# **ESSAY/PERSONAL REFELECTIONS**

# Midwifing distress at end of life: Missed opportunities?

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#### INTRODUCTION

Birth and death are rites of passage, and preparation is important (Richards, 2007). Palliative care clinicians describe end of life as a meaningful stage of life filled with opportunity and mystery. However, in palliative care, we have a tendency to overlook dying as a means of spiritual awakening, and there is little understanding, and little or no demand, among palliative care patients, or in the broader culture, to learn the skills of dying.

Many suggest that we have become good at managing death by managing symptoms (Bradshaw, 1996; Halifax, 2009). Real care has been replaced by the application of palliative care techniques to manage the unpleasantness of death (Bradshaw, 1996). Although we acknowledge the spiritual dimension of the individual as important in palliative care, and the fact of existential suffering is well established in the literature, it is rarely the focus of care planning (Boston et al., 2011). We have become good at what Kearny describes as "surface work" (Kearney & Mount, 2000), i.e. alleviating physical discomfort, but we also need to consider depth work, interventions that might bring someone an experience of the soul.

Stories are a fundamental dimension of human experience (Smith & Liehr, 2005) and are a powerful vehicle for communication (Davidhizar & Lonser, 2003). Remen (2008) suggests that the world of meaning is made up of stories; stories help us understand our world, ourselves, and others (Schmidt-Bunkers, 2006), and share important values with others (Yoder-Wise & Kowalski, 2003). In this article I will explore existential suffering and how we pre-

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pare people for the end of life through the telling of a story.

I had the opportunity of being with my mother in her existential distress, and the opportunity to actively be her midwife, to help her make the transition out of her body. The observer may have perceived her death as bad and undignified. However, it was transformative for all present, including my mother. This experience raised questions that took me into the realm of awe, wonder, and "don't know." It is this experience and this realm that I explore in this article, to continue this dialogue and to contribute to what anthropologists call a "thick description" of a phenomenon.

# PREPARING FOR BIRTH AND DEATH

There is much "don't know" around the more significant things in life, including birth and death. There has been an ongoing dialogue in the literature grappling with existential and spiritual suffering at the end of life and questioning if we are doing enough with our focus on managing or controlling symptoms (Cohen et al., 1996; Fahnestock, 1999; Ohlen et al., 2002; Terry & Olson, 2004; Breitbart, 2006; Mako et al., 2006; Jenkinson, 2007; Mount et al., 2007; Balducci, 2011; Boston et al., 2011; Hui et al., 2011; Krikorian et al., 2011). This dialogue has been increasing recently. There are a range of ways that women prepare for childbirth and are coached throughout the pregnancy and the birth by healthcare professionals, midwives, and doulas. There are ranges of ways and places they give birth; in a hospital attached to a monitor, in the operating room with sedation, at home, in bathtubs, lying in bed, squatting, among others. Some women and their partners are more actively involved and some women even report transcendence in the birthing process (Lahood, 2007). Generally, however, women undergo some

preparation for the birth. Are we equally prepared for dying? Many in our western society (Levine, 1982; Byock, 2002; Mount, 2003; Jenkinson, 2007; Halifax, 2009) would suggest that we are not.

The ability for death to foster meaning in life has been attested to by wisdom traditions and palliative care professionals. Also, gerontology theory identifies that finding purpose and meaning in life is a significant developmental task of the older adult (Thompson & Chochinov, 2010). Sinclair's (2011) ethnographic study with experienced palliative care leaders and experienced palliative care clinicians found that the participants consistently described end of life as a meaningful stage of life. Personally, their work also had significant impact on how they lived their own lives. Their work at end of life positively transformed the way they lived, helped them live in the present, helped them move from their head to their heart, opened up a world of mystery, expanded their capacity to face fears, enhanced their spirituality, and helped them to practice dying. Working in end-of-life care can be transformative for the practitioner. However, Westerners typically avoid questions that search for some meaning in death (Levine, 1982; Byock, 2002; Jenkinson, 2007; Halifax, 2009). However, as the participants in Sinclair's (2007) study identified, death can serve as a stimulus for personal growth. It also prompted them to practice dying, to prepare for their own death. If this is true for those who work in palliative care, could it be helpful to our patients also?

#### **EXISTENTIAL SUFFERING**

There is a substantial body of literature that looks at spiritual and existential suffering, attempting to define and distinguish the terms from one another. Existential pain is mostly used as a metaphor for suffering (Strang et al., 2004) and is often taken to mean spirituality (Strasser et al., 2005). Byock (2002) suggests it is imperative for those who care for the dying to understand something about spiritual and existential experience as they relate to life's end, as we often deal with spiritual and existential suffering. Existential suffering is one of the most debilitating conditions that can occur at end of life. Hui and colleagues (2011) found that nearly half of the patients admitted to the palliative care unit had spiritual distress. Terry and Olson (2004) found that even when pain was declared as the cause of suffering, there was no clear relation to pain scores. Most palliative care is directed at the obvious wounds, the physical symptoms; however, we may not be able to adequately treat the pain without treating the wounds that are not obvious; the suffering. Although this is not new to those working in palliative care, we do need to remember to consider the whole person because, as Mount and colleagues (2007) identify, suffering is experienced by whole persons, not bodies. Existential well-being is also considered an important determinant of quality of life (Cohen et al., 1996). However, Blinderman and Cherney (2005) found that whereas existential concerns are endemic in patients with advanced cancer, interviewed patients identified that significant distress is less common. If existential concerns are endemic, what are we doing about this with our patients in palliative care? How are we preparing the people we care for, for dying?

# THE STORY

My mom died April 13, 2011 at 11:15 in the morning; she was 80 years old. She had emphysema and rheumatoid arthritis and had gradually been deteriorating over the last few years. She was feisty, strong willed, and independent. She refused to discuss death or think about funeral or end-of-life plans, although we attempted many times to have these discussions with her. After a number of admissions to hospital over the previous 2 years, she reluctantly presented to the emergency room (ER) on a Saturday morning with difficulty breathing. She took the time before going to the ER to put on her eyebrows and lipstick and was fussing with her hair to be ready when the doctor came in to see her. Test results showed pneumonia, O<sub>2</sub> saturation 50, lungs completely destroyed by emphysema, likely fluid on the lungs, and congestive heart failure. She needed to go on a BiPAP machine overnight to help her breathe; then had oxygen running at 18 with a rebreathe mask.

It was agreed that a trial of antibiotics was reasonable to attempt to treat her pneumonia. Mom was very agitated Sunday, not wanting to keep her oxygen mask on, and trying to get out of bed. Monday she was still having trouble breathing despite the oxygen and morphine; tests showed that the antibiotics were not working. The decision was made to stop the antibiotics and other medications and to continue morphine for pain and dyspnea.

My mom was still very alert and agitated about her breathing, pulling the mask off, wanting to leave the hospital. I told her the news about her pneumonia and that she might not pull out of it this time. She was surprised and did not believe that this could be true, and spent the next 2 days extremely agitated, yelling, insisting that she didn't want to die; saying "I'm not going to die." She was given a dose of Ativan on Monday to help her quiet. We asked for a spiritual care consultation, and the chaplain came by late on Monday afternoon. My mother was able to talk and pray with Adam, still insisting she was not going to

die; it seemed to provide some quiet for a short time after his visit.

Tuesday morning mom had not eaten for several days (her appetite had been poor prior to her admission), but she was still drinking water. She was very angry Tuesday morning, yelling she didn't want to die, questioning "why am I dying?" over and over again. She was desperate to take in water, saying "give me water." Adam came in late in the morning to talk and pray, and she was calmer after his visit.

Mom had a nap, and when she woke up she looked at me and said, with some irony and humor, "so, why am I still here, I thought you said I was going to die?" She was still angry and not wanting to die; her anguish was palpable. She continued to sleep and wake up, quite able to interact.

A priest we had met previously through a family friend came to talk and pray with mom late on Tuesday afternoon. Diane asked my mom if we had all had individual time with her to say any last things we wanted to say; we hadn't, so we took the opportunity to do it then. Mom was less agitated and managed to sleep through the night.

On Wednesday morning around 8:30 I noticed a shift, and knew she was actively dying. Mom was still angry and afraid to die. She had such a will to live, and have another minute. Her urgency to have water, saying "give me water," continued. I asked her if she thought the water would keep her alive. She said "yes," and asked how long it could keep her alive. I told her it wouldn't, that she was dying soon. On Monday I had done a relaxation with her to help her agitation and help her focus on love in her heart. I found myself starting this again and for the next 2.5 hours or so I was given the gift of being her midwife.

Mom wouldn't keep her gown, on and her round ball of a tummy (from a hernia and constipation) was uncovered. She looked as if she were pregnant and positioned for birth. The head of the bed was upright; she hiked her legs up into the lithotomy position and stayed in this position all morning. I found myself talking out loud and silently with her, inviting her to move within, to feel love, that it was okay. She had lots of anger, still asking for water. What I realized in that moment was it wasn't all about her fear of dying; she loved living and wanted so much to be alive. I asked her to feel her heart, to feel the love. I asked her if she could feel it, and she nodded sadly that she couldn't. So I tried different approaches to help her find her way to connect within, and to find a center from which to leave her body.

I found myself standing and cradling her feet, doing Reiki and just feeling her presence, urging her gently to let go. I found myself repeating "Yea though I walk through the valley of the shadow of death I will

fear no evil, thy rod and thy staff they comfort me," as Adam and Diane had done the day before. I reminded mom that she wasn't the body, that it had served her well.

Then she spoke loudly and was angrily telling Evelyn not to pull her. Evelyn was her older sister and my mom had been very close to her. Evelyn had died many years ago. With Evelyn trying to help her out of her body from the other side, I started working with that and gently, very gently, pressed through her feet, gently rocking, making wavelike movements, working with her breath. We continued to work gently in this way, mom continuing to respond and be alert, her eyes usually closed. With her last breath her face became distorted, her eyes squeezed shut, her mouth open in an O shape. A cry of agony escaped her lips, a tear fell from the outer corner of each eye, and she was gone.

She was amazing. All morning she had been looking death squarely in the face, not wanting to die, as she loved life so much, and also afraid of dying, holding space for both. It was one of the most amazing experiences of my life. Such an auspicious death, what a gift she gave all of us in the room. What a gift she gave me to help her leave, to give birth to her self.

There are stories similar to this told elsewhere. Levine (1982, p. 175) reports this story: "The groans were labour pains, only she was giving birth to her soul out of her mouth, letting it fly free from her body; and the death agony – labour pains. I couldn't see how it was because I wanted her to be out of what appeared to be a struggle".

Tolstoy tells a similar story in *The Death of Ivan Illych* (Tolstoy, 1960). Papadimos and Stawicki (2011) suggest that Ivan's story offers a blueprint for modern dying, and illustrates in a number of ways the modern death. They identify that patients in Ivan's day did not know they were dying, and that today patients do not know they are dying, because there is still this dance between patients and physicians, which Lovell (2012) calls the "dance of denial." Prognostication was difficult in Ivan's day and still remains difficult. People still experience pain and despair just as Ivan did. In time Ivan came to resolution and acceptance, but it was a difficult, distressing, and lonely journey.

And there is also a story told by one of the participants in a study by Boston and Mount (2006, p. 19):

My friend was struggling with...death, to a point where she even sat up in her bed – and went like this with her fists (gestures with fists) – like, "I don't want to die, Go! Like, leave me here!" Anger! – a lot of anger – and I didn't know what to do. But her suffering was enormous...her inner suffering, her existential suffering was horrible...It

was a very bad death...and I felt helpless because I felt I should know better after all my experience. I've assisted so many people dying, you know. I've been able to really just be with them, and soothe them, and feel that I made a difference!

There are two interesting comments I will follow up on from these stories; it was a very bad death, and I was able to soothe them.

# THE BAD DEATH

A good death is often associated with awareness, acceptance, and preparation for death, a peaceful, dignified dying (Green, 2008; Floriani & Schramm, 2010), and pain and symptoms are managed. Bad deaths are often associated with lack of acceptance of death, failure to pursue living until final stages (Green, 2008), and pain and symptoms that are not managed. However, death for most people is messy, painful, and full of contradictions and fear (Green, 2008). The concept of a good death is not value free (Masson, 2002) and can put unbearable pressure on the dying and on the healthcare professional, give rise to subtle or direct coerciveness and the tendency to manage death, and take us away from the mystery and richness of not knowing (Halifax, 2009). Masson found that the notion of what is good about death and dying is not clear cut, and suggested that the term "good death" is too limited and absolutist to capture this complex understanding. Perhaps, there is no good or bad death. Halifax reminds us that being with dying is simply being with dying; people die in their own way. It is suggested that we need to give up the notion of a good death or that we have any idea what it looks like (Levine, 1982; Halifax, 2009). These experiences are a normal part of dying, yet often get managed as problems (Halifax, 2009).

# TO SOOTHE THEM

Nurses describe mental suffering as being confusing and awkward, and are bewildered working within chaos and uncertainty (Graham et al., 2005). However, existential and spiritual suffering can bring increasing maturity and deepening spiritual experience (Sinclair, 2011). I wonder about the effect soothing would have had on the person in the Boston and Mount story or on my mother? Would soothing or managing their experience as a problem or symptom have robbed them of the opportunity of expressing the deep sadness or anguish and giving voice to their deep suffering? Existential concerns will not be paramount, conscious, or open for discussion with everyone, patient or clinician (Bruce et al., 2011); however, these concerns are part of the terrain of sickness and death; we need to attune to patients who do wish to engage with these concerns. Whose discomfort is the soothing for?

#### STAYING WITH THE DISSONANCE

Makowski and Epstein (2012) use Kandinsky's painting, Composition 8, to illustrate the spaces of cognitive, emotional, and spiritual dissonance that we often find ourselves in in our day to day work. The "clashing discords" (Makowski & Epstein, 2012, p. 293) illustrated in the painting and resultant loss of equilibrium are identified as our harmony. They suggest that we need to be prepared for discord as much as we want or seek acceptance, comfort, and harmony. Our patient's story, especially when that patient is suffering and in distress, invites us into dissonance. If we are able to do this, Makowski and Epstein suggest that dissonance can teach us that there is potential for resolution if we are willing to stay, that we may discover a sense of wonder about the rich complexity of the human experience, and we may develop mental stability and courage. Other terms that are used to describe this dissonance include "groundlessness" (Chodron, 2001; Olshansky, 2005; Bournes & Naef, 2010; Bruce et al., 2011); "trajective courage" (Sasser & Puchalski, 2010); "don't know" (Levine, 1982); "the existential moment" (Mount, 2003); and "engaging the abyss" (Mitchell & Bunkers, 2003). Moving into dissonance involves learning to let go and live with ambiguity, moving into the discomfort and working with the instability, stopping the search for stability and grounding, being curious and okay with "don't know," and choosing to stay present with the unfolding story. The locus of healing is in the space, what Desmond terms "the Between," that is created by connection, not in the patient or the clinician (Scott et al., 2008, p. 320).

This is not easy. We need to discover courage and curiosity in order to be in the discord. The literature and wisdom traditions identify some of the ways that this can be done. A meditation practice helps develop the ability to pay attention, to be present when situations are uncomfortable; it trains the practitioner to explore uncomfortable moments with curiosity and silence (Boerstler, 1986). We learn to know ourselves. As Makowski and Epstein (2012, p. 296) phrase it: "Our minds and bodies learn how to stay, how to stretch, and how to lean into the experience and explore it instead of moving onto another task."

Art, literature, and music can build an ability to stay present in moments of tension. We build this capacity by staying through to the resolution of dissonance in a piece of music or staying with the narrative in a good story as it builds to its climax and resolution (Makowski & Epstein, 2012).

Mount (2003) suggests that healing has to do with slowing down, coming into the present, listening, accepting, forgiving, and entering into community with. This slowing down gives the clinician a moment to pause, to move from the head to the heart, to quiet, which can create a possibility that we actually see who is in front of us.

Makowski and Epstein (2012) suggest that by developing our steady presence through meditation or the arts, we create the space for a quiet transformation to occur in our work with dying individuals and their families. This practice is not merely a cognitive or behavioral act. It is an artistic mastery that demands patience, attention, and curiosity. They call this practicing beauty. By practicing beauty we can grow into experienced, compassionate, and effective clinicians.

# SO WHAT CAN WE DO FOR EXISTENTIAL SUFFERING?

An integrative literature review by Henoch and Danielson (2009) found no studies that described interventions for existential concerns that could easily be implemented in everyday healthcare practice. The interventions rest, in many ways, on the spiritual and death work we, as clinicians, do for our selves. However, there are interventions suggested and practiced that can help: medical interventions, psychotherapeutic interventions, assessment of suffering, whole person care, preparing for death, and developing the capacity to be present with suffering.

#### **Medical Interventions**

Lundstrom and colleagues (2009) looked at the existential impact of using corticosteroid treatment for symptom control in advanced metastatic cancer. They suggested that talking with patients about their expectations and experiences of corticosteroid treatment can have profound existential consequences in end-of-life care. They suggested that symptom relief produces existential consequences that have been underestimated in the palliative care literature. For example, do we prescribe corticosteroids to primarily increase appetite and strength, or do we prescribe them to increase hope?

There is much in the literature about palliative sedation as an intervention for intractable suffering. The literature suggests that palliative sedation for existential suffering remains an uneasy practice (Bruce & Boston, 2011). Clinicians are less comfortable with palliative sedation for existential and spiritual distress than they are with using it for physical symptoms such as pain and dyspnea (Blondeau et al., 2005). In an editorial, George (2009)

asked if palliative sedation mitigated suffering or if it only ensures that it is not witnessed or authenticated. I do know that if I had not been present for my mother she would have been sedated; we had discussed this with the physician 2 days prior to her death as likely being needed. I wonder about the lost opportunity for transformation and growth that would have been missed for her and for all of us present.

# **Psychotherapeutic Interventions**

Psychotherapeutic interventions appear to be the most prevalent interventions discussed in the literature. LeMay and Wilson (2008) reviewed the evidence supporting eight manualized interventions that indicated that they addressed existential themes. All interventions emphasized the importance of the therapeutic relationship, and of clinicians doing their own spiritual work. Breitbart and colleagues (2004) described meaning-centered group therapy as a modality that successfully integrates themes of meaning and spirituality into end-of-life care. Gehart and McCollum (2007) challenged our culture's belief that suffering is the result of psychological or emotional failure of some sort. They suggested that therapists engage suffering and describe a therapy approach based on mindfulness. Chochinov and colleagues (2011) have been doing pioneering work with dignity therapy, an intervention to address psychosocial and existential distress. Patients are invited to discuss issues that matter, issues that they would most want remembered. The taped sessions are edited with a returned version that the patient can bequeath. They found that dignity therapy was significantly better than client-centered care in improving spiritual well-being, and was significantly better than standard palliative care in lessening sadness or depression.

# **Assessment of Suffering**

Discussion of spiritual issues is an advanced communication skill (Ford et al., 2012). However, this skill can be learned. We need to be including existential and spiritual distress in our assessment of patients, scheduling a few extra minutes allows time to screen for this distress (Lehto, 2012). Strasser and colleagues (2005) emphasize that the screening process for existential and spiritual distress relies on the experience clinicians have in doing their own personal work, dealing with their own unfinished business. To assess existential meaning, Lyon and Younger (2005) have developed the Existential Meaning Scale based on Frankl's works and that of other related existential philosophers. In 1996, Cohen and colleagues published the McGill Quality of

Life Questionnaire to correct what they believed to be a flaw in other quality-of-life instruments, the neglect of the existential domain. In this assessment, we need to determine what suffering means to a particular person. In their analysis of the everyday discourse of suffering, Schwartz & Lutfiyya (2012) found a complete disengagement between everyday discourse and the palliative literature. They suggested we can re-envision suffering by moving away from the assumption that people suffer without hope and with indignity.

Mundle (2011) identifies spirituality as an untapped strength in patients, and suggests that we ask patients what spiritual strengths they draw upon to address their spiritual needs/distresses. This helps the clinician work with the patient to discern deeper meanings of the patient's "spiritual strength story."

# **Whole Person Care**

Whole person care demands that we look at existential suffering. We know that suffering is experienced by whole persons, not bodies. Whole persons include our shadow side, all that is dark in us, too (Younger, 1995). We can no longer make the medical distinction between mind and body; they are not separable (Cassell & Rich, 2010). Ohlen and colleagues (2002) looked at how suffering is experienced through the body. The participants' narratives revealed a complex body-soul-spirit experience, which supports the suggestion that we replace our focus on symptoms with a focus on the suffering person. Terry and Olson (2004) found that patients' identified sufferings were not closely related to their reasons for admission. Even when pain was declared as the cause of suffering, there was no clear relation to pain scores; some of these patients scored their pain in the lowest category. Interestingly, Strasser and colleagues (2005) found that patients could learn to differentiate physical pain and existential pain sensations in their body.

Boston and Mount (2006) suggest that creating openings to dialogue at the intimate level of spiritual and existential concerns is at the heart of the caregivers' art, and is the key to effective whole person care. Although we have professionals on our palliative care teams who provide spiritual and psychosocial care, we have a long way to go to fully and consistently integrate what they do into our plan of care. Otis-Green and colleagues (2012) report on nine demonstration projects to integrate spiritual care within palliative care in hospitals in California. These projects were developed to meet the desire, expressed in the literature, by patients to have spirituality included in their care.

# **Preparing for Death**

We have become quite competent at what Kearny (Boston et al., 2011) calls surface work, interventions aimed at doing; alleviating pain and discomfort. However, given that existential and spiritual suffering can be, and often are, embodied, we may actually manage physical symptoms more effectively by addressing existential suffering (Terry & Olson, 2004). We are not as good at doing what Kearny describes as "depth work," interventions that might bring an individual into an experience of the soul. Although this work is being done by people such as Joan Halifax, Rachel Remen, Stephen Levine, Richard Boerstler, Ram Dass, and Stephen Jenkinson, among others, this work primarily occurs outside of or on the fringes of the healthcare system. Dying, letting go of one's life, is no small task (Lavoie et al., 2008). Levine (1982) suggests that there is no other preparation for death except opening to the present; if you are here now, you'll be there then. How are you preparing for your own death, doing what Sinclair (2011) found participants in his study did, living in the present while practicing dying?

# Developing the Capacity to be Present with Suffering

Although there is some good work happening to introduce these concepts to students (Remen et al., 2008; Halifax, 2009), developing the capacity to be present with suffering is not something that is taught in medical or nursing school, but we need to explore how we can intentionally do this (Cassell, 1999). We need to find our own ways to investigate our minds and hearts, there are many ways to do this. We need to get in touch with our deeper selves and our own spiritual beliefs (Melo & Oliver, 2011). We need to find practices that develop our stamina in remaining present with our own suffering, so that we can be present with others in their suffering. We build this stamina day by day; our lives present many opportunities each day to suffer. We need to be vulnerable (Boston et al., 2001), curious (Fitzgerald, 1999; Dyche & Epstein, 2011), openhearted (Galvin & Todres, 2009; Melin-Johansson et al., 2012), and compassionate (Sasser & Puchalski, 2010; Halifax, 2011). We cannot eliminate uncertainty (Connelly, 2009). We need to be okay in that place of groundlessness and dissonance, not scrambling to find solid ground, to resolve the dissonance prematurely. We need to be conscious of those moments of choice to engage or to not engage the abyss (Mitchell & Bunkers, 2003), that fleeting moment when we become aware that we have the opportunity for an intense connecting with another or to dis-engage. Perhaps the greatest regret is when we do not cross the abyss, when we are left with the "what ifs" (Mitchell & Bunkers). As Mount (2003) suggests, we can ignore what he calls "the existential moment" or "leap into the void." This means being fully present without expectations of outcome. He suggests that this entails a paradigm shift, a jarring visceral reframing of reality.

It is a challenge to do transcendent work in a death-phobic and grief-illiterate culture (Jenkinson, 2007). Jenkinson suggests that we need to give patients and families strategies of wonder as another option to death phobia and the managed death. Our job then is to teach people how to die or how to live as if what is happening is actually happening. Sinclair and colleagues (2006) warn that there is a risk in this of creating just another tool, stripped of its mystery by empiricism that we administer to the dying patient. Levine (1982) warns that one of the worst abuses we can inflict on others is to make them feel they need us to discover their true natures. We cannot make our suffering go away (Halifax, 2009), we cannot manage suffering (Jenkinson). What we do is find a voice for our suffering (Younger, 1995). We find a way to speak, what Miller (1992) calls the "inarticulate tongue of anguish." We can attune to patients who do wish to engage in these concerns (Bruce et al., 2011), let go of the known, abandon our fixed ideas of outcome, acknowledge our fear and anxiety, as these are not easy places to go, and create space for the work of healing to occur.

# **CONCLUSION**

Roy (2011) questions whether we are promising more than we can deliver in trying to work with a patient's spiritual suffering. Perhaps we are, but if we in palliative care don't, who will? Younger (1995) suggests that we are midwives of rebirth. As compassionate people, we help others find their own language, broaden their perceptions to a wider spectrum of meaning and values, and care for the spirit to allow the struggle, pain, suffering, anger, despair, fear, loneliness, and joy to be articulated. We become a midwife to the expressions from the patient's soul. Therefore, I am interested in thinking about ways that we might be these midwives, to help prepare patients for dying; ways we can be present to, rather than manage, existential suffering; to go into the mystery with curiosity and wonder and, if needed, to actively coach people as they leave their bodies, to be present to any opportunity that might present itself at the end of life. Because, as Kubler-Ross (Webb, 1997, p. 290) reminds us: "If we can shift our angles at death...slightly alter and expand our view, we will better learn to see unimaginable mysteries that lie at the edges of life."

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# REFERENCES

- Balducci, L. (2011). Suffering and spirituality: Analysis of living experiences. *Journal of Pain and Symptom Management*, 42, 479–486.
- Blinderman, C.D. & Cherney, N.I. (2005). Existential issues do not necessarily result in existential suffering: Lessons from cancer patients in Israel. *Palliative Medicine*, 19, 371–380.
- Blondeau, D., Roy, L., Dumont, S., et al. (2005). Physicians' and pharmacists' attitudes toward the use of sedation at the end of life: Influence of prognosis and type of suffering. *Journal of Palliative Care*, 21, 238–245.
- Boerstler, R.W. (1986). Meditation and the dying process. Journal of Humanistic Psychology, 26, 104–124.
- Boston, P., Bruce, A. & Schreiber, R. (2011). Existential suffering in the palliative care setting: An integrated literature review. *Journal of Pain and Symptom Management*, 41, 604–618.
- Boston, P.H. & Mount, B.M. (2006). The caregiver's perspective on existential and spiritual distress in palliative care. *Journal of Pain and Symptom Management*, 21, 13–26.
- Boston, P., Towers, A. & Barnard, D. (2001). Embracing vulnerability: Risk and empathy in palliative care. *Journal of Palliative Care*, 17, 248–253.
- Bournes, D.A. & Naef, R. (2010). Human becoming practice around the globe: Exploring the art of living true presence. *Nursing Science Quarterly*, 19, 109–115.
- Bradshaw, A. (1996). The spiritual dimension of hospice: The secularization of an ideal. *Social Science & Medicine*, 43, 409–419.
- Breitbart, W. (2006). The goals of palliative care: Beyond symptom control. *Palliative and Supportive Care*, 4, 1–2
- Breitbart, W., Gibson, C., Poppito, S.R., et al. (2004). Psychotherapeutic interventions at the end of life: A focus on meaning and spirituality. *Canadian Journal of Psychiatry*, 49, 366–372.
- Bruce, A. & Boston, P. (2011). Relieving existential suffering through palliative sedation: Discussion of an uneasy practice. *Journal of Advanced Nursing*, 67, 2732–2740.
- Bruce, A., Schreiber, R., Petrovskaya, O., et al. (2011). Longing for ground in a groundless world: A qualitative inquiry of existential suffering. *BioMed Central Nursing*, 10, 2.
- Byock, I. (2002). The meaning and value of death. *Journal of Palliative Medicine*, 5, 279–288.
- Cassell, E.J. (1999). Diagnosing suffering: A perspective. Annals of Internal Medicine, 131, 531–534.
- Cassell, E.J. & Rich, B.A. (2010). Intractable end-of-life suffering and the ethics of palliative sedation. *Pain Medicine*, 11, 435–438.
- Chochinov, H.M., Kristjanson, L., Breitbart, W., et al. (2011). Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: A randomised controlled trial. *The Lancet*, *12*, 753–762.

Chodron, P. (2001). The Places that Scare You: A Guide to Fearlessness in Difficult Times. Boston: Shambala.

- Cohen, S.R., Mount, B.M. Tomas, J.J.N., et al. (1996). Existential well-being is an important determinant of quality of life. *Cancer*, 77, 576–586.
- Connelly, J.E. (2009). The avoidance of human suffering. *Perspectives in Biology and Medicine*, 52, 381–391.
- Davidhizar, R. & Lonser, G. (2003). Storytelling as a teaching technique. *Nurse Educator*, 28, 217–221.
- Dyche, L. & Epstein, R.M. (2011). Curiosity and medical education. *Medical Education*, 45, 663–668.
- Fahnestock, D.T. (1999). Partnership for good dying. *Journal of the American Medical Association*, 282, 615–616.
- Fitzgerald, F.T. (1999). Curiosity. Annals of Internal Medicine, 130, 70–72.
- Floriani, C. & Schramm, F.R. (2010). Journey of struggle: Kalothanasia and the hospice way of dying. *Palliative and Supportive Care*, 8, 461–468.
- Ford, D.W., Downey, L., Engelberg, R., et al. (2012). Discussing religion and spirituality is an advanced communication skill: An exploratory structural equation model of physician trainee self-ratings. *Journal of Palliative Medicine*, 15, 63–70.
- Galvin, K. & Todres, L. (2009). Embodying nursing openheartedness: An existential perspective. *Journal of Holistic Nursing*, 27, 141–149.
- Gehart, D.R. & McCollum, E.E. (2007). Engaging suffering: Towards a mindful re-visioning of family therapy practice. *Journal of Marital and Family Therapy*, 33, 214–226.
- Green, J.W. (2008). Beyond the Good Death: The Anthropology of Modern Dying. Philadelphia: University of Pennsylvania Press.
- George, R. (2009). Suffering and healing our core business. *Palliative Medicine*, 23,385–387.
- Graham, I.W., Andrewes, T. & Clark, L. (2005). Mutual suffering: A nurse's story of caring for the living as they are dying. *International Journal of Nursing Practice*, 11, 277–285.
- Halifax, J. (2011). The precious necessity of compassion. Journal of Pain and Symptom Management, 41, 146–153.
- Halifax, J. (2009). Being with Dying: Cultivating Compassion and Fearlessness in the Presence of Death. Boston: Shambala.
- Henoch, I. & Danielson, E. (2009). Existential concerns among patients with cancer and interventions to meet them: An integrative literature review. *Psycho-oncology*, 18, 225–236.
- Hui, D., de la Cruz, M., Thorney, S., et al. (2011). The frequency and correlates of spiritual distress among patients with advanced cancer admitted to an acute palliative care unit. American Journal of Hospice and Palliative Medicine, 28, 264–270.
- Jenkinson, S. (2007). Suffering: The hundred little deaths before dying. In *Palliative Care: Core Skills and Clinical Competencies*, Emanuel, Linda L. & Librach, S. Lawrence (eds), pp. 15–26. Philadelphia: Saunders Elsevier.
- Krikorian, A., Limonero, J. & Mate, J. (2011). Suffering and distress at the end-of-life. *Psycho-oncology (October)*, published online in Wiley Online Library. doi:10.1002/ pon.2087
- Kearney, M. & Mount, B. (2000). Spiritual Care of the Dying Patient. In *Handbook of Psychiatry in Palliative Medicine*. Chochinov, Harvey M. & Breitbart, William (eds), pp. 357–379. New York: Oxford University Press.

Lahood, G. (2007). Rumour of angels and heavenly midwives: Anthropology of transpersonal events and childbirth. *Women and Birth*, 20, 3–10.

- Lavoie, M., Blondeau, D. & De Koninck, T. (2008). The dying person: An existential being until the end of life. *Nursing Philosophy*, 9, 89–97.
- Lehto, R.H. (2012). The challenge of existential issues in acute care: Nursing considerations for the patient with a new diagnosis of lung cancer. *Clinical Journal of Oncology Nursing*, 16, E4–E11.
- LeMay, K. & Wilson, K.G. (2008). Treatment of existential distress in life threatening illness: A review of manualized interventions. *Clinical Psychology Review*, 28, 472–493.
- Levine, S. (1982). Who Dies? An Investigation of Conscious Living and Conscious Dying. Garden City: Anchorbooks.
- Lovell, M.R. (2012). Preparation is the key to death being our friend. *British Medical Journal*, 344, e436.
- Lundstrom, S., Furst, C.J., Friedrichsen, M., et al. (2009). The existential impact of starting corticosteroid treatment as symptom control in advanced metastatic cancer. *Palliative Medicine*, 23, 165–170.
- Lyon, D.E. & Younger, J. (2005). Development and preliminary evaluation of the Existential Meaning Scale *Journal of Holistic Nursing*, 23, 54–65.
- Mako, C., Galek, K. & Poppito, S.R. (2006). Spiritual pain among patients with advanced cancer in palliative care. *Journal of Palliative Medicine*, 9, 1106–1113.
- Makowski, S.K.E. & Epstein, R.M. (2012). Turning toward dissonance: Lessons from art, music, and literature. *Journal of Pain and Symptom Management*, 43, 293–298.
- Masson, J.D. (2002). Non-professional perceptions of 'good death': A study of the views of hospice care patients and relatives of deceased hospice care patients. *Mortality*, 7, 191–209.
- Melin-Johansson, C., Henoch, I., Strang, S., et al. (2012). Living in the presence of death: An integrative literature review of relatives' important existential concerns when caring for a severely ill family member. *The Open Nursing Journal*, 6, 1–12.
- Melo, C.G. & Oliver, D. (2011). Can addressing death anxiety reduce health care workers' burnout and improve patient care? *Journal of Palliative Care*, 27, 287–295.
- Miller, J. (1992). The way of suffering: A reasoning of the heart. *Second Opinion*, 17, 21–33.
- Mitchell, G.J. & Bunkers, S. (2003). Engaging the abyss: A mis-take of opportunity? *Nursing Science Quarterly*, 16, 121–125.
- Mount, B.M. (2003). The existential moment. *Palliative* and Supportive Care, 1, 93–96.
- Mount, B.M., Boston, P.H. & Cohen, S.R. (2007). Healing connections: On moving from suffering to a sense of well-being. *Journal of Pain and Symptom Management*, 33, 372–388.
- Mundle, R.G. (2011). The spiritual strength story in end-oflife care: Two case studies. *Palliative and Supportive Care*, 9, 419–424.
- Ohlen, J., Bengtsson, J., Skott, C., et al. (2002). Being in a lived retreat-Embodied meaning of alleviated suffering. *Cancer Nursing*, 25, 318–325.
- Olshansky, E. (2005). Nursing research in the context of awe and wonder. *Journal of Professional Nursing*, 21, 135–136.
- Otis-Green, S., Ferrell, B., Borneman, T., et al. (2012). Integrating spiritual care within palliative care: An

- overview of nine demonstration projects. *Journal of Palliative Medicine*, 15, 154–162.
- Papadimos, T.J. & Stawicki, S.P.A. (2011). The death of Ivan Ilych: A blueprint for intervention at the end of life. *International Journal of Critical Illness and Injury Science*, 1, 125–128.
- Remen, R.N. (2008). Practicing a medicine of the whole person: An opportunity for healing. *Hematology/Oncology Clinics of North America*, 22, 767–773.
- Remen, R.N., O'Donnell, J.F. & Rabow, M.W. (2008). The healer's art: Education in meaning and service. *Journal of Cancer Education*, 23, 65–67.
- Richards, T. (2007). A better way to die. British Medical Journal, 334, 830.
- Roy, D.J. (2011). Does "Spiritual" indicate a limit to palliative care? *Journal of Palliative Care*, 27, 259–260.
- Sasser, C.G. & Puchalski, C.M. (2010). The humanistic clinician: Traversing the science and art of health care. Journal of Pain and Symptom Management, 39, 936–940.
- Schmidt-Bunkers, S. (2006). What stories and fables can teach us. *Nursing Science Quarterly*, 19, 104–107.
- Schwartz, K.D. & Lutfiyya, Z.M. (2012). "In pain waiting to die": Everyday understandings of suffering. *Palliative and Supportive Care*, 10, 27–36.
- Scott, J.G., Cohen, D., DiCicco-Bloom, B., et al. (2008). Understanding healing relationships in primary care. *Annals of Family Medicine*, 6, 315–322.

- Sinclair, S. (2011). Impact of death and dying on the personal lives and practices of palliative and hospice care professionals. *CMAJ*, 183, 180–187.
- Sinclair, S., Pereira, J. & Raffin, S. (2006). A thematic review of the spirituality literature within palliative care. *Journal of Palliative Medicine*, 9, 464–479.
- Smith, M.J. & Liehr, P. (2005). Story theory: Advancing nursing practice scholarship. *Holistic Nursing Practice*, 19, 272–276.
- Strang, P., Strang, S., Hultborn, R., et al. (2004). Existential pain—An entity, a provocation, or a challenge? *Journal of Pain and Symptom Management*, 27, 241–250.
- Strasser, F., Walker, P. & Bruera, E. (2005). Palliative pain management: When both pain and suffering hurt. *Journal of Palliative Care*, 21, 69–79.
- Terry, W. & Olson, L.G. (2004). Unobvious wounds: The suffering of hospice patients. *International Medicine Journal*, 34, 604–607.
- Thompson, G.N. & Chochinov, H.M. (2010). Reducing the potential for suffering in older adults with advanced cancer. *Palliative and Supportive Care*, 8, 83–93.
- Tolstoy, L. (1960). The Death of Ivan Ilych and Other Stories. Scarborough: New American Library.
- Webb, M. (1997). The Good Death: The New American Search to Reshape the End of Life. Toronto: Bantam Books.
- Yoder-Wise, P.S. & Kowalski, K. (2003). The power of story-telling. *Nursing Outlook*, 51, 37–42.
- Younger, J. (1995). The alienation of the sufferer. Advances in Nursing Science, 17, 53–72.