

Dwelling in the Realm of Death: The Lived Experience of
Counsellors' Encounters with Mortality in a Palliative Care Context
by

Susan Mary Fownes Breiddal

B.S.W., University of Victoria, 1982
M.T.P. Institute of Transpersonal Psychology, 1996

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Supervisory Committee

Dr. David Blades, Co-Supervisor
(Faculty of Education: Department of Curriculum and Instruction)

Dr. Daniel Scott, Co-Supervisor
(Faculty of Human and Social Development: School of Youth and Child Care)

Dr. Anne Bruce, Outside Member
(Faculty of Human and Social Development: School of Nursing)

Dr. Ted Riecken, Departmental Member
(Faculty of Education: Curriculum and Instruction)

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ABSTRACT

This research explores the lived experience of encountering mortality in the palliative care context. Six counsellors included in the study had served on a Palliative Care Crisis Team in the community and/or the in-patient unit of a hospice in a mid-sized Canadian city. Conducted as a phenomenological study, all co-participants electronically or face-to-face, answered 18 questions that were generated from an initial open-ended question, and answered other clarifying questions as requested. The author also tracked the experience of the experience, of encountering mortality, by creating a Sacred Mandala—a painting that involves a particular structure, meditation practices, and journal work—and analyzed her notes as part of the data. Themes identified were: responding to the call; the realities of death; being in the know and the impact of knowing; relationships—intensity, intimacy, connection and identification; the gift of stillness; encountering mortality can be mundane; being of service; finding balance between giving enough and receiving enough; being in the face of D/death; staying awake; and living life. It was found that encountering mortality is paradoxical, and that the struggle of holding opposing

forces is necessary for transformation toward wholeness but requires structured support that needs to be offered when caregivers are entering the field and throughout their careers. Support also needs to provide discipline and structure that is complex enough to encourage, contain and support participant's expression of strong emotion, exploration and self-reflection of practice, sharing with others, and being witnessed.

Keywords: palliative care, death, lived experience, Mandala, mortality, palliative care curriculum, phenomenology, self-care, social worker's experience, creative expression.

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Dedication

In the words of Paul the Apostle, there are three things that last forever: faith, hope and love; but the greatest of them all is love.

This work is dedicated to my husband, Bruce John Breiddal.

Words cannot express my gratitude for this man who has loved and supported me for the past forty years. My dissertation has brought us to the outer edges of what we could bear.

My dearest Bruce, I could not have done this without you.

You know that I love you with all my heart.

Susan

Chapter 1: Drawing the Circle: Searching for the Whole

a companion of descent

you've been down underground
you walk the shores of the Styx
coal black eyes glint at you
from the far shore silent, cold
watch for you to stumble
wait, but you refuse to cross
stay there on the edge of the bank
before it slopes down impossibly
give a hand to those who stagger
reach to board Charon's boat
you hold them briefly, help them
say goodbye, soft whispers
intimate glances in the grey
there beside the departure point
to eternity, every breath tinged
with unknowing, with emptying

you turn, climb against
the descending stairs
back to air so crystal clear
it blinds you, brings you
the gift of forgetting
yet you cannot shake
your calling nor the heavy
dark smell of earth's
underground passages, death
clings to you, marks you
drains you of days, of nights
leaves you so often alone
to await the next time
you will descend, down
to the river, to the edge
of nothingness
to give yourself away
to ease passage
wondering which time
you will board
and not return

Daniel Scott, 2013

Journal Excerpt

Excerpt from my journal, at the end of Unitarian Family Summer Camp (Seabeck, Washington, August 1993. Unpublished):

*When it is my turn, I get up and say that I had thought that I was going to look after a baby for the next five years, but as it turns out, that is not going to happen. I have realized that I am moving in **sacred time**, time meant for (my son) Dante. Whatever I do with this time will be inspired by him, his gift to me, and for that reason, I want to use it wisely.*

I don't really know what is in store for me now. What I do know is that I have been profoundly touched by Divine love. My love for Dante made this possible. Now, I want to reach out and be with other people in a new way, a way that allows my creative spirit to shine, and for others to be touched by that light.

Note from my present self to my past self:

Hey, Susan, in the end, it turns out okay, just keep going.

Note from my future self to my present self:

There is no end, and it is still okay.

The disciple of a Sufi of Baghdad was sitting in the corner of an inn one day when he heard two figures talking. From what they said he realized that one of them was the Angel of Death. The Angel was saying to his companion, "I have several calls to make during the next three weeks."

Terrified, the disciple concealed himself until the two had left. Then applying his intelligence to the problem of how to cheat a possible call from death, he decided that if he kept away from Baghdad he should not be touched. From this reasoning it was but a short step to hiring the fastest horse available and spurring it night and day towards the distant town of Samarkand. Meanwhile Death met the Sufi teacher and they talked about various people. "And where is your disciple so-and-so?" asked Death. "He should be somewhere in this city, spending his time in contemplation, perhaps in a caravanserai," said the teacher. "Surprising," said the Angel, "because he is on my list. Yes, here it is: I have to collect him in four weeks time at Samarkand, of all places." (Shah, 1993, p. 191)

Intellectually, you and I both know that we are going to die. Whether we embrace this knowledge, understand it, run from it, or pretend that it's not going to happen, we all have an appointment with death.

When I tell people that I am a palliative care counsellor working in a hospice, I hear a response such as, "That must be hard," or "You must have to be detached so that you don't get too close to people." The most common response is, "You must have to be a special kind of person to do that work." Although we know some things about what it is like for some people to work with the dying and bereaved, there is still a lot to be learned. The entire professional team, as well as palliative care volunteers, all offer psychosocial care, which makes it difficult to articulate, even for other professionals, exactly what palliative care counsellors do, what kind of orientation our academic training provides, the value of that orientation, and where we fit within the team.

I understand that for patients and their families in a medical setting it may be difficult to distinguish or define our role, and perhaps it is a testimony to teamwork that, even after having

been introduced as a counsellor, we are still referred to by patients and their families as nurses. Perhaps the term *nurse* is simply a generic term for *caregiver* when it comes to health-related concerns. Maybe it is also a testament to an individual counsellor's skill that, after being in conversation with a family member, that family member turns to the nurse who is filling medication and says, "So is this how it goes, you do all the work, while she [pointing to the counsellor] sits and has tea?"

While it may not be important for patients and families to understand or distinguish our role as counsellors from other members of the team, it is important for our professional identity that we reflect upon, explore, understand, and talk about not only what we do and how we do it, but also how we make meaning of experience and how it shapes who we become. This exploration is important for our colleagues, because they also work in the palliative care setting and may relate to our experience. It is important that those who support, supervise, manage, and educate us, and those who design educational and institutional programs for us understand what it is like to come to work every day and bear witness to death, dying, and bereavement—to think about it, see it, feel it, and listen to it. It is my intention to explore the day-to-day experience of being a palliative care counsellor by asking those who are palliative care counsellors, "What is the lived experience of encountering mortality in a palliative care context?"

This dissertation is based on phenomenological research that combines my direct experience as a palliative care counsellor with reflective practices—journal writing, painting a particular mandala called the Sacred Mandala, mindfulness practice, and expressive writing as well as academic writing. Although the mandala work will not be fully explained until Chapter 4, I will show how earlier chapters relate to the beginning of the Mandala, specifically the gathering of the materials, the ritual beginning, the drawing of the circle, and the painting of

the Ring of Fire. My intention in documenting my use of art and meditative practices is to explore the value of using a structured, creative process to contain and express the impact of exploring such a powerful topic as death.

In Chapter 1, I take an academic perspective and lay out the groundwork, introducing the reader to the concept of death in a palliative care context. I define terms and articulate the importance of the study. In terms of phenomenology, Chapter 1 identifies my pre-understanding of the phenomenon of encountering mortality daily in a palliative care context, for the purpose of bracketing, and setting aside this understanding in order to look at the phenomenon itself in a fresh way. The subjects that have come to my attention as I reflect upon and compare my own experience with what I find in the literature are as follows: turning away from or toward death, how we talk about and meet death, what it means to be whole, how my personal experience with death called me to work with the dying, and how encounters with death might shape those who work in the field of palliative care. This exploration is not meant to provide a structure or outline of themes for the entire paper; instead, it is meant to assist the reader in understanding and identifying my perspective as I engage with the topic. It demonstrates my commitment to be transparent. I have opted to use “their” as singular gender-neutral pronouns throughout this text to avoid the awkwardness of double pronouns.

The Subtle Differences Between Death, Dying, and Mortality

Death is the event or state of not being alive, and dying is the process we live through in order to arrive at death. Technically, death can be defined as “the final cessation of the vital functions” (*Oxford English Dictionary* [OED], 2011). In palliative care, the dying process leading up to the “final cessation of the vital functions,” and the subsequent bereavement of that

person's social network, typically follows identifiable patterns, both physically (Downing & Wainwright, 2006; Murray, 2008) and psychosocially (Cairns, Thompson, & Wainwright, 2003). Death and dying are unique experiences for the people experiencing dying or bereavement, and also for the people who provide care during this time. The "final cessation of vital functions" (OED, 2012) does not in any way capture the complex physical, social/relational, spiritual, emotional, and intellectual experience of encountering mortality. In Toews's novel *The Flying Troutmans* (2008), the main character describes a strange liminal world where her sister is alive, but not really here, illustrating the particularity, for family members, of encountering mortality.

She was a strange, unsettled planet that had once sustained life. She was a language that I had thought I almost understood even though I couldn't speak it. She hadn't always been this way. She used to wear high knee socks and short shorts and tube tops, and travel everywhere on roller skates. If our parents took us horseback riding, she'd pick the wildest horse and have it tamed in five seconds, flying joyously across fields and through rivers and leaping over fences. She taught me how to bumper-shine and cannonball and roll a joint and make a homemade bong. She went barefoot from May to October and once, on a dare, swam across Falcon Lake in the middle of the night. (pp. 12–13)

For the individuals who make up a social network, and for the professional caregivers who interact with that social network, death, dying, and grief are personal, specific, and relational. For palliative caregivers, death is not abstract but rather part of every workday.

Throughout time and across cultures, death has been portrayed through metaphor and image. Death personified—Death—is usually portrayed as a skeleton, and has been known as the Angel of Death, La Morte, one of the four horsemen of the Apocalypse, and the Grim Reaper, to name but a few. These images of Death can be particularly stark. Consider, for example, the art images in tarot cards. Figure 1 (below) shows the Death card from the Thoth Tarot deck.

Figure 1: The Death Card from the Thoth Tarot Deck¹

The Thoth deck shows Death as a dancing skeleton bearing a scythe. He wears the Crown of Osiris, the Egyptian god of the dead and is shown in the waters of Amenti, an Egyptian after-death state. The sweep of his scythe creates bubbles which contain the seeds of new life. ... This card represents death and sudden change. The imagery suggests Jung's archetype of rebirth. (www.schuelers.com/chaos/chaos7.htm).

In this version, a figure appears to be almost enthusiastically destroying life. As a palliative care counsellor I see the results of D/death's arrival, and it is easy for me to relate to the sense of randomness and chaos depicted. Haunting voices echo through my memory: "A week ago she was in her garden." "She's only 17." "He thought that he had pulled a muscle." "We've never spent a night apart in 68 years." The image of a wide swath from Death's scythe captures the lived experience of encountering mortality in a way that words cannot. Rather than being a theory or a detached idea, being *face to face* with death, or *facing* death, implies immediacy and intimacy. *Facing* D/death might indicate that a person "looks seriously and steadily at and doesn't shrink from (an issue, idea, unpleasant fact, etc.)" (OED, 2012), and perhaps Death stares directly back. The personification of Death then, represents more than death, that is, the cessation of bodily functions, focusing on our relation to certitude that death is inevitable.

Facing Death

Is it possible to refuse to "confront" (OED, 2012) all of what death means physically, socially, mentally, and spiritually—that is, to deny D/death? Can we just say "no"? It is a common belief that Westerners are a "death-denying culture." It is a matter of speculation as to whether or not it is possible to refuse to recognize death. I have experienced several

¹ <https://www.google.ca/search?q=death+card+thoth+deck&safe=off&client=firefox-a&hs=tCE&rls=org.mozilla:en-GB:official&tbm=isch&tbo=u&source=univ&sa=X&ei=-P6cUdz2Oab9iQLXhICACw&ved=0CDgQsAQ&biw=1360&bih=557>

conversations recently that illustrate this point. While speaking to a friend about his recent health crisis, a woman tearfully said, “I thought that you were going to die.” He responded by saying, “I didn’t ever go there, I just *refused* to think about it.” Implied but not spoken: “I didn’t want to think about it then, and I definitely don’t want to think about now.” In another conversation, a woman whose husband was dying told me, “I can’t think about life ... after ...” She couldn’t bring herself to name it. In neither of these interchanges do I see denial; I see an attempt, a desire, or maybe a hope, to avoid an appointment with death. It seems to me that the person, in the process of choosing *not* to think about death, *has* to be thinking about it. How else could they choose not to think about it? As in the Sufi story “When Death Came to Baghdad,” running away from D/death becomes running toward D/death. Every time I refuse to think about dying, I think about dying.

Does refusal to face death invariably denote a denial of death? Many patients and families tell me that they are focusing on life and hope. That seems different from denying death. From where does this desire to focus on life and hope originate? Is it not a response to the compelling call to attend to the reality that death comes no matter what, and there is no hope of escaping? To resist coming face to face with death is to acknowledge the fear and ambivalence with which we encounter death. Even if a person can resist by fending off the intellectual or emotional consequences of knowing that death occurs, there is still no escape from an appointment with death.

The impression that people in Western culture are death-denying seems to come from the Western practice of isolating the dying in hospitals and seniors’ facilities. Some think that the sequestering of the dying and their families “in impersonal institutions is inherently undignified” (Matzo et al., 2003, p. 74). Others believe that the substitution of family care by care from

professionals with specialized knowledge about death and dying leaves the dying and their families in a state of ignorance and fear, lacking information, skills, and social models of how death can or might be encountered (Kellehear, 2007). The experience of dying has gradually become more private at the same time as its recognition has become more publicly controlled and defined, or “well-managed” (p. 251). This practice has led to a widespread “assumption that Western societies are a death denying culture” (Papadatou, 2009, p. 3). Zimmerman (2004) makes the point that it is perhaps our discourse about death, or rather our lack of it, rather than our actual attitude, that gives this impression. She thinks that the palliative care discourse manoeuvres individuals toward a managed death that is perhaps self-serving:

The very interest in death denial may itself be seen as part of a larger discourse on dying, reflected in the field of palliative care, in which denial is problematized. ... Rather than being a defence mechanism at the level of individual psychology, denial can be seen as an instrument in a larger discourse on dying, which both invites patients to participate in the planning of their death and labels those who do not comply. (p. 1778)

It seems to me that the physical, emotional, and spiritual care of the dying has become complex in our society because it has been taken out of daily living, thus compartmentalizing both our living and our dying. Rather than encountering our own mortality in a gentle, organic way, brushes with death jolt us into awareness with an often traumatizing realization that “one’s death is an inescapably real event in the unpredictable or actually foreseeable future” (Frommer, 2005, p. 482). Papadatou (2009) contends that palliative care is a response to the difficulty of continuing to hide death, and hide from death, in our technological world. She says that palliative care brings death and dying into the mainstream of everyday life, and through individualized care, delivered in the community, at home, or in hospices, death and dying become a social occurrence rather than an isolated, alienated, or “marginalized” (p. 9) event.

This social occurrence is peopled not only with the patient and their network of family and friends, but with the professionals and volunteers who provide care.

The Importance of Turning Toward Death

As a counsellor who provides care for the dying and their families, the lived experience of encountering mortality daily in the palliative care context is a question of great importance to me, but why might anyone else care? By focusing on a small group of hospice counsellors, including myself, I provide responses to what it is like to encounter mortality daily in the palliative care context. I hope our experience will arouse curiosity and stimulate conversation among my colleagues, at the same time as promoting self-awareness in us all. This exploration may stimulate interest and discourse with other disciplines within the palliative care field, but need not be limited to palliative care contexts given that grief and loss are associated with many psychosocial and physical issues. It may raise questions for those who imagine that someone who works with the dying and their families must be a special kind of person. Furthermore, this exploration may stimulate similar discussion among those who fund, design, or direct palliative or health care programs, or who prepare, train, educate, or supervise related professionals, volunteers, or others who deal with mortality either routinely (for example, police officers, firefighters, funeral operators, soldiers, and clergy), or suddenly or unexpectedly (for example, family members, educators, students, or colleagues).

Given the inevitability of every person's appointment with death, this exploration may have a broad appeal, ranging from those who have never been close to death or the dying process, to those who have had an intimate experience with one or both. For some of us, the prospect of interacting with the uncertainty and emotional, physical, and spiritual suffering

associated with death, on an ongoing basis, can be frightening and overwhelming. For others, or at other times of life, death can be welcomed and anticipated, and can provide relief. Being present, not being present, living with the reality that we are all going to die, the visceral experience of coming face to face with death and grief—the desire to step closer and the equal desire to look away can be confusing, creating waves of emotion that can be overwhelming to the psyche. Therefore, this study may be of interest to anyone who has wondered what it might be like to encounter death on a daily basis in a palliative care setting or who have ever wondered what it would be like to encounter their own death, or the death of others.

The Power in Words

Van Manen (2007) tells us that words are inadequate for defining our life-world because they are dependent on shared understanding; they are embedded in a social and cultural life that cannot be fully bridged by language. Even so, he sees value in “the paradox of theorizing the unique” (p. xiii) through working at capturing fuller meanings contained in the words themselves. Phenomenology is the process of making implicit meanings explicit and in order to expand our understanding of experience within the limits of language (van Manen, 2007). The subtleties of meaning, however, can be hidden, and for this reason it can be helpful to turn to dictionaries and etymology. Words that once may have been fresh and meaningful and able to convey nuances in often sensual, powerful ways, can become stale through overuse, thus losing their ability to speak to our experience. Being attentive to the origin of a word can therefore sometimes reconnect us to the source of liveliness to which it was once linked (van Manen, 2007, p. 58). The phenomenological method, then, requires the researcher to be artful at listening, attending to what lies beneath and between words. For this reason, throughout this text, I pause at times to focus on particular words as a way to clarify what a word commonly

means, as well as to explore the subtle undertones that might be uncovered through a variety of different sources. Exploring the etymology of a word reveals its original meanings and associations reminding us of nuances that might imply, and in this way has the potential to expand our understanding and discussion of the lived world of palliative caregivers.

“Words are the building blocks of meaning, social interaction, and language itself. The ways people speak say a lot about who they are” (Groom & Pennebaker, 2002). Where I work in palliative care, when a person dies or is about to die, we use the words *dying*, *die*, *death*, or *dead*. For example, we might say to a patient’s family member, “Your father will most likely die in the next few hours,” or “Your mother is dead”; or to the patient, “What would you like to happen to your body after you die?” This direct speech must be understood in the context of the larger hospice/palliative care movement which avoids euphemistic terms that replace a word such as *died*, which can seem stark or harsh, with a less offensive but also less accurate or descriptive term, such as *pass away*, *gone*, or *gone to Heaven*. By being specific, “we think that your mother is actively dying and has hours to days to live,” we can be much clearer than if we said, for example, “your mother is nearing the end of her life,” or “your mother’s time is short.” Although these words can be hard for a family member to hear, for some it is helpful to know that “a short time” is not a few years, or even a few months. Practising direct speech reflects and reinforces our mandate and our intention to provide clear, accurate, and complete information to patients and their families, and is understood to be an invitation and a model for others to speak openly with us.

The word *death* describes a physical experience, while the word *mortality*—“the condition of being ... subject to death” (OED, 2012)—is somewhat broader in that it is related to the Latin word *subjectus*, “something thought about,” and the French *mortal*, “destined to death”

(*Chambers Dictionary*, 2008, p. 679). The concept of mortality, then, includes both the “cessation of vital functions” and the knowledge that one is “subject to or fated to die” (OED, 2012). By asking what it is like to encounter mortality, rather than to face death, it renders it unnecessary to evaluate whether or how much a person has taken in, faced up to, or confronted death.

What does it mean to encounter mortality? The word *encounter* typically means to “meet as an adversary or enemy ... (or to) engage in conflict” (OED, 2012). Psychosocial care in palliative care provides support for those patients and families who struggle between the wholly natural dying process and the equally natural desire to maintain hope and focus on life and living. *Encounter* can also mean to “come upon, or to meet unexpectedly or by chance” (*Merriam-Webster*, 2012), or “to be presented or confronted with something.” I specifically use the word *mortality* rather than *death* to encompass both the physicality of death’s final cessation of vital organs, and the process of becoming dead—that is, dying—and the emotional, intellectual, social, and spiritual aspects of anticipatory grief and bereavement. *Encounter* is used with the conscious intention of being non-evaluative and non-judgmental, and in the sense of coming upon death through conscious knowledge—watching, waiting, and expecting death. In other words, mortality is the lived experience of coming upon and waiting for death. For those of us who work in palliative care, having both the opportunity and the expectation of encountering mortality daily is a given, and sets the scene for everything else that we experience.

Encountering Mortality Daily in the Palliative Care Context

While speaking with a fellow education student about my work, she asked me, “Do you actually deal with death on a *daily* basis?” Perhaps the answer seems obvious to those of us who

work in palliative care. Death permeates every aspect of our work. It is the unseen third party in every interaction (Papadatou, 2009). It is visibly, palpably present every day when I go to work, and its effects spill over into my time away. Observing and interacting with those who are dying and bereaved automatically produces a questioning of life: how we have lived it, how we are living it, and how we will live it. When I asked what it is like to encounter mortality daily, I was assuming that even when caregivers are not actively engaged in their work, any thoughts of work involve an encounter with mortality.

Encountering mortality in an environment where there is a network of people and systems to respond to the expectation that death is present, and where there is a set of values that connect these networks, is referred to as the palliative care context. This context is different from encountering mortality in a hospital, on a battlefield, in someone's kitchen, or in a public place like a highway or recreational area. It is different from experiencing death due to a widespread disaster such as a plague or an earthquake. Within a palliative care context, death is inevitable and will happen within a relatively short period of time. To address all that this means, the treatment or care provided considers the needs of both the patient and their family (World Health Organization [WHO], 2011). The words *palliative care* reflect a program of care—the physical space where all the services are provided, and the philosophy of the care—with a unique combination of values, attitudes, and belief systems all reflected in relational ways of interacting. Papadatou (2009), one of the few psychosocial experts who explore the experience of palliative care providers' encounters with mortality, identifies a number of beliefs that define palliative care. The first is an overarching acceptance that death is a natural part of life and “that the focus of care for both patients and families is the experience of living with the awareness and reality of death” (p. 8). Caregivers demonstrate through their way of being and

relating that encountering mortality is a profound experience that results in “networks of people who are changed forever as a result of loss” (p. 8).

A second belief is that holistic care must be provided by an interdisciplinary team. Hall et al. (2006) explain that the interdisciplinary team in palliative care sits between two ends of a spectrum of ways in which teams function. At one end is the multidisciplinary team—traditionally the predominant medical model team—where team members do not communicate with each other but instead give information to the physician who maintains control of and responsibility for patient care. At the other end is the transdisciplinary team where boundaries between disciplines are blurred to allow team members to take on significant portions of the others’ jobs, sometimes referred to as role release (King et al., 2009). In actuality, the team members form a transdisciplinary team when they practise collaboratively without regard to their individual primary disciplines. In palliative care, the interdisciplinary team work together to solve problems, with each member contributing their knowledge and skill set but remaining clearly identifiable as a doctor, nurse, counsellor, or spiritual care provider. The team, however, must create synergy to be effective and sustainable and to provide holistic, individualistic, and seamless care to patients and families (Breiddal, 2011a; DiTullio & MacDonald, 1999; Wainwright, 2011).

A third belief is that personal relationships with the dying and their families are both important and necessary (Papadatou, 2009). A powerful, authentic, human-to-human relationship is so essential to palliative care that it requires a system of support to be woven into the fabric of an organization (Dechamps, 2011; DiTullio & MacDonald, 1999; Jones, 2005; Nugus, 2011; Wainwright, 2011). A reliance on relationships requires “a rare mixture of

interpersonal skills, compassion, and professional acumen ... that constitutes the 'soul' of hospice" (DiTullio & McDonald, 1999, p. 641).

Relational values are supported differently in every context and organization. In one study it was found that for most palliative caregivers interviewed, "philosophical allegiance extends beyond a commitment to organizational mission and is wholly embraced as a personal philosophy of life" (DiTullio & MacDonald, 1999, p. 647). For palliative caregivers, expectations commonly match the reality of hospice work, and when equilibrium between the caregivers' internal and external resources and the demands of the job is found, a sense of wholeness can be experienced by the caregiver (DiTullio & MacDonald, 1999; Jones, 2005). Palliative care is thus the stage on which personal values can be and often are enacted. Personal values may be part of what accounts for how I relate to my job as a counsellor, working on the Palliative Care Crisis Team (PCCT), where a nurse colleague and I respond to crisis calls from registered hospice patients and their families living in the community, or follow up on the in-patient unit when not in the community.

The Job of a Palliative Care Counsellor

During the past 15 years I have anticipated many deaths—that is, anticipated in the sense of waiting for death. If I see an average of 10 dying and/or bereaved people in a seven-hour workday, I have quite possibly interacted with over 7,000 people. That's a lot of people—and a lot of death. Interactions with colleagues, and with patients and their social networks, occur as the patient lives through their last months, weeks, days, and hours. My role is to establish relationships and to help clients to explore, express, or contain feelings, to obtain and process information, and to communicate. As a team member I strive to find a balance between being a

unique and freethinking individual and a collaborative team member who is part of a cohesive team that patients and families can rely on and trust. It is important to me to cultivate a loving, calm, and reassuring presence. My sincere desire is to connect—with my own experience, with others' experience, and with the life force that is indescribable and unknowable.

I am also called upon to witness death itself, which can occur very peacefully, as expected, in a beautiful way that connects me to a force, nature, or spirit greater than ourselves—even if it is simply the realization that death is an inevitable part of life, one that people throughout history have been challenged to accept. At other times, death comes under extremely difficult, stressful, ugly circumstances that challenge every person present, and cause me to wonder why life can be so painful and why some people have to struggle so much. Heidegger (1953/1996) says that “we do not experience the dying of others in a genuine sense; we are at best always just ‘there’” (p. 222). In describing what it is like for nurses to witness their patients die, Camargo (2005) reflects upon her experience:

I can share my life, my dreams, my grief and all the things that join me with another person, but at the moment of death the word “share” is left behind. We cannot delegate our death, for this moment just arrives. Where and when it arrives is impossible to know. Unable to share death, human beings share their lives. As a nurse, I just can be with Mr. Ricardo. I can share those last moments with him. I can rub his skin, control his vital signs, but I cannot die with him. I cannot feel what he is feeling now in those last moments. I am just a watcher. Although I am with him, at the same time, he is alone. As a nurse, I can cross death, but my experience is different from his experience. I could feel some kind of the same feeling when someday I die. (pp. 8–9)

None of us, however, can know what we will experience until we are actually dying ourselves.

For counsellors, attending to the dying requires us to respond to what is asked of us in any given moment, and although there is much that we can anticipate there are always aspects for which we cannot plan. Attending to the dying might involve holding a person's hand,

speaking quietly, praying, meditating, or maintaining silence, as a person takes their last breaths. It may mean a silent, solo vigil at the patient's side, or staying with a patient's family and friends, other hospice colleagues, or volunteers. It might mean standing, sitting, or kneeling at the bedside, in the corner of the room, at the foot of the bed, or in the doorway; or it might involve comforting the dying person or their family, providing information or practical help; or it may mean simply being present. Sometimes I enter the space after the death has occurred and, together with family and most often a nurse, attend to the body by cleaning, straightening, washing, or tidying the body and the surroundings. The work also extends into bereavement, creating a space for family and friends to continue to process the many losses triggered by the death.

At times I meet death with compassion and a loving presence, and at other times I feel fractured and disconnected. I can swing between the extremes of this spectrum, from moment to moment. Sometimes I am met in my attempt to connect as others express a need or wish to connect with me, and other times I am not. It is my desire to meet each circumstance with equal ease—both my own disconnection and that of others. At work, as in life, encountering mortality is not something that is done once, and then again; it happens continuously, over a long period of time. I can envision the process of connecting to and disconnecting from the reality of death as a spiral that takes me deeper and deeper into life, while at the same time moving me closer and closer to death. The spiral also moves through the paradoxes that are created as we approach and support death.

What It Means to Provide Holistic Care

Hospice as a movement claims to provide holistic care, or “medical treatment that attempts to deal with the whole person and not merely with his or her physical condition” (OED, 2012). Whole means to “have all its proper contents” (*Merriam-Webster*, 2012), or refers to “the full or total amount of, as distinguished from part of or some of,” in this case the fullness or totality that makes the person who they are. In terms of care this means that we have both a philosophy and a practice of addressing—that is acknowledging, focusing on, and attending to—a person’s physical, social, mental, emotional, social, and spiritual reality. The complete services that the interdisciplinary team offers may be considered adequate to address the whole person, in that each member of the interdisciplinary palliative care team has a particular lens through which we view a patient and their family members. However, as I believe that there are no separate parts of a human being, from my perspective, there is also a call for us to make available, at least to ourselves, all aspects of our humanness in order to meet and care for the whole person/patient.

The Value of Psychosocial Care

Although by definition palliative care addresses psychosocial issues (WHO, 2011), not every palliative care organization employs a psychosocial specialist, such as a counsellor, psychologist, or social worker. The hospice in which I work—and which I will refer to as Meadowview (pseudonym)—has a psychosocial team of about 20 members. Our numbers alone create a constant reminder of the psychosocial aspects of palliative care, and the fact that our leader sits at the management table, providing a strong voice for psychosocial interests, reflects the importance of our role.

There are a number of different areas of work for counsellors at Meadowview. Among them is the PCCT, which operates seven days a week, 24 hours a day. I work on this team. The PCCT is made up of a counsellor-nurse team and is supported by a physician who is available to us 24 hours a day by phone and, if necessary, in person. I interpret this configuration as a statement and acknowledgment by the organization that psychosocial care is inextricable from physical care, and is therefore best provided for by an interdisciplinary team.

Although it has been suggested that we are a death-denying culture, I wonder if our reluctance to encounter all of what death means is a reflection, at least to some extent, of the Cartesian split between body and mind. Papadatou (2009) suggests that palliative care philosophy is an attempt to move away from a mind/body split and the medicalization of dying, toward viewing death as a natural occurrence. This view attempts to find balance with medicine by combining physical care with emotional, spiritual, and social care, and treating the whole person. As expressed by Williams, however, within the word *whole* we find the word *hole* (Williams, 2000, p. 269), which carries a number of connotations, such as “a secret place, a hiding-place ... (or) ... a term of contempt or deprecation ... an unpleasant place ... a cavity ... a position from which it is hard to escape” (OED, 2012), or having the experience or sense that something is missing. It seems to me that there will always be a part of the whole that is hidden, unacknowledged, and unknown. Perhaps I can respond to the implied invitation arising from a subtle meaning of the word *hole*—an “opening” (OED, 2012)—to look into the w/whole and see the possibilities of stepping into the emotional and spiritual aspects of encountering mortality.

The Call of Hospice

Despite conscious thoughts or theories about encounters with mortality, each of us working in palliative care is informed by our cultural experience. Individual biology, family attitudes, and social, religious, and cultural overlays play into our experiences. Encountering mortality in western Canada in the 1950s, where I grew up, was perhaps a different experience than it would have been in other parts of the country, other parts of the world, or today. Vestiges of dated social rules remain and values of that time form the foundation of how we encounter mortality today. Attitudes that had perhaps served people through a challenging political era encouraged them to be “pleasant” and to maintain a “stiff upper lip” in the face of adversity, making the realities of death and bereavement unacceptable to “polite society” by keeping them hidden from view.

For as long as I can remember, I have been fascinated by subjects that others do not want to talk about—religion, sexuality, underlying anxiety and tension, family secrets—as well as existential questions about life and death. The first two encounters with mortality that I remember happened when I was about five years old. One involved my maternal grandfather who lived with our family in a Vancouver suburb in western Canada’s version of 1950s Pleasantville. I was at a friend’s house when her mother told me to go home immediately. Arriving at home on my bicycle moments later, I saw an ambulance parked in the driveway, lights flashing and doors open. My mother had covered her face, and her body was hunched over and heaving. My grandfather was lying on the stretcher and I could see that his face was a strange grey colour. He was not moving. Was he dead? Standing alone on the lawn I wondered, “Did I just see a dead body?” No one told me directly that he had died. There was no mention of a funeral, although I know that one occurred. Several years later, I asked my mother where my

grandfather was buried. She told me that she did not want to talk about it, it was too sad. I told her that I wanted to take some daffodils to his grave. She gasped and began to cry, repeating more adamantly that it was too sad to talk about. Ten years later, sitting at the kitchen table with my parents and 21-year-old sister, I once again asked where my grandfather was buried. My sister burst into tears, and ran out of the room in disgust, spitting at me, “Why do you have to be so ... so morbid?” I still do not know where he is buried.

It seems as though my family culture—and perhaps the greater culture—was not prepared for a child’s questions about death. “Children repeatedly ask questions. When children are not given accurate information, they will create information to complete the story. Unfortunately, such information can be more frightening to children than what really happened” (Worden, 1996). Lacking anyone to clarify my information, I believed that a box in a storage cupboard in the basement contained my grandfather’s skull, stored there by my mother. It never occurred to me to ask my mother about it. Every time I had to walk past the cupboard to go to the piano, which had now been moved into the place where my grandfather’s bed used to be, the place where he had died, I ran past in fear. My parents could not understand why I suddenly did not want to practise the piano. It was only in passing conversation, many years later, that I realized that it could not have been my grandfather’s skull in the box.

My second encounter with mortality involved a woman named Alice who took me to kindergarten. I heard that she had breast cancer and I remember the whispers about her breast being removed. For some reason I thought it had been replaced with a wooden prosthesis. I can still picture the imagined wooden carving—a perfect cone, banging against her scarred chest, filling the empty side of her bra. I speculated as to which one it was, looking for clues, rubbing up against her to see if I could feel the hard edge. Once again, it was only later that I realized

that she had never had a wooden breast. The secrecy created a sense of shame. I felt ashamed for wanting to know. This sense was reinforced a few years later when I ran up the street to witness a child who had been hit by a car being placed in an ambulance. I remember the rush of emotion—both fear and excitement—and the embarrassment of wanting to look. I was shooed away. I was beginning to understand that serious illness, injury, and death were not talked about, and that people who wanted to talk about it were not okay. By the time some friends decided that it might be cool to dig up a pet turtle that we had buried, I was unable to look, afraid of what I might see, and I thought that they were being mean to even think of it. And so I arrived at estrangement from death, a stranger to death, or maybe just strange. It was clear that it was not socially acceptable to wonder about death or to ask questions, and that my curiosity was painful to others, and that this and all other topics that had an emotional charge were dangerous. It was easy as a child to then assume, from the responses so far, that people around me would crack if emotion was present. So rather than be responsible for them coming undone, I cut off my own feelings and my sense of what it was to live life as a whole being.

My next encounter with death and serious illness was at age 14 when my paternal grandfather died. Shortly before he died, and after several years of awkward visits to a seniors' home, which smelled strongly of urine and exposed me to an array of limp, white-haired people staring into space, I found out that my grandfather had contracted gangrene and had to have his leg amputated. I overheard conversations between my parents and refused to visit, fearing what a man without a leg might look like. By then I had developed a fear of sickness, hospitals, hospital equipment, doctors, and any disability, including—in fact, especially—anything associated with old age. It wasn't until I was 31 years old, however, that I really sank into despair. My father died within six months of receiving a terminal cancer diagnosis, my aunt died

from a heart attack on a visit intended to console my grieving mother, and my brother died suddenly from a rare form of leukemia. All this occurred within a five-month period, during which time my second child was born. Encountering mortality became unbearable. I was completely unable to process the overwhelming array of feelings and there was no one to guide me through.

Addressing one's relationship with death ... can feel fraught with uneasiness. People who dwell on their mortality are suspect. Culturally to do so is often experienced as crossing a boundary, breaking a taboo. And there are consequences: one runs the risk of being viewed as "other," labelled gloomy—a downer—or, in our own circles, imagined to be clinically depressed. The subject of mortality raises powerful anxiety, and our minds employ all manners of defence in an effort to shield us from a full awareness of our transience and its implications. (Frommer, 2005, p. 481)

I felt shame at being unable to "get over it," and I had a sense of stigma and self-consciousness, an irrational fear that maybe there was something inherently wrong with my family, as a group of people, for having so many awful things happen to us in such a short time. Frommer (2005) helps me to understand my fear of becoming known as a member of what I called the "bummer" family.

Over the following 10 years I was able to come to understand and assimilate the multiple deaths I had experienced through the development of a supportive network of friends and improved relationships with my sisters. Sensing what seemed like a lack of wholeness and having a desire to heal, I became a seeker by engaging in long-term in-depth psychotherapy, meditation, prayer, and reflection. Like Isis collecting the body of Osiris, I tried to collect and put back together my disjointed, disconnected pieces in the hope that I would feel whole.

Nothing, however, prepared me for the death of my three-month-old son, Dante, from Sudden Infant Death Syndrome eight years later. It was by far the most difficult death that I

have ever had to go through; it was the event that had the most impact on my life. Surprisingly, and perhaps paradoxically, the time that I felt the most alone and vulnerable was when I also felt the most connected and supported. The profound grief that I experienced was met by the equally profound loving presence of a wide network of friends, family, acquaintances, and in some cases even strangers. Through their actions they showed me that it is possible to make a space for, to be present for, the intense, irreversible, emotional, physical, intellectual, spiritual, and social effects of encountering mortality.

Two aspects of this experience are particularly relevant to this discussion. The first was that the care offered by the people around me—the quality of their presence—allowed me a protected space in which to process the extreme, incapacitating grief that I felt. Arrien (1993) teaches that “showing up” or “choosing to be present and visible” is recognized in many indigenous societies; it means to be able to bring our minds, emotions, spirits, and physical beings to a situation. “When we choose to ‘show up’ energetically, with all four intelligences, we express the power of presence” (p. 23). I learned from my own experience when Dante died that when people “show up” it really does matter. Being on the receiving end of that presence clearly shaped me.

The second important aspect was an experience that I have rarely heard others talk about. Frommer (2005), in explaining that the “liminal recognition of mortality” (p. 487) can be met with ambivalence, described his clients’ experiences as they remembered the events of September 2001.

It was a seemingly paradoxical experience that in the midst of intense anguish and grief, they felt an opening in themselves to an uncommon experience of connection with humanity. Some have since bemoaned the gradual fading of this capacity, coupled with a

return to a more familiar self-state organized around denial of the human condition.
(p. 487)

I can relate. Shortly after Dante's death, I had an extraordinary experience that words cannot adequately describe. For a period of time I became acutely aware of being alive. Every sensation was bright, clear—almost magnified. Everything was peaceful and very beautiful. Being so close to death, so aware of the fragility of life, I saw how thin the veil is between life and death, and in the process I experienced what can only be described as ecstasy. Looking back, I believe that I had this experience because I felt connected—to myself, to my own internal moment-to-moment experience, to my friends who offered a compassionate presence, and to the great cosmos that contains the mystery of life and death. Experiences such as this were identified by Otto (1923) as numinous, and were often referred to by Jung (1965). I saw clearly that life is intrinsically connected to death—they are inseparable. Most importantly, I realized that facing death can be an opportunity to open up to life.

Rogers (1957), in writing about the therapeutic or healing experience in therapy, said that when a client has the direct experience of the therapist's acceptance, for whatever feeling is being expressed at the time, in whatever mode it is being expressed—through words, gestures, or tears—the client will feel wholly accepted or “received” (p. 143). Having felt received by the people who surrounded me, I wanted to provide this same experience to other bereaved people. Like an elder who has acquired wisdom and experience, I saw myself as having an important role in helping people to find their own ways through grief, by providing a safe space for them to express their powerful emotions and to explore what for some can seem like a dark and frightening place. For many years I opened my bereavement groups, and my training workshops with a gender-neutral version of Judith Duerk's *Circle of Stones* (1993):

How might your life have been different if, as a young ... [person], there had been a place for you, a place where you could go to be among ... [elders]... a place for you when you had feelings of darkness? And, if there had been an ... [elder], to be with you in your darkness, to be with you until you spoke ... spoke out your pain and anger and sorrow. ...

So that over the years, companioned by the ... [elders] you learned to no longer fear your darkness, but to trust it ... to trust it as the place where you could meet your own deepest nature and give it voice. How might your life be different if you could trust your darkness ... could trust your own darkness? (p. 39)

Through my social network, with the help of those wise, kind, brave people who were able to show up, I found a home, a place where “I could trust my own darkness” (p. 30). By going into that darkness and reclaiming all of me, or my “whole” self, I wondered if wholeness, in the sense of being “restored or healed ... to not be wounded, injured or impaired” (OED, 2012), needed to be expressed or manifested in order to be fully integrated into my being. Not only did I want to savour and repeat the sense of having gathered the parts, I wanted to understand how it had happened and to participate as a healing force in other people’s lives, in an ongoing way. I wondered if service might become both the path and the destination. This quest to find that which is whole/holy/sacred led me to transpersonal psychology, and eventually to hospice. It was a search for an understanding of what it means to be wholly present in my own experience, not just for my own sense of being integrated, but to understand and connect with others and their experiences. It was also a quest to discover what it means to be human. Hospice held the promise that the profound effect of encountering mortality would be recognized, and my desire to be wholly present might be respected, valued, and held sacred.

Hospice Is a Call to Wholeness

It is probably not surprising that my quest for meaning and an authentic life would lead me to palliative care. However, paradox abounds in encounters with mortality. Why would I

think that I would find meaning in my life and live authentically by coming into contact with mortality? The word *palliative* derives from the Latin word *palliatum* and means to “alleviate without curing” (OED, 2012), but it is also associated with the Latin word *palliare*, “to cover with a cloak,” and with *pallitum*, “to conceal” (2011). In palliative medicine this means that symptoms are masked by medication, but the cause of the disease is not significantly affected. Therefore, the expected course of the disease will continue, but the patient will not experience physical symptoms. The term *palliative care* can be distinguished from *palliative medicine* by the values, attitudes, and beliefs that allow for attending to emotional, spiritual, and social needs (WHO, 2011). Similarly, as a palliative care counsellor, I cannot and do not hope to cure a person of their suffering. Rather, I accept suffering by holding people with/in their suffering, helping them to be able to better bear their pain through a compassionate presence and by making space for emotions and spiritual experiences to be *uncovered*, if that is what is required.

The sense of having been drawn to palliative care through the experience of loss is not unique to me. “Many of those who help others do so because they genuinely care. They have deep compassion for the suffering of the dying and want to contribute in easing their pain” (Rokach, 2005, p. 327) and many “see their work as a calling” (Jones, 2005, p. 325). Joseph (2010), a Victoria Hospice counsellor for 20 years, ends a touching exploration of her experience in palliative care with words that speak of that same sense of calling.

For a long time, it was not just work; it was a calling. Not a religious call, although one can't do the work without a deep sense of the mystery that surrounds the dying; rather, it was the thing I did that made me feel most alive. Like writing poetry. Hopkins referred to the state of being aware, responsive, and open as the taste of the self. A state, paradoxically, in which we are fully present at the same time we disappear. To work with the dying was to enter the darkness without a map of the way home. It was to merge, briefly, with something greater than ourselves; to accompany them as far as possible and to stand alone under the stars they disappeared into. (p. 12)

There is a remarkable paradox that a palliative care counsellor experiences working with the dying as something that would be “the thing that I did that made me feel most alive” (p. 12). Hers was not an experience of standing on the edge looking in, but rather her own powerful experience of the wonder about what it means to live and die.

Having worked at Meadowview for 15 years, I notice that some people seem to thrive in the environment while others do not. Not all people who are called to palliative care leave feeling healed or whole and I have heard disenfranchised workers say that they have experienced “death saturation,” or as one person described it, “aversion to death,” resulting in her doctor’s diagnosis of “death overload.” The research on which I now embark is one avenue for exploring possible responses to encounters with mortality. Mapping the territory may make the journey less stressful for those who work in palliative care, and might provide some insight into understanding the responses of patients and families who also experience overwhelming feelings in the face of D/death.

Chapter 2: Literature Review—Understanding the Lifeworld

In Chapter 1 I laid the groundwork for an exploration of the lived experience of encountering mortality in the palliative care context. I defined the terms that I use within this document, such as the words *death*, *dying*, and *mortality*. In order to be transparent about my pre-understanding of the question, I discussed my own call to service and laid out my initial assumptions and questions about encountering mortality and, in particular, how it might shape people who work in palliative care.

In Chapter 2 I identify what is present in and what is missing from the literature and define the boundaries of my review, followed by an explanation of why it is important to study the lived experience of encountering mortality. While little has been published about the lived experience of encountering mortality in a palliative care setting, there is a discourse that identifies the proximity to mortality as being either detrimental to the caregiver—requiring someone, something, or some system to be fixed—or beneficial to the caregiver, requiring someone, something, or some system to be emulated. I give an example of how the self-care literature has responded to the perceived stress of working in palliative care and discuss some limitations of these responses. I then introduce a complexivist lens that is actually in alignment with the prevailing discourse in patient and family palliative care which says that as caregivers, we need to be artful in interweaving what is common to all dying and bereaved people with what is unique about each particular person and their situation (Cairns et al., 2003; Downing & Wainwright, 2006; Kuhl, 2002; Papadatou, 2006, 2009). My hope is that the same spaciousness that allows for uniqueness in patients and families will be extended to caregivers. If this is to happen, it is important to describe the experience of encountering mortality and to explore the meaning of the experience from the counsellor's perspective. In this way the counsellors

themselves, and all others interested in understanding their experience, may be better informed about what it is like for a particular group of counsellors to encounter mortality.

The Literature

There is no existing research that focuses specifically on the lived experience of counsellors in palliative care, although there is one important book that opens the door for discussion about the palliative caregiver's experience. Papadatou (2009), a clinical psychologist, focused on issues relating to paediatric palliative caregivers' responses to death in a comprehensive and relevant book titled *In the Face of Death: Professionals Who Care for the Dying and the Bereaved*. She provided a model of clinicians' grief in caring for the dying that was based on her grounded theory research with nurses and doctors in paediatric oncology and critical care settings in Greece and Hong Kong (2001). In this book she thoroughly described the elements of the caring relationship as it pertains to end-of-life care, identifying the distinct features of encountering mortality and the implications for bereavement for professionals. She advocates teamwork, collaboration, and education in relational and reflective practice. Although her experience was based on her work in non-palliative care settings—settings that seem less receptive than the palliative care setting to the idea that professionals have a legitimate grief response that can be expected—her work goes a long way in describing and helping us to understand the experience of professionals who encounter mortality. While her studies were limited to nurses and doctors, her training and practice as a psychologist provide a psychosocial perspective that is ground-breaking in its depth of understanding of professional responses to encountering mortality.

Another book, *When Professionals Weep: Emotional and Countertransference Responses in End-of-Life Care* (Katz & Johnson, 2006), is also relevant. Katz, a clinical psychologist, and Johnson, a mental health counsellor collected a series of essays, written by psychosocial specialists, that focused on transferences (any emotion felt by the patient towards the counsellor), and counter-transferences, (any emotion felt by the counsellor towards the patient). They emphasized the wholly natural and human emotional response of professionals to encounters with mortality. They explained that counter-transference dynamics are an expected part of all helping relationships and “affect every interaction, every theoretical discussion, every diagnostic workup, and every treatment plan” (p. 4). They contended that when these dynamics become conscious they become an important tool in helping professionals become more effective, especially when addressing the powerful feelings that occur when encountering mortality. Many of the essays described the pitfalls of encountering mortality as a professional, with advice for alternate responses, but not, specifically exploring the lived experience of palliative caregivers. However, awareness of counter-transference is a beginning step in acknowledging that as professionals, we do have internal responses to encountering mortality and there is value in exploring these responses.

I was unable to discover anything about encounters with mortality from the perspective of nurses or counsellors who work on a counsellor-nurse palliative care crisis team. This may be due to the scarcity, at least in Canada, of community palliative care crisis teams. I was also unable to find anything written by psychosocial experts that focused on the lived experience of working in a palliative care setting or on encounters with mortality. Steigman (2007) used grounded theory in her doctoral dissertation to produce a model of death awareness from a transpersonal perspective. The model of death awareness was based on interviews with

professionals who were both recognized scholars and also transpersonal psychologists, spiritual teachers, or professionals who worked in palliative care. Steigman's research revealed that these practitioners came to understand the inevitability of death through encountering mortality, leading to a "nondual mode of awareness that is characterized by increased engagement of the present moment and deeper embodiment of the evolving Transpersonal Identity which ... is utilized and practiced in everyday life, ... improving its quality" (p. iv). Although not all people in her study worked in palliative care, all the participants had regular contact with the dying. Her work adds to our understanding of how some professionals describe their own transformation as they encounter mortality and reflects Steigman's own transpersonal perspective.

Studies on lived experience abound, but they reveal life experiences other than encountering mortality (Cameron, 2004; Dobson, 2002; Eddy, 2008), non-professional responses to encountering mortality (Bruce & Davies, 2005; Leavy, 2009; Ryan, 2003), or professional responses to mortality in non-palliative care settings (Carmargo, 2005; Corker, 2010; Gerow, Conejo, Alonzo, Davis Rodgers & Domain, 2010; Hopkinson, Hallett & Luker, 2003; Ronayne, 2009; Wu, 2008). Other materials stress the meaning and power of relationships between hospice caregivers, and patients and families (diTuillio & McDonald, 1999; Jones, 2005; Kearney & Weininger, 2011; Kuhl, 2002) but none specifically explore the impact or experience of encountering mortality on professional caregivers, and none explore the lived experience of encountering mortality from the perspective of a counsellor in a palliative care, or in any other setting.

Myriad aspects could be studied when exploring encounters with mortality. Before continuing I will identify and justify what I will not be covering. I am not exploring the influences of ethnic, social, spiritual, or religious attitudes and values on a palliative caregiver's

experience of encountering mortality, although those themes may arise or become important in the co-researchers' discussion of their own experiences. Nor am I claiming that the co-researchers and I are unaffected by the diversity within our community and our world. In a phenomenological study such as mine, the participants are not meant to be representative or typical of any group, whether cultural, professional, or religious. Although diversity and its impact on how encounters with mortality might possibly be experienced could be relevant, I contain my study to palliative care counsellors at Meadowview because I have access to and relationships with the counsellors in that location. I have also opted not to delve into the literature on bereavement. I suspect from others' writing (see, for example, Kearney, 2009; Papadatou, 2009; Vachon, 2011) that in settings other than Meadowview, or perhaps settings outside palliative care units (Pereira, Fonseca, & Carvalho, 2011; Wilson, 2009), the literature on disenfranchised grief might be relevant. I have also opted to refrain from exploring the experience of family caregivers, or of the dying themselves, even though there is a strong likelihood that there are common experiences between all those who encounter mortality, from any perspective, in any setting.

Thus, in this study the focus will remain on the experience of counsellors who work on the Palliative Care Crisis Team at Meadowview Hospice because this kind of exploration is currently lacking in existing palliative care literature. I begin with a brief review of the self-care literature followed by a discussion of the limits of the present discourse of palliative care work. I then outline my framework as a researcher and provide a discussion of the complexivist lens through which I view encounters with mortality in the palliative care context.

The Self-Care Discourse

The modern hospice movement is generally thought to have begun in 1967, when Cicely Saunders founded St Christopher's Hospice in Britain; the first hospices in the United States and Canada were founded in 1974 (WHO, 2012). In Vachon's (2011) most recent review of the literature on burnout and occupational stress in oncology, hospice, and palliative care, she reported a small body of literature that aimed to support the care of the dying and their caregivers from the 1960s to the 1990s. In the 1960s and into the first decade of the 21st century, the literature began to focus on burnout and distress and, to a lesser degree, on moral distress. The three components of burnout related to emotional exhaustion, cynicism, or detachment, and a sense of being ineffective. The work on burnout led to the pathologizing of professional responses to death and dying, and identification of compassion fatigue and vicarious or secondary trauma, which is considered to be a form of post-traumatic stress disorder that arises from witnessing the trauma of another. According to Vachon, until recently palliative caregivers consistently showed less stress than those working in other areas of health care. Although Vachon was clear that stress exists in palliative care, according to her research and her review of the literature, encountering mortality itself has not been found to be as great a stressor as lack of funding, organizational attitudes, and issues arising from team conflict and lack of support.

Another comprehensive review, by Pereira, Fonseca, and Carvalho (2011), showed that stress was related to chronic tension arising from bearing witness to human suffering without the caregiver's being able to share the feelings of tension with colleagues or having opportunities to learn how to cope with their own emotions in a healthy way. It is important to note, however, that none of the studies were conducted in dedicated palliative care contexts but on oncology wards, and the reports they studied were based solely on the experience of nurses and physicians.

It was not clear whether this was because there were no volunteers, spiritual carers, social workers, or other members of an interdisciplinary team available. However, I mention this study because it is consistent with Vachon's findings that outside of palliative care settings, without the palliative care culture, proximity to mortality does seem to contribute excessively to stress, at least among nurses and physicians.

My review (Breiddal, 2011) revealed that the palliative care context is usually described as a difficult work environment for a number of reasons, ranging from the personality and motivation of the individual caregivers (Jones, 2005; Kearney et al., 2009), through team dynamics (Kearney et al., 2009; Papadatou, 2009), and organizational deficits (DiTuillio & MacDonald, 1999), all the way to society's avoidance of the reality of death (Papadatou, 2009). In response, practitioners have developed strategies that have suggested a need for action to "improve health, maintain optimal functioning, and increase general well-being" (Acton, 2002, p. 73). These actions range from simple activities that an individual caregiver can take (Kearney et al., 2009), to strategies that address the organization or health care system itself (Kiedal, 2002), or to societal changes, such as educating the public on how to have a "good" death (Agrawal & Emanuel, 2002). More recently, the focus in the literature has begun to shift toward the positive results of working in a palliative care setting, resiliency and the satisfaction that comes from working in palliative care (Ablett & Jones, 2007; Weininger & Kearney, 2011).

In *Caregiver Stress and Staff Support in Illness, Dying, and Bereavement* (Renzenbrink, 2011), professional caregivers from around the world wrote about self-care in palliative care, collectively emphasizing the reality of the stresses of working in a palliative care setting. Although the offerings were not directly addressing the lived experience of encountering mortality, but rather the general stresses of working in palliative care settings, some authors

presented snippets of everyday life encounters with mortality (Bowman, 2011; Breiddal, 2011; Maasdorp, 2011; Weinger & Kearney, 2011). The general theme of the book is that compassion, connection, and collaboration are antidotes to some of the stresses experienced when working in a palliative care setting (Bertman, 2011). In an article that examined the self-care discourse in the book, it was found that the authors viewed self-care in palliative care as necessarily embedded in the culture: staff members from all levels of the organization individually and collectively acknowledge, value, support, and practise self-reflection, self-knowledge, and self-awareness (Breiddal, 2012b). While the book identified the value of understanding lived experience, there was still a focus on interpreting on behalf of palliative care workers, rather than allowing them to describe their own realities and make meaning for themselves.

Why Study the Lived Experience?

We know that encountering mortality is a distinctive factor in working in palliative care (Papadatou, 2009), and we know that encounters with mortality can be both stressful (Papadatou, 2009; Renzenbrink, 2011; Rokach, 2005; Vachon, 2011) and enriching (Ablett & Jones, 2007; Alkema et al., 2008; Papadatou, 2009; Rokach, 2005). While these terms—*distinctive*, *stressful*, *enriching*—identify the common understanding of palliative care, without exploration they do not help us to understand the actual experience of what it is like for a palliative caregiver to encounter mortality. The summations carry assumed understandings, evaluations, and interpretations that make it all too easy to use them to support or defend a particular stance—which carries the risk of a drift toward formulaic approaches, with the potential to dehumanize the actual experience. Unless we fully understand the meaning of the experience for the person who is having the experience, we cannot hope to guide, direct or even support them because their experience is complex and unique.

For caregivers, providing palliative care is an artful balance between what we can know—from theory, skill development, and experience—and what we will never know—how this particular patient or family member will respond in this particular setting, at this particular time, to these particular people and to death. To imagine differently is a dangerous practice because it gives us false confidence, implying that we can anticipate and know what we or another person will feel or do. For example, in health care, our models, protocols, and best practices imply that we can imagine and have imagined the possibilities of what might occur, and that the model or protocol is providing not only appropriate responses, but the best responses which will then become standard. The individual caregiver or team can follow these steps and be confident that they are doing it or getting it right. But we know that in facing death, real life does not work like that.

We can know what some of the hazards of encountering mortality might be through our theoretical knowledge of providing palliative care, and we can know how we have responded to mortality in the past, but we can never know what a particular encounter with mortality will stir in us. We cannot prevent our own suffering by prescribing either a prophylactic that diverts or transforms unpleasant feelings or a salve to treat feelings after the fact any more than we can prevent suffering in our patients. There are far too many shifting variables within our own beings and the world in which we interact to be able to accurately anticipate our own actions, thoughts, and feelings.

To illustrate what is lacking in providing strategies, I refer to an article on responding to the stressors in palliative care, “Burnout and Compassion Fatigue Among Hospice Caregivers,” in which the author (Keidel, 2002) reviewed the literature on causes for distress, provided a list of 13 strategies on how to address stressful situations, and gave advice to caregivers. She

instructed them to “see things from the family’s perspective rather than feeling their emotions; feed your spiritual side, whatever that means to you; and keep interested in and challenged by your patients’ spiritual, emotional, and physical problems” (p. 204). While I agree that there are typical stressors and some common strategies that might be helpful, without dwelling with/in the experience of a particular caregiver, there is a risk that frustration and even a sense of blame will arise should change not occur. Dwelling in the experience means exploring what an experience entails—physically, mentally, socially, and spiritually—for the person having the experience. It could be that a caregiver is failing to “see things from the family’s perspective.” This so-called failure could be one of a myriad of reasons why an experience might be stressful. However, it would be difficult to know for sure without asking the caregiver who is having the experience, and even then it might take some exploring in a safe environment for that person to more fully understand their own experience. Giving advice to “see things from the family’s perspective” seems simplistic, and perhaps arrogant in the assumption that we not only can know what the experience is like but can know what to do about it. This evaluative perspective can lead to the caregiver attempting to follow the advice to “see things from the family’s perspective,” as if having not done that was the “problem” and this is the “solution.” Yet we know that the next encounter will not have exactly the same elements that made up the previous situation. I also object to the evaluation of the response, the implication that feeling “stressed” is the wrong response, and that had the caregiver set out to “see things from the family’s perspective,” then they would have had a more acceptable response and no stress. Yet, mindfulness practice tells us that “feeling stressed” might provide some useful information to a caregiver, were they aware of that feeling in the moment (Kabat-Zinn, 1990; Katz & Johnson, 2006).

My work as a counsellor supports the notion that if it were that easy to prescribe antidotes for troublesome feelings, our work would be unnecessary. We could simply eradicate pain and suffering. Such simplistic solutions dehumanize our professional role. If we could just will ourselves to “keep interested,” or to “see things from the family’s perspective” we would not have conflicts, burnout, or stress, and we could change lifelong patterns of behaviour by simply imposing our will, or worse, the expert’s will. While identifying possible responses can be useful, representing them as inevitable, the only possible response, or the most desirable response is reductionist, and minimizes, if not denies, the endless variations of human experience.

One of the first rules learned when becoming a counsellor is to never give advice or presume that you know what is best for another person. Perhaps, then, my counselling background provides an orientation that allows me to dwell, to “remain for a time” (*Merriam-Webster*, 2012), “to linger over ... to let things remain as they are, or to let them be” (OED, 2012), rather than to jump into adopting strategies—a word that implies militaristic schemes to win battles. Phenomenological studies provide a forum in which the researcher can get beneath and behind quick descriptions, assumptions, and solutions to reveal some of the actual lived experience. For instance, in the example from Keidal (2002), what *does* the caregiver think is their “spiritual side”? What is it like to be in need of spiritual food? Are there other options for whatever that feeling is that being in need of spiritual food evokes?

What does it mean to the individual caregiver to “keep interested”? Why is keeping interested a challenge or an effort? As van Marie (2007) said, “The essence of reading and interpretation must be to create an opening, not to find a resolution” (p. 25). The opening appears through dwelling in the experience itself, by looking again and again at what encounters

with mortality—physically, emotionally, socially, and spiritually—entail for the people who experience them. For this reason it makes sense to choose a research philosophy and method that support exploration without seeking resolution, a philosophy that supports dwelling in the unknown, and in so doing, as John Caputo (1987) urged, restores life to its original difficulty.

To illustrate a complexivist approach, I turn to another example from the palliative self-care literature. Sally Jones (2005) presented a plan that encourages caregivers to reflect upon their work life and to identify areas that they experience as stressful. They then make a concrete plan with the support of their supervisor that will help them to ameliorate their stressed responses, regularly reviewing this plan to evaluate and revise it. This is a valuable tool and one that I have recommended (Breiddal, 2011a, 2011c). It does, however, require both supervisor and staff member to be willing to dwell with/in the staff member's experience, to pause or linger, to recognize the unending variations of human experience, and to explore with an open mind and an open heart, letting go of preconceptions and detaching from any investment in a particular outcome. This is a skill related to mindfulness and the practice of being present, a cultivated skill that has been extensively documented in the literature (Bruce & Davies, 2005; Hessel, 2009; Kabat-Zinn, 1990, 1995, 2005; Kearney & Weininger, 2011b; Papadatou, 2009; Wilbur, 1979/1985; Zyblook, 2010). In *Finite and Infinite Games*, Carse (1986) said that in the game of life, learning requires the players to be prepared to be surprised by the future, which requires complete openness.

It is not an openness as in *candor* [emphasis in the original] but an openness as in *vulnerability* [emphasis in the original]. It is not a matter of exposing one's unchanging identity, the true self that has always been, but a way of exposing one's ceaseless growth, the dynamic self that has yet to be. (pp. 18-19)

This ceaseless growth occurs from anticipating surprise and being willing to be transformed. Carse saw the kind of *training* that is so common in the palliative care discourse as a way of defending against the unexpected, contrasting it with *education* which prepares us to be surprised.

Education discovers an increasing richness in the past, because it sees what is unfinished there. Training regards the past as finished and the future as to be finished. Education leads toward a continuing self-discovery; training leads toward a final self-definition. Training repeats a completed past in the future. Education continues an unfinished past into the future. (p. 19)

If there is a willingness to be open in the sense of being vulnerable, and an awareness of moment-to-moment experience, combined with an understanding of an unfinished past and an evolving future then a program such as Jones (2005) suggested might be helpful. Even so, complexity theory tells us that there is more to understand than the complexity of each individual's unique and changing living system.

Each person is attached to other individual living systems that are similarly changing, and those individuals are embedded in other changing systems. Without taking into consideration the complexity and spontaneous, evolving elements of any situation, any plan that we make provides false assurance that we will know what to do in any given situation. Our theories and models of palliative care, together with our values, are the foundation of hospice work, but there will always be a space between what we can know theoretically and the moment-to-moment experience of encountering mortality. From my perspective, the gap between what we can know and what there is to know is not a flaw in our knowledge but rather is an essential part of the complex nature of what it means to be human.

The Research Perspective

From a social constructivist standpoint, words and the understanding of words are reliant on a shared context. “Social objects appear only as perceived objects, depending on human recognition for their existence and because of this, social reality is in constant flux and ambiguity” (Online Dictionary of Social Sciences, 2002). Words, maps, and models, for instance, obviously represent only an approximation of a described experience. As Crotty (1998) said, constructionism is “the view that *all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context*” [emphasis in the original] (p. 42). Of course, this means that understanding human experience is complicated because we cannot assume shared understanding.

In exploring the lived experience of encountering mortality then, understanding must necessarily evolve through the trust that is present in my relationships with my colleagues, through the shared context of our work in the palliative care context, and our social culture in which that setting is embedded. Understanding will develop gradually through ongoing communication that can only approximate the experience of encountering mortality. Because communication is so heavily dependent on context and assumptions are so difficult to identify, understanding will not be immediately recognizable.

My perspective as a counsellor is also complexivist. According to Wilson (2009), complexity theory emerged in the 1980s, building on scientific theory that moves away from the Newtonian metaphor of life as a machine and toward the view of life as a “living system, with a non-linear characteristic and the ability to adapt” (Wilson, 2009, p. 18). Doll and Trueit (2010)

provided an excellent summary of the evolution of science from a natural philosophy standpoint to chaos and complexity. They said that the idea of representing lived experience by using models is too restrictive and that it is more useful to use metaphors because they allow for more possibilities without implying that the correct way has been found once and for all. They said that complexity thinking reflects the “throbbingness’ of life, the dynamic interplay of events, and the messiness of personal experience” (p. 842) and opens our thinking from models that give us the one true, best, or right way to a readiness to imagine various ways that respond to the distinctive aspects of each new situation or event.

[C]omplexity seeing/thinking asks us to see, to deal with a world in continual flux: but a world that does have patterns to it, patterns that bind and structure through their interplay. In short, complexity seeing/thinking asks us to envision our world and events within that world in terms, not of “things” but of process. In so doing, we are moving from a science that studies particles to the new sciences of chaos and complexity that study the interactive relations between and among particles, events, happenings. (p. 841)

From this perspective, one would see that the health care system with its rules and regulations is caught in a “modernist trap” (p. 841), which challenges health care professionals to think about how chaos and complexity affect our practice and our way of being.

From a complexivist perspective there is naturally an endless creativity to our being-in-the-world. To imagine that we can pin down the experience of encountering mortality, and fully understand it, and then meet it with formulaic responses is to be in an endless game of catch-up. If we are not caught up in looking forward, preparing a script for an imaginary dialogue, we get caught in looking backward, trying to articulate and add one more possibility to the list of ways to encounter mortality, and therefore needing one more unoriginal response to add to the list (Snowden, 2003).

Plsek and Greenhalgh (2001) identified the health care system as “a complex adaptive system” defined as a “collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent’s actions changes the context for other agents” (p. 625). The recognition of the qualities of change and unpredictability necessarily requires a different response than if a system were viewed as static. By recognizing and accepting that lived life is dynamic, it is more likely that we will be prepared to be surprised (Carse, 1985).

According to Doll and Trueit (2010), “a distinctive characteristic of chaos theory is that order and disorder are intertwined, not separated categorically ... and each are embedded in the other” (p. 843). Reflecting on the role of palliative caregivers, and in particular palliative care counsellors, the palliative care discourse is that our role is not to “fix” the suffering that is related to mortality (that is, order or in this case what we know about suffering) but rather to hold it, be in it, and engage with it, human to human (that is, disorder or what we cannot know about suffering). Perhaps support for caregivers might be most useful if it were focused on supporting the caregiver in their efforts to weave the unknown with the known, rather than attempting to fix their problems by providing scripts and protocols. Morris (as cited in Wilson, 2009) pointed out that, when we first enter the palliative care field having attained our various qualifications, we hopefully begin as being competent, which Fraser and Greenhalgh (2001) defined as “what individuals know or are able to do in terms of knowledge, skill and attitude” (p. 799). Through practice, however, we hope to become capable, which they defined as “the extent to which individuals can adapt to change, generate new knowledge, and continue to improve their performance” (p. 780). Perhaps by dwelling in the experience of encountering mortality we can experience the essence of our own discomfort—in order to understand it rather than to fix it—

and by strengthening our capacity to dwell—making a conscious effort to notice and articulate how we make meaning—we become more skilled at responding to an evolving situation.

Building on what we can and do know about working in the palliative care setting I have identified a doorway, an opening that might provide an opportunity to dwell in the experience of encountering mortality from a social constructivist perspective where the goal is to come to a shared understanding of what the experience of encountering mortality might be, from the perspective of a small group of palliative care counsellors. The very process of being open to multiple meanings that are continually evolving can connect us with those who work in a palliative care setting and have daily encounters with mortality, inviting us all to ponder our own encounters with mortality and to attempt to articulate our own meanings. Similarly, a complexivist lens encourages flexibility of thought, moving away from a static or rigid model towards a metaphoric view that allows for subtle and multidimensional ways of making meaning, as Doll and Trueit (2010) suggested.

Palliative Care Education

A number of pedagogical issues stand out for me, all connected to the sense that encountering mortality might have the potential to uncover our wholeness. I see the importance of interdisciplinary education for preparing students to be part of an interdisciplinary team. In a recent paper (Breiddal, 2012a) I explored the need for educational institutions to recognize their responsibility in providing palliative caregivers with opportunities to learn and practise the necessary skills to work as a synergistic team. I also suggested that a model of education such as the Emancipatory Model of Education be used, as its ontological orientation is directed toward interdependence and collectivity, framing knowledge as fluid, relational, contextual, and based

on multiple ways of knowing (Swartz, 2009). I referred to a number of programs that fit within the Emancipatory Model of Education in established programs and that have managed to overcome challenges that include identifying the need for interdisciplinary education and developing skills for team-teaching, and using innovative teaching strategies (Bratjman, Hall, & Barnes, 2009; Cadell et al., 2007; Hall & Weaver, 2001) and the system issues such as timing of interdisciplinary courses in the educational curriculum, modes of teaching, and content (Hall & Weaver, 2001). In a literature review on interdisciplinary education, Hall and Weaver's (2001) findings are consistent with more recent literature (Cadell et al., 2007; Fraser & Greenhalgh, 2001; Perrault, 2010) that reports that problem-based learning that allows for small groups working together and applying theory to real-life examples in a collaborative effort to solve community-based problems that focus on an idea, is better than focusing on an individual's realm of expertise.

Wilson (2009) made a distinction between training caregivers to be competent and training them to be merely capable. Fraser and Greenhalgh (2001) defined *competent* as "what individuals know or are able to do in terms of knowledge, skill and attitude," and defined *capable* as "the extent to which individuals can adapt to change, generate new knowledge, and continue to improve their performance" (p. 780). From a complexity perspective, learning takes place in the "zone of complexity" (Plsek & Greenhalgh, 2001), where relationships between items of knowledge cannot be predicted and are not sequential, but neither are they outright chaotic:

Learning that builds capability takes place when individuals engage with an uncertain and unfamiliar context in a meaningful way ... capability cannot be taught or passively assimilated: it is reached through a transformation process in which existing competencies are adapted and tuned to new circumstances. Capability enables one to work effectively in unfamiliar contexts. (Fraser & Greenhalgh, 2001, p. 800)

Fraser and Greenhalgh (2001, p. 800) suggested a number of concepts from complexity theory that might assist educators when it comes to education and training that have capability as their goal. They suggested that students be provided with relational and non-linear learning as well as process techniques to meet and adapt to the complexity of the health care system. They said that these creative approaches can help students to become adept at applying complex skills and integrating numerous factors by appraising situations, prioritizing issues, and then integrating and making sense of all the variables in order to arrive at a solution. “Problem solving in a complex environment therefore involves cognitive processes similar to creative behaviour” (2001, p. 801). Complexity theory has helped me to see the value of learning opportunities that help students to move from being competent to being capable.

Kenneth Gergen, in *Relational Being: Beyond Self and Community* (2009), also contributed to the complexivist perspective of education by moving away from the view that the student and the teacher are bounded individuals who make disconnected and individual efforts to offer or receive knowledge. He advocated for “educational practices that reflect, sustain, and advance productive forms of relational being” (p. 241). He linked “excellence in education with excellence in relationship” (p. 241), and said that “*the primary aim of education is to enhance the potentials for participating in relational process—from the local to the global*” (emphasis in the original, p. 243). He then continued,

When education focuses on relationships as opposed to individuals, we enter a new world of possibility. Our concern shifts from what is taking place “within minds,” to our life together. And within this space of collaborative meaning-making, we can appreciate our multiple traditions and their various potentials. Further we can ask about the kind of world we wish to create for the future—both locally and globally. When education is sensitive to relationship, we realize that in terms of future well-being, “we are all in it together.” (p. 269)

Doll has written extensively on curriculum, and always with a complexivist lens. In *A Post-Modern Perspective on Curriculum* (1993), he notes that,

the art of curriculum construction is that of helping students develop their own creative and organizing powers. This cannot be done by overdirection or by underdirection: Creative organization requires a tension between set practices and infinite possibilities, between our need to find closure and our desire to explore. Obviously, what we call the facts or basics of a field are needed; but we also need to play with these facts, to rearrange them in imaginative ways. Facts take on the colors of the contexts in which they are placed and at times are transformed by their interactions with and within these contexts. (pp. 117–118)

As educators we need to cultivate this art, both in theory and in practice, in order to find out what amount of direction helps students to move out of disequilibrium and chaos as they are confronted with encounters with mortality to be supported and challenged enough to transform their own thinking into a more complex understanding of palliative care. Doll (1993) believed that this happens through dialogue, through the interplay of logic and metaphor, and that this interplay needs to be built into all curriculum.

The following chapter introduces the hermeneutic circle and then provides a short history of phenomenology and how phenomenological philosophy informs this research. I linger on some of Heidegger's work (1953/1996) on Dasein to show how his thinking is helps to move away from what we can *do* in palliative care toward how we can *be* in palliative care as we encounter mortality. I then discuss the challenges approaching this research from a phenomenological perspective. In Chapter 4 I provide a description of the Sacred Mandala and demonstrate how phenomenology is both a forum and a process that helps to uncover the lived experience of encountering mortality, thereby getting beyond technical speculation and beyond evaluating whether one's experience in encountering mortality is "good" or "bad."

Chapter 3: Research Methodology

The word *search* means to discover through exploration. To *search* derives from the Latin *circare*, which means “to go about, wander, traverse . . . from Latin *circus*, or circle” (*Chambers Dictionary*, 2008, p. 976). The combination of wandering through the encounter with mortality, in order to come to know it and then systematically observing, reflecting on, and studying it (OED, 2012), only to return to encounter it again, forms the hermeneutic circle. The circle could be seen to stretch out into a spiral that takes us from the experience of encountering mortality, through the model—the ideal or “best” practice—and back out to what is actually experienced. Movement will always exist when examining a living system, and might be thought of as an exploration of the experience of the experience, which pulls us deeper into the specific experiences of particular people and, at the same time, provides a wider or more complex understanding of the experience in general, which then pulls us round a new curve that once again opens onto another space between what we think we know, and what is actually occurring. There is always more to learn when we are focusing on human experience. Carse (1986) imagined this process of evolving understanding as a view of a horizon that moves as the viewer moves:

A horizon is a phenomenon of vision. One cannot look at the horizon; it is simply the point beyond which we cannot see. There is nothing in the horizon itself, however, that limits vision, for the horizon opens onto all that lies beyond itself. What limits vision is rather the incompleteness of that vision. One never reaches a horizon. It is not a line; it has no place; it encloses no field; its location is always relative to the view. To move toward a horizon is simply to have a new horizon. (pp. 57-58)

This is a continuous process as new information, awareness, and experience are introduced (Koch 2008). Coming to a new understanding that then creates the need for further understanding is a concept that is fundamental to embarking on a phenomenological study. In

order to understand the significance I situate phenomenology in the research world, and explore its roots.

The History of Phenomenology

Historically, the research world was caught in a hierarchical system that separated thought into divisions that differed widely from and seemed to contradict each other. Logical, objective, observable, and reproducible studies were valued more in the academic and research world than subjective studies. Irwin (2004) reports that over the past three decades, at least in arts-based research, there has been a movement to acknowledge the tension, and to attempt through discussion to move toward regarding both ends of the research spectrum as equal partners, which has in turn allowed both to become more vital. My experience (Breiddal, 2012a) has reinforced what others have said—that each perspective creates a sense of value that is more productive than promoting one way over another (Barone & Eisener, 2012; Denzin & Lincoln, 2005). Qualitative enquiry has distinct ontological, epistemological, and theoretical worldviews that profoundly affect how research is carried out, interpreted, and used. While there are many differences between qualitative methods, Merriam (1998) lists the common elements as focusing on the participant’s perspective, placing an emphasis on the relationship between the researcher and participants, carrying out observations in a natural setting, creating concepts rather than testing theories, and producing rich descriptions. The common wisdom in doing research is that the question that the researcher wants to explore dictates what method will be used. My question clearly lends itself to a qualitative approach that “relies primarily on human perception and understanding” (Stake, 2010, p. 11). Phenomenology is a sub-set of qualitative research that studies life as it is perceived through direct experience (OED, 2012). It is important to

understand how this research method evolved and where it sits in the spectrum of research choices.

Although phenomenology can be linked with the work of Kant, Hegel, and Mach (Moran, 2000), it was the work of Edmund Husserl and Martin Heidegger that governed the development of phenomenology from mainstream German philosophy (Lavery, 2003). Both Husserl and Heidegger intended to reveal the lived world of experience, rediscovering through critical reflection what they thought had been lost by empirical science (Lavery, 2003). Husserl, sometimes referred to as the “father of phenomenology,” changed his views over the course of his career (he was first a mathematician and evolved into a philosopher), moving away from the positivism of the natural sciences and rejecting the historical notions of theory and categorization, and instead focusing on life as it is lived by the act of returning to the phenomenon itself (Lavery, 2003). He became interested in the epistemological question of “the relationship between the knower and the object of study” (p. 14)—finding the essence through intentionally setting aside, or bracketing, preconceived ideas. His exploration of “givenness,” or self-evidence, required the phenomenologist to verify what is known by connecting it to evidence that is grounded by being self-explanatory (Moran, 2000). Although he examined and repudiated attempts to use empirical psychology as the ultimate basis for logic through subjective consciousness, his early scientific background seems to have influenced him in striving for certainty (Lavery, 2003), assuming that reducing phenomena to essential structures (Moran, 2000) could lead to discovering knowledge that was separate from the intersubjective experience of the people living it, which he called the “essence” of an experience. By the end of his career he came to “believe that the source of all acts of meaning is transcendental subjectivity” (p. 190); that is, meaning comes from within an interaction between the self and

other.

Franz Brentano (1838–1917), known for his radical departure from the scientific method, was in the vanguard of phenomenology, influencing Husserl and others. Phenomenology is the “story of the deviations from Husserl” (Moran, 2000, p. 3), beginning with Heidegger’s book *Being and Time* in 1927, when phenomenology was transformed and became “known exclusively in terms of the *combined* [emphasis in the original] contributions of both Husserl and Heidegger” (p. 3), and developing over the past 100 years through the work of many other philosophers such as Gadamer (1900–2002), Sartre (1905–1980), Arendt (1906–1975), Levinas (1906–1995), Merleau-Ponty (1908–1961), and Moran, (2000). While a number of Husserl’s associates continued in the same way, his best-known assistant, Martin Heidegger, took phenomenology in a new direction. He embraced Dilthey’s philosophy of life and the “notion of the *historicity* [emphasis in original] of human being in the world” (Moran, 2000, p. 191). This led to an ontological exploration of “nature and reality, and ‘being’ in the world” (Lavery, 2003, p. 14), concluding that what one knows and understands is inextricably related to how one interprets phenomena that cannot be divorced from historical consciousness.

As both a philosophy and a method, the development of phenomenology illuminated human experience, reformulated scientific questions, and influenced thinking across disciplines (Wojanar & Swanson, 2007). It not only avoided dogma but also rejected imposed methods or presuppositions of the ways things are, returning instead to the phenomenon itself as it is lived in the natural setting, in interaction with the surrounding world (Moran, 2000). It has become a “practice rather than a *system* [emphasis in the original]” (p. 4) that is meant to look freshly at human experience through attending to human consciousness as it is experienced. It began to gain popularity from the 1980s onward (Osborne, 1991) in response to the realization that the

logical-empirical, positivist aspects of quantitative research were not always adequate for answering the questions that are most relevant to social scientists (Lavery, 2003). It has been found that these questions can be better answered through qualitative methodologies such as ethnography, action research, case study, discourse analysis, and phenomenology.

Ontological concerns arise from philosophical questions that have to do with the nature of reality, or the “essence of being” (OED, 2012). Both palliative care counselling and phenomenology define the experience of being alive and interacting with the world as subjective, and see the purpose of the interaction—the counselling process or the research—as resulting in a deeper connection to our own being-ness and to the people for whom we care, or for whom we feel responsible (van Manen, 2007). There is a relationship between a being and their surroundings or environment, which can be referred to as context or world. To understand this I turned to Heidegger (1953/1996) who used the term *Dasein*, which comes from the German words *da* (there) and *sein* (to be). The nature of being can be difficult to understand but for Heidegger that was all the more reason to persist (p. 3). I have come to some understanding of Heidegger’s perspective with the help of Bolt (2011) and others (Eddy, 2008; Lavery, 2003; Moran, 2000; Sadala & Adorno, 2002; van Manen, 2007). Unlike the Cartesian position whereby a person believes that it is possible for cognition to be objective, or apart from the world, Heidegger wanted us to understand something very particular about our existence, “something about our being-right-there” (Bolt, 2011, p.18). He saw *Dasein* as being intertwined in a subjective world—not just one world, but many overlapping worlds, which results in both possibilities and limitations (p. 18). From Heidegger’s (1953/1996) perspective, we are thrown into a world that has particular qualities, which he referred to as “facticity” (p. 20) and which shapes our experience. Heidegger wanted us to take time to reflect upon our everyday life in

order to see it freshly, without taking it for granted, not to focus solely on the facts of our lives but rather on the meanings of existence.

Heidegger's words suggest, in terms of my research, that we are thrown into a world where death occurs which has an impact on our lives. He urged us to allow that occurrence—that is, encountering mortality—to stay alive through active interaction or reflection in order to give it meaning, not just once but over and over again. This process of bringing awareness has everything to do with the ability to be human by not allowing repetitive encounters of mortality to be experienced in a routine or automatic manner. In Heidegger's (1953/1996) own words:

Dasein is an entity which does not just occur among other entities. Rather it is ontically distinguished by the fact that, in its very Being, that being is an *issue* [emphasis in the original] for it. But in that case, this is a constitutive state of Dasein's Being, and this implies that Dasein, in its Being, has a relationship towards that Being—a relationship with itself is one of Being. And this means further that there is some way in which Dasein understands itself in its Being, and that to some degree it does so explicitly. It is peculiar to this entity that with and through its Being, this Being is disclosed to it. *Understanding of being is itself a definite characteristic of Dasein's Being* [emphasis in the original]. Dasein is ontically distinctive in that it *is* ontological. (p. 12)

From Heidegger's perspective, the world cannot be defined without Dasein to imagine it, interact with it, reflect upon it, and articulate it through words and actions. Dasein cannot exist without being in relation to this world, and the world does not exist without it being defined, imagined, articulated, and acted upon. The world and Dasein define and shape each other. This awareness of the interaction actually makes Dasein, or *being* human, what it is. Dasein is not only alive but is also concerned with existence. Contained in this awareness or concern is the understanding that the relationship between the world and Dasein cannot be fully known or defined because both parts are always in flux. Being-in-the-world cannot be predicted or fully described because the more we know, the more we discover that there is still more to know. In other words, people are endlessly coming-in-to-being.

How Can Understanding Dasein Contribute to My Study?

Encountering mortality daily can provide a sense of purpose and the opportunity to be present and to connect but at the same time can increase existential angst that leaves one wondering how to live and how to be. I understand from a personal perspective that encountering mortality daily, and returning again and again to the often startling knowledge that I am going to die, can be exhilarating in the sense of being awake and alive in the present moment, but it can also be immediately replaced with fear, despair, even terror, that the appointment with death seems to be closer than I want, with no hope for escape. Then again, I sometimes long for relief from the fear and I experience hope that death will release me from my unknowing, which leaves me feeling intrigued, curious, and open to whatever may come. In my own experience I live in a swirl of all these thoughts and feelings, none of which are distinct or linear. I approach this study with an understanding that there is not only one way to encounter mortality. Mortality is not just a fact or a thing. All human beings have a relationship with mortality that is dependent on their beingness in the world, or on what Heidegger (1953/1996) terms being-in-the world, which is a “unitary phenomenon (emphasis in the original, p.79). “By this “in” we mean the relationship of Being which two entities extended ‘in’ space have to each other with regard to their location in that space (p.79). Entering or being thrown into the palliative care world brings both limitations and possibilities that have shaped, are shaping, and will shape the lived experience of the patients, families, and caregivers. From this perspective, “the now” includes all the variables that occur for the individual and the collective, bringing together the past, present, and future.

While there are patterns of encountering mortality that can be identified and articulated (Downing & Wainwright, 2006; Thompson & Wainwright, 2006), each person’s experience is

unique. This understanding is reflected in the principles of palliative care, and of psychosocial care, based on the work of Carl Rogers (1961). For instance, in *Medical Care of the Dying* (Thompson & Wainwright, 2006), psychosocial care is described as interactions that empower people to act in a way that is meaningful and allows them to stay true to themselves. “Patients and families are seen as holistic beings whose life experiences are woven into coherent and understandable patterns of meanings and behaviours” (p. 537). We are taught to respect these unique preferences and ways of being. I can think about what it means to encounter mortality daily in palliative care, and I can read what others write about it, but as Heidegger (1953/1996) wanted us to understand, the *being* of being-in-the-world comes through the interaction itself. If I want to understand this particular experience then I must put aside theories and preconceived notions and re-open myself to the experience of encountering mortality as it happens, on a daily basis, in the palliative care context. How can we *be* in the face of death? By asking the co-researchers to become conscious of their own experience of being-in-the-world of mortality, I offer them the opportunity to wonder with me, and in wondering, to co-create a deeper understanding of the limits and possibilities of response that are perhaps present for us all. In so doing, my actions, thoughts, and feelings are congruent with a strong desire to move toward expressing humanity or humanness in encounters with mortality. To understand is to interact, to enter the world of death and dying, not just through my interactions as a caregiver and as a human being who experiences loss and who will most certainly die, but also as a researcher. The process of attempting to understand and explore the possibilities of responses for palliative caregivers brings me, as a phenomenological researcher, into being.

Understanding Lived Experience

Having decided to use phenomenology, I wondered what kind of phenomenology to engage in. How do I know which is the right or best kind of phenomenology? It seems important to recognize that phenomenology and hermeneutic phenomenology, although arising from the same roots, have similarities and differences and our understanding of what they mean is still evolving (Lavery, 2003). A major difference between phenomenology and hermeneutics is that phenomenology uses the technique of bracketing to guarantee validity, which rests upon the notion that the researcher can be objective. Hermeneutical phenomenology assumed that there is no objectivity, that we are already in the world in a pre-reflective state, and that we can only make explicit what is already understood (Koch, 1995; Lavery, 2003).

Johnson (2000) said that phenomenology as an approach lets us see by helping to uncover what is hidden or concealed. Phenomenology resists imposing a structure of understanding and instead tries to let things reveal themselves through a spiral movement of reflecting on the phenomenon and then returning to it again. Van Manen (2007) said that phenomenology does not provide a step-by-step method but rather “requires an ability to be reflective, insightful, sensitive to language, and constantly open to the experience” (p. xi).

A well-established, respected scholar and teacher, Max van Manen’s (2007) approach to research is often referred to as phenomenology but is understood to be hermeneutic phenomenology. This approach is most appropriate for informing understanding of the lived experience of encountering mortality daily in the palliative care context. Although I have also read and absorbed many other texts on phenomenology, particularly Finlay and Evans’s *Relational-Centered Research for Psychotherapists* (2009), I am relying mainly on van Manen

(2007) to guide me through my current research. His approach is “avowedly hermeneutic, and semiotic or language oriented” (p. 2), focusing on the specific, viewed from the perspective of the participants as expressed through interviews, participant observation, discussion, personal texts, or conversation. As he saw it, the primary job of the phenomenologist is to reflect upon the text and the acts of everyday life, with the intention “to increase one’s thoughtfulness and practical resourcefulness or tact” (van Manen, 2007, p. 4). The idea that I can become more sensitive, more aware, and more thoughtful through phenomenological enquiry is a meaningful goal that integrates beautifully with my clinical practice.

It is understood in qualitative research that a method is chosen in response to a research question that holds great meaning and relevance not only to the researcher but to the field of study, in this case palliative care (van Manen, 2007, p. 30). *What is the lived experience of encountering mortality in a palliative care context?* This question comes from the need to understand how encountering mortality in a palliative care setting is experienced, and how that experience shapes the people who provide care. In understanding this experience my research may contribute to palliative caregivers being able to connect with our own ways of being—and by doing so better care for ourselves—but also allows us to find compassion for colleagues as they care for others, and for all other human beings who share with us an inevitable appointment with death.

Phenomenology provides both a philosophic foundation and a system of exploring a question rather than a rigid method to be followed step by step. Like my work as a counsellor, phenomenology is as much about a way of being as it is a way of doing, requiring sensitivity in cultivating relationships through the use of self in an authentic and genuine way. Like counselling, it requires a conscious effort to remain open, without clinging to pre-set agendas,

and it examines everyday experiences in order to understand what it means to be human.

“Human beings do not often take into account the commonplace and ordinary; indeed they do not even notice it” (Holloway & Wheeler, 2002, p. 174). Very much like counselling, phenomenology can help us to understand everyday experience, primarily through sitting with, thinking about, and interacting with information that has been shared and gathered. Beginning with conversation, the phenomenologist primarily comes to an understanding through the process of writing. Therefore, I will first examine what it means to reflect upon day-to-day experience and then address the challenges of using language and writing as a way to understand.

The Challenge of Seeing Through Fresh Eyes

If phenomenology is the study of everyday life, I wondered how I could be sure that I was looking at the phenomenon through fresh eyes when I continued to work in the setting that I was studying. In some ways it might have been easier if encountering mortality in palliative care were not my daily work. However, my position as trusted colleague might have allowed me access to a more intimate conversation with the counsellors. I do not believe, as Husserl did, that it is possible to be objective but, like Heidegger (1953/1996), Gadamer (1960/1998), and van Manen, (2007), I do believe that there is value in being transparent about my interests and thoughts and that by highlighting particular aspects of approaches to encountering mortality from the literature, as I did in Chapter 2, I am more able to identify what is new and fresh.

I was interested in the co-researchers' experience as they experienced the effects of their proximity to death and dying. How do they encounter mortality? How does that interaction affect their thoughts, emotions, and actions? Does their encounter affect their relationships? I took up the cry of Husserl (Sawicki, 2011) to return again and again to the things themselves in

order to research with a deeper, fuller understanding after having been through a process that observes, reflects, attempts to be aware of preconceived notions, and interprets the essence of what makes the experience what it is. Throughout this process I needed to find a balance between establishing enough distance that I might be able to see clearly, and not be blinded by my own experience, and resisting a tendency to objectify myself, or the people with whom I interacted, by imagining that I was outside the experience, looking or observing without pre-judgment.

In order to do this I needed to be able to find the essence of their experience. However, there is tension between finding the essence of something, like the essence of being human, without creating fixed ideas that can lead to attachment of a moral conviction (van Manen, 2007). For instance, the intention of this study was not to outline the only way to encounter mortality, or to comment on the adequacy or appropriateness of any particular person's response. Rather, it was to describe the experience as the people who encounter mortality experience(d) it. There is nothing wrong with defining something in a way that describes the qualities that make it fit within a particular category, without which it would not still be in that category; the danger is in reducing it in a way that does not acknowledge the complexity, or traps it into this category, or that does not weigh the importance of one quality over another (van Manen, 2007). To do this authentically, my own everyday ways of being and thinking had to be articulated, revealing underlying assumptions that could then be identified and suspended in order to look freshly at the actual data. Phenomenology, by turning to the phenomenon itself, by searching for the essence, "asks what something 'is' for the one who asks the question" (van Manen, 2007, p. xv), therefore attempting to accommodate understanding by reflecting on researcher bias and assumption, in an attempt to come to shared understanding.

Looking with fresh eyes sounds easy but is quite difficult. How was I to see what I could not see? A blind spot refers to something that you cannot see. How would I know that I had come to a *shared* understanding? Walsh (1996) expounded on how a phenomenologist might conduct research by identifying their own pre-understandings, thereby avoiding projecting their own prejudices onto the experience of the participants:

By examining my prejudices and placing them alongside those of my colleagues I may become attuned enough to ask questions that would otherwise have gone unasked and come to understandings that would otherwise not have been reached had I tried either to remain objective, and therefore detached, or to act purely on prejudice. This then is an example of the Heideggerian aphorism; to the facts themselves. . . . The interpretation I put upon the lived experience of my fellow nurses, when using prejudice as a tool, is my interpretation (and everything we do entails interpretation), but it is anchored in the facts, or experience, of my fellow nurses. Through this interaction a new, richer understanding emerges, which is greater than the original individual understandings. (p. 234)

Examining prejudices required the same kind of skills that are needed for counselling, and for the same kinds of reasons—to see patients or clients as they are—in order to respond appropriately. This would suggest that I could use my prejudices as a “tool” to help me to expand my understanding, as long as my interpretations are rooted in the facts, the experience of my fellow counsellors.

While phenomenology is conducted primarily through reflecting on written or spoken text, language will never capture the nuances of individual lived experience. Phenomenology’s validity arises from its relevance, its honesty, and its ability to motivate, connect, and embody through being principled and collaborative. For this, I had to depend on my skills as a counsellor and on my previous relationships with the co-researchers. My outlining my presumptions, experiences, and unfolding process allows the reader to decide to what extent I have come to a shared understanding. In looking for the essence of experience, my intention was to expand horizons of understanding rather than reducing, oversimplifying, or objectifying the experience.

The process of reflecting and of returning again and again to the phenomenon itself has inherent value, just as a work of art has both a process and an outcome. I found that my reflection was enhanced by my practising a particular type of mindfulness called dual awareness where the clinician, and in this case researcher, tracks the needs of the other and the elements within the environment in which the interaction is taking place, and their own subjective experience as it unfolds (Weininger & Kearney, 2011). In a practical way, this required the ability “to notice our thoughts, feelings, bodily sensations, triggers, and reactions, while simultaneously holding our outer experience, including how we experience the person in front of us, without being drawn into or overwhelmed by that experience unwillingly” (p. 56). Paying attention to both prior and unfolding understanding can be challenging. Dual awareness requires practice and is part of the art of being a counsellor. I used this concept in my research analysis as I considered what the co-researchers had to say, noting my own responses and taking in their perspectives and using my own reactivity to point me to my prejudices, or to the need for more understanding. These pre-conceptions and responses were extensively explored through the process of painting and writing in my journal as I moved through my mandala, and rather than being bracketed were, as Lavery (2003) suggested, embedded in my work.

Returning again and again to the phenomenon itself so that preconceived notions and accepted ways of understanding are not imposed allows for amassing of new knowledge or understanding. Paradoxically, however, I had to prevent myself from either appearing or being objective or distanced. This can create tension, or a sense of “nervous strain” (*Chambers Dictionary*, 2008, p. 1125), which may mean that familiar ways of interpreting representations of experience cannot be used, requiring me to be “constantly open to experience” (van Manen, 2007, p. xi). From a phenomenological perspective, however, this might be seen as positive.

Tension also refers to tautness or “a stretched condition” (*Chambers Dictionary*, 2008, p. 1125). In botany, tension refers to “the pressure on cells or tissues of plants ... in the course of growth” (OED, 2012). As a counsellor, I am trained to keep my attention or hold space for tension in order to discover what it holds, and experience tells me that there is something to be learned or discovered from naming and exploring “forces” within a person or situation that are balanced between pulling apart and holding together. Growth or new understanding can occur by focusing on what the tension might point to. Phenomenology requires insight, which stretches what we already know to include new possibilities; it requires us to see with fresh eyes.

My interest is in uncovering the subjective meaning of the situation of palliative caregivers’ experience in order to understand aspects of what it means to be human. My skills and knowledge as a counsellor in private practice and as a palliative care counsellor can be applied to phenomenology because being in the role of researcher required me to relate to others in an authentic way that requires deep listening, attempting to free myself of a pre-set agenda, living with the unknown, and acting without a script. This is congruent with the client-centred humanistic approach to psychosocial care that is practised in palliative care. Phenomenology, like counselling, has a lot to do with being aware and reflective, being present, and, most of all, having the “capacity to wonder” (Eddy, 2008, p. 116).

The Challenges of Language

There is tension in relying on language because it is difficult to understand both the cognitive and the pathic meaning of words. There will always be separation between an experience and the words used to describe that experience. Nuances can be lost and misinterpreted from one person or group to another (van Manen, 2007). Phenomenology

provides a way, by trial and error, to discover both personal meanings and collective understanding. I hoped that if I was able to go through the phenomenological process, my thinking would open up into a new understanding of the experience of encountering mortality in the palliative care context as it is lived by people as they interact or create their world. To do this, I challenged myself to let go of my previous conceptualizations and theories of what it is to be in the world. Lived experience is the starting and ending point of phenomenological research.

As Gadamer (1960/1998) said:

Understanding is always more than merely re-creating someone else's meaning. Questioning opens up possibilities of meaning, and thus what is meaningful passes into one's own thinking on the subject ... To reach an understanding in a dialogue is not merely a matter of putting oneself forward and successfully asserting one's own point of view, but being transformed into a communion in which we do not remain what we were. (pp. 375–379)

To demonstrate this reflective thinking, I share an excerpt by Camargo (2005) in which she related her experience as a nurse, beginning with the naïve version.

I hang up and quickly scan my surroundings. All the same in the ICU. As usual there are the annoying sounds: monitors and ventilators; nurses, therapists, and doctors all in their own world. No one is concerned but me that this man is dying. I walk to the window and look out. Bogota is cold tonight. It is raining and sleeting. My thought in this moment is simple: life marches on. It does not care who is in its way, who falls and gets trampled. Yet, here in 311 it is a different night. Intense. Bright. And strangely silent. Mr. Ricardo's heart is fighting for his life. The heart rate continues at 70. (pp. 7–8)

Then, reflecting upon her experience, she revealed the richness of that experience.

This is a moment of aloneness. I am alone with my thoughts and although he is with me, Mr. Ricardo is alone with his death. Around us everybody is busy in other activities. No one seems to realize that something of grave consequence is happening in room 311: a life is lost. It seems like the color of the death is reflected in the place where I am. Death comes closer. My room is silent and bright. But nevertheless death becomes significant and different. I look at my surroundings and only find a contrast between the darkness of outside with the brightness and intensity of the room. Both inside and outside have in common the indifference to this man's death. Life goes on. As his nurse, I think how difficult it is to be fully aware of the moment of death of someone else. Although his

body is barely responding, his heart continues beating for his life. In the end humanity creates a fine bond between hopefulness and hopelessness, and the body responds to it. (p. 8)

In this encounter the nurse is remembering engaging with the patient, but it is only in reflection and in the retelling of the story that it comes to life.

I wanted to be able to truly enter the space of the Other and be willing to be touched by that experience in order to understand the meaning in the description—the meaning for the person experiencing it. This way of understanding is a powerful experience in itself. I expected to be an instrument of the work, because data are necessarily filtered through the researcher's understanding and thoughts in order to discover the complexity and authenticity of human experience. In order to understand the lived experience of those who encounter mortality I needed to co-construct interpretations while remaining open and reflective in attitude, attending to relational practices so that, through observation and understanding the words, the relation of the words to each other and the meaning and thinking of the co-researchers come together as one. By this process I wanted to expand understanding in a way that might not have been available to either me or the co-researchers had we been working independently to find understanding.

Hermeneutical phenomenology follows the work of Heidegger and Gadamer, as Koch (2008) explained:

Understanding occurs through a fusion of horizons, which is a dialectic between the pre-understanding of the research process, the interpretative framework and the sources of information. The implication for hermeneutic inquiry is that research participants are also giving their self-interpreted constructions of their situation. The result would be many constructions or multiple realities, including the researcher's constructions. (p. 835)

Because language is intersubjective it depends on both individual and shared cultural and inherited meanings and nuances. This was further elaborated by Schmidt (2006) who said that language has two interconnected, interdependent parts—the grammatical, which has to do with the totality of language, and the psychological, which is related to the “whole thinking of the author” (p. 14). The totality of language, however, can never fully express what is intended. The art of understanding language as a phenomenologist requires the same kinds of skills—and for the same reasons—that are required of a palliative care counsellor: understanding and connecting, revealing through inference of both words and meaning gleaned from the context of what a person is trying to express, and reflecting that expression in a way that conveys “deep” understanding, as in what lies “below the surface; not superficial [but] profound (OED, 2013).”

Palliative care counselling and phenomenological research have many essential commonalities. Both share the purpose of exploring a question important to the people involved in the exploration. Because the people involved are invested in the exploration, change or transformation is a natural outcome. In both the counselling and researcher roles, the relationship between people is characterized by qualities of openness, intimacy, and mutual respect. Barone and Eisner (2012) asserted that arts and science—in general use—are only useful if they are well done, that they are “useful in enhancing certainty in the mind of the reader, or in raising significant questions regarding stale, tired, commonplace ways of viewing the world” (Barone & Eisner, 2012, p. 47). Van Manen (2007) similarly said that phenomenological description helps us to see the “consequential in the inconsequential, the significant in the taken-for-granted and if done well, is compelling and insightful” (p. 8). These statements are also true about counselling, since counselling can be a process that helps people to look freshly at old ways of being by articulating and challenging assumptions, and that, when done well, leads to

transformation (Jung, 1960; Rogers, 1975; Rosenberg, 2003; Rowan & Jacobs, 2002). Both counselling and phenomenology incorporate the discursive with the intuitive to form a sensuous whole; tend to highlight complexity rather than simplify, condense, prove, or summarize (Barone & Eisner, 2012; Irwin & de Cosson, 2004); and use reflexive processes that accept multiple realities. Each contains an element of art or craftsmanship, requiring “*composing, orchestrating, and weaving*[emphasis in the original]” (Leavy, 2009, p. 10) through creative processes.

As I reflected on the difficulties of using language, I realized that painting the Sacred Mandala expressed my evolving understanding of encountering mortality in a form other than words, and yet was still in relation to language. The painting and the writing were not separate or distinct but interpenetrated each other in a process that altered, influenced, and articulated both, producing complex, layered meaning making. “This doubling (between art and graphy) is not a static rendering of two elements positioned as separate and distinct; but it is in the contiguous interaction and the movement between art and graphy that research becomes a lived endeavor” (Stinggay, 2005). The contiguous relationship with the text was an extension and a reflection of the hermeneutic circle, the meaning of which will be explained in Chapter 4 and further articulated in Chapter 7.

In Chapter 4, I describe what a mandala is in general, in order to provide a context for the particular type of mandala that I painted, the Sacred Mandala, and what painting it entails, and then provide a detailed example of how I used my painting, together with reflection and journal writing, for further understanding.

Chapter 4: The Sacred Mandala

Once again I find the paradox in my work. As a crisis team counsellor I am “familiar” with moving in “unfamiliar” territory. I work between being scripted and unscripted, between what is common to many people facing death, and what is unique about the person in front of me. I work between my own desire to come forward and be present, and my tendency to hide or turn away. I have learned to have faith in the creative process that occurs as my colleagues and I act in spontaneous response to each other, and to the people and the environments we come in contact with every day. I entered into my research in that same spirit—aware that I was moving between my preconceived ideas and what was unfolding, not yet knowing what I would find, what I would experience, or what I would write or come to understand, and not knowing what the consequences would be. Complexity theorist Steven Kaufman (2008) affirmed the unpredictability of this experience on a far grander scale. He described a scientific worldview that encircles the reality of emergence, stating that we cannot predict the changes that will occur.

We cannot even pre-state the possibilities let alone predict the probabilities. *These phenomena, then, appear to be partially beyond natural law itself* [emphasis in the original]. This means something astonishing and powerfully liberating. We live in a universe, biosphere, and human culture that are not only emergent but radically creative. We live in a world whose unfolding we often cannot prevision, prestate, or predict—a world of explosive creativity on all sides. (p. 5)

Reality is being constantly created in mysterious ways, combining a myriad of known and unknown forces, which made my work at Meadowview and my research so paradoxical, fascinating, puzzling, appealing, and rewarding. The combination of painting, journal writing, and academic work was creative in itself, and a “liberating force” (Kaufman, 2008, p. 5) that opened up my own complex ways of knowing and unique ways of expression. Using art, particularly in arts-based research, is commonly thought of as being useful in the representational

stage of research; it is actually valuable throughout all stages of research, and especially in the incubating stages where the researcher is looking for themes and meaning (Hunter et al., 2002). For me, the combination of painting and phenomenological process was a wholesome/holy experience that was personally and professionally meaningful, and “explosively creative” (Kaufman, 2008, p. 5). Practices that go with the painting, such as journal writings that contained active imagination exercises, tracking of synchronicity, dream work, and reflection (Johnston, 1996), contributed to knowledge and understanding of the research question, and were integrated with phenomenological writing. The visual representation of the endless possibilities that mirror the breadth and depth of human experience can be more easily understood through images and words than through words alone, and explore and reveal the complexity of the space between theory and practice, where human-becoming is.

Piercy described this complexity in a different way:

Connections are made slowly, sometimes they grow underground.
 You cannot tell always by looking what is happening.
 More than half the tree is spread out in the soil under your feet.

...Keep tangling and interweaving and taking more in.
 A thicket and bramble wilderness to the outside but to us
 interconnected with rabbit runs and burrows and lairs. (Piercy, 1982, p. 128)

In allowing for “connections [that] are made slowly,” and by looking closely at the “rabbit runs and burrows” (p. 128) that underlie my research question, my intention was to bring what was unconscious to consciousness. Painting a Sacred Mandala was a way to enrich the exploration in order to generate a “more interesting conversation” (Barone & Eisner, 2012, p. 6). I envisioned this endeavour much like the IMAX movie *Cosmic Voyage* (2011), (originally called *Cosmic Zoom*), which provides an embodied experience of using art to convey a message. It places

human beings between the great cosmos, seen from a giant telescope, and the microscopic sub-nuclear perspective, each providing a unique and fascinating view. The aim in returning again and again to both my own and the co-researchers' experience is to open up microscopic, interconnecting universes within each experience, thereby magnifying various aspects of their experiences, in order to understand the lived experience of encountering mortality. Painting a Sacred Mandala helped me to dwell in the underground world, between the words, by providing a physical and psychic place to explore the hidden or unconscious meanings of the research work.

Hunter, Lusardi, Zucker, Jacelon, and Chandler (2002) explained that using art can provide methods through which researchers can integrate the information that comes from the invitation to integrate epistemological diversity. They said that between the formula and the answer is the “aha.”

The four-step process of creativity—insight, saturation, incubation and verification (Amabile & Tighe, 1992)—is similar to the research process of problem identification, literature review, methods, and result. However, the incubation phase is not legitimately recognized in the research literature. Incubation is the process of living and breathing the data, by which the researcher tries to understand its meanings, find its patterns, and draw legitimate yet novel conclusions. It is described as the intellectual chaos phase. Within this chaos, however, there are techniques that provide structure. (p. 389)

While I was in the incubation stage of research, thinking through and trying to articulate new meanings, the mandala work provided a structure through exercises that used stillness, moving meditation, contemplation, imagery, fantasy, active imagination, dream work, and the tracking of synchronistic events. These practices, together with the painting, helped in calling to consciousness that which lies beneath the surface.

The Mandala

I begin with a brief description of mandalas in general, followed by an outline of the structure of the Sacred Mandala, which I began painting at the same time as I was starting my research. In this study, I am the only co-researcher who is providing artwork or journal work. This is intended to add another layer of reflection and to explore the valuable role that a creative process can play in providing self-care. The mandala work served as a way for me to process the strong emotion that is evoked when contemplating such a profound area as death and mortality during my workday, my writing and study time before and after my workday, and on my days off from work. It provided an opportunity to represent the interaction with the concept of death that lent itself to mindfulness and served as an antidote to my sense of urgency—to strive, to excel, and to accomplish.

Although it is important to place the Sacred Mandala within the larger context of meditation practices, Jungian-related psychoanalysis, and other types of mandalas, a detailed examination of these is outside the scope of the current study. Instead, I will briefly explain where the Sacred Mandala fits in with other forms of mandala-making, and then outline a few of the Sacred Mandala's distinctive characteristics.

In general, a mandala is art that is created in a circle, symbolizing the world, the universe, or the whole. Mandala-making is a practice that has been used in many cultures across time (Arguelles & Arguelles, 1972; Johnston, 1996; Jung, 1959/1969). The Navaho Sand Mandalas and Japanese Yin/Yang Mandalas are characteristic of sacred “art throughout the Hindu, Jain, and Buddhist world, which extends from Central Asia through India to China, Korea, Japan and Southeast Asia” (Walcott, 2006).

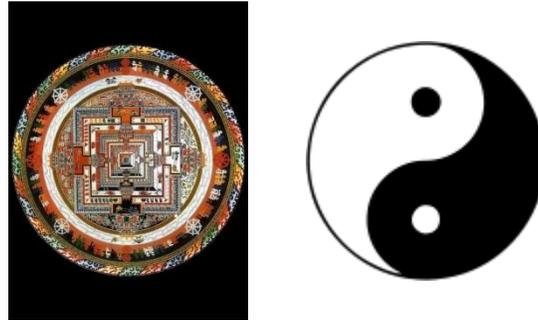


Figure 2: Examples of Mandalas from Different Cultures

Tibetan Sand Mandala and Japanese Yin/Yang Mandala. (Sources: <http://en.wikipedia.org/wiki/File:Kalachakra.jpg> and http://commons.wikimedia.org/wiki/File:Yin_yang.svg)

Tibet has developed the mandala most extensively in the East, both as a form and as a practice (Arguelles & Arguelles, 1972). An Eastern mandala can be seen as a cosmic map or mirror, and an observer interacts with it on three levels (Walcott, 2006).

One example sees the outer level as a divine form of the world, the inner levels a map through which the ordinary mind can be transformed by following it, and at the secret level as a balance of the clear light dimensions of the mind and subtle body energies. Creation of the mandala acts to purify all three levels, with the central object of bringing about the acquisition of the associated virtues of wisdom, compassion, and healing. (pp. 73–74)

The purpose of an Eastern mandala, then, is to provide a particular experience for the meditator, based on historical religious and spiritual experience.

In the West, Jung (1931) introduced the mandala as an integrative and transformative tool in therapy, “in the tradition of the alchemical tradition” (Arguelles & Arguelles, 1972, p. 13). Jung’s work in *The Secret of the Golden Flower* (1931) reintroduced the use of the mandala ritual as a therapeutic tool of “mystic exaltation” (Arguelles & Arguelles, 1972, p. 13). Jung (1965) believed that mandalas occur naturally in the dreams, fantasies, and artwork of patients

during turbulent times, especially when they are trying to come to terms with the disequilibrium that arises when experiencing opposing forces. He thought that a mandala could compensate for this disorder by providing a holistic form—a square within a circle, representing seemingly “irreconcilable elements” (Jung, 1959/1969, p. 4) that are integrated, or become resolved through the creation of a mandala. By working with both the symbol for wholeness (the circle) and the symbol for the consciousness of the whole (the square), it was thought that integration could occur (Jaffe, 1959/1964).

This concept is of interest to my study because it provides an opportunity to bring to consciousness the many tensions and paradoxical elements within the lived experience of encountering mortality, and provides a process by which to explore and contain that tension. The square within the circle was a visual representation of the resolution of opposites. It is important to add here that in the work of the Sacred Mandala, the word *resolution* does not refer to “the action ... of finding the answer to a question, the solution to a problem, etc.; the elimination or easing of doubt” (OED), although aspects of the original question asked by the student when beginning the mandala may be more fully understood, but has another meaning. The term *resolution of the opposites*, as I learned it from my mentor, (Shields, personal communication, 1984), referred to bringing an experience to consciousness through the process of painting and mandala work. As suggested by Jane Johnston (Johnston, personal communication, December 13, 2012), words like “assimilation (mutual penetration of conscious and unconscious contents) ... or integration” might be more accurate terms. By viewing the finished mandala (the painting) we see the whole, as we know it in that moment, with an understanding that the mandala images may continue, and most likely will continue to, stimulate the conscious mind.

Arguelles and Arguelles (1972) asserted that Eastern and Western approaches to the mandala have a common aim of helping the observer to enter deep states of meditation, integrating levels of awareness and healing, and honing and freeing the mind of “mental obsessions” (p. 14). In the East, contemplation of a mandala gives the observer a sense that life has meaning and order, while in the West this same sense of order occurs in psychotherapy when mandalas appear spontaneously in dreams (von Franz, 1959/1964, p. 230). The main difference between Eastern and Western approaches seems to be that the Eastern mandala is constructed to provide the meditator with a particular kind of experience, moving through sacred, internal geography, through an idealized environment (Walcott, 2006), while in the West a mandala is more of an expression or exercise that meets the individual’s need for expression. Both are believed to lead to balance, integration, and wholeness (Jung 1959/1969; von Franz, 1959/1964; Walcott, 2006).

In this study the mandala provides a framework for creating meaning and order, but not a specific meaning and order as it does in the East. Rather, it is used in the Western way, in that it is meant to provide a structure within which the student can explore and express unconscious connections to a specific question, in this case encountering mortality. The Sacred Mandala is also a way to express and contain intense emotion that, in my experience, is always part of the process. In this particular project intense emotion was perhaps inevitable, or at least expected, because I was dealing with such a powerful subject matter for a sustained period of time.

The Sacred Mandala

The Sacred Mandala is a variation of a traditional mandala that was inspired by Canadian artist Jack Wise’s (1928–1996) work with Tibetan mandalas, but adapted for Western purposes.

Wise's student Madeleine Longo Shields (1933–2005) began studying with him in 1981. She then went on to develop several forms of mandala, one of which was called the Sacred Mandala. Some of her first students began working with her in 1984. I was part of a group of three students, with two other women. I worked with her on a weekly basis for two years, completing two mandalas, and then carried on the work by myself for the following seven years. There is only one written document that I know of that describes Shields's work, and that is an unpublished dissertation (Johnston, 1997), written by a fellow mandala student. While Johnston described a particular form of mandala called The Path of Bliss, a later mandalic form developed by Shields, I will be outlining the form that she taught me, referred to as the Sacred Mandala.

It is always difficult to decide where any process actually begins, but somewhat arbitrarily, I would suggest that the Sacred Mandala begins with an attraction to the form, an interest in spirituality or inner work, and a willingness to come with a beginner's mind. In an interview (Johnston, 1997), Shields says that while all people can create art in a circle, not all people have the qualities needed to create a Sacred Mandala.

First and foremost, they need to be strongly drawn to the Mandala form; then have a felt need to find a tangible, meaningful expression for inner work, and have the time in which to do it. A modicum of artistic ability is required—skill can be developed. (p. 66)

None of us in my group had any art training, which Shields saw as a blessing because it enabled us to paint without having to “unlearn” what she saw as constricting rules. According to Shields, mandala work should only be done in later life—that is, after the age of 40—because she believed that a person does not have enough depth before that age (personal communication, 1984). Perhaps because I started almost 10 years before that age, I disagree with that idea, but I take her point that the work does require a certain amount of maturity to be able to contain the overwhelming amount of stimulation that is generated.

The Sacred Mandala is a form of analysis that might be said to lead toward self-realization, much like therapy. While the process is different from therapy, it is therapeutic. Because of the complicated nature of what arises from the unconscious, and the intensity of the emotions that follow, it is my opinion that a student must find a teacher who has the capacity to act as a guide, spiritual director, and therapist.

According to Johnston (1997), Shields described her relationship with Jack Wise as mentor/teacher (Wise) and disciple (Shields). In the process of conveying the structure of the Mandala, which was based on Buddhism, and giving her simple directions that formed a structure for her psyche, the relationship became transformational for her. She referred to the aspects of her work as yin/yang (see Figure 2), “the combination or fusion of the two cosmic forces, (represented and known by a circle divided by an S-shaped line into a dark and a light segment...each containing a ‘seed’ of the other” (OED). It is my understanding from our conversations, that when she spoke of yin and yang she was referring to complementary forces that act together to form a greater whole as part of a dynamic system and not as opposing forces or dualities.

Our conversations were richly illuminating and nourishing for me. It was like a door opening into another realm. My western “yang” way of thinking and doing was at first challenged, and eventually, in the doing of the work, transformed. I learned the beauty of “yin”—the gentler, slower more intuitive way of discovery rather than imposition, first in the working of the Mandala—then as time went on, I saw its value and power in all my life processes. Thus, I began to understand the importance of balancing the opposites. (p. 64)

The mandala is a relational process because of the mentoring between the student and teacher, with other co-students, and between the student and the people who view the Sacred Mandala. Shields believed that this work was a powerful therapeutic tool that was both integrating and centring, adhering to Jung’s belief that we can only be whole by being in relation

to others (Johnston, 1997). Her work as a mentor was her way of completing the circle of her “own living mandala ... through relatedness” (Johnston, 1997).

Shields used various terms to describe the role of teacher or guide but I use the term *mentor*—“a person who acts as advisor or supporter, especially to one who is younger or less experienced” (OED, 2012). I considered various options for the one who paints. Combined words such as *seeker/student* seemed redundant, while phrases such as *one who seeks* seemed cumbersome. The term *artist* would be confusing because of the association with the production of art. I therefore referred to the person who makes a mandala as a *student*, while acknowledging that terms such as *seeker*, *meditator*, *mystic*, or *creator* could also work. The term *student* emphasizes the desire and intention to learn, to observe and to study, to engage in a relationship with a teacher or mentor, and is related to the idea of a beginner’s mind. I use the term *teacher* and *mentor* interchangeably, to emphasize the role of both instructor and emotional and spiritual guide.

It is important to mention that the process of painting a Sacred Mandala is meant to be transforming. Having a mentor is essential to the process because the change process is so intense and complex. The mentor helps to keep all the pieces in place, such as serving as a guide for the structure and painting of the mandala, noticing and exploring resistance to the structure, processing emotions, assisting with understanding symbolic meanings of dreams and material that comes forth in the dialogues, providing emotional support, and, in general, bearing witness.

During the two years that Shields served as my mentor, I attended weekly sessions with her. In between sessions I painted on a daily basis. Her studio was in an upstairs room in her home and there was a sense of being invited into sacred space when entering. There was no

clutter, only a few of her paintings, books, art supplies, two easels and tables for supplies, and small souvenirs from nature. Sometimes she played soft background music. There was never anyone else in the house, the phone was turned off, and she appeared to be completely present to her students. There was a sense that being in her space and having the opportunity to learn from her was an honour. A two- or three-hour session finished with tea in her kitchen, where we engaged in casual conversation.

The Sacred Mandala itself represents a snapshot of the student's psyche at a particular moment in time. It is to be understood as one frame or picture taken from a long movie, rather than as something separate, complete, or final. While the mandala or painted image might have aesthetic value and be considered art, the artistic merit is not evaluated throughout the process of painting, meditating, and working with the images and synchronistic events that occur during the creation of the mandala. Although choices are made by sensing what "seems right," any evaluation is based on what the painting or image can offer as a meditative experience, a method for having ideas and insight, and as a way of expressing what the psyche has to say. It could be that the aesthetics are dependent on whether or not the student is centred while painting. Shields reported that Wise could tell if she had been in a receptive or centred space, or if she was ungrounded, and would point out to her places in the painting that seemed to indicate that she had not been present when she was painting (personal communication, 1984). Presence is fundamental to the process.

In the following section I will describe the steps that are involved in creating a Sacred Mandala. Shields was directive and particular about her instructions, and I have thought about, discussed, and debated at length the merits of these rules with another of Shield's students, Jane Johnston, but I report here the rules that she gave to me. These were not written down at the

time, although some of them were documented in consultation with her while she was still alive (Johnston, 1997, unpublished dissertation). Although to an outsider the rules may seem oddly prescriptive, I have come to value these rules, because I believe that the structure that they provide creates the essence of the work, and that without them that essence would be lost, or at least diminished. In the following section I report the steps that I was taught. In my consultations with other students (Johnston & O’Gorman, personal communication, 2012), I may have inadvertently consolidated their recollections with my own, but in general my memory of the rules was consistent with theirs. If the rules seem strict or rigid that is because Shields conveyed them to me in that way.

Before I outline the steps I will explain a few overarching principles. When painting a Sacred Mandala the movement always begins from the outside edges of the circle and always moves clockwise in a spiral moving toward the centre. In general, the mandala work moves from the outer rings, which are thought to represent what is relatively more physical or material and external, toward the centre, which is thought to represent what is relatively more spiritual and internal.

Practising forms or images on a piece of paper other than the mandala, with the intention of then using that form on the mandala, is not allowed because Shields believed that practising an image would be serving the ego more than the psyche. The use of a pen or pencil to draw on the mandala paper, with the exception of drawing the initial forms of the structure, is also not allowed. There are specific ways to paint each section, which will be explained below. When one section is finished, the student cannot go back and change it. This encourages care and attention. Students are expected to paint an image until their own psyche is satisfied that it is the best possible work, which sometimes requires painting and lifting paint, and repainting again,

over and over again. Work that Shields considered to be sloppy or done without due care was criticized because she considered the work to be a reflection of the students' reverence for the process and so doing less than one's best work was disrespectful to her and to the process.

Preparing to Create a Sacred Mandala

The materials for making a Sacred Mandala must be of the best quality that the student can afford. While Wise made his own brushes, Shields recommended sable brushes that range from a few tiny short hairs to slightly longer and more densely packed hairs, as well as some brushes that are larger and suitable for applying washes to larger areas. The brushes must be handled mindfully and kept clean and dry when not in use. The paper must be Arches 300 pound, cold-pressed, watercolour paper because it has an uneven surface that lends itself to absorbing paint. When using this paper the paint can easily be lifted off with a tissue, leaving interesting markings that become the basis for projecting and outlining images. The paints must be Windsor Newton Gauche paints, because unlike regular watercolours, they are opaque and can obscure paint that has been laid before. Colours must include the primary colours so that the student can mix subtle hues. These variations are made by putting small amounts of paint on a palette and mixing them with varying amounts of water, depending on the intensity of colour that is desired. In addition to paper, brushes, and paints, the student needs a notebook (now replaced by a computer), a pencil for drawing the circle and scissors for cutting it out, an art eraser, a large compass, a ruler, a jar of water, tissue, and a plate or palette on which to mix the paint. Some students use an easel, while others rest the mandala on a table. Shields only painted with natural light but headlamps and large spotlights can be used when natural light is not available.

It is important that the student create a peaceful and orderly environment to work in, outside the sessions with their mentor. Painting this type of mandala and completing all the work related to it requires a reverence that is reflected in how the tools are handled, how the physical and psychic spaces are entered, how the images—which appear in the imagination, on the paper, or in dreams—are met. Respect is shown in the tone in which we communicate while talking about or working on the mandala, and how we handle the information or insight that is gained. It is important to become centred before beginning to paint, and techniques for quieting the mind such as meditating, listening to music, or praying could be used. The physical space should reflect the intention to be mindful.

Entering the Ring of Fire

The student begins by building a fire and meditating upon it. This is a sacred ceremony that formally begins the process. During this meditation the student is to pay particular attention to the colour and shape of the flames, and then make a journal entry describing a shape that will become a repetitive pattern around the circle. The student then draws a series of concentric circles beginning with a circle that measures approximately 22 inches across (the full width of the Arches paper) with a square in the centre:

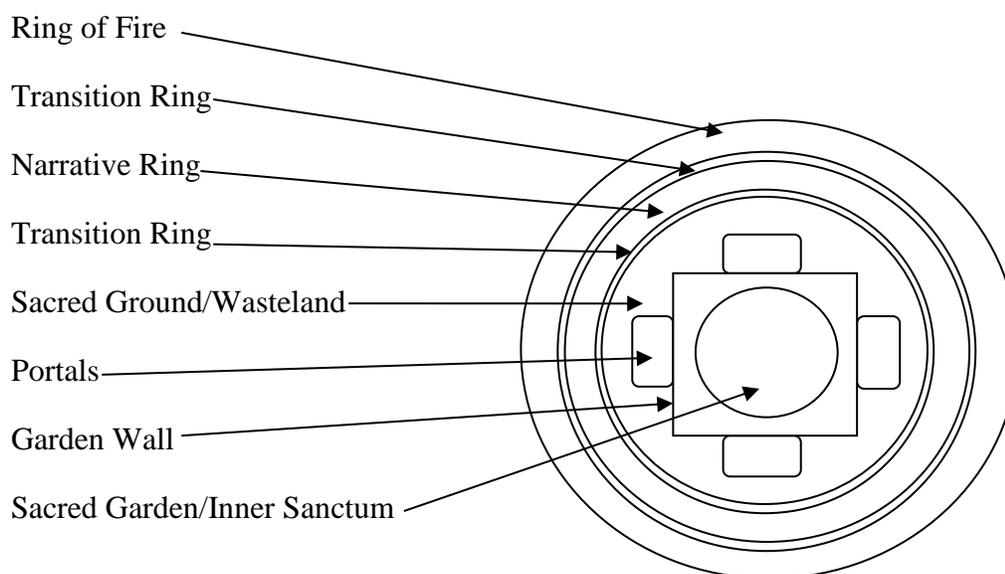


Figure 3: Structure of a Sacred Mandala

From the outermost ring: Ring of Fire, Transition Ring, Narrative Ring, Transition Ring, Sacred Ground, Gateways or Obstacles, Garden Wall, Inner Sanctum.

The Ring of Fire represents initiation, cleansing, and transformation through the burning away of ignorance into a sacred or conscious way of being. Shields believed that the flames served as a protective force that not only contained the images and their meanings, but also protected the student's psyche from harm. The Ring of Fire also represents authority. Any issues that the student has with authority, structure, and rules will manifest while painting the Ring of Fire. The discipline simultaneously allows and requires the student to focus on what is at hand, and to leave the irrelevant behind. Notes are kept in a journal and these issues are discussed in the regular sessions that occur with the mentor. The rules, the precision of the painting, and the skills required to handle the tools, as well as to maintain a meditative state, are challenges that can be magnified or ameliorated depending on whether the student welcomes or resists the structure. Responses, both the mentor's and the student's, are expected to be discussed openly.

The first step is to lay paint around the Ring of Fire. To prepare, the student chooses colours intuitively, mixing small amounts of colour or colours with water to form a very thin, watery paint. When the colour seems correct (that is, it appeals to the student's psyche), it is laid on the outer ring with a large brush in a clockwise direction. The student gives full attention to each loading of the brush with paint, and to each stroke across the paper. After the initial paint has been laid and dried, another choice is made—either a simple form or a colour—and the colour or a form is laid, evenly spaced, one at a time, in a clockwise repetitive motion around the Ring. Then the next colour is chosen, and another refinement is made to each existing form, continually moving clockwise, continually adjusting the image to match the other images, until both the form of the flame and the negative image (in art, the space surrounding an object is referred to as the negative image) between the flames are completed. The image that is chosen represents flame and usually is in some way recognizable as a flame or as fire. The final shape and colour of the flame are arrived at one step at a time through an organic mindful progression that gets closer and closer to a perfectly repeated pattern.

The First Transition Ring

The second ring is a narrow band called the Transition Ring. Any personal issues with change or transition will be manifested in this Ring. The student keeps notes in their journal and the mentor notices and makes observations about how the student is transitioning. As with the first ring, the student intuitively chooses a colour and lays it down in a clockwise motion. The student then can proceed to paint that ring in any way that seems correct to them. There is often some blending of design between the first ring and the second, but it is not a rule that it should be done in that way. The first Transition Ring leads to the Narrative Ring.

The Narrative Ring

The purpose of this ring is to allow the student to explore their unconscious story. The painting begins as in the previous rings, with a watery wash of paint being laid down. Students have approached the sections of the Narrative Ring in a number of ways. Some have had no demarcations, others have had four large sections, but Shields asked me to intuitively mark off small sections of the ring with my brush. My understanding was that using a measuring device such as a ruler would bypass the necessary concentration that was required to turn out equally spaced panels and that any reaction to this requirement was just part of the refinement process. In all of my mandalas there have been 22–26 small sections, depending on how far the initial markings were from each other.

The student then lays down either one colour or several colours with a fairly wet wash, and then, using some tissue, blots up some of the paint. When the paint dries, patterns or images appear. The student, in a meditative state, watches until an image appears. This is akin to seeing shapes in clouds, and calls to mind the Rorschach Test. These images are outlined, and details added until the panel appears to be finished. There are many choices and if multiple images appear the student can choose to highlight an emerging image, let it fade into the background, or cover it up completely. Of all the images that appear, what is not only worthy of attention but is also most important? How does importance get decided? Shields would say that the image speaks to the psyche, and that the student must wait until there is an intuitive feeling that the psyche has been heard.

If no images appear after the first laying of paint, most of the paint can be lifted off with tissue and more paint added and lifted. This process can damage the paper so there is a limit to

how many times it can be done. If images are not appearing, Shields would interpret that to mean that the psyche is not ready to proceed and would suggest taking a break from painting, and/or to meditate. It is important to understand that images are outlined from the blotted paint that appear and not thought of independently and then imposed into the painting, although some details may be intuitively added, such as a pattern on fabric, or buttons on a coat. The student is often surprised and puzzled by what appears and does not consciously know how one image is related to another, or what the images represent, until the dialogues are done in a meditative state.

Dialogues

To explore the meaning of the panel, the student writes in their journal. First the panel is described in detail, using words that are objective such as “I see a figure, holding an oval object,” rather than, “I see a woman, holding an egg.” The subjective details are added later. The purpose of describing the panel is for the student to look closely in order to really see what is before them. Then the figures and objects in the panel are addressed the way one would work with dream images, for example, by using active imagination—an imaginary dialogue between the student and the images. The student asks the figure what they have to say, or why they have appeared. Once again, in a meditative state, the student writes whatever comes to mind. The process might be similar to other art forms like creating dance or poetry, and there is often a musical flow to the words that can easily drift into poetry. Through dialogue, the images or figures reveal a deeper understanding thought to arise from the unconscious. Shields believed that “images evoked from the unconscious, and the energies they can release, can manifest in physical symptoms and external events” (Johnston, 1997, p. 20). It should be noted that the story that is revealed may not be entirely the student’s own story. It may be a cultural myth or

collective story, or may refer to people other than the student; in some cases it may have a resemblance to unfolding current events, or, for some people, may in retrospect, seem prophetic (Johnston, personal communication December, 2012).

The dialogues are often surprising to the student because the language is not language or words that they would normally use, either because it is formal or archaic, or it introduces words that the student does not usually use, such as in my mandala where figures describe themselves as “guides,” or appear as “angels,” or speak of “God.” The dialogues can be as surprising to the student as the images were, and the student may have no conscious thought of what will be said before the dialogue begins. It is also remarkable that the figures seem to have different voices: some are very tender, some authoritarian, and some humorous, and there are often puns and plays on words.

The dialogues may reveal something about daily life but often focus on the student’s way of being in the world and draw attention to patterns of behaviour that may not be serving them. There are often images and dialogues that relate to aspects of the past, which the student is then able to connect with the present. Sometimes the images and dialogues seem to prophesy where a particular behaviour or attitude will lead. Shields believed that by tracking synchronistic events the student is responding to the psyche’s efforts to draw attention to elements that are in need of their conscious attention. Both seeing the images and entering the dialogues can be intense and the student will benefit from the emotional support, direction, and insight provided by their mentor.

Journal Work

Once the student has described the panel and dialogued with the figures, the features of the landscape, and any other items that appear in the panel, the student writes about the dialogues in their journal. The benefit of doing this is that connections can be made to daily events, or to synchronistic events—such as some aspect of the dialogue that mirrors other events in daily life. Shields thought that it was important to notice repeating themes, and believed that the unconscious mind is trying to bring something to the student’s attention by repeatedly providing messages, through daily events, through the images in the paint and the dialogues, and through dreams. Throughout the mandala, both dialogues and journal writing are done, in order to make subjective sense of the painting.

The Second Transition Ring

The fourth ring is another Transition Ring. It helps the student to move away from the personal story in the Narrative Ring and toward the Sacred Ground or Wasteland. In this transition, the student leaves the story behind, rests, reflects, and prepares to journey solo into unknown territory. It is a place to prepare to shed one’s old self. Once again, the transition represents change, and how the student responds to or moves through change will be reflected in this Ring. It should be noted that as the student gets closer to the centre, more time has been invested in the mandala, so that each choice about colour and shape seems more important, and there is more insecurity about making a “good” or “right” choice. There are no rules about how this Transition Ring should be painted other than it begins with a thin wash of colour and is painted in a clockwise direction.

The Sacred Ground or Wasteland

Although both terms, Sacred Ground and the Wasteland, were used by Shields to describe the ground before the square (and the Portals that lead into it), I prefer the term Wasteland. The Wasteland is the part of the process where the student is alone after having uncovered their complexes (in Jungian terms), or unconscious story. This can be a time of intense feelings of aloneness, as the student leaves what is familiar, the known story, and sets out to find their unique pathway through the Wasteland. During this time the student can feel disoriented and have a sense of despair, but may also feel relief at having been freed from the intensity of having thoroughly explored the story, which often has an emotional, disturbing quality. At some point in this wandering, the Portals appear, and it becomes apparent that they are either Gateways or Obstacles that invite the student to go deeper and more fully into understanding the original question without being weighed down by the “old story.” In any case, the world appears to be different now that the story is conscious. It is here that the student prepares to see the world, or the issue that they have been focusing on, in a new way. The student paints the Wasteland by laying a thin wash of colour. The brush work becomes finer as the student moves toward the centre. Shields did not suggest a particular technique or any rules about painting this section.

The Portals

The preparation that was done in the Wasteland is needed to face the challenges that arise as the student passes through the Garden Wall, shedding the old self as they gain entry through the Portals into the Sacred Garden or Inner Sanctum (see Figure 3). The student is now in a transformed state, and each portal contains a key, an opening, or an insight that helps them to see

in a new way whatever they have been struggling to understand. It is not that the student has become a new person but that they have returned to a simpler state where the “story” recedes and the essence of their humanness emerges.

To paint each portal, the student, once again, begins by using a thin wash, followed by the application of more paint that is lifted with tissue, allowing an image to emerge. It is important to understand that the image appears *from* the paint rather than being imagined and imposed on the paper, allowing what is unconscious to become consciousness. The student then outlines and fills in details, and then dialogues with each figure and part of the landscape in a journal. When all four portals are completed the student gains entry through the Garden Wall and begins to understand what has been protected or defended, helping the student to understand what has been both lost and gained by having erected a metaphorical wall. Once that understanding is gained, the student enters a final transformational stage, where the opposites come together to provide resolution. Resolution is meant in the sense of being able to hold the tension created by opposing forces, being able to see them as separate and yet interpenetrating and defining each other. Whatever the student has been struggling with is now more integrated into the psyche.

A Focusing Question

Working within the structure of the Sacred Mandala requires a complex method of exploration that necessitates focus, mindfulness, and commitment to one’s inner processes. It provides a structure or container for a profound psychological exploration, and when paired with a question such as mine—“What is it like to face death every day?”—provides a focus for meditation, contemplation, mindfulness, and journal writing. Subconscious material rises to the

surface and presents insight that can take years to understand and integrate. Adding a focusing question was my own addition, based on my research on synchronicity (Breiddal, 1996).

Johnston (1997), a mandala student herself, described the mandala process:

Ritual mandalas often take up to a year to complete, as the brush work is precise, and there are many layers, levels, and passages, which allow for integrating of emerging contents and knowledge. At each step of the way, encouragement is received to record and process thoughts, feelings, sensations, and intuitions in a mandala journal, with a corrective view for distortions, and other ways in which we may be “off our mark.” The journaling and painting create balance between the masculine and feminine elements, in that one enters into the lunar irrational world of deep imagination, coupled with the solar process of thinking, writing and articulating ongoing processes of discovery. Overall, ritual mandala work is an integrating “wholing” process. (p. 80)

My hope in creating a mandala was to represent the whole of the experience of encountering mortality, and in so doing to uncover and reveal, or hold in full view the opposites or paradoxes.

I began my own mandala with a variation on my research question, “What is it like to face death every day?” Concurrent with thinking, participating in research activities, and writing my dissertation, I continued working on my mandala by painting and keeping a journal. The phrase “journal writing” describes both a psychic space and a physical place to write thoughts and insights about my research. In my journal I tracked synchronistic events, defined as “the simultaneous occurrence of a certain psychic state with one or more external events which appear as meaningful parallels to the momentary subjective state” (Jung, 1960, p. 441). I also explored images that arose from paint and paper, and from dream images. I made use of my imagination to assist in understanding, along with thoughts, memories, and feelings about my research project in general.

It might be helpful at this point to make an explicit connection between the structure of the mandala and the writing of my dissertation, although it should be understood that I

experienced the painting as unfolding in a natural way, and it was not consciously meant to coincide with any particular chapter. Although the table below shows a linear progression that appears neat and tidy, the experience was neither linear nor simple. It seemed more like a spiral swath than a line from one point to another, as I moved in a clockwise direction around the mandala, and at the same time wrote toward the final chapters, constantly circling back to earlier chapters. Although I had completed an entire draft of the dissertation, I continued to be affected by the painting. For instance, I made substantial changes to Chapters 2, 3, 5, and 7 after the painting was completed. The mandala work and the academic work continuously interpenetrated each other.

Mandala

- Preparation for beginning the mandala: gathering materials, ritual beginning by lighting a fire, drawing the circles and squares
- Ring of Fire
- First Transition Ring
- Narrative Ring
- Second Transition Ring
- Sacred Ground or Wasteland
- Portals
- Garden Wall
- Inner Sanctum or Sacred Garden

Dissertation

- Reading, preparing for exams, writing a proposal
- Writing the first chapter.
- Writing the second chapter.
- Gathering the data and analyzing it.
- Submitting a partial first draft, of the data analysis, getting feedback.
- Resting, thinking, reviewing, integrating
- Refining my understanding of the data through thinking, painting, and writing. Writing about my experience with the mandala, adding to the literature review.
- Writing the final chapter.
- Ready for submission.

For a more detailed understanding of how I approached the entire research project I turn now to an outline of the method. In the following chapter, I will describe the setting for my study and outline the steps that I took. In the interests of confidentiality, I will continue to refer to the particular organization for which I work as Meadowview, and I will not identify the city in which the study took place. The term *hospice* is used interchangeably with *Meadowview*.

Chapter 5: Study Method

The Setting

Meadowview hospice is located in a mid-sized Canadian city. The hospice is supported through gifts from the community, and is in partnership with the local Provincial Health Authority, which also provides care to dying patients at home, in hospitals, and in care facilities. It is a medium-sized unit serving approximately 400 registered patients, with a substantial counselling department that includes a spiritual and religious care provider, as well as a nursing department, support staff, a number of leaders/managers, a medical director (physician), and a small group of physicians. Meadowview's interdisciplinary team is primarily made up of counsellors, nurses, physicians, and volunteers. In addition, there is a roster of community doctors who are contracted to assist with coverage on weekends and evenings, and a pharmacist, an occupational therapist, and a physical therapist. Psychiatrists are available for consultations. Meadowview's palliative care program is comprehensive and well established in the community.

Meadowview's website reports that the manager of Volunteer Services is responsible for training, supervising, and supporting a large group of trained volunteers. These volunteers are assigned in shifts to the in-patient unit from 8:30 a.m. until 11:00 p.m., doing such tasks as answering call bells, delivering meal trays, helping the nurses set up and feed patients, sitting vigil, comforting family members, making and delivering tea, doing errands, and providing hands-on healing. Volunteers work in the bereavement department and in the community both in direct service with patients and families, and indirectly behind the scenes.

This is the general context within which the co-researchers work. The term *counselling department* at Meadowview refers more to the people and their training than to a physical space,

since our work is done not only in our offices or at our desks, which are spaced throughout the building in small groupings, but on the unit in patients' rooms; in common spaces such as the lounge, sunroom, or meditation room; and the counselling offices, as well as in patient's homes, or occasionally in coffee shops or outdoors. The counselling "department" is not seen or experienced as something separate from other parts of hospice.

The co-researchers are all counsellors drawn from the counselling department at Meadowview hospice, and work within the context that it provides. It is an advantage as a researcher to be part of that culture because phenomenology is contextual, specific to the lived experience of particular people in a particular setting. Understanding that context and having established relationships within it offers the potential to reduce the gap between researcher and participant. This is essential in relational research because understanding experience arises out of the relationship between the researcher and the co-researchers (Finlay & Evans, 2009).

The co-researchers are a group that is often caring, favours being non-violent, and can be sincere, earnest, serious, co-operative, gentle, and actively engaged in life. But these are all value-laden words that paint a particular picture—albeit a fairly positive picture—and might be equally true if prefixed by "overly." Despite reservations about stereotyping, I can say that we are a group of middle-aged people with varying degrees of experience at Meadowview. We are all Caucasian, born and raised in Canada, and appear to be from a middle-class socio-economic background. Some have partners, some have families, and some are single. I have not specified whether I have included any men in the co-researcher group, and have been vague with pronouns in certain instances. We are fairly representative of the other counsellors who work at Meadowview. The counsellors in our department are mainly Caucasian, we identify as heterosexual or homosexual, and some of us belong to one of a variety of religious groups such

as Buddhist, Catholic, Jewish, and Protestant. From casual conversation, most of us seem to follow spiritual practices such as prayer, yoga, or meditation, and/or view physical activity and interaction with nature as providing similar benefits to those derived from spiritual practice. Our staff members appear to me to be fairly representative of the relatively homogeneous community in which we live, albeit with a noticeable absence of staff members representing the First Nations population.

All members of the Palliative Care Team encounter mortality daily in a palliative care context but I decided to focus on those who work on the crisis team because it is one of only three teams in Canada that provide 24-hour counsellor-nurse service seven days a week. There is no literature on the lived experience of a counsellor/nurse palliative care crisis team. In other parts of Canada it is more typical for homecare nurses, who may or may not have formal education in palliative care to serve the community's palliative care patients. From conversations with other social workers at conferences, and with nurses and homecare nurses across Canada in my online classes, I have discovered that it is uncommon to have a team that is available 24 hours a day, seven days a week, or for there to be such easy access to a psychosocial care expert.

Meadowview hospice is housed in a building on the grounds of a hospital. It houses only palliative care patients and palliative care offices. While there is a dedicated unit counsellor who works five days a week, from 9:00 a.m. to 3:00 p.m., serving the patients and families who are being cared for in the hospice building—that is, on the in-patient unit—PCCT counsellors are expected to cover the unit patients and families when not called to the community. The regular unit counsellor also may work casually on the PCCT, and in the Bereavement Department. For this study, I chose to focus on counsellors rather than nurses and physicians because of the dearth

of studies to date that have focused on the experience of psychosocial specialists—that is, counsellors or social workers. It is important that the voices of counsellors are heard because of their essential contribution to the palliative care team, to patients and families, and to palliative care as a whole. This study is an opportunity to give voice to the lived experience of this under-reported group.

The Co-researchers

Other successful phenomenological studies have focused on one person's lived experience (for example, Camargo [2005] and Johns [2007]), while other studies have consisted of small groups of four to eight participants (Eddy, 2008; Steigman, 2007). In choosing participant numbers, I faced a significant practical constraint: the crisis team and the in-patient unit have a limited number of counsellors. My request for volunteers, however, yielded six, including myself, which in phenomenology is considered an appropriate number (Eddy, 2008).

While all interdisciplinary members of the team are expected to provide holistic care, the main job of a counsellor is to address the psychosocial needs of patients and families, as well as the needs of colleagues and the process issues of the team as a whole. In other health care contexts, psychosocial care-providers are usually referred to as social workers but at Meadowview the term *counsellor* is used. We belong to various professional bodies including counselling and social work associations. No one in our department belongs to a psychological association. In this dissertation, the term *counsellor* refers to professionals who have a Master's degree in Social Work, Counselling Psychology, or Child and Youth Care, and who were hired into the position of counsellor. Although spiritual and religious care is provided at Meadowview by a specific member of the counselling department, I have excluded this category from the

psychosocial care/counsellor designation because that role requires distinctive training with different goals and purposes than that of a counsellor, even though there are overlapping roles as in all parts of the interdisciplinary team.

The Research Steps

An application for approval of ethics on human studies is a requirement of this research. In this application I outlined the proposed research and the potential harms and benefits. Once my study was approved I sent a letter to the managers so that they could have any questions or concerns addressed, and so that they could let the greater staff know what I was doing (see Appendix A). I then sent an email to the counselling department in which I outlined my project and arranged to make a presentation at a counselling meeting, followed by an outline of the project in writing to the target group (see Appendix B); a clerk at Meadowview sent an email inquiry from my University supervisor to preserve the anonymity of the counsellors. If they were interested in participating, they were invited to contact me via email. I assured the co-researchers from the beginning that I was only interested in understanding their experience; our supervisor would not know of their specific participation and therefore there would be no evaluation of either their writing or their counselling practice.

As van Manen (2007) clearly outlined, the people who are in conversation with a researcher are participants but because they are in a dialogue that creates meaning they can also be seen as co-researchers. I prefer the term *co-researcher* to *participant* as the word *co-researcher* establishes from the beginning that I wish to share exploration, interpretation, and control of the findings of the project. My intention from the beginning was to invite my colleagues to engage with me in a way that would ignite their interest, particularly in describing

the lived experience, but also in thinking further about the findings and their implications as we worked together to discover the experience of encountering mortality. I hoped that by participating in this exploration we would be better able to connect with others' experience of encountering mortality and in this way contribute to the body of palliative care knowledge.

To make my process clear, I provide a step-by-step summary below. It is important to remember that although I am not reporting the mandala work alongside the phenomenological work, they were parallel processes that melted or fused together, so for me it seems not quite accurate to discuss them separately. For clarity, however, it seems most appropriate to describe them as separate processes. The step-by-step method for the mandala was explained in Chapter 4 and the analysis and findings will be tied in with the analysis and findings of the phenomenological material in Chapter 7.

Outline of the Research Steps

1. Creating a process journal
2. Gathering the data
3. The first request and response
4. Identifying tentative themes
5. Creating stimulating questions
6. Creating categories
7. Forming a narrative
8. Taking time for reflection
9. Going deeper
10. Searching for the essence of encountering mortality

11. Seeking verification of my interpretation
12. Returning to the literature
13. Integrating the mandala
14. The role of the mandala
15. Discussing issues
16. Putting it all together
17. Looking ahead

Step 1: Creating a process journal. I began the research process by initiating a journal right at the beginning of the project. This journal was distinct from the personal journal that I was keeping for my mandala work because it tracked my thoughts and questions about the research itself as the research evolved. I wanted to be able to review my thought processes retrospectively as I came to a new understanding and to document my reasoning for the choices made at the time. When I eventually reviewed the process journal I could see the evolution of my thought process and could point to concrete evidence that I was coming to a new understanding. Without this documentation it might have been difficult for me to believe that I had not always understood encounters with mortality in this new way.

Step 2: Gathering the data. After receiving signed consent forms from my co-researchers, I began the study with an email request (see Appendix C). I chose to use email for correspondence rather than face-to-face or telephone interviews for the convenience of the co-researchers: not only would it allow for confidentiality, it offered the added benefit of allowing them time to consider and revise their responses. Online educators such as Meyers (2006) have suggested that in order to create a safe environment, the online facilitator can “validate students’ contributions and opinions, remaining attentive to students’ reactions and emotions, establishing

a norm of cooperation, ... and remaining open and available” (p. 220). Having been an online teacher, I knew that it was possible to create a sense of safety and intimacy by monitoring the tone of my emails. This can be done in composing emails by taking the time to reread the initial draft, trying to imagine different tones with which it might be read, and inserting words that direct the reader to understand it in the way that it was intended. It can also help to be attentive and sensitive to the nuances in the emails received from the co-researchers, to make a point of responding to every email, and to always remember to thank each co-researcher for their contribution.

I decided to use an open-ended question in the first round in order to allow plenty of room for the co-researchers to reveal their lived experience in their own ways (van Manen, 2007). In an email, after welcoming them, I once again explained the study in general and gave them some specifics, such as why I was using the word *mortality* rather than *death* (see Appendix C). I asked each of them to share a story or two about their encounters with mortality as a palliative care counsellor, inviting them to write as much or as little as they wanted.

Van Manen (2007) suggested that researcher’s practise writing a description of lived experience before asking the co-researchers to do so, because it helps the researcher to understand more exactly what is required. I wrote about several experiences of encountering mortality so that I would know what it might entail for the co-researchers. This helped me to instruct them, when it came to writing and responding to later questions. I also thought that if I answered all questions before reading the responses of the co-researchers, I could be sure that my answers would not be influenced by theirs. My goal was to “pay close attention to the other with curiosity, empathy, and compassion, encouraging them to share their perspective” (Finlay & Evans, 2009, p. 38), while at the same time recognizing the differences between myself as a

researcher and them as co-researchers, maintaining “sufficient distance to challenge and be critically analytical where appropriate” (p. 38). It was also important to me that I was not asking the co-researchers to write about aspects of encountering mortality that I was not willing to write about myself.

When one person did not respond in a timely fashion I wondered if they were having difficulty expressing their thoughts in written form and so I decided to offer a face-to-face meeting. This worked well and we ended up meeting four times for about three hours each time, totalling about 12 hours of face-to-face time. I wrote down what was said verbatim, which was not difficult as I am used to making detailed notes when my private therapy clients are speaking. I used pen and paper the first time but switched to using my laptop computer after that. In retrospect, the combination of email and face-to-face meeting allowed for some variety, and enabled me to ask clarifying questions in the moment. The variety may have led to different results than only email would have produced, however. I wondered if face-to-face interviews would have produced fuller answers because I was encouraging the speaker to continue to speak through my body movements and my words, and in some ways may have challenged the speaker to think more deeply about the subject. If that occurred it might have added to the study, but I was aware that my presence and interaction had the potential to inadvertently direct or lead this co-researcher, and the potential to taint the study because the other co-researchers did not have that option. I have a background in child protection interviews, where it is very important to let children use their own words, and I was trained to use open-ended questions and not leading questions. I referred back to this training and made a conscious effort to stay very close to what the co-researcher was saying without imposing my pre-understandings or personal biases.

When I analyzed and summarized my own responses, I wrote in the third person, as I did for the others. For example, I summarized my own writing: “She seems to enjoy the process of becoming attuned to another person and incorporates ways of doing so that involve internal actions, like noticing her body sensations, but can also be an action such as making eye contact.” By conforming the style of my written responses to those of the co-researchers I was able to take some distance from my own writing, which made it easier to search for themes, and to blend my responses with others, with the conscious intention of not privileging my own perspective.

It is the responsibility of the relational researcher to use their own unique ways of building relations in order to reach out to the co-researchers (Finlay & Evans, 2009). I had informal conversations on the topic of encountering mortality with four of the five other co-researchers, as well as other members of the team, such as our nursing colleagues, other counsellors not participating in the study, several physicians on the team, and my supervisor at Meadowview. I had the co-researchers’ permission to use informal data, but was unable to directly use the information from others on the team because I not did have their permission. The conversations with team members did stimulate my thoughts, however. For instance, when a new person came to Meadowview and joined our counselling staff, we were at our regular counselling meeting when a spontaneous discussion began about our lived experience of the work. At other times, I was able to talk about related topics with my nursing colleagues as we drove to our community visits. A few times I met individually with co-researchers for dinner, and the conversation naturally moved toward related topics. I was also aware that some co-researchers identified themselves to each other and discussed the survey questions together. I interpreted these conversations as a way in which the study was enriching the co-researchers’ thoughts, as I had promised in the invitation that I had sent out when we first began. A few times

co-researchers commented to me, after reading an initial draft of my analysis of the data, that other people seemed more articulate, or seemed kinder or more present in their counselling practice. When co-researchers compared their experience with that of their co-workers, usually in a way that made them seem less than their co-workers, I made every attempt to be supportive and to acknowledge their feelings. I also pointed out that I was looking for a range of experience, and I appreciated the uniqueness and authenticity of their experience as reflected in how they had presented it to me.

Step 3: The first request and response. When I received the first responses by email, I read each one carefully and where I had done the face-to-face interviews with one of the co-researchers, I included the transcribed interview with the rest of the data, as if it had been sent to me by email. I then put them aside to read later because “the purpose of reflection is to try to grasp the essential meaning of something” (van Manen, 2007, p.76), which takes time. I continued to read and re-read with periods of incubation so that I was immersed in the co-researchers’ responses. Findlay and Evans (2009) said:

It is important with phenomenological analysis to take time to dwell with the raw data such that implicit, layered meanings come to the fore. The process involves a focused act of discovering sedimented meanings, nuance and texture out of silence. The more you stop and linger, the more you will feel yourself engaging the phenomenon, perhaps re-experiencing the sense of it. (p. 229)

Then I read all the responses together, in order to move toward understanding the essence of the experience through “reflectively analyzing the structural or thematic aspects of the experience” (van Manen, 2007, p. 78).

There are advantages, when there is a great deal of data, to being systematic. Van Manen offered three ways of looking for themes: the wholistic or sententious approach; the selective or

highlighting approach; and the detailed or line-by-line approach. Although elements of all three were used, I began with the line-by-line approach. I took each separate response and created a page with two columns: the left-hand column was the verbatim response, broken down one sentence at a time, and the right-hand column was where I recorded my thoughts and comments. In the right-hand column I also inserted dictionary meanings for some words, to try to understand more fully what the co-researcher might have meant and to ponder the underlying nuances (Finlay 2011; van Manen 2007). I then summarized the response, incorporating my expanded understanding, and focused on what was being said about encountering mortality on a daily basis in a palliative care setting. I made daily entries in my process journal as I went between the individual responses and the responses as a whole, identifying tentative themes with the purpose of developing a “narrative that (could) explicate themes while remaining true to the universal quality or essence of ... the experience” (van Manen 2007, p. 97).

Step 4: Identifying tentative themes. I then took these tentative themes and went through all the data in the left-hand column, assigning each sentence a theme. If there was no theme into which the sentence seemed to fit, I created a new theme to add to my list. Van Manen (2007) distinguished between essential themes and incidental themes and encouraged the researcher to ask, “Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon?” (p. 107). I used this question as my guide.

Step 5: Creating stimulating questions. I then created a list of questions that might stimulate more writing on each theme. My questions grew out of the first responses and were closely linked to what some co-researchers had said, which meant that some questions resonated more with some co-researchers than with others. Each co-researcher received four sets of about 10 questions (see Appendix D). Some people wanted to have one set sent every week, while

others wanted me to send a new set of questions as soon as they responded. For the person whom I interviewed face to face, I set up a series of weekly home visits and once met spontaneously at work.

This created an overwhelming amount of data, which I struggled to keep up with at times, and yet in retrospect I can see that the design helped to string out the responses, giving me time to ponder the responses as I received them. By going between being active and being reflective—that is, by writing and then having periods of not writing—I was able to absorb the material, so that thoughts occurred spontaneously throughout the day, not just at my desk when I was actively seeking ways to understand. I continued to keep a process journal whether I was in an active period of writing or in a period of rest in order to record my continuously occurring thoughts.

Step 6: Creating categories. By following Husserl’s maxim to return to the things themselves—that is, the co-researchers’ daily encounter with mortality—I moved constantly between what is apparent and what is hidden. “The hermeneutic circle states that one cannot understand the whole until one has understood the parts, but one cannot understand the parts until one has understood the whole” (Schimdt, 2006, p. 15). This conundrum was addressed by my beginning with a description of the main features of the data, in the summaries that I wrote, followed by a review of “grammatical and psychological interpretation of the parts” (p. 15). In this way I kept looking toward an ever-changing horizon of understanding.

I pondered the categories and rearranged them, trying to see how they fit together or related to each other, trying to get at the essence of experiencing mortality, sometimes putting two or even three together and sometimes breaking one into two. For instance, I realized that

working at Meadowview regularly brings home the idea that we are going to die and bearing witness to the physical reality is the avenue for that idea to become real. Knowing that we will die, and recognizing the myriad ways that this might happen, becomes one category with two parts.

The categories evolved, grew, and shrank as I worked with the data by reviewing it sentence by sentence and organized clusters of sentences or paragraphs that seemed to belong together from the verbatim responses, cutting and pasting them into the categories that I had identified. I considered putting some snippets of the co-researchers' responses into multiple sections but realized that would become unwieldy very quickly. By that time I knew the material very well and could recall stories and responses easily if I was writing and thought of a particular piece that might fit well. I was extremely careful not to screen, filter, or show preference to any particular writer or perspective. It should be noted that there was a range in the responses, with one co-researcher answering as few as five of the 60 questions, while the others answered every question or almost every question. For all co-researchers there was a range in the length of responses from a few words to several pages for one question. If I wanted the co-researcher to say more on the topic I asked further questions and usually got longer responses, but in the case of one co-researcher I did not receive further elaboration.

Step 7: Forming a narrative. I placed the responses into categories and systematically worked through each one to form a narrative, working with whatever sections I had placed there, reorganizing as I went. I realized that there was a developmental sequence to the responses, beginning with the initial call to palliative care, moving on to early responses such as shock at the physicality of dying and the realities of death, the intimacy and intensity of relationships and making (or not making) connections, that then lead to more discriminating aspects of practice

such as stillness, the realization of the mundane or ordinary aspect of the work, and in a sense, a return to the call resulting in a sense of service. The time-line of how the co-researchers were affected by encounters with mortality became the foundation of what seemed to be a story or narrative.

Van Manen (2007) said that in order to co-create meaning we must dwell within the text. By writing, rewriting, and reflecting I had to focus on the experience of encountering mortality as it was reported to me. To do this I continued to email the co-researchers, asking them for more and more specific descriptions of their experiences. To understand the experience of encountering mortality daily in the palliative care context, I had to allow myself to go through a process. This resonated with my experience as a counsellor, where I co-create understanding with the people with whom I work through reflection and discussion—over time.

Step 8: Taking time for reflection. I had been focused on the data, completely immersing myself in it for hours before my afternoon shift at Meadowview and on all my days off. When I referred to van Manen (2007), I found that taking a break after reviewing the responses from the co-researchers was a necessary step in the process. I decided to take a break from writing and from all school work for a week and to spend time painting instead of writing. This break allowed me to come back to the material in a fresh way. Van Manen (2007) wrote that a phenomenological study is of life as it is lived, but it can only be understood after the fact as it is not possible to have an experience and reflect upon it at the same time.

I was able to refer to my experience as a counsellor, where I do not expect to discover the meaning of someone's life or the troubles they have interacting in their lives by "intellectual training and the acquiring of information" (Rogers, 1957, p. 246), but to understand them

through a relationship. This concept could also be applied to the data. I needed time to be with it, to think about it, and to be able to ask more questions, even though I knew that the reality was that I could not expect to ever truly, fully understand another person's reality. I was not looking for or expecting to find a final statement of truth, because everyone and everything in this study—the co-researchers, the patients and families, the community, and the world in which we live—were always changing and simultaneously interacting with other changing systems.

Step 9: Going deeper. As I began to write my way into understanding the material, I realized that I had to ask more pointed questions about what the co-researchers were experiencing. For instance, if I ask someone what it is like to work at Meadowview, I am asking a very open question that can be interpreted in many ways, thereby generating a wide range of answers. One person might respond with “It’s great! My work is different every day.” Or, “It’s a great organization, really supportive.” Or, “It’s a job.” These responses are first-level responses, they do not tell me about the lived experience. But if I then ask what it is like for work to be “different every day,” I might get a response such as, “I have to be on my toes, I can’t just get into a routine, there are no formulas.” I might then ask that person to tell me what it means to “be on [your] toes,” or to “work without formulas.” And so it continues, with one question leading to many more. A similar process of clarification with individual co-researchers went on by email, over a period of four months, and various topics were revisited as my understanding became more complex. I had to constantly ask myself how the co-researchers’ responses and comments related to their *lived experience* of encountering mortality, which is the fundamental question of phenomenology.

Step 10: Searching for the essence of encountering mortality. To enact the hermeneutic circle required me to return to the co-researchers, which I did on numerous

occasions, to clarify and confirm that I had understood what they had said. This gave them an opportunity to make changes as well, as they had more time to think about what they had said, and I made all changes as instructed, until they agreed and were able to validate that I had understood what they had said and meant. As my writing and thinking expanded and my understanding of the lived experience revealed the complexity of the experience, I sent them newer versions. They then began adding to what others had said, sometimes agreeing and at other times vehemently disagreeing.

As my writing formalized into chapters, I continued to send it back to my co-researchers. I received a wide range of responses. One told me that she had been “deeply touched” by the content, another wrote back that it was “beautiful ... it’s perfect.” Some were meticulous in their comments, asking me to make what seemed like minor changes while others wrote to me that they were sure that what I had sent them was fine, which led me to suspect that they had not read what I had written. One person openly admitted to not having read all of it, but suggested that I had used more quotes from other people than from her. I was able to talk to her about this, assuring her that I used every piece of data that she had given me.

Step 11: Seeking verification of my interpretation. Ultimately, completing the hermeneutic circle required me to return the final piece to the co-researchers to see if it seemed authentic and accurate. I hoped for and received the hermeneutic nod of recognition that, yes, this is what the everyday experience of encountering mortality daily in a palliative care context is like. Almost all the co-researchers expressed gratitude that they had been heard and acknowledged and commented that they felt that having spent the time thinking, writing, and discussing their experiences and then seeing their words in print had been enriching. Once again

there was a range in responses, from a long email thanking me for providing such a “powerful and enriching experience” to a one-line email that said that my rendition was “fine.”

Step 12: Returning to the literature. As I came to see the whole, I became curious about what the literature might say about some of the topics that my co-researchers were discussing. I turned to the literature to enrich my new understanding of what I was finding. This was in line with what van Manen (2007) suggested, that turning to the literature is most appropriate after the lived experience has been thoroughly examined. “In this way” he said, “the work of others turns into a conversational partnership that reveals the limits and possibilities of one’s own interpretive achievements” (p. 76).

Step 13: Integrating the mandala. Fairly early on, I made a decision to include an edited version of the dialogues together with a photo of each panel, so that the reader could see the narrative in both words and images, but later integrated these into the text. I considered the journal entries—where I processed my feelings, worked with dreams by dialoguing with the characters and reflecting on the meanings of the objects in the dream, tracked synchronistic events, and recorded meditations on the Tarot card Death—to be equivalent to the co-researchers’ responses to my questions. This recognition formed the basis for my decision to treat the journal writing in the same way that I treated the co-researchers responses, that is, as raw data that would not be published in its entirety. Instead, I quoted liberally from the journals and the dialogues, as I did with the other data.

Phenomenology requires the researcher to move beyond ordinary thinking, and although that is a skill that is used in counselling, I wanted to know how I might do that in this study. In preparation for my exams and eventually my research, I decided to experiment by writing about

an incident that happened at work to see what it would be like to reflect upon a journal entry of an encounter with mortality. Below is an example of my first attempts at moving beyond ordinary thinking, in preparation for my research. I began by reflecting upon a community visit where I met Mrs. White.

Mrs. White had appeared in my mind for several weeks after I visited her in her home. Imagine that a lens focuses on the notation that might appear in the psychosocial notes in her hospital chart after a palliative care crisis team visit. It might also be referred to as the naïve version of the story. In my journal I wrote:

The team was notified by the Home Care Nurse that Mrs. White's condition was changing and a route change was required (indicating the patient was too weak to swallow pills, and needed her medicine delivered in liquid form under her tongue, or by a small needle under her skin). While my nursing colleague prepared medications and spoke to Mrs. White's caregiver, I took over from the Home Care Nurse who was seated at the bedside, holding the patient's hand. Mrs. White had been well cared for by a privately hired caregiver, and died peacefully within thirty minutes of our arrival, before medication had been given. The family arrived just as Mrs. White took her last breaths, and I facilitated them to gather at her bedside. Information and support was given to her caregiver, who had never witnessed a death before, and to the family whose grief was complicated by other recent losses.

The lens moves closer, toward one small part of the story—"I took over from the Home Care Nurse who was seated at the bedside, holding the patient's hand"—shifting ever so slightly then speeding up, and moving further into the words, revealing the enormous landscape within that small image. This is an entry from my journal:

I arrive at the house with my nursing partner and go into Mrs. White's bedroom where she is neatly tucked into bed. Cathy [the Home Care Nurse] is seated at the bedside, holding her hand and leaning into the bed towards Mrs. White. Cathy asks me if I will take over for her, gesturing with a shrug towards Mrs. White. I notice the hearing aids resting on the side table at the same time that Cathy says to Mrs. White in a tender voice, "Mrs. White, I'm going to take my hand away, but someone else is here." I say to Cathy, is she holding your hand? Cathy replies, "Oh yes, she's holding it." I take a seat and put my hand where Cathy's was, underneath Mrs. White's hand.

The lens hones in on a closer view as revealed in my journal entry:

I feel hesitant at Cathy's invitation. I ask her if Mrs. White is holding her hand because I want to determine whether she welcomes this contact. I feel warmth towards Cathy because she appears to feel comfortable, so caring towards Mrs. White. She wants to hold Mrs. White's hand—she wants Mrs. White to know that someone caring is for her. Cathy has her hand placed under Mrs. White's hand so that Mrs. White can be in control, so that she can move her hand away if she wants to. This is what we have been taught.

I want Cathy to stay, so that I can talk to the caregiver. I feel better able to talk or listen than to be. I feel no connection to Mrs. White and I don't want to touch her dry and papery hand. I don't want Cathy to think badly of me, to think that I am uncaring. Am I uncaring?

Cathy has shown me that Mrs. White is worthy of attention, of tenderness, of the intimacy of touch. Her gaze creates a bridge that takes me from the edges of the room, where I want to be, to taking a seat beside Mrs. White. I place my hand under hers. It is soft, dry and unmoving. Because I don't want to hold her hand, my hand is not savouring her touch, I don't lean my skin into hers, but rather hold it stiffly, making as little contact as I can manage.

The lens zips forward through the present scene, into my imagination. In my journal I wrote:

My imagination wanders as I dissociate from what is happening. I wonder what it must be like to lie there, unable to hear, and too weak to open my eyes. I visualize myself in a small light body. Immediately I feel vulnerable ... I wonder if she is in a state of trust, just lying there. She certainly is in a position to need to trust, but to trust she would need to surrender. Maybe she had no choice but to surrender. I don't really know what is happening inside her, I can only imagine what it might be like for me, with the experience that I have now. What would it be like to outlive a lifetime partner by twenty years? I see my husband in a coffin, me crying at his side, having to build a new life. A change in Mrs. White's breathing brings me back to her side. She has my attention; I lean towards her and make a slight adjustment so that the palm of my hand touches the palm of her hand.

As is evident from the samples provided, there are layers to any story. By dwelling or lingering on my own experience a shift occurs in my understanding of what took place in my interaction with Mrs. White. I was able to experience what it might be like to enter a phenomenological exploration.

To add to the complexity of my academic and personal thinking and writing, I had begun my mandala work, and was painting a repetitive image of fire around the Outer Ring. I was keeping track of synchronistic events and dreams, and was working with the images that appeared in the painting, through active imagination. Having finished the flame, I was staring at the spaces in between (see Figure 4). (All the photographs of the mandala in this dissertation were photographed by Jane Johnston, 2012.) I was wondering how to paint the spaces between the flames (known as the negative space). I wondered what I would do about the “negative spaces.” I was struck by the term *negative space*, and I explore through writing in my journal what “the negative spaces” mean to me, as the lens moves closer.

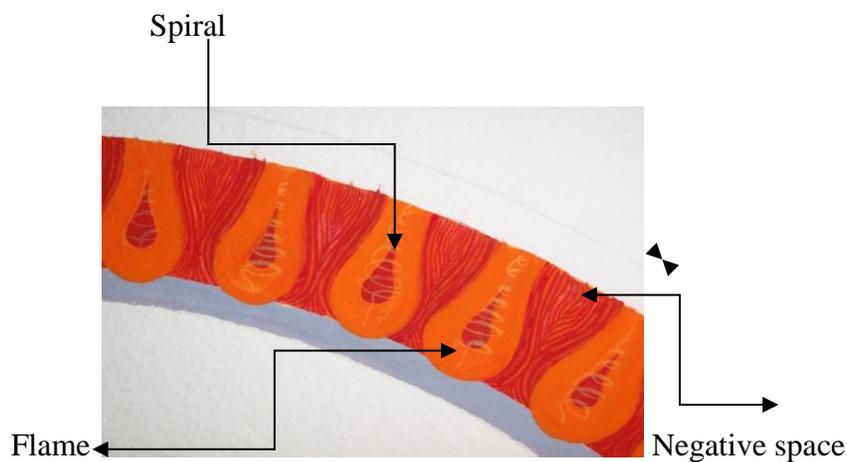


Figure 4: Section from the Ring of Fire

A section of the outer ring of the mandala that shows the flame with a spiral in the centre and the “negative space” between the flames.

In my journal I wrote:

What could the negative spaces mean? What is the negative space of death? Is it life, or is it nothing? I tend to think that it is life, but what if it is nothingness? It seems that the flame is life and that the reverberations of our lives flow into space, creating ripples in other people’s lives through their memories. Those ripples are superimposed on the environment that is already there, creating a unique pattern, and in that way, we leave a legacy.

Now I am thinking about Mrs. White again. I was in a “negative space” when I was with her. I did not want to hold her hand. My response was not life enhancing really—feeling nothing, in the sense of not wanting to move towards her, or feeling no connectedness. Those moments of holding her hand, of being invited to come closer, moments that I did not physically run away from, but rather stepped closer into, have lingered. The family expressed appreciation for our efforts—grateful that we could be there. I am sure that I appeared caring, even when I first arrived, but as Heidegger warns, the semblance of something can hide something else.

As I continued to paint I began to see not only the reverberations but also the cups or chalices that had formed between the flames. And now the lens takes us through another image, and a world within a world is revealed. I write in an academic paper:

Does familiarity with mortality appear to create comfort or ease with mortality? Does this semblance or appearance of understanding cause me to appear as a “special” kind of person? I agree with Heidegger (1953/196) that the danger comes when I believe that I am comfortable or at ease in my encounter with mortality, and even worse, as Dechamps (2011) points out, that I think that I am special.

I ponder this idea of being, or seeming, special, and again the lens moves deeper into the experience. I write in my paper:

At times I meet death with compassion and loving presence, and at other times I feel fractured and disconnected. I can swing between the ends of this spectrum, from moment to moment. Sometimes I am met in my desire to connect, and other times I am not. It is my desire to meet each with equal ease—both my own dis/connection and that of others. At work, as in life, encountering mortality is not something that is done once, and then again, but rather continuously, over a long period of time. I can envision the process of connecting and disconnecting to the reality of death as a spiral that takes me deeper and deeper into life, while at the same time moving me closer and closer to death. This spiral contains within it a circle or whole that contains the paradoxes that are created as we approach and support death. Even so, the spiral, although describing a circle is always moving and stretching its outer boundary.

And so it goes, back and forth between thinking and imagining, contemplation and action, and words and images. In terms of the IMAX lens that either moves into microscopic detail or pulls back and looks from a distance, the writing, painting, and exploration of lived experience represent an inexhaustible exploration, bound only by where I decide to draw the line.

The Sacred Mandala provided data that informs the topic, interweaving and complementing all that phenomenology has to offer. Through its use I discovered aspects of the daily encounter with mortality in a palliative care context that may otherwise have been inaccessible to me.

Step 14: The role of the mandala. Initially, I had provided the above description of the interweaving of my mandala work in the Ring of Fire with my academic work to help me to understand the idea of being present. I thought this might be sufficient to describe the role that the mandala had played but was left with an uneasy feeling that I had not done justice to its powerful role in helping me to understand the data, and to process the sometimes overwhelming feelings as I lived and breathed encountering mortality. I wondered how I could convey the importance and power of the Sacred Mandala work without fully discussing the role that it had played in helping me understand the lived experience of encountering mortality. I turned to van Manen's Phenomenology Online and noticed that he described three ways that knowledge arises from phenomenology: "knowledge as text (product), knowledge as participation (understanding), and personal knowledge (being)" (Inquiry: Epistemology of Practice, para. 1) I read that knowledge as text must be understood to include the embedded meaning in the text and that "Phenomenological knowledge-as-text has cognitive and pathic, conceptual and poetic, informative and formative dimensions" (Inquiry: Epistemology of Practice, point 1). This knowledge then is integrated not just into our intellectual understanding but into our way of being which affects how we interact with the world, "it enhances our perceptiveness, it contributes to our sense of tact in human relations, and it provides us with pathic forms of understanding that are embodied, situational, relational and enactive" (Inquiry: Epistemology of Practice, point 3).

That clarified that the provision of a detailed phenomenological description of the lived experience of creating a mandala while studying encounters with mortality could provide “cognitive and pathic, conceptual and poetic, informative and formative dimensions” for my research. It would contribute to understanding in a deeper way encounters with mortality and ultimately provide a “pathic” form of understanding, and I began to think of it as representing the experience of the experience of exploring the lived encounter with mortality.

As I was reading, writing, and reflecting, I was also painting, meditating, and writing in my personal journal. This was an intense, rich, and powerful experience in itself. As stated above, it did, however, create the conundrum of how to represent the mandala work. It was difficult to conceive of exactly how I would integrate this data into the rest of the paper. Should I present it on a chronological basis, keeping up step by step with the dissertation, inserting journal entries and images alongside the discussion? I tried to do this initially but found it more disruptive than helpful because I was tracking two separate processes—that of the co-researchers as a whole and also my own personal process—and it only seemed to interrupt the flow. The most puzzling aspect—and the most difficult to deal with—was that the material generated from the mandala seemed to be primarily personal rather than of universal interest.

As I neared the end of the data analysis, I realized that I faced a timing issue too. How could I finish writing the analysis and the final discussion if the mandala was not painted? How could I finish the painting and have it accurately represent the journey if I finished it before I finished the paper? In order to be true to the method I set for myself, I decided to stop writing at one point in order to concentrate on painting so that the Narrative Ring would coincide with my writing the data analysis section. The other sections fell nicely into place so that when I was painting *The Wasteland*, which is a place between what the student has known, or the story, and

a new place that has yet to be discovered, I was integrating what I had learned from the data.

It was after this period of dwelling in the Wasteland, somewhat lost, that I had the idea of linking the themes from the co-researchers with the themes in my mandala. At first, keeping aware of the themes that I had identified in Chapter 6, I specifically looked for ways in which the mandala work had contributed to my understanding, beginning with *The Call*, and systematically linking my mandala work to each one. I then began a phenomenological analysis of my mandala journal, treating it in much the same way as I had the data that was gathered from the co-researchers. I read each entry separately, then every entry as a whole, several times, and later highlighted what I thought might be important themes. I found, however, that I could not make a linear link either by theme or in time by associating the images I was painting with what I was writing about. Instead, I realized that the value of the mandala really lay in the emotional connection that I felt with the images and the journal work. It was the emotional impact that brought such vitality to my research. I then decided to represent the mandala work by following the turning points in my understanding as the mandala work unfolded, linking those turning points back to the themes provided by the co-researchers.

I began the four portals as I was writing Chapter 7 and finished them as I was writing Chapter 8. When I got to the Garden Wall I was involved in the final editing—deciding what would be in the final version and what would be cut or left undeveloped. I arrived at the place of knowing, the Inner Sanctum, as I finished the final chapter, Chapter 9, and actually finished writing within hours of painting the centre of the mandala. As mentioned earlier, however, I did go back and make substantial changes in my writing after completing the mandala.

Step 15: Discussing issues. After completing the analysis of my mandala work I then read my entire dissertation thus far and identified issues relating to the lived experience of encountering mortality daily in a palliative care context. It was important at this point to include the voices of the co-researchers from Chapter 6 in order to fulfill a commitment to recognizing them as collaborators in meaning-making. In Chapter 8 I included excerpts from my mandala to give an example of how the phenomenology work and the mandala work weave together.

Step 16: Putting it all together. As I re-read my dissertation, and after reviewing the feedback from my committee, I still felt unsure about the role of the mandala work. I was concerned about its place within the whole, wondering if, by describing its background and creation and articulating my own process, it had overshadowed the material provided by the co-researchers. I also realized that by putting my story into the public domain I had an ethical responsibility to protect the identities of my friends and family members. Although I had included everything that the co-researchers had written so as to accurately reflect what they had told me, I had left out details that referred to our specific family members. For instance, one co-researcher wrote at length about a situation with relatives, and I was able to discuss the issue without including personal details that might identify those family members. It was even more challenging in Chapter 7 to protect the identity and experience of my family members, because they would be immediately recognizable. I wondered if I could refer only to the issues in the mandala work and still convey its richness.

To provide some context I will briefly describe the situation that led me to recognize the place that I wanted the mandala work to take and how defining that place provided the criteria for making decisions about what would be included and what would be excluded. Several years before I began to write my dissertation, and while I was still doing coursework, I was introduced

to reflective narrative work (Johns, 2007, 2009). Dr. Johns, a nursing professor and alternative health care practitioner specializing in palliative care, focuses his work on the exploration of everyday experience with the purpose of advancing practice. He described the narrative journey in the preface to *Guided Reflection: A Narrative Approach to Advancing Professional Practice* (Johns, 2011) as

a journey of self-inquiry and transformation towards self-realisation—a way of enabling health care practitioners to research self in the context of their clinical practice within a community of inquiry. Self-inquiry, through skilled and dedicated guidance, is *seeing what is and going beyond it* [emphasis in the original] towards self-realisation, however that might be known. (p. vii)

Around the same time, our manager at Meadowview had approved a request that counsellors within our department be allowed to form small groups to provide peer support on paid time. I shared some information on dialectics (Johns, 2009) at the first meeting of my small group and we agreed to work toward writing about everyday experience in the way that was suggested by Johns (2011). Since I had kept journals of my working shifts for several months for one of my research courses, I had a huge source of material to work from. Following John's suggestions for dialogical movements, I wrote a number of stories and then read them to my small group. Not only did the stories stimulate discussion on practice issues, they inspired my colleagues to share their stories. Our time together helped us to think about our practice and created an emotional bond between us. For me, the memories of our shared stories and discussion remained long after our meetings.

I realized then that I had a need to be witnessed, which I believe my co-workers shared, and that by listening to and telling stories of everyday life at hospice, we were participating in what seemed to be a sacred process of honouring our work. Furthermore, I recognized that it can often be difficult to express our experience outside of our work environment and our discussions

were a much-needed way of validating our experience as palliative care counsellors. Seeing the value of this approach I began to think about how I might use creative processes as a way of improving our team relations and advancing our practice. Furthermore, since our organization was experiencing some stress in interpersonal relations among our team members as well as with various community partners, I wondered if I might use John's methods to help repair and develop relationships at work, particularly with colleagues from other disciplines.

I approached my supervisor to ask if I could trial a session within the counselling department. I was hoping that if the session was successful, I might apply for a research grant or submit a project plan that would enable me to extend an invitation to staff and community partners to meet regularly in order to continue the work that I had started in the small counsellor group. The session with the larger group of counsellors went well and I was encouraged to reach out to the nurses at Meadowview.

Later, while I was still struggling to decide how much of my mandala work to include in my dissertation, I happened to have two conversations with different co-workers in rapid succession, one a counsellor and one a nurse on the in-patient unit. They each expressed to me that they had a need to enter some kind of discipline or structure that would allow them to understand and process the intense emotions of their work. Each was looking for some way to make meaning of what they were doing. It was then that I finally realized that the mandala is one example of how creative processes can not only provide understanding and advance practice in a palliative care setting, but also create the necessary structure to safely express feelings, contain moments of understanding and insight, and honour the sacredness of everyday life.

I hoped that my own sense of being vulnerable by sharing my struggles with encountering mortality might be offset by the value of offering a valuable creative process, as a form of self-care. Just like the structure of the dialectic movements provided by Johns (2009) had allowed our small counselling group a structured way to reflect upon our everyday activities at hospice, the mandala was a creative process that might provide others with the needed guidance and structure (Johns, 2009, 2011; Johnston, 1997) to explore not only issues in palliative care, but any topic of importance.

I then understood how to decide what was reported and what was not reported about my personal process. I would focus on examples that revealed my dawning understanding of encountering mortality, or demonstrated the value of the mandala work as a creative process for caring for the self and advancing practice. That way, the focus would remain on what the researchers had to say, but would clearly demonstrate the value of the mandala, providing an example, and an alternative to the prescriptive approaches to self-care that run through the self-care literature.

Step 17: Looking ahead. Van Manen (2007) said that phenomenology is primarily about “thoughtfulness . . . a heedful, mindful wondering about the project of life, of living, or what it means to live a life” (p. 12), and that the ultimate purpose is to the “ministering of thoughtfulness” (p. 12) through being responsible and responsive. Moving towards the goal of being responsible and responsive, I explored some ideas about ways in which this research might help those of us who support, train, and educate palliative caregivers to become more thoughtful in our practice.

In this chapter I have outlined the steps that I took in conducting my research and in the next chapter, Chapter 6, I present the co-researchers' perspective. In Chapter 6 the terms *us* and *we* refer to my co-researchers and me, unless otherwise noted. To preserve anonymity I have deliberately chosen to be vague in attributing quotes to any one person. The reason for this is that the co-researchers or our colleagues may have heard, or read in the charting, about another counsellor's involvement in a specific case, or recognize personal histories, and would therefore be able to identify that person and all other quotes attributed to their alias. In being vague I reduce the possibility of connecting a known story to an unknown narrator and thereby identifying the writer. I have used two letters without periods to represent names, and I may have assigned more than one set of initials to each person, so that the reader remembers that it is a real person who has spoken, but will be less likely to identify the writer. I have at times, used gender-neutral language where it is possible to tell the story gracefully without identifying the gender of the writer. This is a strategy to further protect the identity of the co-researchers by creating doubt about their gender. I have tried to avoid the awkwardness of using double pronouns throughout this dissertation and continue this practice here.

Chapter 6: Giving Voice: Returning to the Phenomenon

Talking about dying is very difficult. We are afraid that talking about death beckons it. We all know death is inevitable; death fascinates and disturbs us; but we don't want it to happen. Maybe, we think, if we don't talk about death, death might not notice us. Maybe if we ignore death, we might delay or even elude it. (Kuhl, 2002, p. xv)

Grief is different for everybody. Not everyone cries. Some people have feelings of overwhelming sadness. Others feel guilty, thinking that if only they had said or done something differently things would not have turned out as they did. People may also feel angry, lonely or confused. Such feelings can be frightening. We may feel a loss of control, or that expressing strong emotions is not appropriate. (Lipsett, 2006, p. 1)

Facing death prompts a spectrum of complicated responses that can range from relief and welcome, to fear and avoidance. It may be difficult to understand why people would choose to place themselves where death is inevitable and recurrent. When we were children and were asked what we wanted to be when we grew up, I'm fairly sure none of us said, "I want to attend to the dying and bereaved." So, how did we choose this occupation? Did life events play a part? Or is there something particular about our makeup? Did this occupation fill a need for employment, or does the work have a deeper meaning? What made us think that we could do this work and why would we even want to? Responses to these questions varied among those contributing to this study, but a common factor is the remembrance of a defining moment when each of us was called to palliative care.

The Call

KZ's initial motives for applying for a position at Meadowview were economic. She was apprehensive when her friends directed her to the hospice, wondering whether she could do a good job in this field, but applied anyway. In her interview she exposed what she calls "the good, the bad, the ugly" about herself. Being hired indicated to her a confirmation that this was a place where she was welcome to be who she was: "a person who thrives where there are

intimate connections,” where meaning is in the “fabric of the environment,” and where this meaning becomes the “shawl I wear around my shoulders.” When she arrived for her first shift, she immediately had the sense that she had “come home,” in the sense of feeling at ease or finding where she belonged. As she looked around the patient unit, she noticed the serenity and the intimacy between people.

Being called to the realm of death for some is the surrender to divine guidance, the call of fate, to what we feel moved to do, a call toward a vision of what might be, or better yet, how we might be. In retrospect KZ believes that God guided her friends to direct her to Meadowview, or in other words, that hospice found her rather than her finding hospice. She thinks that by not resisting the work because of her fears of not being able to handle the “abyss” of grief, and by accepting that she was reticent before she came, that she “arrived safely” to this field of work, “like being carried by a divine river that deposited [her] on to safe ground.”

For many students, choosing social work as a career “represents a response to a call and a context for fulfilling one’s purpose” (Joseph as cited in Faver, 2003, p. 64). Gustafson, in “Professions as ‘Callings’” (1982), said that where there is a sense of calling “there is a perception and interpretation of the significance of one’s activities as contributing to human well-being and to a larger whole, and there is a self-perception and self-understanding that adds dignity and meaning to one’s own life” (p. 504). JJ said that in the aftermath of the sudden death of a close relative, friends, family members, acquaintances, and professionals just “showed up.” Some—a few—met her grief. They stroked her sweaty, shaking body, they fed her and all the people who arrived, and they tended to her bewildered children. They attended to practical tasks, like buying groceries and vacuuming. They did not appear to be afraid of her utter despair, expressed in long periods of primal wailing. Their presence, the solidity of their being—physical,

emotional, and spiritual—provided refuge, something to hold onto in the storm of her emotion. But something else happened. JJ found that the safety afforded by their presence allowed her to let go, to just let go and give up. “Surrender” was the word she used. She felt that she became no longer apart from her grief; that she no longer clung to what was. She allowed herself to be “tumbled in the waves ... turned upside down.” She was no longer commenting on or evaluating the pain, but being the pain, and from there,

it just happened, I felt a sense of unity with all people who have ever lived, are living now, and ever will live ... a deep getting it ... in every cell of my body, beyond what words can describe. I knew it in my whole being that to be human is to suffer, and in our suffering we are connected. In that moment I felt deep, deep love for myself, for my intense pain, and for all living beings that feel pain and struggle with what it means to be alive. By coming to hospice I hoped to be the kind of person that turns towards death, the kind of person that provides refuge through knowing what death can offer. I believed that the people at hospice would understand the profoundness of death and the potential for transformation when death is embraced rather than avoided.

This glimpse of a different reality, one in which interactions with others are loving, extending beyond the personal to a visceral sense of unity, provided her with a sense of being deeply connected to all of life. As EO cared for her dying loved ones she noticed that the regular “masks and personas” that people so often don in social situations fall away in the face of death. She felt herself arriving at the bedside “as herself,” which naturally, effortlessly brought about a delightful, surprising ability, a willingness, to welcome the Other in whatever form it came. She found herself not “acting loving” or “becoming loving,” but “being love.” She described this being as a sense of uncovering, or better still, a way of remembering what was always right there in her very nature:

I feel intensely present in the unfolding of the moment—all senses wide open; deeply engaged, attentive and curious; non-attached—to outcome, people’s decisions, what will happen ...—but not detached; willingness—to feel and be moved by life; grounded; compassionate; open-hearted—literally open/spacious in the centre chest; empty/spacious/still—like an enormous container in which the experience of connecting

is unfolding; and yet full—vibrant/humming. There is a timelessness. In these “experiences” there is the sense of the particular beingness of the one meeting the particular beingness of the other “underneath” social construction—roles, status, gender, race, etc.—and recognizing/knowing itself as Beingness.

For me there is a sense of sacredness and deep respect here—a meditative, devotional stance in the world within which my training and skills are employed.

The call to the realm of the dying is a dawning awareness that there might be a different way to encounter mortality. Service calls to us by offering a hope that caring for the dying and bereaved will teach us something about how to live, will teach us something about what it means to be human. JW’s father died when she was young. She wanted to understand her own experience, why she was the way she was. There was no one to help her. This longing to feel at ease, to accept what was so unacceptable and yet what was, became the call to service, the promise that it was okay, it was safe to not know, to stand amid “the sparks that death continually emits.” As a way of explaining, she told of holding the hand of a young woman who was dying, and, as she did so, noticing everything.

I sit by her bed. She is beautiful and does not look like she is dying. She has make-up on and a slouchy cotton hat to cover her bald head, her beautiful lithe body conceals the dying that is happening within her. I slip my hand under hers, and feel the heat of her hand, notice the long, slender, young fingers and the beautiful nail polish and I wonder ... I breathe and I allow myself to enter this vast space of unknowing. I don’t seek answers. In a sense, the question is the answer and that is enough, I feel full.

Being called to the realm of death is to be pulled out of the everydayness of life, a willingness to be off-balance, to have our sense of safety and familiarity challenged, to have the comfort of thinking that we know how it is, constantly disrupted. The call to the realm of death is to surrender to uncertainty, change, and discomfort. CW was drawn to that which is outside normal experience. She wanted to be awake, alert. She liked to be the “stranger living on the edge.” She was not interested in “the realm of normal.” She said that the sick are isolated in leper colonies, isolation wards, support groups, palliative care units, away from “domestic

reality,” and to heed the call of service was to follow the dying to “the outskirts of society.” In that society, in one particular week, for instance, there were 15 deaths, too many too fast to really know anyone or even remember their names.

[A]ll that remains are impressions: flickers of conversations, the colour of one daughter’s hair, a tea cup held like an urgent promise, a photo of youth propped next to the bed. In the moment of being with that dying person and his or her family/friends, there can be a shock of intimacy, a connection that is real and mysterious. That, in itself, feels like something that happens outside of the centre. I am not seeking anything—I am not looking for a date or a job—I am only there to be present and, hopefully, useful. I have no expectation of a future with any of these people—everything is focused on this moment. This is not an exchange—I am not a neighbour who is offering a casserole to a widow knowing that someone else might do this for my husband when I die. This is a blessing pulled out of us.

The call to the realm of death was a call to an alternate world, a world outside day-to-day routines, a world where the shock of death brought her into the moment—no plan, no agenda, no control. For CW, when she is at her best her “work is a prayer.”

How does the promise of a different way of being get lived out? Is it possible to maintain that desire, that commitment? In coming to hospice there is a feeling of uneasiness, uncertainty, self-doubt about whether we can provide all that caring for the dying and bereaved asked of us. Will we be able to sustain caring through the “depth, heaviness, and messiness of people’s sorrow and despair” (KZ)? There are challenges in turning toward death, even when we have the desire and the willingness to do so. What has it been like to have D/death arrive at our doorstep every day?

The Realities of Death

The experience of working in the palliative care context apparently offers depth, meaning, and purpose to those who work as professional caregivers and provides an opportunity

to practise being present, loving, and kind (Collett, 1997; Groves & Klauser, 2005; Papadatou, 2009). It also necessitates what can be an uncomfortable proximity to the ugliness of death (Papadatou, 2009). Despite having various comfort levels and experience with the physicality of death when we began, the reality of death and dying was a powerful experience. As WF said, “What really hit home to me was the incredibly vulnerable state that we humans operate from on a daily basis. Sometimes, if I let it, this fact almost takes my breath away.”

Typically the counsellors at our hospice came from social work, child and youth care, or counselling backgrounds. One co-researcher has degrees in psychology and counselling psychology, and the others have degrees in social work, counselling, leadership, or transpersonal psychology. Half obtained a social work degree at the local university, where the course, when I attended, focused on preparation for child protection or probation work in rural settings. None of our degree courses included preparation for working in a hospital or medical setting. In my social work class we were trained to help people deal with their emotional, social, financial, and spiritual concerns. In practice situations we sat face to face, or side by side, and talked. Social workers studied family systems, social policy, child protection law, and the effects of colonialism on First Nations people. We learned to solve practical problems such as how to fill out financial forms, find housing, or offer strategies to improve parenting skills. If we took psychology electives, we studied unconditional positive regard, cognitive dissonance, or dream analysis. My cohort was required to take one counselling course, in which we studied active listening, Robert’s Rules of Order, and how to facilitate workshops. Half of the co-researchers attended this same university, and most likely their programs varied slightly, depending on the year of study. The content of my professional training did little to prepare me for palliative care social work. BH had a similar experience but identified as helpful both a course on “the art of

listening” and writing a dissertation on coping skills, which was beneficial in understanding the various ways in which most people deal with adversity.

Aside from academic training, some co-researchers had had a close relative or friend die, and some had participated in a dying friend or relative’s care. Although RB had seen several dead bodies, she had no direct experience of caring for the dying and what she knew of impending death was gleaned from whispered conversations that may or may not have accurately described dying, and from the media—books, TV, and movies. As she said, “My vision of death from illness came from movies where family members surrounded a plump, rosy-cheeked patriarch, who gave a heartbreaking speech, before closing his eyes, after which someone pronounced, ‘He is gone.’” JJ had never been close to illness, and had never been admitted to a hospital. She had no medical training, other than mouth-to-mouth resuscitation for a swimming badge. “I came to hospice and it was like walking into an alien world, where everyone was speaking a foreign language, except I was expected to understand and converse fluently. I was definitely a stranger in a strange land.” JW’s understanding of death before coming to hospice came courtesy of Hollywood.

I really didn’t question that notion of just laying down, putting your head on the pillow and letting go. All airbrushed and beautiful. I guess in a way, ignorance is bliss! When I started at Hospice I was in for a rude awakening about the process, the actual physical and emotional and spiritual process of dying.

She remembered what it was like when she first started at hospice.

I could barely bring myself to enter a patient’s room, it seemed so sacred, so intense, so precious and profound, sometimes I would catch myself, in those first weeks, saying things to myself like “My God, someone is dying in there!!” And thinking about it a lot, afterwards, mulling over the experience and sometimes even shuddering when thinking about the fact that a patient was no longer. Period. Their world on this earth had gone black.

SW was taken by her mother, out of a sense of honour and respect, to see Diefenbaker after he died in 1979. Her mother believed that visiting the elderly and attending funerals were ways of honouring their elders and paying respect to history and culture. Later, as a world traveller, SW saw the starkness of death in conditions of war and during the HIV/AIDS epidemic.

I saw bodies wrapped in blankets in Swaziland, being carried to graves. I saw dying people sitting, legs straight in front of them, in the hallways of hospitals in Malawi. MANY people in Swaziland and Malawi had HIV+. They called it the “slimming disease.” People were skeletal. I saw many malnourished children in the clinics I visited in Malawi. Their arms were threads against bloated bellies.

When she settled in our community, she volunteered through her religious community to visit the sick and to prepare bodies for burial. She responded to a woman who announced to the congregation that she was dying—“I leaned in and took a risk and became her friend”—sitting vigil at her bedside at hospice in the final weeks of her life, she recalls...

I did not have any medical knowledge before working at hospice. I did not have any medical training, not even first aid. My training was in visiting old relatives and travelling and sitting down next to people and trusting that words would find their way between us.

In my imagination, death looked like old age and a surprise and a relief and a horror. This is still true for me now. I never trusted what I've seen in movies. My fiction-based impressions of death and dying came more from literature. It was useful and mainly accurate. I had an awareness of the imperative of living well in order to die well. Kindness. Truth. Integrity. These and other values are our only options as preparation for illness and death.

BD had always been interested in medicine, medical language, and the workings of the body, particularly after dealing with her own injuries and through her interest in yoga. She had a background in biology and her father, who was a “geologist and nature buff,” provided her with “road kill” to dissect when she was growing up. Although she had a number of childhood friends die, she did not see a dead body until she saw her partner after he died.

She said,

I'm not particularly troubled by dead bodies—there's a kind of serene beauty and peace around them I often find, and one of the most rewarding aspects of the work for me is to have the opportunity to help the family or the RN wash and prepare a body for transport to the funeral home. My spiritual practice also helps as I see/feel the separation of the essential/energetic self from the body around the time of death.

BH had only Hollywood movies for information about what a dead person looked like, until one day while at the beach BH stumbled upon a dead body in the water while snorkelling, and then later came upon another at the family cabin. Later, enrolled in a two-year medical training program, BH said that, "In my work life, I saw many, many, many dead bodies, from many, many causes including peaceful death from illness, to traumatic deaths of adults and children."

It is obvious from the co-researchers' stories that there is a tremendous range of prior experience with illness and death. While some were well versed in caring for the dying and witnessing death, and familiar with hospitals, hospital systems, medical language, and medical knowledge, others had little or no previous exposure. The desire to work at hospice does not seem to be related to the amount or kind of prior experience, but rather that we had all been touched by death in a personal way or had witnessed death on a larger scale. But what was it like to encounter death from illness?

All of us were given a short introduction to hospice, lasting from one to three days, where we were told about the structure of Meadowview, and how our services fit into community services. We were also given three to four buddy shifts over a two-week period where we worked side by side with another counsellor, learning about our role as a counsellor working with patients and families, our place on the interdisciplinary team, and the flow of paperwork.

We attended any courses, professional meetings, and social events that were of interest or were relevant. With the exception of BH who started in the bereavement department, we came onto the palliative care unit, or we entered a person's home, and were taken straight to the patient's bed, where we were met by the smell, the sight, and the visceral experience of emotion surrounding a dying person. We maintained a cool exterior, hoping that no one would detect the inner turmoil, the instinctive response to pull back, to shield our eyes, nose, ears, and skin from what was happening. Despite the call that each of us felt to be there, on a visceral level there was a part of us that did not want to know. EO said that it was as if her "animal body" was running from what she felt bound to witness. RB experienced a sense of surprise and disbelief, mixed with revulsion that bordered on horror:

Who knew that a person can bleed from their eyes, and that tumours can poke out of the chest, neck, or back, erupting like some alien body snatcher, or that your skin can become so swollen that it bursts, seeping fluid through multiple openings in the skin, the body literally weeping?

Being confronted with what it actually means to have a body full of tumours, a body that is actively breaking down, can be a shocking experience. BD could hardly believe that there are so many ways for the body to "compost itself while we are still using it!" Our brains could not absorb the reality as we watched "living bodies breaking down and returning to earth—rotting (necrotic or fungating tumours and fistulas), recurrently vomiting (obstructions), horrendous odours, hemorrhaging" (BD). The smell of feces caused KZ to feel woozy, like she might pass out, when she was helping a woman to the toilet; she felt an urge to gag when she saw a man with no tongue or jaw spilling gin and tonic on himself as he tried to drink. RB recalled a vivid memory of her first day.

I'll never forget my first day when I was led by the unit counsellor to the bed of a woman who was the colour of yellow lentils, the whites of her eyes a bright pea green. She was

eating some kind of mushy food at her bedside table. All of my good intentions went out the window. I wanted to run—I certainly did not want to be present, or to accept things as they are. She had a kind of pleading look in her eyes, and in that moment I wanted nothing more than for her to be spared.

SW hoped that her response to the physical would get easier, but even after years as a palliative care counsellor it has not.

I am resistant, I am scared. I do not want to be exposed to stiff limbs and the heavy, dark, hidden smell of earth. I used to think that caring for the dying and the dead would become easier with time. This is not my experience. The images—visual, olfactory, and tactile—accumulate and live in me.

KZ remembered the nurses talking about a wound or a tumour, or some aspect of bowel care. She would freeze, feeling the need to protect herself, an internal protest, a long “Noooooo! Don’t!” The nurses would say, “Okay, KZ, cover your ears.” She came to realize that “people can bleed to death,” and says that, “I have a weak stomach when it comes to things coming out of the mouth—mucus, shit, vomit, blood.” She said that when she first came to Meadowview it was like being abruptly awoken from a deep sleep and having no time to get her bearings, a “slow but rude awakening.” Like losing your innocence, it is an adventure that you cannot come back from. “You can’t go back and not know, or not remember horrible images” (KZ).

Under these circumstances, how were we to maintain a loving presence? What happened to our meditation practice, our desire to be present—non-attached to outcome and able to accept that death occurs? For some, it seemed natural to wonder if, even to hope that, this person in front of us could be saved. How did we fight the impulse to run away, and instead move toward the people who were suffering, which is what we were trained for what we were called to, and most wanted to do?

The specialized knowledge of caring for declining bodies is hidden, so that those without training are naïve and unprotected. For RB, there was fascination, mixed with revulsion, wanting to know but not wanting to know, a deep ambivalence that did not go away. For instance, an innocent question—“What do you actually mean when you say you did bowel care?”—produced horror and embarrassment when the nurse took out a piece of paper and drew a sketch of the bowel, followed by a demonstration, “charades style,” of how she puts her finger into the patient’s rectum and, hooking her finger, pulls out a hardened stool. After that, whenever RB saw a nurse coming out of a room with gloved hands, she “steered clear.”

RB said that she wants to help people to recognize that what is happening is natural, and is therefore nothing to back away from, but she knows that she doesn’t actually feel that way herself. She wants so much to convey to patients that she accepts them the way they are, with the body they have, and when she sees others, whether patients, families, or colleagues, who seem more at ease than she does, she feels badly. She says that she never knows for sure how much she should admit to her own sense of squeamishness, and feels fearful of “being put to the test” of being exposed, of coming up against something that she just cannot bear. She explained that, for her, a tension underlies every visit: “what will I see, or smell, or have to touch?” There is a strain, a discomfort, a pull between her desire to appear comfortable in front of patients, family members, and colleagues, and her secret revulsion. It is an effort to disguise her apprehension, and she finds ways to not have to touch, see, or smell. She remembered a home visit to a woman who was lying in a hospital bed in a tiny living room. There was no place to be except right in front of the patient. It was shocking to her because the woman “appeared to be nothing more than a breathing skeleton.” She described how the husband looked so worried and

was so tender and loving toward his wife. The nurse asked RB to put her hand under the woman's head while she shifted the patient in the bed.

I looked at the greasy, wispy strands of hair stuck to her scalp and I just could not bring myself to touch her head. There was a long pause while I stood dumbstruck, the nurse and the husband looking expectantly at me. The nurse nodded, which was more of a prod, and I knew that she had no idea why I was just standing there. I slipped my hand under the pillow and supported the woman's head that way. . . . I hate admitting this . . . I feel ashamed of myself, and very much alone. My squeamishness is a barrier that separates me from the patients that I really want to be close to and it separates me from my colleagues too. I can comfort myself by saying that I am fearless when it comes to emotional or spiritual pain, but it doesn't really make up for this sense of inadequacy that I feel, this sense of being a fraud. I know that I am being deceptive. Now that doesn't fit with how I present myself, does it? It is very uncomfortable.

BH, despite having had experience as a paramedic, was afraid to work with the dying—not so much because they were dying but because of a feeling of inadequacy in the role of hospice counsellor.

I did see patients being wheeled around in wheelchairs and beds and I have to say that I was somewhat scared of them, or more likely their circumstance. . . . I felt totally inadequate in my role. What if I said something inappropriate and embarrassing to all of us? I believed this time is an important, meaningful and even sacred time in people's lives and I think small things said by "professionals" can make a big difference. What kinds of things were patients and families struggling with? Would I have the answers? Upon reflection, I think my fear was a mixture of fear of death and fear of inadequacy, probably more so the latter. Once I felt more comfortable speaking with family after months in bereavement, I didn't feel so unprepared when I later ventured into the land of patients.

The willingness with which we came to hospice was clearly tempered by a tentative entry as we began to understand the process of dying, and experienced the full impact of what occurred on a physical level and how that affected the emotional, spiritual, and social aspects of being human. Initiation into the realm of death comes through bearing witness to the physical frailty of the human body.

A person's dying process and death are lived experiences, recorded by all our senses. The sight, the sounds, the smells and the physical touch of the dying person and to the dead body all trigger unique feelings, thoughts and response that often leave lasting imprints. (Papadatou, 2009, p. 43)

The relentlessness of the interaction is something that we could not wholly prepare for. Something within us constantly wants to pull us away from the reality of death, and at the same time provides a push toward that reality—out of compassion, the desire to help, curiosity, fascination, and wonder. Encountering mortality can challenge our sense of how to be in the world, leaving us at times disoriented and disheartened, and at other times inspired and filled with awe and reverence for life. For some of us, how to be in the face of death remains an ongoing question.

Being in the Know and the Impact of Knowing

As difficult as it was for the co-researchers to experience the shock of the physical reality of the frailty of the human body, we also appreciated having the opportunity to “demystify death” (WF). KZ thought that it was “a privilege to be aware,” and as BD said,

[B]ecause I am so regularly exposed to the fact of dying, the compartmentalization (that others feel) is harder to maintain—so I know in an embodied way (I FEEL it in body/mind/heart) that those I love will die and I will die.

JW said that although she has been shocked many times, working at Meadowview has helped her to learn about how the body moves through the dying process.

In a sense, it helps me with my spiritual practice of not identifying too closely with the body. The idea that I want to do all I can to maintain it, and be grateful and to hold it lightly as it really does have a mind of its own during the dying process. I think my innocence helped me to make the choice to come to Hospice. I've been initiated into the process of accompanying the dying slowly, sometimes harshly, over the past ... years. In the end, this work and this constant reminder that “death, too, is in the egg” as poet Anne Sexton says is a spiritual practice in its own right. For that fact alone I am ever grateful to have this work.

We as co-researchers admitted that, before coming to Meadowview, when we experienced losses in our own lives—the death of a loved one—we felt the immediacy of death, but that immediacy quickly dimmed, so that death could remain distant and mysterious. It was not until death was encountered closely, and daily, that the reality “hit home” (JW).

The physicality of death does not allow much room for us to believe that we can avoid our own appointment with death, and cannot be separated from the confrontation or knowledge that death is real and that dying is not just a possibility. Knowing this in an immediate way can be isolating. As WF shared, “I am so used to brushing up against death and mortality that I forget that most of the world does not live with this intimate knowledge on a daily basis.” Being reminded of our own mortality daily became woven into our daily lives. The fabric of the weave comprised both the urge to pull back and the urge propelling us forward into service. It is as if we have been allowed into a sacred order. In this sacred order we learned about what it was to be human, about “the fragility and uncertainty of life; a noticing of the truth, which is constantly reinforced” (SW).

Any illusions of being in control faded as we found out that we “cannot guarantee ourselves a long life through exercise, or diet, or lifestyle” (SW). We longed for safety, for comfort, for refuge from the face of death. The shocking physicality, together with the awareness of our own mortality, however, cannot remain foremost in our minds all the time. And even if it could, would we want to stay in a constant state of awareness? Is that something that we should strive for? Is it something we can achieve? Despite what we want, or what we think might be best, the knowledge that we are going to die does not seem to be a static state, even for us. For instance, caring for the dying and bereaved makes SW’s “life more vivid,”

which she noted was both “good and bad.” The experience is good in the sense that she feels “surrounded by blessings”:

I touch my children and my husband with an urgency that is rooted in awareness that health is fragile and random. I touch my husband as a way to defy death and to taste life. I tell my children to notice life, to notice the strange powerful gifts of daily life. (SW)

The experience is bad in the sense that she said she feels guilty for not being more grateful:

[O]ften I am exhausted and numb. Entire days can go by, when I am off, in which I cannot speak or see anyone. I say that I am a zombie. Zombies are the living dead; zombies are the dead eating the living. On my dark days it feels like too much. It feels like death is in my hair, in my clothes, soaked into my skin in a way that marks me and wounds me and makes me untouchable.

Our strengthened capacity to be in the presence of death is a rising and falling tide that regularly wakes us up, carrying us toward the realization of our own mortality, and just when it seems too much, we are lulled back to sleep again, into the rhythm of our lives. WF said that there are times when she feels the opposite way: “I must confess, sometimes I feel more in denial about dying than ever before! I don’t know if it is adapting to death occurring on a frequent basis, but I can’t ‘feel’ the reality of death anymore.”

There is tension between being conscious of our mortality and the need to live well. For JW it becomes an effort to balance the strong directive to live life “NOW” without it “manifesting as an impulsive, urgent energy.” RB referred to a letter, apparently written by Steve Jobs, that was circulating on the Internet and that articulated a common piece of advice that we should “live each day as if it were our last.” “Really?” she questioned. “Living with that kind of intensity is unbearable.” For the co-researchers, that philosophy of life is a double-edged sword: appreciation for our lives creates a self-conscious pressure that can immediately dissolve any pleasure in savouring the moment. Then we feel as though we are being buffeted on the

waves—rather than lulled to sleep—moving between intense awareness of the reality of death that causes us to savour life, and a sleepy, numb, or frozen state, leaving us feeling guilty. As CW said, “Sometimes I feel guilty because I should be electric with life, savouring the gift of my good health.”

Being called to hospice through a defining event, and then recognizing the reality of what it actually means to work at hospice was an awakening that was, for most of us, horrifying, shocking, and intense. The knowledge of the frailty of the human body, and how it breaks down during the dying process was received with a mixture of awe and gratitude for the opportunity to understand what awaits us.

Relationships

Intensity. Intensity is certainly an outstanding feature of the experience of encountering mortality in palliative care. If *capacity* refers to the “ability to receive or contain” (OED, 2012), while approaching the “outer limits of what can be held” (OED, 2012), what does it mean to increase our capacity for intensity? The word intensity derives from two forms of the Latin term *intendere*: *intensus*, which refers to being “stretched or strained in a physical sense,” and *intentus*, which is to be “mentally or nervously stretched, intent, eager, attentive” (*Chambers Dictionary*, 2008, p. 535). Interacting with the dying and their families has an “extreme quality ... a high-strung quality of personal feeling or emotion ... strained or (to a) very high degree” (OED, 2012). *Intensity* also refers to the “quality ... of energy or feeling” (*Merriam-Webster*, 2012) and is related to the word saturation which refers to being saturated or “in a state of maximum impregnation” (*Merriam-Webster*, 2012). Tending to the dying and bereaved involves

intense energy and emotion and as caregivers we can feel saturated, like a sponge that cannot absorb or take in any more liquid—maximally impregnated with emotion.

It is like being absorbed by the other but the other is being absorbed in me. It is a blending, a coming together as one. Intensity is when there is nothing in my field of awareness other than the person that I am with, or the situation that is unfolding. Time stops and there is only this one person, this one interaction, this one situation. (RB)

For RB, intensity on a physical level is a rush of adrenalin associated with fear, but it can feel like excitement and has an “addictive” quality. She described a “flow of blood through my veins, an actual rush, more like a raging stream than a flowing river, or maybe like a flashing light that says wake up, be wary, and watch out” (RB). Intensity can be a strong emotion, such as a sense of deep sorrow that elicits tears. “I cry,” said SW, but the sorrow is “blurred—not really mine, but so acutely witnessed that I can feel the truth of the pain, or the love, or the loneliness.” JW used words and expressions like “stunned,” “being in a time-warp,” and “melting.” At the beginning her sorrow was so strong that it could not be contained, and ended in uncontrollable “bawling” (JW).

Intensity can manifest as a sense of inadequacy when we see family members who express the enormity of their grief with anger, “stuck in blame and judgement that lead away from the present moment back into historical stories and patterns of behaviour” (EO). Inadequacy is mixed with a sense of sorrow for the lost opportunity for love and connection that is so possible in this moment. Intensity contributes to the internal struggle to return to the place inside ourselves where there is compassion for those who are angry, with “closed and armoured hearts,” for those who cannot or will not be comforted (EO). Intensity might be part of the intent to realize, to accept that everything is impermanent—“everything in the world is coming and going including the body” (EO)—and to recognize as natural our frustration when the natural

flow toward death is prevented or resisted, or when the busyness of the system prevents us from “noticing what is sacred.” Intensity can be resentment, the sense of lost opportunity, and betrayal when bureaucratic blockades turn “honouring each moment of life” into “waiting for death.”

In the context of everyday language, we might describe a person as intense, and that might mean that they are extremely focused in a particular direction, without regard to anything other than the object of interest. Describing a person as intense could range from feeling admiration to feeling dismay, depending on one’s perspective. Or intense might refer to the experience of being in that person’s presence, which requires attention and focus to interact with them, and the comment that this person is intense is rooted in fatigue and relief that the interaction is over. In that case, to be described as an intense person can be a criticism.

Intensity can be the process of transforming anger or frustration into compassion. For JW, it begins with a tightening or hardening in her body as she feels her judgments of the “other” rising and her empathy “shrinking.” She reminds herself to breathe. This is how it plays out in practice:

In the situation where the woman was having a difficult time receiving the support of her family, and was blocking their efforts by endless chatter, I interrupted her, asked her if I might try something and then I breathed myself, this conscious breathing was my attempt to slow myself down, but had the effect of slowing the others down too. Then I intervened, asking her to be still and hear what her family member was saying to her, in effect, I was directing her, coaching her in “being” in a different way. Her son then said he would be happy to come and stay with her, he **WANTED** to do that. She quickly interjected, and I slowed her down again, and asked her to simply receive this statement. She tried it again. He then added a bit more, especially around the part of needing/wanting to be part of this process of supporting his Dad in his dying. I then asked her if she was able to hear this, to really hear it. By now, the emotional field had shifted to one of receptivity rather than defensiveness and she nodded and her eyes teared up. I didn’t say anything else, then the daughter also added a similar sentiment, and within a few minutes they were working out something of a schedule as to when they would come, and relieve each other etc. When the woman would try again to push them

away, they were both more confident in slowing the interaction down, and I heard the son say, “Mom, I WANT to be here, this is about me too.” She really got the message. (JW)

Alternatively, we might think of an intense experience as one that is too meaningful, or too much to bear, and in this way it has a negative connotation. An intense experience can be thought of as exhilarating and in that case the sense of intensity is a positive. Even so, there is a subtle warning implied: although this may be exhilarating it takes you to the edge of what you can bear. JW watches and observes herself and said that no one other than herself would know that she is “consciously practicing with her emotions,” but she can feel the softening as the frustration gives way and the frustration, rather than driving her response, “informs” her response. It is as if, by slowing things down, she becomes clear, within herself, and when this occurs she can meld reason with feeling.

Or intense might refer to the quality of attention required in order to be in that person’s presence, in which case the description implies “too much,” culminating in fatigue and relief when the interaction is over. In that case, to be described as an intense person can have a negative connotation. Likewise for an event or situation that is too meaningful or serious, or too much to bear. While some might feel admiration for intensity, others might feel dismay, depending on their perspective.

Rushing, over-functioning, or rescuing creates a feeling of disdain in SG—“self-imposed drama” or “self-importance.” For us, being compassionate requires being grounded, not easily knocked off balance, which is a cultivated skill, a value—noticing and resisting the urge within us to physically create distance, space out, disconnect, ask questions, divert or distract, comfort, or to take charge, or to control or change intense feelings. It is the constant reminder to “stay close and do nothing” (Collett, 1997).

We practise, over and over again. Come back. Everything is okay. You are safe. Be still. Take your time. It is okay to not know. What is happening right now ... and now, ... and now? Be tentative, respond with care. (RB)

Even though we work on a “crisis” team, where patients and families are “in crisis,” as KB noted, we consciously make ourselves slow down in the face of escalating feelings.

Intensity occurs or arises in standing firm in the face of anger directed at us. It is recognition that anger is a call for more attention, for more effort to understand. It is like “pushing energetic roots” into the ground in order to bring attention to what is happening in that very moment (RB). It is focusing on the fear that is arising, taking a deep breath (SG), pausing, dissipating the sparks “that can so easily turn to fire” (KZ). It is global concentration, a conscious effort to anticipate things that might trigger the other’s anger, frustration, or fear (KZ). It is the amount and quality of the concentration required to be guided by the feeling of fear and wariness, stepping carefully, taking nothing for granted, recognizing the instability and fragility of the other person (KZ). It is utter exhaustion at the end of the interaction (BD, JJ, KZ, and SW).

JJ put it well:

Intensity is thinking while having strong feelings. It is the art of knowing what is the most important thing to address, when to offer information, and how much, when to reassure, when to speak out, when to stay silent. It is trying to assess, in the midst of internal and external chaos. It is the effort to get to the calm at the centre of the storm, the effort to effortlessly become the calm at the centre of the storm, more like remembering to be calm than trying to be calm. It is a three-legged race with our medical partners, being distinctly separate, but needing to act as one, finding whatever it takes within us to make our muscles and bones move together.

Intensity was described by the co-researchers as a physical sensation that is associated with strong emotion such as fear, excitement, sorrow, shock, or anger, and sometimes mixed

with a sense of inadequacy. We learn to deal with this over time through practice and exposure, and through support from colleagues.

Over time, our capacity for intensity is increased through practice in being present for strong emotion, without our own physical response being “stirred” (SG) in a way that distracts our attention from the other person. There is satisfaction in keeping the focus on the other person, a sense that a service has been provided, and that it has been done in an artful way (KZ). The capacity to contain intense emotion and respond to it appropriately was already a valued quality, and a cultivated skill, before coming to hospice, but one that further developed on the job (RB). There is willingness to engage intensely, and reassurance and meaning in doing so, because congruency between action and reaction validates our perceptions. For those of us who have felt that our own intense emotions were not welcomed or validated (JW), or for those of us who have felt judged, or felt ourselves inadequate in responding to intense experiences (JJ), interacting with and managing the intensity of palliative care can be a healing and corrective experience (KZ). Responding appropriately to intensity is a cultivated skill, and the willingness to mirror intensity is a gift that is repaid by the ability to manage and process our own feelings and actions in order to demonstrate wisdom through the ability to be helpful (WF).

Another reason for appreciating congruency is the sense of surprise when intensity is absent. Why is there not more anger, “more rage, more frustration, more grief, more display” (SW)? The social norms that train people “to behave in public, to mute the full enormity of our feelings” (SW) are met with dismay, and can be deeply disturbing. For instance, SW was witness to a situation in which a wife drove her teenager to the airport to return to university for her final exams only 30 minutes after her husband died. SW did not wish that the wife’s feelings had been less intense. Not at all! She railed against the wife’s lack of recognition of the

sacredness of this moment, and the disregard for the emotional impact. So much about it “troubles” her. It is a feeling of desolation that the patient has been abandoned, “horror” at the image of this young person “alone with the ringing loss of a father.” She felt shocked at “the loneliness of this woman, who allowed efficiency and schedules to trump the importance of pausing in the face of death.” She felt a powerful urge to find the man’s body and sit with it, to gather the family, and serve them tea. She protested; she was bewildered, thrown off. She felt the dissonance within her. It felt so “wrong.” Despite acknowledging to herself that she was feeling judgemental, every part of her wanted to do something to correct the situation, to meet the profundity of this death with the honour and respect that she thought it deserved, that was appropriate, that just seemed right. SW said that intensity reassures us that we are okay, “not frozen, not cynical, not too smooth in processing pain and suffering,” and that she could not work at hospice if she did not feel intensely. Intense feeling is an antidote for numbness, a protection from the risk of becoming “prone to generalizations, unnaturally focused on bowels, cynical, weary, desensitized” (SW). Intensity helps us to gauge a situation, and as RB explained,

Feelings are the world in which we live. Without feelings we would look and feel wooden. It is not that we like these feelings. Do we like breathing air? Do we like eating? We have feelings because that’s what it means to be a human, to be alive. (RB)

Through our colleagues’ gentle compassion we learn to be patient with our own experience, to meet it softly and with a sense of gratitude for authentic expression of emotion that is congruent with what is happening. When our rawness shows, our colleagues reassure us, comfort us, give us space. JW, in her first weeks at hospice, was comforted by a colleague and told to take all the time she needed; she was advised that there is “a process of growing our skin.” It takes time. It takes being easy on ourselves. Can we sustain being in such a state of

intensity? How can we continue if we cannot keep up some semblance of calmness, even if it is just a veneer?

In facing the profundity of death there is an overriding sense among us that it would be incorrect to respond with anything but intensity, and in fact, we find it deeply troubling when intensity is absent (SW). Rather than being averse to or wary of the intensity of emotions that are generated as we approach death, the co-researchers all reported feeling drawn to the intensity of the work primarily because of its invitation, its possibility, its tendency—no, it's command—to come into the present moment. We find intensity comforting in that intense responses affirm our perception that something big, something important, something sacred is happening. When intense emotion is present, it can seem “easier to know what to do and how to be” (JJ).

While the capacity to contain intense feelings is strengthened and reinforced through the work, there is a need to find balance when the limits of what a person can hold become strained. Sometimes it means making a conscious decision to allow vulnerability by “shoving emotions down” (SG). RB said that she puts her feelings in a room and closes the door. “The room inside my psyche, and inside my thoughts, is also inside my body, bounded by skin and muscles.” By tightening her psyche, her brain, and her muscles, she keeps the door closed, keeping the emotions inside for a while. At the same time, those boundaries, or muscles, get stronger, she explained, and as long as the door can be opened at will, there is a sense of confidence that her own system can be counted on to keep her safe. Being able to “come and go at will” from this “room” is a type of “emotional fluency, or maybe emotional capability that feels akin to wisdom.”

Intense emotions wear on us, and to counterbalance the intensity of our work lives we feel the necessity of avoiding or limiting our exposure to intensity in our private lives. Some of us no longer read newspapers and avoid or limit watching emotionally charged movies or TV programs. We specifically avoid people who have too much “drama” (JJ) in their lives, or who are “emotionally needy” (JJ). As KB said, “At the end of my shift, I have very little helping, tolerating, or compassion left. It takes extra special intention to draw these up. Thank god my friends don’t request these things from me in great amounts!” The need to meet or go with intensity and the equal need to withdraw from intensity seem to be the natural rhythm in palliative care. CW described it beautifully.

I continue to love connecting with strangers, befriending the dying and their families, falling in love with people and their stories. Like with any long bout of travel there are times when I want to step out of the work of travelling. I get tired of being on the train of death. In those moments, I step off. I hike and sit and hang out with babies and eat too much chocolate and drink just enough dry bubbling wine and then, when I’m ready, I get back on.

Encountering mortality daily in a palliative care context requires our bringing our energy and attention forward in order to meet others with strong emotion, and then letting that focus retreat in order that we can be restored.

Intimacy. Intensity in our encounters with mortality in the palliative care context is tied to intimacy. Although the word *intimacy* is sometimes used as a euphemism for sexual activity, in palliative care the word is associated with what people might normally think of as private or “close,” involving a sense of “friendship or familiarity” (OED, 2012), enabling people to feel relaxed with each other. Intimacy in this setting has to do with what might be shared only with close family and trusted friends because what is being shared is concerned with one’s “inmost nature” (OED, 2012), that which is integral to who we are, or what we value the most.

Recognition of every person as an embodied being-in-the-world ... is fundamental to ethical nursing practice. Touching the body of another in nursing is a healing and interpretive modality; trust is built, comfort is offered, and a deeper understanding of how illness affects the individual is achieved [Thomasma, 1994]. For example, in an interview study with nurses about their experiences of washing patients' feet, de Vries (2004) shows that through connecting in this intimate way both nurse and patient experience a transformation in their relationship, where these acts of caring touch bring about mutual relaxation, comfort, and happiness. (Wright and Brajtman, 2011, p.25)

While touch is a fundamental and accepted part of the nursing role, for counsellors, at least in the last 30 years, it has been discouraged if not forbidden, and has been closely tied to concerns about sexual abuse and misconduct on the part of the therapist or counsellor. For physical contact to remain safe for the client, research suggests that touch must be non-sexual in nature and its intent and its effect made explicit, with clear boundaries exercised. Any physical contact must be subject to open discussion both in therapy and in supervision. (Hetherington, 2007, p. 363)

I begin with what touch means to the co-researchers in this setting, followed by examples of the bittersweetness of intimacy. Within the boundaries set out in our training, the rules of touch are relaxed in our setting, and not only is it not forbidden, it is encouraged. Those of us on the crisis team are needed to assist the nurse in all manner of personal care such as washing, the occasional dressing change, the insertion of catheters, and transfers from chair to bed or commode. SW said that she cannot imagine another (social work) job that requires so much physical touch. For her, touch is part of intimacy—"a handshake, a hand on an arm or back, a hug, a kiss" (SW). A touch can say to a patient or family member, "Yes ... thank you ... oh my god there are no words" (SW). RB said that a touch can say, "You are doing a good job, or I feel for you, or you are not alone, or this is okay—everything is unfolding as it should." Touch in the form of stroking, holding, hugging, and physical proximity is common and seems appropriate given the emotional connection that is often being shared.

SW compared palliative care to midwifery in that intimacy is present in "the borders of life and death" (SW), and despite the brevity of our encounters, we create connections that seem to be "deeply mutual, ... a little like falling in love: a surprised stumble into intimacy" (SW).

There is an invitation, “a pull through a secret door, into the most poignant physical and emotional displays of affection and love” (JJ), sometimes ending in the sting of tears, or a melting, warm fullness (WF). The sweetness of intimacy for RB is holding a teenager who is watching her mother—jaundiced, skeletal, and clad only in a huge adult diaper—being cradled in her husband’s arms like a baby, as he tenderly strokes her breast, her heart, and whispers “I love you.” “Being heard, hearing, being seen or seeing—this is powerful” (SW).

That pull through the secret door into intimacy can be uncomfortable, requiring us to withstand tension, uneasiness, and “a restless desire to get away” (JJ). It can be a “hornet’s nest where there is stigma, taboo, shame, and embarrassment” (SG); a painful, uncomfortable, “distant, awkward sense of disconnect and alienation” (SW). It is not as easy as when there is love and affection and ease, but it is more important and necessary to support when “rooted in failed relationships, abuse or cruelty” (SW). We know all too well that the hidden or rejected past interacts with the present moment, affecting how a person experiences the now, and how they experience and go forward in the future (JJ). We feel a sense of responsibility that we do not add to a patient’s difficulties but rather that we attempt, through our relationship, to help the patient to heal and to prevent further harm (RB).

Intimate relations often get beneath the social constructs and uncover truths that lie below the surface. “Speaking the unspeakable” is at the “heart of the work” (JW) and getting behind the social facade to find what is true—or more true—and being able to see what is usually only revealed to close family members or friends, if at all, is all part of intimacy. SW related an incident with a patient.

A middle-aged woman was dying. Her siblings and her mother were very present. ... On the surface: a mother with a broken heart who could not bear to lose her well-loved

daughter. On the surface: sisters who could support and love one another and would care for their mom after their sister died. However, at a more intimate level, at the level of truth, the story was so different: this was the story of a mother who had abandoned her older children to the cruelty of her husband, their father. This was a mother who had refused to believe her daughter when she disclosed sexual abuse. ... This was a mother who chose one daughter and rejected the others. (SW)

The layers of human relationships are painful, and we are powerless to heal the wound, or to even provide temporary relief from the hatred, pettiness, and harm. Encountering mortality can bring out the most loving, tender behaviour in all of us, but it can also uncover the meanness, cruelty, and indifference that can be part of being human.

Intimacy also takes the form of touch with colleagues. RB explained that a touch with colleagues can mean “I agree with what you are saying or doing,” or “That was hard,” or “I am with you.” It can mean “Wait!” or “Look!” or “That is enough!” A hug can say “I can see how hard that was for you,” or “I really appreciate the work that you do,” or “I feel close to you right now.” It is common to touch a colleague by casually putting an arm over a shoulder, or to touch an arm or hand as we speak to each other. At the end of every shift, at least on the crisis team, many counsellors hug their nursing partners. It is an expectation of working in palliative care and at our hospice that we will nurture and build our relationships with the team.

The interdisciplinary team is the foundation and core method of palliative care programs. ... The successful functioning of the palliative care team is often described in terms of collaborative practice, characterized by self-awareness, cohesiveness, shared decision-making, trust, respect, accountability, mutual support, self-care, positive work environment, recognition for a job well done, and attention to retention and job satisfaction. (Meier & Beresford, 2008, p. 677)

The values that underlie working within a team—such as respect and collaboration—are dearly held beliefs at our hospice, and yet we find the reality of putting these ideals into practice to be difficult at times. The spectrum of human responses is also reflected in our relationships with colleagues, requiring the ability to adapt. “Some people just blend together well, while

others are like oil and water” (SG). Still, we must find our way in emotionally charged situations, under time pressures, and with constant distractions to find some kind of “peace,” otherwise the work is “really, really unpleasant” (SG). JJ said that by speaking openly and listening non-defensively to her partner, “things just feel better between us.” For her, this is generally not difficult. Most things can be talked about in a natural way, without being confrontational. When it does seem difficult to say something, she is motivated by remembering times when she did not say what she was experiencing and relations became tense. If she has strong feelings, such as anger, hurt, or frustration, she tends to be quiet and to withdraw until she has had a chance to think.

First of all I assume that all of my colleagues have goodwill and do not want to be in conflict with me. I think this is true because when my colleagues have been in conflict they are very unsettled, so I assume that my partner would most likely be upset if she knew that I was unhappy with her. Then I try to imagine what my partner might have been thinking, feeling, or needing. Usually this process works for me and I don’t need to say anything in the end, because I have a sense that I now understand. If I find myself carrying resentment, then even if it is difficult I try and say something, otherwise I know that I will feel tense and I hate that feeling! (JJ)

The co-researchers seemed to agree that working with colleagues is important, challenging, or both. JJ said that she has become better at relating to colleagues over time because she has learned from “hard experience” that if she does not address issues the work does not go well. She recommended “practice and determination.”

Intimacy requires finding a rhythm. Lindbergh (1978), in *Gifts from the Sea*, described it perfectly when she compared a good relationship to a dance.

The partners do not need to hold on tightly, because they move confidently in the same pattern, intricate but gay and swift and free, like a country dance of Mozart’s. To touch heavily would be to arrest the pattern and freeze the movement, to check the endlessly changing beauty of its unfolding. There is no place here for the possessive clutch, the clinging arm, the heavy hand; only the barest touch in passing. Now arm in arm, now

face to face, now back to back—it does not matter which. Because they know they are partners moving to the same rhythm, creating a pattern together, and being invisibly nourished by it.

The joy of such a pattern is not only the joy of creation, or the joy of participation, it is also the joy of living in the moment. (p. 104)

For RB, intimacy means that she is “alert” to subtle changes in the environment, and as she notices these changes she tries to bring her “energy field” into sync with her partner’s energy field so that she can pick up, or “anticipate,” what is happening with her partner. She reported that it is as if she has a “hyper-sensitivity to small signs” that indicate what is happening for her partner, mentally, emotionally, and physically. She matches her own actions to what she thinks is required, such as refraining from speaking so as not to interrupt a train of thought, or handing equipment without fumbling or bumping into her.

Intimacy is like a dance where I sense the rhythm and bring myself into step. Such a good feeling! When I am successful, I feel very close to my partner. When things are good, there is no stepping on toes, or competition for the limelight, no working at cross purposes, but rather a united effort towards the goal of being of service, a dance in time to the music. (RB)

Having a good relationship fosters intimacy and intimacy fosters the relationship. Where there is discord, however, there is distance, and where there is distance there is discord, with one feeding the other. Being out of step is awkward and unpleasant.

Weinenger and Kearney (2011), in “Revisiting Empathic Engagement: Countering Compassion Fatigue with ‘Exquisite Empathy,’” discussed the hazards of training that focuses on medical tasks, assessments, and proscriptive advice.

For a long time I had felt a silent dissonance underlying my experience as a therapist, as a leader of groups for people with AIDS, and as a physician. My training emphasized the need to keep strict boundaries and distance; that becoming too close and too “loving” with patients would make me “less professional” as a clinician. I was also taught that

less distant behaviour would take a personal toll and leave me depleted and worn out.
(p. 49.)

Although keeping strict boundaries and distance does not represent the totality of medical training, it is the exact opposite of the training and orientation of counsellors, and most likely forms the basis of much of our interpersonal conflict. For instance, nurses are duty-bound to complete assessments, manage physical symptoms, and prepare and administer medication, all of which can, but do not necessarily have to, interfere with, trump, or even block emotional and spiritual responses (EO, JJ, SG, WF). Unfortunately, the nurses are held accountable for completing these tasks, which we can often find frustrating, as will be discussed below. When there is discord we find ourselves with “competing needs for silence, to complete tasks, to get going, to stay, to slow down, or to speed up” (SG) which complicates the work that both nurses and counsellors are meant to do with patients and families. When we cannot tune in to our partner, patients and families sense it and become confused (JJ). We compete for space, we imagine motives, and we feel physically tense (RB), and then we begin to dread coming to work (KZ). Being distant, or feeling ill at ease can produce sleepless nights (RB). Even if we find the courage to address what has happened between our colleague and ourselves, it may not have an easy solution, but not addressing and resolving differences causes us to withhold our energy, or to guard ourselves, or to maintain a wary watchfulness, which is counterproductive, interfering with the way that we wish to be (SG). I find it ironic that when there is no intimacy, no tuning in, we are most likely to misunderstand, experience resentment, and become angry, but it is our anger and resentment that cause us to resist opening ourselves to our partner. We then do not want to “meld our energies,” and this distaste feeds the cycle. When relationships are contentious, we feel resentful that an already difficult job is being made even more difficult, and we can feel discouraged and drained (KZ).

Getting back in step can happen between visits—on the unit in the charting room, in the common areas, or off-site in the car—there is a sense of relief when we can be close. Closeness can be “like a friendship, but with a professional aura” (JJ). There is laughter and tears; we share memories that have formed as we interact with patients and families; and we process what was happening for each of us as we were working—sometimes admitting to judgments, fears, irritations, and puzzlement (SG, RB). When our relationships with our co-workers are strong and positive, we see them as a source of strength and safety, turning to them for support and understanding, whether that is emotional, intellectual, or philosophical (WF). SW said,

With colleagues, I ask what is going on. I do not edge away. If a colleague is struggling, I want to know why—I want to hear how they are still finding a way to be alive within the range of feelings and experiences. I want to support them, and, just as much, I want to be near the heat of their truth.

EO explains that in our culture we live “as though our life will carry on—as though death will happen for others but not for those we love and not for ourselves.” In this culture, when we are faced with death we experience a brief “sense of timelessness, spaciousness, and sacredness.” She said that because death is so present, she

cannot maintain compartmentalization. ... I know in an embodied way (I FEEL it in body/mind/heart) that those I love will die and I will die. And sometimes knowing this helps me be more courageous in the expression of my loving or in what I will/will not risk to say to someone. This knowledge that everything is impermanent (not as a theory, ... but as an experience) also leads to a deep sense of sacredness/gratitude for life on a very daily, mundane level.

There is a sense of immediacy that comes in encountering mortality that can provide the necessary courage to address issues between colleagues. For some, the intensity of the relationships at work with patients and families and with colleagues can be very satisfying, but also stressful, as expressed by the co-researchers. This has an impact on our personal lives.

Intimacy in the palliative care context is absorbing and it is ironic that the energy that is required to enter intimate spaces with others—whether colleagues or patients and families—leaves us drained of energy for intimacy in our own lives. Our “intimate energy” uses up a “limited store” (SW). For BD, the demand for deep emotional contact at work can be so taxing that when she goes home she is emotionally and physically fatigued, and just “craves” quiet. She wants silence. She wants “to meditate or to do yoga or to read from sacred texts.” Having spent her day at “the border of life and death” she finds herself making judgments that day-to-day troubles are trivial. At these times she is impatient and a poor listener. Caring for others at hospice, as a teacher outside hospice, and as a parent and daughter of aging parents can leave her physically, mentally, and emotionally tired. She can feel resentful about being asked to listen in what have come to feel like non-mutual relationships. SW said that she becomes exhausted, that work is “gouging energy out of my flesh, leaving me weary and blank” (SW). The truth is that at times some of us are too depleted emotionally and socially to “savour the preciousness of life, to be joyful and fully engaged and steeped in rich meaning,” and want only to be “alone, to be silent and withdrawn” (SW). It is as if we give our “life force to working with the dying, stealing from life to give to death” (SW).

Intimacy at work can end with a feeling of sadness or disappointment that the act of really seeing others, really being there for them, in service is not replicated in private life (KZ). Sometime when we get home from work everyone is asleep and “there is no one (other than ourselves) to make contact with” (BD). When we do engage with our family and friends there can be tension, it is like having a “different set of intimacy muscles” (JW) that result from spending a working day “swimming upstream emotionally, and talking about taboo subjects” (JW). We find that social situations seem to lack intimacy and intensity and we “crave the

meeting below/behind the masks that can happen in our work” (BD). People in our lives can find it difficult when we have a desire to interact on “deep topics” and a need to be “emotionally expressive” (WF). These differences among family members necessitate finding others who share the capability and desire for “heartfelt connection” (JW).

Through empathy we temporarily live in another person’s private world. We do not conflate his or her world with our own. Instead, with a genuine curiosity and concern, we strive to understand it as if it were our own. *As if* [emphasis in the original] is a critical element that helps us maintain two separate perspectives: the other’s perspective and our own perspective of the same reality. We relate as two separate human beings as *I* (a subject—not a professional title or role) relates to *you* [emphases in the original] (a subject—not a patient or a client). While empathy is usually limited to the person’s lived experiences, sometimes it extends to his or her life condition. This broader form of empathy requires a deep acquaintance with the individual’s private and social world, which is brought into the intersubjective space of a shared relationship. (Papadatou, 2009, p. 99)

SW thought that it would be “naïve” to think that intimacy at work is the same as intimacy in our private lives. She said that we “perform compassion, perform intimacy,” rather than “truly, deeply **being** compassionate, **being** intimate [emphases in the original].” But, she said, “performing can be the real thing, it can be professional compassion, professional intimacy.” The distinction comes from the need to “hold something back” from our work that would be there with members of our own families. But JW thought it was real. If she is tired, she brings her “tired self to work”; if she is joyful, she brings her “joyful self to work.” When interacting with patients and families, she expresses her emotions, and “can’t think of anything further away from performing.”

Connection. There is a fine balance between having enough professional distance to be able to analyze the situation, while at the same time having enough intimacy to create a compassionate, meaningful connection. Perhaps it might be useful at this juncture to pause and explore the meaning of the word connection. Connection derives from the “Latin *connexiōn-em*

(in classical Latin *cōnexiōn*)” meaning “binding together, close union ...of action (OED, 2013).” It is defined as “the condition of being related to something else by a bond of interdependence, causality, logical sequence, coherence, or the like; relation between things one of which is bound up with, or involved in, another OED, 2013). For counsellors, the act of connecting begins with focussing on our own body sensations, thoughts, feelings and way of being. The term “dual awareness (Weininger & Kearney, 2011).” helps us to understand more about how we go about connecting. It refers to the ability to bring to consciousness all that is happening within one’s own realm of experience, while at the same time, taking in what might be happening with another person—through sensing the meaning of language and nuances of speech. Implied in dual awareness, is awareness of the even larger context within which the interaction with another person is embedded. The practice of dual awareness is an art and a skill, requiring practice, attention, and the desire to connect through understanding.

Compassion is linked to connection and Thompson and Wainwright (2006) identified two conditions necessary for compassion to occur.

Compassion has two conditions: the care provider must be invited in to participate in the suffering experience where sufferers lead and caregivers follow and the response must be empathic and authentic caring where the person’s suffering is recognized, validated and embraced. Compassion requires more than listening skills and a pleasant manner. Fundamental to compassionate response is empathy and a wellspring of understanding of a person’s suffering and where it is located, in their bodies and in their lives (English, 1994).

Compassion requires care providers to feel helpless, vulnerable or powerless in the face of mortality and in the face of the chaos and disintegration that is happening to the person before them. It requires a willingness to go, if invited, “beyond the domain of listening to emotional realms that are neither easy nor comfortable” (Boston, Towers, & Barnard, 2001) and place people at personal risk of developing emotional closeness and discovering ones’ own suffering. (p. 538)

Gregory et al. (as cited in Thompson & Wainwright, 2006) suggested that this requires courage and commitment from care providers because “the cost of this journey is high ... it means being exposed to one’s own suffering, woundedness and grief. Yet it is our own experience of suffering that enables us to be compassionate, to share in the plight of another” (p. 538).

We are told and come to know for ourselves that the most important thing that we can do as counsellors is to be present—which requires us to give our full attention to the present moment. This is easier to do when the situation creates pleasant feelings than when it creates unpleasant feelings. As CW said, “Coming to work is like getting on a train that runs along a long and poorly defined border: sitting with various passengers, hearing stories, making connections, missing connections. Wanting to linger, wanting to escape—all common moments in travel.” How can we stay focused in the present in an often chaotic environment, filled with busyness, myriad people, and all the activity required to provide medical and psychosocial care?

In the palliative care context, interactions with patients and their social networks range from small, one-to-one meetings to large, family/whole team meetings. They can be formal—an appointment is arranged beforehand—or can be as informal and spontaneous as a chat between people passing in the hall. On the unit we meet in the patient’s room, the sunroom, meditation room, or counselling office; in a home environment we meet in someone’s living room, bedroom, kitchen, or porch. Sometimes it is hard to find privacy and uninterrupted time, and there are often other people in the room when counsellors and nurses have what would usually be considered intimate and private conversations. Meetings range from fleeting but meaningful interactions and brief social chats, to lengthy, intense, heartfelt encounters that may be personal and private, or involve large groups of close family and friends, and possibly also complicated and long-standing family dynamics. SW said that she wonders sometimes what can possibly be

accomplished in seeing one person, for one hour, in the face of a profound loss for that person, and yet is often surprised when that person seems inordinately grateful for this one hour of attention. At the other end of the spectrum, JJ described being in homes with up to 40 distressed people. Although this is not typical, it does happen. She said that in some ways dealing with patients and family members together increases intimacy and intensity because the family is exposing not only individual experiences, but their dynamic as a group. This can be overwhelming for everyone, but especially so for the counsellor who must track what each person is feeling, while at the same time noticing the group as a whole. In other ways, she says, family groups decrease intimacy and intensity because the attention is divided among many and the energy is dispersed, which can sometimes make it more difficult for the counsellor to make a connection. How the counsellor experiences this seems to vary from person to person, and is affected by the range, intensity, and type of emotions displayed, and in what setting—home or hospice—we are meeting. BD admitted that she has never liked working with family groups, and prefers one-on-one meetings. RB likes family groups because they are so challenging, and said, “It is a place where I can really be useful.”

No matter what the circumstances, where we meet, with whom we meet, and whether it is a planned meeting or not, the expectation is that we will connect. This expectation can create anxiety. “What can be achieved in such a short period of time? How am I going to be useful? What will happen?” wondered SW. It can be surprising that the simple act of sitting and listening to people telling their stories can have such a meaningful impact. The co-researchers have a lot to say about connection because it is such a fundamental part of the experience of being a palliative care counsellor. “Connection is at the heart of this work. When I am able to connect, heart to heart, it does not matter what I do, as the connection is the doing that nourishes

me” (KZ). Connections are a major source of satisfaction. “Connection within me is the feeling of being centered and grounded. Connection with others is the feeling of being together and it feels good” (JJ).

KZ said that making a connection is like “graceful energy,” something like “a hot knife through butter ... not effortless but it moves with ease.” For her, connection can be intuitive and requires “mutuality, shared values, and appreciation,” as well as “the ability to remain open and to suspend judgment.” She said that connection is facilitated when she is able to correctly “read another person,” and to “go at a pace that is comfortable for them.” It requires “gentleness, patience, and silence, as well as adaptability, good social skills, and curiosity.” She emphasized the importance of “caring about the things that are significant to the other person.” For her, connection is about “making the other person more important than your own problems.”

For this we need to be alert, to pay attention. While connecting often involves our emotions, we also connect by making eye contact, mirroring body language, opening our senses, and bringing forward or withdrawing energy (RB). These activities require concentration, focusing on what the other person is saying, while at the same time using our body and our words to communicate that we have understood (KZ). We absorb, intuit, or sense what others are feeling, “not to feel it for them, but to feel a shadow of it, an echo of it” (SW). This is done “by paying attention, by watching and listening and feeling the energy that ropes through the room” (CW). As JJ explained,

One time we arrived at a home and when I introduced myself as a counsellor the husband of the patient seemed taken aback. There was a very uncomfortable silence. I withdrew my energy, which is kind of like making yourself small, or fading into the background. I was trying to be as non-threatening as possible. I let the nurse take over, but when she had finished her assessment and was preparing medications, I began asking him about his work, and I told him about my dad who did the same kind of work. After a long

animated discussion, I very tentatively and gently asked him how it had been for him to care for his wife, and from there he talked quite openly about his feelings. By withdrawing my energy at the beginning of the visit, I believe that I conveyed to him that I had received his message—that he was wary, unsure, or fearful of me or my role, and wanted me to back off—and I respected his experience until I thought that it had shifted.

Tuning in takes concentration because at the same time as attending to what might be happening for the other person, we also need to know what we are feeling. “I go between what I am sensing, what generates from me—body sensations, thoughts, feelings—and what I am picking up from others. Then I have to decide how to respond to each of those stimuli” (RB). Connecting is an art that must be practised with sensitivity and awareness.

In order to connect we have to let go of our own personal history, preconceived ideas, and prejudices, as well as information that has been provided through our rounds, or charting before meeting people (WF). This is a difficult goal to achieve because words not only form our thoughts, they are linked to preconceived notions and ideas: we cannot really let go of our own reality. Perhaps all that can be expected is that we attempt to suspend, as best we can, what we think we know, by noticing, acknowledging, and being open to learning something new (WF). “Connecting really means emptying myself enough to be present and letting that person’s experience enter into me” (JW). Quietening the mind allows for a relationship to form in an organic way, uncontrolled by the counsellor. “People talk about automatic writing. Just putting pen to paper and seeing what emerges. In a similar way, each time I go into a stranger’s room, I am putting my heart to the air and letting knowledge emerge” (CW). Connection is more of an exploration and a process than a goal that is ever achieved.

The connections that we make are a “peculiar kind of intimacy” (JW) because they seem so powerful at the time, and yet, for us, it can later be “hard to put a name to a face” (JW). On meeting a family member in the grocery store, for instance, JW said with some dismay that “he

had felt supported by our team, and yet here I was not remembering him!” At other times, connections are so emotional and enter us so deeply that they are never forgotten. WF described a situation where she met a woman who seemed to have a similar nature to her which allowed for a powerful connection that was “a rare and precious gift.”

I am thinking in particular of a woman we supported who had a very sensitive nature. Her overriding experience was one of being tossed about in this huge medical machine which had shown no regard for her as a person. She was battered, bruised, and deeply hurting from this experience, and now too, she was dying. I remember how delighted she was that the team simply listened without judgment to her story, how we let her take all the time she needed to speak, or find her way. She was teary ... sat and sobbed while the nurse and I bore witness to her deep anguish.

Later, WF visited her again, this time on the unit when she was in her final days. The patient remembered WF, reaching her arms out when she walked in the door. WF knelt by the bed, holding the patient while she wept. After some time, WF pulled up a chair, and with the patient’s head in her lap, allowed her to continue to cry, a silent witness to her despair.

Identification with the patient, and a willingness to come close on both their parts, contributed to a strong connection being made.

KZ told a story of connection when she was visiting a woman who had collected her dead mother’s medication with the intent of killing herself. KZ asked her to take the medications to the pharmacy for disposal and the young woman became defensive. KZ sought supervision and was able to “unhook” from her fear and her sense of being responsible. On a subsequent visit she was able to shift her focus away from her own fear and see that the woman was struggling. KZ told her that she was worried about her because the medication she was taking could cause her to feel suicidal. She asked the woman if she could turn to her boyfriend and tell him about her risky behaviour. “I tried to connect with her person to person ... I simply let her know, I see

you, I feel you, and I know you.” Making a connection appeals to our own sense of what it means to be human.

Making connections requires effort, a willingness to understand another’s perspective in an effort to enter their world. This can be difficult when death is involved because for many people in our culture the natural reaction to death is to avoid, run, or curl up, instead of to confront, come closer, stay present, or be open. Connecting requires more effort when we are ambivalent, but can be satisfying when we manage it. As SW said, “it is easy to meld with someone when love is present, but more important to stay present when there is hatred and cruelty.” The co-researchers agreed that giving our time, listening, allowing the patient or family member to lead, focusing on what the other wants and needs can be powerful ways of connecting.

Weininger and Kearney (2011) offered palliative caregivers support and encouragement when they cannot meet the expectations of their professions.

Making an accurate assessment of the clinical situation and accepting the limits of our clinical competence helps to create a safe container for the interaction, in which client and clinician can feel relaxed and open towards each other. Besides the obvious professional boundaries, clinicians also need to be aware of their internal limits and reserves, of what they can or cannot give. (p. 59)

The co-researchers are well aware of their limits and sometimes struggle when connections cannot be made. Since connection can be so satisfying, it is easy to understand why we feel upset about situations where we do not or cannot connect, or when interactions do not go well.

The role of counsellor provides both the opportunity and the expectation that we be open to other people. What happens when we are unable to make connections? “My initial reaction when I cannot connect is a feeling of either rejection or inadequacy. I wonder if someone else

might have done a better job” (JJ). These feelings are usually counterbalanced by self-soothing talk, finding reasons that are not personal. Sometimes an assessment is made that it would not be appropriate to try to connect because the patient is too sleepy, is in pain, is non-verbal, or appears not to want to engage. “It’s also important not to meet our own needs to be useful, through engaging with tired people” (SG). The counsellor has to find satisfaction in other ways. “When I don’t connect I can compensate by staying connected with myself. I learn to soothe, comfort, entertain, or occupy myself” (RB). When no connection is made it can be like “molasses,” in that interactions take effort and feel like work.

I feel like I have to try, even when it’s not natural. It’s expected and yet the cues are saying don’t ... especially during second visits ... you’re there waiting (for the nurse to fill medications), trying to relate to them, and they’ve already been counselled to death. (SG)

Sometimes there are personal reasons for not connecting. “There are times where I cannot or do not connect with another person, and I have to forgive myself for being too tired, not interested, or repulsed” (JJ). Accepting that connection does not always happen is part of self-reflection. “Although I feel a responsibility to do what I am paid to do, I also recognize that I am a human being, with my own needs” (JJ). It helps to know that we are part of a team, and that if one person does not connect someone else may (RB). BD could relate to being a “private person,” and could therefore easily imagine being reserved, or not wanting to connect with a new person at such an intense time. SW said that she was “startled by the frequency of connection ... more surprised by how many people appear to be open to making new connections even while preparing to die, or while supporting a dying person.”

An example of not being able or not knowing how to connect was given by KB who was once asked to visit a man of a similar age. They had many things in common that gave KB a

strong sense of identification with him, although these similarities were not known to the patient. Connecting with the man was difficult for a number of reasons—his parents were always present, making intimate dialogue unlikely, he tired easily, and he was completely dependent on others. KB had a strong desire to help but even indirect attempts to help by offering support to the man's parents were refused.

A period of months went by until I noticed one day that the man was going to be admitted to the Hospice respite bed, and I was both scared and drawn to connect with him again. By now, though, he was totally paralyzed and his speech was affected, so that it was difficult to understand him without careful attention. This of course only added to my sense of helplessness—how were we to connect if we couldn't easily converse? I was afraid to go and see him more than once—what could I offer? He didn't appear to want to engage with me and so my discomfort magnified as the week went by. ... I felt at a distance from having any effect on his life, yet I also felt a pull to be involved, do something "heroic" that might make a difference. But I didn't act, I couldn't act—I really didn't have a role in what was happening. This young man died somewhat unexpectedly a few nights later ... I was so very saddened at hearing this. Also somewhat ashamed that I had not done more to make a difference, even though I also knew realistically I couldn't have done more than I did. I still think of him sometimes—something left unfinished, unsettled, unrevealed. (KB)

Connecting requires giving of ourselves, engaging in a real way, using our own impulses and feelings as guides, while at the same time being alert and attentive to cues in the environment. We connect with people through our own curiosity and desire to meet them, and our willingness to know what is real and true, allowing the full impact of knowing that death is inevitable for us all, and moving through our own ambivalence. But it is just as important to accept when there is little or no connection.

The co-researchers find many reasons to connect with others. In some cases it is easy to imagine what another is going through because elements of the situation resonate with something in our own lives, past, present, or what we imagine to be our future. Whether the ability to relate to another person in this way is helpful to the patient or family member depends on whether the

counsellor is able to refocus attention on the patient or family member without dwelling on or being distracted by his or her own thoughts and feelings. As counsellors, we are expected to be aware of and reflect upon elements that stimulate our own emotions or memories so that we can separate our experience from that of patients and family members (Wainwright & Breiddal, 2011b).

JW articulated how she does this:

When I work, the practice of mindfulness goes hand in hand with the natural tendency of being a counsellor, that is, a witness, a mirror, a benevolent observer/participant. When I am working, especially in the highly charged emotional field that is dying, I diligently implement my “witness” self in order to manage my own reactivity and emotions. One of the benefits of this is a natural “slowing down” effect within the relationships that I’m a part of during work. That is, whomever I am supporting at the time. In that I mean, there is a pause, an emotional pause, between what is being stirred in me, and my response to that.

Many of the other co-researchers also admitted to some kind of formal mindfulness practice such as yoga, prayer, and meditation, and/or retreats into nature or journal writing, as well as religious or spiritual practices that help them to deal with strong emotion and counter-transference that gives them space for self-reflection.

Identification. Identification occurs in many ways, but three variations emerged from the data collected. The first is when we know the patient or family member in another role, as a teacher, trainer, or psychotherapy client, or as a colleague. The second is when we are reminded of our past and when we place ourselves in a patient/family scenario in a particular role—such as youngest daughter or parent—and view the situation from that perspective. The third is when a situation mirrors something that is currently happening in our own lives. Identification with those who are ill or grieving, and overlapping or dual relationships, while creating hardship for the co-researchers, also help us to be compassionate and empathetic.

What is it like for us when we know our patients personally, or members of our social network are going through illnesses similar to those of our patients? Does it affect our ability to be present? Dual relationships can create uneasiness as we make ourselves known to clients or students whom we may have seen in other roles such as therapists in private practice, teachers, or trainers, or in other professional roles, such as chaplains, medics, or spiritual guides. JJ is a therapist in another setting. She reported being surprised and dismayed to see someone with whom she had worked closely admitted onto the unit. As part of her duties on the unit, she was asked to speak to the family, all of whom she knew second-hand from her therapy sessions with the woman.

First of all, I was saddened to see my client so close to death, and second, I was in a terribly awkward position of meeting her family, all of whom knew that I had played an important and intimate role in her life. (JJ)

Before she could continue working with the patient and her family she had a long session with her supervisor where she expressed her sorrow. BD was in the same position, and when a client asked for support because of her association with hospice, she found it was “disconcerting” to realize that she had “compartmentalized ‘where I work with the dying’ and ‘where I teach.’” Although she was able to adjust, she was initially surprised to feel resentment that people were dying on her “time off.”

Another form of dual relationship is when our team provides service to a colleague’s family and we meet not as a colleague, but as a member of the patient’s family. For instance, when AB’s close relative died, she said that “the overlap was excruciating.” In her dual role of family member and colleague she felt exposed and vulnerable.

I remember feeling stretched and really a bit resentful that my family stuff was going to bleed into my work life. It is only now, after ... some time has passed, and the continued

good relationships with my work colleagues, that I realize no one has judged me for my relative's addiction, or disparaged me for choices made. I am very, very grateful for the depth of this maturity now that I reflect on it. It was very tough to not have a "picture perfect" family for the team to support. All my life I've yearned for that.

In this situation, our colleagues, who are now in the role of a family member, feel overly responsible for the patient and not only wonder if their colleagues are judging their family, but worry that their family is judging their colleagues (JW). As team members we feel self-conscious about our care and a great sense of responsibility about providing the best service possible for our colleague and their loved ones (RB). JJ is adamant that colleagues need special consideration.

I think that when our colleagues are family members that we owe it to them to bend over backwards to provide whatever they need. Some people worry about not wanting to give "special treatment" but I think that when you work at hospice it is harder, because you know so much about what is happening and everyone is turning to you to make decisions. You need extra support at that time. Also, your reputation with your friends and family, as a hospice worker, is reflected in how well the team serves your family. (JJ)

At our hospice we have agreed to identify when someone is related or known to us in a different context by writing a note in the chart. This helps the team to provide support to both the family and the team.

In the history of our work at Meadowview we have had to tend to a colleague on several occasions. Because our relationships with colleagues are so close, we have a great deal of empathy for our colleagues if they become patients. RB remembered feeling uneasy and unsure of how to interact when a fellow counsellor was dying on the unit. "I felt sorry for her as I flipped from images of her vibrant presence on the unit, to her present reality of shuffling down the hall in a hospital gown, pushing a walker" (RB). RB said that in order to deal with the tremendous sorrow that staff was feeling, nurses who were newer were assigned to her care wherever possible. The colleague let the manager know that she was too tired for the numerous

people who “popped their head into her room.” We are presently caring for a woman who worked alongside us for many years on the unit. Another staff member has a child with a life-threatening illness, and another has just been diagnosed with cancer. JJ said that she identified strongly with the woman whose son is so ill, and felt conscious of talking about similar patients—a teenage boy, or a man with the same kind of cancer as the woman’s son. “I want to spare her pain, even though I know that is impossible.” At our hospice we are very responsive and considerate to staff members who are going through illness or loss.

We have all faced major losses through death, and when working with the dying and their families it is easy to place ourselves in the position of the patient and family through our memories and our imaginations. While identification helps us to understand, it can also be extremely painful to relive our own losses. AB attended the death of a 40-year-old woman and found herself remembering her father’s death at a similar age.

The 13-year-old in me had never viewed my father as a *young* man [emphasis in the original]. He was my father. A fully grown-up man with a beard, a wife and 4 children! ... I imagined now, for the first time, what it must have been like for him to have been only 40 years old and to be saying goodbye to everything. Until that moment, he had remained in my mind a grown-up man. But because of this experience with this 40-year-old patient my perception of age and dying and grown up-ness changed completely. I saw how he had to say goodbye right at the upswing of his life, just getting the hang of stretching his legs into adulthood. He didn’t even own his own home. ... How sad for a man of 40 to die. Suddenly, I had empathy and compassion for HIM, not just for me and my loss of him. It was a very emotionally intense time.

The opportunity for healing our own losses while encountering dying and death in our work does not occur only once, or even a few times, but over and over, adding to the intensity and the complexity of encountering mortality. Whether we embrace this opportunity or protect ourselves from feeling the pain is up to us. AB’s experience of understanding her father from his own perspective was only one aspect of her loss. In another situation, she relived being a young

child and receiving the news that her father was dying as she engaged with a young child who had been told that her parent was ill and would recover, when in fact the parent was hours or days from death. When AB met the family, out-of-town relatives had arrived with a plan to take the child from her home to the country that they lived in and to become her guardians as there was no spouse to care for the child.

It fell to me and the patient's nurse to break the news ... My imagination and memory were fully activated. ... I kept projecting myself into the child's experience ... getting tangled up in the child's experience. I was emotional when I delivered the news. I wasn't overwhelmed and certainly it was heartbreaking news to have to deliver, so it was understandable that I might be teary in breaking this news. But, my tears felt more "personal" and indeed they were. I hugged the child and felt the youth, the tiny body, and the small frame. In my own imagination, I wondered if this is what I must have felt like at that age, when others were holding me after my father died—so young.

AB says that, as painful as it was, the impact of remembering provided an opportunity for further healing as she was now mature enough to allow the grief that she felt as a child to be contained by the adult that she had become. She felt that, through her experiences at hospice, "something has changed in terms of my own protective covering and self-preservation." She has gained confidence that she can now face these deep emotional pockets of pain because she now knows there is nothing to fear.

There is tension, however, in allowing our identification to inform our practice. We need to be able to relate to the patients and families, but we also need to be able to distinguish our experience from theirs in order to be helpful. We notice things in our interactions that signal that we might not be "seeing" the person but rather ourselves or someone in our lives instead.

It happened that I was with some of the nurses who were talking about how demanding he was, how constant his requests to be moved ... The nurses were complaining about how much work his care was and how it took them away from other patients. I wanted to defend the patient—I was so identified with him that I was losing perspective around how his behaviour affected others. I just imagined being trapped in that bed myself, in

constant physical discomfort, having to ask for even the smallest bit of assistance because I couldn't do for myself. (KB)

In this case KB could identify that the associations were getting in the way of being helpful. In order to deal with over-identifications, we separate ourselves by deliberately trying to identify the other person's emotions and experience to keep them distinct from our own. AB explained the process that she goes through:

I took a few minutes to "pull back" into my adult self, as I felt that my memories and imagination were on the verge of "clouding" my ability to be there for the family. I just sat silently and energetically tried to ground myself and separate myself out from them. I remembered a saying that one of my colleagues always said: "The grief is not our grief, it is their grief." I reminded myself that I could seek support afterwards, for my own grief that had been triggered, for the memories that were coming up.

We have come to recognize that one way to tell if we have crossed the boundary between empathy and over-identification is if we feel a desire to do more than we would typically do, or to have extraordinary contact. When we feel those urges, we take it as a sign that we are looking to have our own needs met, and that we have lost our professional perspective.

I still felt a desire to stay connected to the young woman, I wanted to give her my email address and keep in touch. Obviously I wanted to take care of my younger self through caring for her. I noticed this and kept myself in check, and I sought support for the new layer that my grief had opened. (AB)

Clearly, we feel a responsibility to notice what is happening inside of us and take seriously the need to address our own needs in appropriate ways, to avoid burdening the people we serve. The impulse to exchange email addresses served as a reminder of "why it is so, so important to know myself well as a counsellor" in order to "continue to develop around my own losses, triggers and vulnerable spots" (AB). This sensibility may have come from our formal training if we were schooled in psychology or counselling, or it may be encouraged in our informal culture. KB told of strong feelings of identification.

The parallels in our lives were significant, sobering, and in a way profound. I didn't know this person and yet I felt like I was connected, not personally yet somehow emotionally. I knew that the patient would not necessarily have the same information about me and so would unlikely feel the same, which made it worse because I wanted not to be alone in the experience—I wanted the patient to be there with me.

Self-awareness helps us to track the situations that we find most difficult, or where we are most likely to lose sight of the patient or family member and instead prioritize meeting our own needs.

JJ gave an example of meeting a young, loving couple and illustrated the confusion that ensues when lines are crossed.

When I first met them they seemed scared of the team, so I began building rapport slowly, we talked about common interests, favourite places, activities, and they shared their life stories. After many visits with them it began to be very easy for me to imagine myself in their positions, either as the dying partner, or as the supporting partner. Now, I feel dread when we have to visit them, because I like them so much, and I know what is coming for them. I don't want to see the patient die, and I find the partner's pain unbearable. I feel a desire to distance myself in order to not see their suffering, to guard myself, by not knowing any more about them. Yet strangely, I feel drawn to find out everything that has happened since I was last there. I keep hoping that she gets more time, a reprieve. I even wonder if she might be spared. I'm hoping for a miracle.

The bond continues after work hours as JJ thinks about this couple as she drives around town, remembering their stories of hiking at a particular park or going to a specific nightclub, and imagines how they once laughed and enjoyed themselves. Interspersed, however, are terrible visions of what will inevitably occur. "I have to block images of the patient when she can no longer eat at all, her gaunt face, blank staring eyes ... I have to stop myself from envisioning her as a corpse" (JJ). Once again there is paradox as the bonds we so eagerly form, and believe are so necessary, begin to bind. Connection makes our work both rewarding and painful. The co-researchers and I are not only professional palliative care providers, but also parents, siblings, children, and friends, and are just as vulnerable to loss as the people we serve.

Two co-researchers experienced the death of a close relative fairly recently, and two mentioned that they had been thinking about their aging parents and were feeling a need to anticipate or prepare themselves emotionally for their deaths. Several have chronic, non-life-threatening illnesses themselves, while others have close relatives with terminal illnesses. Another had just returned to work from providing primary care for a relative. While we encounter mortality daily, we also have our own lives outside work, our own networks of people who are subject to illness, and, of course, to mortality. This means that we will inevitably face illness, death, loss, and grief over the course of our careers in palliative care. The fact that we are middle-aged also intensifies the reality that we will encounter the deaths of our parents, siblings, friends, and spouses. RB described a recent time when death was everywhere:

Although not at all typical, during one four-month period, last year, I had four acquaintances—all parents of children that went to school with my own children, who had sat beside me at the baseball park, the theatre, the hockey arena—registered with hospice. For two, I companioned the now adult children through to their parent's death, consoling them as they watched their parent die. The other two, I attended at their homes, or on the unit, during times of crisis. At the same time, one of my closest friends was having a mastectomy and another dear friend's mother—who had been a surrogate grandmother to my son—was registered with hospice, seen by our team, and later died on the unit. Meanwhile, another friend's husband was seen by our team, and died at home.

Over those four months, she described bouts of tears at work—in the office, in the car before visits—her colleagues providing a listening ear, hugs, and words of encouragement. She appreciated how they went out of their way to keep her updated so that she would not stumble upon information. No one told them to do this—they knew from their own experience that she would be sensitive. She said that she had been tired, overwhelmed, and stressed, “Just barely managing.” Somewhat shamefully, she admitted that she had been unable to be of much support to her friends. “I say ‘shamefully’ because I expect so much more of myself.” When her sister

had tests for a life-threatening condition later in the year, she was unable to come to work for five days while they waited for the test results.

Papadatou (2009) acknowledged the impact of death on palliative caregivers. She pointed out that encountering mortality can become a force that enhances our lives. “Dying and bereaved people offer us a gift: the opportunity to reflect upon the fact that what is reversible in life becomes irreversible in death” (p. 43). By taking the opportunity to face our own inevitable death and to review our lives we have the chance to make life-affirming changes. Death in this context invites us to face our mortality and review our lives. Exposure to death “makes us aware of the freedom we have to determine how to live a life that is worth living” (p. 43). SW gave an example of this.

It felt like I was supposed to pay very close attention to my own family, my own kids, and the jolting fragility of life. ... I don't normally have a very strong need to direct how people do things or experience things, except in cases like this. I've told my own family that when I'm dying I want them to be nearby. I don't want to be left alone; I don't want them to carry on as if all was normal. I want them to be with me. I am more likely to imagine that this is what someone also wants if they are “like me,” demographically. I'm guessing that most healthy women (who are relatively young) ... have not so vividly imagined their death bed and issued instructions! This is one of the impacts of the work.

Sadness can be triggered when we see patients or families struggling with the same issues that are happening in our own lives—coping with aging parents, for example—or the helplessness we feel about certain family dynamics—ongoing bickering or selfishness, for example. Although personal loss can help us to empathize, and to eventually provide better care, personal losses strip away our “sense of safety” (SW), which allows us to stand on solid ground. While the co-researchers and I agreed that being palliative care providers creates opportunities to heal, opportunities to imagine ourselves in a variety of situations, and to prepare for our own

deaths or that of our loved ones, we also agreed that when we are dealing with grief and loss in our own lives, we cannot work effectively.

As best as I can I think about what I would want to experience during an experience like dying, and or being a family member, and I hope to offer that. Often, it is a sense of space and time. Letting folks take their time to unravel their experience, giving them space and reassurance that I care and that I am free of an agenda. (WF)

The ability to use our imagination lets us create in our minds scenarios that can help us to understand. Emotions can draw us like an incoming tide, toward the people in our care, but can also frighten or repel us, pulling us away, and even pulling us under at times.

In palliative care we use our memories either from our personal lives, or from work experiences, to help us to anticipate what is about to happen. We use our imagination in order to hear people's stories, "we imagine what it would mean to be experiencing their reality. This is not always done consciously; our subconscious flickers movies of grief and shock and resilience even while we are connecting calmly with a family" (SW). We also share our own stories as a way of building rapport and creating connections. CW said, "Good travellers often tell stories in order to gain access to the stories of others. Being vulnerable by exposing our own memories can make others feel safe enough to tell their stories." Sometimes we use imagination and draw on memories without using words, "sometimes it is even more subtle: simply having memories in our eyes can help someone else to tell us their stories" (SW).

We remember images that inspire us, such as when "their dying or the way they met their family member's dying" (BD) is touching in some way. Conversely, we also carry haunting images of "people whose death was very painful, especially emotionally/spiritually speaking, and those who died a painful or visually disturbing death" (BD). EO said that she has only once "required support for having witnessed physical trauma after companioning someone through to

death by a very severe hemorrhage.” JJ described a scenario that lingers in her memory. She and her nursing partner visited a home where the child had just fallen asleep after hours and hours of crying, but the nurse woke the child because she felt that it was necessary to insert a catheter. She was a little unsure about inserting a catheter in a child, having only done the procedure on adults, so when the catheter would not go in, she stopped, feeling like she was torturing an already very sick child. The parents and the child were now all in tears.

The parents reluctantly agreed to go to the hospital. Perhaps they were just too exhausted to fight and most likely didn't know what to do anyway. I'll never forget walking down the long deserted hallway at the hospital, at 2 a.m., with these exhausted, zombie-like parents, and seeing the child, who had a very low blood count that produced a weird translucent, pale skin colour, stumbling behind the umbrella stroller—looking more like a ghost than a child.

These images remain frozen in time, coming back to trouble our memories, and sometimes show up in dreams. Some interpret these dreams as a need to process an event, as a “warning sign of burnout” (SG) and a reason to seek supervision. The following dream precipitated BD's first visit to the hospice staff counsellor.

I woke in the middle of the night because I had been dreaming I was driving around with a dead blond woman in the trunk of my car. She was not someone I knew but a symbol, I felt, of carrying the dead around with me. I called the counsellor as soon as I got up the next morning.

JW reported that she had walked into the room of a patient, not realizing that the woman had just died. Later that night the patient appeared to her in a dream, asking for guidance on “which way to go.” KB remembers very little about what happens at work, said that “each new contact is a new experience,” and views this lack of memory as a way to “stay sane on the job,” but admitted that “every once in a while, that one case comes by that penetrates whatever protective sheath that exists, and I guess reminds me of my humanity.”

Imagination and memory provide us with pathways of connection to others by creating empathy and compassion, but create difficulties when these visions come unbidden, especially into our personal lives. JJ said,

It is easier for those who don't work in palliative care to "hope for the best," or to "just not let myself go there," when there is no picture bank from which to draw, no death and dying clips from which to scan.

Imagination is defined as

the power or capacity to form internal images or ideas of objects and situations not actually present to the senses, including remembered objects and situations, and those constructed by mentally combining or projecting images of previously experienced qualities, objects, and situations. (OED, 2012)

This means that we can conjure up pictures or images of events from the past in order to understand what is happening in the present. CW said that she uses her imagination to create metaphors that bring vividness to a situation, highlighting the nuances. She said her "best work can happen when translating the prosaic details of someone's story into a metaphor." She does this for herself as much as for the patient and family, as she explains dying, changing, or caregiving.

JW employed metaphor in speaking to a child about her impending death. The child had been told from an early age that she had a life-limiting illness, and nursing care had been a normal part of her daily life, with many hospital stays over the years. The child would regularly ask if she were dying every time she was in hospital, but was always reassured that she would recover from that particular event. She had already outlived her expected prognosis by a number of years, and was now registered at hospice. The family was struggling to come to terms with the reality that she would soon die. Every time the team visited she asked if she was dying, and a team member would tell her that she was not dying at this time. When it became apparent that

the child was approaching death, the nurse and counsellor felt that they had a moral obligation to tell her. The team sat down with the family, and the nurse reviewed what had been happening, letting them know that death was now approaching. “The family began to weep. We stopped speaking. The room was vibrating with sorrow. The tears were a testimony to the fact that this news was unwelcome and yet necessary.” Deciding that it might be best if the nurse delivered the news to the child, “reluctantly” and with a “heavy heart,” everyone went to the child’s room. They found her asleep and were on their way out when the child awoke and yelled out “in her famous direct way, ‘Hey, what’s up? Am I dying?’” Rather than the nurse stepping forward, as had been planned, her closest family member slid onto the bed beside her.

He put his arm around her and softly leaned into her, his nose and mouth close to her ear. His eyes were shut and tears were falling from his eyes. Quietly and with enormous grace he expressed to her that unfortunately, at this time, her body was very tired after fighting so hard for so many years, and her body wouldn’t be able to recover ... and that “yes, you are dying now.” (JW)

They continued holding each other in silence, their bodies rocking together. Those who bore witness cried silently at such a “phenomenal expression of protection and love.” After a long silence the family member went on to reassure the child that she would not be alone. Then, without warning, the child addressed JW who was kneeling at the side of the bed. Making direct eye contact she asked JW what it would be like to die. Remembering to breathe, JW looked squarely back.

“Well,” I said, matching her matter-of-fact energy, “it seems the best way to describe it is to think of your body kind of like a car that has been into the shop a lot of times, and has healed so many times. Your car can’t be fixed this time.”

Conscious of keeping it simple, JW watched to see if the explanation was helping or confusing her, and seeing that she “got the drift,” then said, “When you die, you leave your body, just like you would get out of a car ... you are still you, but you won’t need your body anymore,

and you just open the door and step out.” It appeared to JW that the child was able to understand that she could remain herself while letting go of her body. JW, while admitting to having “no idea what happens at the time of death, ... felt very certain in that moment of not wanting to draw this young girl into a situation of staring into an existential abyss of ‘non-self.’” This was a first for JW, who said, “I had never ... spoken to a young person about what it was like to die, but I know enough developmental psychology to know that the young ego needs strength, not annihilation.” After the child had had time to think in silence, the focus changed and the atmosphere in the room lightened.

A difficult truth shared among family is deeply intimate and surprisingly bearable. I often think of this experience and how changed I’ve been since that visit. I am not afraid of anything in this work anymore. Love truly does conquer fear. I experienced it in that room. (JW)

Perhaps it is not only children who need ways to process or understand the mystery of life and death. Metaphors and imagination create a bridge between what we know and what we do not know for all of us.

KZ described how metaphor can be embedded in a situation. She told of a time where she was asked to sit on someone’s unmade bed which “transgressed” KZ’s sense of what is socially acceptable. She said that she “cringed” as she took a seat, and that it was all she could do to sit there. KZ saw the gesture as an invitation into the intimacy of the woman’s marriage. KZ observed that the woman was comfortable, and wanting to meet her where she was, opened herself, not forcing it, she said, but “gently, in an organic way” she let her heart expand, which felt “almost like a pain in my heart as it got bigger in my chest.” Her receptiveness was apparently felt by the woman who responded by telling her a heartbreaking story of betrayal, disappointment, and anger. Another time, KZ visited a couple in their home, and found herself

following the woman through a padlocked gate, then a locked front door that opened onto a bewildering labyrinth of corridors and staircases, leading to what was almost an inner sanctum. When the woman, without preamble, began to speak of her most intimate problems, KZ understood the sense of safety that this woman needed in order to be able to share her intimate thoughts and feelings.

The Gift of Stillness

As an opening to healing workshops, I often begin by reading this selection from Wendall Berry's (1968) *Openings*.

When despair for the world grows in me and I wake in the night at the least sound in fear of what my life and my children's lives may be, I go and lie down where the wood drake rests in his beauty on the water, and the great heron feeds. I come into the peace of wild things who do not tax their lives with forethought of grief. I come into the presence of still water. And I feel above me the day-blind stars waiting with their light. For a time I rest in the grace of the world, and am free. (Cited in Unitarian Universalist Association, 1993, selection 483)

Our hospice is part of a medical facility and system that can be busy, and like any other medical facility, there are many people coming in and out of hospital rooms: visitors, cleaning staff, funeral home staff, medics accompanying stretchers, nurses, counsellors, spiritual care providers, physiotherapists, family physicians, doctors, volunteers ... the list goes on. Bells and telephones ring incessantly.

People who attend have their own agenda for their visits and usually feel a responsibility and an attachment to fulfilling that purpose. When we make home visits, we experience a different kind of busyness than on the unit; there can be numerous people arriving and leaving, the phone ringing, other professionals, dogs, and even farm animals interrupting or competing with our own agendas. Where in all of this is the time to sit with patients and families and be

peaceful? Robin Youngson, a physician, wrote about his experience of learning to relate more peacefully and said that,

To step aside from the expert role and to bring the quality of compassionate, non-anxious presence requires a great deal of inner work. Humility and non-judgement are important qualities. As the inner resources are cultivated, so one develops greater mindfulness, presence, patience, gentleness, and a powerful sense of meaning and purpose. The end result is great joy, satisfaction, and increased resilience. (Youngson, 2011, p. 44)

The co-researchers agreed that there is value in “silence, no action, and stillness” (BD) and thought that these qualities are “desperately needed” (WF) as an antidote to the busyness of palliative care. Silence can be satisfying to us, and as SW said, “some of the best moments are sitting alone with a dying person, doing nothing more (nothing less) than breathing.” WF loves being quiet and expressed gratitude for “opportunities to remember that silence and presence are very healing in and of themselves.”

My experience is that when someone is very ill, they process information at a different rate than when they feel well. I don’t mean we have to talk slowly and talk down to someone, but a wall of noise can be excruciating to the mind and sensibility. (JW)

Silence can be a benefit to the patient and family, contrasting with the rest of the “medical journey” which is, WF said, “So information focused, so do, do, do, and talk, talk, talk, that silence and witnessing can truly feel like a holiday.” EO said that her mentor used to say “Don’t just do something, stand there!” Just standing there, however, is an active response. “Silence is a calling up of our capacity to be, in the face of the urgent temptation, to do” (SW), requiring practice and discipline, “like in a yoga class, when the teacher says that we must allow our back muscles to be alert while sitting, no-action is only useful if there is an underlying alertness, subtlety, and intelligence at play” (SW). Silence is not simply an absence of words—silence can, as CW said, “hum with sympathy, compassion, and love.” In silence, we communicate our

compassion, our wonder, our acknowledgment of the enormity of what is happening, and our intention to be present.

For counsellors, many interactions involve words, and because actions and words are easy to observe, it might be perceived that they comprise the most important part of our interventions. Certainly, being articulate, and possessing a large vocabulary of words that express feelings is important and words are one of the tools of our job. However, as SW pointed out, “words can be reckless and dangerous. Words can be essential and revelatory. The gift is to know when to do, when to be, weaving the two together.” Knowing when to speak, and when not to speak, when to act, and when to be still, is an art that is clearly valued by the co-researchers. JW said that she tries “to match ... silence with the needs of the moment.” BD pointed out that “silence and not knowing and ‘waiting without waiting’ is critical in encountering the mystery of mortality.” WF said that if action is required she accommodates it, but if providing information, for example, “is a way to avoid feeling,” she prefers to “hold off and slow down the pace, so that something deeper can unfold, perhaps contacting the feeling and waiting.” SG said that “even when a dauntingly uncomfortable silence pervades, I tend to remind myself that there is no problem—it’s all happening as it ‘should.’” For WF, silence is an opportunity to breathe, and a way to allow patients and families to “connect to themselves in a deeper way by being given space.” SG thought that keeping silent was a matter of respect, or honouring, and recognized that “something important is taking place.” If colleagues fill the silence, not recognizing that it is intentional, it can be disruptive.

Where there is intentional silence, what is happening is presence. I’m present, in that space, I’m just there. I am in a state of openness, of non-expectation, receptive ... I truly, truly, value silence, and I have a hard time when a colleague fills the silence. (SG)

Counsellors consciously practise restraint, especially when unsure or uncertain, as a way to allow intuitive knowledge to surface. “Sitting in silence and connecting to the energy of the interaction between myself and a patient and or family member allows me to respond organically rather than from the ego/problem solving/fix it place in my head” (WF).

WF said,

All it requires of me is to remember the power of silence and the healing experience of having oneself held in silence and I happily go there. ... I simply hold myself still and wait, I love waiting, I love attending to someone in silence, and seeing what comes up and where they go.

BD used the metaphor of “waiting for birds to come and peck at your feet, rather than always feeling we have to ask a million questions”—the idea being that if we are still, people will come closer of their own accord, and that constant chatter, or questioning, can scare people, causing them to withdraw or retreat.

When asked what is happening when there is stillness, WF said, “I may be getting my bearings, I might be struggling with a way to respond, or not connected to my own intuitive sense of the situation and so I’ll sit and go into myself.” Silence allows for “receiving, resonating, listening deeply, opening to, and being changed by what is occurring” (BD). For counsellors, there can be comfort and peace in being both “alone and together, in silence” (BD).

EO lamented that she was better at “being silent, and at engaged waiting, before I worked so closely with medical professionals and their need to ‘fix’ things.” She said that she feels pressure to do something, or to “counterbalance the medical ways of knowing,” and finds it alarming when she finds herself speaking from a “position of authority or knowing.” WF waits until the busyness of the medical assessment, “which can be draining for all,” is finished, and

shifts the energy and pace by going into “therapy mode,” which is slower, more open ended and non-goal oriented, allowing the patient or family member to initiate the topic of conversation, or to sit in silence. WF pointed out that there are “many ways to be of service” and she sees the presence of the counsellor and others on the team, such as the music therapist (who is on the unit, not the crisis team), as a reminder to everyone that “we’re dealing with a whole person here.” Even when she is in a period of waiting for the nurse, WF is aware that her presence is “making a statement.”

Encountering Mortality Can Be Mundane

Dechamps (2011), in discussing the palliative caregiver’s role, cautioned us to be aware of the motivation and purpose in our work. “Working with the dying can be seductive, feeding stories of ourselves as somehow being very special. Those are dangerous dreams, for patients and practitioners” (p. 130). The danger lies in first seeing ourselves as heroes who rescue or save people, and then having to defend that “heroic stance” (p. 130). Accepting the ordinariness of our work allows for a sense of pride that is tempered by acknowledging what we cannot do and what we still have to learn. “It is from this place of human ordinariness, where real connection with others becomes possible” (p. 130). Perhaps it can only be said that we may be more sensitive to and can instruct others on some aspects of living and dying because we have dared to enter the realm of the dying.

SW pointed out that we have a preference for focusing on the transformational aspects of encountering mortality. Whatever variation each of us gives in answer to the question of what we do at hospice, it likely does not include a description of the many boring and non-engaging parts of our day. When asked directly about the mundane aspects of our job, however, we

readily admit to finding many aspects tedious. The most frequently mentioned part of our job on the crisis team is waiting for the nurses to fill medications. A typical home visit involves responding to a call from a health professional or family member, reading the patient's chart, driving to the patient's home, talking with the patient and/or the family, and doing a medical assessment which involves the nurse talking to our on-call physician in order to decide a course of action and to get orders for medications. As counsellors we conduct a psychosocial assessment and intervention. The nurse is charged with filling syringes with medication, organizing pills, and instructing the family on administering the medication. Filling medications can take an hour—sometimes longer, depending on the number of medications, how long it takes the doctor to return the call, and whether we have to wait to see if the medication has been effective. This can take 20 to 30 minutes for each dose and may need to be repeated numerous times until the symptom has been relieved to an acceptable level. Once we know how much medication is required, the nurse can fill enough syringes to last a minimum of 24 hours, at which time we will return and go through the entire process again. Despite the relief from the intensity of interacting with family that comes with assisting with tasks such as taking the paper casing off syringes and caps, waiting can be extremely boring, and at times can cause anxiety and frustration as the exhausted family feels a need to interact or engage with us.

Other tasks that are not always welcomed can include duties such as attending rounds (which often focus on physical symptoms and medication changes), updating supplies, getting gas or cleaning the car, charting, and waiting for the nurse while she makes phone calls to other professionals. Not being fully in charge of our own time creates a need to wait without the option of beginning something new or moving on. On the unit, tasks may include delivering or filling out paperwork related to parking, compassionate leave, insurance, accommodation, and

bed allocation, and can involve discharge plans, funeral arrangements, and other practical tasks to support the patient or family members.

Dealing with such tasks is not always experienced as boring, though. SG explained that mundane tasks can be satisfying. She gave an example of working with a man living very simply, in a house made of plywood, with dirt floors and tree stumps for chairs. The man felt that he could not die in peace without making sure that care for his wife was in place. SG spent “a phenomenal amount of energy” to grant him his wish by contacting the public trustee and arranging for them to act as his committee for both his and his wife’s estates. She then advocated with a funeral director for a funeral service to be provided as there was no money to pay for one. SG then arranged for the wife, who was mentally challenged, to be placed in a group home and for her mental health worker to take her for regular visits with her husband when he was on the unit, and for her to attend his funeral and burial after he died. SG felt it was rewarding to be able to see things through from beginning to end. Taking responsibility for practical details provides variety and can be a relief from the intensity of relationships and emotional expression.

Advocacy might be thought of as mundane and it can be tedious, tiring, and stressful. Encountering mortality can expose us to the inequities of society and can move the co-researchers to become advocates. Whether advocacy takes the form of small acts that make a difference to the individual, or larger acts that change systems or attitudes, it is an important part of caregiving. As EO said, “the strongest challenge in the work is systemic oppression or barriers that the person or family is facing.” She finds herself feeling “very frustrated” when facing “poverty, racism, abuse, and institutional barriers.”

Collett (1997) pointed out in *Stay Close and Do Nothing* that caring for a dying person requires small everyday activities that become tiring through repetition. Helping a loved one to eat, sleep, use the toilet, take pills, and stay clean can all have an amplified meaning in the face of death. In the face of the fragility of the patient in every sense, “the caregiver must summon up large amounts of emotional, and sometimes physical, stamina to meet the many needs. It is precisely the demanding intensity of the work that gives it its transformative power” (p. 31). The importance of acknowledging the mundane quality of encounters with mortality is illustrated in the following story because it reveals how acknowledging the everyday challenges of caring for the dying opens the topic to exploration and gives permission for it to be discussed.

SW was called to care for a relative who was receiving treatment for life-threatening cancer. She was the relative’s primary support and advocate, and, being from out of town, was struck by the boredom of being a caregiver, with no ability to balance this out by maintaining her normal daily rhythm. Why had she never heard of this aspect of care from the families with whom she works? “Do we lean into the stories of drama and crisis, and look away from the day-to-day erosion of energy and vitality?” she wondered. She likened it to “running a race where the distance keeps changing.”

For example, at the time of diagnosis my relatives were all shocked, convinced ... by the words of the doctor ... that the prognosis was short.

We were in a 100-metre sprint. Everyone came, everyone called and sent letters and flowers and made declarations of love. Nobody was thinking about pacing. And then things changed. It became clear that we were in, maybe, a 10 km race. She had a treatment plan. There was hope being offered by her oncologist. We needed to slow down.

We wished we had trained.

Then she had the surgery and it was awfully hard and everyone moved in again. We were back in a short-distance mentality; maybe not a 100-metre dash,

maybe an 800-metre race. We needed to give everything, but we had to save a little for the finish. Now she is doing well again. The prognosis is very uncertain. There is talk of survival. Everyone realizes that we are in a marathon.

Nobody trained.

Someone needs to take responsibility for the water and food station. We need volunteers to stand at the tricky corners to make sure we don't get lost. As hospice workers we are the ones at the tricky corners. We don't need to run the race, but we need to know how hard it is. We need to know how confusing and exhausting it is when the finish line keeps getting moved. Imagine being in a marathon and having 2 miles to go and then seeing a new sign that says "only 10 miles to go." How does one continue? (SW)

She said that palliative care workers are more like "daycare providers or pre-school teachers, whereas the families are the parents ... having all of the responsibility, worry, sleepless nights, interrupted capacity to earn money, and no energy to exercise, eat well, or have fun." In acknowledging the mundane properties of care, we allow for the whole picture to be seen, which is more realistic.

We need to be open to the truth of boredom and weariness so that we can also hold that truth of the more transformative narratives of love and enlightenment and reconciliation and gratitude. The uncomfortable truths, such as "caring for my husband is boring" or unpleasant or irritating, are the truths that isolate families. Our work is to create a space in which the truth can be told and seen and felt. (SW)

Daily tasks that have little intrinsic reward, especially when repeated, are the unseen foundation of caring for the dying. In some ways these tasks provide structure and relief from the intensity of the emotional impact of what is occurring, and can be soothing, giving a sense of much-needed normalcy to the caregiver. However, these same tasks can be exhausting in themselves. The sheer volume of what is required to care for the dying can be overwhelming and relentless. By recognizing the mundane aspect of the work, we acknowledge that caring for the dying is more than showing our concern on an emotional and spiritual level. Some of the

work of caring for the dying is unseen, unacknowledged, and often unappreciated, even by the people providing the care.

Service

The first thing that I asked of the co-researchers was to share a story of an encounter with mortality. When I read their stories and thought about my own, I was touched by how much patients, family members, and the co-researchers themselves give to others. Caregivers “surrender or give up (something) for the attainment of some higher advantage” (OED, 2012), which is the meaning of the word *sacrifice*. We sacrifice our own comfort in the hope that our presence would comfort or be reassuring for others because we believe it is for the purpose of serving the greater good. The term *sacrifice*, however, was not embraced by the co-researchers. SW said that sacrifice is a word that she “very intentionally” does not include in her vocabulary, because she has been the recipient of other people’s sacrifices and has not found them to be “loving or neutral in any way,” but decidedly “unloving” and even “punitive.” It is easy to understand then why she is “more interested in focusing on loving-kindness, not sacrifice, when reflecting on the work of hospice” (SW). Others would agree. BD said, “I don’t really believe in ‘sacrifice’ and have a reaction or discomfort at the idea.” Like others, BD prefers the word *service* which reflects “a strong commitment to compassionate care, even if it means going beyond what is comfortable.” JW said that the word *sacrifice* seems “negative,” and that even the idea is “a bit of a tough sell” because no one really wants to give up their “goodies” to get “less.” We are in agreement that there is value in making a deliberate choice to be of service, but it must be for the right reason.

What does it mean then, to serve? According to the *Chambers Dictionary* (2008, p. 988), *service* is related to Old French *server* and from the Latin *servire*, both meaning to serve, and originally related to being a slave, but later coming to mean “being a servant of God.” There is also a Middle English adjective *serviceabul*, meaning “willing to serve, ready to do service ... and useful.” The desire to be of service was a common reason that we gave for coming to work at hospice. It has intrinsic value to us and is something that we strive to do more and to be better at. Being of service is reinforced at hospice through our own experience of satisfaction, through expressions of gratitude, and through witnessing the good deeds of others. Dr. Robin Youngson (2011) an anaesthetic specialist in New Zealand, was moved to action after his daughter was severely injured, and joined a worldwide movement to bring compassion to health care (Rezenbrink, 2011). He now realizes that it is important for him to serve patients on their own terms, and that he knows they have truly been served if he can see them grow personally through taking personal responsibility for their own health. His role is only to coach and support. “The relationship is one of deep, mutual respect, honesty, and openness” (Youngson, 2011, p. 45). The co-researchers agreed that in order to provide care that is caring, there can be no hidden agendas for personal recognition or gain. CW explained that she sees her presence as being “invisible,” or at least “translucent,” and said that if anyone remembers her, then “something has gone wrong.” “When one thinks back on a trip, the road signs or maps should not be the most memorable details, they only work if they are where they need to be: present and useful, but not central.” If she stands out in the memory of the family, she has failed to be of service in her opinion.

Being in the company of people—patients, families, and colleagues—who give so much of themselves to others every day is inspiring. As WF pointed out, some family members speak

to us about having an opportunity to “give back” to a loved one. At the same time, she pointed out, they are facing exhaustion and loss of finances, and leaving the everyday comfort of their own homes and social networks, often being pulled between responsibilities at work or at home, leaving them “not quite able to be in either place.” Sometimes their homes and families are very far away, and they are on the telephone, constantly trying to co-ordinate the people who are helping out “back home.”

Maybe what I see most people sacrifice is their comfort, their “known world,” and peace and quiet, for a chance to be with someone in their final chapter. This is beautiful to witness even though it often includes considerable tension on the part of the caregiver.
(WF)

Who shows up can be surprising. “Sometimes I wonder what a person must have done to inspire such kindness” (JJ). We watch with amazement as a neighbour quits work to look after an elderly person who has lived beside her for years, or when a cousin from Australia moves to Canada for the last six months of someone’s life. Relatively young grandchildren care for aging grandparents, landlords for tenants, and new partners all “step up to the plate” (JJ).

At other times we see something quite different. Some family members do not travel across the country, or even across town. They respond in a minimal way, if at all, or leave one family member to carry the load. Sometimes they send paid caregivers. This can challenge our sense of what is an appropriate response, and we can become critical. As WF said, she has to remember that she is only “seeing a little ‘snippet’ of someone’s life. Perhaps there has been a history of terrible abuse and the adult child is no longer willing to sacrifice themselves for the sake of a parent.” We attempt to make room for many possibilities as we wonder if there is more to the story to which we are not privy. As WF pointed out, we have to allow for the possibility that the family member is actually making a good personal choice, one that is in their own best

interests, and we need to be careful not to impose our own ideas of what service is and how it should be enacted.

Finding Balance Between Giving Enough and Receiving Enough

AB related her own struggle of being torn between her sense of urgency to savour each moment of her children as they are growing up, and her need to address her own well-being. She gave the example of her desire to attend a spiritual retreat. She wondered if it was right to take time, money and energy from her family in order to serve her own need for spiritual renewal. She vacillates between the thought that she must attend to her spirit now, because she does not know how long she will live, and the thought that her own nourishment can wait until her children are grown. Her concern is that she will have a “life not lived,” that she is so caught up in her roles as “wife and mother” that she has lost contact with herself. She does not want to “wait until I’m literally screaming in order to give myself time and attention.” In trying to understand the difference between sacrifice and service, the co-researchers distinguished between care that is enriching or nourishing, and care that simply drains energy. When something is given freely and has intrinsic satisfaction, it then qualifies as service.

The co-researchers admire and are moved by the love and tenderness that patients and family members show to each other. We too want to give, but at the same time we recognize that we have needs that must be addressed; as SG said, we need to accept that “there is a time to focus on our own pain and sometimes our needs will encroach on the needs of others, and vice versa.” Although we all had personal reasons for choosing this work there was a sense of being of service and we have learned that we need to be discerning about the energy we put out. We all seek the appropriate balance.

Collett (1997) pointed out that although it is difficult to accompany a dying person to their last breath, at the end “we find ourselves changed” (p. 1). What begins as a gesture toward another person ends in transformation for us. “We begin wanting to help and we end simply wanting to be. Looking at life from the perspective of death, embracing our transience, we stop straining to make each moment more enjoyable and start savoring existence itself” (p. 1). As I discussed previously, finding this balance can be difficult, but the co-researchers would agree that we are changed by the experience of serving rather than sacrificing and that there is intrinsic value in being of service.

Another Turn Around the Circle

Van Manen (2007) says that every question must be motivated by an “abiding concern” (p. 31). For me that concern was about understanding the lived experience of encountering mortality. Van Manen (2007) commented on the commitment that phenomenological enquiry demands:

This commitment of never wavering from thinking a single thought more deeply is the practice of thoughtfulness, of a fullness of thinking. To be full of thought means not that we have a whole lot on our mind, but rather that we recognize our lot of minding the Whole—that which renders fullness or wholeness to life. So phenomenological research is a being-given-over to some quest, a true task, a deep questioning of something that restores an original sense of what it means to be a thinker, a researcher, a theorist. (p. 31)

The mandala work I was doing while writing and reflecting on the experience of the co-researchers reinforced and intensified my findings, and was one more step in being-given-over to the quest.

As explained in Chapter 4, the mandala’s structure is meant to create a particular experience symbolic of a journey of discovery (see Chapter 7). When I use the word *mandala*, I

am referring specifically to the Sacred Mandala rather than mandalas in general. I have also deliberately avoided emphasizing the timeline of its creation in the following section, because the themes that helped me to understand what it means to encounter mortality occurred throughout the mandala, and it was only in retrospect that I was able to collect evidence of how my thinking developed. Likewise, while I present my dissertation in a linear way, my thinking was non-linear. I have organized my representation around the turning points in my understanding—the evidence of these turning points appears throughout my dissertation.

In understanding the role of the mandala it might be useful to refer back to the complexity lens and to think of the mandala as the experience of the experience of encountering mortality on a daily basis. McMurty (2008) reminded us that a complex system's most important characteristics are self-organization and adaptation: "A crucial consequence of complex systems' self-organization is that they cannot be reduced to, or understood in terms of straightforward, causal inputs and outputs." In this way, then, it is difficult to explain exactly how the mandala influenced the dissertation writing, and vice versa.

At the same time complex systems are adaptive, because they change their own structure in response to internal or external pressures. A complex system's structure—that is the dynamic relations among its component parts—adapts to, or couple with, its environment (though always in a way that is governed by its own self-organizing internal structure). (p. 268)

Like my analysis of what the co-researchers told me, the mandala work was a changing system that was interacting with another changing system. As the co-researchers articulated their thoughts, and as I asked them further questions and they read what they and others had said, changes occurred in all of our lives. For me—two close friends and a close colleague were diagnosed with cancer; my son was on a very dangerous, at times life-threatening, outdoor adventure; and a member of my family had a health scare that brought mortality one step closer.

My mandala work was changing me and every system that I came in contact with, and like all complex systems, the sum is greater than the parts—although my academic writing was valuable in itself, and my mandala work was also valuable in itself, together they became a more powerful entity, contributing more than each could contribute separately.

Chapter 7: The Experience of the Experience of Encountering Mortality

The psyche can be defined as the “mind, soul or spirit ... the whole conscious and unconscious mind” (OED, 2012). Mandala work is a visual record of a person’s psyche over the period of time that the painting takes place, which is typically nine to 12 months of daily painting. Of course, it will never represent all that was going on—that cannot be captured—and so it provides *a* picture, not *the* picture of the psyche. The mandala is a project in itself, a painting with a beginning, middle, and end.

In both my mandala work and in my academic writing I applied my technical skills, attended to the moment-to-moment process, and allowed the work to unfold rather than adhering to a prior vision of what it would be. My research and writing were also creative processes that had a beginning, middle, and end. In both projects I needed to decide what to include and what not to include, establishing criteria for what was important, what was worth dwelling upon, and what could fade into the background. This is where it gets complicated. My intention when I began the mandala was to ask, “What is it like to face death?” The mandala then became a reflection of the process of my life journey as I faced my death, so that the mandala work was not only an entity in itself but also represented my research, my work as a counsellor in palliative care, my life outside work and school, and my way of being as I approach my own appointment with Death.

How I went about living my life, my way of being as I moved toward my death, was also a creative project that involved the technical details of creating a day-to-day schedule that attended (or not) to my physical, emotional, social, and spiritual needs. The mandala reflected back to me the choices that I made—what I turned my attention to and what I let fall into the

background. The mandala was a repository, a container, and a process, all of which tracked and mirrored back to me how I operated, how I was coming-into-being. As I created (my mandala, my dissertation, my life as I move toward my death), my psyche was commenting throughout in the form of images and I was further clarifying my understanding through reflecting, writing, collecting dreams, and noting synchronistic events that brought my attention to the commentary. The mandala uncovered my way of being as a painter/student/meditator, as a student/researcher, as a palliative care counsellor, and as a person living in and interacting with the living, evolving network of life. It was also one possible response to encountering mortality.

The Impact of the Mandala Work

Painting a mandala creates a powerful response that is contained and represented within the circle. It seems obvious to me now that the psyche does not take death in the literal sense, as I had imagined when I began, but instead takes it as a metaphor. For instance, during the process of painting and writing I was compelled to reflect upon what was lifeless, dying, dead, or deadening in my life at the time. I examined my desire to run away, to think about with whom and under what circumstances I am intimate, and where I connect and disconnect. This helped me to integrate the information that appeared when the co-researchers were describing ways of connecting and disconnecting in relationships. Much like the palliative care context, where encountering mortality is part of our daily work, the mandala work provided a platform for me to engage in an intense evaluation of my life, what I hoped to accomplish, and the impression, impact, or legacy that I would leave behind. It also challenged me to address my health, my frailty, and my vulnerability. It reminded me of my losses, the ones I have had and the ones that I will have. More than ever, both at work and during all my time off, I was immersed in thoughts of death. This intensity was a mirror of both my work life and my research. Much like

encounters with mortality over time, working within a Sacred Mandala is a thorough process that does not allow for looking only at what is palatable. Like Death's scythe, it mows everything in its path without regard to what is fair, what is reasonable, sacred, or precious. It certainly did not care about what my ego wants uncovered and what it prefers to be left undisturbed.

I have mentioned that while I was conducting my research several events brought death closer to me. Shields (Johnston, 1997) would have considered these events to be synchronistic, meaning that I was to pay close attention to them. It is outside the scope of this work to explore synchronicity at length but it is of interest to me. In my Master's research (Breiddal, 1996) I had asked students who were exploring their spirituality to ask a focusing question and to note synchronistic events over a period of several months. By examining these notations, they gained insight into their original questions, and I was able to show the value of tracking synchronistic events. There are many ways to make meaning of synchronicity, but for the purpose of this dissertation synchronicity can be defined as "the phenomenon of events which coincide in time and appear meaningfully related but have no discoverable causal connection" (OED, 2012).

My mandala was a poeticizing of my own encounters with mortality as I proceeded with my research. Van Manen (2007) compared phenomenology to a poem and said that:

To summarize a poem in order to present the result would destroy the result because the poem itself is the result. The poem is the thing. ...

We must engage language in a primal incantation or poeticizing which hearkens back to the silence from which the words emanate. What we must do is discover what lies at the ontological core of our being. So that *in* the words, or perhaps better, *in spite of* (emphasis in the original) the words, we find "memories" that paradoxically we never thought or felt before. (p. 13)

Because the mandala is “the thing,” (p. 13) it is important to me that I do not lose “the result” in making an academic summary or a rational ordering of themes, but rather allow the impact of the opening in my thinking to be my guide.

In the following section I share some of the more meaningful examples of synchronistic events. The Panels of the Narrative Ring are numbered in the order that they were painted and are presented in small groupings. Although each one is not specifically referred to, I have included a photograph of each panel, and given detailed examples of how the dialogues, dream work and synchronistic exploration combined to form insight. It should also be noted that I have chosen to summarize what I came to understand through my journal work in some sections because although important to me, they relate less to encountering mortality and more to my struggles with the writing of my dissertation or to other areas of my life.

Turning Points

The mandala is circular, so in some ways each movement with the brush is a turning point. However, when I use the term *turning point* I am not referring to the physical turning of the mandala but rather the emotional, intellectual, and spiritual turning points—with one exception. At exactly the halfway point of the Narrative Ring, my sleepless, restless nights, peppered with nightmares, ended abruptly, and I had a feeling of well-being, as if I now understood what was required. From then until I reached the end of the Narrative Ring, I began to feel less stressed and more peaceful as the messages from the figures in the panels began to focus more on expressing love and letting go of worries. The other turning points were not actually singular moments or events, but were the result of a slow dawning of understanding that came through repetitive messages. I described the first turning point (which can also be

understood to mean theme) in Chapter 5, where I reflected on the “negative space” I encountered in interacting with the patient Mrs. White.

Journal Work

Before I begin the next section, I want to emphasize that the themes that I will be describing are not at all distinct but rather artificially and temporarily separated here for the interests of discussion. This separation may make it easier to see that these themes were contiguous with each other and also with the themes that arose for the co-researchers. By seeing this “part,” the “whole” can be better understood when the themes come back together in Chapters 8 and 9. In the following section all quotes, unless otherwise indicated, are quotes from the dialogues, dreams, or discussion recorded in my journal. It should also be noted that I have changed to writing in the first person, so as to convey the emotional impact of the unfolding story. The journal writing is written in the first person present tense, while the narrative that ties the themes together is written in the first person simple past tense.

In the following section I present three turning points or themes: being in the face of D/death, staying awake, and living my life.

Being in the Face of D/death

Figure 5: The Death Card from the Rider-Waite Deck²

As I meditated on the Death card (see Figure 5, above), which was posted above my computer so that I would “face death” daily, I wondered for some time about the nature of death

2

http://www.google.ca/imgres?imgurl=http://www.learntarot.com/bigjigs/maj13.jpg&imgrefurl=http://www.learntarot.com/maj13.htm&h=600&w=350&sz=109&tbnid=UREsTgM4P8JApM:&tbnh=91&tbnw=53&zoom=1&usg=__wD2F0rQBSBZTltInf3X78iFnyVE=&docid=-xaOpdA3bqfKIM&sa=X&ei=hkYDUZSyBMmwiQKWYDwDQ&ved=0CEQQ9QEwAw&dur=292

and what it means to die. I noticed that it was difficult to keep my focus on death when I first began meditating, finding it disturbing and somewhat frightening. My first dream, which Shields considered to have prophetic significance (personal communication, 1984), featured a snake. I wrote:

The snake is nothing special, not dangerous, but it scares me anyway, the snake, death. I can see that death is a non-issue. Life leaves so slowly and peacefully usually, not a big event in some ways and yet the biggest event other than birth.

In one meditation on the Death card I was struck by the “smallness of Death” in relation to the armour.

From the outside you would think that you would find a robust person, sitting straight, powerful, and invincible but like the great Oz you find small brittle bones that don't seem to have much potency. Could Death itself be dead?

I wrote in my journal that it was “strange” to think of Death as dead, and wondered if instead the image might be portraying death as being impersonal, but still a “lively force.” I also wondered almost superstitiously whether my focus on Death, would lead it to focus on me.

Death was being carried by a living horse, which I took to be a symbol of nature.

It is nature not Death as an entity that takes us into death. Death does not exist separate from life—each step towards death is still life and then that one last second is not life but is now called death, my state of being at this point, is dead. The essence of life is one thing and the essence of death is another but both create the whole.

In my journal work, I made a connection between death as in the end of life, and death as in a dehumanizing force. For example, in another dream I met with a couple whom I had known in my twenties. The dream was set in Italy, and I was having an affair with the man. Later, the woman was telling me, quite smugly, about her boyfriend and in my journal I wondered why she and her husband continued to live such a “sham.” I wrote:

Milton is a man who is a shyster, a liar and a cheat, a little man who has delusions of grandeur. He is in charge. Mary is the young, seemingly naïve wife who appears not to know what is going on but really does, and gets her secret revenge. We are in a city that is stimulating and a bit overwhelming. A place I return to again and again in dream time. I always feel a little desperate here, like I have to fit everything in and I have to see Milton and Mary. It's like it is my last or only chance at something. I am in bed with them, so to speak.

Meanwhile, I recorded events in my journal that I was later able to connect to this dream.

For instance, I was listening to a program on the radio that was about why people cheat. I also noted that I was handling the mandala in an offhand, almost irreverent way, and not strictly following the rules that had been laid out by Shields, such as moving counter clockwise, doing more than one task at a time, and practising forms on another piece of paper. I explored the concept of cheating in my journal:

On the radio there was a program on intellectual integrity, aka cheating. They were saying that cheating occurs when someone (me?) thinks that they cannot do what is required. I have found out the hard way that in the end it is easier to do an assignment, or a job, or whatever, the correct way—getting away with something always takes more effort in the end. ... Feeling guilty, worried about being caught lingers long after the job is over. Why am I thinking about that right now? What does the dream want me to pay attention to? Am I looking for the easy way out in doing my research, by doing narrative and artwork? ... What is it that I think that I cannot do?

The *place* that I return to again and again is this overwhelming desperate *feeling*. Trying to escape this feeling by rushing is inappropriate and cheating is useless and a waste of time.

The advice: You won't be overwhelmed or distressed if you stick with being honest about what is really happening and do every task with integrity—with all of your being. The yearning should be satisfied ... by having integrity.

I think I am on the right track.

A committee member pointed out to me that people also try to cheat death. I wrote that “my way of cheating death is to fit in as much living as I can.” This was the beginning of a dawning understanding that, paradoxically, rushing or in some way losing one's integrity by

taking a short cut or trying to get away with something is cheating life not death, because rushing, being dishonest, or not having integrity is a “sham.” I wrote that cheating “may provide the appearance of fullness, but the experience itself is empty and unsatisfying.” In another dream I was in a café, on a computer. I received a text message saying that I was not allowed “to play games” on this computer, but I kept falling asleep. Someone came over to my desk and repeated that I was “not allowed to play games.”

On the night before the 19th anniversary of my son Dante’s death, I had a dream. I present the dream and some of the journal work in detail to demonstrate how dream work helps to understand the unconscious message of the dream:

I am in London with Bruce [my husband] and Dante [who died when he was an infant]. We come out of a store and I ask him, “Where is Dante?” He says, “He has been taken by the Germans ... they are programming children from all over the world with German propaganda because they want to promote Germany.” He tells me that their plan is to return Dante, but I know that he will not be returned as the same person but will be a zombie. Bruce seems unconcerned. I start screaming hysterically.

Then I am on a bus with all of my children, including Dante, and I arrive at a house. When I walk in I see that Bruce is sitting with the Germans and they are waiting to take Dante. Bruce gives me a look and shrugs his shoulders in a way that says, “There is no point in fighting.” I go to the door of the house and begin to shriek into the darkness of the neighbourhood, “Help me ... help me ... I am in terrible trouble!” But no one is listening.

I awoke from the dream sweating, my heart pounding, actually screaming for help. I worked with the dream, as I had learned to do in my Jungian Dream Analysis classes (in my Transpersonal Psychology Master’s Program), and as I help my clients to do in therapy and Dream Groups. This entails going through the dream word by word, substituting my associations with all the nouns and verbs, and then retelling the dream. My training in Dream Analysis focused on the dreamer’s associations with words, and although as a therapist or guide I might make comments or associations with words after the dreamer has explored the dream, in

my training, the meaning of the dream comes from the associations of the dreamer and not the therapist. This means that another person reading or hearing the dream might project different associations onto the symbols and the action of the dream, and therefore find a different meaning or that at another time the dreamer may also interpret it differently. For instance, in this dream Dante represented spiritual awareness to me. My interpretation at the time read as follows:

A rational, grounded, reasonable person comes out of a place where action takes place, and things are kept for later. He is without spiritual awareness and says that some highly rational people who want to make things better but have crazy ways of doing so, and who don't care about the means to an end, want spiritual awareness, so that they can use it to make things better, but they don't care who they hurt to get it. A feeling person is frantically raising her voice but she cannot express herself and she cannot be heard.

The woman and three small offspring who are sweet and innocent, and the spiritual one, are travelling in a vehicle that takes people from one place to another place. When she arrives at a new place, the man is seated in a chair. The people, who want to make things better in crazy ways, are there. The man accepts that there is no escape and says that it is futile to resist. The woman tries to escape and raises her voice but no one is listening. She says in an even louder voice, "I am in danger, something seriously wrong is happening and I need your assistance." No one hears.

This was a significant dream. Fear lingered for days. I returned to my journal work many times to try and further understand its meaning. In retrospect, I saw that the dream was foreshadowing my struggle to pay attention to the process, rather than the goal. I was engaged in what seemed like a good cause, to contribute to the body of knowledge of palliative care, which was meaningful and part of my spiritual calling, but I was not fully able to hear the message and the nightmares and anxiety continued for the first 13 panels of the Narrative Ring.

It was not until later that I wrote, "I have used my body as a tool to get the job done, objectifying myself to get what I wanted. I have dehumanized myself, creating the living dead, and becoming a zombie." I realized that even if my work had value to the world, it could never make up for destroying my spirit, or being disrespectful or hurtful to others. As I began my

correspondence with the co-researchers and was immersed in my studies, a close friend was diagnosed with a life-threatening illness, and went through treatment and its aftermath.

Although I made some efforts to connect with her, I was not successful. In my journal, I wrote about a conversation I had with my friend. In this conversation I had somewhat defensively tried to explain that, although I deal with death every day, having someone in my personal circle of friends and family face death was completely different. “It’s not even related,” I said. That statement kept coming back to me because it seemed like an odd thing to say.

Shortly after this conversation, a discussion came up with the co-researchers about whether or not we “perform compassion” (SW) in our work, and I struggled to understand how it is that I could be feel so adept in assessing situations at work but feel so inadequate in this situation with my friend. Was I just “performing compassion” while I was at work, and not being authentic? Was I not able to show genuine compassion toward my friends, like the family members who could not be present, as described by EO, SW, and JF? At the same time, the co-researchers were also writing about the fatigue from the intimacy and the intensity of our work, and feeling a need to withdraw and even take distance from family and friends. I found this validating, which was comforting. I wrote at length, trying to understand how it came to be that I had been such a disappointment to my friend and to myself. I realized through my journal writing that there were complicated dynamics involved, and that my friend and I had many “underground connections” (Piercy, 1982, p. 128) that are not present in my relationships with patients and families. With her, I not only had to notice and care for her feelings, but I had to notice and care for my own feelings too, which are far more powerful and complex than what I feel for patients and families.

I think that I have learned something important about the underground connections. Although there were reasons that I can give for not being more available, in some ways they are just excuses for not wanting to face that [my friend] might die. I make a solemn vow right now that I will make friends and family who are sick a priority, even if I feel uncomfortable. I made a big mistake and I can learn.

I then recorded a dream in my journal in which a woman is found dead in a bathtub, while I am “changing” in a nearby room. I believed that I might be blamed for her death. “I begin to scream but no sound comes out. I am actually screaming and continue until Bruce shakes me awake. I am so scared that I am paralyzed, unable to move my arms and legs.”



Figure 6: Panels 1-4 from the Narrative Ring

I noticed that waiting caused me stress. For instance, as I waited for my candidacy exams to be evaluated I compared it to waiting for the death of a loved one. “I can’t concentrate or rest. I am neither here nor there. Not knowing is the worst, everyone says that.” I also related waiting to the idea of legacy, wondering if I will ever know for sure that I have done enough and been enough. In dialogue with various figures in Panel 3 (see Figure 6, above) I was told:

As in facing death, there are periods of the unknown, and like an underground fire they [periods of waiting] have an effect. ... Pay attention, notice that it creates tension and do not give into worry. Enjoy the warmth and do not let it get out or control for then it will truly burn and hurt you.

Later, in other panels (see Figure 7, below), I was told:

[It is important to be] ... patient, to not anticipate, to not worry, to not prepare in an anxious way. Prepare by enjoying life, and being present in the moment. Enjoy the ride even when it doesn't appear to be moving. Accept what is. Allow for rest and fermentation, it is just as important as movement, maybe more important. Be careful with your impatience and tendency to be impulsive. Think before acting.

In the case of my exams I knew that no matter the outcome, I would only become a better writer, but I did not want to fail or be considered "not good enough." This feeling was present when I thought about my career and my family life too. I kept wondering if I had the right priorities, and if I had accomplished enough or the right amount in my lifetime. At times I wondered if some of my struggles were the same kinds of processes that dying people face and I wrote in my journal, "Is this like a life review?"

In Panel 4 (see Figure 6, above) I was told:

I come to remind you of your purpose to do good—to communicate something important about your work. There is no need to be stressed in any way, you have something to give and you give it. Only good things will come of this ...

There is nothing to be afraid of, whatever happens, you have what you need to be bereaved and to face your own death. Salvation is in our love for other people and their love for us. Never forget the good will of others.

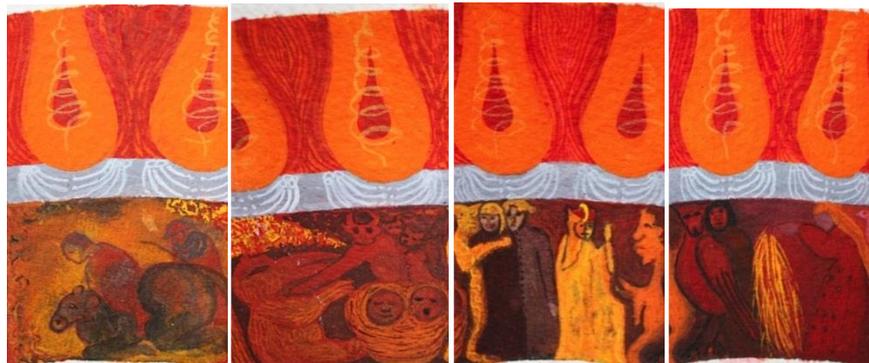


Figure 7: Panels 5–8 from the Narrative Ring

In Panel 6 (see Figure 7, above) I was told that those who are willing to stand near the fire (death) will be “illuminated” and “transformed.” However, I was warned not to take it all too seriously, and assured that “it all turns out alright.” This theme continued through the next few panels (see Figure 7, above) when I was instructed to enjoy life without “fears and defenses” by embracing my own fragility. I was reminded that death is a mystery as the masked figure in Panel 7 (see Figure 7, above) said:

You know nothing about dying because you have not done it. Never forget this. It is mysterious as it is meant to be. I hold the light so that you can see how little you know. Have great awe for this mystery. There is no possibility or need to try and solve it—death reveals itself when it wants to.

I was reminded that we are only here for a short period, and in Panel 9 (see Figure 8, below) the figures urged me to “dance to the tune,” pointing out that we are only here for a short time and then “dissipate.” In Panel 11 (see Figure 8, below) I was shown a couple. The sleeping man said, “I rest peacefully. I am very close to death and am happy and satisfied. Fear not, death comes peacefully.” I was able to, at least for a time, let go of my fear and discomfort in facing D/death, and the dialogues began to shift.

Staying Awake



Figure 8: Panels 9–12 from the Narrative Ring

The grey Transition Ring can be seen running between the flames of the Ring of Fire and the images in each panel.

My journal work began to move me away from focusing on the personification of Death as a heartless and detached force and to bring me toward an understanding that heartlessness (being without love) and disconnection (being without attention) were dead-ening. I was facing mortality in a personal way that was still related to the theme of being in the face of D/death, but also evolved into the next theme, staying awake. The word *awake* means to me that I am aware of the present moment. Being awake seemed to be related to the co-researchers' concerns about relationships and the intensity that is required to connect and be intimate.

For instance, a friend's husband was on the hospice unit and then later died at home. During that time and the immediate aftermath, I had a glimpse of the reality of being a widow. A different friend said to me, "It [the grief experienced by a widow] is not only about losing a spouse it is about being alone." I recorded this conversation in my journal and as I did so I had a memory of something that I had completely forgotten. When I first came to hospice, and after attending the death of a man where I was supporting his wife, I was quite shaken because it had reminded me of the devastation that I had felt when Dante died, and I had been imagining what it

would be like if my husband were to die. At the time I had spoken to a colleague about the incident and said, “I don’t ever want to feel that much grief again.” Then somewhat wistfully, “I wonder if when your husband dies, you can just refuse to feel grief.” I remembered my colleague looking at me, as if to say, “Are you crazy? That will never happen.” I continued, however, to create scenarios in my mind where I was speaking to my children, dry-eyed and saying things like, “That was great, now it’s over and I’m moving on.” I kept wondering, “Could it be possible?”

As I watched my friend’s journey into widowhood, and listened to her speaking about her relationship with her husband, I started to think not only about my relationship with my husband, but also my relationships with family and friends. Through the images in the painting, and the subsequent dialogues and journal work, I began to see myself as I was at home—withdrawn, distracted, irritable, volatile, inconsiderate, self-centred, and seemingly uncaring. Although I could sometimes join in the fun of our lively household, I was mainly interested in achieving my goal. These glimpses of how I was actually living my life were painful revelations that left me in despair, seeing my most precious relationships withering and perhaps even dying. Not only that, I was thinking about legacy again, and what I was leaving my children. Would they be inspired by my accomplishment without remembering my lack of presence? How could they not remember both?

When I had been working on the Transition Ring, which I painted a grey, ash colour (see Figure 8, above), I remembered the question that Shields had asked me—“What feeds the flames?”—and realized that the bones are what feed the flames, the leftovers or remainders of life. I painted an image of clasping hands, but unexpectedly, the “shape” of the hands suddenly “shifted” and I saw them as ripples in water, which I associated with the reverberations between

the flames in the Ring of Fire. I was able to see the “shape-shifting” that occurs when looking back at life stories. I reshaped the story with each telling. The story of my life would not be static, but would be reinterpreted as my life and the lives of my children unfolded. The changes that I made now could influence how past events are viewed.

Another aspect of being awake emerged. When I was still meditating on the Death card and in the early stages of the painting, I had written:

I see the death card, I notice the red eye of the horse—it doesn't seem to be seeing or taking anything in. The rest is so life-like. The eyes are said to be windows of the soul—is this horse soulless then? Is it blindly walking about? If it can't see then it can just walk on by the destruction, it can trample on life and not really be aware of the destruction in its wake. Is that how we go through life too, unaware of our effect on other people? I keep coming back to the necessity of being aware of our effect on others. It seems to be a lesson that I need to learn, to notice the response (that I get).

I then had a dream, which will be explored below. It sent a strong message to me that my work at hospice, my dissertation, the mandala work, and my relationships at home were sacred processes, and through my work/research/life I had the potential to be a healing force in the world. However, if I did not pay attention to the process of how I went about my work/study/life, I would become dehumanized by objectifying myself and others, joining the “undead,” going through the motions but not being present in spirit. Becoming present became the overarching theme, pointing to all areas of my life, that was reflected in the quality of the painting itself, and the content of the images in my painting, the process of how I went about my research and writing, and the way in which I was relating to all the people with whom I came in contact at work, school, and home. Most of all, it pointed to my relationship with myself, my way of being, physically, emotionally, and spiritually.

As I entered meditative states, dialoguing with the figures who claimed to be guides and who were almost always extremely loving and compassionate, I was over and over again urged to stop being so aggressive, so forceful, so goal-oriented, and to “take in” the forces around me that were there to help. In Panel 10 (see Figure 8, above) a wise man is instructing a girl who appears to be “underdeveloped” to let go and to “accept what is gentle and true and loving. Act love, feel love, think love, be love.”



Figure 9: Panels 13–16 from the Narrative Ring

To give some context, it might help to understand that one way that I can be in the world is by focusing my attention and going after what I want. For this I am socially rewarded in many ways, but often left personally wounded—at all levels of my being. In my mandala, in the Narrative Ring, the images and the dialogues gave me very clear messages about this style of being.

Variations on this theme were repeated throughout the next section of the Narrative Ring. For instance, the next set of panels revealed three ghostly figures that were quickly fading (see Panel 12, Figure 8, above). In the dialogues, they warned me that my refusal to see what was happening was sending me “in the wrong direction,” and admonished me, pointing out to me that

only I could decide if I wanted to “return to the living.” In Panel 13 (see Figure 9, above) I am warned that my refusal to listen to the warning was causing me to live in “the land of the dead.” I was told to wake up, to open my eyes, if I wanted things to be different, and was shown a wolf “howling” in despair at being separated from its loved ones. I got the message, and it rang true. I felt scared and I sunk into despair.

Synchronistically, right at that time I received the news that someone very close to me was going to need to be tested for cancer. Vivid images of suffering and dying made it very clear to me that I could not put off reconnecting. Just as I see with patients and families, when death is in the picture, my priorities came clearly into focus. Bargaining with God, I wrote in my journal, “Oh God, please don’t make us go through cancer to wake us up! I hear you!”

It was only in the last stages of writing my dissertation, after I had painted the Wasteland and gone through the Portals into the Inner Sanctum that I realized that the separation that I had felt from my loved ones was not unlike that which families feel when someone they love is dying. I wrote in my journal:

They want to be present for each other but they are preparing for very different futures. They feel close because they are supporting each other to do what they need to do, but in the process they are separating and following their own paths.

The challenges and stresses of exploring encounters with mortality, both academically and personally, through my mandala work were transformational. I began to understand that my separation had been necessary in order for transformation to have occurred. It was necessary because a new aspect of my coming-into-being was occurring. I was finding my own capability. I was trying to change something within me, the part of me that had never felt good enough.

I *had* [emphasis in the original] to face the challenges alone. There was no other way ... no one could save me from the pain. I felt despair because this was the Wasteland. I felt relief because I was leaving the old story behind. Who was I without [those that I loved]? Who was I without depending on them to fix the hard things? Who was I if I could fix my own hard things? In order to get to the Inner Sanctum, I had to let go of the old story, not knowing if there would be a way through the walls or defenses.

Although separation was happening between me and others, I was also separating from a way of being.

Living My Life



Figure 10: Panels 17–20 from the Narrative Ring

I could clearly see now the places in all areas of my life where I was inattentive. I was too busy rushing toward my goals. As I continued painting, I was urged to let things unfold, to go more slowly, to remember what is important in life. In Panel 14 (see Figure 9, above) a figure wearing a crown told me that she was trying to make it better “in the kingdom” by making it easier to take the “right action.” She urged me to “slow down and be kinder ... because it is the only way to live life without regret.” In Panel 21 (see Figure 11, below) a robed man pointed out a dead man to me and expressed concern. “I see you killing yourself. I have compassion for the dead man who lets his life energy flow into the ground. I am here to help and support.” In dialogue with the dead man, he told me that he had squandered his life. “See? It all ends anyway. There is no rush.” The egg represented “unlived potential”; that is, not the things that I

could have done “but the missed quality of beauty, stillness, peace, and love.” In contrast, Panel 22 (see Figure 11, below) revealed a woman “who cherishes the quality of life.” I was asked to notice how she sits and does not “run, push, or press,” but rather enjoys what is precious in life. When asked why I should care, she said simply that “being an instrument of peace is a better experience.”

The mandala showed me that I was constantly losing sight of what is most precious to me and that there has been a black hole inside of myself that I have been trying to fill with accomplishments. The vessel, which becomes an egg in later panels, was repeated until I got the message. I had a choice. I needed to be conscious of how I filled my vessel, or body, and of what kind of legacy I create, especially for my children.



Figure 11: Panels 21–24 from the Narrative Ring

I came to understand that my drive to accomplish goals in my life had left my vessel empty. My accomplishments have not affected my sense of being worthy of love, because I have not been present. My body had been doing tasks but I could see the many ways in which my spirit had not been present. How could I feel love—either given or received—if I was not there? The angelic figure in Panel 23 (see Figure 11, above) urged me to “be loving now.” In the next panel, I was given a graphic image of myself rotting, and the figure said:

I am here to remind you that it ends the same for everyone. There is nothing to protect or rush towards. This is the reality—you know how it turns out. Why be curious? This is you, get used to it ... It's just the way it is, no horror necessary.

In Panel 25 (see Figure 12, below) I saw what it is like to be “the living dead.” Anything can be mindless, even so called meaningful work. “Be wholehearted or don’t do it.” In a heartbreaking realization, I saw myself as I was and at least for that moment I fully understood that I could not be fulfilled if I was not present, and I could not continue in any area of my life as I had been. I knew that I could not and should not sustain the focus that I had been giving to my research. It was clear that I must make changes, that there was no “later,” only now. Although I have never been diagnosed with a life-threatening illness, I believe that my focus on death, through writing, reading, painting, and meditation, as well as through my work and the events related to mortality that were happening in my life, generated the kinds of thoughts that those who are diagnosed with a life-threatening illness might experience (Kuhl, 2002).



Figure 12: Panels 25–26 from the Narrative Ring

At this time, I had characteristically been thinking ahead and wondering what I would do when I finished my dissertation. Sometimes those thoughts would consume me, and distract me from my studies and my work. In the final panel, Panel 26 (see Figure 12, above); I was revealed to myself in a coffin, having lived a more gentle life, fulfilled by the practice of kindness. I told the figure that I wanted to understand what it means to encounter mortality daily

in a palliative care context so that I could be of service, and that I wanted to help palliative care workers through education. I asked the figure if she had any advice for me. Expecting to be given an idea about a topic that I might teach at the university once I had graduated, I was surprised when the figure replied,

Maintain loving kindness and non-violence in all that you do. Whatever steps you take towards education, focus on non-anxiety, peace, consideration of others, and moving slowly. In this way you become what you wish to teach and everything else will follow.

I was moved to tears in an almost religious moment of insight that words cannot describe. I cry now as I write these words. Clearly I was again looking into the future and asking the wrong question. A better question might have been “Where are you right now?” or “Are you here?”

The mandala work produced a vivid recollection of the myriad issues that arise for those who encounter mortality daily in a palliative care context. It was also a re-living of my own experience, together with the experiences reported by the co-researchers. Although I have given only a few examples of how the mandala work interwove with my understanding, it should be understood that this process affected every one of the themes and all my thinking throughout the writing of this dissertation. The paintings told both the story, in a generic sense, and my story of being called to the realm of death, answering the call, and then surrendering to the transformation that occurs through engaging in the work itself —of being or not being intimate, intense, connected, empathic, silent, and in service to others. The mandala taught me on a visceral level that encountering mortality daily in the palliative care context provides an opportunity to constantly be present and not just to practise love but to become love (as EO said) through action or kindness, which was certainly reinforced by what all the co-researchers had to say.

Early in my journal work I asked, “How can I be in the face of death?” I imagine that before I began this journey I might have answered this question by saying “by being present.” But now I understand so much more about what that means. I wrote a sign and placed it beside the photograph of the Tarot card of Death, above my computer. The sign reads “Susan, Be Kind.” For me, that says it all.

Connecting My Experience to That of the Co-researchers

In the next chapter I connect the work of the mandala with the voices of the co-researchers and with my voice as a researcher. Although all three voices are inextricably woven together I have pulled them apart briefly in order to highlight the parts. In the same way that separate words come together to form a poem, or separate brush strokes come together to form an image, the parts lose their meaning unless they are viewed as part of the whole. This is the phenomenological journey of going between the parts and the whole. There is a sense of unity with the co-researchers as I bring the pieces of our story together.

Chapter 8: Issues

Being Special

We are special. Working with the dying is special. We lean in. We approach. We touch and hold and soothe and stay. There have always been people who have cared for the ill and the dying: amongst them, midwives, witches, shamans.

We are special. I do not believe that anyone was ever meant to do this as a job, as a profession. Caring for the dying should be embedded in one's community, in one's family. I meet sons and daughters who hold their hands at their sides and say that they cannot. They cannot volunteer. They will pay someone else to do this. They pay for people to care for their babies. They pay for people to care for their dying. We have lost the edges of what it is to be human. And when you pay someone to care, to love, to comfort, what does that do to the person being paid and to the person who needs to receive paid care? Does it distort something very human within us all? We are special. We show up. We see and speak and hold the truth. (SW)

SW felt despair and wondered if we are losing “the edges of what it is to be human.” Her questions are important to ponder. As members of society, how much do we value those who are most vulnerable? What kind of society do we want? At what point is any one of us willing to put our own needs aside to help someone else? The co-researchers did not have definitive answers to these questions, but while we become clearer that we want to be of service, we also know that we must account for our own needs too. How can we know what is best for all?

The idea that those who work in palliative care are in some way special has fascinated me since I began work at Meadowview. For me, there is tension in accepting that I am special because of the work that I do. I feel resistant—the word makes me squirm. Why? On reflection, I wonder if the discomfort has to do with my experience growing up and being considered “weird” because I was interested in all that was hidden, protected, and unspoken. Is this a question of identity, then? Perhaps I have an underlying fear that being drawn to the intensity and the intimacy involved in caring for the dying and the bereaved reveals something

“not quite right” about me, or as WF put it, means being special in a “creepy” way. Conversely, maybe the work reinforces and verifies that I am not weird, that my way of being in the world is worthy of respect and honour after all. JW reluctantly admitted that it feels good to be seen as “smart” or “wise” and “better than average,” but agreed with SG who was “irritated” and BD who was “bugged” by the depiction, because it seems like an “ego trip.” My tension was shared by the co-researchers as a group, and I wondered why we feel so uneasy.

It might be useful to explore the meanings of the word *special* to find clues about what it actually means. The word *special* derives from *spetiale* meaning uncommon or exceptional, and later from *species* meaning appearance, kind, or sort (*Chambers Dictionary*, 2008, p. 1042). Another meaning of the word *special* is related to palliative care work being specialized—requiring knowledge and skill outside what the ordinary person knows or does, resulting from “devotion to a particular or limited field of study or research” (OED, 2012). There is no evaluative quality necessary here, simply the facts. We know more about this subject than most people because we have special knowledge, meaning that we have been “particularly interested or informed” (OED, 2012). A subtle distinction creeps into the definition, however, with the comment that *special* “exceeds or excels . . . that which is usual or common.” Is there an implication that this is a better or more desirable state? I think there is, and this is reinforced by the further clarification that special means “notable, important, or distinguished” (OED, 2012). For some, at least at times, there is a status that comes with working at hospice.

On a practical level, having been devoted to learning about palliative care because of a particular interest means that we are able to guide those who find themselves in the foreign territory of illness, death, and bereavement. AB found herself at the “front of the convoy” when her own mother was dying, able to recognize the physical signs of impending death. As BD said,

she can feel grateful for what she knows and is not “unduly afraid” of death. Our specialized knowledge provides an opportunity to know the secrets of the body, what can go wrong, how to be in the presence of suffering, and at times how to comfort those in pain. In some ways our specialness is ordinary, and as EO said, “everyone has a gift of some kind to offer to the world.” KZ thought that people say that we are special because “we touch their hearts, we are like a lifeboat in a storm. We give them a refuge, a place to rest in their struggle.” While some mentioned other caregivers whom they might call special—like those who work with profoundly physically and mentally challenged children (KZ)—others dismissed the epithet out of hand.

I think my accountant is a special kind of person, my God, if he didn't like his work, I might have to do my taxes!! And I think bus drivers are special people—that work looks to me to be so mind-numbingly boring, thank goodness they do it!! And what about the woman who sets rat traps in my house when I need them. She actually likes her work! She says she grew up on a farm and is drawn to her work. Wow, to me that is a special person. (WF)

It may be that we are “suited to and can do this work where others might not be able to, there are many things others do that [we] ... could not” (BD). It is not that we want to make light of the question, but rather that we want to say that we do not generally think of ourselves as better than others, we are just people who are happy, or perhaps willing, to do the work. We can appreciate that there are many who feel relief that we are willing to do it.

Another reason that we may want to reject being deemed special is because it seems to imply that because we “lean into death” (SW) there is something inherent in us that does not see or feel what other people experience. We know that is not true, because if it were, it would negate our struggle to be present, it would dismiss the discipline, the energy, the focus that we must find on a daily basis. It would deny our overriding desire and valuing of being of service for the good of humankind as a spiritual practice. I think that where we differ from most people

is that we have both the opportunity and the willingness to walk into this sacred, often frightening, fascinating, and enriching territory.

SW disagreed. Our answering the call to explore the mystery of life and death does make us special in that we have bucked societal norms, and our own cultural history, by resisting “the impulse to shy away from death, to flinch in the face of suffering, to look away, to isolate” (SW). SW contended that we are different because “we meet those who have been removed by society by approaching, by ... touching, holding, soothing, and staying.” She pointed out that the perception that the dead and those who attend them are impure is well established, and noted that some religious leaders are forbidden to enter graveyards and must keep their skin and their robes away from the dead. There is a long history of separating out, and even ostracizing, those who care for the ill and the dying, “among them, midwives, witches, and shamans” (SW). The cost of being respected, or held in awe for exploring, learning, and knowing the most profound human experience is that we are isolated or separated to some degree from the ordinary person. So perhaps that does make us special in the sense of being different from most people in our culture.

It often happens that when we leave a family we remark on what an “amazing job” they are doing, or comment, “I don’t know how you do it.” The recipient often seems startled. One man I visited said, “I’m just doing what any loving person would do.” KB reported a family member saying, “I can’t imagine doing anything else.” Family caregivers experience the same surprise and discomfort as we do when labelled special. Although it can serve our ego, as several co-researchers (BD, JW, RB, KZ) pointed out, the “aim is to be of service, not to be special” (KB).

Being Authentic

What did SW find “different” between intimacy at work and intimacy at home? In palliative care encounters, we meet because of our roles. As Gergen (2009) explained in *Relational Being*,

Virtually all intelligible action is born, sustained, and/or extinguished within the ongoing process of relationship. From this standpoint there is no isolated self or fully private experience. Rather, we exist in a world of co-constitution. We are always already emerging from relationship; we cannot step out of relationship; even in our most private moments we are never alone. (p. xv)

From a social constructivist point of view, the players are both given the opportunity to meet because of the context of palliative care, and are limited by the social expectations of the roles that are inevitably played. For instance, a “counsellor” is expected to interact in particular ways that have been pre-defined and largely understood. The same can be said for the role of a “nurse,” “patient,” or “family member.”

Palliative care values require transcending our professional roles in order to connect as human beings. All the players will, however, always be in flux between our being-*ness* and the world. In other words, in the palliative care context I will always be moving between interacting with the other from my *role* as a counsellor, and interacting with the other as a *human being* encountering mortality. In this context, then, the other can also move between interacting with me in the *role* of the patient, and interacting with me as a *human being* encountering mortality. It is not that we cannot or are not enacting our humanness but more that the role defines, controls, and contains what is expressed and what is censored to some extent.

When SW used the term *performing compassion* in describing our role with patients and families, was it an attempt to describe our ability to summon feelings “as if” an event were

happening to our own mother, child, or spouse? My feeling of what it might be like “if” my husband were dying is not the same as what I would feel were he actually dying. Of course! How else could it be? When I recently got the news that a friend has prostate cancer, I immediately thought of all the social situations we shared and especially thought of his quirky sense of humour. Then I flashed forward to holidays, dinners, afternoon walks without him, and the picture seemed so empty and flat without his presence. Our plans to travel just will not happen without him. Then I imagined supporting his wife, for possibly years, as she goes through the painful adjustment to being single again. My response was a complicated ball of emotion that cannot be isolated from my past or my future. I do not have that past or future with the patients and families whom I visit during my work day. Perhaps it as Papadatou (2009) said, and that when we are in a professional role, we practise holding both our own perspective and our imaginative idea of what another’s perspective might be.

To perform can mean “to act,” as in to “feign or simulate” an emotion, behaving in a manner “suggestive of a particular characteristic, quality, emotion, or feeling” (OED, 2012). Are we merely simulating emotion? Are we displaying mannerisms that are suggestive of the real thing, the real emotion, or the real caring person? To perform can also mean to “carry out” or to “come up to an assumed standard” (OED, 2012). Might that imply that we are simply carrying out the “job” of compassion? It does not feel like that to me. There seems to be some truth in how we respond to grief in the standard or expected way—with caring, with compassion, with kindness—while each giving something of ourselves that is unique and what I would call precious, which the word *standard*, or *expected*, does not encapsulate. The voices of the co-researchers said that quite clearly.

We agreed that the feelings that arise when we connect with families and patients are genuinely compassionate. The interactions that we have, however, have neither the depth nor the complex set of ties that take years to develop. Imagination is not the real thing, as anyone who has ever had a person close to them die will tell you. Although we can be empathetic by drawing on real feelings we cannot be expected to share the depth or breadth of grief of the people whose lives are being directly affected.

Not Everything Can Be Known

It would be expected that after a number of years in palliative care we might know something about death and dying. We recognize the physical signs and the changes that patients and families can expect as the body shuts down, and for which they can prepare—we have pamphlets that explain various aspects of the dying process. We can connect with patients and families by offering hope that their symptoms will be relieved (JF). However, there are always unique variations for each person. As Amy Rokach (2005), from *The Institute for the Study and Treatment of Psychosocial Stress* said, it is our nature to desire order so that we can place our experience into the category of the known. She said that theories address that need, but cautioned caregivers to let our theoretical explanations be “provisional” (p. 330) to let us see the uniqueness of a person’s concerns and struggles.

Allowing the uniqueness, strangeness, and newness of each person to complement the knowledge, theories, and models that the carers were taught will introduce uncertainty, mystery, and maybe even some anxiety into their professional world—but it will also make them much more sensitive and in tune with their patients’ and their own inner experiences, emotions, and needs. (p. 330)

There is so much that we can never know. We can never know when death will occur, or exactly how it will unfold. Dying is not neat and tidy, it can be “hard, hard work” (SG). For

some it can be filled with emotional, spiritual, and physical suffering, while others seem to simply drift away with few symptoms. How death will be met by each individual ranges from agonizing resistance to completely graceful surrender. We cannot predict what it will be like for a particular person, and we can only guess at why some people go willingly and others resist. We know something about what grief is and what it looks like, and something about comforting the bereaved. We cannot know how each individual will go through their particular grief, or why for some people there is no comfort. Our knowledge, while not unrelated to other circumstances, is particular to the palliative care context (JW).

Because of the constantly changing context, what we know is more than what can be written about, studied, or contained. We can take what we have learned through what has been written and studied in the field, and what we observe—a person is no longer eating or drinking, or does not have the strength to bear their own weight—and weave it with what we feel, sense, or intuit from being close to the situation, in the same way that a “mother might ‘know’ something about her baby” (WF). Patients and family members can also know something intuitively about themselves and each other. Our acknowledgment of their intuitive knowing can be empowering, and our encouragement a relief. We cannot contain our knowledge in a neat package—there is always more to know.

In my journal writing the figure in the coffin (see Panel 26, Figure 12, above) told me:

Those of you who work in palliative care are the loving and caring guides who accompany people to the edges of life, who stand at the border of death as the people enter. You witness the leave taking but you know nothing of the other side. Do not forget that. Your value is in loving presence, your knowledge of what is happening in the present, but not in your knowledge of what is to come. Of course this creates anxiety for you, but do not fear, for all is well. Live your own life with this same loving kindness and you will be ok.

Allowing ourselves to not know seems the antithesis of being special. Then again, perhaps knowing that we cannot know is something special in itself. There can be tension between knowing what we do know and accepting what we do not and cannot know. I understood this to mean that we are to be compassionate and loving toward ourselves as we balance the tension of wanting to know with not being able to know.

When it comes to death itself, we can know “what it is like to accompany the dying, and what we observe about the process” (BD) but we cannot know what it is actually like to die. EO said that it is worrisome to her when “we tell people stories about dying, as if we knew, though we actually have little evidence.” I share her concern. For example, we tell family members who miss the actual moment of death by days or hours that “people choose the time of their death,” and that their loved one may have been “trying to spare them from pain by dying alone.” Or we may say with assurance, when someone dies moments or hours after an out-of-town relative arrives, “She was just waiting until you arrived.” We tell people that a person “did not suffer,” when we really can only tell our own experience, which is that the person did not appear to us to suffer. In our desire to take away the sting of death, we say, “He is at peace now,” or “Her suffering is over.” Does anyone really know? JJ said that,

It is one thing when family members make these definitive statements but on the rare occasion when someone on our team says statements like that, I cringe inside because it seems to me that we are serving our own discomfort and giving a subtle message that they don't “need” to feel badly.

We Are Not Helpless in the Face of Death

How can we, as palliative caregivers encountering mortality, operate when there is so much more to know? How do we deal with the feelings of anxiety that can arise when we feel uncertain? When I read the co-researchers' accounts of encountering mortality I asked them to

expand on the idea of being helpless, mistaking *not knowing* for *helplessness*. As with the word *special*, the co-researchers did not relate to the word *helpless*. JW took umbrage with it, attempting to make a distinction between *helpless*, which to her meant “having an inability to affect change, to be totally responsible,” and *powerless*, which she understood as “there are limits to what I can do but that doesn’t mean not being able to be helpful.” She said that we learn to accept that we cannot change the fact that the patient will die, but through knowledge, training, and willingness to be of assistance, we are not helpless but empowered! KB thought that it was important not to evade feelings of uncertainty by getting caught up in tasks or information giving, and was aware that while we cannot change the outcome, we still have ways to be helpful. It is an important distinction, and one that, if we are to function well in the palliative care context, we must come to terms with early in our careers, since on arrival at hospice we were immediately confronted with the fact that 100 percent of our patients will die, and sooner rather than later. This can be tough news to digest. “I feel sadness when I see young parents, or newlyweds, or teenagers, or children, and I wish they didn’t have to die” (SG).

Making Sense and Embracing Change

We know that death occurs, and we can know some things about how certain diseases behave, but we do not know exactly how it will be for a particular person. Neither do we know why a particular person is afflicted. “I think about people with ... [certain kinds] of cancer and wonder what causes it—toxins, diet” (SG). In order to face the reality that death is occurring we acknowledge that “everything changes.” RB notes:

We learn that it is more effective to *go with* [emphasis in the original] change, rather than resist change, and we do this by recognizing the impermanence of things, by noticing our human tendency to be attached to outcome, and by consciously practising letting go of expectations. (RB)

We try to “avoid thinking that we know and speaking with authority, except in the most general sense” (KB). As JJ said, by “expecting change, we are less likely to be thrown off balance by it.”

Embracing the unknown has its rewards, as KB said:

For the most part, I don't have expectations of how death will occur. I do try to help families understand when I see something I have seen before, but I don't expect it before it happens, other than things progressing in a general sense. I tell myself and patients and families that things can happen unexpectedly as each person and his or her circumstances are unique. This is what I like about the work. I never really know what is going to happen next. I also tell myself that I do not have to have the answers or be the expert, but that I need only companion the people I'm with through whatever ends up happening. On the other hand, when I do open my big mouth and say something prescriptive that turns out to be off track or wrong, I don't mind showing the patient and family that I am fallible and make mistakes too.

BD pointed out that being “skillful at navigating change” is an opportunity, a duty, even a responsibility to provide a model of how to face change.

Working without an agenda is a discipline that requires us to continually remind ourselves that we do not know what another person is experiencing, and that we cannot know what will happen. As EO put it, “we cannot know unless we are willing to not know, or to be uncertain.” WF said we learn through experience that “certainty clouds our vision, making it difficult to see what is actually there.” Paradoxically, by allowing ourselves to not know, we are more likely to come to know. EO has the following posted above her desk: “Do you have the patience to wait till your mud settles, and the water is clear? Can you remain unmoving till the right action arises by itself?” We want to be still, to be open, and to be present.

We build the capacity to hold the tension that comes from uncertainty, and come to enjoy the feeling. EO explained that she can tolerate uncertainty because she has the ability to stay

firmly rooted in her own sense of knowing, but is also able to take in new information, integrate that perspective, and develop a new stance. As JW said, “being uncertain or unsure is actually an invitation to be ‘awake,’ to be really present in the moment.” The willingness to be knocked off balance comes from being certain of our own ability to regain our equilibrium. Paradoxically, the more we live with uncertainty—with the threat of becoming unbalanced—the more we have the opportunity to learn to right ourselves, and through this process, we come to recognize and value both knowing and not knowing.

Although we may have the intention to accept change, our ability to do so is no more constant than a high or low tide. We do not achieve equilibrium, but it seems that we become more comfortable with being carried along by the ebb and flow. We use words like “letting go,” or “flexibility,” or “non-attachment,” and we talk of decreasing the need for “control and rigidity” and “having access to the wide view—letting go of wrong and right” (WF). We feel an increased comfort with the “grey zone” (JW). We feel “braver” (WF, BD), bolder, more able to take emotional risks, and eager to take advantage of the “opportunity for evolution and growth” (JW), recognizing that life may be short (SW).

JW gave an example of attending to a woman in her early forties who was preparing to go with her daughter to a fancy health resort for her birthday. In the morning she was discharged from hospice service, but later that evening she was in extreme pain and was admitted to the unit the next day. She admitted that as sad as this was, this kind of change “happens more often than not,” and she takes it as a lesson in “holding the now lightly.” Accepting change, tolerating—even enjoying—uncertainty, are all part of going with the flow, so to speak.

Understanding Mortality

When being in the presence of death is a daily event, it is natural to wonder what it all means. Does daily exposure bring us closer to understanding? Three of the six co-researchers told stories of their own mother's death. AB came away with confidence in her own ability to apply her intuitive knowledge, and almost a new respect for death and "confidence in the body and its capacity to die." She said:

I also had an opportunity to be with my Mom for her dying and her final breath. I think this was an amazing teaching for a parent to offer a child. My relationship with my Mom has not been an easy one, and at the same time, she shared with me, and me alone, her final breath on this earth and it was very healing, very powerful teaching in the sense of I need not be afraid of dying, that dying is not scary necessarily. ... I do feel that my opportunity as a daughter to witness my mother's death was very beneficial to me as a parental gift.

Two co-researchers, however, had experiences that they had never previously encountered in their many times of watching death take place. KB described a "vivid memory" of witnessing a death that occurred in an unfamiliar way. "Her breaths were minutes apart for hours," and to the counsellor's dismay, "after her final breath ... her eyes went from a general glaze, straight ahead—to me. And that was it! It still 'haunts' me to this day." RB had a similarly disturbing experience when her mother made rhythmic grunting sounds as she was dying, as if she were in labour. "It was like she was giving birth to her spirit." RB had never witnessed anything like this or heard about anything similar from her colleagues, and said she would never forget the eerie sound.

Daily contact with mortality seems to leave us with preferences, thoughts, fears, and hopes about our own dying. As WF said, "Always in the background of my daily life is the known truth/reality that death comes," and even though she said she is not always consciously

aware, she believed that it still affects her daily life. CW reported being “calmer, more matter of fact, somewhat curious,” and even though being well aware of the realities means that for her “death does not unduly alarm me, at least in theory,” she admitted that “I feel secure because I am buffered by my own health” and went on to say:

Like when travelling to developing countries, there is the possibility of a huge power imbalance: what does it mean to witness someone’s suffering, be that the patient or the family ... or the starving family in Africa? Do we fool ourselves into thinking that we have a passport out of the country of death and illness? I think so. And it’s often not until our own health is impacted (or the health of a family member) that we realize our passport has been stolen and we don’t get to return to the safety of “normal,” our comfort, our good health, our crazy subconscious belief that we are immortal.

As much as we try, and despite all our knowledge, our own death is still just a fantasy until it comes. That does not stop us from wondering, though, and we find it is easy to imagine in full colour and intricate detail many variations of our own death. This should come as no surprise given that we have had plenty of time and occasion to refine our stories. For instance, SW said,

I hope not to leave a messy corpse—I am horrified by fistulas and seepage and gaping wounds. I want, somewhat absurdly, beauty in death—I do not want to be destroyed and maimed and smelling of death. I want to be clean and dry and surrounded by soft fabrics. I will be one of those women who bring her own sheets to her death bed, if that bed is in a hospital setting. I do not want polyester against my skin as I am dying.

JJ said:

I think that when I face death, it will be with the same awareness that I have gone through life. I will pay attention and notice what is going around me. I hope that I can think of others, be brave, and teach my family that death is not to be feared, but a natural part of life. I hope it will be one more chance, the last one, for me to engage in deep, real, and loving connection.

Our imagination can take us from the worst of what could happen to the best. We have many people with whom to compare ourselves. KZ commented that if she was given a palliative

diagnosis she might travel, but then remembered that she most likely would not have the energy. She hoped that she would have the good sense not to “fight too much” because she does not want to be like those who do “crazy, crazy fighting,” where it is no longer about “fighting for life but about enduring treatments.” She said she might “pray for guidance.” At one time she used to talk to patients and families about what she believed happened after death, but now she “doesn’t say a word,” and as much as she would like to believe that there is life after death, she is no longer sure. Instead, she now refers to a more open attitude by saying, “I know nothing.”

Two co-researchers wondered if they will feel like they have lived life fully. At one time we thought we had answers but we now recognize that both dying and death are a mystery. Even life and how to live it well are no longer clear. SG said, “As I engage more on a spiritual journey I am finding my inner life to have more and more meaning.” JW said, “It’s an incredible opportunity for ongoing personal evolution to do this work and I am always amazed at how there is never an end to things to learn, to see, to witness.” SW said that “in this moment of my presumed good health, I expect to be curious when faced with my own death.” RB was fearful of death but hoped to find peace by being able to accept that her life is over.

It is one thing to imagine our own deaths, or that of our parents, but like most people we find it difficult to accept the death of children and even young adults. “I have no capacity to imagine any harm coming to my children” (SW). Witnessing the death of a child can be the most difficult for all of us, and the subsequent identification with the parents a real challenge in processing the raw emotions that are stirred in us as fellow humans, and in some cases as parents.

We feel secure in and grateful for what we do know, and try to accept that we cannot know everything. CW said, “I love that death is not ours to know, truly and deeply, until it is our turn. We can observe and notice and create theories, but it is not ours. It is a bit like god, but more certain.” KZ used to believe in “paradise, nirvana, or heaven,” but said that now, “death is a transition, or passage, between what we may think of as reality, and something else ... the end, nothing, an afterlife?” RB said that she thought that by working in palliative care she would become clearer about what happens after death but now has more questions than answers.

Mystery

Mysterious things happen in the course of encountering mortality in a palliative care context, and as we work we hear nurses, doctors, other counsellors, family members, and even patients tell of events that are difficult to explain or interpret. At Meadowview, we rely on a book called *Final Gifts* that was written by hospice nurses (Callanan & Kelley, 1992). We purchase it by the case and hand it out to families. The book contains story after story of patients who may at first appear to be confused but who actually provide important information about what they are experiencing as they die, or what they need in order to die peacefully. The information often arrives clothed in metaphoric language and requires skillful listening to interpret its meaning. One story concerns a patient who had been a bus driver and who told his family that he needed to catch a bus but could not find his ticket.

Nearing Death Awareness often includes visions of loved ones or spiritual beings, although they don't necessarily signal deaths imminence. Dying people may see and speak with religious figures. They may feel warm, peaceful, and loved; some see a bright light or another place. Some review their lives and come to a more complete understanding of life's meaning. Realizing they are dying, they don't seem to feel fear; rather they express concern for those who will be left behind. (Callanan & Kelley, 1992, p. 15)

Comparing and contrasting Nearing Death Awareness with Near Death Experience, Callanan and Kelley (1992) said that these two experiences are similar but because our patients are dying gradually rather than being flung suddenly into death, they have time to explore this in-between state, and to assess their lives and to decide if anything needs to be completed before they die.

AB told a personal story that falls into the Near Death Experience category. It began with an idea when she first came to work at hospice that she would like to become more empathetic and compassionate toward the dying and bereaved. She noticed that it was much easier to do this with the bereaved, not being able to get a “felt sense” of the experience of those who were dying. To get closer, she began reading about dying, and sometimes tried consciously to enter “the dying world of our patients” simply by stating her intention to do so at times, or by focusing on a dying patient and allowing herself to imagine their experience, “willing” herself into their experience, doing so “energetically” at times. During this time, she became very ill and took some strong medicine, which suppressed her respiratory system to such an extent that she came close to dying. At the moment of being revived, she saw at the foot of her bed the figure of a patient who had died, and then watched as he dissolved as she came awake. In retrospect she thinks that she was erroneously “flirting with a powerful energetic component of the dying process.” She said that she gained a “profound awe for the dying process,” and a respect and appreciation for the gap in her understanding.

There is a certain intimacy I will not be able to share with a dying patient ... I can be intimate with them in other ways, supporting them in their grief, connecting with them in their sorrow. But I now reverently respect the space between us that exists because of their dying process, and I have a far deeper understanding of the majestic, enormous, energetic ground that is dying, and I happily stay outside of that sacred process, and lovingly support our patients to the best of my ability as they experience dying. (AB)

Almost apologetically, she added, “I hope this makes sense.” How can we make sense of this experience? Each person is likely to interpret a story like this through their own lens. For the person who experienced it, the profound sense of knowing that something important happened cannot be denied. Each of us cannot help but hope, in our own way, that our experience will “make sense.”

Another example was provided by KB who told of a woman who had been in a deep sleep for days.

There was a vigil of friends and family was around her bed, talking amongst themselves. There was also a small dog who had been this woman’s companion and when I went up to the dog, I said, “And what is your name, sweetie?” at which point the patient replied in full voice with the dog’s name. The woman never spoke again. How do I make sense of this? Had this woman been travelling between this world and the next, and I just happened to catch her when she was briefly in this one?

RB told of visiting a family whose baby who was dying.

It was the strangest thing, because I imagined that if it were my baby I would have held him, but the parents and the nurse and I were watching him as he lay in his little bed. We were all mesmerized by his tiny breaths, just watching as his little chest rose and fell until at some point he just didn’t take another breath, and then nothing ... the parents weeping silently. After a while, we began to talk quietly. Maybe twenty minutes later, the light from the bedside lamp snapped on and the music box that was attached began to play. The parents’ heads jolted around and then they began to laugh. They had always turned that light on and played the music box when the baby began to cry. They believed that he was responsible somehow, and that it was a sign that he was trying to comfort them.

Sacredness

In *The American Book of Dying: Lessons in Healing Spiritual Pain*, Groves and Klauser (2005) attempted to guide lay caregivers as they accompany their loved ones to death.

There is ultimately only one great spiritual question, “Who am I?” The answer to this question is rarely known except in the dark night of the soul. Terminal illness has the power to silence us and create a crisis of meaning. Whether it is through personal chaos due to a recent cancer diagnosis or a public social catastrophe like September 11, few

experiences have the power to awaken our truest Self like a brush with mortality. These liminal moments have the potential both to create and solve a painful crisis. (p. 43)

With the exception of one co-researcher who did not mention anything on the subject, all the co-researchers made references to some kind of spiritual practice. We are drawn to make meaning, find purpose, be of service, and cultivate presence. SW said that when she is doing her best work it seems like “praying ... serving as a conduit to something transcendent and sacred, mysterious and rewarding.” KZ struggled for a while with a sense of meaninglessness and hopelessness but now, through spiritual practice, is “consciously choosing to be happy.” The practice is inspiring and “full of grace,” giving her glimpses of unity of all living beings. “It fulfills a need for intimacy, shared spiritual practice in community and sharing in beauty.” She mentioned a strong belief that “we can pray to be inspired, and to ask for healing.” Although not sure to whom she is praying, when she prays she says, “Give me guidance, show me how I can be of service, help me, and keep guiding me.” JW explained her approach by saying, “I try as much as I can to empty myself of myself, and to show up as a servant of whatever is needed.” For her, there is meaning in showing kindness, and “the opportunity to offer timely information and reassurance that one is not crazy during this trying time.” Trying to imagine what might be appreciated,

I try to bring curiosity to my interactions and a straightforward showing up for whatever unfolds. This practice helps me to “hammer my mind into my heart” as a beautiful Sufi saying goes. The best I can do is to develop awareness to recognize when I’ve strayed from this intention.

Practice in being present suspends time, and is a spiritual experience, “no mind, nothing else exists, it is practice in centering” (KZ).

For me, although I had always been interested in developing my spiritual nature, it was not until the death of my son Dante that I began an earnest search to understand the meaning of

life. My very first piece of writing—which was to become an important avenue for expressing, exploring, and finding my own spiritual path—was the story of Dante’s death, entitled “Sacred Time.” In this story I outlined four extraordinary experiences that brought me to a decision to devote my life to service. This is reflected in the first two panels of the Narrative Ring:



Figure 13: Panels 1 and 2 from the Narrative Ring

At the beginning of the Narrative Ring, I had a dream. In my painting of Panels 1 and 2 (see Figure 13, above) I was reminded of my spiritual quest and of the role that my encounter with mortality had played. The emotion in the dialogue and the memories of the grief I felt when Dante died were intense.

In the first panel a bereft man kneels in despair as an angel takes his dead son. In dialogue he revealed his utter despair, his “complete vulnerability,” and his feeling of being lost forever. The angel has nothing to offer except a reminder of the “desolation that death brings.” The angel represents herself as a “tender,” and my interpretation was that she was showing me what it means to be love—a synchronistic reference to a later comment made by a co-researcher about “becoming love” (EO). The baby represents the spiritual teaching that came to me through the death of my son. In Panel 2 (see Figure 13, above) I saw two more “tenders” who care for all those who are lost or vulnerable, for whatever reason. They were demonstrating to me that

through tenderness and attention to my spirit I am nurturing my potential to come into my own power as a caring person who can help those who are poor in spirit. This is both the beginning and the end of my Narrative. It reminds me of why I was drawn to dwell in the realm of death, and shows me that through becoming a “tender” I am transformed.

Chapter 9: The Circle Is Really a Spiral

Tonight I went to the home of a woman who had been wheelchair bound for the past twenty years and at the age of 105 was nearing death. Her 70 year old daughter Jeanie had, with the exception of a few years, provided almost total care for her mother, including coming home on her lunch break to feed her and take her for a walk. The nurse and I were at their home when Jeanie's mother took her last breaths. After a long period of silence, and with a wistful sigh, Jeanie said, "I just wish we'd had a little more time." (SB, Journal)

As this dissertation comes to an end I am reminded about and can relate to all the people whom I have met who yearned for one last summer, one last birthday, or one last hug. When we are engaged in life, it seems that time is too short, there is still more to say and more to do.

As I moved away from the Narrative Ring, through the second Transition Ring, and into the Wasteland my attention began to turn toward the relationship between what I was learning about the lived experience of encountering mortality, and providing support and education to palliative caregivers. In this, the final chapter of my dissertation, I address my initial questions, and discuss the limits of the study. I then focus on what the implications of what I have learned as I went through the four portals and the Garden Wall, and moved into the Inner Sanctum. I then make recommendations for future exploration.

My Initial Questions

Being special revisited. Initially I felt resistance to the idea that palliative caregivers are special, but as the study progressed I came to understand more about what it means to be special. The co-researchers *are* special. What makes us special is that we are drawn to do the work. Our willingness, at least in this culture, sets us apart from others, and because we bear so much knowledge of what it means to be dying and to feel bereaved, we are set further apart. However, hearing the call and being willing to answer is not the whole story. In another way, we are not

special at all. Like people in every profession, we have specialized knowledge that we accumulate by doing the work. The significance of this finding is that working with the dying and the bereaved can be learned by those who are willing. Serving the dying and bereaved is something that we can learn through a combination of education and participation, not something inherently special about us that we brought to hospice when we came.

Being shaped. Kübler-Ross (1975), one of the pioneers of palliative care, said,

There is no need to be afraid of death. It is not the end of the physical body that should worry us. Rather, our concern must be to live while we're alive—to release our inner selves from the spiritual death that comes with living behind a façade designed to conform to external definitions of who and what we are. Every individual human being born on this earth has the capacity to become a unique and special person unlike any who has ever existed before or will ever exist again. But to the extent that we become captives of culturally defined role expectations and behaviours—stereotypes, not ourselves—we block our capacity for self-actualization. We interfere with our becoming all that we can be. Death is the key to the door of life. It is through accepting the finiteness of our individual existence that we are enabled to find the strength and courage to reject those extrinsic roles and expectations and to devote each day of our lives—however long they may be—to growing as fully as we are able. (p. 64)

While I would not presume to say whether or not another person needs to feel afraid, I think that what the co-researchers revealed in their stories, and what my mandala work pointed to, was that by being willing to be in the presence of death, we experience a sense of our own opening and closing, surrender, and resistance to the flow of life. Awareness is something that can be taught, learned, and supported.

My research shows that, encountering mortality continually shapes us. We operate within the tensions and paradoxes that encountering mortality provides. Our willingness to show up every day amidst the tensions and paradoxes of opposing forces creates change. For me, and at least for these palliative care counsellors, in this context, there is a sense of being pulled into a more whole version of ourselves. The struggle to understand, to persist, to hold intense emotion,

to not know, and to express ourselves has helped us to become, again, who we are. This leads me to wonder if it is possible to remove the struggle or the tension and still be shaped, or as I like to think of it, transformed.

The co-researchers know that we cannot stop the dying process for patients, but we can be of service to patients and families as they go through the dying process. We do not expect to change the fact that there will be sorrow but we have found that through creatively combining our knowledge of theory, our clinical experience, and our moment-to-moment experience, we can respond to the needs of the dying and their families and be of help. Before I began this study, I had hoped that I could find a way to take away the struggle of learning how to be of service in a palliative care context, but now I see that I cannot. There is value in the struggle because that is how growth can occur.

As palliative caregivers, whether about to enter the field or in need of on-going support and education, the co-researchers clearly revealed a need for support that is not unlike that which we provide for patient and families. We need to be witnessed. We need creative responses to our struggles. We need supervisors, mentors, and teachers who can be present and can meet us where we are, unscripted. We need those who are grounded in theory, knowledge, and experience, and we need compassion. We need a beacon in the dark to guide us. I understand now that no one can prevent us from suffering. Encountering mortality in a palliative care setting on a daily basis will be painful because suffering is part of what it means to be human.

Palliative caregivers need teachers and mentors who can provide an artful combination of both content and process, a combination that promotes our ability to respond to our own moment-to-moment being-in-the-world. Self-care, supervision, support, and education cannot

be predetermined, but must be in response to the unique circumstances of the people who are having the experience—of living, of exploring, of wanting to know. The co-researchers tell a powerful story. Encountering mortality in a palliative care setting on a daily basis creates an intense flux between internal and external happenings—the intensity is relentless. We need support to contain, express, understand, and make meaning of our experience, to stay connected to ourselves and others, and we need that support not only as we enter the field, but also throughout our careers.

Implications

The co-researcher's graphic portrayal of everyday encounters with mortality in the palliative care setting, clearly reveal the need for self-care. By outlining the Sacred Mandala and revealing the mandala work, I provided a detailed example of how a structured creative process can help to express, contain, and explore internal experience. It helped me to know what was happening inside me, and provided a way to respond and care for my S/self. The process helped me to feel more compassion for myself as a human being, and to find the place where I could love. It provided me with a way to connect with other people so that my struggles could be both witnessed and shared—a way for me to reach out to them as they were inspired to think about and express to me their own experience.

It is clear from my study that it can be difficult to manage the intensity of the work. The counsellors in this study feel discomfort with the team's tendency to focus on completing tasks and at being so busy. We yearn for more silence, reflection, and non-action. At times we feel isolated because of what we experience and what we know about death, and find that we cannot share our experience with our loved ones because we know from first-hand experience that

encounters with mortality are intense and can be too much to bear. It is clear to me that providing structured ways of reflecting upon our practice is one response to these concerns. By establishing right at the beginning of a career in palliative care that there is both a necessity and an expectation for process work that involves self-reflection and sharing, we build a foundation of knowledge and practice in self-care that will actually help us to advance our practice. At the same time we strengthen our ability to work within the complicated dynamics of the team. By attending to internal processes and sharing our experience with colleagues, we create intimacy, which is a necessary part of being a member of an interdisciplinary palliative care team. By strengthening our ability to hold the paradoxes of encountering mortality on a daily basis in the palliative care setting, through meditating and reflecting on our everyday experience in a structured way that allows for sharing, witnessing, and expressing strong emotion, we will be more equipped to become the caregivers that we so obviously long to be.

Obstacles and Openings

When I began this study, I had hoped to co-teach a palliative care nursing course with a nursing colleague, with the goal of building an in-road toward a teaching job at the university. I wanted to create a curriculum that would be taught by an interdisciplinary team to interdisciplinary students. I had imagined that my research would confirm my desire to address knowledge gaps that I had previously identified through my writing and teaching. For years I had been creating a list of subjects that I thought needed to be included in palliative care education: communication skills, including conflict resolution and non-violent communication, intercultural and religious perspectives on death and dying, medical language, the physiology of death, pain management, mindfulness practice, and bereavement theory. I thought that if these were taught in creative and experiential ways then students would enter palliative care more

prepared. I see now that I had not fully understood what it means to attend to process in the educational setting. Although my writing pointed in the direction of process, my agenda was still technical-rational, despite some of the process-oriented content (Breiddal, 2011a, 2011b, 2011c, 2012c).

At first the responses of the co-researchers seemed to confirm that certain kinds of content were needed. When I initially read the co-researchers' responses I was incensed that we had received so little orientation. I wrote in my journal:

It seems so unfair to place either care-givers or patients and families in the position of having to interact when in a state of shock. It is most definitely against our values of being genuine and authentic. It is so unfair to assume that anyone can enter environments that are so focused on the physical, without preparation or training. How can we be expected to act professionally and respectfully towards the people that we care about when we are battling our own sense of shock? Lack of training suggests to me that the impact of the physical breakdown of the body is minimized, implying that we "should" be able to take it in stride. This implication then makes it difficult to talk about, because we feel ashamed that we are not able to do what is required. It concerns me to think that our attempts to cover up shock with a professional mask, is most likely not successful. Do we really believe that patients and their loved ones don't pick up our horror? How does it feel to be the recipient of a forced smile, a reluctant touch? Wearing a professional mask is not consistent with hospice, nursing, or counselling values that call for respect and human to human interaction. There must be a way to help students of palliative care to better meet the physical aspects of death and dying. (SB, Journal)

I can see now that I had mistaken content for process, imagining that if we had been taught about what happens to the body as it shuts down, for instance, we would not need to suffer when faced with the reality. While I acknowledge that it may have helped some people at some point in their orientation to understand what can happen to the body, we all seemed to need some support in containing and processing our responses to the shocking reality. The required support had less to do with the physical processes of the body than with our own internal experiences.

By exploring the lived experience of encountering mortality through my academic writing, I came to understand the interplay between the palliative care environment and the counsellor's internal processes. The first-hand experience, however, of painting the mandala and contemplating its meaning will not easily be forgotten, even without the visual reminder provided by the painting itself. So much of what I have come to understand about encountering mortality is about process. I find it surprising and a bit embarrassing that, as a counsellor who identifies as a person who is "all about process," this lesson has been so difficult. However, like the co-researchers who were both shocked and grateful to find out about the physical reality of dying, I am thankful for what I have learned. My struggle brought attention to the need for a particular type of care and support for palliative caregivers.

As I wrote about the experience of the co-researchers' encounters with mortality, I was aware of the power of words and imagery. It was surprising that so much emotion was stirred within me, given that I encounter mortality daily in my work. The relentlessness of my schedule at hospice, followed by reading, thinking, writing, and painting on my days away from hospice, was far more wearing than I had imagined it might be. My ability/tendency/capacity to persist through this period resulted in what felt like an explosive breakthrough, or breakdown, of my inner defences. As I passed through the four portals of the mandala, I was able to integrate what I had learned and I now briefly outline what I came to understand through the painting and the journal work.



Figure 14: The Four Portals of the Mandala

The four Portals of the mandala (see Appendix E for the dialogues in their original form) represent obstacles that become openings, or gateways, allowing the student through the Garden Wall. The Garden Wall defends or protects the Inner Sanctum. In dialogue with the figures within the four Portals, it became clear to me that in order to fully transform and fulfill the directive given in the Narrative Ring—that is, to stop focusing on the content of my life and instead focus on my way of being—I must do several things. The first was to pay attention, to stay consciously aware of myself as I interact with the world in order to be present to myself (Portal 1, see Figure 14, above). The second is that I must also bring my spirit to everything that I do so that I will be fulfilled (Portal 2, see Figure 14, above). The third is that the practice of kindness will help me to heal myself (of being split, or divided in intention) through being of service. This means that I must focus my attention on the needs of others and let those needs guide me. My role as a teacher will actually be that of a student, and must be approached with humbleness and humility. I can share my knowledge and experience, but my learning and healing begin when I interact or engage with students, focusing on what they need, listening to their ideas, and helping them to express and develop their own ways of being in the world (Panel 3, see Figure 14, above). Finally, I must cultivate my capacity to encompass and respect all of what it means to be human, even when some aspects are more or less appealing, or create tension

within me (for example, being/doing, caring for self/caring for others, practice/theory, materialism/spirituality). The state of being whole or holy is when all aspects are in harmony, and so that I can be wholehearted. As the figures in the fourth Portal told me, integration of these two parts is “holy matrimony,” and when all parts work together it is easier to be kind, and as they said, “together we make LOVE” (Portal 4, see Figure 14, above).

To be of service to palliative caregivers, mentors and educators need to be artful in providing opportunities for caregivers in the field and those entering the palliative care world to explore palliative care-giving in their own way, in their own time, with the uniqueness of their own beings, as they weave their way between known and unknown territory. Support and curriculum need to be more focused on each individual’s journey, rather on pre-conceived ideas of what they need to know. Just as we can know in general what the needs of the dying and their families are, and in that way prepare ourselves, we cannot know what a particular caregiver or student or group of learners will want to know and learn until we engage with them. As palliative care providers, the PCCT for instance, represent a substantial body of knowledge but we would never consider walking into a dying person’s home and attempting to impart all that we know. It is considered to be a matter of respect that our team members first establish the needs of the patient or family member before offering what we think they might want to know, and even then we offer tentatively.

In the same way, the palliative care educator also represents a substantial body of knowledge, but can begin by meeting the student wherever they are in their understanding of palliative care. Curriculum can prove a structure for learning in an organic fashion, arising out of the stated and apparent needs of each person and the class as a whole, attending to relationship

and process as much as content, so that while each class may appear to have a similar structure, the content will always be unique.

Further Study

Cross-cultural studies. It might be useful to engage in other phenomenological studies, asking the same question—what is the lived experience of encountering mortality daily in the palliative care context?—for other members of the team both at Meadowview and in other settings across Canada, especially where psychosocial and spiritual care providers are not as well established on the team and/or are not represented on the management or leadership team. It might also add to the body of knowledge of palliative care to conduct this same study in settings that have a strong cultural or religious influence. For instance, Meadowview has a reciprocal relationship with a hospice in a developing country. I would like to repeat this study in that hospice to try to understand their experiences in a very different palliative care, religious, and cultural setting. A study such as this might offer us some insight into how the distribution of resources, the practice of religion, and the influence of culture play a part in encountering mortality. Historically there have been ways to accompany those in grief and those who are dying, and it would be useful to explore diverse cultural and religious attitudes to facing mortality.

The role of the mandala. When I began this research I hoped to gain some understanding of the lived experience of encountering mortality daily in the palliative care context. I wanted the counsellor's voices to be heard by a larger audience, and to make sense of my own experience in palliative care. The writing of the dissertation was a huge undertaking in itself, one that was simultaneously intellectual, emotional, and physically tiring, and yet exhilarating.

It does not begin and end with the first and last word written but has a whole life story, the seeds of which were sprouting as far back as I can remember. Did it begin with that first encounter with illness when my kindergarten teacher had her breast removed? Or when my grandfather died? Or was it earlier, when it became clear that I should not question or explore certain areas, or express strong emotion? Perhaps my training as a counsellor influences me to frame these questions from a child-development and family-system perspective. Will my exploration end as I find my way into education and curriculum design? I believe it will continue to evolve as I encounter and adapt to new environments. The process has been absorbing, and I have been immersed in the questioning. The accompanying mandala work has been an opportunity to express and process my thoughts and emotions.

One of my co-supervisors, Dr. Blades, suggested to me in early discussions that I might want to answer the question, “Would you recommend to someone else that they paint a mandala as a research method in order to strengthen their understanding of a question?” I fully expected that the answer would be a resounding yes. Why would I even start if I did not think that it would be of use? Perhaps painting a mandala is like giving birth to a baby. As I was giving birth to my second, third, and fourth children, overwhelmed with physical pain, the forgotten memory of the physical pain of prior births resulted in the same tearful lament: “I cannot believe that I am doing this again.” How could I have forgotten how difficult it was? Painting a mandala is arduous, and at times I questioned whether it was good for me to open myself to such an intense emotional process about such a charged topic as death. What was I inviting into my life? The purpose of the mandala is to resolve opposites, to dwell with and within tension and to allow that tension to be transforming—the circle within the square is contained as one whole. As

I near the end, I feel more settled, more able to hold the pull toward and push away from the reality of encountering mortality. In this respect the mandala has done its work.

The answer to the question—would I recommend the mandala as a form of research?—is yes. However, a word of caution is due. It is not a simple or easy process. The painting requires full attention for many hours, the journal work—dream work, active imagination, tracking—must be consistent, and the self-reflection exhaustive. The content can be brutal at times, and requires the support of a counsellor, psychologist, or spiritual caregiver, to help process the overwhelming content, and to offer comfort, direction, and stability. However, I hope that it is evident that it is an enriching process. There is a feeling of vulnerability at exposing the content because it is so personal and yet I hope to be of service by sacrificing that privacy, and my ego, in order to reveal another aspect of the lived experience of encountering mortality daily in a palliative care context—in its full intensity.

This study has revealed to me that there is a connection between the co-researchers' need to respond appropriately to the intensity of encountering mortality, and their need to be met by supervisors and colleagues with the same intensity. It seems appropriate to meet intensity with intensity. Anything else seems inappropriate. The literature on self-care fails palliative care workers because it does not meet us with the force that is required. Much of the responses to our work seem trite, like a pat on the head that says “there, there, it will all be better in the morning.” The mandala is a powerful process that mirrors the strength of encountering mortality on a daily basis in the palliative care setting.

I could therefore add to my list of further studies, a more thorough study of the role that the Sacred Mandala can play in helping students to transform through holding the tension of the

opposites. It would be especially interesting to anyone with a spiritual, religious, or process-oriented psychology background, but I believe that education has the potential to be transformative and that the mandala work could be an enhancement for any student who is drawn to the form, is willing to work with a mentor, and commit to the mandala's structure and practices.

The mandala might record the peak and nadir experiences of writing a dissertation. Clarke-Steffen (1998) defined a peak experience as “an intensely meaningful or highly significant and unforgettable experience that is often accompanied by feelings of awe, wonder, unity fulfillment, or going beyond ordinary experience” (p. 26), and a nadir experience as “an intensely meaningful or highly significant and unforgettable negative experience that is often accompanied by feelings of agony, distress, pain, embarrassment, sorrow or regret” (p. 26). Papadatou (2009) said that a person must be open in order for transformation to occur.

While we all have peak and nadir experiences, it is the way we perceive and cope with them that determines whether we lose or gain something from them. Those who remain open to such experiences and take the time to reflect on and process them—alone or with others—are more likely to learn something new that may subsequently change and enrich their view of themselves. Of others, of life, and of caregiving. Key experiences invite us to revise our goals, values and interventions and enable us to invest our role and work with personal meaning. Most importantly, they help us build upon our strengths, accept our limitations, and learn how to transform nadir experiences into peak experiences and opportunities for the development of self-awareness and personal growth. (p. 184)

The mandala provides a process that supports reflection with the intention of transformation and the resolution of the opposites (Johnston, 1996; Jung, 1931, 1959/1969) that occur in peak and nadir experiences. Of course, the Sacred Mandala does not have to be limited to students or palliative caregivers. It could be used to support any transformational experience because it really is an exploration of what it means to be human.

Limits of the Study

The biggest limitation for me is that I cannot continue the conversation here. I want to go on to see how a complexivist lens affects my teaching. While I may be considered to be an expert in palliative care, I find myself facing a new beginning when it comes to being an educator. As I read Doll (2012) and Gergen (2009) I see that a whole new world of curriculum philosophy and design is opening to me. I will not know until I am in the classroom what students will want to know or what they will want to teach me. I do know that I will begin with where the students are. Perhaps I will ask them to share a story about their own encounters with mortality. I imagine providing stimulating resources in order to help them to engage all that death and dying means. I see the classroom as a place of discussion and assignments as being an opportunity to explore issues of immediate importance. I see the importance of working cooperatively, intimately and reflectively with other students developing and exploring questions that are generated from the students own curiosity and desire to know. I see myself as a learner and the students as my teacher. However, if there is one thing that I have learned it is to try to stay in the present and not to look too far into the distance.

When I began I thought that the study would be limited by choosing only counsellors, by choosing only staff from Meadowview, by being the only co-researcher to paint a mandala, or by having an established relationship with the co-researchers. I feared that I would not have enough material or that I would be unable to see what was being offered in a fresh way. I feared that I would not be enough, and that the study would therefore not be enough.

What I now see as the biggest limitation of the study was explained in my descriptions from van Manen's (2007) and others' work about the constraints of language, which ironically,

were “only words” when I first began. Now I understand the inadequacy of these words. I can never write all that I know, and the words I use only approximate what I mean. Even my images do not convey all that they have to give. Paradoxically, what I experienced, what I found, and what I tried to report felt like too much, rather than not enough. I have had to curb my desire for more time and more space and still it seems that what I have reported is so small compared with what I have taken in and absorbed. The limitations are clearly not what I was expecting.

The Inner Sanctum



Figure 15: The Inner Sanctum

The centre of the mandala looks like a circle but is actually a spiral.

I am limited by time and words, and yet I must draw a line and say, now, this is the time to stop. How can I do that when I am so excited to continue? In an email to my supervisor, I said that I feel like I have been in the IMAX movie that I referred to previously, with my eye to the microscope for three years, and then as I stand up and look around, I am disoriented. I feel dismayed to see that there is a magnifying glass, a telescope that is pointing at the universe. Have I said anything of importance? What do I know? My supervisor reassures me that “the

scholar recognizes the limits of the research” (Dr. Blades, personal communication, October 15, 2012). Paradox is apparent once again. The limitation now becomes the liberation.

As T.S. Eliot (1944) said:

We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time. (p. 43)

It seems that the circle is a spiral. What I have come to understand and am most interested in now is the idea that education for both student and teacher can be just as much of an opportunity to learn about what it means to be human as working in palliative care.

I have been shaped, transformed by this enquiry. I have no way of knowing what I will create with my new knowledge or by my new way of being. I hope that I can be more sensitive and responsive to students’ needs, and that change will occur—which, after all, is the purpose of phenomenology (van Manen, 2007).



Figure 16: The Completed Mandala

The completed mandala includes the Ring of Fire, the Transition Rings, the Narrative Ring, the Wasteland, the Garden Wall, the Four Portals, and the Inner Sanctum.

References

- Ablett, J., & Jones, R. (2007). Resilience and well-being in palliative care staff: A qualitative study of hospice nurses' experience of work. *Psycho-Oncology, 16*(8), 733-740.
- Acton, G. J. (2002). Health-promoting self-care in family caregivers. *Western Journal of Nursing Research, 24*(1), 73-86.
- Agrawal, M., & Emanuel, E. (2002). Death and dignity: Dogma disputed. *Lancet, 360*(9350), 1997-1998.
- Alkema, K., Linton, J., & Davies, R. (2008). A study of the relationship between self-care, compassion satisfaction, compassion fatigue, and burnout among hospice professionals. *Journal of Social Work in End-of-Life & Palliative Care, 4*(20), 101-119.
- Arguelles, J., & Arguelles, M. (1972). *Mandala*. Boulder, CO: Shambala Publications.
- Arrien, A. (1993). *The four-fold way: Walking the paths of the warrior, teacher healer, and visionary*. San Francisco, CA: HarperCollins.
- Barone, T. E., & Eisner, E. W. (2012). *Arts based research*. Thousand Oaks, CA: Sage Publications.
- Bertman, S. (2011). Foreword. In I. Renzenbrink, (Ed.), *Caregiver stress and staff support in illness, dying, and bereavement* (n.p.). New York, NY: Oxford University Press.
- Bolt, B. (2011). *Heidegger reframed: Interpreting key thinkers for the arts*. London, England: I. B. Taurus.

- Bowman, T. (2011). Reflections on caring: A brief essay on presence. In I. Renzenbrink, (Ed.), *Caregiver stress and staff support in illness, dying, and bereavement* (pp. 189-196). New York, NY: Oxford University Press.
- Brajtman, S., Hall, P., & Barnes, P. (2009). Enhancing interprofessional education in end-of-life care: An interdisciplinary exploration of death and dying in literature. *Journal of Palliative Care*, 25(2), 125-131.
- Breiddal, S. (1996). A phenomenological study of the experience of participants attending a course written for the Unitarian Church, entitled: "Spirituality in everyday life." Palo Alto, CA: Institute of Transpersonal Psychology.
- Breiddal, S. (2011a). Palliative care: A place for care-givers to thrive. *Illness, Crisis and Loss*, 19(2), 111-124.
- Breiddal, S. (2011b). Staff support: A shared responsibility at Victoria Hospice Society, BC, Canada. In I. Renzenbrink, (Ed.), *Caregiver stress and staff support in illness, dying, and bereavement* (pp. 119-126). New York, NY: Oxford University Press.
- Breiddal, S. (2011c). A place to thrive. *Insights into Clinical Counselling*, August edition, 5-7.
- Breiddal, S. (2011d). A fate worse than death. *Illness, Crisis and Loss*, 19(4), 389-393.
- Breiddal, S. (2012a). Self-care in palliative care: A way of being. *Illness, Crisis & Loss*, 20(1), 5-17.
- Breiddal, S. (2012b). Being there: An ethnographic study of hospice counselling. *Insights into clinical counselling*, December edition, 9-10.

- Breiddal, S. (2012). Interdisciplinary education in palliative care: A bold strategy, solution and political statement. *Illness, Crisis and Loss*, 20(4), 375–386.
- Bruce, A., & Davies, B. (2005). Mindfulness in hospice care: Practicing meditation-in-action. *Qualitative Health Research*, 15(10), 1329-1344.
- Cadell, S., Bosma, H., Johnston, M., Porterfield, P., Cline, L., Fraser, J., Boston, P. (2007). Practising interprofessional teamwork from the first day of class: A model for an interprofessional palliative care course. *Journal of Palliative Care*, 23(4), 273-282.
- Cairns, M., Thompson, M., & Wainwright, W. (2003). *Transitions in dying and bereavement: A psychosocial guide for hospice and palliative care*. Victoria, BC: Health Professions Press.
- Callanan, M., & Kelley, P. (1992). *Final gifts*. New York, NY: Bantam Dell.
- Camargo, P. (2005). What is it like for nurses to experience the death of their patients? *Phenomenology Online*. Retrieved from <http://www.phenomenologyonline.com/sources/textorium/camargo-pilar-what-is-it-like-for-nurses-to-experience-the-death-of-their-patients/>
- Cameron, B. L. (2004). Ethical moments in practice: The nursing “how are you?” revisited. *Nursing Ethics*, 11(1), 53-62.
- Caputo, John. (1987). *Radical hermeneutics: Repetition, deconstruction, and the hermeneutic project*. Bloomington, IN: Indiana University Press.
- Carse, J. (1986). *Finite and Infinite Games*, New York: Free Press.

Chambers Dictionary, The. (2008). "Serve." *The Chambers Dictionary* (11th edition).

Edinburgh, UK: Chambers Harrap Publishers.

Clarke-Steffen, L. (1998). The meaning of peak and nadir experiences of pediatric oncology nurses: Secondary analysis. *Journal of Pediatric Oncology Nursing*, 15(1), 25-33.

Collett, M. (1997). *Stay close and do nothing*. Kansas City, MO: Andrews McMeel Publishing.

Corker, D. J. (2010). *Physician's experiences with death and dying: A phenomenological study* (Unpublished doctoral dissertation). Retrieved from South Illinois University, Carbondale, IL.

Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*. London, UK: Sage Publications Limited.

Death Card from the Rider-Waite Deck. (n.d.). Learntarot.com. Retrieved from

http://www.google.ca/imgres?imgurl=http://www.learntarot.com/bigjpgs/maj13.jpg&imgrefurl=http://www.learntarot.com/maj13.htm&h=600&w=350&sz=109&tbnid=UREsTgM4P8JApM:&tbnh=91&tbnw=53&zoom=1&usg=__wD2F0rQBSBZTltInf3X78iFnyVE=&docid=-xaOpdA3bqfKIM&sa=X&ei=hkYDUZSyBMmwiQKWYrYDwDQ&ved=0CEQQ9QEwAw&dur=292

Death Card from the Thoth Tarot Deck. (n.d.) Google Images. Retrieved from

<https://www.google.ca/search?q=death+card+thoth+deck&safe=off&client=firefox-a&hs=tCE&rls=org.mozilla:en-GB:official&tbm=isch&tbo=u&source=univ&sa=X&ei=-P6cUdz2Oab9iQLXhICACw&ved=0CDgQsAQ&biw=1360&bih=557>

- Dechamps, A. (2011). Leadership and staff care, self-care and self-awareness: Reflections from St Christopher's Hospice, London. In I. Renzenbrink (Ed.), *Caregiver stress and staff support in illness, dying, and bereavement* (pp. 127-137). New York, NY: Oxford University Press.
- Denzin, N., & Lincoln, Y. (2005). The discipline and practice of qualitative research. In E. G. Guba & Y. S. Lincoln (Eds.), *Sage handbook of qualitative research* (3rd ed.) (pp. 1-32). Thousand Oaks, CA: Sage.
- DiTullio, M., & MacDonald, D. (1999). The struggle for the soul of hospice: Stress, coping, and change among hospice workers. *American Journal of Hospice & Palliative Care*, 16(5), 641-645.
- Doll, W. (1993). *A post-modern perspective on curriculum*. New York, NY: Teachers College Press.
- Doll, W., & Trueit, D. (2010). Complexity and the health care professions. *Journal of evaluation in clinical practice*, 16(4), 841-848.
- Downing, M., & Wainwright, W. (2006). *The medical care of the dying* (4th ed.). Victoria, BC: Victoria Hospice Society, Learning Centre for Palliative Care.
- Duerk, J. (1993). *Circle of stones: A woman's journey to herself*. San Diego, CA: LuraMedia.
- Eddy, W. (2008). Re-discovering identity: A phenomenological study exploring the ontological complexities of being gay. (Doctoral dissertation). University of Maryland at College Park.
- Eliot, T. S. (1944). *Four quartets*. London, UK: Faber and Faber.

- Ellis, C. (2003). *The Ethnographic I: A methodological novel about autoethnography*. Walnut Creek, CA: Altamira Press.
- Faver, C. (2003). Being called. *Social Thought*, 22(1), 63-76.
- Finlay, L. (2011). *Phenomenology for therapists: Researching the lived world*. Oxford, UK: Wiley-Blackwell.
- Finlay, L., & Evans, K. (2009). *Relational-centered research for psychotherapists: Exploring meanings and experience*. Oxford, UK: Wiley-Blackwell.
- Fraser, S., & Greenhalgh, T. (2001). Complexity science: Coping with complexity: Educating for capability [Clinical research edition]. *British Medical Journal* 323(7316), 799–803.
- Frommer, M. (2005). Living in liminal spaces of mortality. *Psychoanalytic Dialogues*, (15)4, 479-498.
- Gadamer, H.-G. (1960/1998). *Truth and method* (2nd ed.). New York: Continuum. (Original work published 1960.)
- Gergen, K. (1985). The social constructionist movement in modern psychology. *American Psychologist*, 40(3), 266-275.
- Gergen, K. (2009). *Relational being: Beyond self and community*. New York, NY: Oxford University Press.
- Gerow, L., Conejo, P., Alonzo, A., Davis, N., Rodgers, S., & Domian, E. W. (2010). Creating a curtain of protection: Nurses' experiences of grief following patient death. *Journal of Nursing Scholarship*, 42(2), 122-129.

- Groom, C., & Pennebaker, J. (2002). Words. *Journal of Research in Personality*, 36(6), 615-621.
- Groves, R., & Klauser, A. (2005). *The American book of dying: Lessons in healing*. Toronto, ON: Celestial Arts.
- Gustafson, J. (1982). Professions as "callings." *Social Service Review*, 56(4) (December), 501-515.
- Hall, P., & Weaver, L. (2001). Interdisciplinary education and teamwork: A long and winding road. *Medical Education*, 35(9), 867-875.
- Hall, P., Weaver, L., Fothergill-Bourbonnais, F., Amos, S., Whiting, N., Barnes, P., & Legault, F. (2006). Interprofessional education in palliative care: A pilot project using popular literature. *Journal of Interprofessional Care*, 20(1), 51-59.
doi:10.1080/13561820600555952
- Heidegger, M. (1953/1996). *Being and time* (J. Stambaugh, Trans.). Albany, NY: State University Press. (Original work published 1953.)
- Hessel, J. A. (2009). Presence in nursing practice: A concept analysis. *Holistic nursing practice*, 23(5), 276-281.
- Hetherington, A. (2007). The use and abuse of touch in therapy and counselling. *Counselling Quarterly*, 11(4), 361-364.
- Holloway, I., & Wheeler, S. (2002). *Qualitative research in nursing* (2nd ed.). Malden, MA: Blackwell Publishing.

- Hopkinson, J. B., Hallett, C. E., & Luker, K. A. (2003). Caring for dying people in hospital. *Journal of advanced nursing*, 44(5), 525-533.
- Hunter, A., Lusardi, P., Zucker, D. Jacelon, C., & Chandler, G. (2002). Making meaning: The creative component in qualitative research. *Qualitative Health Research*, 12(3), 388-398. doi:10.1177/104973202129119964
- Irwin, R., & de Cosson, A. (Eds.). (2004). *A/r/tography: Rendering self through arts-based living inquiry*. Vancouver, BC: Pacific Educational Press.
- Irwin, R., (2004). A/r/tography: A metonymic metissage. In R. Irwin & A. de Cosson (Eds.), *A/r/tography: Rendering self through arts-based living inquiry* (pp. 27–40). Vancouver, BC: Pacific Educational Press.
- Jaffe, A. (1959/1964). Symbolism in the visual arts. In C. Jung, *Man and his symbols* (pp. 230–271). Garden City, NY: Doubleday and Company.
- Japanese Yin/Yang Mandala. (n.d.). Wikipedia. Retrieved from http://commons.wikimedia.org/wiki/File:Yin_yang.svg
- Johns, C. (2007). Towards easing suffering. *Journal of Holistic Nursing*, 25(3), 204-210.
- Johns, C. (2009). *Becoming a reflective practitioner*. Oxford, Wiley-Blackwell.
- Johns, C. (Ed.). (2011). *Guided reflection: a narrative approach to advancing professional practice*. Oxford, Wiley-Blackwell.
- Johnson, M. (2000). Heidegger and meaning: Implications for phenomenological research. *Nursing Philosophy*, 1(2),134-146.

- Johnston, M. J. (1997). *Remembering wholeness: The hero's-journey-in-relation a mandalic study*. Unpublished manuscript. Carpentaria, CA: Pacifica Graduate Institute.
- Jones, S. H. (2005). A self-care plan for hospice workers. *American Journal of Hospice and Palliative Care*, 22(2), 125-128.
- Joseph, E. (2010). Intimate strangers. *Malahat Review*, 173, Winter, 5–12.
- Jung, C. G. (1931). *The secret of the golden flower* (R. Wilhelm, Trans.). Princeton, NJ: Lund and Humphries. (Original: n.d.)
- Jung, C. G. (1960). The structure and dynamics of the psyche. . In R. F. C. Hull (Trans.), *The Collected Works of C. G. Jung* (9)1, Bollingen Series XX, pp. 222-265. New York, NY: Pantheon Books.
- Jung, C. G. (1959/1969). Mandala symbolism. In R. F. C. Hull (Trans.), *The Collected Works of C. G. Jung* (9)1, Bollingen Series XX, pp. 355-384. Princeton, NJ: Princeton University Press.
- Jung, C. G. (1965). *Memories, dreams and reflections*. (Revised ed.). New York, NY: Vintage Books/Random House.
- Kabat-Zinn, J. (1990). *Full catastrophe living: Using the wisdom of your body and mind to face stress, pain, and illness*. Surrey UK: Delta.
- Kabat-Zinn, J. (1995). *Wherever you go, there you are: Mindfulness meditation in everyday life*. New York: Hyperion.

- Kabat-Zinn, J. (2005). *Coming to our senses: Healing ourselves and the world through mindfulness*. New York: Hyperion.
- Katz, Renee S., & Johnson, Therese A. (Eds.). (2006). *When professionals weep: Emotional and countertransference responses in end-of-life care*. New York, NY: Routledge.
- Kaufman, S. (2008). *Reinventing the sacred: A new view of science, reason, and religion*. New York, NY: Perseus Book Group.
- Kearney, M., Weininger, R, Vachon, M., Harrison, R., & Mount, B. (2009). Self-care of physicians caring for patients at the end of life: Being connected ... a key to my survival. *Journal of the American Medical Association, 301*(11), 1155–64.
- Keidel, G. (2002). Burnout and compassion fatigue among hospice caregivers. *American Journal of Hospice & Palliative Care, 19*(3 May/June), 200–205.
- Kellehear, A. (2007). *A social history of dying*. Sydney, Australia: Cambridge University Press.
- King, G., Strachen, D., Tucker, M., Duwyn, B., Desserud, S, & Shillington, M. (2009). The application of a transdisciplinary model for early intervention services. *Infants & Young Children, 22*(3), 211–223.
- Koch, T. (2008). Interpretive approaches in nursing research: the influence of Husserl and Heidegger. *Journal of advanced nursing, 21*(5), 827-836.
- Kübler-Ross, E. (1975). *Death: The final stage of growth*. New York, NY: Prentice-Hall.
- Kuhl, D. (2002). *What dying people want*. Toronto, ON: Doubleday Canada.

- Laverty, S. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, 2(3). Retrieved from http://www.ualberta.ca/~iiqm/backissues/2_3final/pdf/laverty.pdf
- Leavy, P. (2009). *Method meets art: Arts-based research practice*. New York, NY: The Guilford Press.
- Marvin, Jeffrey (Producer), & Silleck, Bayley (Director). (1996). *Cosmic voyage* [Motion picture]. USA: Warner Bros.
- Maasdorp, V. (2011). The challenge of staff support in hospice care in Zimbabwe. In I. Renzenbrink, (Ed.), *Caregiver stress and staff support in illness, dying, and bereavement* (pp. 82-97). New York, NY: Oxford University Press.
- Matzo, M., Sherman, D., Lo, K., Egan, K., Grant, M. & Rhome, A. (2003). *Nurse Educator*, (28)2, 71-76.
- McMurty, A. (2008). Strategies for teaching loss, grief, and bereavement. *McGill Journal of Education*, 43(3), 265-281.
- Meier, D., & Beresford, B. (2008). The palliative care team. *Journal of Palliative Medicine*, (11)5, 677-681. doi:10.1089/jpm.2008.9907
- Merriam, S. B. (1998). *Qualitative research and case study applications in education*. San Francisco, CA: Jossey-Bass.
- Merriam-Webster. (2012). "Dwell." <http://www.merriam-webster.com>.

Merriam-Webster. (2012). "Intensity." <http://www.merriam-webster.com>.

Merriam-Webster. (2012). "Whole." <http://www.merriam-webster.com>.

Meyers, S. (2006). Using transformative pedagogy when teaching on-line. *College Teaching*, 56(4), 219-224.

Moran, D. (2000). *Introduction to phenomenology*. London, UK: Routledge.

Morrow Lindbergh, A.. (1978). *Gift from the sea*. New York, NY: Vintage Books.

Murray, K. (2008). *Essentials in hospice care: A resource for caregivers* (2nd ed.). Victoria, BC: Life and Death Matters.

Nugus, D. (2011). Seeing beyond the sadness: Hope, resilience, and sustainable practice in childhood bereavement. In I. Renzenbrink (Ed.), *Caregiver stress and staff support in illness, dying, and bereavement* (pp. 119-126). New York, NY: Oxford University Press.

Online dictionary of social sciences (2002). "Social Construction." <http://bitbucket.icaap.org/>.

Osborne, J. (1991). Some similarities and differences among phenomenological and other methods of psychological qualitative research. *Canadian Psychology*, 35(2), 167-189.

Otto, R. (1958). *The idea of the holy* (Vol. 14). Oxford University Press, USA.

Oxford English Dictionary, The. (2012). "Capacity." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Connection." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Deep." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Imagination." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Intensity." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Intimacy." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Mentor." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Perform." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Phenomenology." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Psyche." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Resolution." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Sacrifice." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Search." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Special." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Synchronicity." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Tension." <http://www.oed.com>.

Oxford English Dictionary, The. (2012). "Yin/yang." <http://www.oed.com>.

Papadatou D. (1997). Training health professionals in caring for dying children and grieving families. *Death Studies*, 21(6), 575-600.

Papadatou, D. (2001). The grieving healthcare provider. *Bereavement Care*, 20(2), 26-29.

Papadatou, D. (2006). *Caregivers in death, dying, and bereavement situations*. *Death Studies*, 30(7), 649-663.

- Papadatou, D. (2009). *In the face of death: Professionals who care for the dying and the bereaved*. New York, NY: Springer Publishing.
- Pereira, S. M., Fonseca, A.M., & Carvalho, A S. (2011). Burnout in palliative care: A systemic review. *Nursing Ethics*, 18, 317–326. doi: 10.1177/0969733011398092
- Perrault, H. (2010). Integrated thinking, integrated learning: Changing our ways for changing global realities. *Learning Landscapes*, 3(2), 115-122.
- Piercy, M. (1982). *Seven of pentacles. Circles on the water: Selected poems of Marge Piercy*. New York, NY: Alfred A. Knopf.
- Plsek, P., & Greenhalgh, T. (2001). The challenge of complexity in health care. *British Medical Journal*, 323(7313), 625–628. doi:10.1136/bmj.323.7313
- Renzenbrink, I. (Ed.). (2011). *Caregiver stress and staff support in illness, dying and bereavement*. New York, NY: Oxford University Press
- Rogers, C. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology*, 21(2), 95–103.
- Rogers, C. (1961). *On becoming a person: A therapist's view of psychotherapy* (Sentry edition, 1970). Boston, MA: Houghton Mifflin Company.
- Rogers, C. (1975). A process of conception of psychotherapy. *American Psychologist*, 13(4), 142-149.
- Rokach, A. (2005). Caring for those who care for the dying: Coping with the demands of palliative care workers. *Palliative and Supportive Care*, 3(4), 325-332.

- Ronayne, C. (2009). A phenomenological study to understand the experiences of nurses with regard to brainstem death. *Intensive & Critical Care Nursing: The Official Journal of the British Association of Critical Care Nurses*, 25(2), 90.
- Rosenberg, M. (2003). *Nonviolent communication: A language of life*. Encinitas, CA: PuddleDancer Press.
- Rowan, J. & Jacobs, M. (2002). *The therapist's use of self*. Philadelphia, PA: Open University Press.
- Ryan, P. (2003). Approaching death: A phenomenological study. Retrieved from <http://hdl.handle.net/10755/165360>
- Sadala, M., & Adorno, R. (2002). Phenomenology as a method to investigate the experience lived: A perspective from Husserl and Merleau Ponty's thought. *Journal of Advanced Nursing*, 37(3), pp. 282-293.
- Sawicki, M. (2011). Edmund Husserl. *Internet encyclopaedia of philosophy*. Retrieved from <http://www.iep.utm.edu/husserl/>
- Schmidt, L. (2006). *Understanding hermeneutics*. Stocksfield, England: Acumen.
- Shah, I. (1993). When Death came to Baghdad. In I. Shah, *Tales of the Dervishes: Teaching stories of the masters over the past thousand years*. Arcana, USA: Penguin Books.
- Sherwood, G. (2009). The power of nurse-client encounters: Interpreting spiritual themes. *Journal of Holistic Nursing*, 18(2), 159-175.

- Snowden, D. (2003) Managing for serendipity. Retrieved from http://cognitive-edge.com/uploads/articles/39_Managing_for_Serendipity_final.pdf
- Stake, R. (2010). *Qualitative research: Studying how things work*. New York, NY: Guildford Press.
- Springgay, S., Irwin, R. L., & Kind, S. W. (2005). A/r/tography as living inquiry through art and text. *Qualitative Inquiry*, 11(6), 897-912.
- Steigman, I. (2007). *Journey into the numinous: A grounded theory exploration of the stages and meaning of death awareness development*. Palo Alto, CA: Institute of Transpersonal Psychology.
- Swartz, E. (2009). Diversity: Gatekeeping knowledge and maintaining inequalities. *Review of Educational Research*, 79(2), 1044-1083. doi:10.3102/0034654309332560
- Thomasma, D. (1994). Toward a new medical ethics: Implications for ethics in nursing. In P. Benner (Ed.). *Interpretive phenomenology: Embodiment, caring and ethics in health and illness*, (pp. 43-63). Thousand Oaks, CA: Sage.
- Thompson, M., & Wainwright, W. (2006). Psychosocial care. In M. Downing & W. Wainwright (Eds.), *Medical care of the dying* (4th ed.), (pp. 535-591). Victoria, BC: Victoria Hospice Society Learning Centre for Palliative Care.
- Tibetan Sand Mandala. (n.d.). Wikipedia. Retrieved from: <http://en.wikipedia.org/wiki/File:Kalachakra.jpg>
- Toews, M. (2008). *The Flying Troutmans*. Toronto, ON: A. A. Knopf.

- Trueit, D. (Ed.). (2012). *Pragmatism, Postmodernism, and Complexity Theory: The “fascinating imaginative realm” of William E. Doll, Jr.* New York, NY: Routledge, forthcoming.
- Unitarian Universalist Association. (1993). *Singing the living tradition*. Boston, MA: Beacon Press.
- Vachon, M. (2011). Four decades of selected research in hospice/palliative care: Have the stressors changed? In I. Renzenbrink, (Ed.), *Caregiver stress and staff support in illness, dying, and bereavement* (pp.). New York, NY: Oxford University Press.
- Van Manen, M. (2007). *Researching lived experience: Human science for an action sensitive pedagogy* (2nd ed.). London, Ontario: The Althouse Press.
- Van Manen, M. (2012). Phenomenology online. Retrieved from:
www.phenomenologyonline.com
- Van Marie, K. (2007). Law's time, particularity and slowness. In W. Roux & K. van Marle (Eds.), (pp. 11-32), *Law, memory and the legacy of apartheid: Ten years after AZOPO v President South Africa*. Pretoria, South Africa: Pretoria University Law Press.
- Von Franz, M.-L. (1959/1964). The process of individuation. In C. Jung, (pp. 157-254), *Man and his symbols*. C. Jung Garden City, NY: Doubleday and Company.
- Wainwright, W. (2011). Staff support: A shared responsibility. In I. Renzenbrink, (Ed.), *Caregiver stress and staff support in illness, dying, and bereavement* (pp. 111-118). New York, NY: Oxford University Press.
- Walcott, S. (2006). Mapping from a different direction: Mandala as sacred spatial visualization. *Journal of Cultural Geography*, 23(2), 71-88.

- Walsh, K. (1996). Philosophical hermeneutics and the project of Hans George Gadamer: Implications for nursing research. *Nursing Inquiry*, 3(4), 231-237. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9117772>
- Weininger, R., & Kearney, M. (2011). Revisiting empathic engagement: Countering compassion fatigue with “exquisite empathy.” In I. Renzenbrink, (Ed.), *Caregiver stress and staff support in illness, dying, and bereavement* (pp. 49-61). New York, NY: Oxford University Press.
- Wilbur, K. (1979/1985). *No boundary*. Shambala Boston & London.
- Williams, W. (2000). Epistemological background for knowing and naming. *ETC: A Review of General Semantics*, 57, 268-289.
- Wilson, M. (2009). Complexity theory. *Whitireia Nursing Journal*, 16, 18-24.
- Wojanar, D., & Swanson, K. (2007). Phenomenology: An exploration. *Journal of Holistic Nursing*, 25(172). doi:10.1177/0898010106295172
- Worden, J. W. (1996). *Children and grief: When a parent dies*. New York, NY: Guilford Press.
- World Health Organization. (n.d.). WHO definition of palliative care. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>
- Wright, D. & Brajtman, S. (2011). Relational and embodied knowing: nursing ethics within the interprofessional team. *Nursing Ethics*, (18)1, 20-30.
- Wu, H. L. (2008). The lived experiences of Taiwanese hospice nurses caring for dying patients. UMI Microform 3319957, Ann Arbor: ProQuest.

Youngson, R. (2011). Compassion in healthcare: The missing dimension of healthcare reform?

In I. Renzenbrink (Ed.), *Caregiver stress and staff support in illness, dying, and bereavement* (pp. 49-61). New York, NY: Oxford University Press.

Zimmerman, C. (2004) Denial of impending death: A discourse analysis of the palliative care

literature. *Social Science and Medicine*, (59)8 1769-1780.

Zyblock, D. (2010). Nursing presence in contemporary nursing practice. *Nursing Forum*

April/June 45(2), 120-124. doi: 10.1111/j.1744-6198.2010.00173.x

Appendix A: Letter to Meadowview Leaders

As you all know, in addition to my work as a counsellor on the palliative care crisis team, I am engaged in doctoral studies at the University of Victoria, in Education: Instruction and Curriculum. I was part of the staff group that formed the Charter of Values for hospice and I take those values to heart by demonstrating my commitment to excellence through pursuing education. While I have always been interested in the well-being of the interdisciplinary team, and in self-reflective practice, I am beginning a more formal study that can contribute to the greater body of knowledge about palliative care, by asking the question: What is the lived experience of encountering mortality, on a daily basis, in a palliative care context? Surprisingly, encountering mortality has been cited as a reason that supports both palliative caregivers stress *and* palliative caregiver's job satisfaction. A thorough review of the literature has revealed no studies on encounters with mortality itself, or of the lived experience of palliative care counsellors. My goal is for colleagues, managers, supervisors, and educators, to be better able to prepare and support each other, by engaging in reflection and discussion. By understanding how a small group of caregivers articulate their own experience of being in the face of death, we can perhaps expand our concepts of the possible responses, and enter into conversations that can inform our practice, and this understanding may help us to support patients and families through their encounters with mortality. I am hoping that my study will contribute to the community through writing my dissertation and in academic journals, as well as through presentations at academic and professional development conferences and workshops. To do this, however, I am making an application to the joint ... [governing body] and University of Victoria ethics committee.

The study will not take any work time, or require any special equipment, and therefore there are no costs to Hospice at all. The counsellors will be to answer some questions, on their own time, about their own experience in encountering mortality in the palliative care setting. Given my long association as a Clinical Counsellor (30 years) and as a palliative care counsellor (15 years), where confidentiality is very rigidly followed together with my experience as a paid employee of the BC Clinical Counsellors Association, on the ethics committee and responsible for de-identification of documents, I am certain that I have a sensitivity to these issues and can ensure protection of all identities.

The study itself will involve 3-4 counsellors on the PCCT [pseudonym], as well as me. Also, I want to address the potential risks involved in this research study. The study is considered to have minimal risks to the participants, as the research activity will include activities that are akin to daily practices of counsellors-- debriefing visits, and reflection upon and discussion about one's own experience. It is possible however, that participants could feel fatigued by the extra effort of writing. To counteract the potential for fatigue, I will suggest that they take as much time as is needed to answer the questions.

Another potential harm is that a participant might in some way feel uncomfortable about an aspect of their practice as revealed in their journal writing. It will be explained beforehand that all data is in their control, and can be deleted before sharing with me. Should harm of any kind

occur for the participants, I will be available for debriefing, and professional counselling is available through our Manager.

The benefits to this research will occur on several levels. Individual staff members who participate will be attending to their own experience, which is a valued skill in the counselling profession. They will have the opportunity to meet with other counsellors to discuss and learn from each other's experience. They will be given an opportunity to give voice to their unique perspective and experience the satisfaction of helping others. They also have the potential to be given instruction and assistance in writing a personal and most likely powerful account of their own experience. They may also enter casual discussions with other colleagues about the experience of encountering mortality, which could lead to a sense of raised consciousness on this subject for other staff members. Their increased awareness and understanding may contribute to the care they provide for patients and families who are also encountering mortality. The study may contribute to society in revealing the previously unstudied and unvoiced experience of counsellors in palliative care.

I would like to give you time to think about this, and to raise any questions or concerns. Please contact me directly in the next few weeks at susan@thebreiddals.com or by phone at 250-370-1641. If you have any questions or concerns that can be answered by my co-supervisors at the University of Victoria please feel free to contact them as follows:

Dr. David Blades Phone: 250-721-7775 or E-Mail: [dblades@uvic.ca](mailto:d blades@uvic.ca)

Dr. Daniel Scott Phone: 250-7775 or E-Mail: dscott@uvic.ca

If you would like to communicate with me please email, phone, or arrange to meet me in person. Thank you for taking the time to read this.

Susan Breiddal

Appendix B: Letter to Potential Participants

Informed consent forms: Participants

Study name: What is the lived experience of encountering mortality, on a daily basis, in the palliative care context?

Researcher: Susan M. F. Breiddal, PhD Candidate, University of Victoria, Department of Curriculum and Instruction, and employee of Meadowview Hospice (pseudonym)

Contact: susan@thebreiddals.com

Co-Supervisors:

Dr. David Blades, Department of Curriculum and Instruction d blades@uvic.ca PH: 250-721-7775

Dr. Daniel Scott, School of Child and Youth Care dgscott@uvic.ca PH: 250-721-7918

Purpose of the Research:

The purpose of this research is to explore the lived experience of encountering mortality, on a daily basis, in a palliative care setting, in the hopes that describing this experience, and understanding the meaning from your perspective, will help those who work or plan to work in jobs that encounter mortality. The research will also help those who train, supervise, design programs, teach, and support palliative caregivers.

You have been approached because you work on the Palliative Care Crisis Team (PCCT) (pseudonym) at Meadowview Hospice (pseudonym), you are in a [redacted] position, and you are a counsellor who encounters mortality on a daily basis, in the palliative care context. By studying the collective experience of PCCT counsellors I hope to uncover a rich narrative that will speak to all those who wonder how we do our jobs and what it is like to be in the face of death every day. It is also hoped that you will benefit from the process of articulating your experience and that your subsequent discussions about this topic will be stimulating. Overall the experience of participating in this project is designed to be an affirmative and informative experience in itself.

What you will be asked to do in the research:

As a participant, you will be asked to volunteer your time to this study. Time spent on the project must be outside working time, as you will not be paid from any source for participating.

- You will sign an informed consent form.
- You will answer a question in writing that I will send to you by email. (You will not need to be concerned with writing style, punctuation, grammar etc.). You will also be given guidelines for maintaining confidentiality of others who might be represented in your writing.

- You will elaborate if asked, on particular sections of what you have written.
- This process may be repeated with up to a total of eight questions over a one to two month period and may take up to twenty hours.
- You will review what I have written, to make sure that you feel comfortable with the content, that confidentiality has been protected, and that your thoughts have been expressed completely and correctly. You will provide feedback, and give your verbal consent that you wish to continue and to have your material included.

Data Collection:

The data for this study will be the material that you send me in answer to my questions, together with my responses to the same questions, and my personal process journal that will accompany a piece of art work that I am painting. Your individual responses will be presented anonymously in the final research paper. Confidentiality will be provided to the fullest possible extent.

Risks and Discomforts:

There are a number of risks to participating in this research that you would otherwise not experience in your regular role as a PCCT counsellor. Although the study is considered to have minimal risks to the participants because the research activity is made up of activities that are akin to daily practices of counsellors, such as debriefing visits, and reflection upon and discussion about one's own experience. It is possible that you could feel fatigued by the extra effort of writing. To counteract the potential for fatigue, I will be flexible with due dates and allow you to set your own pace.

Another potential harm is that you might in some way feel uncomfortable about an aspect of your practice, or about your writing. I want to assure you that you are in control of what I see. You can review your writing before sending it to me and delete any content that you don't want to share. The purpose of your writing is to understand your experience, not to evaluate the writing itself or your practice.

Researcher's relationship with participants:

I am both your colleague and a co-participant in this study, which may make it easier to discuss sensitive material, and add to a sense of trust and confidence. It might also mean that more is at stake, should for any reason, the research not be experienced in a positive and affirming way. I assure you that should you not wish to participate, or withdraw from the study, for any reason, it will not be held against you, or influence our working relationship. To prevent any feelings that either of us carry that might affect our working relationship, we can turn to ... [our Manager] or ... [our staff counsellor] as a resource. I am fully committed to keeping good relationships with my colleagues.

Benefits of the research and benefits to you:

By participating in this research it is my hope that you will find the process itself to be enlightening and enriching through self-reflection, identifying themes, and discussions with co-participants. In a pilot study that I did using themes from my journal writing as the basis for stories, I found that there was satisfaction in sharing these stories with my colleagues, and that my experience was affirmed in the stories that my colleagues felt inspired to tell, after hearing my experience. I am hoping that you will have a similar experience. You will also be potentially helping others on a larger scale in that this study will be shared with academia and professionals who work, train or support, those that face death on a daily basis. Our exploration may also attune you to possible responses to encountering mortality and this knowledge may be applied in your role as a counsellor when supporting colleagues and patients and families, who share the necessity of encountering mortality.

Voluntary participation:

Your participation in this research is completely voluntary and you may choose to stop participating at any time. Deciding not to participate, or withdrawing your consent at any time will not influence your relationship or the nature of your relationship with me, or with staff from Hospice, or the University of Victoria, either now or in the future.

Withdrawal from the study:

You may stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating or to decline answering particular questions, will not affect your relationship with me, the University of Victoria, or anyone within [Meadowview] or ... [Meadowview's governing body]. In the event that you withdraw from the study, you will be consulted about whether you want all or part of the data that has been collected thus far to be included or destroyed. If at any time you wish to withdraw from the study contact the researcher at susan@thebreiddals.com.

Dissemination of results:

I intend to disseminate results in the form of a PhD dissertation. Additionally, I intend to publish results in academic journals and at academic and professional development conferences and workshops, and I may decide to rewrite my dissertation as a book, immediately following graduation. The results, as synthesized in the dissertation, will be made available to participants.

Confidentiality:

In signing this form you agree to keep the identity of the people you interact with confidential. You are also agreeing to abide by professional standards that protect the identity of patients and families, and to guard the identities of colleagues. Your participation will not be reported to ... [Meadowview] or ... [their governing body].

If you choose to discuss your contributions with other colleagues then it might be possible for them to identify those comments in the final written version of the research. Nonetheless, every effort will be made to protect the identity of participants in this study.

Questions about the research:

If, as a research participant, you have questions about the research in general, or in your role in the study, please contact me at susan@thebreiddals.com or contact either of my co-supervisors at the University of Victoria: Dr. David Blades: dblades@uvic.ca or Dr. Daniel Scott: dscott@uvic.ca.

This research has been reviewed by Management of Hospice and by the University of Victoria Human Research Ethics Office (250-472-4545, ethics@uvic.ca) and conforms to the Canadian Tri-Council Research Ethics guidelines.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity have your questions answered by the researcher.

Name of Participant

Signature

Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix C: Email to the Co-researchers

Hi and welcome to the study.

I am exploring the lived experience of encountering mortality, on a daily basis, in a palliative care setting. I have chosen to use the word mortality rather than word death because the word mortality includes both the process of the body shutting down, the knowledge that death is inevitable, and the grief that results from death. Ethics has brought to my attention that work email is more secure than other servers. For this reason you can use your work email to mail me confidential material. If I mail you anything confidential I will use your work address—which can be accessed from home. Please let me know if you would like me to alert you that there is mail, by sending you an email at home.

Here is the first question:

Please share a story or two about your encounters with mortality in your work as a Palliative Care Counsellor. Write as much or as little as you like. I want to assure you that I am in no way judging your writing or how you express yourself. Neither am I evaluating the content. I am simply interested in how you experience encounters with mortality. Also, for this story and all other entries, please use non-identifying information, such as the nurse, the doctor, the family member; the home (rather than apartment, condo, etc.); the disease process, (rather than for example, cancer of the stomach). In this way we can reduce the possibility that any staff, patient, or family member will be identified.

Thank you so much,

Susan Breiddal

Appendix D: Questions for the Co-researchers

First Round: Summary of THEMES and further questions for Round 2

SET ONE

1. **Intense emotions of self, colleagues, patients and families**

- What happens within you when yours or other's emotions are intense?
- Has your experience of intensity changed you in some way? If so how?

2. **Not/Connecting**

It could be said that counsellors are supposed to connect with people.

- What does this term mean, and how do you do it?
- What is it like for you when you connect or do not connect with someone?

3. **Identification**

- What is happening inside of you when you closely identify with a patient or family member? What is the impact on you and your experience?

4. **Human frailty**

You are often called upon to image or anticipate what will happen, in relation to death.

- What has it been like for you to learn about the physical realities of dying?

SET TWO

5. **Imagination and memory**

- What is the role of imagination and memory in encounters with mortality?
- How do you use your imagination and memories?
- What is the impact or consequence of carrying images and memories?

6. **Unexpected elements of encounters--knowing and not knowing how to proceed, what is or will happen**

There seems to be unexpected elements in encounters with mortality, such as surprises in how you and patients, families and colleagues respond, or surprises in how events unfold, and a sense of being unsure, or being knocked off balance, or out of one's comfort zone.

- What is it like for you when you are unsure or uncertain?

7. Feeling helpless

- Share what it is like to feel helplessness in the face of mortality?

8. Sacrifice

- What role does sacrifice play in encountering mortality?
- Have you learned anything about sacrifice from working in palliative care?
- Under what circumstances do you make sacrifices?

SET THREE

9. Intimacy

Here are some of the meanings of intimacy:

Close: having, involving, or resulting from a close personal relationship

Cozy: quiet and private or secluded, enabling people to feel relaxed with each other.

Private and personal: so private and personal as to be kept secret or discussed only with a close friend or relative

Sexual: involving or having a sexual relationship

Closely connected: very close because of the influence of one thing on another; involving the innermost nature of something

- Please share what it is like for you to be witness to and be part of intimacy.
- How does intimacy in your personal life relate to intimacy in your work life?

10. Being special

Sometimes we are viewed as special people because we work with the dying, usually we deny it without too much thought. Sometimes we find people in the course of our work day that seem special to us.

- Explore the idea or the perception that people are special.

11. Active/passive responses

- Explore the significance of silence, no action or stillness in encountering mortality.
- What is happening in moments of no action or silence?
- What does it require of you to not act or be silent?
- What is it like for you to respond to mortality by taking no action or by being silent?

12. Mundane/transformative aspects of encountering mortality

It seems that we tend to focus on the positive or transformative aspects of providing palliative care.

- If we were to focus more on tedium and weariness in encountering mortality what would happen?
- Have you learned something, or is there something to be learned through the boredom and weariness of encountering mortality?

SET FOUR

13. The sense of change over time for self, colleagues, patients and families

We talk a lot about “things changing.”

- What have you learned about change as you have encountered mortality?
- How do you meet change?
- What has changed within you or for you?

14. Calling

- What drew you to palliative care?
- What meaning do you make of your presence or interactions with those that you serve?
- Have you gotten what you came for?

15. Challenging what we know and can know

- What can we know about death and dying?
- Is there anything that you think you know about death and dying?
- Is there anything that you think you know about life or living?

16. Time-being in the past, present, future

- What role does time play in encounters with mortality?
- Have you ever been aware of the present moment containing the past and the future? If so what are your thoughts about that?

17. Overlap

- What is it like for you when work overlaps your personal life or your personal life overlaps your work?

Appendix E: Dialogues of the Portals



Portal 1

Description

A woman stands with her arms out, holding a black snake in each hand. Her hair is a mass that stands on end. She wears an orange gown. Behind her is a vague sketch of the world.

Dialogue

Who are you, *Woman*, and why are you here?

I am the great protectress but I am also a temptress. The snakes represent two possibilities. You have a choice to make and it is up to you. The snake can protect you or bite you. I can protect you or lead you astray. In order to choose to be protected you must be conscious, otherwise you will choose the same way that you have in the past, rushing on and getting distracted from your mission, which is to be kind. You are impulsive and that is because you have lost touch with something essential within yourself. It's your choice, choose wisely.

Thank you.

Snakes, why are you here?

We are here to remind you that you are loved whichever way you choose.

How can that be if you poison me?

The poison is to stop you from going too far down the wrong road. It is actually protective, but a warning. You are still loved, even if you choose poorly.

Thank you.



Portal 2

Description

Two figures approach a skeleton. The first figure is hooded in an orange robe and carries a flame. The figure's face is obscured by a mask that is striped in the contours of a face. The second figure is behind. He is also in a hooded orange robe and has the same kind of mask. He looks down, as does the first figure. The skeleton sits cross-legged with an orange pot, arms crossed.

Dialogues

Woman, who are you and why are you here?

I come to shine the light. Inside everyone there is a skeleton and an empty pot. The animating force is the spirit, the structure is the bones. Fill your pot with spirit. Be present in

everything you do. It will go better that way. The bones and the pot provide structure but you must come present in order to flesh out, to contribute to the world. Acting from an empty pot will, of course, be empty. Think about this.

Man, why are you here?

I travel with the enlightener. We are kindly spirits who want the best for you. We are guiding you and helping you. We serve to remind you when you go astray. The bones and the pot are materialistic and they will fade away but your spirit will not. Whatever you have done with spirit will remain a reverberation of your life. Remember to give freely of your spirit, it is an unending source and every time you share it, you strengthen your connection to the flow.

Skeleton, what do you have to say?

I sit here folded up waiting to be directed. My pot is empty and so am I. I am content. I just am.

Pot?

I too am content to sit here and wait to be filled. We sit. We wait. Be like the pot, empty, waiting, receptive, willing.

Skeleton?

Yes. Be willing to act. Wait for the spirit to fill you, however, before acting otherwise you are just an empty bag of bones banging around without purpose.



Portal 3

Description

Four figures gather around a round-shaped object. The main figure is in an orange hooded robe, the other three are in brown and orange hooded robes. There are mountains in the background and the largest figure sits on a rock throne or chair.

Dialogues

Main figure, who are you and what do you have to say?

This is you, with your students. Your mission is before you. Your mission is to heal yourself through helping others. You help them through being kind, through your relationship with them. This has to do with your intention to be helpful. They are helped by being cared for. Caring for them means that they are honoured, listened to, respected in the sense that their needs are amplified—you can help them to do this—and then respond to their needs, let their needs guide you.

Figures, who are you?

We are your students. We come because you love us and we need love so that we can grow. We are part of the mission, the intention to heal. We come to heal you. By being willing

to voice our needs, with your encouragement, we feel nurtured, we want to relate to you. Our love will heal you.

Thank you. I am afraid that I will not be able to do this. I am in need of healing, I want to love, I want to be loved.

Be humble, have humility, learn from those whom you serve, remember that they are the teachers and YOU are the student. You can bring what you know but the learning begins when they respond, engage, and put their brain and their heart to what you have brought. It is what they bring that is important.



Portal 4

Description

A man with a hat on puts his arms out to a woman. The man's eyes are closed and there is a tear on his cheek. The woman reaches out to him but there is some distance still.

Dialogues:

Man, who are you and why are you here?

I long for your embrace. I love you truly, dearly, and deeply. I yearn for you, for you have been gone so long. I cry because I have missed you. Your refusal to engage has caused me sorrow and is very painful.

Woman: I am here now. I am sorry that I have hurt you. I feel wary, but I am here.

Man: It makes me so sad that you are wary.

Woman: I am wary because I don't completely trust you not to want to take over and be right/eous. You are very willful and not caring of me in that state. I want to trust you and be close.

Man: I am so sorry for being willful. I see how I have driven you away.

Woman: How can we live together in peace, love, and harmony? That is what I want. I think that we are better together than apart. I need your strength.

Man: Yes, it is too lonely without you. I need your gentleness.

Couple, what do you have to tell me? Why are you here?

We want to show you that you must bring us together. We belong together. We are part of the whole of you. Do not allow us to separate, each one is not functional without the other for many different reasons. Alone we wreak havoc, we may temper each other but our TEMPER is dangerous and ugly when separate. Together we make a whole, we are in holy matrimony, united. Together we make LOVE.

Thank you, I understand.