

Fighting for Control

I'm in a new battle.

My left ankle is the size of a baseball.
It doesn't hurt but it is bloody.
Sores open up.

I called the Hospice 24/7 Emergency Line.

I'm having a hard time fighting all this:
First it was the left lung clot.
Got rid of that.
Then the left leg clot.
Got rid of that.
Now the right lung clot—
still trying to get rid of this,
and now the left ankle…

I'm constantly Tired.

The tumors are in Control of my body.
I spend most of my time
sleeping.

The Reality of me dying has kicked in.

The problem with me
is Control—
when & how I want to go.

Control.
I don't have that.

I'm blessed to have so many friends

wanting to come and just sit with me. And yet,
some friends find it very hard to see me this way.

I feel like a Door.

My open Door
was eating and feeling okay.
Then Bam!
The Door shut and everything
about my life
stopped.

I can't function.
I hate it!
I tried fighting,
but there is nothing left in me…

Home

Something in me kicks in:

a need
a longing
to comfort.
To soften. Ease
the swell of panic.

Grace's? My own?

I want to offer her a home
to rest: a Place of No Struggle.

And to remind her of the home
she always has,
within.

Figure 4.14. “I Love Water and Boats and Westerns.”

The Care Package

During childhood, we went to my grandfather’s home each summer.
My dad would visit on the weekends, my mom would gather
canned goods, wool blankets, some dresses,
and a small bag of candy—a care package
for her best friend who lived
on the other side
of the tracks.

But I never saw any tracks,
just plenty of water.

All the boats swayed back and forth, waves crashing.
Other boats were lined up along the dock
with men cleaning the catch of the day—
        buckets of crabs trying to crawl out—
and kids running and playing.

I wanted to run and play, too,
but had to stay on the houseboat.
My mom’s friend told us it wouldn’t be safe.
Not everyone agrees to us white folk being here.

We still returned, weeks after, with many more care packages
for her friend, and enough
to share with others
who needed help

Gear Jamming Double Clutch Diesel Demon

When I was cruising around town, everyone knew me
as Mountain Girl. We were all CB buddies,
living more on our radios
than in our homes.

We would sit in our cars past midnight, talking,
and sometimes skip
to another state,
then chat some more.

When Sunday night came, it was time to load up
and join the eighteen-wheelers on the highway, going back
to my home and job
in Pennsylvania.

Months of traveling back and forth,
I learned the language of the road
and all the smoky locations.

I had plenty of buddies. The truckers
gave me the handle: Gear Jamming Double Clutch Diesel Demon.

I had a heavy foot.

One day,
I pressed the pedal
to the metal and zoomed past a trooper
tucked away
behind some bushes.

Looking in my mirror, he was coming for me!

Heart beating like a drum,
I heard a trucker tell me to swing
in front of him, while another came up
alongside me. This gave me time to exit the ramp.

One of the truckers told me,
"We are the whales and you are the guppy." I laughed!
It must have looked funny to see
all these big rigs, and me
with my VW bug.

Searching for Home

My friend told me
she has three-phonebooks-worth of addresses—just for me!

Grace proceeds to name all the Places she has lived that she can remember:

The first place I lived, South Ozone Park, in Queens—

> *That wasn't home.*
> *It was hell!*

Later, I lived wherever I got a job.

There was Forest Hills; Avenue of Americas in Manhattan, when I worked for JP Stevens Fabric (I shared an apartment with nine others and slept on the floor); W. Saugerties; Woodstock; Glasco; then back to W. Saugerties and South Ozone Park/Richmond Hill and Woodstock, where I lived in a teepee for two months during the summer. Then there was an A-frame in Phoenicia, a cabin in Big Indian, back to Woodstock, and a Boarding House in Kingston.

For one year, I was a live-in pet-sitter.

Once, I lived in my mother's antique store in the village of Saugerties. Then there was Berwick, where I lived in a trailer, and an Amish farm in Buckhorn, Pennsylvania. Back again to Saugerties. Then Lake Katrine, Washingtonwille, Middletown, New Hampton, and Unionville, near New Jersey. The longest place I lived, aside from my childhood house—and favorite—was Stevens Manor, an apartment complex in Scotchtown, in the Middletown area. I lived there for thirteen years. I also lived in Wurtsboro for four years. Then there was Hurleyville, Middletown again, Virginia Beach, and Maryland. Most recently there was High Falls; and, now, Ellenville.

I also had eight cars.

Right now I can't drive.
Soon, I will need to decide
whether I should renew my car insurance.

I lived in one of those cars, a VW Bug, for six months
through the winter, Surviving
on $46 a week from Worker's Comp.

During that time,
I suffered
from malnutrition.

First thing in the morning,
I would drive to the mall
where there was a community lounge room.

There, amongst the old men playing checkers,
I would rest on the couch.

The men offered me lunch.
I think they knew
something was wrong.

They were right.

Figure 4.15. “I Made the Best of Everything.”

Figure 4.16. Detail of “Searching for Home” (Caged Nest).

Figure 4.17. "Searching for Home: Tribute to Grace." Ingredients: bird and wasp nests, wire, branches, bark, glass, moss, stones, skull, shells, seed pods, stamps, feathers, flowers, beads, paper, and paint.

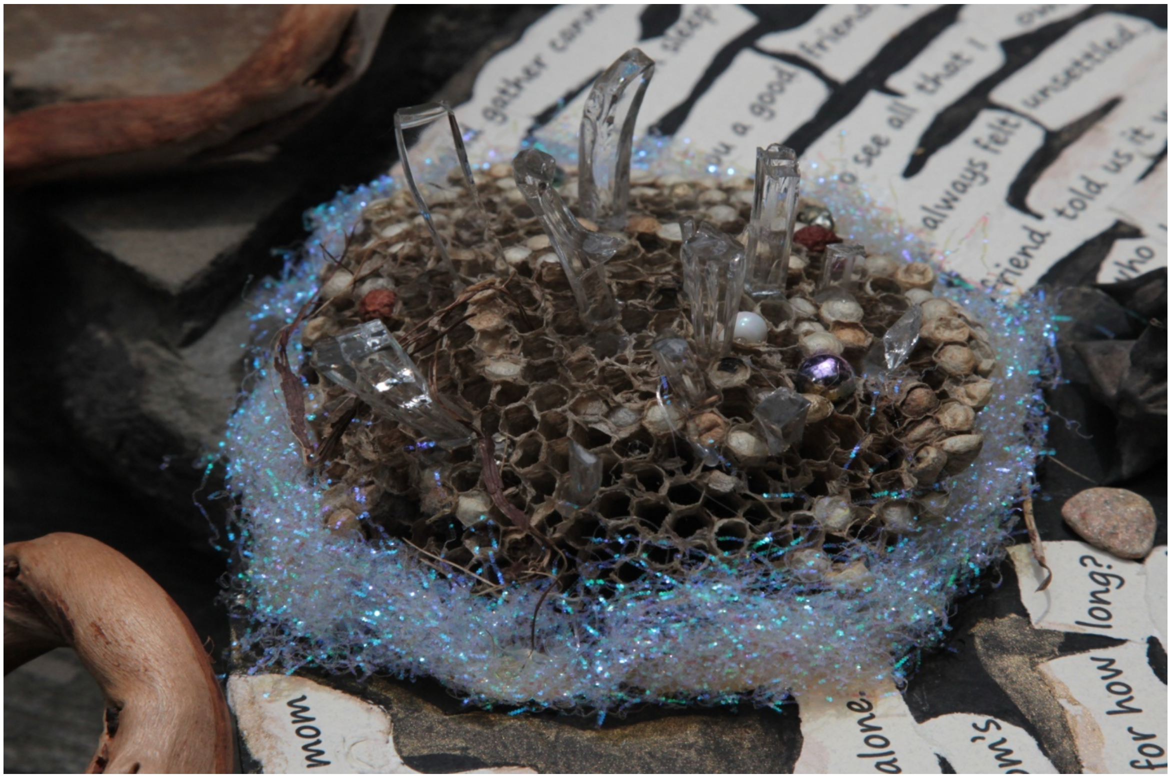


Figure 4.18. Detail of “Searching for Home” (Nest and Shards).

Figure 4.19. Detail of “Searching for Home” (Winged Heart and Skull).

Commentary on Grace's Portrait and Collage

Knowing another person is in the savory—and thorny—details. Grace's lending of her unpublished manuscript of original poems, *On the Wings of Angels*, represents a turning point in our relationship. It is a gesture of trust. Offering a rich supply of data and emotional resonance, the manuscript sheds light on Grace's experience of navigating the long dark tunnel of *living,* for which the "long dark tunnel of *dying"* is merely a continuum. Early on, prior to the first interview, Grace admits not feeling at home in the world. This refrain echoes in her poetic diary, portraying a history of abuse and long-standing financial, social, and existential struggles just to survive, she declines the invitation to excavate these emotional and existential landmines, saying it is too dangerous and painful. I respect her boundaries.

Grace's personal poems flesh out and contextualize her *herstory*, revealing the full spectrum of her humanness, ranging from unguarded vulnerability to streetwise sensibility. Lacking misery and self-pity, they speak the unspeakable. The poems widen my heart and perceptual lens; fill gaps in her story and prompt fresh questions; and validate emergent life-themes of survivorship, longing to belong (not-at-homeness), the search for 'home' and safety, and the responsibility and gift of giving. I select two poems from the manuscript to include in Grace's portrait (with her consent). *The Care Package* reflects the ritual of giving instilled in Grace's life and identity, influenced, in part, by her mother. The second, *Gear Jamming…,* represents her sense of humor and adventurous spirit. I believe my responsiveness to her personal poems was the key to Grace's touching statement that I knew her best of anyone.

Home "is not a *place,*" Grace articulates at our first interview, but the capacity to provide concrete, basic emotional needs—which, essentially, only she can reliably fulfill. For Grace, home is a tentative place within an untame, sometimes violent, oftentimes beautiful world. It is just another station on a long, bumpy train ride. Grace makes ‘home,’ and a life, through the things she creates with her hands and imagination; the simple memorabilia she collects and carries as she migrates, place-to-place; and through small acts of kindness to those in need, particularly underserved and seriously ill children. Neatly stacked large plastic totes line her front doorway or fill the trunk of her car, care packages in transit. In my small poem, “Home,” dedicated to Grace, home is not a physical space, but rather a state of mind and being: a “Place of No Struggle”.

Acting as a companion to my poetic text, the collage provides a visual and textural text. The layered complexity of Grace’s life is conveyed by islands of images awash in a spiraling sea of emotive words. Excerpts from her manuscript form the backdrop—and backbone—of the collage. The mandala forms a holding space for symbolic objects, chosen intuitively, as a material representation of Graces lifeworld. It is a world of paradox, juxtaposing the prickly and barbed with the fragile and feathery soft. Images and words portraying darkness pair with expressions of lightness, brokenness with wholeness, earthly poverty with spiritual richness, conflict and neglect inflicted by those familiar with the simple kindness of strangers, and the harsh limitations of reality—and her own body—with freedom of imagination. The collage is a vehicle to integrate and embrace these paradoxes, mirroring Grace’s similar efforts.

Initially, I imagined creating the collage with Grace, as I did not have the opportunity to do so with Diana, but she never felt up to it. Providing opportunities to give feedback on my poetry and collage construction (as well as this commentary) put Grace in the driver's seat, which she appeared to enjoy. She approved of my ideas of a circular shape and using phrases of her poems that I resonated with; the latter, in particular, represents a way in which we *did* collaborate. Grace admitted disliking the skull because it reminded her of death. When I reminded her that my research is about people living with dying, she relented, adding with a chuckle, "I don't think about death; I think about life!" That day I also learned that Grace does not like to think about, or wish to "practice," saying goodbye (not knowing if it is a *final* goodbye,) as Diana had requested prior to my being out of town for a period. Grace invited me to say goodbye to *her*, if I needed to, but she did not "believe" in goodbyes. As it turned out, it was the last time, prior to hospitalization, I visited Grace in her apartment.

From the hospital, Grace is discharged on hospice services at a contracted nursing home. She quickly adjusted but experiences conflict with residence staff. Fortunately, she is able to transfer to a hospice residence where she continues to reside at the time of this writing (May 2014).

In the collage, a nest, placed in the hub of the mandala, symbolizes home in its multi-faced meanings. The search for a good home, throughout Grace's life and at the end of life (when she is no longer able to remain in her private apartment), animates the wheel of the mandala. At times, despite external circumstances, Grace is able to find the resting place for which she searches, within. This inner space is a place she needs to, but perhaps cannot adequately, protect; hence, the tenuous wire. Viewing Grace's collage without any prior knowledge of her life, Paula, a friend and cancer survivor, makes the following interpretation, which I paraphrase:

> I feel drawn to two powerful images. First, I see the central image as a protected nest—

> but this home or 'safe spot,' I realize, is not accessible. In the second nest image of the hive—infested with broken glass—I see [she hesitates and looks distressed] what *should* be a womb—a safe place for the insects to grow—is penetrated. The glittering tinsel encircling the nest reminds me of the dower birds' dressing, luring its prey, transforming the nest into a decoy-like attractor—a place of desecration (P. Bojarsky, personal communication, August 31, 2013).

The images have their intended effect.

Odd Jobs Unlimited

I Moved Around a lot.   Got bored,
in most cases, where I was
and wanted to see and experience   a New Place.

Often I moved to be a little closer to my work.   Maybe the jump
with jobs was a matter of 'I could, so I did'.
No real commitments
to hold me
down.

Also, some jobs required me to work in another location.
I liked that.

Layoffs would happen.
I could have collected unemployment, but I'd rather work, so I moved away
to find another job, instead of laying around
collecting State money.

I never had a problem finding a job.
I was willing to try anything.
If I didn't know how to do the job,
I could learn, and did.

It doesn't hurt to know more than you already know.

I worked as a 'gofer'; as a glass designer in a factory (where I severed
my right wrist from my hand); in a school system where there was a lot of violence;

at an airport office; insurance company; at JP Stevens Fabric; and did lots of odd jobs.

I even had my own business: Odd Jobs Unlimited.

I worked on a bomb squad, on a medical emergency team, and as a salesclerk.
I worked in an antique shop; as a wildlife photographer, selling my photos at a flea market;
and at Rotron, a fan company.

At Manpower, a county unemployment agency, I was a receptionist and did payroll.
I owned Martin's Acres, a horse farm. Later, I was a horse and stable manager.

I was a receptionist, a corporate investigator, an apprentice private investigator,
an undercover agent for Worker's Comp, and a guard at a Walden's Books warehouse.

For eight years, I was a store detective at Shoprite. I was also a bounty hunter, but only
for a week. I trained at the Tactical Handgun Survival Academy. That got me hired
as a Security Supervisor, providing personal protection for federal employees. I was
a security guard at Pet Boys, did more pet-sitting, and worked at Times Warner for six years.
I was a process server—Dangerous Work—delivering legal papers to people
who were being sued. I was also an overnight guard at a knife company.

I often juggled several jobs and roles at once.
At Worldwide Employment Agency, I was a receptionist and did undercover work.
At a golf club, I changed hats between manager, short-order cook, and bartender,
serving beer on tap. Then there was the time I was hired as a security guard
and a switchboard operator at ***both*** *the Orange County Home and Infirmary*
and *at the Homowack Lodge—that was like four jobs at the same time!*

The nursing home job was my favorite, because of the residents. They awaited my visits.
I always kept my word;
I always came back.

Finding Home, Briefly

When I first moved to Stevens Manor, it didn't feel like a home.
I had looked at other apartments;
Stevens Manor was huge in comparison.
In time, I realized it was close to work and most of my friends.
And there was a huge separate building on the grounds with laundry machines.
Everything was right there.

I felt like I took good care of my Place,
as far as keeping it very clean and handling repairs, which were few. When it came time
to sign another years' lease, they didn't raise my rent,
which was honest.

I guess, for the most part,
I felt Safe there.

The first eight years at Stevens Manor, I worked so hard, so many hours, and traveled so far,
that I never saw my partner much.
She worked a full-time night job and a part-time day job,
so we never saw each other.

I was much more relaxed
when she moved out.
The fighting stopped
and we were better friends.

I'm not sure if the Safety Factor came in then.

I kept the apartment because I could afford it on my own, while she could not.
I think now, with her gone,
my friends could come over when they wanted.
It felt more like home to me—
more than just a place

to store my clothes,
                    my cat,
                              and a few belongings.

The Place came alive
                    with music,
                              and laughter,
and a lot of friends coming and going, constantly!

Today, I'm having another very bad day.
I can't even
          stand up.

It's not so much the pain—
I'm just so
exhausted.

I slept a lot yesterday
and I am still sleeping today, on and off. Going out
puts a huge strain on me;
I'm never good after.

6/12/13 Leaving Home

I was hoping God would take me on the surgery table, she tells me.

Until now, Grace has side-swept hospital admissions
or being transferred to Rosary Hill, the nursing home
for terminally ill indigent people with cancer, nearly two hours away.

"What do they do,
ship out all the poor people?"
she asked, exasperated, months ago.

Emergency surgery fails to remove the large kidney stone
she has been unable to pass for a week, or the severe pain
she finally surrenders to.

Now she spikes a fever, due to infection,
accompanied by hallucinations.
She is shakably cold.

    "I wasn't supposed to die from kidney failure!" Grace exclaims, half joking.
    "It was supposed to be the cancer".

She wears the docile uniform of suffering
printed with blue geometrics,
her skin the shade
of dull surgical blades.

I offer to straighten up her bedside tray, encouraging directives.
Reluctantly, Grace catches onto the ritual.
She has me discard straw wrappings;
small cartons of cranberry juice,
too sweet to drink;
and half-used milk.

    I say, "This is not the chair-side Command Center, back home." We chuckle.

Grace tells me she has no more fight left in her.
At last, she has   gone beyond
her Threshold of tolerance

    I am ready to go, she says, frailly.

But Grace is not "actively" dying—*yet*.
She will have to be transferred.   *Somewhere.*

Don't let them throw me in a dump, just to get rid of me, she pleads
to the hospital discharge planner while I am present.
The discharge planner, appeasing, nods her head.
Grace understands, the discharge planner will do her job.
I tell Grace I would not permit this, knowing
I, too, am powerless.

She reckons with the fresh loss.

It's not the place I will miss;
it's my cat, Noel.

Why is God keeping me here
with all this suffering—
it doesn't make any sense?, Grace asks, bewildered.

I ask to hold her hand. She is raw.
As suffering takes on a new pitch,
meaning becomes increasingly obscure.

"I don't know.
What do you think?" I rally back.

"It's to teach my friends.
But if my friends haven't gotten it by now,
they never will…"

How precious.
How precarious.

I think to myself,
if *I* haven't gotten it by now,
I never will.

Figure 4.20. Grace and I at the Kaplan Family Residence.

More Bad Days Than Good

She forewarns:

> *Today is a bad day.*
> *Just feeling sick*
> *Not right at all.*

For the first time, Grace doesn't rise
from her recliner
when I visit,
but, she tells me,
she is still making friends.

Weaker, sleeping more often,
Grace learns how to be
less mobile:

> *legs*
> *barely walk*
> *lungs*
> *barely breathe*
> *eyes*
> *won't focus*
> *right arm*
> *useless*

She is becoming light
as a feather.

Is her body
failing
or preparing
for flight?

Figure 4.21. Grace White Feather’s feather collection. Grace’s composition, 1/10/14.

Cultivating the Immeasurable: The Residence at the Nina K. Miller Hospicare Center

Figure 4.22. Water Lilies (Detail of Restorative Garden).

For needlepoint and flowers: The vision. “We didn’t set out to change history, but we did!” Judy Malloy resounds, triumphantly, at the beginning of our phone conversation. Her firm belief in the need for a hospice residence arose from being in close contact with staff, patients, and families through the local start-up hospice organization, in Tompkins County, Ithaca, in the early days of the hospice movement. It began when the agency started to care for caregivers, most often women who previously cared for their dying spouses in their own homes. When it was the widows’ turn to need and want care in their own homes, there was no caregiver for them. Against their wishes, they ended up dying in a nursing home or hospital. “It was a dilemma that broke our hearts,” Judy recalls.

Judy felt compelled to document one early scenario, from decades ago, of an elderly couple. The woman, in her early 80s, was able to remain at home under the care of her husband

and medical oversight of hospice. After nearly a year on hospice services, the wife was in a coma. She had rallied twice before and “wasn’t ready to die,” Judy writes. Judy had the burdensome task of having to tell the husband that the expenses of sustaining services for daily nurse IV checks and expensive medications were too great for the agency to bear. Reluctantly, she drove out to a cozy little cape with a greenhouse in the backyard to address the agency’s dilemma. The couple supplemented their retirement income by raising seedlings and flowers to sell locally. Though slightly threadbare, the house was filled with handmade touches: needlepoint pictures and pillows, and lace doilies on the arms of all the chairs. The woman was resting peacefully in the dining room, now converted to a bedroom. Light filtered through gauze curtains and there were fresh flowers everywhere. A recliner with an afghan draped over it occupied the center of the room with a small pile of newspapers on the floor alongside. The home held their love and spoke their lives, together.

As expected, the woman’s husband did not take well the news and suggestion to enter his wife in a hospital. Shedding a tear, he shared that the two had not spent a night apart in over 40 years. He was not about to let that happen now. Judy considered his response and then proceeded to strategize with the man on how the agency could continue to provide services. They managed to mobilize volunteers from the couple’s church community; obtain a generous donation of the woman’s medication from the local pharmacy; and make arrangements with an agency nurse who agreed to check on the IV nightly, on her way home from work. The woman died quietly in her sleep within a month, after having regained consciousness for a week. Judy pondered: “The fledgling agency would struggle through *this* time, but what would we do next time?”

Attached to this tender story, included in a care package of important early documents, is a note from Judy in neat cursive handwriting: “I can’t recall why I wrote this, but after reading it I realize why I went through all that…for needlepoint and flowers and a lifetime together.”

Realizing the vision. Judy was convinced: having a residence for the dying made sense. It would make pain control, central to good end-of-life care, easier, and provide respite for caregivers exhausted from the strenuous work of caregiving. It would offer patient’s family and friends the time, support, and education necessary to absorb the shock and assimilate the reality of their loved one’s serious condition and pending death. What is more, it would provide a homelike environment, compatible with hospice philosophy, for those unable to remain in their own homes.

It also made sense to Beverly Hammons, another central character in the early story. Beverly’s personal loss of several important female family members sensitized her to the predicaments of an aging American population. She witnessed the social impact of losing core caregivers, “the matriarchs who serve as re-constituting agents and the familial glue.” While Judy was referred to as the mother of the residence, Beverly, who also served as President of the Board of Directors multiple times, was considered the mother of the hospice agency. Beverly describes herself as a born and professionally trained planner. She possessed the necessary tools to translate possibilities into reality. Her involvement in the planning of the residence reaches back to its pre-conception, in 1977, when she first saw it—the organization and its residence—in her mind’s eye, long before conversation and activity began. With a foundation in healthcare-related community development and formative experience as a Peace Corp volunteer in Ecuador (then a country with few organized resources), Beverly learned “how to read communities and what was possible when people were motivated, given tools, and the opportunity to participate and contribute.” Moreover, she had an understanding of “how different environments, whether urban, suburban, or rural, are suited toward different organizational structures and services.”

Incorporated in 1983, Hospicare and Palliative Care Services of Tompkins County, Inc. is the mother ship of the Residence at the Nina K. Miller Hospicare Center (a.k.a., Hospicare Residence or residence). Two years later, the grassroots organization became the second hospice in New York State certified by the Health Department to operate as a hospice and to qualify for Medicare and Medicaid reimbursement. An accountant by profession (and in the construction business with her husband), Judy started out as the agency’s financial director. That was when the organization, in its infancy and lacking a site of its own, operated on a shoestring out of a tiny office in the Health Department building. “We couldn’t afford paper and we brought pens and pencils from home,” Judy notes in her early text.

The residence project began in 1991 when the Board solicited a feasibility study including a needs assessment and a community survey asking, “If we built it, would you use and help fund it?” The 1992 report confirmed what the planning committee already knew. In the early 90s, Judy and her husband led a team effort to raise seed money for the residence by building and selling a house. The Hospicare Residence opened its doors to the community in 1995, representing the first free-standing hospice residence in New York State. No one on the Board expected it to take so long.

We belong to the community: Community-minded design. Community-minded design promotes community-minded care. The custom-built, multi-purpose Center, featuring a six-bed residential wing, was to be located in a residential neighborhood. The goal was to build a non-institutional-looking structure—“a not-so-big house,” says one staff member—to blend with the surrounding neighborhood homes. To this effect, the building’s unique architecture emphasizes non-linear curves and slopes to make the elementary school-size structure appear smaller. Also thoughtfully planned, the eleven acres of open land, immediately surrounding the Center, further soften and visually re-proportion the size of the structure.

Communicating the intent and design of the center and developing relationships with neighbors was critical during the initial planning phase. Neighborliness was central to decision-making, for example, in the design and position of the sign to avoid looking commercial. Efforts continue in order to divert the impact of occasional overflow from the large, partly camouflaged, parking lot, inadequate for larger community events also held at the center. A Japanese "restorative" garden.

Figure 4.23. The Nina K. Miller Hospicare Centre and Grounds.

The quote by local author, Diane Ackerman, is inscribed within the spiral stonework by the front entry (a deliberate contrast to the parking area) enfolds the house and adorns the entranceway. Paths lead to cloistered sitting areas featuring a fountain that empties into a goldfish pond where young visitors happily engage in feeding the fish under the gentle supervision of some young volunteers. Arterial walkways of multi-textured stone are inscribed in memory of departed loved ones. Though lovely to stroll along, I find it cumbersome in spots to negotiate a resident's wheelchair. When I take Bob out for some fresh air, his ride is rather bumpy! Five of the six residence bedrooms, connected by a deck, overlook a wilder expanse of land, consisting of a pond with lotus flowers in summer, ornamental grasses, and trees. Out of residents' visual reach are a seasonal vegetable garden and a more hidden, slightly overgrown, meditative labyrinth.

The overarching message Hospicare strives to convey is summed up by the notion that the organization "belongs to the community," as Saoirse McClory, the agency's Director of Community Support, elegantly articulates. This also means recognizing and responding to local trends, such as increased demand for bereavement services attributed to local economic turbulence. Free bereavement services offered to anyone in the community is an example of circular programs underwritten and sustained by community support. Moreover, it illustrates reciprocity between the commitment of the agency to the community, and that of the community to the agency.

Figure 4.24. The Restorative Garden and Meadow.

The residence garden supports the organization’s mission in numerous ways; it is a storehouse for meaning-making. Nature serves as a container and contemplative space for grieving family members and friends. Some plant a gift in memory of their deceased loved one. It is gift symbolizing continuity. The garden further engenders the perception that the residence is a gift to the community. An array of organizations and neighborhood activities come together in the use of Hospicare's grounds and garden, which function as public space. Various community groups are involved in outdoor activities and the agency's Intergenerational Nature Program, including local day care centers, Cayuga Addiction Recovery Services, students from nearby Ithaca College and Cornell University, and teens from at-risk programs to help with garden maintenance and clean-up. Nature herself is the restorative agent for forging new relationships as young ones bring posies to the residents, teens bring in fruit from the garden and make sorbets, and addiction-recovery folks find renewed meaning and esteem through engaging in service. Locals feel invited to enjoy the extensive grounds. Community members walk their dogs, jog, and, in the winter when the pond freezes, come to play ice hockey.

Wish Lists are Telling

Listed on the back
of Hospicare's fall/winter 2012 newsletter,
featuring a woman on the front cover leaping exuberantly
into Cayuga Lake, are three requests:

Fabric;
Sunflower seed & suet cakes; and
Copy paper.

The fabric
is for handmade bags,
sewn by the local Quilting Club,
"gifted to deceased patients' families
with their loved one's possessions enclosed."

The seeds and cakes
are for bird feeders hanging outside
residents' bedroom windows
to entice feathered visitors.

The first two are the Immeasurables.

The last,
still a need
after all these years!

Figure 4.25. Origami (Detail of Ceiling Hanging).

Fabric, sunflower seed, and suet cakes: Cultivating the immeasurable. What lies within the center's doors is the result of a vision to create a homelike atmosphere where beauty and warmth coexist with practicality and function. The main family and community room is a blend of familiar and pleasing elements: brimming bookcases, casual seating and gathering areas, a piano, a lantern-shaped curtain of origami cranes, and a handmade quilt featuring silk-screened swimmers. These things invite folks in. Saoirse attributes the overall ambiance to the vision of one of the early executive directors, Nina Miller, the building's namesake. "Nina had a lot to do with setting the tone here. She definitely had a very big heart and accentuated the individual and the humanity of the care we provide. She was always very guarded about the potential for things to become too regimented. She believed that the power of what is possible at the end of life comes from human relationships."

The vision was to create a humanistic environment, a place that makes the people in it feel secure and significant. This is apparent in the architecture, its scale and materials, which features an abundance of golden wood and natural light, and the surrounding gardens. There is a flow between spaces, serving fluid functions, and a balanced sense of spaciousness and enclosedness in the rooms within. Jeff Collins, a staff social worker, is sensitive to residents' experience of the various spaces and what may be felt as too much space, which could elicit anxiety. For this reason, some residents prefer room six, which lacks the expansive views of nature accessible to the other five rooms. In room six, "They're in their swaddling clothes," he remarks.

Figure 4.26. Common Spaces: The Great Room and the Residence Wing Living Room.

The plan was to make the six-bed resident wing, with its communal and private spaces, as un-institutional as possible and to impress a sense of belonging through furnishings and images reminiscent of home. Reflected in the décor is sensitivity towards orienting dimensions of time and place, drawing upon the local landscape, craftspeople, and businesses. For instance, furniture is from a shop down the road. Impressions of nature abound indoors. Inspired by regional wildlife, a volunteer made the ceramic number and nameplates for the resident's rooms: one turtle, two birds, three dragonflies.... A series of snapshots, taken in the meadow out back, feature milk thistles, their bare conical bodies and spiky limbs soothed by sepia tones. My favorite side table has the Hospicare logo of a tree delicately carved on the tabletop and filled with tiny pebbles. Beauty and comfort go hand-in-hand, as, for example, images of local scenery in handmade wood frames adorn resident bedrooms. Residents find this comforting, as often the scenes are familiar to them. More nature scenes placed along the resident corridor rotate with the change of seasons. They invoke pleasure and invite pause.

At the tail end of the residence wing, next to a small nurse's hub, is the quiet room, as Saoirse has taken to calling it. As an alternative to the expansive main room, this cozy space, with patterned rose and amethyst stained glass windows, invites relaxation and contemplation. It is equipped with comfortable furnishings, magazines, a small selection of spiritual and religious books, and a "suggestion board" for anyone to post. The sticky notes read:

- better sound insulation between resident rooms to muffle TV's;
- speaker system to play soft music in background;
- more art, especially by staff and patients;
- solar panels on roof;
- warmer shaving cream;

- more plants; and
- individual temperature controls in resident rooms.

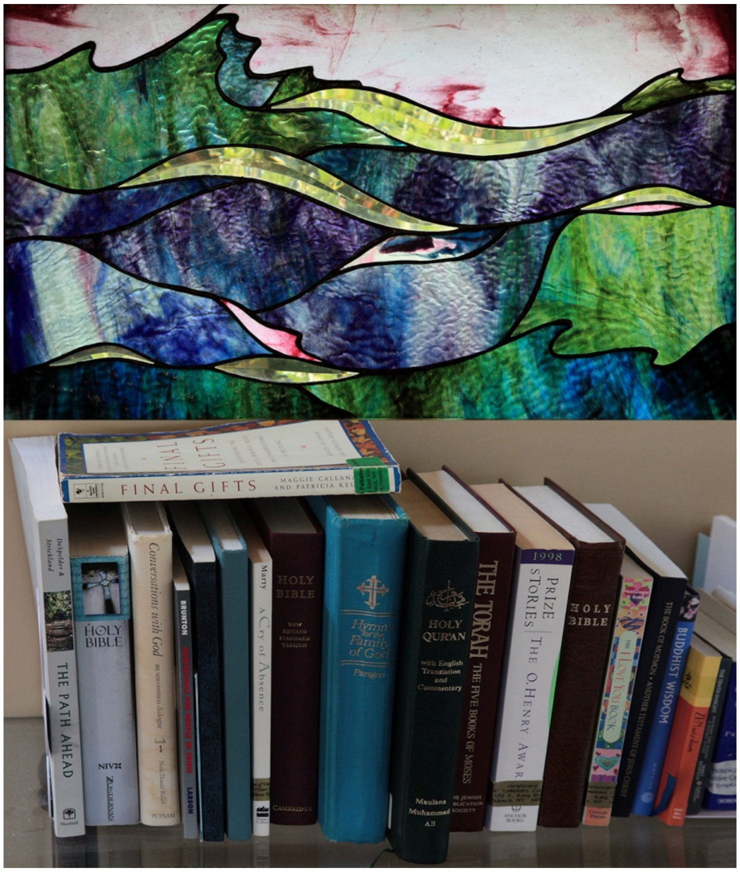


Figure 4.27. Quiet Room (Details).

“We always have a fresh pot of coffee brewing in the communal kitchen,” says Tricia Conroy, nurse manager of the residence. A local company donates coffee beans. Like many other amenities and special services Hospicare is able to provide for residents and their guests, local businesses, non-profits, and the community pitch in. Tina and Saoirse reiterate how staff, with the extra hands of community, work hard to “make things happen”—particularly things residents consider meaningful. A recent example is Sentimental Journeys, started by a local ambulance company in coordination with the hospice agency. Drivers and paramedics volunteer to assist residents, accompanied by family (or staff, if needed,) in fulfilling a wish. One resident wanted to visit his oncologist's office to thank the doctor and staff. Another longed to visit his family farm. Each found it very gratifying.

Physical features of the center and residence wing dovetail with its social characteristics. Together, they are means to cultivate the immeasurable, a word introduced by Saoirse. "What may seem small is not small; small things add up and make a big impact," she says, reflectively. The immeasurables promote dignity, pleasure, a sense of the ordinary, and opportunities for meaning-making—true gifts when a person's usual capacities to socialize and participate in life are diminished by illness. They constitute what really matters to terminally ill people and their kin. Saoirse illustrates this concept with a memorable story, from my initial visit, in 2010, about a resident who, prior to admission to the residence, had been unable to garden for the last five years due to his illness. Her face brightens as she recounts how the resident gardener had built a special raised bed for him to plant and tend nasturtiums and beans. "As the man lay dying, the beans were ripening. During the last days of his life, the man continued to reap pleasure from the garden. As the family was keeping vigil with him, folks were bringing in baskets of beans."

Things fall into place: The formative years. The organization suffered its fair share of growing pains as it matured from a grassroots to a state licensed and regulated, federal funded entity. Things fell into place—gradually. In the early days, before the residence was built (and prior to an established funding stream), Jerry Nye, the first executive director, had the initial idea that the enterprise was going to be primarily voluntary. Jeff initially imagined he would be one of the volunteer leaders. "It was totally unrealistic!" he and everyone else involved quickly realized. What evolved was a reconceptualization of the residence along with a turn toward professionalism. "It's almost like we stumbled into this," Jeff shares. "Jerry had the idea, he'd raised some money—and there was a momentum to it, and it just kind of happened. We didn't know what we were getting into!" Jerry decided to hire a social worker "and I guess he thought I had the qualifications," Jeff remarks, still disbelieving. After finishing social work school, Jeff's father died and left him some money. He seized the opportunity to take a long period of intensive meditation. "It was fabulous preparation for Hospice work," Jeff recalls, enthusiastically, "but it was an odd entry on your resume!" That didn't stop Jerry Nye from recruiting him. For a time, there was concern among staff that the residence was pulling out too many resources and was going to be a "money sink," affecting their ability to do home care. Nobody even thinks about that anymore.

How a place is conceptualized, and its interior space apportioned, reflects changing organizational and community needs against a backdrop of changing social, political, and economic conditions, as well as changes in the agency's leadership. The center, wherein the six-bed residence is situated, has gone through several incarnations, reflecting periodic organizational changes over the years. Initially an apartment, the downstairs now functions as a bereavement service area. According to the original vision, the apartment was to accommodate two overnight volunteers with paid staff during daytime hours. That plan didn't pan out. The volunteers were unable to meet the needs of the residents, considering the number of residents and complexity of care required. The apartment remained rented as a means to offset residence costs, until about a decade ago.

Throughout the developmental phase in the residence, including a period when it closed for re-assessment and re-grouping, the agency continued to provide services in private homes. During this time, a woman the agency cared for in her own home died, leaving her entire estate to the Hospicare Residence, amounting to around $200,000. It paid off the mortgage. The residence re-opened. “It was totally unexpected!” exclaims Saoirse. “The woman had lived a simple life. She had no family. The organization never approached her and there was no organized effort for planned giving at the time.” The story exemplifies a core operational principle embodied by Hospicare staff: If you do the right thing, things fall into place. The spiritual and ethical principle of reciprocity, manifested as timely good fortune and abounding community generosity, continues to sustain the residence. Supporting this tenet are the organization’s mission and core values—“the driving force of our day-to-day work,” posted visibly on the residence kitchen refrigerator. It reads:

> Our mission is to bring medical expertise and compassionate, respectful care to people and their loved ones at any stage of a life-threatening illness and to provide information and education about advanced illness, dying, and bereavement to the entire community.

Below it is a summary statement: “When problems arise, all of us will help in generating solutions, and all decisions will be grounded in these values,” listed as: Compassion, Excellence, Respect, Empowerment, Trust, and Partnership.

Established in the early phase of the residence, an abiding commitment to provide care to residents, regardless of ability to pay, has continued throughout challenging economic times. Since the residence’s inception, the agency has implemented a sliding scale fee policy despite the fact that, initially, there was no funding stream. “Reimbursement” continues to be a misnomer, Judy points out, falling short of expenditures for all the physical and emotional care patients and families need. Due to these factors, the agency operates at a deficit (like all other hospice residences in New York State) which the community helps to cover, through events like Women Swimmin’, Hospicare’s most elaborate and successful fundraiser. In 2013, Hospicare incurred $260,000 in unreimbursed expenses for the special 24/7 care provided in the six-bed residence. More than a fundraiser for the agency, Women Swimmin’ has grown into a major community event, rippling beyond the region and overseas, with an entity of its own. In 2013, donors across the nation—plus 16 countries, contributed $390,000, a record since its inception in 2004. Ample corporate sponsorship permits 100% of the proceeds to go to patient and family care.

Figure 4.28. Women Swimmin' Quilt (by Sarah Demo, 2014).

The non-negotiables. The culture and values of the organization are demonstrated by its operations. At the heart of what staff espouses as good practice are holistic, relational, and community ways of thinking. Good practice is conveyed in the linkage of culture, values, and purpose (or mission), with operations and practice. There is congruency between what the organization says and what it does. Optimally, all organizational parts work together seamlessly and synergistically. Saoirse points out, “The how of operations reflects the *why* of mission and organizational philosophy; essentially, we want people to know us before they need us.” She explains, “This is the prevailing commonsense theory, although it is difficult to gauge in numbers how this helps in terms of community support, by way of donations, and how it influences people feeling good about the organization and using our services, or in fulfilling the mission of education.”

Holistic thinking is about recognition of relationship, whether between individuals; different parts of an organizational structure and its whole; or separate, sometimes competing, organizations and the whole community. An example of holistic thinking and comprehensive services is Hospicare’s working partnership with Cayuga Medical Center via a hospital-based palliative care program operated by the agency. An educational imperative permeates this program. This program provides hospice a continuous presence at the hospital, reinforcing the agency’s community commitment, range of expertise and services, and forging professional relationships. Additional educational outreach focuses on helping medical professionals understand how hospice can partner to help manage illness symptoms. Holistic thinking is further conveyed by a philanthropic, holistic, and noncompetitive philosophy, founded on recognition of one’s relationship to and dependence on the community, and the larger whole. “Encouraging giving benefits *all* organizations,” Saoirse emphasizes. For example, the nearby

Keuka Comfort Care Home, inspired by Hospicare's successful Women Swimmin' event*,* offers a similar fundraiser adopted from the hospice agency's How To manual.

Reflecting on the changes observed over the twelve years she has been on staff and articulating what makes a place special, Saoirse has an opportunity to take stock of what she regards as important, and to safeguard those things as she prepares to leave the agency. What stands out most to her is how extraordinary the staff is. "What motivates us humans to do things—and to do the *right* things—is having a sense of meaning behind our work. I think everyone feels that," she says. "Recently, we talked about what is really important and what are the non-negotiables." The non-negotiables pertain to the mission-driven aspect of the organization and the challenges administrators, like herself, face in their role of balancing the "bottom line" with "what folks really need," as clinical staff stalwartly remind her. "The non-negotiables are the Immeasurable!" I remind her; the latter, a word she introduced during my first site visit several years prior. Saoirse illustrates the non-negotiables by sharing a dilemma. "The fact that the agency is currently operating at a loss due to low census means the community event-fundraising department I head has to raise a lot of money. This puts the Women Swimmin' event at the forefront of planning. But two other events are on the agenda. One is Light the Landscape, an annual event for bereaved families. The clinical staff reminds me: 'But folks need that one on holidays!' I've got a big heart *and* I've got my hat on—the hat of what is really practical—as far as what you can reasonably do." Maintaining sensitivity and dedication to meeting both needs is what makes her job, a difficult balancing act at times, interesting.

The building itself serves to ground and reinforce the mission, and to optimize human connection. "The mission is so clear here," says Saoirse. "It is a product of having a residence with beds. Having the residence and communal events here, and having opportunities to connect with the families is a good way for everyone in the organization to remain in contact, in some way, with the work and mission." Mission links the upstairs, comprised of the large, multi-purpose community/family/kitchen space and cozier resident wing, with the downstairs clinical/administrative space. Saoirse points out, "So even if we have our little separations, I think everyone feels connected. You might be pouring your coffee next to a patient." Jackie, who works alongside Saoirse in the community support department agrees, "The kitchen is the place where you run into everybody—family members and volunteers; you can't avoid knowing what is going on."

We are all in this together. Jeff, doesn't hesitate to respond when I ask him what makes this place a good place to die. "Respect!" he exclaims. "And part of the respect is the beauty," he emphasizes. "There is an attitude of respect toward this place, grounded in the day-to-day physical care of it, that is a way of respecting and caring for the residents; it opens something for them." He adds, "And there's something about the kind of body care offered by the hands-on caregivers—a sense that they're just taking care of business—that just really pleases me. There is nothing cerebral about it," Jeff says. "They are just working with the people, and they are in there working with people's everyday lives and fears. There is a real sense or quality of participation, of coming forward." He further explains, "It is the opposite of the atmosphere of one of the local nursing homes where there is a sense of everybody's holding back and defending something. There is stinginess in the air. This place is like the opposite of that stinginess. There is just a sense of deep generosity here."

When I ask Tina, a home health aide, what her primary role is, she responds, "I put people at ease." She is sensitive to the subtle day-to-day physical and emotional changes of residents, recognizing they have good days and bad days, and she is attuned to non-verbal expressions of pain. She follows their lead and acclimates to their needs. “I let them stay as independent as they are able and want. I let them have as much space as possible. Over time, little by little, I do more, but I don’t push—I let them go at their own pace.”

Another quality noted by the Hospicare staff is flexibility. “That’s one of the great things here, supported by all our executive directors,” Jeff reports. “Each has imparted the sense of letting clinical do its work as they define it. There is trust. If you wind up visiting a patient or family for two hours, nobody questions you.” There is role flexibility too. The amount of time he spends and the role he plays with residents varies enormously. He elaborates, “I’ve gotten used to being aware of the medical side of things so I will help the nurse—I’ll hold up an enema bag or whatever, things like that. I am very comfortable with that. Alternatively, I sometimes help explain to families why the meds are the way they are. How involved are we in the care? We’re very involved.” Jeff illustrates the care culture at the residence by sharing a resident story. “We had one rather acerbic, rather nasty guy who came in last fall and he said, ‘I don’t know if I can believe it, but these really are very nice people,’” Jeff laughs. “He’d never quite encountered anything like that. That’s an accurate description: nice people, very competent, really paying attention. Some of the folks in here might need a lot of psychological care and all of us try to gather around for that.”

“There’s very little turf here,” Jeff continues. “I mean there is obviously professional responsibility, there’s licensing, there’s differences in education, but the culture is kind of like, the staff person who has a relationship with the patient, works with that relationship. So there’s not a turfy sort of thing going on. Sometimes, a staff member will see someone and then, naturally, will continue with that person. Staff might have different capacities, different orientations, but if a staff member has developed a closeness, he or she will move with that closeness. Like with that nasty, old guy. I spent a lot of time with him!" I interject, "That's where your meditation practice comes in handy." "Exactly!" Jeff exclaims. "The nurses would call down to me and explain what seemed to be happening, because he had all kinds of relational difficulties, so I was elected to see to it."

Jeff states, "There seems to be very little of what can be found in a nursing home or a hospital, of 'it's not my job' sort of thing. Our staff really does seem to have a 'We take care of the residents as a whole' orientation." Tina, a home health aide, says it succinctly, "My work is my life." Connie, a residence nurse who works with Tina, emphasizes a "do what needs to get done" approach, reiterating themes of role flexibility and teamwork. "As a team we consider, 'what can we all do together to make it the best possible day and moment for the residents?'" says Connie. "There is a sense of 'we are all in this together.'"

Tina's role and extensive hours on the job position her to have maximum contact with patients and families, and to observe "the little changes," Tricia says. Among staff, Tina tends to be the most intimate. She sees what residents eat and how they sleep; she knows the names of residents' family members and their dogs; and when and how often the family visits. Tina is usually the first person to meet residents and she is often present when residents die. "When people get close to dying," Tina shares, "I find myself telling them, 'It's time to take care of yourself. Everything is going to be okay. Just let go.'"

Workability in action: Working with the great concern. "It's not just a job," was a sentiment echoed by several staff. It's not just about *what* staff do, which is "to take care of people," Jeff says; it's about how they do their job. Despite changing times influencing organizational changes over the twenty years he has been a staff social worker, "the quality of our engagement with patients and families has not changed." Key to Jeff's personal and professional philosophy, which he conveys to patients, families, and staff, is the notion of "workability." Workability shifts the focus away from "feelings of hopelessness and loss." It lends malleability to the problem and stability to the person facing a challenge or crisis. It makes space for people to find their own way. This framework keeps him and other staff, for whom Jeff also provides support, on target honoring each patient's choices. As a seasoned practitioner, he has learned to "respect that people have their own way of doing things." This includes knowing when "to leave things alone."

The core of the "great concerns," as Jeff refers to "spiritual" and "existential" issues, terms he views as interchangeable, "is death. That is what it all boils down to," he remarks. Working with the dying in a professional or voluntary capacity, we agree, is a means to address this concern. He admits, at times, to intentionally contemplating, "This is me in this bed," as do I. One woman I meet in the kitchen, preparing a resident's favorite sandwich, tells me she previously volunteered to give haircuts to the deceased at a funeral home as a way to overcome a debilitating fear of death. "It worked!" she chuckles. "It helped clear a path to being a volunteer here."

I ask Jeff whether he perceives existential suffering as workable, too. "I guess that's a forever question. What I would call spiritual. When I'm talking spiritual, I'm actually speaking existential," he responds. The first person who comes to mind is Lori, a resident with ALS (Lou Gehrig's Disease), whom he encountered in his first year working as a hospice social worker. When he first started to work with Lori, she was fully paralyzed and wheelchair-bound, but she could still speak. Within one week, she lost her capacity to talk. She was in "incredible despair." Jeff remembers, "Tears were coming down, and they were falling in such a way that she actually made these big bubbles because she couldn't clear them. It was terrible despair—and it was an incredible moment for me because it was so clear in my mind, 'I cannot make this one better.' This was so obvious!" But what he did say was, "'This disease owns your body. Let's talk about your soul.' And I actually used that word!" He pauses, cradling his chin. "I don't know why because I don't typically use it." Jeff later discovered that it made something of a difference. Soon after their meeting, Lori was given a special computer program that came with a special mouse. She had a tiny bit of movement in her right hand, so she could click on letters, and laboriously, but very accurately, build up words. "She actually wrote poetry and a short story about bubbles—how they float, and some pop soon, some later."

Jeff visited Lori again three weeks before she died. It was a clear, crisp October day. "Lori had gone through this despair. She was very quiet, and I was quiet," Jeff's body settles as his voice dims. "We were just sitting there. Light was coming through the window, and you could see the branches dancing in the wind." His hand is lifted by an invisible current. "She typed out the words, 'This is so beautiful. I am so blessed.'" He looks astonished. "And it was just like—what *I* did with her existential concerns—I don't know. *We just met*. I mean, I don't know how to say this… If you have a certain presence it helps with many people."

Death is happening all around me: Working with everyday dying. Tricia, the residence nurse manager asks, "How do we create an environment where the occurrence of death is not going to disturb people?" I wonder if this is plausible. "When orienting patients and families, we don't say 'people are coming here to die,' but we might refer to the residence as a 'final home,'" Tricia says, "or if I find something not up to par I might remind staff this is the person's 'last home.' Then everyone remembers that's why we are here!" While aware of being at the hospice residence until she, too, dies, one resident, Deidra refers to her experience here as one of “starting a new life.” She admits it is hard to deal with other residents’ deaths, even though she did not get to know them.

“Death is happening all around me,” says Bob, a resident. But he is placing his bet on becoming strong enough to return to chemotherapy and sticking around awhile longer. An entrepreneur throughout his life, he still has plans to bring in some earnings on a small business concept he is actively planning and offers to share a percentage of the proceeds with me! Wheelchair bound, Bob says he prefers to remain in his bright corner room, large enough for receiving family and guests on occasion, though he takes me up on my offer for a garden tour. Staff handles the regular occurrence of death “discreetly in order to protect residents,” says Bob. Following a death, Tricia explains, administrators and clinical staff try to create an atmosphere of respect. Each staff-person “has their own style,” says Tricia, for handling a resident’s death. “But there is no set way.” Tricia agrees, “We need a meaningful ritual to help staff transition, especially when there is pressure for turnover, and a way to let others, residents and visitors—including my own children who visit regularly—know that somebody died here.” Both practical and symbolic, her ritual is to escort the deceased body out the main door, in the same fashion as when they arrived. “It is my way to be there to support the staff,” she shares.

Connie, a resident nurse, says her approach is simply to ask residents if they prefer to have their door closed when another resident dies. “These situations,” she adds, “call for a lot of honest communication.” For Connie, they also require self-care and “maintaining balance.” She admits, “Sometimes I am up at night, reflecting on my day with the residents. I think to myself, ‘I can’t imagine what the end of my life will be like.’” She has created her own personal ritual for when a resident dies. “I find it to be a necessity to talk to the body of the person; to offer my respects, and to bid the person a good journey. I am cognizant of this being a final contact with the body, which, following death, is a totally different entity. It is my personal send-off."

"In tune" is the way Steve, a friend and co-worker of a former resident, Fred, for thirty-five years, describes residence staff. Humble and loyal are the ways I might describe Steve, who, together with staff, enjoyed "indulging" Fred's needs and whims, which included a predilection for playing the lottery. Prior to becoming a resident, Fred lived with his 12-year-old son. He was separated from his wife, estranged from much of his family, and his daughter was tied up with other responsibilities. When Steve was asked to step in as Fred's primary caregiver he did not hesitate.

Fred had been a successful machine operator but he always had a tendency to get "out of sorts," Steve shares. "His anxiety was heightened by loss of control and not knowing if he was going to be able to resume control." These tendencies exacerbated as his condition deteriorated, Steve observed. Fred was prone to panic attacks and was especially anxious about what was going to happen to his son after he died—and what was going to happen to *him.* On several occasions he asked Steve directly, "How do I know what's going to happen to me after I die?"

Sometimes the most effective support to a dying (or any) person comes from someone who doesn't carry a history with the person and is less close. For Fred, Lance was that person. While Steve never addressed the matter candidly, he suspects Lance, a volunteer, may have. Lance spent countless hours with Fred, and drove a significant distance to be at the residence, even on days when he was not scheduled. The two developed a special bond. "They talked about everything." When Fred was declining, staff called Steve daily, sometimes several times a day, just to update him. "They knew exactly what to say during that time." Although Steve was not present for Fred's death, Lance was. "Fred got to resolve a few of his issues," Steve believes, which he attributes to the care providers at the residence. It is fair to say Steve's steady friendship and presence helped, too.

Connie emphasizes the continual challenge of working with residents that comes with the territory of hospice work is the art of knowing "how to communicate care without being invasive, and how to convey 'you are not alone.'" Lance, perhaps more than anyone else, was able to do this for Fred. "The hardest thing," says Connie, "is when there are no words," as is often the case when death approaches. "Then there is only gentle touch." She intimates a question: How does one speak and touch or listen with honesty?

On the days I visited, Deidra was the most active of the six residents at Hospicare, and appeared to be the best interview candidate. Her cropped, spiky hair was dyed red. She also stood out as the youngest of the current group, in her early 40s. Though rare, there have been minors, even infants, as residents. While most residents are older adults and bed-bound or remain in their room until a family member, friend, or volunteer offers to escort them outdoors, Deidra ventured out to the Japanese garden benches several times daily to hand-roll a stash of tobacco and enjoy a solitary smoke. When she spoke, her voice was gritty but her mind was sharp and pensive. She told me she used to own an antique shop and was an expert at refurbishing. Her specialty was finding "gems" stashed in junkyards. Deidra's rounded posture, forward-sloping walk, and dense aloofness, in contrast to the impenetrable outpouring of her history, suggested ambivalence. She was a bright flower that closed as readily as she opened, and then remained closed—at least toward me. Yet Deidra was refreshingly sober in her admission that this was the last stop on her journey; she said she would die at the Hospicare Residence.

On our first encounter, death was a backdrop offsetting the richly ordinary details of her former existence. When she spoke, she was an ocean. Words surged forcefully, denying the privilege to interrupt, record, or take notes in her presence. I resolved to pay close attention. Pulled in, no longer a researcher, I was her willing and captive audience. Most words escaped, but I retained a few phrases and the essence of her revelations and hidings combined: “Twelve friends died in motorcycle crashes…I was the kind of gal’ who could change things…I was a hell-raiser—and a good step-mom…I’m like an old junker…My shell is failing.” Above all else was the desire to find peace. Words receded as spontaneously as they gushed, then Deidra briskly walked away, as if she had never spoken. I wanted to hear more.

The next day, Deidra received company she had been anticipating on her bedroom deck, overlooking acres of green expanse. I saw two bodies at a distance, bent together, held by an invisible force. Afterward, and for the duration of my visit, the door to her bedroom remained closed. I read this as a statement of boundaries and privacy. Her red bicycle, parked casually outside the front entry to the Center, also represented autonomy. Tomorrow, Tricia told me, Deidra would be leaving the grounds for a weekend outing with her step-son and grandkids.

On the morning of my final day on-site, Deidra was out front taking a smoke. She commented about the kayaks fastened to the top of my car and recommended a few local waterways. I realized I was still hopeful she might allow a formal interview. Later, when Tina, the staff person who probably knew Deidra best, approached her on my behalf, she gave a final refusal. This, like her impulsive sharing, was symbolic of Deidra’s fiery will. She was still alive and burning.

A Home for All: Portrait of Isaiah House

Figure 4.29. Portrait of Isaiah House.

A man wearing a white tee shirt and gray sweatpants sits at the kitchen table reading the *Democrat and Chronicle*, the local paper, while sipping coffee from a mug. A woman stationed by the stove chops onions and celery, preparing a large pot of soup. If not for the small wood sign located at the top of the porch stairs and the brochures on a small table in the front entry hall, one would never know that this is a special house. Nor would they know that the man, Bill, is a terminally ill resident and the woman, Libby, also known as the "soup lady," is a volunteer. Like the other 75 volunteers at Isaiah House, Libby wears multiple hats. In addition to cooking a batch of soup from scratch every Tuesday for residents, their guests, staff, and volunteers to enjoy, she also offers a free spiritual support workshop to her peers and helps to create memorial services for staff and resident families.

I visit Isaiah House in late May and June. Flower boxes and hanging baskets overflowing with pansies in shades of violet, gold, yellow, and white line the front porch. Purple irises pave the path leading from sidewalk to front door. Built in 1914, Isaiah House blends in with the row of modest cape-style houses along Prince Street, in the inner city of Rochester. Founder and former Director, Kathie Quinlan, calls it an “ordinary extraordinary” house. Kathie’s petite frame, white hair, soft blue eyes, and sweet, grandmotherly voice camouflage her fiery nature and mission.

Figure 4.30. Isaiah House.

Sharing the dream: History of Isaiah House. Like a rare astonishing flower, 30 such homes for the dying, also known as “comfort care homes” (or “homes,” as I shall call them) have spawned across the region of Rochester in the upper western corner of New York, including a few sprouting up in other northern parts of the state. Unlike other care settings, including hospice residences, lack of finances and insurance are not barriers at the homes. None accepts fees for providing a home and care to residents, who must have a prognosis of three-months or less to live. Most homes have no guaranteed means of income and are dependent on the generosity of the communities they serve for financial sustenance.

Location was strategic to the mission of the first two Homes, planted in the heart of the inner city of Rochester. Rose and Raoul Grossi, a couple with no medical training, parented the first Home for the Dying, opened in 1984, in the early days of the hospice movement in America. This was many years prior to the first hospice residence in the State, the Hospicare Residence, established 1995, in nearby Ithaca. The couple were lay Carmelites, a Catholic religious order influenced by Mother Teresa; hence the home’s name, Mt. Carmel House. Thirty years ago, when Mt. Carmel House opened its doors, there was minimal information about hospice, a little known service, and there was no sophisticated blueprint as to how to structure or operate a Home. The Grossi’s nephew, Jim Brenna, a lawyer, did a lot of the investigational groundwork. He learned, for example, that three or more beds constituted licensure as a healthcare facility. Hence, each Home has two resident beds. Most have at least one additional bedroom reserved for residents’ guests. The House the Grossi’s envisioned was clearly not a medical facility although they, like Kathie, understood the “necessity” of having a nurse on staff.

In 1984, Kathie, a nurse by profession, met with Father James (Jim) Callan of the Corpus Christ Church to share her dream of opening a second home. A visionary, Father Jim was known for his radical social activism in service to the health, well-being, and healing of the community, especially the needy and marginalized. “The goodness of Kathie, and knowing she would do it well, made me think this would be a good project for the church,” says Father Jim. He adds, “I think she just wanted the opportunity to offer bedside care, but I said, ‘It’s your idea’ and encouraged her to run it. She didn’t think she could.” Kathie refers to that momentous and affirmative meeting as the “sharing the dream” or “sowing the seed day.” Isaiah House opened its doors three years later, on August 6, 1987. Isaiah House was to become one arm of a body of outreach “ministeries” to the community. It was grounded in what Quinlan describes as a “wholesome commitment” to social and health care justice, which drew her to Corpus Christi’s vibrant parish. As Director, Kathie nurtured her vision for 20 years. She has since stepped down from her role and board, but continues to facilitate a “Nearing” class to new volunteers and has lunch with Kristin, the current director, on a regular basis.

Father Jim shares his memories of the transformative phase, from dream to reality: “In our church community, we have the principle: if you want a big response from the community, you offer a big challenge. So I asked for a house!” Jack Rogers, a 72-year–old parishioner, retired firefighter, and widower of five years stepped to the plate and offered to buy the house. Jack imagined he would live upstairs and serve as a volunteer. “Some people didn’t think it was a good arrangement. Within four weeks, Jack met a widow, they fell in love, we married them—and we got the house!”

The summer before opening, all kinds of work needed attending. The sense of anticipation was high. Father Jim introduced another parishioner, Betsy Inglis, to Kathie. Betsy helped Kathie and her husband paint walls, along with a few other volunteers. She remained a weekly volunteer at Isaiah House for the next 18 years. According to Betsy, the Grossi’s interest was focused solely on Mt. Carmel, while Kathie was interested in "spreading the philosophy." Thus, she and others refer to Quinlan as the mother of the Home for the Dying movement. Similar to Cicely Saunders, Quinlan was interested in the big picture. She sensed her responsibility was not limited to opening a single Home. Rather, it encompassed the development of "a whole little movement." Quinlan attributed their development and success to a combination of hard work and trust.

Bev Clark, who volunteered at Isaiah House under Kathie's wing for numerous years before proceeding to open another home, attributes the success of the homes across the region to four pillars: simplicity in caring for the dying; consistency in operations; respect for individual needs of residents; and maintaining independence and vigilance against bureaucratic intervention. All homes abide by the low-profile tradition aligned with Kathie Quinlan's encapsulation: "Keep it simple; keep it grassroots." By doing so, Bev believes, "people will resonate with your vision and support it simply because it is the 'right' thing." Spared the political and bureaucratic constraints tied to federal funding (and regulation), the homes may be better suited to uphold hospice principles and grassroots ideals than hospice residences. In this sense, "the little houses are the last bastion of preserving the purity of the hospice philosophy," a nurse who works in a Rochester hospital once imparted to Kathie.

A home for all. The chief principle at Isaiah House, to serve those with "the greatest need and the fewest options," also reflects the mission of Spiritis Christi, initially Corpus Christi. Father Jim explains, "Our central metaphor at the church is Open Arms, with one arm extended to the poor and the other welcoming everybody else. Inclusivity—black and white, gay and straight—is a pillar. In the same manner, Isaiah House is a House for Everybody." Since opening, Isaiah House has served over 475 residents. The average length of stay, holding steady over the past years, is one month. Symbolic of the home’s multicultural spirit, a flag with an image of the Earth, encircled by the word “peace” in varied tongues, hangs by the front door.

Isaiah House was the first home in the region to welcome people with AIDS. “That was a time of confusion, fear, and misinformation,” Kathie recalls. Father Jim referred to Kathie as “brave” in her decision to include people with AIDS, demonstrating a commitment to meet the most urgent needs of the community throughout changing times. “It was never a question or a matter of deliberation,” Kathie insists, “but it required a lot of teaching for our volunteers.” For a number of years during the height of the AIDS crisis, about a quarter of the residents at Isaiah House were people living with AIDS.

In Father Jim’s perception, Kristin Catalano, the current Director of Isaiah House, was similarly brave to include John, a person with a serious psychiatric-related legal history. It was particularly meaningful to Jim when John, whom he knew 35 years ago from the Church’s prison program, became a resident. “It’s an example of the circle of care in action.” Father Jim shares another coming full circle story from the early days at Isaiah House. “Some people in the neighborhood initially opposed us—a case of ‘not in our neighborhood’ syndrome. Years later, who comes through our door but the leader of the opposing organization. Now, she needed us most!”

“Inclusivity,” is not a word typically associated with the Church, yet it was the cause of Father Jim’s excommunication from Corpus Christi. His “transgressions” included allowing women on the altar, inviting non-Catholics to receive communion, and blessing gay unions. “Great issues!” He gleams. Kathie and Betsy, like other parishioners, did not perceive these issues as “radical”. Initially incorporated under the umbrella of Corpus Christi parish, following Father Jim’s expulsion, in 2000, Isaiah House became separately incorporated. The new congregation of Corpus Spiritus continues to thrive under Father Jim's leadership and to support Isaiah House through contributing $100 weekly.

Both Kathie and Jim refer to Isaiah House as a "ministry," for me, a word laden with religious connotations. When I mention to each that I do not resonate with the word, Kathie responds matter-of-factly, "Ministry is simply another word for caring. We are ministering not just to an ailment or a diagnosis, but to the person." For Jim the word "ministry" is synonymous with service and life enrichment. He explains, "As a ministry, Isaiah House is helpful to everybody's spiritual life," whether on the giving or receiving end of care. For Jim and Kathie, the word imparts an ecumenical rather than religious flavor, embracing and transcending all religious and spiritual traditions. The principle of embracement is visible. In the garden, not far from a statue of Buddha stands one of St. Joseph. A mezuzah hangs on the front doorway. The universally soothing message inscripted in chips of colored glass, *All Will Be Well*, from Christian mystic Julian of Norwich, frames a garden window. Kathie acknowledges, "We have cared for Buddhists, Quakers, every Christian tradition, agnostics, and atheists. Each one has taught us something. We are a home for all."

Figure 4.31. Isaiah House Garden.

Kristin Catalano learned about the Homes for the Dying in her previous job as a hospice liaison with Lifetime Care, one of two hospice organizations serving Rochester. Part of her job was to coordinate discharge plans for terminally ill patients, from the hospital to either a private residence, a hospice contracted nursing home, or one of the homes. “Some people were really desperate to get into one of the homes,” she remarks. “When we had a patient who was homeless or different, or just very challenging, it was Isaiah House that would open its doors. They were the home that always said ‘Yes.’ *That* is why I fell in love with this house.”

Currently a volunteer at Isaiah House, Frank Tiberio was first introduced to the house professionally, as a social worker involved with discharge planning at Lifetime Care. One of the nine comfort homes across the county was the “ideal choice for about half the total caseloads. There are never *not enough* people to serve.” The difficult part of the job is each home picking just two people out of between 40 to 50 referrals, and that’s just from one agency; two hospice agencies are competing for these beds. Nine homes is not enough, echoes Marj, a social worker at the Visiting Nurse Service, the second regional hospice agency. The task of discharge planning is a little like matchmaking. You need to consider appropriateness: the personality and needs of the resident and family and the personality and capacities of the staff. Some Homes seem better equipped accommodating the more anxious family or the family dealing with mental illness.

Associations of home and preferences for one Home over another are largely subjective. Frank is partial to Isaiah House, while Marj admits feeling most connected to Aurora House, “in part because of the personality of the house—each house has its own, and in part because when both my parents died the family sent memorial donations to Aurora House when it was in its beginning stages. So it feels like my mother and father helped build it.” It also happens to be in the neighborhood where Marj grew up. This is how bonds to a particular Home develop. Location matters a lot when facilitating a discharge. Marj explains, “People want a home that is close to their own home.” In a perfect world, we conjecture, where resources were not finite, there would be a Home for the Dying in every community.

Like other health care professionals in the region, Kristin recognized Isaiah House’s openness and responsiveness to providing a home for the most “socially-injured persons.” Here, they can find shelter and discover trust and unconditional love, perhaps, for the first time. Providing emotional safety is one of the main goals. About 70% of Isaiah House residents are people who are indigent or living under “harsh circumstances,” according to Kristin. People who go to the top of their referral list are those who have no one. “Whether it’s the person who has lived a life of drug addiction, the person with a brain injury, an AIDS patient, or the schizophrenic person who’s up at the Rochester Psych Center that’s dying, you can bet the nurses and social workers are calling Isaiah House, knowing that if we have a bed we are going to take them,” she says, ardently. “That is the population we are committed to and why our Home is located here, in the inner city.”

Referrals are not only for indigent persons; they are for anyone who has lived his or her life in the city. Kristin elaborates, “City folks don’t want to be out in the suburbs; they want a person who knows the city and city people to be taking care of them. And don’t forget you need bus routes for families!” she adds. “There is just a certain type of resident that appeals to your type of volunteers. Our city-bred volunteers are going to treat everyone beautifully,” Kristin says with admiration.” They are especially drawn to the bedside of those residents who have been “shunned by society” for different reasons, and who don’t have anybody. “You can feel the passion in the house when that is happening. They are going to give that person wonderful care.

That's their thing. It's about seeing the value in each person. It is part of the culture of being in the city and it is part of the culture here, at Isaiah House." This was the case with John, the man with the serious psychiatric history. According to his advocate, John had been deemed unlovable by society. The advocate, whose family member had died at Isaiah House, wanted John to have the opportunity to feel the same kind of love that Isaiah House volunteers gave to her family member. Isaiah House agreed to admit John. "Caring for this gentleman wasn't easy for the volunteers—or for me, by any means," she admits, "but it was very rewarding."

A place of stories and rituals. When I enter Isaiah House, my eye is immediately drawn to a mandala-like sunburst hanging in the front hallway, a contrast to the otherwise soothing palette of decor. Flames of red are threaded with gold. In my journal I jot: *Sunburst / Radiance / Flame of Life / Flame of Death /One Flame.* Kathie calls the painting *Radiance,* "perhaps because it will ever remind me of Teri, a truly radiant being." Teri had a Master's degree in audiology and worked at Strong Memorial Hospital. Near the time of her diagnosis of uterine cancer, she had received word of her acceptance into medical school. She was only 32 years-old. "Oh my, lost hopes, lost dreams!" Kathie laments. "Despite these losses, Teri lived so fully the days of her dying," Kathie says. Betsy remembers Teri, too, as well as her female partner and large network of women friends. "It was such a tender time, seeing the love all these women had for each other," Betsy recalls. The painting was gifted to Isaiah House in Teri's memory. A contrasting image hangs opposite to "Radiance." It is a small, wispy painting the artist titled "In the Between," suggesting a family in waiting. A luminous figure hovers in the background. Kathie tells me it portrays the artist, Louise Werner, sitting vigil with her dying mother. Sometimes Kathie would escort family members over to the picture "to illustrate their loved ones' place on the dying journey."

Figure 4.32. Radiance (Artist Unknown).

Each resident’s journey at Isaiah House begins with the Welcoming. Admission and discharge of “expired” patients are routine procedure (and vernacular) in institutional care settings. At Isaiah House, transitional phases of entry and departure are treated with utmost importance. “It’s about creating an aura of welcome,” says Kathie, as she describes the Welcoming, the Isaiah House way of receiving new residents. It is a time of excitement and preparation for the house. Kathie elaborates, “It is always a hectic day! We put fresh flowers in the room. We have the bed all made with linens and quilt folded back. Sometimes, families will bring their loved ones’ things over beforehand. We always have something baking in the oven. Upon arrival, we run out to the ambulance. We shower the person and family with attention. We are also busy drawing up the care plan and getting the care ‘journal’ set—an adaptation of the conventional medical chart—including a narrative of how the person was *before* they arrived, written upon our first encounter in the hospital or other setting. A significant question we ask during that initial meeting is 'What are you hoping for now?'" Most responses are rooted in reality; they serve as useful guides. The message Isaiah House wishes to convey to the new resident and their significant others is fourfold, Kathie explains: "We are here for you; our care is unconditional and non-threatening; we don't care about the past; and we will do our best to help you survive this a little more intact as a family. Isaiah House is a neutral place."

Each person's life and each death is perceived as a mystery. Kristin's intention is to remain open to whatever is going to happen. When she meets a new resident, she thinks of her or him as embarking on a journey. "There is a story that is going to unfold here," she says. "We provide the safe space, but we don't write the story; we let it happen." Kathie refers to this precept as "Doing by not doing at all." Kristin underscores the import of the Welcoming, a tradition she carries forth as the new Director: "I can't tell you how many times a prospective resident has broken down when I've said, 'We are not here to judge you; we are here to take care of you'." This message opens possibilities. "People who have been addicted to drugs or have been homeless have cried and opened their hearts to me when they hear that." Kathie describes the "demeanor of care" bestowed upon residents and their significant others as one of "tenderness," consistent with hospice philosophy. Like others, Frank, the social worker, senses something palpable upon entering Isaiah House. "A tremendous community need is met and transformed by an atmosphere of gentleness. It's like being wrapped in a blanket," he says.

Resident families also create their own rituals and celebrations. I arrive at Isaiah House on Tuesday on a subsequent visit —a day too late. Over the weekend Mary, a resident, had a big family gathering. "We cooked and feasted here," says Marge, an extended family member who refers to herself as Mary's adopted daughter. Her face brightens. "There were 27 of us, including some staff and volunteers. The three of us made four pounds of macaroni with Joanne's homemade meat sauce, and four roasted chickens. We brought in coffee, lots of pies, and doughnuts. We took over the whole house! We set up tables on the porch and spread out into the garden. There was a crowd in Ma's room. Her 90 year-old sister came. Ma ate some macaroni. She was awake every minute of it. She loved it!"

The next day, following the party, Mary was spent. But she managed to pop up briefly and even put on her wig to greet and take a photo with a local celebrity, joined by her family. Marge, who gets along with and likes to feed everyone, including me, also made certain to feed the other resident, Bill. "I would put my arm on his shoulder, serve him some coffee, make him a bacon sandwich, bring him pie, and fruit. We became buddies." Marge looks wistful. Recently, Bill was transferred to a hospice inpatient unit. She and her family do not want that to happen to Mary**.**

"Initially, Ma' was totally against leaving home," explains Marge. "She wanted to stay home to die. She was told she could come here, to Isaiah House, during the week and go home on weekends. When Ma' heard that she agreed to do it." But things quickly got worse. "We didn't tell her the extent of her illness. We still haven't. But we knew what was in store for her." Mary's son, Ralph, finally told his mother that she could no longer return home on the weekends. "Ma' was fine with that," Marge says, "she liked the care she was getting here. You have to come here to see what it's like. It's an endless caring."

Today, Mary sleeps continually and does not easily stir. She has turned a corner. Up until now, she has stoically declined pain meds. Now her pain quickly escalates and she is having difficulty swallowing. The hospice nurses come by to meet with the family. Initially, they talk about transferring Mary to the hospice inpatient unit, but when the family insists otherwise, they carve out a new pain management strategy. The nurses understand the importance to the family of trying to keep Mary comfortable here. Marge has stayed overnight previously, and is planning to stay again this evening and, "probably, until things come to an end," she says quietly.

The Nearing is the bookend of the Welcoming. It signals death is approaching, sooner rather than later. "Everything we do at Isaiah House leads to, and is a preparation for the Nearing time," loosely defined by Kathie as "hours-to-days or hours-to-minutes before death. It is a range of weeks to days, but more often it is days to hours. People in the Nearing describe it as a fatigue they have not previously known—bone tired—when every cell of the body feels exhausted," she explains. Kathie recognizes the tendency to think there is—and hope for, more time. The Nearing is a way to offer families a range and frame of reference. She distinguishes between predicting versus serving as an interpreter of the dying person's physical signs and symptoms. Explaining things can help alleviate fear and anxiety from the experience of witnessing a death.

In this manner, Kathie refers to herself and other caregivers of the dying as midwives, gently guiding people and their loved ones through the labor of the dying process. Betsy, who was a birth-coach for unwed mothers before becoming the Director of Shepherd House, also uses this metaphor. "Dying is another kind of labor," she says; "and working with the dying is surely a labor of love and a lesson in patience."

Kathie reminisces and draws up a story from her inner archive, to highlight the mysterious cycle of life and death. In 1991, Tim, a former top model in New York, was the first of many young male AIDS residents. Kathie speaks affectionately: "He was beautiful in body and spirit. As his character was unchanged by fame and fortune as a model, Tim's spirit remained unmarked by this disease." Tim's sister brought her newborn baby to meet Tim on what turned out to be their last visit. She placed the infant on Tim's chest while he drew his final breath. “We felt Tim’s life went into this child,” Kathie says. “It was one of the most beautiful deaths.”

Life skills 101. What does it mean to care? This is Bob Kane’s leading query drawn from a well of provocative “teaching questions” in the elective hospice care course he teaches to 15–18 year-old high school students at the Harley School Hospice Program—the only one of its kind in the country. He also favors artist Paul Gauguin’s existential triad: What are we? Where are we going? Why are we here? On a more concrete note, Bob asks, *“How do we actually get dead?”* A mentor in the true sense, Bob promotes self-awareness, responsibility, and community service in his classroom. With a background in teaching English supplemented by training as a hospice nurse assistant, Bob incorporates literary classics, meditation, classroom discussion, reflective practices, and hands-on caregiving, under his supervision, at Isaiah House in addition to eight other Comfort Care Homes, as he, like most locals, refers to the Homes for the Dying in Monroe County.

Bob is well aware he is competing with an inundation of virtual opportunities promoted by the culture-at-large. By contrast, the situations the students encounter as volunteers at the homes are very real. “Through real-time, real-life encounters, students are presented with opportunities for making authentic connections; what’s more, they discover all the essential requirements of caregiving can be found within.” The course, Bob insists, is not really about death; “It is about life and life skills and living—and it’s about relationship.” One can say the same about a Home for the Dying.

The idea for the Hospice Program took seed in 1999 while Bob was teaching at another private school, for children with learning disabilities. It was then he first conceived of caregiving as a vehicle for students to challenge preconceived notions they had about themselves, and as a way to experience *self*-compassion. Authentic connection, especially through touch, is the “real healing,” Bob attests. “The biggest thing about this mortality stuff is the touching,” which he regards as a kind of sacred language. Gentle touch is a conduit through which the meaning of friendship is transmitted and the bond of personhood forged. “Something extraordinary happens when physically touching another person, especially if that person is suffering from some kind of social illness on top of a terminal illness, and is not long for this world,” Bob shares. “There seems to be some remarkable transference through simply holding another person’s hand, and vice-versa. It is a two-way street.”

Kathie also speaks of the “sacredness” of touch, thereby, requiring permission as well as respectful restraint, if requested. One of the hardest parts of being a caregiver, echoed by Isaiah House staff and volunteers, is working with people who do *not* want all the touch and fanfare. “It’s the resident who says, ‘Don’t knock on my door; don’t even peek in,’” Lynda, a volunteer who is a retired nurse and massage therapist, explains. These residents offer important lessons about respect, which Kristen frames as “learning opportunities.”

Another question Bob asks his “kids,” as he affectionately refers to his students, is, “What does it mean to be kind?” It is about giving without expecting anything in return, but rather, “just because something needed to be done, and you were there, and you could do it.” This kind of matter-of-fact action, informed by “selfless intention,” as he calls it, “can translate into all kinds of things in life. It’s *unconditional.* This unconditional thing is rare these days. It’s not part of the culture. This caring for another person, it is all about relationships.” For Bob, relationship and community service starts in one’s own backyard and expands in widening circles. Some of Bob’s kids continue on in his Hospicorp Program, traveling to India, South Africa, Belize, and, most recently, Ireland, to provide end-of-life care to those in need.

Bob cultivates open-mindedness in the field by approaching tough issues like diversity and fairness with his students head on in the classroom. He poses this challenge: “Can you give the same level and quality of compassionate and kind care to someone who has a very different background and belief system than yours—or a person with *no* belief system?” In this manner, students are encouraged to examine their own personal belief systems and motivations. Bob is clear: “It’s not about denigrating anything. It’s about letting go—for that person, and putting your ideas and beliefs in their proper place. This is what is needed if you really want to connect with another person’s story.” For Bob, making space for dying means “making room for whatever is happening for the person.” For Kristin, it all boils down to ‘walking the talk’.

Walking the talk. While Isaiah House struggles financially from time to time, there is no shortage when it comes to volunteers. Word-of-mouth, rather than newspaper ads, delivers prospective volunteers, without which the home would not exist. Kristin conceives volunteering, like professional careers in end-of-life care, as a calling. When prospective volunteers come for an initial interview, she is frank: “You can bet I’m telling them stories to illustrate the kind of work that goes on in the house.” The hands-on work is only a very small part of the caregiving experience with residents. “The pivotal part,” Kristin clarifies, “is the spiritual component and the emotional piece. When you have a hard day on your shift, it is not going to be because you were lifting someone up in a bed. You are going to feel drained because of the kind of work that you did with a family. We take the Long Route here in working with the dying. In an institutional setting, it’s the Fast Track way of doing things because you have other patients waiting on you, but at Isaiah it’s about optimizing dignity.” This requires time and people power.

Storytelling is the chosen medium for teaching and connecting to volunteers, fresh and seasoned, each weekday during early morning coffee hour, and during volunteer trainings. When faced with a difficult resident, Kristin regularly sends emails to volunteers, sharing information and encouragement, “to help them understand what is happening with the resident, and to make sure that they’re not internalizing and taking things personally.” Recognizing the complexity of caregiving, amidst psychosocial and family dynamics, she directs volunteers to look within and models self-care by regularly calling in the hospice agency social worker for guidance. “I congratulate them for walking—not just talking—the talk. It’s about challenging oneself to be a better, more conscious, person, day-by-day, moment-by-moment, and resident-by-resident.”

The challenge in this work, Kristin points out, is to be with those residents who have lived “anti-social lifestyles.” She explains, “These folks don’t want to socialize and may not wish to be touched. They have issues with trust. These residents tend to be more difficult, and even hostile. They may choose to remain behind closed doors. They may not want volunteers around, checking in on them.” Kristin intervenes when she is aware of a volunteer who may be struggling, “because I struggled with this myself,” she discloses. “I remind them, ‘This work is not about us!’” With a dose of tough love, she directs volunteers to venture onward with their caregiving endeavors, regardless of their personal feelings: “Do the same work. Give the same amount of energy and caring to the person who doesn’t want you around.” She underscores, “The volunteers get a lot of satisfaction out of feeling personally challenged; they find it very rewarding.”

Inner work. Kristin works with doubt by working with her mind. She refers to her decision-making role and responsibility as nothing short of “sacred.” Sometimes, she loses sleep, like the time when John was a resident. “It was horrific for me, personally,” she admits. “Yet, at the same time, I had this belief that God was guiding me and it was going to work out. I had a clear sense of doing the right thing. I had faith in the volunteers and in the person who ended up here." Ultimately, she is responsible for choosing who ends up at Isaiah House from the list of referrals. "It's an intuitive, gut thing," she says. Kristin tumbles difficult decisions around in her mind, talks to herself a lot, and draws strength from her religion—"I put a lot of faith in my Faith." She also shares tough decisions with other people, including the Isaiah House Board. Before admitting John, she also talked to Father Jim, who knew John and his history. "When I feel doubt, I ask myself, 'What am I doing here? Then I remember what we are *supposed* to be doing. I have to believe, as hard as some of these cases are, that we are doing just what we are supposed to be doing. I am also constantly working on me. There is a lot of inner work. It includes the ability to step back and remind yourself why and for whom you are doing this work. You have to stay humble."

Both the pleasure and the pain come with the territory of connecting with and becoming part of someone's story at the end of life. Kristin allows herself to get close to the residents, "whether they are here six hours or six weeks." One of the hardest parts of working with the dying, Kristin shares, "is carrying the pain of the families and the residents. I don't *want* to do that, but the pain is just inside of me." For Kristin, loss remains a continual struggle. She admits, "I will have pain if there are two deaths in a week—I mean *tons* of pain, in my neck and shoulders." This is especially the case with residents without family and those whose existence lack "social value". She observes, "Those people who have been of seemingly little importance in their lifetime, seem to have the largest impact on me and the volunteers when they die."

This was the case with Tom, who had "zero" family. "No one seemed to know a thing about him," says Kristin. He had lived in a group home for years before coming to Isaiah House. During the first twenty minutes of their initial meeting, Kristin learned more about Tom's life than his previous care providers had imparted. At Tom's funeral, she found herself in "excruciating" pain. "I was aware that something spiritual was going on—not in a God sense, but in a Universal sense. All of a sudden, a tremendous amount of pain came over me and I just sat there with the pain. I had never done this before. I said to myself, 'This isn't *my* pain; this is *Tom's* pain. I thought I was supposed to feel this pain but now I need to let it go. I just sat with the pain until it let go, and it actually went away! It was the first time I ever experienced something like that. I had never been so mindful. I acknowledged, 'Okay, this pain is happening. But who says it's because of *stress*?' So this continues to be the big struggle."

The circle of caregiving. When Dee's father entered Isaiah House as a resident, both he and his dad were at a low point. After years of daily caregiving, Dee was exhausted. He was about to give up. Isaiah House offered him a needed break from the intensity of daily caregiving, during which time his father rebounded. Dee rebounded, too. Dee and his father's physician attributed his Dad's improvement in health and well-being to the excellent quality of care and attentiveness of staff and volunteers. Marj, a social worker who refers hospice patients and follows their care in the homes, comments: "People may stabilize because they are getting immensely wonderful care; they are getting every need met. So, on occasion, they improve." After nearly five months of respite, along with the support and guidance he receives at Isaiah House, Dee built the necessary confidence and strength to move his father into his own home for the remaining months of his father's life. Before Isaiah House, this was unimaginable.

Recalling the final phase and days of his father's life, Dee poignantly recalls, "My father was never alone". Nor was he. Throughout, Dee remains indelibly connected to Isaiah House staff and volunteers. Loretta, an Isaiah House volunteer, whom Dee describes as being "like a sister," moved into his home during the last week of his father's life. Kristin, just a phone call away, visited daily, before or after work. “As a backup, I knew my father was always welcome back at Isaiah House, so long, or as soon, as a bed was available.”

After his father’s death, Dee gradually transitioned to becoming a fixture at Isaiah House, volunteering regularly. More recently, Kristin linked him to Tommy, a new resident, a woman of color who has pancreatic cancer, just as Dee’s grandmother had. They formed an immediate bond. He visited Tommy three times a week through the duration of her final days of life at Isaiah House, over the course of six weeks. Upon Kristin’s suggestion, he also provided support to Tommy’s daughter “to help get her through it,” says Dee. Now, Dee is in a career transition, marrying his prior expertise in marketing with a growing passion and proficiency for caregiving, in his new position at a home health care agency. “This is the kind of work I want to do: hands-on, people care,” Dee states resolutely.

Caregiving weaves through the cycle of life. The cycles of life/death and giving/receiving care go arm-in-arm. “It was my dad’s life, the *way* he lived,” Dee believes, “that attracted a circle of goodness in the final months and days of his life.” Being an integral part of that circle is an act of reciprocity, a continuation of the cycle of care his father provided for him in the beginning of Dee’s life. “My father planted the seeds of being naturally caring, a ‘natural caregiver’. Caring for my father hasn’t changed my life; it has *enriched* my life. This whole process of being with dying has taught me patience, for sure! It has taught me compassion and kindness.”

Kristin referred to volunteers as the heart of Isaiah House. Volunteers are diverse in their life experience, including retired health care and other professionals, and age, ranging from teenagers to elders. Mariana, a 29-year-old physician, arrived in Rochester circuitously, through a sequence of “magic steps.” Deep personal reflection and progressive magic steps landed her at

Isaiah House as a volunteer. The first monumental step was leaving her practice as a hospital-based general practitioner in Chile. Only recently, has she begun to understand the root of her despair and distress.

Mariana's words and bodily expression are laden with emotional energy. Hands dance and frequently land on her belly and heart when she speaks. "I am a feeling person," she begins shyly, waiting for a response. I reassure her she is in good company. "I had to quit my job because I was so uncomfortable with dying patients," she shares. "I wasn't aware at the time that this was my specific problem." She pauses, looking thoughtful, as if trying to find the right words. "I wanted to take care of my patients in a complete way—but I didn't know how. We didn't have hospice philosophy at the hospital. The setting wasn't for hospice. I was so scared that one of my patients would die on my shift," Mariana admits. A shadow of distress passes over her face. "The only time it happened, I called the older physician on my shift and pleaded, 'Please come and stay with me'. He said, 'What is the matter with you?' I just needed him to hold our hands," she says, gesturing with clasped hands.

Looking back through the lens of her experience as a volunteer at Isaiah House, Mariana recognizes "the circle of care was not complete," neither for her patients nor for her. "I was only doing the *clinical* half." At the time, Mariana took her emotions home; she cried and experienced headaches. "I was holding a lot of incomplete circles. The path to death that I made for my patients wasn't peaceful." She tries to identify what was lacking. "It's about the person, the human being, the whole person, and the roles we play." What was missing, I suggest, is the *relational* half. Mariana lights up. "Yes! The painful part for me is the disconnection," she emphasizes. "With friends, if you have a problem you can just put things on the table," she explains matter-of-factly. "With doctors, it's 'I can't talk about this' and 'I don't really know how to take care of you'—so you hide." Mariana looks as if she is holding her breath. She lets out a sigh. "When you can put hearts on the table and prepare for death together, then it's not so scary. Why couldn't we just be friends?"

The real medicine for ailing and dying people, and the balm for what ailed her own spirit, she discovers, is the same. It is relationship. At Isaiah House, Mariana discovers how much she enjoys optimizing residents' enjoyment. Things that never occurred to her previously in her doctor role, she learns, are the ones that often matter most, such as "asking a person what they like to eat—even if it isn't good for them!" She cherishes the non-clinical, non-verbal gestures of care and reassurance she can offer just by placing a hand on Bill's shoulder, as well as being the recipient of friendly hugs offered by this bear-like, though tender man.

An early encounter with death was a catalyst for Anna becoming a volunteer at Isaiah House. "I have a huge fascination with death and I am always learning," says Anna, a bubbly, 26 year-old volunteer. Anna started volunteering at another home, Teresa House in 2005, when she was only 18. Charlie, her childhood friend, was the same age when he died of cancer. A college freshman at the time, Anna was unable to be there for Charlie and his family, but she had the option to do a community service project for college credit. That is when Anna started volunteering at Teresa House. "I was only required to do ten hours total, but I wound up volunteering a four-hour shift every Sunday—for all four years of college!" she says with astonishment. "I was aware that it helped ease my guilt about Charlie. It also provided respite from academic life. When I went to the home, I could put those things aside and just focus on what really matters in life. It was restorative." After school, she took a break from hospice care for a while. It helped her realize how much she really missed working with people facing the end of life. When Anna started a Master's degree program in counseling, she had the opportunity to do an internship at Isaiah House. “This time,” Anna insists, smiling, “I am not doing it out of guilt!”

The perception that death is a natural part of life was something that Lynda, another volunteer, learned from her family while growing up. Her elderly great aunts and uncles were “laid out” in their homes with Lynda and the other kids running around. “I came from a family of superstitious and religious people who talked about the deaths and near death experiences of family members,” Lynda says. As an adult, she extracted what she found useful and “left behind the religious overtones,” Lynda explains, to serve as the foundation of a career in nursing for forty-five years. Early in her career, one of her nurse colleagues happened to be Kathie Quinlan. The pair was amongst the few nurses who helped to prepare their patients for death. “We felt comfortable being with them at the end point, and also helping the families to be part of it.”

When Kathie left nursing to start Isaiah House, Lynda told her that someday she would join her. Twenty-five years later she did! But doubts arose once she arrived at Isaiah House’s door. Just two days before she planned to start volunteering, Lynda’s 93-year-old mother died. She thought to herself, “I was just the daughter, when my mother died, and I was just the mother, when my sixteen-year-old son, Brian, who was born with a congenital heart defect died, but I wasn’t exactly sure what I was going to be when I was here.”

For the past four years, on the Monday morning 7am to 11 am shift, Lynda is, in her own words, “just a volunteer.” She offers hands-on care: she bathes, soaks feet, and offers Reiki and some massage, providing residents comfort and touch. After her son Brian died, she had stepped away from 1:1 care to do administrative nursing. Now, as a licensed massage therapist, “I am back doing what I became a nurse to do!” Volunteering offers Lynda and her peers “a constant lesson to be present, and to be truly present in a way that the person who is dying needs, not that we, as volunteers, need. That is a continuing challenge," she underscores. It was her fiercely independent son, Lynda explains, who "trained" her to be respectful and sensitive to the preferred needs of the dying person, even when they were contrary to her own. One of Brian's doctors, a "wise" cardiologist who had known Brian throughout his life and knew the family well enough, made her aware of the weight of words when talking to vulnerable people. Near the end, the doctor "addressed me on a spiritual level, not a pure medical level, which is the level I was on. It soothed and offered me solace."

Now Lynda feels at home at Isaiah House in her role of helping residents and their significant others feel at home. "I think people feel safe here; we lift burdens," she shares. Lynda feels most appreciative of being permitted to observe the changes as people get closer to death: "We become more vulnerable, we drop the masks, we stop the posturing, we can't stand behind what our job was. You see people become their essential selves. Caregiving invites us to do—and to be—the same."

Chapter V: Reflections

I try to get closer to death, close enough so that death is no longer a spectacle.
(Behar, 1996, p. 84)

We are Nature,
long have we been absent, but now we return….
We have circled and circled till we have arrived home again.
(Whitman, n.d., pp. 91-92)

I want to tell a story…

I segue into this discussion chapter by stepping back and reaching into the well of my own lifeworld, to share a few key experiences and images from dreams that have shaped my development as a person and scholar/practitioner. They are lessons in liminality.

In my research creation process, I have struggled with what data to include. I have also struggled with (and resisted) inclusion of personal material. What stories do I wish to tell and how important is my personal her-story? How much self shall I reveal? Perhaps the voice I have been seeking, needed for the discussion, is tied to my silenced story. Then I come across the words below, cited in friend and colleague Lucy Barbera's (2009) dissertation. Suddenly, I feel freer.

> I want to tell a story that reveals the roots of my inquiry: the ways in which concepts, issues and interests interconnect; the ways in which taste, textures and tempo resonate with purpose, content, process and form, asking me: Why am I doing this? What am I unearthing? How do I dig? How do I present this? (Luciani, 2004, p. 40)

These are my questions, too. They point to the pieces—of myself—left out of the dissertation, thus far. These puzzle pieces contextualize and illuminate the roots of my inquiry—I initially read as injury—regarding dying and death. They give me a voice, and further position me in relationship to my inquiry. They also make me feel more vulnerable, present, and real. These "stories" manifest in the shape of memories, dreams, and reflections. Perhaps they will allow me to frame the perspective of this dissertation creation process with which I have been struggling.

I take Luciani's (2004) words as an invitation. While my research methodology is not auto-ethnographic, like Barbera's, I believe qualitative research, and the impetus for inquiry, is reflective of the investigator. This appears to be the case for the end-of-life researcher, as Hockey (2007) suggests; the inquirer's story often remains lurking in the shadows, unacknowledged. Acknowledging the presence/position of the self strengthens a study's authenticity and validity. Importantly, the character/istics of the measuring 'instrument' must be known in order to understand the resulting data.

Through choosing portraiture and an arts-based approach, I give myself permission to depart from conventional discourse and make some space for creative expression, yet I also continue to compartmentalize, to some degree, a space for self and self-expression. Where do the scholar/the clinician/the artist/the woman facets of self begin and end? What artificial boundaries do we impose between our different selves?

A space for my writing process/voice opens up when I decide to elaborate on the nest theme/image and add the nest collages, which are personal explorations. Is it appropriate to give myself more space and how much? Bullough and Pinnegar (2001) recommend a middle-way approach, between "self and arena," highlighting "the space between self and the practice engaged in" (p. 15). This seems apropos, as attention to "between spaces" has been a thread.

I initiated all my research interviews with a version of the prompt: "Tell me your story…" (of living with terminal illness; of how you came to your professional/volunteer role in this care-setting; of your role as caregiver and how your loved one/friend came to this care-setting; of how you came to be a resident here). Nearly every response from an end-of-life care leader, professional or lay caregiver started with an unsolicited tale, sometimes tragic, of a loved one's death. I am fascinated by this unanticipated theme of the growth and development of caregivers, from early impulse (or calling) to maturity, a journey often catalyzed by a significant death. Death is life changing.

Such is the case for Kathie Quinlan (2011), Founder and former Director of Isaiah House, a Home for the Dying, as she shares with me personally and in her autobiographical narrative that stories the creation and care culture of the home. It is the early deaths of two of her five children, due to a rare degenerative disease, each around their first birthday, which compels her to become a nurse and, in particular, to follow a passion to provide hands-on care for the dying. I will begin my story here, too.

Lessons in Voice

My father died twice. First, when I was 16, after my parent's marital separation, when I confronted him about abuse throughout my childhood. It turned out to be the last time my father spoke to me. Estrangement is a kind of death worse than death. It is a state of sustained or permanent limbo or liminality. Of lostness. Being lost is a familiar theme in my dream life; I seem to have a propensity for it in my waking life, too.

In my early 30s, my father died a second and last time. His physical death represented a profound psychological death. It was the death of hope—hope for reconciliation. I had mourned the delusion, privately sustained for many years, that somehow, someday my father would need me, especially toward the end of his life, and would wish to see me. It was death of the opportunity to say goodbye, and to speak the healing phrases that transcend injury: "I love you," "I forgive you," and "thank you." My father's death also represented a rebirth. It felt safe to be in my body, to be embodied, perhaps for the first time. The world was a safer place. His death ushered in a phase of personal growth and gradual movement into the world. A few years prior, in my late 20s, I experienced another unexpected and life-shaping death, this time of a full-term stillborn baby. (This incident occurred about twenty-five years ago in the hospital where I presently work, although I was living several hours away at the time.) Her name is Selena.

In my first learning achievement for the Leadership and Change Program, “Breaking Silence: A Healing Sojourn of Discovering Self and Voice” (Lark, 2009), an autobiographical essay, I write about my father, and finding self/voice. I will share a few excerpts pertaining to the latter:

Through these early experiments of using my voice and speaking my truth I learned that truth is not benign. I learned that truth can be distressing to speak and can carry a terrible price. It can wound the truthbearer and the truthhearer. I learned that truth is not always welcome, and is often diluted or avoided. Yet despite all the fear, guilt, grief, and ambivalence associated with these early experiences in truthtelling, something in me was also strangely certain that the secret, the truth—my secret, my truth—had to be spoken. It was my experience, my perception; therefore, the burden of responsibility fell on me and me alone. I had to speak. I learned that using voice, speaking truth, speaking taboo, is an act of courage. It is a formidable act of power. It has taken years to claim the courage and power as my own. Voice continues to be my edge.

To speak or not to speak. That is the crucial question linking women to their internal sense of personal authority, power, and external sense of accomplishment (Ziv, 2001). It is also a central question for would-be leaders. The words ”voice” and “silence,” in light of women’s voices, have personal, social, literal, and metaphorical levels of meaning:

> The word Voice [is] a metaphor for the recognition of Self and its authentic expression, and the word Silence [i]s employed to describe feelings of powerlessness, loss of Self and presentation of a False-Self in their relationships….[Further] women's experience of taking charge of their lives is a

> life long process, a way of being in the world and fulfilling their potentialities. A woman taking charge of her life is a woman who sees herself as an autonomous, unique and capable individual, who recognizes her Voice/Self, and knows her personal-power, her ability to shape, direct and live her life in ways that are meaningful to her and that honor her existence as a human being. (Ziv, 2001, p. 1)

Voice is the single common thread that yanks at my personal story and weaves itself into my current workings, impulses, and reachings. Gradually, through a growing urgency to share and to be, and the invaluable encouragement of others, I am discovering Voice: mine. It is the voice of a vulnerable woman, of a curious explorer and truth-seeker. It is the voice of an artist/poet. It is the voice that seeks to engender a sense of wholeness and aliveness in self and others. It is the voice of the wounded healer. It is a voice that questions reality, sparks possibility and sometimes controversy; a voice that inspires reflection and conversation. A voice that increasingly speaks out, softly but passionately, about issues related to death and dying, and one that advocates for change. It is a voice sought by patients and health care professionals to facilitate dialogue on difficult matters and decisions, difficult truths.

It is a voice that ventures to dream out loud.

Lessons in Liminality

My life, my vocation, and my research have been indelibly shaped by personal loss. Responding to the call to serve those who are suffering and dying is a necessary response to learning how to live with adversity and loss, and how to be/become human. Through the losses I have sustained and witnessed, I have learned that while death is permanent and leaves an indelible mark, it need not debilitate. Rather, being with and making space for dying and grieving can lead to resilience, depth, compassion, humility, and a renewed sense of purpose and aliveness. It can foster healing. Loss is the sacred wound and the healing balm of the wounded healer. The journey toward a more meaningful life and delivery from meaningless suffering is everyperson's journey and task.

The impulse to return to school in my late 30s with the vision of becoming a hospice social worker was stimulated by a convergence of events, including these significant losses. After a period of working with my own grief (including reading books on death and loss, and trying to make sense of my own experience), and several years of participating in study programs on body-centered psychotherapy and psychospiritual development, I enrolled in a hospice volunteer training course. The facilitators, mostly social workers, asked questions and spoke about things that mattered to me. At the time, I was immersed in reading a collection of intimate vignettes, by Marie de Hennezel (1997), about the terminally ill patients she works with as a hospital psychologist. I decided, "This is the kind of work I want to do," as spoken by Dee, a participant, for whom caregiving becomes a vocation after many years of caring for his father. A social work license symbolized the privilege to engage the dying in intimate conversations, and to listen to their stories. However, in my role as an oncology social worker, interfacing with patients, families, and medical professionals, and in this research, I discover this is the exception rather than the rule. I have the following dream shortly after I begin my job at the Oncology Support Program (OSP):

> I am at an amusement park accompanied by my partner, Will. Amidst the crowd and ruckus, we lose sight of each other. In my searching, I come upon a steep winding slide. The landing below hides in darkness, beyond sight. Standing at the edge, peering down, I glimpse a body quickly descending. I seem to recognize my mother. She is tumbling unstoppably down, discombobulated. I only glimpse scattered body parts. I have the awful feeling that Will has arrived here, too, before me, and gone this route. Then the dark truth dawns on me: **There is only one exit to this amusement park.** It is my exit, too!

I can still feel this nightmarish dream in my body. I associate the dream with the death of Marybeth, the first program member I was assigned to work with at OSP, a woman around my own age at the time, in her 40s. Her death jolted my psyche, dislodging my own submerged grief and death anxiety. There was no separation: her mortality was my mortality. In retrospect, the dream served as a point of departure on my personal/clinical/scholarly journey; a journey toward consciousness. It was an initiation.

The dream motivated me to create a space for conversations about dying and death. I invited friends and colleagues to join in an intimate yearlong exploration of “A Year to Live: How to Live This Year as if it Were Your Last,” based on a book with this title, by Levine (1997). It was during this experiential group that I decided to return to school once again. I thought, Time is ticking, regardless of how much longer I have to live. Why wait?

Lessons in Being With Dying

Journal extract: August 31, 2011:

> How refreshing death can be when there is no “story.” This is what I contemplate perched on a recliner at Lima Memorial Hospital, in Ohio, on the cusp of morning. I am sandwiched between a hospital bed with Lou, [my partner Will's father,] who died about an hour ago, and Will, who now falls back to sleep on the convertible window-seat/bed where we had rested together before a nurse breaks into sleep to alert us: Death is here. I settle in-between “twos: two ‘worlds, two realities, two mysteries, two bodies—one breathing, one not-breathing, as I breathe myself back to sleep.
>
> Life and death are of such great magnitude! Viewed side-by-side, each appears simpler, more wondrous, less surreal. Less separate. How can I make direct contact with death as a natural condition of life, and what can I learn about being human through making closer contact?

Anticipating Will’s father’s death, I wondered, What is my capacity to be present to the scenario, as it unfolds? I insisted on the impromptu 8-hour drive to Ohio to arrive on time prior to the planned withdrawal of life support. Also intentional was the offer to remain overnight in the hospital room, sensing death’s nearness. At the hospital, I consciously positioned myself “in-the-between.” It was my intention to remain psychically awake.

I was not able to say a final goodbye to my father, but I could be there to say goodbye to Will's father, and to encourage Will to take advantage of this precious opportunity.

Another significant dream, from March of 2012, occurred just a day after Elizabeth, an Oncology Support Program member I was close with (and interviewed, potentially for this study) dies. She spent her final days in a hospice bed planted in the center of her beautiful living room where I visit in the last weeks and days of her life:

> I am at Elizabeth's house, although it does not quite look like her home. The living room is nearly empty of all its usual furnishings and décor. It is missing warmth. One of the only pieces of furniture is the hospital bed. It is empty and, I assume, unplugged. Stripped of its bedding, it is ready for the next occupant.
>
> The room is cast in partial light. It is not quite peaceful, merely very quiet. First, I don't touch the bed; then I do. At first, the bed doesn't move; then it does. The bed tilts and repositions itself. It is no longer in the corner of the room, but moved toward the center, though up against a wall. Now, Elizabeth is in it. Her skin is pearly, her head (still bald from her umpteenth time of chemo, often covered with a soft, crocheted pastel cap) is pearly too, as it was near the end, when she was hardly responsive, and then mostly unresponsive, to my presence and touch.
>
> I touch Elizabeth's head now as I did then, with curiosity and tenderness, longing to know the person and experience within, and to soothe. Only now, she is a bit more animated. Elizabeth moves and even speaks as if she is not dying, not dead, though not with the full vitality of the living. She is something, somewhere in-between. I assume she is dead but, apparently, she assumes otherwise. I think or imagine asking her what it feels like to be dead. She responds (or I think she responds, or I am afraid she will say): "It feels like being alive—almost." She behaves as if death is ordinary, nothing special, perhaps, even familiar. As if this world of the dead is not so separate and distinct from the world of the living. In this 'place,' one goes on with (everyday) dying, as one goes on with everyday living.

I awaken feeling a kind of psychic vertigo, and think, "This bed could be—or is—for me, too! I could be the next occupant." This encounter with Elizabeth feels real and natural; she feels real and natural. In the dream, Elizabeth is "at home" with death, so to speak, I am not. She no longer separates life/death, living/dying; they are one thing or merely a continuum. Through my dream, I discover the unexpected: that the seemingly separate worlds of the living/dead are equally ambiguous, and surprisingly similar. The first dream was a confrontation with mortality; this time I am confronted with liminality. Again, I am jolted. The dream illuminates my relationship to death and dying, as my psychic borders (defenses) appear to be eroding. I am myself in the dream—and I am Elizabeth, as my psyche grapples with the non-dual experience of living dying.

Nesting and Nest-Making

I share these seminal auto-ethnographic fragments and images that have emerged from the ground of my being as a way to map my personal/professional/scholarly development, and to contextualize my inquiry and discussion in the next chapter. My intent in sharing them is to provide clues for the reader to understand the conceptual framework, themes, and points of learning.

Furthermore, the stories shed light on the creative/intuitive distillation process which leads to the emergence of the nest as an image and symbol of physical and existential dwelling—a place for gestation, for being in the world, and for safe passage from this world—and the overarching themes of my learning: Nesting-in-Being and Nesting-in-Place.

Nests are places of conception, birth, nurturing, comfort, protection, vulnerable life, tender growth. The nest collages emerge during what I initially perceive as a dormant phase in my dissertation writing and my life. During this period, I needed to make space for rest and play: to regenerate. It begins with the impulse to explore the idea and possibility of creating a nest in the world for myself (see Figure 5.1). A place to land and to rest and nest in being. To nurture voice.

Figure 5.1. “Nesting-in-Being,” Dec. 2013.

Circle Making

Circle making is a theme that emerges early on in the aforementioned autobiographical essay, as I begin to connect the dots of my life and to imagine myself as a woman in the world, as a leader, an artist, and social change agent. It has been a rather slow, humbling, sometimes arduous process. The reemergence of the circle theme seems apropos in this current phase, as I return to my dissertation writing with the intention of arriving at completion.

Dillard (2008) says, “Every experience in our lives is sacred and the coming together of all life’s experiences is but preparation for whatever happens next in our lives. That is full circle work” (p. 290). Full circle work encapsulates the work of our living and of living dying. It is the task of making a circle from wherever one starts, and has travelled, and ends on the life journey, and of weaving the pieces into a collage. Circle work is about seeing the whole gestalt, making connections, and recognizing wholeness. As is the research process.

Virginia Woolf’s notion of a “room of one’s own” represents a physical, psychological, and existential space. It is a space for generativity. Room making/space claiming has been a long-time vision and invitation in my dreams, and a process of making space for self and creativity. Last year, it manifested as a yurt, birthed on the back property of my home to use as my dissertation writing and art-making space (see Figure 5.2). A yurt is a circular shelter of ancient Mongolian origin, valued for its lightweight strength, open space, and portability. I work on Grace’s collage in the yurt. More recently, I work on the nest collages here as a way of initiating the space and my relationship to it for art making. Solitude, *soulitude,* quiet, place in the woods, circular, primitive, open volume, dream space, art place: Nest of Emergence.

It is a turning point.

The circle, the central image of the second collage, is an archetypal symbol (see Figure 5.3). It represents the cave-like womb, pregnant fullness, wholeness, the self, the sun, life, the cosmos, existence, the wheel of life and death, creation and dissolution, regeneration. It is a container for “the10,000 things,” a Taoist expression referring to form in its myriad manifestations. The circle holds and represents energy prior to matter, that which births from primal chaos. It is a cauldron for the creative process to simmer and cook (perhaps dying, too, is a creative process): the soup pot of transformation. Symbol of possibility. The circle is a holding space. A nest. Informed by Winnicott (1980), Moss (2007) conceptualizes psychospiritual development as a process whereby we recapitulate our earliest holding environment throughout the life cycle, as we seek shelter within others and, ultimately, within the self. This is Nesting-in-Being.

Figure 5.2. Lark's Yurt, Newly born, Feb. 2013.

Goldsworthy (2000) notes the circle is the shape of humans' earliest dwellings. Children are particularly inventive at creating temporal dwellings, adapting anything at hand. One person told me he used to comfort himself when he was a small boy by using a vacuum cleaner hose to make a circular space within which he curled up, fetus-like, and rested. A brilliant nest! He interprets this as a way to compensate for an absence of parental sheltering; to self-soothe.

Figure 5.3. “Nesting-in-Place,” Jan. 2014.

Related to my work with Circle of Friends for the Dying, and our mission to establish a Home for the Dying, the circle is a symbol of a communal dwelling space and a space for existential sheltering. It is a space for human connection. I conceptualize the home as a circle-making space. It is a place for coming home to oneself and to each other, to complete the cycle of life, and to come full circle. The nest, then, is a symbol of physical, psychic, and existential dwelling.

Figure 5.4. CFD Logo Design by Friend, Alain Gulant.

Making Connections

In March of 2014, I go on retreat at Turkeyland Cove as a springboard to re-launch my dissertation writing. During this time, I realize the “personal” collages made during the “dormant” period are connected to my dissertation. Synapses flare. My mind starts making connections for space making. For nest making. I also decide to "write myself” into the dissertation during the retreat and begin writing this chapter. In doing so, I germinate the possibility of the dissertation as a holding space—a Nest for Voice. The following is an excerpt from a statement written at the close of the retreat on March 27, 2014:

> About midway through my stay, I had a dream about giving birth. Initially, my daughter is pregnant and I am helping her find a midwife. Then the dream shifts, and I am the pregnant one. Immaculate Conception! Not only am I unaware that I am pregnant, I come to find that I am about to give birth. Now!

> My dissertation writing continues to be a struggle. A lot of wheel-spinning and not much traction. (I did however enjoy writing some poems). The dissertation is the baby I am birthing and I have been stuck on a chapter that requires using my own voice to develop a discussion about my work & learning. While I am aware, symbolically, that I am giving birth to my voice-in-the-world, I was not conscious—as the dream shows/tells me, that I am so near!
>
> Clearly, I am at a pivotal phase in my inner-outer development: standing at the threshold of possibility. The image/symbol of nesting, long circulating in my psyche, came to fruition here as a central thread in my dissertation and in my life. I further conceptualize nesting in two ways: nesting-in-place (an outer shelter, such as a Home for the Dying or the Turkeyland Cove "Tree House") and nesting-in-being (an inner refuge and sense of being settled in being/ness, resting within). Nesting here has allowed me to turn a small but significant corner on my journey. I am almost there…
>
> How do we live, create, give birth to ourselves, and die consciously?

In retrospect, this so-called "dormant" or "stuck" phase in my writing and development has been a period of incubation. By stepping back to reflect on my life in this auto-ethnographic portrait, I make a bridge on which to continue forward. Anchored by the nest/nesting image and metaphor, I can begin to conceptualize the next chapter of this dissertation. I close my personal story with two poems written while on retreat.

Yesterday's Stroll on the Beach

partial sunlight
and cleansing gales
the world   of images
        appears   disappears

i walk along the shore
tracing the changing chalk line
a quivering
crepuscular ribbon
        like the monitors
that chart patients' breathing—
        the incandescent
                in-breath   and out-breath

i follow
skip-and-skate marks

of a lone sandpiper ten-feet ahead

head down
preoccupied
with shell-hunting
i nearly stumble
on a massive boulder

this is a study of liminality:

first association: a dead deer (i live in the Catskill Mountains)
astonished recognition: a beached seal
need to convince otherwise: a sleeping seal

desperately
longingly
i search
for signs of life

her dark round eyes
held wide open
her massively still
earth-colored body
speak the ancient truth

eyes moisten
nose stings
the heart
unplugs
a small
ocean

                    i float
and land
on hard ground

Home

i walk
along the yellow trail
in the Caroline Tuthill Preserve
water destination in mind
wishing for a longer, more vigorous hike
wishing for meadows and kettleholes and glacial knobs along the way
wishing for sanctuary

i come too quickly
upon Sengekontacket Pond

walking along the beach
i collect a handful of large whelk shells
noble sea snails
name origin "weluka"
from the root "wel"
its meaning
to turn or revolve

i turn them in my hands
and discover each whelk tunnel is packed
with white gunk

upon closer examination
it is thick curd-like whey
it is meaty fleshy filament
some covered with a stony shield-like plank

i pick up some sticks
and squat on a rock
to poke and prod at the white filling,
trying to unplug   dislodge the stuffing material
to take my clean prizes home

some of the fill won't budge
some falters
flakes
and breaks off
into clumps and pieces

then the obvious dawns on me:

this meat-filled husk—
food for some—
is alive!
and this small vessel
is home!

i surrender my filleting picks
and lay my prize specimens down along the shore
to sleep or sail

Chapter VI: Discussion

Death Is Inconceivable

Unbelievable, unreal, surreal, unfathomable. These are the words I often hear and use to describe everyday dying. Death is the fact that feels like fiction. Informed by this study and my prior research, in addition to my clinical practice, personal reflections, and dreams, I begin my discussion with the premise that death is inconceivable. Everyone else dies, but not my loved ones and not me. The truth is, we are all on a one-way slippery, slithery slide into the great abyss. The realization that death is inevitable—including one's own—is an "ultimate concern" we must all reckon with (Yalom, 1980, p. 1). Yet it is difficult for the mind to grasp and slippery to hold. Through the daily routines and rituals of culture, we position ourselves in varying degrees of proximity to the "Great Mystery." I conceptualize three existential positions or relationships to death as: This is not me (unconscious dissociation); This is me (unconscious over-identification); and This is me, too (conscious identification). This is somewhat similar to Wright's (2003) understanding of coming to terms with death as an inner-evolutionary process and dialectic between the dying person and their relationship to death, along a continuum of meanings.

"It hit me like a ton of bricks" is the way Grace describes her jolting epiphany, upon realizing the chemotherapy she has been receiving for her advanced cancer is futile. The proverbial "existential slap" beckons to awaken her to the reality of death (Coyle, 2006, p. 267). Similarly, Mount (2003) describes the experience of an existential confrontation as a psychic rupture: "A crack appears in our carefully crafted concept of reality….[and w]e are sucked into the startling realization that the rules of the game are not what we had imagined" (pp. 93-94). We too will die.

The purpose of this study was to explore the everyday lived experience of dying and the care culture within freestanding community-based end-of-life care residences (CBEOLR), and to do so in an artful and compelling manner in order to engage a diverse audience. Those who are dying are best suited to shed light on the experience of dying (Boston et al., 2011; Mount et al., 2007), which is best understood within a sociocultural context (Faber et al., 2003; Komaromy, 2010; McKechnie et al., 2007; Williams, 2004). The discussion corresponds with my research questions: How do we live with dying? What is the lived experience of dying? What is the nature of a good place to die?

Introduced in the previous auto-ethnographic chapter, two broad dimensions emerged through working with the data and engaging in the creative process: Nesting-in-Being and Nesting-in-Place. Together, these dimensions create a framework for exploring care culture and ways of working with existential suffering. Three linked sub-themes related to care culture emerged*:* Nest of Simple Things (meaning making), Nest of Belonging (community making)*,* and Nest of Everydayness (home making). Additionally, building on the literature and informed by my clinical experience, a new construct terminal liminality emerged to describe the lived experience of terminal illness and dying, characterized by descent. Research participants often employed metaphor and drew on contrasting norms within institutional care settings and the culture-at large to describe care culture in response to the questions: What makes this a good place to die? What makes this place feel like home? Presented as a cluster, as shown in Table 6.1, these metaphors and descriptors suggest the nature of a “good place to die.” I end this section with highlights of my learning.

Nesting-in-Place and Nesting-in-Being

Nesting-in-being suggests an interior existential, spiritual, and psychological space or inner nest that constitutes a sense of self and well-being. Nesting-in-place refers to a physical and emotional space or outer nest. This idea is influenced by Winnicott's (1965, 1980) concept of a holding environment*,* as an interpersonal "matrix" essential for growth and healing, throughout life (Moss, 2007, p. 103). It is precisely this quality of nesting another, and being nested*,* that engenders "nesting-in-being." I conceptualize "care culture" as the interface between these coupled dimensions: essentially, nesting-in-place is a means to foster nesting-in-being.

Nesting-in-place: A sense of something more. "We live and die in place," says Kenny (personal communication, October 1, 2013). We also seek to nest-in-place. A nest holds the bare essentials—and something more: Life. For most of Grace's life, home is "just a place." Early on, she shares that she has never felt at home in the world, a feeling exacerbated by periods of homelessness. The poem, "Searching for Home," depicts her moving from place-to-place in search of home. Grace's description of her favorite apartment is closest to a nest: "It felt more like home to me—more than just a place to store my clothes, my cat, and a few belongings. The Place came alive with music, and laughter, and a lot of friends coming and going, constantly!" Music and friends transform "place" into "home." Throughout one's life, to nest-in-place means to be held within a circle of care, respectfully and securely. At the end-of-life, nesting-in-place connotes an environment that fosters well-being and is conducive to living as fully as possible for the remainder of the person's life. An environmental and interpersonal aesthetic is woven together to achieve an aesthetic or nest of care.

At the Hospicare Residence, nesting-in-place is illustrated by the quality of attention given to design and atmosphere: they are relational. The vision was to create a humanistic environment, a structure that makes the people in it feel secure and significant. This is apparent in the thoughtful architecture, its scale and materials, which features an abundance of golden wood and natural light, and in the surrounding gardens. An intentional balance between a visual/kinesthetic sense of spaciousness (spaces for soaring) and enclosedness (spaces for nesting) is evident in the building and grounds, particularly, the scaled-down, cozier residential wing.

Jeff, a social worker, is particularly sensitive to residents lived spatiality in relationship to the residence and what may be experienced as a sense of too much space, which could elicit anxiety. For this reason, he notes, some residents prefer room six, which lacks the expansive views of nature accessible to the other five rooms. In room six, “They’re in their swaddling clothes,” he remarks. This corresponds with Rasmussen’s (1999) notion of “congruence between one’s outer and inner space” (p. 61).

Both Sifton (2000) and Moore et al. (2013) use the term “shelter,” which like “nest,” means something more than just a place; rather, foremost, it is a space for cultivating human connection. Sifton (2000) underscores care setting as being an “emotional shelter” rather a material one, while Manzo (2003) suggests we develop emotional bonds to places in the same manner we do with people. Understood as such, evocations of home, crucial to feeling sheltered, are “never far from the patient’s imagination or the staff’s intention” (Moore et al., 2013, p. 155). Most resonant and in accord with nesting-in-place is Moore et al.’s (2013) expression, to be “sheltered within a certainty of care” (p. 155), conveying a human refuge.

Nesting-in-Being

Nesting-in-being refers to a state of basic ease and existential “at-homeness” within oneself, one’s immediate environment, and the world at large (Seamon, 1979). Mind and body settle and nestle into the present moment. Nesting-in-being at the end of life implies having adequate faith in one’s environment and caregivers, enough to tolerate uncertainty and allowing one’s experience to unfold. This felt sense of ontological security (Giddens, 1990) is contrary to Heidegger’s (1962) assessment of human being’s fundamental not-at-home-ness in the world. Nesting-in-being is the capacity to draw on one’s storehouse—or nest egg of inner resources and recesses. It also suggests adaptability, enabling the person to take advantage of living fully with dying, to the degree possible, even as their physical capacity dwindles.

Nesting-in-being corresponds well with Mount et al.’s (2007) term “inner life” to span interwoven existential, spiritual, and psychological domains of experience (p. 374). It is also similar to several of Yedidia and McGregor’s (2001) motifs connecting existential well-being to meaning-making: endurance (triumph of inner strength); coping (finding a new balance); and incorporation (belief system accommodates death). Likewise, these themes and my perspective are comparable to Lethborg et al.’s (2006) domains of adaptivity: experiencing the reality of advanced illness, responding to its impact, and living life out fully with continued meaning (p. 40).

The poem “I’m Okay with Dying” in Diana’s portrait, which describes a sense of psychological and relational completion, and inner peace, captures the essence of nesting-in being. Through Diana’s hard inner work and self-reflection in the latter years of her life, between cancers, she has built herself a repository of profound self-acceptance—a Nest of Goodness. She explains:

> Coming to a sense of awareness and being able to accept these aspects of myself….has been tremendously helpful. I’m so grateful for that now, because facing the end of my life, having felt the Change—that very, very Serious Change—years-long, has made such a difference. It has given me a Sense of Completeness; of Mission Accomplished—or still accomplishing….What would it be like to be facing the end of my life without that Sense? …. I’ve been able to Transcend...some of the fear, and learn more about love. And that’s enough! To make a life…Worthwhile.

Like Friberg and Ohlen (2007), I agree that the capacity to "discern the existential in the experiential" is critical to confronting and living with existential uncertainty (p. 225); yet I also believe it is contingent upon others' capacity and willingness to also do so. Diana integrates self-awareness with medical information by asking doctors explicit questions and insisting upon direct answers, and discussing her options with health care providers, family, and peers, thus enabling her to penetrate the pervasive culture of silence surrounding death (Becker, 1973; Friberg & Ohlen, 2007). In this exemplary case, all parties worked together to illuminate the liminal and to assimilate the reality of impending death. Care providers play a crucial role in orienting the dying person and her/his family. An example from the Isaiah House portrait is Kathie's resourceful use of a visual cue, escorting residents' relations to view the painting "In the Between," portraying a family sitting vigil, "to illustrate their loved ones' place on the dying journey."

In my observations, most people living with cancer never go beyond managing existential uncertainty, the first phase in Friberg and Ohlen's (2007) three-fold path of existential meaning-making. Rather, progression is compressed or appears to be aborted, due in part to poor communication. The frequent result is inadequate time and support for patients and their loved ones to assimilate the reality of death.

Diana is an exception. Confronting and living with existential uncertainty, subsequent phases in Friberg and Ohlen's (2007) schema, are negotiated and realized by Diana, through action: the choices to discontinue pursuit of medical measures to prolong life and for early enrollment on hospice. Doing so significantly frees her time, energy, and attention to enjoy life for the duration. In this manner, Diana's death-style is consonant with her lifestyle. As a role model of how to live with illness and with dying, Diana has a series of outings, not knowing which may be her last, last hoorah. She is motivated, in part, to change how others perceive hospice and how they perceive her, as a dying yet vital woman: “Hospice doesn’t mean you die in two days. It doesn't necessarily mean you're in bed all the time. You could be on a mountain!”

Care Culture

Cicely Saunders (1995), the mother of the modern hospice movement, touches the essence of the meaning of care culture, recognizing “the *way* care is given can reach the most hidden places and *give space* for unexpected development” (n.p.). In a similar manner, Kathie Quinlan (personal communication, May, 30, 2013) uses the term “demeanor of care,” by which a sheath of “tenderness” is wrapped around the dying person. Nesting-in-place also resonates with Rasmussen’s (1999) recognition of “the importance of an aesthetic physical environment and the congruence between one’s outer and inner space and their relation to the meanings of…care as a healing environment” (p. 61). Kearney (2009), too, suggests the idea of a healing or “sacred” environment at the end-of-life as a nesting space, “where what is most fundamental, natural, and indigenous to the human psyche can most easily do its own work of bringing about integration, balance, and wholeness” (pp. xxii-xxiii). Influenced by his mentor, Rasmussen, Edvardsson’s (2005) conceptual framework of atmosphere is comprised of two reciprocating dimensions: environment, described as “tone or mood” (p. 9), and “people’s doing and being in the environment” (p. 23). Atmosphere is most similar to nesting-in-place.

Importantly, people’s doing and being act to “convey messages” (Edvardsson, 2005, p. 23) of “caring or uncaring” (p. 51), which suggests care culture is a subtle but powerful medium of communication. An effort to transmit and imprint at-homeness on new residents and their significant others begins upon arrival at Isaiah House, through the Welcoming ritual. It is a ritual of nest-making. Kathie explains:

> We put fresh flowers in the room. We have the bed all made with linens and quilt folded back. Sometimes, families will bring their loved ones things over beforehand. We always have something baking in the oven. Upon arrival, we run out to the ambulance. We shower the person and family with attention.…The message we wish to convey is: "We are here for you; our care is unconditional and non-threatening; we don't care about the past; and we will do our best to help you survive this a little more intact as a family.

Kathie describes a Nest of Compassion and emotional safety. Like others I speak with, Frank, a hospice social worker and volunteer, senses an atmosphere of embracement upon entering Isaiah House. "It is like being wrapped in a blanket," he says.

Atmosphere permeates space and matter. More than visible, it is palpable. Rasmussen (1999) refers to atmosphere as the pervasive "spirit" of a place (p. 61). It is not merely what is on the walls, it is **"**a feel for 'what's in the walls'"—and in the air, that registers unconsciously as an immediate visceral response, activating a sense of ease or unease (Edvardsson, 2005, p. 7). Kathie and Anna, a volunteer, both use the word "reverence" to describe the atmosphere at Isaiah House. It is this energy or spirit I sense upon entering the homes, like a current that warms, fills, uplifts, slows me down, and gives me a sense of spaciousness and ease, apparent on the faces I see.

Faces Matter

Faces
need no scientific explanation
or data
to back them up.

Plain to see
they speak volumes
in simple text
Visible Truth.

Tender faces of dying
and faces of loved ones
dying into living
with loss.

Here, softness triumphs
over hardness.

What takes
some time
easing into
is the amplitude of time
when being
outweighs
doing,
and caring is shared;

Time enough
and hands enough
for the small
and un-extraordinary.

Time enough
for measureless kindness.

Figure 6.1. Faces Matter: Participants from Place-based Portraits. (See image key, Appendix H).

The concept "that people's doing and being influences experiences of the physical environment and that the physical environment influences experiences of people's doing and being" (Edvardsson, 2005, p. 5) is illustrated by Jeff's response to my question, "What makes the Hospicare Residence a good place to die?":

> Respect! And part of the respect is the beauty. There is an attitude of respect toward this place, grounded in the day-to-day physical care of it that is a way of respecting and caring for the residents; it *opens* something for them. And there's something about the kind of body care offered by the hands-on caregivers—a sense that they're just taking care of business—that just really pleases me. There is nothing cerebral about it. They are just working with the people, and they are in there working with people's everyday lives and fears. There is a real sense or quality of participation, of *coming forward.* It is the opposite of the atmosphere of one of the local nursing homes where there is a sense of everybody *holding back* and defending something. There is stinginess in the air. This place is like the opposite of that stinginess.

Like Jeff, Kristin distinguishes the care culture in a CBEOLR in contrast to institutional settings. Hands-on work, she explains, is only a very small part of the caregiving experience with residents:

> The pivotal part is the spiritual component and the emotional piece. We take the Long Route here in working with the dying. In an institutional setting, it's the Fast Track way of doing things because you have other patients waiting on you, but at Isaiah House it's about optimizing dignity.

These descriptions align with Saunders (1973) who understands opportunities for emotional intimacy and for reinforcing a sense of dignity need not be sacrificed for efficiency, but rather often arise at the interface of "the practical meeting of a physical need" (p. 26).
A final significant ingredient in nesting-in-place is the presence of a comprehensive and consistent philosophy of care, suggested in the literature as an indicator of 'best' care setting (Briller & Calkins, 2000; Edvardsson, 2005; Realdania Fund, 2006). In this sense, care culture actualizes the organization's core values. For example, the social justice facet of Isaiah House's mission intertwines with philosophy of care. Care culture, then, is *a response* to local culture in

the inner city, where the home is situated and where most volunteers and residents (prior to admission) reside—demonstrating a people-in-place and community-in-place practice (Moore et al., 2013):

> It's about seeing the value in each person. It is part of the culture of being in the city and it is part of the culture at Isaiah House….Our city-bred volunteers are going to treat everyone beautifully, but they are especially drawn to the bedside of those residents who have been shunned by society for different reasons, and who don't have anybody. You can feel the passion in the house when that is happening. They are going to give that person wonderful care. That's their thing.

Saoirse, who attributes the Hospicare Residence's homelike ambiance to the vision of one of the early executive directors, Nina Miller, the building's namesake, threads a connection between aesthetic of place, aesthetic of care, and philosophy of care:

> Nina had a lot to do with setting the tone here. She definitely had a very big heart and accentuated the individual and the humanity of the care we provide. She was always very guarded about the potential for things to become too regimented. She believed that the power of what is possible at the end of life comes from human relationships.

Nest of simple things: Meaning making. Meaning is actualized in the crucible of relationship. A good place to die is a place to cultivate meaning: a Nest for Meaning Making. An understanding of the value of meaning-making at the end-of-life was expressed by participants through a cluster of related phrases: the "simple things," "the immeasurable," "small things," the "non-negotiables", and "the essentials." These terms speak to Mount et al.'s (2007) framework of "healing connections." Enabling healing connections to self, others, the phenomenal/sensorial world (e.g., nature), and to "Ultimate" meaning (however that may be conceived by the individual) is associated with existential well-being (Mount et al., 2007, p. 372). Simple things facilitate healing connections. Saoirse sums up the significance of the small: "What may seem small is not small; small things add up and make a big impact." This echoes Albert Einsten's pithy phrase, "Not everything that can be counted counts, and not everything that counts can be counted" (as cited in McKee, 2004, n.p.).

Simple things constitute the immeasurable*,* a word Saoirse uses in my initial visit to the Hospicare Residence, in 2010. The "immeasurables" refer to a quality of relationship and meticulous attention to the needs and preferences of residents and their loved ones, and to maintaining a comforting and an aesthetically pleasing environment. They give people a sense of meaning and purpose. Saoirse also illuminates this concept with a memorable story during our initial interview about a resident who, prior to admission to the residence, had been unable to garden for the last five years due to his illness:

> The resident gardener built a special raised bed for him to plant and tend nasturtiums and beans. As the man lay dying, the beans were ripening. During the last days of his life, the man continued to reap pleasure from the garden. As the family was vigiling with him, folks were bringing in baskets of beans.

She elaborates:

> This is another example of how difficult it is to calculate the value of any one particular activity. There's the pain control piece. But how does one access what the *meaning* is to a person apart from being there, sensing, and witnessing. It is hard in the traditional medical system to *make space* for that in recognizing such things as valid therapies. (Lark, 2011, p. 58)

It is precisely the cultivation of meaning-making, rather than the mere management of physical pain, that is at the heart of hospice care philosophy practiced in a good place to die. Without the latter, the former is compromised; without the former, the latter is, arguably, meaningless.

Kathie Quinlan emphasizes, "Good pain management *precedes* everything we do" (Lark, 2011). Charon (2010), a physician, drives home the point: meaning-making "and not…the effective banishment of pain, is the deep mission of palliative care. It we are reduced to controlling pain, we have been defeated. We want to control pain…so that meaning can persist, so that meaning even can be gained" (n.p.).

This idea appears again in my early research, in a focus group comprised of nurses, triggering a lively discussion. One nurse, working at the hospital where I am employed comments, it is the "simple things" she can offer her dying patients that often matter most. She imparts a story about a terminally ill woman who, in her final days, requested a Fribble. There was an additional complication. Aside from having to stop her duties, the patient had a tracheostomy (technically speaking, taking anything by mouth is contraindicated). She decided to pick-up the shake anyway and to offer it to the woman. The pleasure was mutual: the patient delighted in the sensation and taste of the thick milkshake, and the nurse, remaining bedside, delighted in the woman's simple pleasure. "I did it as a friend, not a nurse," she states. Simple things counter rote and technological 'things' that dominate institutional care culture. The nurses agree, "rules and regs" impede simple "freedoms and pleasures" (Lark, 2011, p. 51).

Saoirse builds on this thread in the current research. This time, she uses the term "non-negotiables" in regard to the challenges she faces in her administrative role of balancing the "bottom line" with mission-driven core values and "what folks really need" (i.e., the immeasurables). This is a prevalent dilemma shared by hospice (and hospital) administrators and managers, nation-wide. Having a clear and visible mission returns decision-makers to the non-negotiables. Tricia, nurse manager of the Hospicare Residence expounds on the issue:

> Clinical staff does not resonate with the term census. We try not to be a conveyer belt, in terms of filling residence beds. The business end of operating the residence is the pink elephant in the room. It's real! There are multiple realities and needs: the census and money flow issue, tied to interests in retaining jobs; the needs of residents, families, and residence staff to rest and process between deaths and new admits—and then there is the waiting list. Somebody else needs the bed. So what is non-negotiable?

Father Jim points out “the essentials” are an antidote to mainstream culture, which tends to focus on the “non-essentials”. In Jim’s perception, a good place to die is one that demonstrates and cultivates basic human values:

> Personal, no rush, service-oriented, off the mainstream, free from the modus operandi of money-making. It’s about love. Other institutions may say this but it doesn’t get translated. So much of American life and culture that we prioritize is about the non-essentials; here, we pay attention to the essentials. What happens here, Death, is *deep*. It grabs people’s attention, raises Ultimate questions—not that I have the answers, but it feels Real. This is good medicine—a good antidote to American materialism.

Kristin uses the term “the essentials” broadly to suggest the human essentials vital to all folks, not just those who are dying, as the ingredients for meaning-making:

> The essentials are what we *all* need. It’s the simple things that matter here—the fresh flowers from our garden placed in the resident’s bedrooms; the volunteer who drops off chocolate chip cookies because she knows it is a particular resident’s favorite. This is what makes for a very nurturing environment.

Nest of belonging: Community making. The specialized end-of-life setting as a refuge for the dying and a buffer for the living, as conceptualized by McKechnie et al. (2007), remains a structure of separation, rather than one of integration. A thrust of the community-based hospice setting is inclusivity; it is a nest of belonging. Like Froggatt (1997) and Hockey (1990), I recognize environments designed to care for the dying as liminal spaces, within which the usual social boundaries set between life/death and the living/dying merge. The CBEOLR helps to fulfill the mission of the suffering body: to find itself a home, reflected and reconstituted in the human realm (Kirmayer, 1992). As places of liminality, community-based end-of-life residences are sites of passage. Like a bird’s nest, an end-of-life residence is a temporal abode, a space for inner gestation. The bird’s nest provides an elegant metaphor for the special end-of-life residence. Rarely occupied beyond the span of a few weeks, a nest is a purposive space specifically constructed and occupied for the duration of the nesting season (Goodfellow, 2011). So, too, the death nest is occupied for a season.

Community-based end-of-life residences, embedded in neighborhoods, are a co-creation amongst people-in-community; they are a relational endeavor. Kristin deliberates: “We are committed to this community, and this is the community that supports us….I believe the success of the house is in the relationships that you build…. Relationship is what makes us work—and keeps us working.” In a similar manner, Bev, former Director of Benincasa, remarks, “We ask the community for their support. We have an obligation to be open arms to them, to be a refuge” (Lark, 2011, p. 28). The creation of Keuka Comfort Care Home (KCCH) illustrates the “power of place” to magnetize diverse people and establish a mutual sense of respect, commitment, and belonging (Seamon & Sowers, 2009, p. 671). The principle of inclusivity is suggested by Saunders (1998b), who describes the care culture at St. Christopher’s as “a community of the unlike” (p. 94). According to the KCCH Director, Donna Payne:

> The home was donated, literally, room-by-room by a business or a family, aided by a grant of 18k. Aside from local banks and churches pitching in, the local Lion’s Club donated 12k, and most of the interior work was provided by Habitat for Humanity. Members of the Mennonite community [prevalent in Pen Yan,] joined hands with the larger community to raise the roof in a single day—even though they would not be direct beneficiaries of the home, as they ‘take care of their own’ [dying members]. (Lark, 2011, p. 70)

Grady and Boccinfuso, leaders from the Kaplan Family Hospice Residence explain: “The residence demonstrates what we do, who we are, and what hospice is about to the community; it reduces fear” typically attached to the word ‘hospice’. Similarly, Saoirse states, “We want people to know us before they need us.” Along these lines, Halloween provides an opportunity for a community program at the Hospicare Residence targeted to integrate otherwise largely segregated social worlds between young and old, living and dying. Jackie, an administrator explains:

> Costumed kids are encouraged to trick-or-treat at the residence, as they would at any other home in the neighborhood, and to interact with residents. [In this way,] neighborhood kids grow up hanging out here. So the whole mystery and threat that adults feel, like ‘I hear it is nice but I’ve never seen it,’ with the instant refrain, ‘I don’t really want to!’ is swapped with ‘I used to go there when I was five and dig in the garden.

This example demonstrates how intergenerational programming can foster a sense of everydayness within the residence and normalize everyday dying throughout the community-at-large. Moreover, early exposure to dying, imprinted with positive associations and with reinforcement, can help to change the culture of dying over time. Hospicare’s grounds and garden, by far the most elaborate of the sites visited, further engenders everydayness and the perception the residence “belongs to the community,” says Saoirse. Locals feel invited to enjoy the extensive grounds. Community members walk their dogs, jog, and, in the winter when the pond freezes, come to play ice hockey. In the ways described, community places for dying can serve as bridges, securing or re-establishing ties between the dying person, family, and neighborhood, otherwise safeguarded from the liminal (Froggatt, 1997), exemplified in the story of Wendy, below.

Nest of everydayness: Home making. What makes our place a home, Kristin explains, “Is the comfortable furniture, the homemade quilts, the goodies baking in the oven, the homemade pot of soup bubbling on the stove.” It is a sense of the familiar: a Nest of Everydayness. An atmosphere of everydayness evokes a sense of home (Briller & Calkins, 2000; Edvardsson, 2005; Realdania Fund, 2006) and fosters existential at-homeness (Moore et al., 2013; Rasmussen & Edvardsson, 2007). A sense of physical and emotional warmth is conveyed through a care settings’ “readily know[able]” environmental features and caregiver style (Briller & Calkins, 2000, p. 19). Everydayness is conveyed by staff who dress casually, behave like family and friends, and participate in the flow of everyday activity in sync with the physical and emotional needs of residents (Briller & Calkins, 2000; Edvardsson, 2005). A Home for the Dying, made possible by community, may be *better* suited than a private residence, oftentimes lacking an extended circle of care, in order to meet the needs of *both* resident and their kin. In the ways described, the Home for the Dying model most resembles "home," as intended (see Figures 6.2-6.4).

A home-like care setting is one in which in which the resident is able "to *act* and to *be* as if one were in one's own home" (Moore et al., 2013, p. 155). Wendy, a resident in her 50s at Shepherd Home, along with her family and guests, exemplifies this point. Illness forces Wendy to retire early from a career as a speech pathologist in the local school district. Her husband Dale, a retired college professor, also specialized in speech pathology. Now, Wendy barely speaks at all—a tragic irony that is not lost on anyone. Instead, Wendy makes soft, cooing sounds and uses simple hand gestures to communicate. She is like a caged bird.

The daily rhythm and pace of the home mirrors Wendy's illness-altered ways of moving and being: slow and steady. At both my visits to the home, she sits one-on-one at the dining room table with a volunteer, who chats and patiently cajoles her to eat another spoonful. There is no rush. Barbara, Wendy's mother, repeatedly lauds the dedicated volunteers, including several Harley School students, who are "aware of Wendy's needs and likes." Wendy knows them all. For Wendy, home is a Nest of Good Company.

Wendy and her family clearly feel at home at Shepherd Home. Her personal belongings, including her wedding picture and favorite stuffed animals, spread beyond the border of her bedroom into the living area, where she and her visitors spend most hours of the day. Without a doorbell or locked door, residents' guests simply walk in. Wendy has a regular stream of visitors, including Carol, a former colleague, who stops by unannounced. Two of Wendy's former students also drop by regularly. The first time the pair visited Wendy in her new home, I am told, they sat together on the living room couch and cried. Another student drops by between classes just to check in on her. Wendy's students also join her birthday celebration, in April. Between family, guests, and volunteers, Wendy is hardly alone.

For Anna, a volunteer, the kitchen is a symbol of home and the heart of Isaiah House. While the nurse's station is the hub of activity in an institutional setting, in the homes—as in everyday life, it is the hearth, associated with comfort and nurturance. Kitchen-life conjures memories of childhood and family life. There is always someone in the kitchen. The eat-in kitchen at Isaiah House invites socialization. A flow of staff, volunteers, guests, and sometimes residents keep company around the kitchen table, while preparing meals, eating, conversing, reading, or playing cards. Regardless of whether residents are still eating solids, of any amount, they continue to enjoy participating in the everyday ritual of mealtime, as well as being included in holiday festivities associated with home and family life.

Anna notes how everyday activities, like cooking, unloading the dishwasher, folding clothes, and taking out the garbage, provide a harmonious, normalizing rhythm conjuring associations of home-life for residents, who may not directly partake in these activities but, nonetheless, 'catch' nearby kitchen sounds and smells. Activity peaks on weekends and holidays, when resident family and friends join in to prepare and share the meals and company. I arrive a day too late to interview Mary, exhausted from the weekend festivities—her "last hoorah," which Marge, a family member, describes:

> There were 27 of us, including some staff and volunteers. The three of us made four pounds of macaroni with Joanne's homemade meat sauce, and four roasted chickens. We brought in coffee, lots of pies, and doughnuts. We took over the whole house! We set up tables on the porch and spread out into the garden. There was a crowd in Ma's room. Her 90 year-old sister came. Ma ate some macaroni. She was awake every minute of it. She loved it!

Kristin says, “What makes this place a home is the heart in the house”; it is the hearts of the volunteers. According to George, a resident at the Keuka Comfort Care Home, the most impressive distinction between the home and his previous institutional care setting is not a physical feature but the presence of volunteers, instilling an atmosphere of neighborliness. “It’s just the fact that they are volunteers,” George says. While reassuring me that he received exemplary care at Strong Memorial Hospital, he imparts, it is nothing like the volunteer response here. George rings a handheld brass bell—a signature of the homes (and some other CBEOLR models I visit)—to demonstrate. In 18 seconds three eager volunteers appear!

Cognizant of his previous falls and frailty, George is hesitant to leave his bed or bedroom. “The last fall is what got me here,” he says. For George, home is the spatial confines of his bed and bedroom, a place of safety he attributes to the accessibility of volunteers, while for Wendy, home is the shared living quarters of the house. A sense of affiliation and seamless relationship between people and place makes Dee feel, “Being at Isaiah House is just like being in your own home.” For Mary’s relatives, home extends to the exterior spaces of the house, the porch and garden. Most of all, it is the hospitality of the staff and volunteers perceived as a familial-like source of endless caring—also encompassing family, as Mary’s family member infers. This description is particularly apropos to Dee and Wendy’s family. Bonds developed with staff and volunteers over extended stays (each around six months) continue and deepen, even after their loved ones are transferred, due to stabilization, to another care setting (Dee’s father to Dee’s home and Wendy to a nursing home). This, in particular, is of immeasurable value to family members who may come to depend on the emotional support provided by staff and volunteers, as one family member (anticipating her father’s transfer to a hospice residence due to intractable pain) confides. Perhaps most important, continuity of caring transmits the distinct feeling that their loved one is cherished. Marj, a social worker who refers hospice patients and follows their care in the homes, explains, though rare, “people may stabilize because they are getting immensely wonderful care; they are getting every need met so, on occasion, they improve”. (In fact, as of June 2013, only about 5% of over 450 at Isaiah House residents were discharged due to unmanageable pain or rebounding.) While every resident’s stay is temporal, the imprint of the individual person remains. Betsy Inglis, Director of Shepherd Home, where Wendy was a resident, states, “Once a resident stays here they become part of our house and our history.” This sentiment is given thoughtful expression through the Shepherd Home ‘family’ album, with each storied page dedicated to one of over hundred residents that have lived there; yet another homey touch.

It is these bonds, of friendship and kinship—born of necessity, which inspire Dee to return to the home as a volunteer and to change his career course to continue the cycle of care, and which Mariana, in search of the “missing half” of the circle of care, discover. Through the course of my research, my own sense of the meaning of home, initially focused on an aesthetic of place, evolved to appreciate the second, peopled, dimension, and the aesthetics of care. Home then, is indeed “just a place,” as Grace states; it is a container for the possibility of care. What transforms a house into a home, and a good place to die, is the “family” within.

The old woman nests nearby

voice silent
body afloat
in the dimly lit room,
the liminal zone
between inner-activity
and the outer appearance of sleep.

Between tasks
volunteers and staff chat, read novels,
and play card games with a resident
around the kitchen table.

Sandwiched between volunteers,
the old woman's daughter settles on the couch, leafing through
worn shoe boxes brimming with photographs.
She spreads stories across our laps, tying loose threads
of her mother's life, as the faded
though familiar din of home
filters through:
television
coffeemaker
pots and pans
her daughter's lilting voice—

Life's fluid
muffle and hum
rising
and falling in tandem
with the old woman's breath

Figure 6.2. Benincasa.

Figure 6.3. Shepherd Home.

Figure 6.4. House of John.

Terminal Liminality

Grace lapses—then rebounds again and again and again, during her extraordinarily lengthy stay on hospice services (about 18 months, as of April 2014). What Grace calls "the long dark tunnel of dying"—like the long dark slide into the abyss in my dream—is what I refer to as terminal liminality. This concept fills a gap in the literature exploring liminality in people diagnosed with cancer, specifically highlighting the terminal phase.

Terminal liminality triggers or accelerates the momentum of descent, whether perceived as a gradual tumble or plummet. The poem "What Really Matters" describes Diana's life in descent (see portrait). She is heading down the slide, trying to anticipate what waits around the bend. Death moves into her home and she transitions into her hospice bed. During my visit, she appears compelled to play and replay the recorded phone message from Andrea, a peer who died. I find hearing Andrea's voice surreal. This, I interpret, is Diana's way of preparing her psychic "house"; she is trying to comprehend the meaning of "gone" (A. Thomas, 2007): Andrea is gone; she will be gone too. All that will remain are traces.

While a sense of lostness pervades all phases of liminality (Friberg & Ohlen, 2007), descent, generally incremental, is the primary feature of terminal liminality. The trajectory of terminal liminality is characterized by cycles of inwardly spiraling decline, with waning periods of stability. During the stable phase, delusion slips back in. This experience is aptly described by K. Richardson et al. (2010) as "contracting worlds," a felt narrowing and closing of "lived spaces," "lived time" (p. 132), and a lived dying body. The immediate, day-to-day experience of living with a dying body influences patients' perceptions of quality of life (McKechnie et al., 2007). A woman on hospice points out it is the increasing cascades of flesh falling from her upper arms—a withering body-self (Kleinman & Kleinman, 1994), she finds most distasteful and alarming, thus signaling the transition from living/dying to dying/living. The following poem, based on a friend, Tom's journal entry from his semi-public *CaringBridge* virtual pages, illustrates terminal liminality:

Upon awakening

I discover new limitations.
Another
little
death.

I accept this   and move on
to the little discoveries
that make life
a bit
more
palatable.

My days are limited
filled with feeding-tube maintenance
and passive video watching.

Not necessarily tired,
I look forward
to sleep.

Then it seems
just another day
of Barely
Being.

In my clinical practice, Carol, a woman living with metastatic cancer, likens her latest sign of decline to "losing a rung on a ladder," not knowing if she will regain ground or if she is standing at the threshold of freefall. Another person shares, "I am not afraid of dying; I am afraid of how I will get from point 'A' (living) to point 'B' (dead), and that it will be an unpleasantly long journey." She fears the space between points. Terminal liminality marks the last rungs of the liminal ladder, the final downward turn before death. Tom quickly slips from a state of "barely being," to one of "wordless being," as noted by his partner, Kate, who continues to post on the website on Tom’s behalf, until he dies. In van Gennup’s (1908/1960) three-phase rites of passage, it represents a shift in the person’s status from the middle, transitional phase (the liminal) to the third, ‘incorporation’ phase, thus completing a cycle of social metamorphosis. The word ‘disincorporation’ may be more apropos in the case of death, depending on one’s belief.

Participants in my research living with terminal illness demonstrate polarized relationships to dying (This is not me/This is me, too). George, a resident at KCCH, a Home for the Dying, and Bob, a resident at Hospicare, are both aware they are on hospice and living in an end-of-life residence, but they see themselves as the exception: they will not die—yet. George emphasizes he is not at KCCH “on a terminal basis.” Hope—for more time—remains alive. Each believes he will rebound and regain enough strength to resume chemotherapy, crediting the quality of care received at respective care settings. “That is my goal for being here—which is kind of funny, because all my visitors assume I am dying,” says George. “Any time people hear you are on hospice, they think it’s the end of the road; I don’t think it’s the end, so I don’t let it bother me.” On the other hand, Grace (transferred to a hospice residence) and Deidra (at the Hospicare Residence), both acknowledge being at a hospice residence signals their last stop on the journey and final home. Deidra is refreshingly sober in her admission that she will die at the hospice residence. Will her perception shift as death draws closer?

Terminal liminality is an onslaught of insults and injuries, a series of slaps, each fresh and daunting. The sting dissipates—until the next debilitating round of treatment or new serious symptom crops up or piece of bad news or failed procedure or narrow escape. Some folks, I have observed, are able (and enabled by their health care providers) to mask or suppress liminality and sustain hope for a miracle despite glaring evidence of decline, until the final slap. Based on my clinical observations, liminality is not transcended by long-term cancer survivors, as Crouch and McKenzie (2006) suggest. Rather it recedes and is re-sublimated, permitted to lie dormant, until the next threat causes it to resurface. Thus, the notion terminal liminality further substantiates Little et al. (1998) and Thompson's (2007) claim that liminality takes up permanent residence in those living with cancer, lingering and reasserting its presence until life ceases.

Terminal liminality is experienced as a revolving door of periodic existential crises, sometimes manifesting in revolving hospitalizations. In Grace's metaphor, her 'body-self' (Kleinman & Kleinman, 1994) is a door, opening and closing, as she inches closer to death with each harrowing episode: "I feel like a Door. My open Door was eating and feeling okay. Then Bam! The Door shut and everything about my life stopped." Grace's "long dark tunnel of dying" is a continuum of the longer dark tunnel of living, encapsulated in the statement, "My life has been a constant battle to survive." Years of maintaining control over an ill body besieged by multiple medical conditions continues through months of maintaining control over a dying body. Each episodic brush with death is followed by a period of exhaustion from fighting the newest battle, until her hard-earned survival mechanism reasserts itself. The survival theme is epitomized by Grace's motto: "Never give up the fight" and statement: "The problem with me is Control, When & How I want to go." Grace's experience exemplifies the "hard work of dying," including the labor of living with "existential paradox," described by Coyle (2006) as a readiness or desire for death while continuing the struggle to survive (p. 267), and the hard work of relinquishment (Faber et al., 2003; McKechnie et al., 2007). In the following poem, Tom straddles two worlds, on the cusp of surrender.

The Last Stand

Three words uttered:
Thought
Word
Deed.

He stands
straddling
the Threshold,
teetering
between command
and surrender— peeling off
warrior garments,
cracked layers
of crimson and gold—

laying down
the sword.

He stands, one last time, Resolute,
as if recovery
was still possible as if he could walk away from death
the way he stood—steadying himself
in himself— and walked
months prior
after a broken hip.

Now he slips again—
this time
he breaks away.

The final deed done
he repeats the Readying words
I want to go…

Building a nest of compassion: Working with existential suffering. Essentially, it is our sense of *me-ness* (separation)—what Einstein (1950) refers to as an “optical delusion of consciousness,” rather than *we-ness* (connection) that exacerbates existential suffering (n.p.). Einstein refers to our innate connectness and membership in the cosmos as the “Circle of

Compassion." Similarly, Jeff attributes suffering to identification with one's own small finite existence ("me-ness") versus a more generous identification with the vast Universe:

> There's something about a sense of being *of this place—of this moment's presentation,* as opposed to [being] '*me'* in this universe and I'm about to be extinguished…. So that I am *of this Universe, of this Place* in the broadest sense of it—broad enough so that there's a sense of *being home*.

I take this to mean, sentient beings are transient expressions of abiding creation.

Heidegger (1962) suggests hereness/goneness, being/non-being, and at-homeness/ not-at-homeness are interpenetrating phenomena: "This is my world but it is also at the same time not entirely mine" (Svenaeus, 2001, p. 94). Thus Heidegger's (1971b) term "being-in-the-world," as a dual expression of our uniqueness (one's unfolding lifeworld) and our solidarity in the grand scheme of things, implicates that we are "always already in and of the world in which we find ourselves; we are indivisibly intertwined with it…[and] inescapably embedded and emplaced within it" (Moore et al., 2013, p. 152). In this manner, based on Heidegger (1971a), Manzo (2003) refers to "dwelling" as more than a place; it is a way of dwelling-in-the-world, grounded in existential sustenance (p. 49).

Jeff's spacious, adaptive approach allows him to connect with Lori, a woman with ALS (Lou Gehrig's Disease). He shares:

> When I first started to work with Lori, she was fully paralyzed and wheelchair-bound, but she could still speak. Within one week, she lost her capacity to talk. When I next visited with her, she was in incredible despair. Tears were coming down, and they were falling in such a way that she actually made these big bubbles because she couldn't clear them. It was terrible despair—and it was an incredible moment for me because it was so clear in my mind, *I cannot make this one better*. This was so obvious!

In the interim, Lori obtains a special computer program that encourages communication and creative expression. The story culminates several weeks later in a final encounter:

> We were just sitting there. Light was coming through the window, and you could see the branches dancing in the wind. And she typed out, "This is so beautiful. I am so blessed."

> And it was just like—what *I* did with her existential concerns—I mean, I don't know. *We just met*. I mean, I don't know how to say this…If you have a certain presence it helps with many people.

The pivotal moment in Jeff's encounter with Lori is his acknowledgement of powerlessness ("I cannot make this one better"). These instances, when "nothing more can be done," call forth what is most vital within us to offer another: our presence (Kearney, 2009). Presence is the opposite of abandonment. This is how we can humanize the experience of dying.

Jeff's aesthetic of care and my own perception are in stark contrast to the clinical view conveyed in the literature which construes existential suffering as "a *condition* for which there is no consensus on treatment" (Boston et al., 2011, p. 605), rather than a natural and expected part of the human condition. Workability implies the capacity to respond to suffering based on the premise that life itself is workable, and so too is dying. It generously opens and broadens the playing field for ways of responding to suffering, and for allowing things to be just as they are and to unfold accordingly. "Doing by not doing," Kathie Quinlan's maxim, requires faith or what Jeff refers to as "basic trust in the Universe." It requires the capacity to nest-in-being. In sum, making space for dying is about "making room for whatever is happening" for each individual, as Bob Kane says.

While may never be completely at-home witnessing suffering, regardless of our role, Kearney (2007) suggests we can begin to pay attention (i.e., witness) to the quality of unease unearthed in body and being in its wake. This is illustrated by Kristin who openly admits that she sometimes struggles with grief left in the wake of resident deaths; loss remains "a continual struggle." This is especially the case with residents without family and those whose existence lacked "social value." This was the case with another gentleman by the name of Tom. At his funeral, she finds herself in "excruciating" pain:

> I was aware that something spiritual was going on—not in a God sense, but in a Universal sense. All of a sudden, a tremendous amount of pain came over me and I just sat there with the pain. I had never done this before. I said to myself, 'This isn't *my* pain; this is *Tom's* pain. I thought I was supposed to feel this pain but now I need to let it go. I just sat with the pain until it let go, and it actually went away! It was the first time I ever experienced something like that. I had never been so mindful. I acknowledged, 'Okay this pain is happening. But who says it's because of *stress*?' So this continues to be the big struggle.

Just sitting with the "big struggle" allows for healing. Freed from identification and somatization, Tom's/Kristin's pain is transmuted. I am reminded of Stephen Levine's (1989) words: "Compassion comes from feeling another's suffering and transcending it in myself" (p. 157).

To be present in the midst of suffering is to bear witness. Bearing witness transforms a sense of separateness and isolation and allows reciprocity. Roy Remer, the volunteer manager of the Zen Hospice Project Guest House, describes bearing witness, as a mindfulness practice, which joins 'witness' and 'sufferer' and elevates each to their full humanity (personal communication, June 1, 2012). This requires embracing mutual vulnerability. Levinas (1985) asserts the personhood and face of another person presents an existential dilemma; there is always a gap, always Otherness. Witnessing offers a spiritual bridge that respects otherness and allows the person's full humanity and universal goodness to be seen (Levinas, 1985). We can belong to one another through the art of wordless listening (Frank, 1998, 2009; Gadamer, 1998) and being.

Likewise, Kleinman (1988) designates empathetic witnessing as the health care professional's "existential commitment" to the patient (p. 54). As a care principle and practice, witnessing is a spatial and ethical dialogue-in-proximity between two "I am's" (Arman, 2007, p. 85), safeguarding against over-identification (This is me) and dissociation (This is not me). Rather it positions the mindful witness in the "right place" in relationship to the person who is suffering—somewhere in the middle (This is me, too). This is the existential zone in which Jeff and Lori "meet": it is a place of communion. To be present implies the capacity to nest-in-being, thus making space for others to nest-in-being. Jeff makes a nest for Lori, while Kristin makes a nest for herself. It is a Nest of the Present Moment.

Illuminating liminality: Final lessons and continued challenges. In these final pages of my discussion, I return to the momentous question, "How do we live with dying?" and share some key experiences and learning points. This question has motivated my research and lifework; it is the *koan* we are all invited to examine and find a perspective—a way of living with dying we can live with.

I have learned that institutional environments, by virtue of the goals and kind of care they house and espouse, present an extraneous challenge; they tend to act as a barrier to end-of-life care. David, whose 58-year-old partner just spent three weeks in a hospital to receive radiation for cancer metastasized to her cerebellum followed by rehabilitation in a nursing home says, "We need to invest in creating environments that celebrate aging and dying" (D. Levy, personal communication, August 8, 2013). The oncology unit staff acquiesces when he asks to play his flute in the lobby, freeing the flute's voice to fill the hollow spaces and reach for those who need to hear it. Initially, the "cantankerous" nurse manager silences the flute. Also silenced in all those weeks, is the word "terminal" to describe his partner's disease process. He tells me it is very useful when I gently introduce the word. It helps decode his partner's cryptic behavior and communication, expressing that which she is unable to say directly, preparing each for the sojourn ahead. In her final days, hospice called in, David mobilizes their circle of friends in preparation to take his partner home to die.

For my dear friend, Pat, in ICU for three weeks following emergency surgery for a perforated ulcer induced by treatment for advanced pancreatic cancer, the word “hospice” is silenced, too. It pains me to be the one to raise it with her/her family. Afterward, I write her husband, Dick, trying to gentle harsh reality with an apology. I also attach a list of questions developed to help other families in a similar quandary to facilitate communication with a physician. Dick responds: “The hospice question was appropriate; no reason to apologize. You are just doing what you know…. Honesty, reality, and integrity are what we need and want” (D. Ernenwein, personal communication, August 8, 2013). The next day at a family meeting, questions asked and adequately answered, they decide to take Pat home.

Nonetheless, neither David’s partner nor Pat ever leave the hospital.

Through this study and my clinical practice, I have come to a deeper appreciation for life, a greater sense of compassion for our shared humanness, and a more realistic view of how painful death can be, even under the best circumstances. I have also learned just how difficult breaking silence and uttering the word “hospice” can be, given the opportunity to do so for people dear to me. I have lost my taste for the word “denial”; fear and distrust of physicians have softened, as I seek the heart of the matter in situations that appear to be the result of poor communication and care planning, and unrealistic attempts to sustain a person’s life. I have learned that living with dying is an art requiring continuous mindfulness. My faith in community and “ordinary” people to see people through hard times has soared. The facts of our mortality and innate interdependence—our “bonds of impermanence”—can be garnered as powerful agents of healing and change, beneficial to all (Halifax, 2009, p.47). I have learned that human beings cannot do the profoundly important work of dying and caring for the dying, well, alone.

We can build nests for one another. I have learned we make space for dying when we make space for living; and we make space for living when we make space for dying.

Surgeon, Pauline Chen (2007) writes, “Death will always be difficult. We can create reforms, we can institute policy changes….But our professional fear and aversion to dying is the most difficult—and most fundamentally human—obstacle in changing end-of-life care” (p. 217). It is this basic vulnerability and natural response to suffering we must each tend rather than guard. While this is every person’s task, it is a responsibility for professionals. I have learned that existential anxiety is “workable”. It can be tempered through hands-on education and exposure to dying; self-reflection and awareness practices; and willingness to step into the unknown . While there may no longer be options for sustaining a life, there is always something more we can do to ease suffering. When all the standard strategies fail, we can find our “nest” and just be present. I have learned that given ample guidance and opportunity, young people are extraordinarily willing and capable of caring for the dying in their communities. I recognize the immense value and need for early education and exposure to dying to train the caregivers of the future and to change the culture of care for the dying.

The conflicting imperative to “reclaim death from medicine” (Verghese, 2013, p. BR21) on one hand, and the urgency for more treatment or time on the other, are not so black and white. The fierce refusal to “go gentle into that good night,” Dylan Thomas’ indefatigable lines, resounds in my daily interface with people living with terminal cancer. I have learned that we humans are tenacious creatures! The power of will, of hope, of belief, and of love and human connection are death defying, and may indeed be undying. Our reaction to dying and death, especially involving those close to us, is often not rational. Preconceived notions and values in times of health may falter or be stretched from strain or desperation in times of duress. More enduring than our personal, scholarly, and professional perspectives, or our alleged plans assembled in times of health, is the innate human desire to live—and to continue to live. Moments of intimacy and peace during the final hours may blot out or compensate for otherwise unfortunate or traumatic encounters, such as witnessing a loved one's suffering or unresponsive lingering on life-prolonging treatment.

I have learned that a home death is challenging to initiate and sustain, and may not be suitable or feasible for every dying person or their caregivers. Kate writes that Tom's dying has been "cruel". In the end, his pain is unmanageable. Upon the visiting hospice nurse's recommendation, he is transferred from his private residence, where he had initially wished to die, to the hospital, now perceived as a great relief to both Tom and Kate. Here he receives adequate sedation, allowing his last hours and departure to be peaceful/easeful. This drives home a final lesson: there is no inherently "good" or "bad" place to die, but rather more or less appropriate ones to meet the changing needs of each person who is dying and their significant others. When pain, whatever its source may be, is an emergency, a good place to die is one that responds to the emergent and immediate needs of the person and family. It is a Nest of Necessity.

This reminds me of Diana's son, Benjie's words, spoken privately after Diana's memorial service. He said, "I don't want to burst your bubble, but Diana's death was horrific." I was stunned, but appreciative, to hear this sobering truth, albeit his perspective. His sister had sent an email detailing the final hours. She said it was "beautiful". This is what I wished to hear. Perhaps "truth lays somewhere in the middle," as one woman living with metastatic cancer says. This, then, may be the paradox to embrace: that dying and death can be horrible and beautiful, interlaced with moments of each. Frank, a research participant expressed this well: "There's a darkness to death; there's a beauty to death." Those who are dying and those left behind are fortunate to have a balance of beautiful moments. We can help tip the balance.

On October 27, 2013, nearly two years since Diana's death, her family participates in a memorial hike. I am invited to join. Since Diana's death, Benjie and his wife, Suzanne, birthed their third child, named "'Solana Jo,' for the wind"—apropos for the occasion, I realize after the hike. I write to the family afterward, "How amazing that one human being—our Diana—can generate so much love!" This is how *I* live with dying: by illuminating the liminal that permeates our lives, by engaging in ritual, and by voicing the wordless through the arts.

Trail of Remembrance

We hike up
to Huckleberry Point,
one of Diana's favorite spots in the Catskills,
with sandwiches, assorted salads and cookies, and a simple golden tin
holding Diana's remains
in tow.

At the top,
sun peaks through clouds,
igniting the lush landscape of yellow and gold.

It is October, month of Ripeness,
the same month, two year's prior,
Diana had taken three "hospice hikes,"
just weeks before she dies.

After lunch, we walk to the mountain's edge
untwist the canister,
open the lid and clear plastic bag within,
and slide a trowel inside Diana,
now a sandy dune.

Benjie, Diana's son, says he can't say goodbye.
Instead, he recites Camus:
In the depth of winter, I finally learned
that there was within me an invincible summer.

Liam, Diana's 10-year-old grandson, says it all,

I wish 'Graham cracker' was here…
Life is good, but it's okay to die.

We take turns
dipping into and releasing grief— to restless currents
and sudden, wakeful gusts;
gaping at bird-like swirls of sand,
a shifting sky show
of small dust bowls,
feathery twisters,
and spectacular, mute bursts of fireworks.

This is what it all comes down to:
birth and death
and a little living in-between;

a little pile of salt
a little pail of earth
little plumes of dust— blown whichever direction Wind pleases.

I remove wool gloves
and dig into Diana's remains—
the boney grit,
the floury silt—with bare hands:
to sift
to feel
to rub and seal the Goodness
into cracked palms;

then, grab a handful,
touch it to my heart
and let go…

Table 6.1

The Nature of a Good Place To Die

Metaphors of a Good Place to Die

- Open doors (Frank)
- A home for all/everybody; Embracement (Kathie; Father Jim)
- The house that always says ‘yes’-inclusive, non-judgmental (Kristin); We ‘mostly’ say yes (Tricia)
- Wrapped in a blanket – embracement (Frank)
- An ordinary-extraordinary house (Kathie)
- We are all in this together (Connie)- interdisciplinary practice; recognition of human interdependence
- Immeasurables – “Small things add up to big things & make a big impact” (Saoirse); “Simple things” (Saoirse; Sue, FG); “The essentials” (Kristin; Father Jim)
- We belong to the community (Saoirse) – philosophy of reciprocity with community members & organizations
- Workable/Workability – skillful means (Jeff)
- Doing by not doing (Kathie)
- Walking the talk (Kristin)
- Non-negotiables – retain core values while negotiating bureaucratic constraints & bottom-line pressures (Saoirse)
- Our house is your house (Betsy)
- A complete circle (Mariana)
- Circle of care in action (Father Jim)
- Beautiful care (Kristin)
- A neutral place- non-judgmental (Kathie)
- An endless caring – care, also extended to family, is perceived as generous (Mary-family caregiver)
- In tune –to needs of resident and kin (Steve)
- The long route versus fast track care (Kristin)
- Coming forward versus holding back (Jeff)
- Good medicine (Father Jim) “What happens here is good medicine”

Environmental and Organizational Characteristics of a Good Place to Die

- Grounded in hospice philosophy/ethos
- Person & family-centered orientation- wholesome attention to individual resident & kin
- Everydayness- familiar sensory cues; relaxed roles, dress, pace; intergenerational caregiving, socialization
- Relational ethos and practice
- Respect
- Simplicity-“knowing *who you are, what you do,* and *why”*(Bev); “Keep it simple; keep it grassroots” (Kathie)
- Consistency/Stabilizers- e.g.: strong mission drives operations; retention of staff/volunteers
- Vigilance – maintain independence from bureaucratic intervention through retention of grassroots identity (Bev); or mitigate bureaucracy through retention of “non-negotiables” (Saoirse)
- Flexibility-of roles, routines, protocols; adaptive to change
- Hospitality- sense of welcome
- Volunteer presence – the “heart” of care setting; transmission of neighborly love & good will
- Retention of grassroots “spirit” or ethos
- Non-interference and independence (Bev)
- Interdisciplinary team approach –‘soft,’ flattened hierarchy
- Social justice/Service-oriented (Father Jim) (mission-driven)
- Educational imperative (mission-driven)
- Holistic/Systems-thinking- all parts work together seamlessly/synergistically; congruence between mission (what we say) & practice (what we do); strong links with community organizations (Saoirse)
- Middle way practice – “clinical care in a nonclinical setting,” “not being too medically-oriented” (Kathie)

Design Features that Foster At-homeness

- Location – proximity to one’s own home & neighborhood
- Person-centered & Community-minded Design- structural/spatial features: reflect mission, sensitive to resident (spatiality), sensitive to community (scale)
- Aesthetic Features- casual/modest “everyday” ambiance, attention to beauty & comfort, light-filled
- Nature – physical and visual access; optimize opportunities for participation
- Space for family/guests –overnight accommodations

Chapter VII: Leading Change

Toward the Visible Death: Implications for Leading Change in End-of-Life Care

The good which we secure for ourselves is precarious and uncertain…
until it is secured for all of us and incorporated into our common life.
(Addams,1892/2002, p. 17)

What we dream alone remains a dream,
what we dream with others becomes a reality!
(Rolheiser, 2007, p. 41)

So long as humans continue to die, social, political, and economic issues related to death in America, as well as conflict and resistance as to how to address these issues, are here to stay. This final chapter aims to integrate several broad areas focused on leading change in end-of-life (EOL) care. I begin with brief overviews of the state of EOL and hospice care in America and discuss a burning issue likely to stimulate national public debate. This leads to a discussion on community-based solutions and servant leadership. I share about a local initiative, followed by an overview of future trends in EOL care. Next, I provide a retrospective overview of my research journey and discuss areas for future research. I close with some final words on my personal experience as a social change agent, and how it has changed me.

The state of end-of-life care in America. The most recent Dartmouth report on national *Trends in Cancer Care Near the End of Life* (Goodman, Morden, Chang, Fisher, & Wennberg, 2013) demonstrates a significant relationship between where and how people die, regionally and according to the kind of institution in which they receive care (e.g., teaching hospital). Echoing the earlier report, the report indicates a high-tech end of life care-culture promotes high-tech end of life care irrespective of patient preferences (Goodman et al., 2013). This suggests oncologists are not only obliged to offer people the "right care at the right time," (Eastman, 2013, p. 17), they must enable "right choice" through patient education and discussions of options (Byock, 2013, p. 6). Moreover, they must provide respectful care in *right accordance* with peoples' expressed wishes. Troubling trends, based on comparisons of recent (2010) and earlier data from 2003-2007, summarized below, evidence a persistent culture of death-resistant care:

- higher utilization of hospice but very late referrals, often days prior to death (amounting to little benefit to patients and their kin);
- less hospital deaths but higher admissions to the ICU in the last month of life;
- slightly higher use of life-sustaining treatment in the last month of life;
- increase in patients seeing 10 or more doctors in the last six months of life, suggesting fragmentation of care [and, perhaps, desperate cure/life-extension seeking by patients]; and
- continued pattern of futile treatment in the last two weeks of life (Goodman et al., 2013).

The report's recommendations include initiatives for continuity of care, integrative services, and early and ongoing end-of-life conversations. Not mentioned, are the needs to incorporate preferred place of death into these discussions; to prioritize the home death, if preferred and feasible, in the care plan; and to institute protocols to facilitate timely transfers. Reflective of the participants in my study, the report implies, when time is of the essence, most people prefer to minimize time spent receiving futile and life-diminishing treatment and to maximize their time in a "homelike environment close to family and friends" (Goodman et al., 2013, p. 2). A community-based end of life residence (CBEOLR) helps make this possible.

Moreover, the report suggests a radical alternative. Policies and reimbursement structures that promote and foot the bill for futile treatment and death-prolonging procedures in the final months and weeks of life, at great expense to Americans, could instead incentivize end-of-life preparations and palliative approaches, and make provisions for more generous end-of-life care benefits. Reallocation of funds can also include supportive, educational, and financial provisions for lay caregivers, and more humanistic care-settings. Changing the course of end-of-life care will depend largely on public will—and willingness to care for one another in creative ways (Jennings, 2013).

The state of Hospice in America. “Brink of death” care was the term aptly used by Rich Trocino, CEO of Hudson Valley Hospice (HVH), referring to the continued trend of shortened length of stay (LOS) on hospice across America (personal communication, January 17, 2014). The trend over the past several years of shorter median LOS persists, largely unchanged from 2011 (National Hospice and Palliative Care Association, 2013; see stats in Chapter II). Hospice remains one of the most misunderstood, feared, and, thereby, underutilized benefits in our health care system. The notion that the goals and values of hospice philosophy can be integrated into the American lifestyle and medical system remains questionable (Byock, 2010).

Moreover, the needs of the dying do not easily translate into social policy or mix well with bureaucratic institutions and structures of efficiency. Reimbursement structures further complicate and limit utilization. On top of cultural and structural (i.e., policy) constraints, cuts in Medicare funding for hospice services, and increased government regulation and scrutiny of hospice agencies, have produced an atmosphere of increased bureaucratization and vigilance. This is especially the case pertaining to “live alones,” a demographic category perceived as a potential risk and liability concern for hospice administrators. In 2013, noninstitutinalized seniors (age 65-75) who live alone accounted for about 28% of the population (over 12 million Americans), predominantly women (U.S. Department of Health and Human Services, 2013). Hospice agencies’ lack of sufficient policies, resources, and alternative housing to address the needs of patients who live alone (or, in some cases, refuse admission,) was identified by one leader as “the greatest source of moral distress amongst staff” (Kirk & Seigel, 2013, n.p.). For people like Grace, living alone represents an additional burden due to perceived pressure to enact what may be an unpalatable contingency plan that involves leaving one's home and, sometimes, community. In the words of leaders at a hospice ethics conference, "Hospice is not a friendly place to the un-befriended patient" (Kirk & Seigel, 2013, n.p.). The portraits of good places to die in this study demonstrated otherwise.

A burning issue. A good example of the power of language to influence change is the recent tweaking of the term physician "assisted suicide" (PAS) to "aid in dying" as recommended by the American Public Health Association (Orentlicher, Pope, & Rich, 2014). Alternately, I have seen the term physician "assisted-death" (PAD). In this way, we enable mentally competent, terminally ill adults nearing the end of life to obtain a legal prescription for a lethal dose of medication from their physician (Orentlicher et al., 2014). Since legalization of PAS in 1995, Oregon has blazed a path for four other states (Washington, Montana, Vermont, and New Mexico) to follow suit in the ongoing right-to-die movement initiated in the 1970s. Proponents assure opponents that PAD is a "last resort" measure (Orentlicher et al., 2014). In actuality, the people of Oregon demonstrate, when given the right-to-die, very few choose it (under .5% or less than 100 deaths annually) (Orentlicher et al., 2014). Jeff Collins, the social worker from the Hospicecare Residence, appears to embrace both sides, emphasizing that one of the central ethical concerns in end-of-life care is not abandoning people who are suffering, regardless of their choices. On the other hand, Byock (2010) contests both sides, stating we need to respond to the end-of-life care crisis in "life-affirming ways" (p. 306). He claims Oregon's experiment in PAS is "largely irrelevant" (p. 306); it has neither improved pain management for people who are dying, fixed defective care delivery systems (medical, social, reimbursement), or addressed the root of the problem in end-of-life care, which is "fundamentally cultural" (Byock, 2010, p. 305). Rather than promote discourse on controversial PAS/PAD as a solution, Byock

(2010) redirects the conversation advocating for “enlightened” ways “we can care well for each and every person through the end of life” through a community-centered approach:

> Doing so would require demonstrating in practice what enlightened care looks like….[through] proactive clinical and social programs and residential, community-based strategies…. Most importantly, such approaches would preserve the dignity and quality of life for frail elders and terminally ill Americans, as well as the families that care for them….The time and money invested in building enlightened models of living and caring would seem a bargain. (p. 307)

I believe the Homes for the Dying represent Byock’s (2010) conception of an “enlightened” end-of-life care model. In my assessment, the homes embody a refined balance of contrasting elements, resulting in a dynamic tension that is: open yet contained; flexible and non-hierarchal, yet stable and structured; clinically sound yet intimate, humanistic, and non-medicalized; replicable in function yet nuanced in form; and lacking bureaucratic “rules and regs” but self-regulating, maintaining practical guidelines. These elements suit my personal sensibility and professional social work ethics. The home counter-culture has managed to integrate within the larger medical culture, sustaining a delicate balance. Years of researching the homes and regular exchanges with Home for the Dying directors have helped me to understand and to appreciate how. Further, it has positioned me to respect and guard the model in its wholeness rather than speculate on modifications or improvements in anticipation of how the homes will ride the waves of the future. It has positioned me to lead change.

The common good: Community as change agent and servant leadership. Home is something we can all identify with and a universal symbol of belonging. A fellow Antiochian who specializes in housing for another special needs population affirmed, “What’s more fundamental than creating a home for people?” (M. Goetz, personal communication, February 15, 2011). Pastor Max (Max Bishop), a hospice spiritual care provider I met during my earlier research, attributes the enormous regional support for alternative care for the terminally ill and dying in Rochester to synergy and visibility. Collectively, the homes broadcast a message and culture of mutual responsibility, and reinforce a higher standard of end-of-life care. He believes that many people want to help but often lack a sense of direction and vision. They feel the need for an alternative to end-of-life institutional care but they lack a model. They have no focal point or concept of what is possible. On the other hand, leaders *live* in a world of possibility. They foster and investigate a hunch before all the evidence is in. Leaders are community builders. They can mobilize what the pastor describes as "a convergence of [public] interest to support a common need and a common good" (personal communication, October 15, 2010). The last time I heard from Pastor Max, he was involved with starting up a new Home in Rochester.

Cicely Saunders (1973) recognized that isolation is perhaps the greatest cause of suffering for the dying. Community and volunteerism become essential antidotes. Community is central to the principles of servant leadership. Greenleaf (1977) argues, "Only community can give the healing love that is essential for health" (p. 51). Love is not a word or sentiment generally associated with institutional healthcare or medical encounters. Greenleaf (1977) conceptualizes love as agape. Envisioning a humanistic practice of science that incorporates love, Oord (2005) defines agape as "an intentional response to promote well-being when responding to that which has generated ill-being" (p. 919). Greenleaf (1977) implies institutionalized care and care settings fall short:

> Human service that requires love cannot be satisfactorily dispensed by specialized institutions that exist apart from community, that *take the problem out of sight of the community*. Both those being cared for and the community suffer…. [A]ny human service where the one who is served should be loved in the process requires community, a face-to-face group in which the liability of each for the other and all for one is unlimited…. trust and respect are highest in this circumstance, and an accepted ethic that gives strength to all is reinforced. (p. 52)

Here, love, akin to service, functions as perhaps the most fundamental human gesture and social responsibility. The emphasis on community as an agent of change and healing resonates with the popular phrase "it takes a tribe," a notion based on the recognition of our shared vulnerability and mutual dependence. The spirit of neighborly love actualized through volunteerism, conveys the message "We are all in this together," exemplified by volunteer caregivers described within these pages. On the power of affiliation, Charon (2006) asserts, "The *actions* our communities take together are not trivial…They imprint the communities thereby created with traces of conscience, with declarations of values, with aspects of justice" (pp. 232-233). A community-developed, funded, and facilitated Home for the Dying is thereby a symbol of social and health care justice.

Principles of servant leadership fit naturally with the hospice care paradigm and with community-based models of end-of-life care. Articulated by Greenleaf (1977), servant leadership maintains an ethic and practice that is in service to the individual (i.e., patient/resident) first, and promotes interdisciplinary and informal "network[s] of constructive interpersonal relationships that support the total effort" of the organization (p. 73). In these ways, mutual vulnerability and uncertainty are unmasked, allowing a natural flow of human-to-human contact that fosters expressions of care (Greenleaf, 1977) between patients, families, and professionals. These are the ingredients of communion.

Gilliam (2006) understands, in order to "effect a desired change, leaders must engage the rational and emotional capacity of listeners in such a way that they will want to struggle together towards some shared aspiration" (p. 57). As Cole and Knowles (2008) emphasize, "more than [producing] good stories," research must affect goodness, by having moral, educative, and transformative value (p. 67). Portraiture and ABR are salient leadership tools with which to infiltrate the "larger mind" (Cooley, 1956, as cited in Witz, 2006, p. 265) and heart of readers, necessary for social change.

Circle of Friends for the Dying: Community action. The thrust of my vocation and commitment to social change through Circle of Friends for the Dying (CFD) aligns with Stanley's (2004) assertion, "Whenever the cause of isolation in illness is rooted in society and culture, we can effect change, and we are perhaps obliged to try" (p. 361). Established in 2012, CFD is a not-for-profit organization whose mission is to establish and maintain the first Home for the Dying in Ulster County, New York, the community in which I live and work. My central role, as keeper of the vision of the home model, is to make meaningful connections with key stakeholders and community members, to elucidate the model and why it is needed, and to engage each individual's imagination and emotion. Doing so often stimulates a story about a "good" or "bad" death of a family member or friend. What is apparent, through these and wider conversations exchanged at Death Café's, an international movement that makes public space for informal conversations among community members about issues related to dying and death, is that wherever I go and whomever I speak with, everybody has a story. Equally evident, there is ample desire to make a receptive public space where people are, at last, encouraged to share their story.

Based on Rogers (1962), Gawande (2013) reminds us that change is a rather grueling social process, requiring significant time, commitment, and effort. Whether or not any new idea ignites, pivots upon two factors: visibility of a problem and the social will that a prospective solution is worthy of effort and investment (Gawande, 2013). Innovation is highly dependent on human-to-human conversation (Rogers, 1962) and "critical connections" (Wheatley & Frieze, 2006, n.p.) or, more precisely, the critical conversations that reinforce connections. In this manner, every person and each story is a potential change agent. The following excerpt is from local writer and regular participant Patricia J. Anderson, who volunteered to promote the Death Café of CFD:

> Change begins in the heart and mind of an individual. We are, in fact, the very engine of change. Each of us has the power of our personal experience and the capacity to see differently. It is our viewpoint and our attitude that allows change to happen for the good. And small changes, deeply rooted, create authentic transformation over time.
>
> Our pending death is our common ground. We can find answers in communal discourse and the connection that comes from it. We can explore, ponder, and debate together in the sure knowledge that we are, in the certainty of death, all in the same big boat. Let's talk about it. (personal communication, March 24, 2014)

Representing our education and awareness arm since August 2013, CFD has hosted monthly Cafés in diverse neighborhoods and venues throughout the county, from coffee houses and restaurants, to a synagogue and university campus. Attendance has ranged from 25 to 75 people, with some repeat attenders. More recently, we have begun to adapt and use *the Death Café of Circle of Friends for the Dying* forum to promote our mission. Aided by publicity in local papers and a major regional publication, people are beginning to connect the dots between the Café's, CFD, and our mission to establish a Home for the Dying. In this way, CFD is developing a "community of learners" and a pool of potential volunteers and donors.

Aside from a struggling economy, several barriers to the success of our mission are evident. These include: 1) cultural resistance to a project pertaining to dying and death; 2) widespread misconceptions about hospice services amongst community members and HCP's; 3) the model represents a new and foreign entity in the region; and 4) potential donors may be reluctant to invest in a dream. Continuous education will be needed. What keeps me motivated are the members of the Oncology Support program, and other patients and families I encounter in the hospital and community, in need of a surrogate home and/or family.

Trends in making space for living with dying. I believe we are standing at the threshold of a paradigm shift in the experience of death in America, moving from the invisible (Aries, 1982) to the visible death. Current trends in both leadership and medical models of care include a more relational, collaborative, holistic, situational, culturally sensitive practice (Avolio, Walumbwa, & Weber, 2009), and local, community-based solutions and volunteerism (Byock, 2012; Economic Intelligence Unit, 2010). Community and communal ways of being are widespread, border-spanning themes for end-of-life residence development across cultures and the globe (Respeirda Fund, 2006). Emphasis on inclusion, through ground-up citizen participation in establishing the residence, promotes buy-in (Respeirda Fund, 2006) and fiscal sustainability. This is vividly illustrated by the Home for the Dying model, which relies on volunteerism in every phase of organizational and home development, from maintenance of the home to everyday operations and delivery of care. In effect, these trends (outlined in Table 7.1), of significance to policy-makers, health and end-of-life care leaders and practitioners, and the public at large, shift the trend away from conventional institutional practices and delivery of care. Moreover, these qualities mesh with growing interest in shaping more humanistic spaces for health and end-of-life care. The new field of healthcare architecture conceptualizes each building as "a system unto itself….intrinsic[ally] interconnected" to other systems, including, importantly, our ecosystem, thereby emphasizing sustainable design (Guenther & Vittori, 2008, p. xvii). Through imaginative and accessible design, the everyday places we live in or encounter in our daily activities can help redefine the social world, and the *way* we live and die (Guenther & Vittori, 2008).

Table 7.1

The Visible Death: Trends in End-of-Life Care and Care Settings

- Relational versus individualistic and rights-based ethic (Jennings, 2013);
- Local, grassroots versus national solutions;
- Person-centered, humanistic, servant orientation versus business and bureaucracy first;
- Integration of dying into everyday living and environments versus sequestration;
- Secularized versus religious and institutional notions of death, funeral and grief rituals
  - Home death and funeral; “green” burial practices;
  - Influence of non-Western religious/spiritual belief systems (Hockey, 2007);
- Trained multi-generational community volunteerism and informal care networks versus professionalism;
- Public and cyber-spaces for discourse versus taboo, private, isolated experience;
- Shared care via surrogate “family” versus individual family member as primary caregiver
  - “Health fiduciary” as surrogate decision-maker/advocate for elderly without, or in place of, family members (Weiss, Berman, Howe, & Fleming, 2012);
- Collaborative, interdisciplinary efforts, flattened hierarchy versus conventional top-down operations;
- Coordinated care systems promoting less medicalized care settings and practices;
- Hospice emplaced versus “homeless,” migratory philosophy; and
- Home-like and sustainable versus institutional scale and design; less beds = more care.

Implications for Future Research

While this study has stimulated many areas worthy of future research, I will elaborate on a select few. First, if we are to promote more home-like environments for dying across care settings, we need to further investigate the perceived meaning of home at the end-phase of life by those in the final phase of life. While design of sites of passage (i.e., buildings) is now given due attention, I am in agreement with Worpole (2009), who suggests future research look more specifically at the “phenomenology of the room” as a space that promotes meaning (p. 63). More specifically, I am interested in the relationship between perceived spatiality and existential at-homeness in regard to buildings and rooms designed for those living with dying, as Jeff models through his attunement to this subtle relationship, and impact on residents. How can we design and modify spaces to optimize at-homeness in accordance with an individual’s perceptions?

A specific area for future research minimally referred to in American heathcare literature is lay/professional caregiver psychospiritual development, specifically of skillful means and contemplative practices to recognize and work with existential distress in people who are dying, and for self-care. Chan and Tin's (2012) findings suggest self-competence, comprised of self-knowledge (awareness of personal history, beliefs, and attitudes related to death and loss) and "inner" resources (capacity for reflection, self-awareness, and existential and emotional coping), is the most critical skill-set necessary for working with people who are dying or grieving. I agree, but how do HCP's develop such capacities and what practices do those who possess these skills employ? Self-competence implies the right use of self in practice rather than reliance on rote strategies. Making space for the absenced "I" (self-awareness) sphere of influence as a clinical competency represents the next frontier in death education (Wass, 2004; Watts, 2007). The imperative for self-awareness and conscious use of self in practice is woven into Diana's collage through the symbol of the eye, one encircled by the question *"Who am I?"* (see Figures 4.6, 4.8, and Commentary). This happens to be a question Chan and Tin (2012) recommend for the development and integration of self in practice.

Moreover, I am interested in the education and development of high school and other student volunteers from diverse healthcare-related fields and the Home for the Dying as a "learning community" and practicum site. Longitudinal studies following students who have experienced care of the dying first-hand could help us understand the impact of exposure and experiential learning on future lay and professional caregivers, and can inform the development of programs and curriculums for varied age groups and educational settings. How would a Home for the Dying integrated into a multi-grade school campus, as Bob Kane envisions (or a

University campus for that matter) impact students perceptions of dying and death? How young is too young to provide supervised hands-on care for the dying?

Reflections on the Research Journey and Suggestions for (Novice) End-of-Life Researchers

We tend to be wiser in hindsight; this applies to research, too for suggestions culled along the way, as shown in Table 7.2. Research plans fall short of constraints and contingencies. This was especially the case coordinating plans around the changing needs and capacities of dying individuals, and their "schedules" for dying. Time is of the essence! Prospective participants' accessibility and willingness to partake in an interview often changed day-to-day, and hour-to-hour. Interviews with participants who were cognitively impaired appeared, at times, to be distressing for the individual. (This was the case when I interviewed George and Elizabeth). Care setting sites with few beds—the nature of researching the CBEOLR, further narrowed the stream of possible participants. A future study could be designed to focus more broadly, to include more sites and a range of CBEOLR models, or more in depth, such as a longitudinal study of a chosen site.

Foremost, I learned that conducting research centered on people who are dying requires accessibility and adaptability on the part of the researcher. Initially, I planned a weeklong field trip to cover both sites, but ended up taking a second trip with the hope of interviewing a resident at Isaiah House. As a back up, I obtained IRB approval and letters of agreement for two alternate Homes for the Dying prior to making the second trip. Moreover, one would assume that a site with more beds (Hospicare Residence) would yield more participants, but this was not the case. I attribute this in part to the liaison I was assigned who did not appear to have a strong rapport with residents and their families.

Volunteers were most accessible for interviews (though not strongly represented in the portraits). I learned that conversational-style interviews do not lend well to videotaping (and media-enhancements), unless the dialogue is properly staged and captured. Researcher roles (along with research accoutrements) may be viewed as intimidating and intrusive. I learned that research is essentially a relational endeavor; I most enjoyed myself when I relaxed my role and agenda during interviews, and as a participant observer. Along the way, I encountered several unexpected opportunities to learn and to be a resource for others.

Table 7.2

Recommendations for (Novice) End-of-Life Researchers

- Plan ahead, be flexible, expect busy administrators and clinicians;
- Anticipate rapidly changing conditions and needs of residents;
- Select patients/residents with longer proximity to death (more alert, less cognitive impairment);
- Choose accessible sites (may yield more data than “favorite” sites); have back-up plan;
- Make preliminary trip to familiarize/assess site and key staff; scope out quiet areas away from noise/traffic to conduct interviews;
- Develop rapport and interview primary point-person prior to site visit (assess if this is most appropriate person to serve as liaison; if not, identify alternate person);
- Find a liaison with strong resident/family rapport to coordinate introductions with potential participants; a clinician may be more suitable rather than an administrator;
- Build in time to acclimate to research site and to allow for others to acclimate to you;
- Make prior contact/arrange interviews with staff in the same field (this was one of the richest sources of data);
- Plan retrospective family interviews rather than/in addition to families prospectively facing death;
- Arrange staff, volunteer, and, retrospective family interviews prior to arrival;
- Simplify consent forms, especially for residents; have liaison obtain consent prior to interview;
- If staff/family not accessible during visit, request phone interview at their convenience;
- Maintain visible, non-intrusive presence in high volume/activity areas (i.e., kitchen) as a way to engage with staff, volunteers, family, residents more casually;
- Don’t undervalue participant observation and field notes as relevant sources of data;
- Simplify equipment; and
- Stay open to the present moment and enjoy the research journey!

Changing selves and roles (personal/clinical/artistic/scholarly) emerged to varying degrees throughout my research, in response to individual participants during interviews and less formal interactions. My personal and clinical selves were called forth to a stronger degree when interviewing terminally ill participants, eclipsing my research interests. I have learned, most meaningful to the dying person (and most satisfying to me) is being a friend.

This study is the outgrowth of “sustained thinking” and reflection, hallmarks of strong research (C. Kenny, personal communication, January 4, 2013), spanning the early Change Project, pilot studies, and present research. The main challenge was integrating and selecting copious amounts of data from on-site; interviews; focus groups; research planning committee meetings; pilot portraits; and a series of informal visits to a Home for the Dying in the role of volunteer. Throughout, I asked myself, “What shall I leave in or take out?” Also difficult was building a discussion coordinating two types of portraits, people and place-based. While immersion in the data and portraiture development prepared the soil, the over-arching theme/metaphor of nesting (in-being and in-place) transpired through the creative process (i.e., collage).

Several factors influenced shaping the place-based portraits. In addition to limited accessibility of resident participants, determination of data ultimately selected is based upon concurrent criteria: it represents material and themes most relevant to my research questions and most resonant to me, subjectively, as an artist-scholar-practitioner-change agent. What emerged, I now realize, is also a product of concurrent activities alongside my research (within and outside my workplace), reflecting my development as a clinician-social change agent. For these reasons, rather than constructing place-based portraits centered on resident voices (enhanced by staff, volunteers, and resident’s kin), as initially proposed, they highlight the voices of change agents telling the story of a CBEOLR, an evolving grassroots effort, from vision, through continuous challenges, toward fruition and maturity. A final note: an alternative art-based approach, utilizing an interactive installation in a public site featuring Homes for the Dying may have more adequately fulfilled one of the goals of this research, to reach and influence a diverse audience, especially within my own community. This may be a future project.

Dreaming Out Loud

Change begins with—and is sustained by—imagination. Imagination needs wings, voice to capture others' imagination, and space to fly. It also requires sturdy legs. Both visionary and pragmatist, Saunders, who led the modern hospice movement, ascribes to the notion of "practical action within the world" (D. Clark, 1998, p. 51). Similarly, Das and Bush (1995) use the term "compassion in action." According to Saoirse McClory, from Hospicare, persistence was paramount to carrying the original vision to build a residence, representing the first in New York State, through to fruition. Leadership, is about "having a vision and believing in it," she remarks. "The idea of a residency then and now may not make sense on paper; enough people, however, wanted to make the vision work." Similarly, Kathie Quinlan spoke of "sharing the dream day" in which she disclosed her vision of opening a Home for the Dying with Father Callan.

In my dream, quality end-of-life care is not only for those who can afford it. It is not only for people who have a committed and able partner or friend to act as a primary caregiver and advocate, or for those with family members permitted to take leave from work without risk of losing their job, or reprieve from other family responsibilities. It is not only for folks who have a home to call their own, or who have a substantial circle of friends they can rely on to be there for the duration. In my dream, quality end-of-life care is possible for everyone. This means, society as a whole is responsible.

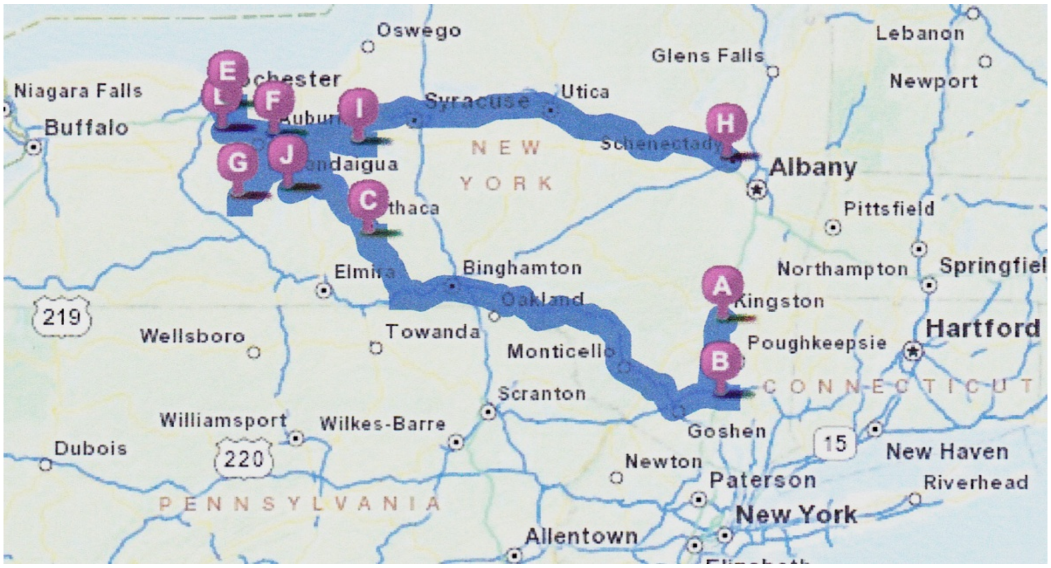
Community-based Homes for the Dying represent a grassroots, remedial response to misguided perceptions about suffering and death, and the dilemmas of biomedical hope. In a truly progressive and integrated society, there would be no need for such a place. Bob Kane insists, “The homes really shouldn’t exist. We should be doing this because it is part of our lives!” All of Bob’s lifework, like all of Kathie’s, Kristin’s and other leaders illustrated herein, is in service to cultivating the kind of world and relationships where there is no need for a Home for the Dying. It is a world in which people are more at home with death, with one another, and, essentially, with themselves. We can start by creating common spaces—from hospice classrooms to Death Cafes—and common opportunities, through volunteerism. The homes can challenge accepted ideas about dying and care for the dying, creating new norms. They can generate new stories.

Despite sometimes discouraging cultural barriers, dreamers continue to dream and to plan. One of the founding Board members of the Joan Nicole Prince (JNP) Home summed up the significance of turning their dream into reality: “The very existence of the home stands in total contradiction to today’s world” (Ferrara, n.d.). Perhaps not. That these homes took seed nearly thirty years ago, developed durable roots, and continue to pollinate and thrive in uncertain political and economic times is a testament to their perceived need and value. Rather than ask whether a Home for the Dying is sustainable, the vital question I hope this document stimulates and speaks to is, What about these homes have proven them worthy of sustaining? The words of Stacey Bentrovato, retired hospice nurse, Co-Founder of the JNP Home, and current board member, appeals to the clinician and dreamer in me: “Professionally, the JNP Home has been the finest thing I have ever been involved in…. It is as good as it gets—the most sacred, compassionate care” (personal communication, April 12, 2011). Indeed, the quiet yet formidable presence of these Homes are a testament to a shared dream and shared voice calling for a better, less medicalized, non-institutionalized, and dignified death. They are a life-affirming gift to the residents, families, and communities they represent and serve.

There are many ways to imagine and pursue acting as a change agent to serve a growing chronic and terminally ill, and elderly population, and to address the inevitable caregiver and care-receiver crises. The dream of creating a special Home for the Dying has taken root in my heart, soul, and imagination—and in others in my community. What started as a Change Project has become a Life Project. Not anticipated was how my project would change me. It has crystallized new vistas for life work, for leading change alongside others, and for acting as a change agent in my community; it has expanded and energized meanings of home, community, and a good place to die. Sharing one's dream aloud is powerful; it empowers others to share their dreams and to discover fundamental commonalities. Hopefully, my research will inspire you, too, to dream.

Appendix

Appendix A: Map of Site Visits in New York



Location of sites visited for Change Project* (2011) and Dissertation✠ (2013) research in proximity to the Cancer Support House ("A") at HealthAlliance Hospital, Kingston, NY.

Map Key

A. Herbert & Sophia Reuner Cancer Support House
B. The Kaplan Family Hospice Residence*
C. Residence at the Nina K. Miller Hospicare Center*✠
D. Benincasa* (behind "E")
E. Shepherd Home*✠ and Isaiah House✠
F. House of John*
G. Hospeace House*
H. Joan Nicole Prince Home*
I. Matthew House*
J. Keuka Comfort Home*✠

* Change Project research
✠ Dissertation research

Chart 1: Categorical List of On-site Visits & Interviews

Hospice Residences

The Kaplan Family Hospice Residence, Newburgh (Hospice of Orange & Sullivan Counties, Inc.); Daniel Grady, President, CEO and Patricia Boccinfuso, Director (informal interview), 6/22/10

Nina Miller Hospicare Residence, Ithaca (Hospicare and Palliative Care Services of Tompkins County); Saoirse McClory, Director of Community Support, 10/13/10; subsequent ✠visit & interviews: Tricia Conroy, RN; Robert J. Jankowski (Bob, resident); Jeff Collins, LCSW; Tina Jacintho, HHA, CNA; and Saoirse McClory, June 26-28, 2013

Hospeace House, Naples, Fran Steitler, RN; Max Bishop (Pastor Max) 10/15/10

Homes for the Dying

Benincasa, Mendon; Beverly Clark, 10/14/10; informal "volunteer" weekend visits spring/summer of 2011

Shepherd Home, Penfield; Betsy Inglis, 10/14/10; subsequent ✠visit & interviews: Betsy Inglis, 5/31/13 & Wendy's family, 6/25/13

House of John, Clifton Springs- Carole Jensen, RN, 10/15/10

Joan Nicole Prince House, Scotia- Susan Tomlinson, RN & Carol Weisse, PhD, 10/22/10

Matthew House, Auburn- Wendy Young, LPN (Barbara Sarah, LCSW, conducted interview), 12/23/10

Keuka Comfort Home, Penn Yan- Donna Payne, RN (Barbara Sarah conducted interview), 12/24/10; subsequent ✠visit & interviews Donna Payne, RN and George (resident) 6/25/13

Isaiah House- informal visit with Kathie Quinlan, RN, 2011; subsequent ✠visits & interviews: Kristin Catalano, RN; Kathie Quinlan, RN; Demetrius (“Dee”) (family member), Anna (vol.), Lynda (vol.), Rev. James B. Callan (Father Jim), Frank Tiberio, LCSW, May 28-31, 2013; Mariana (vol.), Mary’s family 6/24/13

<u>Off-site Interviews</u>
✠Harley School- Robert (Bob) Kane, Hospice Educator, CNA, 5/30/13
✠Visiting Nurse Service of Monroe County (Hospice Agency)- Marjorie A. Smith (Marj), LCSW, 6/X/13

<u>Other Hospice Care Models Outside of New York</u>
Enso House, Whidbey Island, Washington- Ann Cutcher, MD, 1/16/11
Zen Hospice Project Guest House- (informal visit & interviews) Roy Remer, Volunteer Manager, 7/1/12

<u>Additional Phone Interviews (related to on-site visits):</u>
Joyce LeChuga, RN, former volunteer at Enso House, 10/11/10
Beverly Hammons, former President of Hospicare Board of Directors, 11/22/10
✠Kathie Quinlan, RN, Founder and former Director of Isaiah House, 11/1/10, 11/25/10
Judy Malloy, former President of Hospicare Board of Directors, 12/6/10
Stacey Bentrovato, RN, Board Member of Joan Nicole Prince House (informal interview), 4/12/11
✠Connie O Brien, RN, Hospicare Residence, 7/8/13
✠Steve, Caregiver & Friend of Hospicare Resident, 7/22/13

<u>Focus Group Discussion Groups</u>
Social workers & other Human Service Providers
Patients & Community members
Nurses

✠ Dissertation research
vol.= volunteer
HHA= home health aide
CNA= certified nurse assistant

Appendix B: Comparison of End-of-life Residence Models in New York State

What is the difference between a Hospice Residence and a Home for the Dying?*

HOSPICE RESIDENCE	HOME FOR THE DYING
Licensed and certified by NYS	Operates independently (not under State jurisdiction)
4-8 beds	2 bed entity definition
PARTIAL reliance on charitable donations	**TOTAL** reliance on charitable donations
FEE for room & board commensurate with local nursing homes; paid via private pay, Medicaid, some insurance, or some may have sliding-scale fee	FREE room & board; non-profit status; 100% charity-funded, some are faith based affiliated and funded
Hospice services (including medication) funded primarily by Medicare, in addition to Medicaid & some private health insurance	Residents are hospice-enrolled; all finances for hospice services handled by hospice agency
Prognosis of 3 months or less	Prognosis of 3 months or less; preference given to person with “greatest need, fewest options”
Coded building Standards	No special building codes
Large paid staff in addition to mandated percent of volunteers	Small paid staff; dependent on large pool of volunteer caregivers
24/7 nurse presence	Nurse presence varies; most have nurse on weekday shift only, with 24/7 nurse on call
Hospice agency-trained direct care volunteers serve as “friendly visitors”; they are forbidden to administer meds	Based on a family model, trained direct care volunteers, like staff, function as “family” caregivers and are able to administer meds
Includes a ‘package’ of mandated services provided by professionals and volunteers, including bereavement	No mandated requirements; depends on hospice to provide professional services as needed; some offer bereavement
Operates within the codes of national and state hospice & palliative care organizations	No formal organizing body or codes
First Residence in NYS, 1995, in Ithaca; there are 10 free-standing Residences throughout NYS	First Home in NYS, 1984, in Rochester; there are 25 independent Homes in northern NYS

Appendix C: Residence Invitation to Participate in Research

Title of Dissertation: Making Space for Dying: Portraits of Living with Dying
Researcher: Elise Lark, LCSW
University: Antioch University, PhD in Leadership & Change

To Whom It May Concern,

Since 2001, I have been a social worker with a special interest in end-of-life care. I have worked at the HealthAlliance (formerly Benedictine) Hospital Oncology Support Program (OSP), in Kingston, NY, since 2006. OSP provides free supportive and educational services to individuals and families affected by cancer throughout all phases of illness, within the Cancer Support House and within the hospital.

Nearly every day in my clinical practice, I am made poignantly aware of the needs of terminally ill individuals and their loved ones for more, better, and accessible end-of-life care, care setting choices, and care systems. Most communities—like my own—have sparse, if any, alternatives to dying in an institutional care setting if circumstances prevent the person from remaining in their own home. In response to this need, in 2012, I started *Circle of Friends for the Dying* (CFD)*,* an independent not-for-profit organization. The primary mission of CFD is to establish and maintain a Home for the Dying in my community, in Ulster County, NY. The home will represent the first of its kind in the Mid-Hudson region of NY. My earlier, unpublished research, *Dreaming Out Loud: Initiating Plans for a Community-based Home for the Dying,* conducted in 2010-11, will serve as a foundation for this study.

Overview of Research Design

The purpose of my study is to explore the everyday lived experience of dying and the care culture within freestanding, community-based end-of-life residences (CBEOLRs), and to do so in an artful and compelling manner to engage a diverse audience. Based on Portraiture, a research methodology developed by Sarah Lawrence-Lawrence-Lightfoot, a Harvard-based sociologist and educator, I will craft four case studies in the form of aesthetic, story-like narratives. Two *people* 'portraits' will be based on interviews of individuals living with terminal illness; two *place* 'portraits' will be based on interviews of a diverse group of individuals centered on the care of terminally ill residents situated in a CBEOLR. The type of portrait I would develop from data obtained at the residence would fall into the *second, place-based category*.

In my purposive selection of sites, I considered several criteria, including: first or representative model in a region; innovative and well-defined organizational and care practices; community orientation; social and health care justice values; and home-likeness in scale and features. Place-based portraits will represent a diverse group of individuals involved in giving and receiving care in freestanding CBEOLRs, including: residence staff, volunteer caregivers, terminally ill residents, and residents' kin and friends. Portrait construction will be based primarily on semi-structured, conversational-style interviews conducted within the residence. Interviews will vary in length appropriate to the individual needs of participants. An effort will be made to represent demographic diversity. Residence staff will identify potential participants, including residents and their kin.

All interviews will be audio taped with the *option* of supplemental video recording. The final document will have embedded video clips to enhance the data. Based on their verbal and written consent, resident participants (and their loved ones) will understand their resident status and quality of care is in no way contingent upon participation in the study or affected by the decision to withdraw at any point, for any reason. Wherever permissible, I will engage in up-close observation through direct, hands-on participation in everyday caregiving practices. Moreover, all interviews will be enriched through field notes to capture foreground interpersonal (including non-verbal) interactions, as well as background environmental observations (supplemented by photographs). The data will be transposed into an aesthetic, story-like narrative. Data collected from earlier, informal research will be integrated into the final text.

Importantly, due to the personal nature of patient and family interviews and inclusion of video-clips and/or photos, along with other supportive autobiographical material, participation will be contingent upon the verbal and signed agreement that identities and identifying information will ***not*** be confidential. Participants (or their appointed research agents,) will have the opportunity to edit and delete any part of the draft or video clip in which they appear. The Hospicare Director, in addition to other appointed staff, will be offered an opportunity to clarify or correct data pertaining to the residence in the final draft.

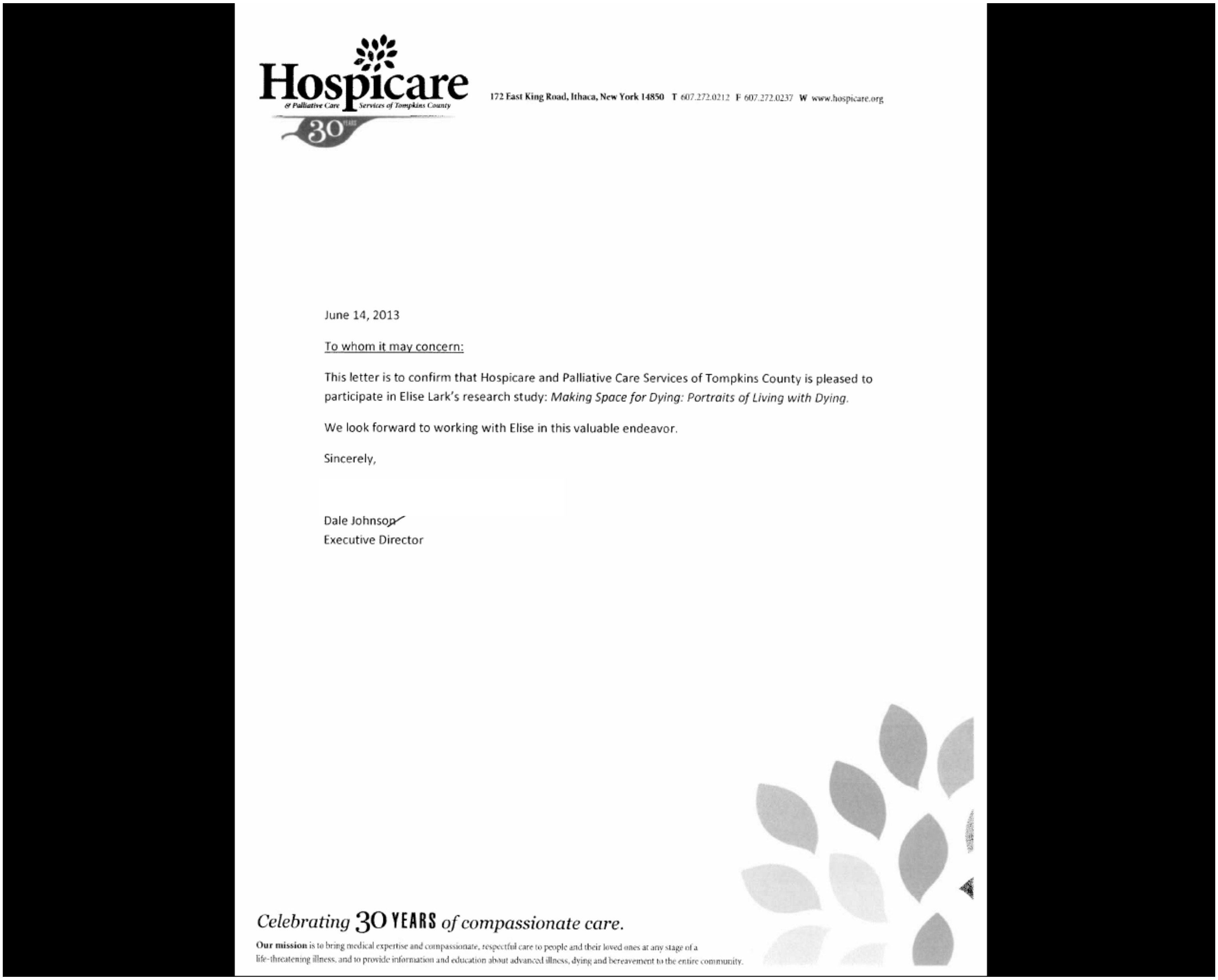
The Antioch University Institutional Review Board has approved my research design. For your review and approval, I have attached a participant invitation and consent form that would be provided to potential participants. In addition, I am required to submit a letter of permission to conduct research from the Hospicare Executive Director or Board of Directors. Prior to conducting research, and for the duration of the research process, the residence can be in contact with my Dissertation Chair, Dr. Carolyn Kenny at ckenny@antioch.edu.

I would deeply appreciate the opportunity for more in-depth learning about the residence and the ways in which it has contributed to the well-being of individuals, families, and the community during such a tender and sacred time in the life cycle.

Sincerely,

Elise Lark

Appendix D: Agency Permission Letters



Hospicare
& Palliative Care Services of Tompkins County
30 YEARS

172 East King Road, Ithaca, New York 14850 T 607.272.0212 F 607.272.0237 W www.hospicare.org

June 14, 2013

To whom it may concern:

This letter is to confirm that Hospicare and Palliative Care Services of Tompkins County is pleased to participate in Elise Lark's research study: *Making Space for Dying: Portraits of Living with Dying*.

We look forward to working with Elise in this valuable endeavor.

Sincerely,

Dale Johnson
Executive Director

Celebrating 30 YEARS *of compassionate care.*

Our mission is to bring medical expertise and compassionate, respectful care to people and their loved ones at any stage of a life-threatening illness, and to provide information and education about advanced illness, dying and bereavement to the entire community.

ISAIAH HOUSE

May 21, 2013

To Whom It May Concern:

Isaiah House is a home for the dying located in the city of Rochester. We have been caring for those with a less than three month prognosis for twenty five years. We are dedicated to caring for those with the fewest options and greatest needs.

Elise Lark has contacted me and asked that she be permitted to learn more about our home by visiting and interviewing our residents, families, volunteers, staff and other leading end of life advocates in our area. She may video tape interviews when necessary .

I trust that Elise will learn a great deal from her experience at the Isaiah House. We look forward to next week.

Sincerely,

Kristin Catalano RN
Director

71 Prince Street, Rochester, NY 14605
tel: 585-232-5221 • fax: 585-232-4679 • email: isaiahhouse@rochester.rr.com • www.theisaiahhouse.org

Appendix E: Participant Invitation

Participant Invitation

Making Space for Dying: Portraits of Living with Dying

Investigator: Elise Lark, LCSW
elark@antioch.edu
Antioch University, PhD in Leadership & Change

Dear Prospective Participant,

This letter is an invitation to participate in unique research in end-of-life care.

Please allow me to introduce myself. Since 2001, I have been a social worker with a special interest in end-of-life care. I have worked at the HealthAlliance (formerly Benedictine) Hospital Oncology Support Program (OSP), in Kingston, NY, since 2006. OSP provides free supportive and educational services to individuals and families affected by cancer throughout all phases of illness, within the Cancer Support House and within the hospital.

Nearly every day in my clinical practice, I am made poignantly aware of the needs of terminally ill individuals and their loved ones for more, better, and accessible end-of-life care, care setting choices, and care systems. Most communities—like my own—have sparse, if any, alternatives to dying in an institutional care setting if circumstances prevent the person from remaining in their own home. In response to this need, in 2012, I started *Circle of Friends for the Dying* (CFD)*,* an independent not-for-profit organization. The primary mission of CFD is to establish and maintain a Home for the Dying in my community, in Ulster County, NY.

In order to enhance understanding of the lived experience of terminal ill and dying people, and the experience of those receiving care within community-based residential settings, it is important to hear from and observe those individuals within the care-setting context. It is also important to hear from and observe those most intimately involved in their lives and care, including family members and friends, and professional and volunteer caregivers. This is the purpose of my study.

The experiences you share will be crafted into a story. The stories portrayed in my final document will allow for an up close, palpable view of an otherwise largely hidden dimension of human experience. Enhancing public exposure through storytelling, education, and opportunities for conversation and hands-on caregiving can influence the ways in which individuals, professionals, communities, and society at large think about and respond to suffering and death. Hearing how others live in the face of adversity, loss, and death instills faith that indeed we can too. It can evoke new stories and fresh possibilities for care and community, and for living with dying.

I would like to spend some time with you to hear about and to observe your experience of living with terminal illness as either a recipient or provider of care. With permission, I would also like to participate in basic care. I will talk with you for a short or long period, and as frequently as you are willing and able, without interfering with the normal flow of your daily routine. The conversation(s) would occur in the private or community-based residence in which you are receiving (or providing) care. The talks would occur on a regular basis until you choose to discontinue them, or are no longer able to participate. At that time, I would wish to be a quiet observer.

With your further permission, the conversations and activities of daily living and caregiving will be either audio and/or video recorded; photographs could also be taken, if possible. A person accompanying me will serve as video recorder and photographer. In addition, I invite you to share any other material considered important to help me understand your life experience, including personal writing, photographs, mementos, and media to include in my research.

Residence staff is invited to share documents pertaining to the residence to help me understand its care culture and operations.

The information you share for this research will be used for my PhD thesis, a public document accessible to anyone through the internet free of charge. It may also be used for future publications and presentations.

If you are a resident (or patient), I will ask you to appoint a person to serve as your "research agent". This person is only allowed to make research-related decisions for you in the event you are unable to do so yourself. You might choose the same person you designated as your healthcare agent or a different person.

Participants (or their appointed research agent) will have the opportunity to edit any part of the final draft or video clip in which they appear. The residence Director will also have the opportunity to clarify or amend data in the final draft pertaining to the site.

Due to the inclusion of the personal information you share, in addition to optional photographs and video recording, it is important to understand that participation in this research will be based on your verbal and signed agreement that your identity and identifying information will **NOT** be confidential.

You are under no obligation to participate in this study. Your decision whether or not to particip,ate, or to withdraw, will have no effect on the care you and your family members receive. You may withdraw from the study at any time.

If you require additional information, please feel free to contact me. If you have any questions about your role as a participant or as a research agent, you may contact me or Carolyn Kenny, Ph.D., my research Chair and the Chair of the Institutional Review Board of Antioch University, at ckenny@antioch.edu.

Sincerely,

Elise Lark, LCSW

Appendix F: Participant Informed Consent Form

PARTICIPANT INFORMED CONSENT FORM

Making Space for Dying: Portraits of Living with Dying

Investigator: Elise Lark, LCSW
elark@antioch.edu
Antioch University, PhD in Leadership & Change

BACKGROUND:
I understand that I am being invited to participate in this study either because I have a terminal illness, OR because I am a family, professional, or volunteer caregiver for a person who has a terminal illness. Elise Lark, a social worker and doctoral student, will be interviewing me about my personal experience of living with terminal illness and approaching the end of life. She will also be interviewing my close family members and friends, and the professional and volunteer caregivers providing my end-of-life care. A person accompanying her will serve as an *optional* video recorder and photographer, if I have elected so.

PURPOSE:
The purpose of this study is to enhance understanding of the lived experience of terminal illness and dying, and the experience of receiving and providing care within community-based end-of-life residential settings.

STUDY PROCEDURES:
If I agree to participate in this study, Elise Lark will interview me for one or more 30 to 90 minute periods for as long as I am willing and able to participate. Interview scheduling, length, and frequency will be flexible and tailored to my needs. The interviews may be either audio and/or video recorded. I understand that Elise Lark will also act as an observer, taking notes about the care I am receiving (or providing). In addition, I can provide personal documents, mementos, photos, and media to enrich the presentation of the information that she documents.

Video recording is *optional*. Also *optional,* if I agree, Elise Lark can participate in my basic care as guided and limited by my family members and professional caregivers.

The information will be transcribed and developed into a document, including video segments. Not all interviews will be transcribed verbatim or included in the final document. Patients/residents will be given the opportunity to edit the final document and video segments in which they appear. Directors of residences will also be provided the opportunity to edit the final document for clarification and accuracy, and to approve video segments pertaining to the site. Any or all approved information from this study may be used for current or future publications and presentations.

RESEARCH AGENT (for terminally ill participants only):
If I participate in this study, I will agree to appoint a research agent. I understand that my *research*-appointed agent may or may not be the same as my *health care* agent. I permit my

research agent to act on my behalf, to change or delete any part of the final document or video segment I appear in, *only* in the event I am unable to speak and act for myself, or if my death occurs prior to the completion of this study. I understand that my appointed agent is also able to make decisions about my continued participation in the study if I am unable to do so myself.

RISKS:
Some parts of the discussion, either with participants living with terminal illness or with family members, may elicit an emotional response, to varying degrees. As an experienced social worker, it is anticipated that this emotional expression will be experienced as beneficial, rather than harmful.

In the event you experience any adverse effects with regard to the content of the interviews, please notify this researcher or the corresponding Director (or other staff person) of either the Oncology Support Program or the residence. You will be offered a choice of resources, other than the researcher, for support and counseling.

BENEFITS:
Participation in this study can have many benefits. You are being offered the opportunity to share your experience and to express your feelings. This may help you to recognize and clarify unresolved concerns that you may then choose to address and possibly resolve. It is anticipated that your participation will be personally meaningful and enriching. Sharing of your experience may also be of value to others in a similar situation, and to health care providers who wish to improve end-of-life care and care settings for patients and their loved ones.

CONFIDENTIALITY:

Participation is this study is contingent upon your comfort and acceptance of public exposure of your identity. Due to the nature of the interviews, which will be personal and biographical, along with autobiographical material which you may wish to include (i.e., photos, unpublished memoirs), your identity will not be confidential and anonymous. Furthermore, participation in this project may include publicly viewed video segments.

You or your research agent (as previously described) will have the opportunity to edit any spoken or written material from the draft and video prior to their final submission. Any deleted material will be destroyed.

If you have any questions about any aspect of this study or your involvement, please contact:

Carolyn Kenny, Ph.D.
Chair, Institutional Review Board
Ph.D. in Leadership & Change
Antioch University
Email: ckenny@antioch.edu

PARTICIPANT CONSENT:

Two copies of this informed consent form have been provided. Please save one copy of this document for your own records. Your signature on both indicates the following:

1) I consent to participate in this research.

2) I understand the nature of this study and all of my questions at this time have been answered to my understanding.

3) I understand my identity will *not* be anonymous and the information shared will be accessible to the public.

4) I understand my participation is voluntary and I can withdraw at any time.

5) I understand that all approved information from this study may be used for future publications and presentations.

6) For patient/resident participants only: I agree my self-appointed research agent can make research decisions on my behalf, in the event I am unable.

Optional consent (please check *only* if you consent)

- ☐ I agree to allow video recording.
- ☐ I agree to allow photography.
- ☐ I agree that Elise Lark can participate in my basic care as directed and limited by my family members and professional caregivers.

Type of participant (please check one)

- ☐ Person living with terminal illness
- ☐ Family or Friend Caregiver
- ☐ Professional or Volunteer Caregiver

Signature of participant Date

Signature of researcher Date

Name of research agent (for patient/resident participants only) Phone number

Address Date

Appendix G: Interview Guide

Prompts for persons living with terminal illness

1. Tell me the story of how you came to be a resident here.
2. Tell me about your illness and how it has affected your life.
3. Tell me about your life before you were ill. What were the most significant events in your life? Who were the most significant people? What gave your life purpose and meaning?
4. How has your life changed since receiving a terminal prognosis?
5. What are your current symptoms? What is most challenging right now?
6. What is your greatest hope; your greatest fear? Do you have any regrets?
7. What has helped you cope and given you a sense of meaning and completion in this phase of life? (personal/spiritual practices, projects you are working on completing)
8. What gives you the most comfort/pleasure now?
9. What comes to mind when you think of the word ‘home’?
10. How has living with a terminal illness changed your perspective on life?
11. Can you share some of your thoughts about death? What are your beliefs, if any, on what happens following death?
12. What matters most to you now?
13. Do you have some final words of wisdom to share?

Additional questions for residents at CBEOLR

- How does this care setting compare to previous settings in which you received care? In what specific ways have staff/volunteers helped you/your family?
- What words characterize this place and the care you receive?
- How is this place like a home? What do you miss most about your own home?
- What makes this place a ‘good’ final home—a good place to live until you die?
- How would you convey the value of a place like this to someone who has never seen it?

Additional questions for person-centered portraits:

- What are some of the challenges of living alone with terminal illness and facing death?
- If you were unable to remain in your own home what would be your next 'best' option?

Prompts for Families at CBEOLRs

1. Please tell me your story of how your family member came to be a resident here and what it has meant to you.
2. How is this place different from previous care-settings?
3. What is the most significant difference?
4. How has life changed for you/your loved one since s/he arrived here? To what do you attribute this? How has being here affected the quality of your relationship?
5. What words characterize this place and the care you/your loved one receive?
6. Please describe the features that make this place look and feel like a home.
7. How would you describe the staff and volunteers?
8. How would you convey the value of a place like this to someone who has never seen it?

Prompts for Residence Staff and Volunteers at CBEOLRs

1. Please tell me your story of how you came to work/volunteer here and what it has meant to you.
2. What is your experience working/volunteering in this care setting and how does it compare with other care settings where you have been involved with?
3. What key features distinguish operations & care from that of institutional care settings? What is the most significant difference?
4. How would you describe the care culture or environment here? How does this influence the quality of life for residents and their loved ones?
5. What is the meaning of a 'good place to die'?
6. What words characterize this place and the care offered?
7. What is the meaning of 'home' to you?
8. Please describe the features that make this place look and feel like a home.

9. What is the relationship between the Residence/Home and the surrounding community? How do you think the community perceives the Residence/Home?

10. How do you work with people who are experiencing existential anxiety or despair? How do you help residents make meaning?

11. How do you work with your own existential anxiety? (Any practices/rituals that sustain you?)

12. How has working/being with dying people changed your perception about dying, death, and loss?

13. Please share a story about your relationship with one of the residents.

Appendix H: Faces Matter: Image Key for Figure 6.1

Appendix I: Image Credits*

August 29, 2014

Dear Elise,

This email is to confirm that I, Will Weber, give Elise Lark permission to use the following photographs in her dissertation for Antioch University:

- all images taken on-site at the Nina K. Miller Hospicare Residence and Isaiah House, unless otherwise noted (Ch. 4);
- all images of Elise's collages (Ch. 4 & 5);
- Figure 4.10. Diana and I at the annual OSP Holiday Celebration, 2007 (Ch. 4);
- images in her auto-ethnographic chapter (Ch. 5);
- photo-montages in discussion chapter (Ch. 6); and
- all images of people in Faces Matter: Participants from Place-based Portraits (Figure 6.1.) and Image Key (Appendix H), with the exception of Mary and family.

The composition of all photomontages was a creative collaboration between Elise and me.

All said individual images are copyrighted by Will Weber and you are hereby granted free license for use in your Antioch University PhD dissertation.

Will Weber, OptiTechure Inc.

June 11, 2014

Dear Elise,

This email is to confirm that Hospicare & Palliative Care Services of Tompkins County gives Elise Lark permission to use the image, "Women Swimmin' 2014 quilt," created by Sarah Demo, in her dissertation for Antioch University.

Jackie Swift

Jackie Swift
Communications Manager
Hospicare & Palliative Care Services of Tompkins County
172 East King Road
Ithaca NY 14850
607.272.0212

607.277.3785 fax
jswift@hospicare.org
www.hospicare.org

August 29, 2014

Dear Elise,

This email is to confirm that Isaiah House gives Elise Lark permission to use the image of Mary and her family in her dissertation for Antioch University.

Kristin Catalano, R.N.

Kristin Catalano
Director
Isaiah House
71 Prince Street
Rochester, NY 14605
Tel: 585-232-5221
Fax: 585-232-4679
Email: isaiahhouse@rochster.rr.com
www.theisaiahhouse.org

September 13, 2014

On behalf of the Board of Circle of Friends for the Dying (CFD), I grant Elise Lark permission to utilize the CFD logo for her Antioch University PhD dissertation.

Elise Lark

Elise Lark, LCSW, LMT
Doctoral Candidate, Antioch University Leadership & Change Program
Co-Founder and Chair, Circle of Friends for the Dying, Inc.
Social Worker, Oncology Support Program at HealthAlliance Hospital
845.339.2071 ext.102- office
office mail: elise.lark@hahv.org

*Permission to use photographs in the portraits of Diana and Grace is covered by the Participant Informed Consent Form (see Appendix F).

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