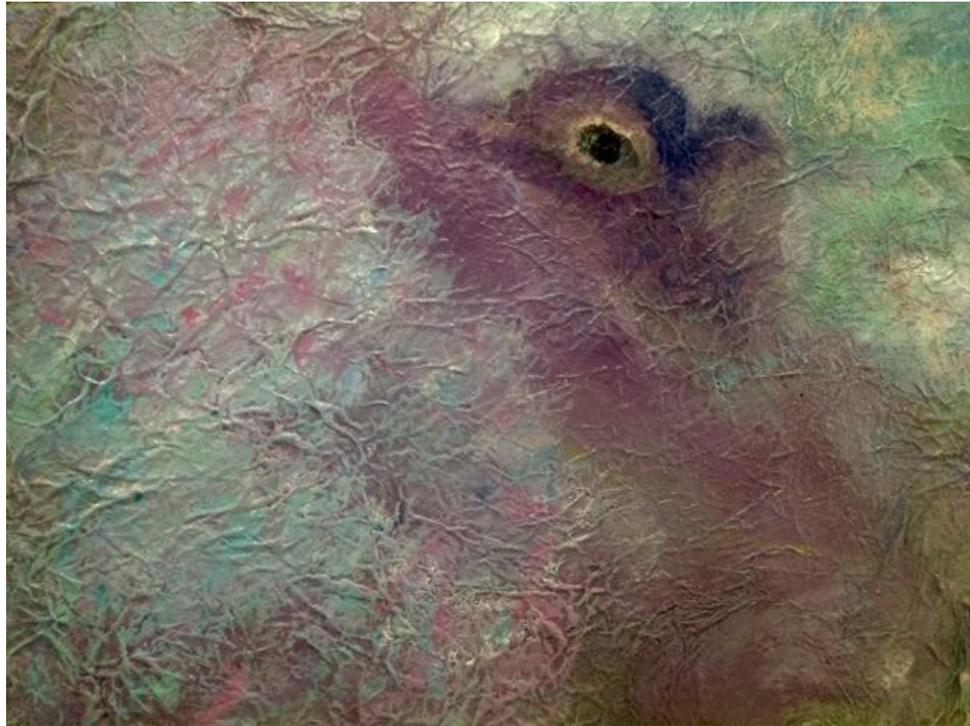


**The Soul's Legacy**  
*Discerning Your Life's Meaning and  
Passing It on to Your Loved Ones*



**Fred Grewe**

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## **Description of the Project**

In my practice of hospice chaplaincy far and away the most common distress I witness is the existential pain caused by a loss of meaning experienced by terminal patients. While an end-of-life struggle to discover meaning is normative, for expediency in contemporary hospital and hospice care, this existential struggle is often pharmaceutically sedated, as contemporary medical practices do not have the resources to address this pain adequately.

Current innovative psychological therapies have made great progress in addressing this pain but they are often begun too late in the end-of-life process and they ignore religion—which for many is a major component in the meaning-making process. Therefore, the central question I propose to address in this dissertations is how can faith communities help prepare their senior adults to effectively cope with inevitable end-of-life existential issues?

The goal of this project, which was developed as a thesis for the Doctor of Ministry Program at Pacific School of Religion, is to provide tools for ministers to utilize in addressing the real issues that terrify us all, particularly the elderly: death, isolation, and meaninglessness. To help ameliorate existential suffering at life's end I propose the addition of a spiritual will or a legacy of the soul to end-of-life planning to help senior adults and their loved ones prepare for this inevitable struggle.

The purpose of the case study that follows was to develop a program to aid in the creation of a soul legacy for three groups of senior adults.

May what you find here aid in your own ministry to those entering life's final stages.

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*Cover picture is an original painting by Cyndi Grewe © 2015*

## CHAPTER ONE

### Introduction

*Preparing ourselves for death is the most important task of life.*<sup>1</sup> —Henri Nouwen

I meet people right where they sleep. I find them, often unconcerned about their appearance, lying or sitting on their beds in homes, adult foster homes, assisted living facilities, nursing homes, or memory care units. A doctor has told them they have less than six months of life. Many require aid to simply breathe. During my visit a concentrator frequently swooshes in the background delivering needed oxygen through a plastic tube into the cannula placed at the entry of their nostrils.

I am a hospice chaplain.

Often the people I meet are overwhelmed. Overwhelmed by the dire news given by their doctor. Overwhelmed by pain and/or the side effects of the narcotics they are on—or both. Often constipated. Overwhelmed by the invasion of hospice workers who have five working days to complete government mandated initial assessments. Overwhelmed by the same questions over and over again. Overwhelmed by the shock and tears of loving friends and family. Overwhelmed by the knowledge that soon they will cease to be.

The waiting is awful. They know something is going to happen ... something not good ... and they don't know when. They know it's coming, just not when it's coming.

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<sup>1</sup> Henri J. M. Nouwen and Robert A. Jonas, *The Essential Henri Nouwen*, 1st ed. (Boston ; London: Shambhala, 2009), 67.

Some folks try to take care of as many personal life details as possible. Some get angry. Some just give up. Many just stare out the window in shock, trying to make sense of so many stitched-together memories, shaping those fragments into something that resembles meaning.

In the past ten years I have journeyed with more than a thousand folks who have died. On an average week I visit twenty to twenty-five terminal patients and in my current job I see about fifty different people each month. Two hundred fifty of my patients die each year. The wisdom imparted by these brave souls has informed and formed not only my practice of chaplaincy but many of the concepts in this dissertation. In writing this thesis, I have included narratives from the lives of patients not only in order to ground the theory presented in real case situations but also as a way of honoring what they have taught me.

Of all the lessons these dying souls have shared, among the most significant is the importance of grasping a life meaning. In my practice of chaplaincy far and away the most common distress experienced by terminal patients is the existential pain caused by a loss of meaning. Now, of course, not all patients have struggles at life's end, but for those who do, existential issues are most common. While an end-of-life struggle to discover meaning is normative, for expediency in contemporary hospital and hospice care, this existential struggle is often pharmaceutically sedated, as contemporary medical practices do not have the resources to address this pain adequately.

Current innovative psychological therapies have made great progress in addressing this pain but they are often begun too late in the end-of-life process and they ignore religion—which for many is a major component in the meaning-making process.

The goal of this dissertation is to provide tools for ministers to utilize in addressing the real issues that terrify us all, particularly the elderly: death, isolation, and meaninglessness. To help ameliorate existential suffering at life's end I propose the addition of a spiritual will or a legacy of the soul to end-of-life planning to help senior adults and their loved ones prepare for this inevitable struggle.

Therefore, the purpose of this case study was to develop a program to aid in the creation of a soul legacy for three groups of senior adults living in the Rogue Valley of southern Oregon. At this stage in the research, a soul legacy will generally be defined as any form of communicating what one has learned to be important from one's years of living to anticipated surviving loved ones, with a special emphasis on the unique relationship between the legacy giver and legacy receiver.

### **The Blessing**

Imogene had been a hospice patient for several months and lived with her daughter, Bonnie, in a very small travel trailer. She slept on a little cot in the midst of a forest of unread paperback books and magazines. Bonnie slept next to her mother on another cot.

Less than five feet tall and weighing less than eighty pounds, Imogene was still a very intimidating personality. She was very precise in what she liked and didn't and let everyone know it. Normally on my visits, Imogene talked non-stop (with great bravado), recounting familiar stories of her broken marriages, her four children, her years of unfulfilling work, her punctilious life philosophy, her unrealized dreams, and her

indomitable spirit. Three sons lived out of the area and out of Imogene's life, so Bonnie was left to faithfully provide the constant care Imogene now required.

Maybe it was the cramped quarters. Maybe it was the pain of Imogene's cancer. Or maybe it was just too many years of toiling at tedious, unrewarding work—but in the months I had known Imogene, I had seen how she and Bonnie could get on each other's nerves.

On one of my visits Bonnie was out running some errands, so I was alone with Imogene. Uncharacteristically, Imogene shared in a vulnerable manner the underside of her life narrative. She told me how as an unmarried teenager, pregnant with Bonnie, she had to drop out of school and was never able to formally complete her education. This was a defining experience in Imogene's life. Believing she was exceptionally gifted intellectually, but unable to gain the formal recognition, she had to settle for a less-than life. Was this why she occasionally made little digs about Bonnie's weight?

That's the backstory.

I honestly don't know how or why, but on a subsequent visit with these women at the stuffed little travel trailer I was witness to a miracle.

Everything started off as usual. I asked if Imogene was in any pain. "No more than usual," she said, then added, "But I know I'm getting close to the end ... and it's OK." The bravado was absent as she began to tenderly recount the same stories I had heard on so many previous meetings. The bitterness and frustration over unfulfilled opportunities was mysteriously gone. I was even more amazed as Imogene began to praise Bonnie, who was sitting next to her. "You know, I love my sons ... but Bonnie's

the one who really loves me and has come to care for me when I needed her. She's a great daughter—and I'm so proud of her.”

And then Bonnie chimed in, “Mom, I'm so proud of you. I'm proud of the way you never stopped learning. You couldn't go back to school, but you never stopped learning ... and you've taught all of us the importance of education. You didn't let anything stop you. You got us all through.”

I remained in hushed silence as for more than an hour these two beautiful broken souls spoke words of love and acceptance to each other, expressing deep words of appreciation for what is so special and unique in the other. It was a miracle. When wounded souls bless each other, it always is.

### **The Project**

Being witness to such healing moments with people like Imogene and Bonnie has fueled my desire to develop tools aimed at alleviating end-of-life existential suffering. Some researchers with a similar aim have suggested the creation of what they call an ethical will. I find this nomenclature to be confusing and restrictive. Confusing because the word “ethical” used in this context is meant to be understood as the personal ethic or values of the person crafting the document. Most people, however, think of the word *ethical* as referring to behavior in line with culturally accepted standards of conduct. It is also restrictive because an ethical will is a written document and thus totally dependent upon words. As I will propose, the kind of bequest I am suggesting can be offered without words, therefore, I prefer the term *soul's legacy* to avoid these difficulties.

Additionally, many ethical wills simply recount stories and historical events from a person's life. In my work with the dying, I realize that they desire something more than a mere narrative of events. To facilitate the kind of therapeutic benefit I am seeking requires a restoration or deepening of relationships with significant others. My desire is to help older adults create a personal legacy to be given to specific loved ones in an experiential manner.

Therefore, to help create a soul legacy I have developed a five-week seminar to aid seniors in the necessary self-reflection to construct such a bequest and consider how best to pass this gift on to their loved ones. This dissertation documents the theory supporting the need for a legacy of the soul and reports on the wisdom gained from thirty-four people who participated in three pilot seminars.

In the next chapter I will explore a review of the current literature from psychiatrists, psychologists, philosophers, theologians, and medical care providers on the importance of addressing existential meaning at life's end. Chapter 3 presents the framework for the five-week Soul Legacy Seminar with supporting rationale from psychological, philosophical, and theological perspectives. A detailed description of each weekly session and structure of the seminar are given in chapter 4. Chapter 5 will present the data mined from the experience. And the final chapter will present the outcomes from the pilot seminars along with implications for further research.

My hope is that those who participate in the seminar will become less afraid of dying, improve their ability to communicate feelings of love and appreciation to their family and friends, and as a result will help alleviate the grief experienced by their survivors once the creator of the legacy has died. Additionally, it is hoped that those who

are not pleased with the life they have lived thus far will go forward and pursue activities to enhance the soul legacy they will leave behind.

## CHAPTER TWO

### The Importance of Meaning at the End of Life

*... the question of the meaning and worth of life never becomes more urgent or more agonizing than when we see the final breath leave the body which a moment before was living.*<sup>2</sup> —C. G. Jung

My first experience in observing the intense pain caused by a loss of meaning at life's end came long before my career as a chaplain began; it began with watching my mother die.

She was only forty-four and had battled cancer for seven years. It started in her breast, then went to the ovaries, then finally and painfully into her bones. Double mastectomy, hysterectomy, chemo, radiation, the indignity of all her beautiful black hair falling out, her caring face mooning up from the medications—none of it worked. For the last year of her life she basically laid in pain on the couch in our family room and had to let my three sisters, my father, and I care for her every need.

The greatest pain she endured, though, was not being able to be our mom anymore. She often told me she hated having everyone wait on her. She felt like such a burden to us. For all our life she had cared for and nurtured us—now she could only lie on that damn couch.

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<sup>2</sup> C. G. Jung and Jenny L. Yates, *Jung on Death and Immortality*, Princeton Paperbacks (Princeton, N.J.: Princeton University Press, 1999), 11.

I remember one evening during her last year, she and I were home alone. I was lying on the floor in the family room watching TV and she asked me, “Do you want some ice cream?” Half jokingly I said, “Yeah, right.”

A short while later she labored to get up off of the sofa, grabbed her crutches and started up the seven stairs from the family room to the rest of the house. I thought she was just going to the bathroom. She returned gingerly balancing a bowl of ice cream in her right hand, walking with the crutches, and cautiously making her way back down the seven stairs. I felt so ashamed, and yet she looked so happy. For just a few moments, she told me she felt like a mom again.

Conversely, those were some of the richest moments in my life. I had just graduated from college and moved home to help care for her. Those last several months of tending to my mother were an opportunity for me to give back to this beautiful woman who had given me and our family so much of herself. Serving her pulled a kindness and sensitivity out of me that I didn’t even know was there. I was a better human being as a result of those months spent caring for my dying mother.

Ironically, letting us serve her as she was dying was the final gift our mother gave us. Her care filled *our* lives with deep meaning. Now I’m not suggesting it was easy, or that it made us happy, but it did make our living very rich. Frequently I share this insight with those I serve who also suffer from a loss of meaning as they lie dying. I suggest that dying patients, even confined to their hospital beds and unable to care for themselves, can still teach the rest of the family how meaningful life can be in serving others.

Nearly forty years later, the impact of those months has never left me. The experience of caring for my dying mother was a major factor in my decision to become a hospice chaplain.<sup>3</sup>

### **Why Is Meaning So Important to the Dying?**

As I say, in more than ten years of working with the dying, the most pressing issue I have encountered with the terminally ill is their struggle with the loss of meaning. My experience is not unique. Canadian psychiatrist Dr. Harvey Max Chochinov, a pioneer in developing meaning-based interventions for the dying, notes, “Existential confrontation with approaching death raises many questions: What is the meaning of my existence? What has my life amounted to? And, as a pressing concern: Once I am gone, what difference will my life have made?”<sup>4</sup> While these queries seem obvious, why is a sense of meaning so important to the dying?

Many poets, philosophers, and modern-day Internet bloggers have proclaimed man is a meaning-making machine. Nazi concentration camp survivor and logotherapy innovator Viktor Frankl considers “man a being whose main concern is fulfilling a meaning.”<sup>5</sup> So, first of all, we can assert meaning-making is hard wired into our nature. Additionally, psychiatrist William Brietbart (building on the work of Frankl) notes, with

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<sup>3</sup> Fred Grewe, *What the Dying Have Taught Me About Living: The Awful Amazing Grace of God* (Cleveland, OH: Open Waters, 2014), 111-3.

<sup>4</sup> Harvey Max Chochinov, *Dignity Therapy : Final Words for Final Days* (Oxford ; New York: Oxford University Press, 2012), 16.

<sup>5</sup> Viktor E. Frankl, *Man's Search for Meaning* (New York: Pocket Books, 1984), 125.

the onset of death meaning “is no longer vague or trivial; rather, it becomes imbued with a sense of urgency and signification that must be discovered, not imposed.”<sup>6</sup>

But even more importantly, it appears for the dying and those who are suffering, a sense of meaning has therapeutic power to alleviate the existential pain. Chochinov’s research bears this out.

We have found that feeling one’s life has enduring meaning and purpose seems to buffer patients from various kinds of end-of-life distress, including psychological (e.g., anxiety, depression, uncertainty), physical (e.g., not being able to attend to bodily functions, experiencing physically distressing symptoms), and existential (e.g., “no longer feeling like who I was,” feelings of unfinished business, not feeling worthwhile or valued) sources of suffering.<sup>7</sup>

Having a clearly defined sense of purpose and meaning is an effective balm to soothe the soul as it is in the process of being dislocated from a diminishing body. One of the ways a sense of meaning relieves this suffering is by “buffering” the dying person from the effects of the great North American mortal sin—*becoming a burden to others*. As in my mother’s case, and for many of the people I have served over the years, the fear of becoming a burden to loved ones is the cause of intense existential pain. Numerous studies verify this *burden to others* fear is “associated with a loss of will to live, a desire for death, and outright requests for euthanasia or assisted suicide.”<sup>8</sup> It is the shadow side of our culture’s obsession with and idolization of *independence*.

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<sup>6</sup> W. Breitbart et al., "Psychotherapeutic Interventions at the End of Life: A Focus on Meaning and Spirituality " *Canadian Journal of Psychiatry* 49, no. 6 (2004): 367.

<sup>7</sup> Chochinov, *Dignity Therapy*, 26.

<sup>8</sup> *Ibid.*, 32-33.

## Understanding Suffering, Pain, Healing and Cure

Thus far I have used the words “pain” and “suffering” nearly interchangeably. In an effort to examine how meaning helps ameliorate suffering it will be helpful to clarify their distinctions. Pain can be viewed as a fracturing of the body (biological in nature) while suffering is a fracturing of the self (existential in nature).<sup>9</sup> And yet this distinction is a bit tenuous, as these two are intimately interrelated. Biological pain can and often does cause emotional suffering while existential suffering will frequently produce physical pain. According to physician and bioethicist Eric Cassell, however, “suffering results when a person perceives the threat of impending destruction and experiences severe distress associated with events that threaten the intactness of the individual.”<sup>10</sup> Suffering is a threat to our identity.<sup>11</sup> Dying can certainly cause this!

While closely connected, the sources of pain and suffering are distinct and require different types of interventions. Far too often in the expediency of contemporary medical practices, including hospice care, analgesics, which are invaluable for relieving physical pain, are also prescribed for the existential distress caused by soul suffering. We do a serious disservice to our suffering patients and their loved ones when we simply “snow under” the dying person who is anxiously struggling with a loss of meaning. As Buddhist

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<sup>9</sup> David Biro, *The Language of Pain : Finding Words, Compassion, and Relief*, 1st ed. (New York: W.W. Norton, 2010), 106.

<sup>10</sup> Eric Cassell quoted in Abigail Rian Evans, *Is God Still at the Bedside? : The Medical, Ethical, and Pastoral Issues of Death and Dying* (Grand Rapids, Mich.: William B. Eerdmans Pub. Co., 2011), 220.

<sup>11</sup> *Ibid.*, 224.

teacher Frank Ostaseski has so wisely observed in his care of the dying, “suffering is not relieved by morphine. Pain is relieved by morphine.”<sup>12</sup>

To properly address this issue of treating existential distress afflicting terminal patients it is important to clarify the goal for a plan of care. Simply anesthetizing it is an option—one that I suggest is less than helpful. Jung is quoted as saying, “If you get rid of the pain before you answer its questions, you get rid of the Self (psyche or the soul) along with it.”<sup>13</sup> So what is the goal? While cure is probably not possible, healing is. There is a difference.

Cure is a medical term that speaks of eliminating a spot from an x-ray, or cutting out diseased tissue, or using pharmaceuticals to destroy unwanted bacteria. Healing, on the other hand, requires a much broader understanding. Healing may involve cure, but it also includes regaining wholeness in the physical, emotional, intellectual, social, and spiritual aspects of being human. Healing involves the experience of transcending suffering.<sup>14</sup>

One prominent palliative physician has written, “Illness and dying are essentially spiritual processes in that they often provoke deep questions of meaning, purpose, and hope. ... Spirituality helps give meaning to suffering and helps people find hope in the

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<sup>12</sup> Frank Ostaseski quoted in Bill Moyers, "Part 2: A Different Kind of Care," *On Our Own Terms: Moyers on Dying* (New York: Public Affairs Television & PBS Thirteen WNET, DVD, 2000).

<sup>13</sup> Carl Jung quoted in Paul Murphy, "Healing Suffering: Identifying and Treating Spiritual Distress," (Lecture, Providence Hospital, Medford, OR, January 25, 2013).

<sup>14</sup> Ibid.

midst of despair.”<sup>15</sup> So before we take a look at what constitutes meaning in order to help alleviate existential suffering, it is necessary to briefly explore that aid humanity has relied on for thousands of years to help frame meaning—*spirituality*.

### **The Connection between Spirituality, Healing, and Meaning**

The Consensus Conference in 2009 developed the following definition of spirituality, which has become widely accepted in the medical community and is very useful. “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred.”<sup>16</sup> What I find so helpful about this definition is the link it makes between our individual search for meaning and our connectedness to others. Meaning requires relationship with others.

From a Christian perspective<sup>17</sup> we were made to be in relationship—relationship with the Sacred (God), with others, and with ourselves. To underscore this point, the first “not good” in the Bible is that the human being was alone. We are created to be in relationships, to give and receive acceptance (to and from others), and to find meaning outside of ourselves.<sup>18</sup>

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<sup>15</sup> Christina M. Puchalski and Betty Ferrell, *Making Health Care Whole : Integrating Spirituality into Patient Care* (West Conshohocken, PA: Templeton Press, 2010), 3.

<sup>16</sup> Puchalski and Ferrell, *Making Healthcare Whole*, 25.

<sup>17</sup> As an ordained United Church of Christ minister, my spiritual reference is Christian. This does not mean I am asserting Christianity is the only viable spiritual perspective. It is simply the one from which I work.

<sup>18</sup> Evans, 7.

Numerous philosophers (particularly the existentialist ones like Heidegger and Sartre) assert it is impossible to know ourselves apart from being in relationship. The word “reflect” is helpful for this insight. “Reflect” means both to see ourselves as in a mirror, and also to look inward in a contemplative way.<sup>19</sup> The existentialists teach it is by getting feedback from others about who we are (mirror reflection) that we can then truly look inward to contemplate our being (contemplative reflection). “By linking ourselves (who can’t be very objective) with others (who can be more so), we gain access to ourselves.”<sup>20</sup> Thus the only way we can truly come to know ourselves and create any sense of meaning is by being in relationship with others.

Martin Buber goes a step further by suggesting these relationships “intersect in the eternal You [God].”<sup>21</sup> It seems the dynamic flow of relating to others informs our knowledge of ourselves and God—while relating to God informs our knowledge of ourselves and others. The importance of relating to the Divine will be explored later in this thesis.

In our efforts to heal the distress caused by loss of meaning, the importance of both our roles and relationships cannot be overstated. John Pilch, in his insightful work *Healing in the New Testament*, does a wonderful job of explaining the necessity of

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<sup>19</sup> Robert Solomon, "Lecture 16: Heidegger on the World and the Self," *No Excuses: Existentialism and the Meaning of Life*, (Chantilly, VA: The Teaching Company, CD, 2000).

<sup>20</sup> Biro, *Language of Pain*, 153.

<sup>21</sup> Martin Buber and Walter Arnold Kaufmann, *I and Thou* (New York,: Scribner, 1970), 123.

restored relationships to any concept of healing.<sup>22</sup> Pilch demonstrates healing includes restoring the sick person to his or her familial relationships and roles in the broader community.

In first-century Palestine, sick people were often quarantined to limit the spread of dreaded diseases like leprosy (a biblical term for numerous contagious skin diseases). Diseased folks were often segregated, forced to live at the margins of the community, and required to yell “unclean” if others approached to keep healthy people at a safe distance. Folks with certain diseases weren’t permitted to live in their own homes, engage in commerce with local merchants, or go to work. These conditions increased the isolation and suffering of the afflicted persons.<sup>23</sup>

Pilch points out this is why Jesus frequently told people he healed to “go show yourself to the priest.” Showing oneself to the priest was the gateway back into the life of the community. Once you were no longer deemed unclean (that is, a threat to the welfare of the larger community), you could move back into your home to resume your role as mother or father relationally, and you could go back to work to resume your role in helping the entire community survive. This is the biblical meaning of healing.

And this is not simply an ancient understanding. The World Health Organization currently defines health as “a state of complete physical, mental and *social well-being* [emphasis added] and not merely the absence of disease or infirmity.”<sup>24</sup>

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<sup>22</sup> John J. Pilch, *Healing in the New Testament : Insights from Medical and Mediterranean Anthropology* (Minneapolis: Fortress Press, 2000), 34.

<sup>23</sup> *Ibid.*, 120.

<sup>24</sup> Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946

Thus one can be healed without obtaining a cure. Pilch adds a further insight: “healing is also effective when the individual experience of illness has been made meaningful, personal suffering shared, and the individual leaves the marginal situation of sickness and is reincorporated—in health or even death—back into the social body.”<sup>25</sup>

Additionally, because of our relational reality, healing is not just for the afflicted person but for the community of the terminal loved one as well. As noted in the Consensus Conference report, those providing care for the dying “have the potential for being transformed by the interaction with one another.”<sup>26</sup> This hope has major implications for the survivors of the dying patient.

### **What Makes Life Meaningful?**

Within this understanding we can now begin to explore what makes our living meaningful. To begin, our concept of our life’s meaning is inextricably intertwined with the story we’ve created to make sense of our existence. Our stories tell us where we fit into this world. And that story usually revolves around two central poles: our relationships and our roles. The following narrative of a former patient illustrates this idea.

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by the representatives of sixty-one states (Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948.

<sup>25</sup> Ibid., 34.

<sup>26</sup> C. Puchalski et al., "Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference," *J Palliat Med* 12, no. 10 (2009): 890.

Sitting next to Jake's bed as he lay dying, watching his fitful sleep, I noticed the framed sign on the wall near his bed in the adult foster home. It read: "When I was a kid, I prayed every night for a bicycle, but then I found out this isn't the way God works. So then I stole one and asked Him for forgiveness."

A hard life of drugs, alcohol, and rock-n-roll had taken its toll on Jake's forty-something-year-old body. Contrary to the conventional wisdom, living fast and dying young doesn't always leave a good-looking corpse. Nearly all of Jake's teeth had rotted out, save the bicuspid on his upper right side. His abdomen was greatly distended (bloated) from terminal liver disease. And Jake was painfully afraid of death.

Jake had some sort of a Baptist background, and had loved to play the drums. Years before, as a result of his addictions, Jake had deserted his wife and daughter. When I first met him, he told me that all he wanted was to see them again, to be given a last chance to "make things right." Mercifully, his ex-wife and daughter did come to see him, bringing along a newborn grandson whom Jake had never seen. It was a beautiful reunion with a lot of love and grace. Before they left, Jake's family made a collage of family pictures and mounted it on the wall next to the framed sign. Jake was so proud of his family. He would lie for hours on his side, simply looking at the collage and delighting in the pictures of his grandson.

But now, weeks later, he was dying, and I was sitting there praying for him. Several times he woke up in pain. His care giver, Joe, and I repositioned him to ease his way. I moistened his lips and mouth with one of those pink sponge swabs soaked in water.

Looking at the pictures of his daughter and grandson, I thought of how much Jake had missed as he wandered the world looking for his place to fit. What if everything his thirsty soul had longed for was right there at home the whole time?

Earlier that morning, I'd read some lines from Antony the Great, the first of the desert fathers. "What must one do in order to please God? Pay attention to what I tell you. Whoever you may be, always have God before your eyes. Whatever you do, do according to the testimony of the Holy Scriptures. Wherever you live, do not easily leave it. Keep these three precepts, and you will be saved."<sup>27</sup>

We're all looking for a place to fit. We're all looking for a meta-narrative, a grand story that helps explain our lives, makes sense of our existence, and provides a source of meaning to our days. Often, we don't need to travel to discover that story. I think that's why St. Antony tells us that, if we find that place, we should not easily leave it.

I was still lost in these thoughts, when Joe the care giver's two young daughters arrived home from school and went running down the hallway outside of Jake's door fighting about something. I said a short benediction for Jake and bade him Godspeed.

As I pulled out of the driveway, I noticed in the rearview mirror two young Mormon missionaries cresting the hill behind me. Their starched white shirts and black ties were a sharp contrast to the gray overcast November sky behind them. *Two more pilgrims searching for a place to fit*, I thought. Aren't we all?<sup>28</sup>

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<sup>27</sup> *The Little Book of Hours : Praying with the Community of Jesus* (Brewster, Mass.: Paraclete Press, 2003), 193.

<sup>28</sup> Grewe, 109-10.

Our effort to make life meaningful draws from the totality of our lived experiences and attempts to make sense of them. Meaning-making includes, “one’s sense of purpose in life, the belief in the values of life, the coherent explanation of life events, well-being, and spirituality.”<sup>29</sup>

Meaning-making is complex because it requires an interpretive construct linking personal events from the past, present, and anticipated future with abstract ideas and cultural values.<sup>30</sup>

### **The Process of Making Meaning**

The struggle to provide a “coherent explanation” is a key concept in this process. Researchers have identified two specific types of meaning: global and situational. Global meaning involves our concept of the universe, the Sacred, or God, while situational meaning is our effort to congruently mesh this global meaning within our particular life experiences.<sup>31</sup> Because our life experiences are ever-changing, our work of meaning making is always either being assaulted or in need of adjustment. It appears the inherent struggle in meaning-making seems to be a necessary component of what makes meaning meaningful.

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<sup>29</sup> Heather Jim quoted in Puchalski and Ferrell, 116.

<sup>30</sup> Roy F. Baumeister et al., "Some Key Differences between a Happy Life and a Meaningful Life", *Journal of Positive Psychology* [http://faculty-gsb.stanford.edu/aaker/pages/documents/SomeKeyDifferencesHappyLifeMeaningfulLife\\_2012.pdf](http://faculty-gsb.stanford.edu/aaker/pages/documents/SomeKeyDifferencesHappyLifeMeaningfulLife_2012.pdf) (accessed August 5, 2013).

<sup>31</sup> *Ibid.*, 117.

A corollary observation about meaning is that it is not a fixed state. It is fluid like blood pressure—it can increase or decrease—which is to say meaning can be lost. This is one of its most frustrating characteristics. Frankl writes, “the meaning of life always changes, but it never ceases to be.” According to his logotherapy we discover the meaning of life in three particular ways: (1) by our work (our roles), (2) by experiencing or encountering an other (our relationships), and (3) by the free choice we make in dealing with unavoidable suffering (our autonomy).<sup>32</sup> Frankl’s insights highlight once again the interconnection between our life’s meaning and our roles and relationships.

Another frustrating aspect of our life’s meaning is that it must be discovered by each of us. This seems to be one of the core tasks in living, and this work is intensified when we face our finitude in death—which often causes distress. So while the struggle to make meaning is in itself meaningful, it is not necessarily without suffering. Simply anesthetizing the pain does nothing to resolve the issue. Hence there is a need for non-pharmaceutical interventions designed to help terminal patients reframe meaning at the end of life.

One final word about creating meaning must be addressed, and that is its paradoxical nature. For thousands of years philosophers and theologians have observed that our lives are most meaningful when we opt not to pursue our own happiness but instead choose to labor for the happiness of others. Frankl exhorts his readers, “The more one forgets himself—by giving himself to a cause to serve or to another person to love—the more human he is and the more he actualizes himself.”<sup>33</sup> This sentiment is verified by

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<sup>32</sup> Frankl, 133.

<sup>33</sup> Ibid.

contemporary research. According to Karen Steinhauser and her team, who developed the QUAL-E instrument to measure quality at the end of life, they discovered that what matters most to dying patients is being able to help others, making a positive difference in the lives of those they care about, saying important things to loved ones, having a sense of meaning, and sharing with family, including time together, gifts, or wisdom.<sup>34</sup> She goes on to note that in a recent palliative care study, “cancer patients reported that ‘feeling useful’ influenced whether their days were ‘good’ or ‘bad.’”<sup>35</sup>

The insights of therapists and researchers such as Frankl and Steinhauser respectively accord well with Jesus’ teaching to his followers. He required each of his followers to love God with all of her or his heart, soul, mind, and strength and love one’s neighbor as oneself.<sup>36</sup> He claimed there was no commandment greater than these. For most of my years as a practicing Christian I thought following these commands were was simply what was necessary to make God happy. I have come to learn, to my surprise, it is what makes me happy and makes my life meaningful.

### **Excursus: The Big Gamble**

The concept of life’s meaning being connected to our service for others was poignantly demonstrated to me by a hospice patient, Walter, and his wife Irene.

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<sup>34</sup> K. E. Steinhauser et al., "Initial Assessment of a New Instrument to Measure Quality of Life at the End of Life," *J Palliat Med* 5, no. 6 (2002): 833.

<sup>35</sup> *Ibid.*, 835.

<sup>36</sup> Mark 12:30-31.

Irene called one afternoon and asked if I could come visit Walter right away, because he wanted “to give his life to the Lord.” Now in the evangelical world, this is code language for getting “saved.” I was glad to oblige.

Walter had just been discharged from the hospital into hospice care and was now living at home. He had lost more than forty pounds during the previous month due to esophageal cancer and the chemotherapy used to treat it. The radiation had burned his esophagus so thoroughly he lost the ability to eat. His wife, Irene, who loved both Walter and the Lord, wanted to make sure the two of them met.

I remember the first words out of Walter’s mouth were, “If I could put a bullet in my head right now, I’d end it all—but I love her too much to do it.”

Walter and Irene had been together for seventeen years, a second marriage for both. He told me his first marriage had lasted forty-plus years, “but it was just companionship. What I have with Irene is deep love.” Walter tearfully shared that his only reason for wanting to stay alive was because he knew that, without his benefits, Irene (who was legally blind) would lose their home.

He survived for three more months on this deep love.

Walter did pray to become a Christian during my first visit with him. After that, he cried all the time. Despite having such difficulty in swallowing, amazing grace entered his soul. Over the course of our visits, Walter told me he’d struggled with a gambling problem for many years, running up huge debts. At one point Irene said she’d leave him if he didn’t quit gambling. As a demonstration of his love and commitment to her, he quit.

For her part, Irene was incredibly selfless in her love for him. She cared for this man 24/7 by herself. As he continued to decline, she helped him keep his skin clean to avoid its breaking down and causing wounds. Because of her blindness, she had to put her nose to his butt to make sure he was properly cleaned.

Walter struggled with being bedridden, being unable to taste food (and later, unable to eat at all), having lost all meaning for his living save the benefits he provided for Irene. But he told me just talking about it out loud helped ease the pain. “It’s funny,” he shared, “talking doesn’t change it one bit, but when you come I do feel better.” I’ve learned that bearing witness to suffering helps break its isolation.

About a month before Walter died, Irene consented to let a friend drive him to a casino about one hundred miles away. Of course he lost some money, but he had a great time.

He told me near the end that he had no regrets about his life. He felt so fortunate to have found Irene, and they’d been able to enjoy the years they had with each other. Walter had gambled on deep love—and won.<sup>37</sup>

The suffering of both Walter and Irene was ameliorated (not eradicated) in Walter’s last days by the meaning they found in caring for each other. Walter by staying alive to provide income for Irene and Irene in so faithfully ministering to Walter’s diminishing body. I was simply a witness to their loving acts and was able to reflect back to them the love they demonstrated for each other.

## **Death and Dissolution**

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<sup>37</sup> Grewe, 107-8.

When I first met Sophia, she was thrashing around on the bed in her hospital room. A friend told me she'd been a spiritual teacher for years. But now she was dying. At four-foot-something, she looked like a little elf. As I sat holding her hand for more than an hour, she came in and out of consciousness. In her more lucid moments, she taught me the three core principles of her teaching: (1) give loving allowance to those who think differently than you do; (2) give greater communication to what you truly believe; and (3) take responsibility for your own emotional health. She told me these principles had been given to her directly from "the Other Side—what you would call heaven." I knew this little woman with the twinkle in her eye had something to teach me, and I prayed we'd have enough time together for me to learn it.

Sophia did recover from whatever had caused her hospitalization and was discharged home to our hospice service. It was my joy and privilege to really get to know this fascinating woman. I learned that Sophia's father had been a Methodist minister. Sophia idolized her dad; her mother, not so much. She really hadn't liked her mother and was troubled by those parts of herself that she saw as reflections of her mother's character. Sophia had only one child, a daughter, with whom Sophia was emotionally estranged. Sophia's daughter was a born again Christian whose goal was to get Sophia saved—a goal Sophia did not share.

Sophia was a true spiritual mentor to many people, both locally and around the country. She referred to God as "the Cosmos," and they (Sophia and "the Cosmos") were in direct communication. When I asked Sophia what she thought about the prospect of death, she responded with glee stating, "Oh, you mean the joyous transition of leaving my body? I can't think of anything more wonderful."

Sophia’s “joyous transition” took much longer than she, the hospice team, or I ever imagined.<sup>38</sup>

At the beginning of our relationship, Sophia was busy with visits from friends and with phone calls and e-mails from followers around the country. But as the months wore on, those dwindled off, and Sophia often sat all alone in her apartment watching the busy traffic run up and down I-5. The traffic was a constant reminder to Sophia that younger and more vibrant people had places to go and things to do—but she did not. She was alone. Alone and unneeded. It was during this time that the Cosmos began to speak to her about “dissolution.”

I remember she asked me to look up the word for her in a dictionary. *Dissolution* means the breaking of a bond, tie, union, or partnership. Sophia was experiencing the *dissolution* of her soul, her mind, her body, *and* her meaning. Her body was decaying, her memories were becoming progressively lost, and her soul ached to be released into the joyous transition of the Cosmos.

### **The Terrible Twin Losses: Autonomy and Meaning**

As the disease process progresses in the lives of dying patients like Sophia, often the capacity to do for others diminishes as well, which leads to an inevitable loss of meaning. For Sophia, the meaningful life she had enjoyed was dissolving. The pain of this loss unleashed deep soul suffering. Symptoms of this suffering include feelings of

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<sup>38</sup> Ibid., 146-7.

meaningless or worthlessness in living, emptiness, loneliness, anxiety, and the dreaded feeling like a burden to others.<sup>39</sup>

One of the significant characteristics of suffering, particularly the suffering of the dying, is that it isolates the sufferer. What Dr. David Biro says about pain is equally true of suffering; it is “the quintessential private experience” because it “underscores our separateness from other people.”<sup>40</sup> With his usual ironic twist Thomas Merton puts it this way; “Death makes this very clear, for when a man dies, he dies alone. The only one for whom the bell tolls, in all literal truth, is the one who is dying.”<sup>41</sup> Pain, suffering, death—all combine to viciously attack the self-narrative we have created to construct meaning for our lives, and the beachhead of this assault is on our roles and relationships. This “tragic trio” (to borrow Frankl’s phrase) unearth our deepest fear. They remind us that in this vast expansive universe we are ultimately, and absolutely, all alone.

Dr. Biro poignantly describes how dying induces such a strong sense of isolation by changing the terminal patient’s point of view.<sup>42</sup> Prior to an incurable diagnosis the silliness of Washington politicians, which team will make the playoffs, the ups and downs of the stock market, and the private lives of the rich and famous all fight for attention. Not anymore. Dreaming of success, getting angry with children, and planning the next meal all lose importance. The thoughts and focus for the dying move inward—to what is happening not *outside* the body but *inside* the body. How quickly is the cancer

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<sup>39</sup> Evans, 223.

<sup>40</sup> Biro, 19.

<sup>41</sup> Thomas Merton, *Disputed Questions* (New York,: Noonday, 1976), 167.

<sup>42</sup> The following insights are inspired by Biro, 23 ff.

growing? What is the source of all this pain? Are my legs as strong as they were yesterday?

Simultaneously Biro adds,

The truth is that the world turns away from the sufferer just as consistently as the sufferer turns away from the world. Consider how society treats the ill—not so differently, as it happens, from the ancient Greeks. We label them sick, dress them in special clothes, and place them in hospitals, nursing homes, and hospices.<sup>43</sup>

More significantly we stop calling or visiting. Who knows what to say to a dying person? What do you talk about?

This loss of meaning and change from an outward perspective to an inward one frequently leads to demoralization. Demoralization syndrome can be identified by feelings of hopelessness, helplessness, meaninglessness, and existential distress.<sup>44</sup> Some therapists differentiate demoralization as a response to meaninglessness without the clinical features of depression.<sup>45</sup> Demoralization also is considered transient whereas depression is more persistent.<sup>46</sup> In either case, assistance from some form of psychotropic medication may be helpful to stabilize a patient's emotional balance before the important work to reframe meaning can begin.

The loss of autonomy has several key stages that I have witnessed firsthand. The first major loss I encounter in hospital and hospice work is when a patient loses the

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<sup>43</sup> Ibid., 30.

<sup>44</sup> Puchalski and Ferrell, 24.

<sup>45</sup> Ibid., 25.

<sup>46</sup> Ibid.

ability to drive a car. The thought of no longer being able to go where you want when you want is a major blow to the North American ego and unleashes for many the horrifying dread of becoming increasingly dependent on others. In other words, becoming a *burden*. The resulting emotional havoc caused by this turn of events can be quite paralyzing.

The next incremental loss is often the ability to walk without the aid of assistance—be it a cane, a walker, or a wheelchair. For some folks, there is also the loss of memory. As the various forms of dementia attack once vibrant minds, feelings of vulnerability and confusion create tremendous fear. Where am I? Who am I? Whom can I trust? Am I safe? Then comes the final indignity, when a hospital bed gets placed in the living room and one loses the ability even to get up to toilet. This loss is often accompanied with the physically painful insertion of a catheter.<sup>47</sup>

As bad as these physical losses of autonomy are, philosopher Ronald Dworkin recognized there is another, more compelling sense of autonomy.

Whatever the limits and travails we face, we want to retain the autonomy—the freedom—to be the authors of our own lives. This is the very marrow of being human. As Dworkin wrote in his remarkable 1986 essay on the subject, “The value of autonomy ... lies in the scheme of responsibility it creates: autonomy makes each of us responsible for shaping his own life according to some coherent and distinctive sense of character, conviction, and interest. It allows us to lead our own lives rather than be led along them, so that each of us can be, to the extent such a scheme of rights can make this possible, what he has made himself.’

All we ask is to be allowed to remain the writers of our own story. That story is ever changing. Over the course of our lives, we may encounter unimaginable difficulties. Our concerns and desires may shift.

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<sup>47</sup> Grewe, 148.

But whatever happens, we want to retain the freedom to shape our lives in ways consistent with our character and loyalties.”<sup>48</sup>

Now, all these losses, and others along the way, come with their own pain and attentive grieving. Most folks are unable to take them in stride. They really hurt.

Recent research verifies how significant these losses of autonomy are to the dying. In one study Steinhauser discovered three essential elements terminal patients want in their preparation for death: to face their mortality directly, *a sense of control* [emphasis added], and strengthening relationships.<sup>49</sup> Even more dramatically, here in Oregon the State Public Health Division statistics show the number one reason why terminal patients opt for Death with Dignity is the loss of autonomy. “As in previous years, the three most frequently mentioned end-of-life concerns were: loss of autonomy (93.5%), decreasing ability to participate in activities that made life enjoyable (92.2%), and loss of dignity (77.9%).”<sup>50</sup>

But as Frankl learned while living in a concentration camp, “everything can be taken from a man but one thing: the last of the human freedoms—to choose one’s attitude in any given set of circumstances, to choose one’s own way.”<sup>51</sup>

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<sup>48</sup> Ronald Dworkin quoted in Atul Gawande, *Being Mortal : Medicine and What Matters in the End*, First edition. ed. (New York: Metropolitan books, 2014), 130.

<sup>49</sup> K. E. Steinhauser et al., "Preparing for the End of Life: Preferences of Patients, Families, Physicians, and Other Care Providers," *J Pain Symptom Manage* 22, no. 3 (2001): 728.

<sup>50</sup>"Oregon Public Health Division: Oregon’s Death with Dignity Act – 2012" <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year15.pdf> (accessed August 3, 2013).

<sup>51</sup> Frankl, 86.

## The Struggle to Surrender

One day as Sophia and I were talking about her experience of dissolution, we began to explore the importance many faith traditions place on the ability to surrender. Surrendering to reality. Accepting things as they really are, not as we wish they were.

So much of our existential pain is caused by this inability to accept reality, particularly the supreme reality that we are not the center of the universe. Our egos, no matter how developed they are, cling to being the center of life and are not easily displaced; yet, paradoxically, we will not find true happiness until the ego is overcome.

During my conversation with this beautifully wise woman, I wondered if this might be what Jesus was talking about when he said, “Blessed are the poor in spirit, for theirs is the kingdom of heaven.”<sup>52</sup> The poor have had a lifetime of experience forcing them to surrender their egos. The poor know firsthand what it is to be dependent on others, to feel like a *burden*. The poor tend to be profoundly aware that they are not independent beings. The surrender that death requires as a prerequisite to entering heaven’s gates is nothing new to those who have been forced to surrender simply to survive.

Not so for the rich. Looking back over the years of my chaplaincy, I’ve found that the rich often have a much more difficult time coping with the indignities that dying demands. Sophia was not wealthy financially, but she was rich in the esteem she enjoyed from others for so many years. As we often discussed, this loss of status caused her a

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<sup>52</sup> Matthew 5:3.

great deal of soul suffering. “How hard it is for the rich to enter the kingdom of Heaven,” Jesus was also known to say.<sup>53</sup>

As we spoke I wondered why surrendering seems to be the last great lesson death has to teach most of us. Is it because we will need to know how to surrender as we move into whatever comes next?

The days turned into weeks, and the weeks turned into months. I visited with Sophia regularly at her beautiful little apartment in an assisted living complex. During that time, Sophia struggled mightily with the ongoing loss of both her autonomy and her meaning.<sup>54</sup>

As it turned out, Sophia would have to endure even more dissolution before her joyous transition. Because she was not dying quickly enough to appease government regulations (for fear of wasting Medicare dollars), we had to discharge Sophia from our hospice service. Initially one might think being discharged from hospice is good news, but folks who have received the wonderful care of a hospice team often feel emotionally set adrift after being discharged from service. No more nurses visiting several times a week. No more home health aides to provide baths and personal hygiene care. No more volunteers coming to read or share stories. No more delivery of needed medications to the front door.<sup>55</sup>

The losses of meaning and autonomy should not be viewed in only a negative light. They have a profound purpose. It seems the struggle against them is in a

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<sup>53</sup> Mark 10:23.

<sup>54</sup> Grewe, 149-50.

<sup>55</sup> Ibid., 150.

paradoxical way *meaning-ful*. Viktor Frankl writes, “What man needs is not actually a tensionless state but rather the striving and struggling for a worthwhile goal, a freely chosen task.”<sup>56</sup>

Doctors Joanne Lynn and Joan Harrold and writer Janice Lynch-Schuster bear witness to this benefit of fighting to reframe meaning in their *Handbook for Mortals*. “Like other times of transition and profound change, this time will not always be comfortable or rewarding. You may think that you have not taken on a ‘search for meaning,’ but that is the one thing most people actually do when dying (though you may say it differently).”<sup>57</sup> They continue this encouragement by stating serious illness “forces us to think about what really matters.”<sup>58</sup>

But to reap the rich reward of this struggle to reframe meaning one thing is necessary—a protracted death. Research suggests that “there is a valuable opportunity in the foreshadowing of a terminal diagnosis—it provides the dying person with the time to discover the meaning to their life.”<sup>59</sup>

Interestingly, it may seem counter-intuitive but this may be why the often voiced desire for a swift death is not necessarily a good thing. This desire, by the way, is a recent development in Western society. According to Philippe Ariès in his study of Western culture’s attitudes of death over the past thousand years he discovered that up to and

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<sup>56</sup> Frankl, 127.

<sup>57</sup> Joanne Lynn, Joan K. Harrold, and Janice Lynch Schuster, *Handbook for Mortals : Guidance for People Facing Serious Illness*, \* ed. (New York: Oxford University Press, 2011), 5.

<sup>58</sup> *Ibid.*, 30.

<sup>59</sup> *Ibid.*

through the Middle Ages, “in this world that was so familiar with death, a sudden death was a vile and ugly death; it was frightening; it seemed a strange and monstrous thing that nobody dared talk about.”<sup>60</sup> So prevalent was this attitude that even the victim of an accident or a murder was considered cursed by God (because of the instantaneous death) and not permitted burial in a Christian cemetery.<sup>61</sup> The reason for these beliefs was the sensitivity to needing time to make things right before death arrived. (Now it must be noted that a protracted death in the Middle Ages was a comparatively short time compared with our modern ability to drag the dying process out for many years if not decades.)

Perhaps the greatest indignity Sophia was forced to face was the move out of her cute little apartment, with all her cherished mementoes from a life well lived, and relocation into a skilled nursing facility. Sophia’s last days were spent in a room with two other bed-ridden residents in a hot, stale, urine-smelling nursing home.

But Sophia thrived in her new environment. All the years she’d invested in her practice of spirituality paid off at the end. Sophia somehow learned to surrender to her fate and found meaning in helping cheer up not only her roommates but also those who worked in the nursing home. I can honestly say that she was radiant the last time I saw her.

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<sup>60</sup> Philippe Ariès, *The Hour of Our Death*, trans., Helen Weaver (New York: Vintage Books, 2008), 11.

<sup>61</sup> *Ibid.*

On that last visit, she was particularly excited because her brother Arthur was present. (Now, Arthur had been dead for many years.) Sophia was sure the Cosmos had sent Arthur to help usher her into her joyous transition. It seems she was right after all.<sup>62</sup>

### **Current Models of Meaning-Making Intervention**

In the past dozen years or so, several psychiatrists have been developing evidence based interventions for treating terminal distress among palliative and dying patients. None are more prominent than William Breitbart at Memorial Sloan-Kettering Cancer Center in New York and Harvey Chochinov at the University of Manitoba in Canada. At this point, a brief survey of their work will be helpful.

#### *Individual Meaning-Centered Psychotherapy*

Building on the work of Viktor Frankl, William Breitbart has developed a manualized seven-week intervention titled Individual Meaning-Centered Psychotherapy (IMCP). It is specifically designed for advanced cancer patients as a tool to help provide meaning, peace, and a greater sense of purpose as their disease progresses.<sup>63</sup> Breitbart's idea was to create a mini-course based on Frankl's teaching (taking Frankl's lessons from surviving a concentration camp and applying them to help patients fighting for survival against cancer) and make it experiential. As Breitbart says, "We had learned from the work of others that learning takes place more effectively when it is connected to a

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<sup>62</sup> Grewe, 150-1.

<sup>63</sup> W. Breitbart et al., "Pilot Randomized Controlled Trial of Individual Meaning-Centered Psychotherapy for Patients with Advanced Cancer," *J Clin Oncol* 30, no. 12 (2012): 1306.

profound, emotional experience.”<sup>64</sup> The goal of the intervention is to teach participants a “fluid and flexible way to think about those sources of meaning.”<sup>65</sup>

IMCP is unlike a traditional cancer support group in that it is simultaneously didactical and experiential. The seven weekly meetings are built around the following themes:

1) Concepts and Sources of Meaning: Introduction and Overview.

Session Goals: Learn patient’s cancer story and introduce concepts and sources of meaning.

2) Cancer and Meaning: Identity before and after Cancer Diagnosis.

Session Goals: Develop a general understanding of one’s sense of identity and the impact cancer has made upon it.

3) Historical Sources of Meaning: Life as a Living Legacy (past, present,

future)—Session Goals: Develop an understanding of one’s legacy through exploration of three temporal legacy modes: the legacy that’s been given from the past, the legacy that one lives in the present; and, finally, the legacy one will leave in the future. Participants also begin developing a Legacy Project.

4) Attitudinal Sources of Meaning: Encountering Life’s Limitations.

Session Goals: Explore one of Frankl’s core therapeutic principals, that ultimately we have the freedom and capacity to choose our

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<sup>64</sup> W. Breitbart, "Reframing Hope: Meaning-Centered Care for Patients near the End of Life. Interview by Karen S. Heller," *J Palliat Med* 6, no. 6 (2003): 5.

<sup>65</sup> *Ibid.*, 4.

attitude toward suffering and life's limitations and to derive meaning from that choice.

- 5) Creative Sources of Meaning: Engaging in Life via Creativity and Responsibility. Session Goals: Develop an understanding of the significance of “creativity” and “responsibility” as important sources of meaning in life.
- 6) Experiential Sources of Meaning: Connecting with Life via Love, Nature, and Humor. Session Goals: Foster an understanding of the significance of connecting with life through experiential sources of meaning—particularly through experiencing love, beauty, and humor.
- 7) Transitions: Reflections and Hopes for the Future. Session Goals: Review the sources of meaning. Review of the Legacy Project. Reflections on the lessons and impact of the therapy, discussion of hopes for the future, and the transition from being in the therapy to enacting the lessons learned in daily life as the therapy comes to an end.<sup>66</sup>

Interestingly, in this guided quest to help patients discover their own meaning the weekly gatherings are intentionally kept non-religious to make them more “universally acceptable.”<sup>67</sup>

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<sup>66</sup> Breitbart et al., "Pilot Randomized Controlled Trial of Individual Meaning-Centered Psychotherapy for Patients with Advanced Cancer," 1306.

<sup>67</sup> Breitbart, "Reframing Hope: Meaning-Centered Care for Patients near the End of Life. Interview by Karen S. Heller," 6.

This intention to keep the intervention non-religious is problematic, however. While an increasing number of people today are not following a particular faith path, many are and have for years. In their dying days, an attempt to estrange religious patients from what has been a deeply held source of meaning throughout their lifetime is not beneficial. Further, what is the impact on surviving family members who share the same faith tradition? Religion for some is a unifying aid for the entire family system.

Another difficulty with this model is its length. Seven weeks is a long intervention with a terminal population. Not only are some patients likely to die during this time, but others may become cognitively impaired or simply lose the energy to continue this therapy model. What impact do these defections have on the remainder of the group?

The strengths of Breitbart's model are its emphasis on making the intervention emotionally experiential and the focus on helping the patient create a lasting legacy.

### *Dignity Therapy*

The goal of Dignity Therapy is to create a generativity document that will outlive the dying patient. Dr. Harvey Chochinov has over ten years of empirical data to demonstrate its effectiveness in ameliorating loss of meaning pain. The method Chochinov prescribes to create this legacy involves audio recording a session wherein a therapist asks leading questions of the patient about his or her life and loves (roles and relationships). This recording is transcribed, editing out the verbiage of the therapist. The patient is then allowed to edit the transcribed document as he or she sees fit.

- Tell me a little about your life history, particularly the parts that you either remember most or think are the most important.

- When did you feel most alive?
- Are there particular things that you would want your family to know about you, and are there particular things you would want them to remember?
- What are the most important roles you have played in your life (e.g., family roles, vocational roles, community service roles)? Why are they so important to you, and what do you think you accomplished within those roles?
- What are your most important accomplishments, and what do you feel most proud of or take most pride in?
- Are there particular things that you feel need to be said to your loved ones or things that you would want to take the time to say again?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, parents, other(s)]?
- Are there important words, or perhaps even instructions, you would like to offer your family?
- In creating this permanent record, are there other things that you would like included?<sup>68</sup>

As with Brietbart, the main difficulty with this intervention is the time needed to complete the process. Dignity Therapy requires several weeks of work.

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<sup>68</sup> Chochinov, 71.

After an initial interview to explain the procedure, the questions are then left with the patient to consider and reflect upon prior to the interview. The actual interview is then arranged and recorded. Time is needed to allow for the recording to be transcribed and then the transcription is given back to the patient for further edits. Following all of this, a final document is produced to be given to the patient's loved ones. The time needed to complete all of this is simply not available in current hospital and hospice settings.

Not only is lack of time a factor but so is mental acuity. Often patients at the end of life are in great physical pain and this pain is managed by strong analgesics. Both the pain and side effects of the pharmaceuticals decrease one's capacity for clear thought and remembering. Additionally, many folks at the end of life are deluged by visits from loving family, friends, and care providers, who occupy much of the patient's waking moments and energy.

## **Summary**

Abigail Rian Evans has noted, "We fear the death of meaning more than the death of the body itself."<sup>69</sup> In more than ten years of chaplaincy I can attest to the truth of that statement. On a weekly basis I encounter numerous patients struggling with existential issues, patients like Maria.

I'd already known Maria for a while when she entered hospice. Her husband of more than sixty years had died on our hospice service the year before. Two years earlier, she and her husband had sold their home and had moved in with her daughter and her

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<sup>69</sup> Evans, 32.

family. My first visit with Maria as a hospice patient found her flat on her back in bed. She'd just been diagnosed with stage four cancer and had declined treatment. Maria's refusal to aggressively fight the cancer was particularly hurtful to her daughter, Lily, who took the decision personally. "Does she hate living with us so much that she'd rather die?"

I'll never forget the first words out of Maria's mouth when I entered her room. She looked up at me with huge brown eyes and simply said in her thick Italian accent, "What do I have to live for?" Her words pierced my heart.

As we talked, she spoke about how she'd cared for her husband and their home for the majority of her eighty-plus years. Now, both her husband and her home were gone. The cancer was simply the final blow. She was no longer able to do many of the things she'd enjoyed, such as playing with her great grandchildren. Even though she loved her daughter, the prospects of enduring chemo and radiation to simply sit on her daughter's back porch and smoke cigarettes was more than she could bear.<sup>70</sup>

What I have learned from those I have served like Maria and from the research for this dissertation is that existential suffering caused by the loss of meaning at life's end is a significant problem. While this end-of-life struggle to discover meaning is a normal human experience, for expediency in contemporary hospital and hospice care, this existential struggle is often sedated pharmaceutically, as contemporary medical practices do not have the resources to address this pain adequately.

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<sup>70</sup> Grewe, 119-20.

Current innovative psychological therapies have made great progress in addressing this pain but they are often begun too late in the end-of-life process and they ignore religion—which for many is a major component in the meaning-making process.

I believe if we are going to help people discern their life's meaning in a way that can ameliorate existential suffering at life's end and strengthen their roles and relationships with loved ones, we must go further upstream—prior to a terminal diagnosis.

Therefore, I propose the introduction of an ethical will or a legacy of the soul be added to end-of-life planning (in addition to such documents as advance directives) to help prepare for this inevitable struggle.

To help achieve this outcome, I have developed a five-week seminar to aid senior adults in the necessary self-reflection to construct such a legacy of the soul and to consider how best to pass this legacy on to their loved ones. Obviously, people at any age can be diagnosed with a terminal illness, but no single intervention is appropriate for everyone. Therefore, I have chosen to focus on developing a specific tool for senior adults, a population I work with on a daily basis. In the next chapter, I will present the philosophical, psychological, and theological foundations for the workshop.

## CHAPTER THREE

### Discovering Your Soul's Treasures

*Perhaps the deepest reason why we are afraid of death is because we do not know who we are.*<sup>71</sup> — Sogyal Rinpoche

Research into current literature on developmental stage theory highlights the importance of end-of-life meaning-making and provides a theoretical foundation to constructively assess this existential issue. In more than twenty years of researching and coaching senior adults, Frederic Hudson has identified six core values as primal incentives for meaningful living in the adult years: a sense of self (“Who am I?”), achievement, intimacy, creativity, a search for meaning, compassion, and contribution (bequeathing a legacy).<sup>72</sup> The seminar I have developed will address these core values and offer seniors a concrete mechanism for implementing them into their lives.

The idea for the Soul Legacy Seminar came as a result of my time with Margaret. A devout Presbyterian ninety-five-year-old bedbound lady, Margaret’s family had lovingly nicknamed her “Bulldog.” After meeting her, I came to understand the appropriateness of the moniker. Barely five feet tall and maybe ninety pounds soaking wet, this little spitfire of a woman had helped guide and shape her family for four generations. She was deeply loved and cared for by her offspring.

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<sup>71</sup> Sogyal, Patrick Gaffney, and Andrew Harvey, *The Tibetan Book of Living and Dying*, Rev. and updated ed. (San Francisco, Calif.: HarperSanFrancisco, 2002), 16.

<sup>72</sup> Frederic M. Hudson, *The Adult Years : Mastering the Art of Self-Renewal*, Rev. ed. (San Francisco: Jossey-Bass, 1999), 134-6.

I wasn't in her home five minutes when she started badgering me, "Why am I still here? Why won't God take me? I'm ready to die ... I've lived a wonderful life and I'm ready to go. What's taking God so long?"

I looked her right in the eye and told her, "Look, I've been a minister for over forty years and if there's one thing I've learned it's this—God is horrible ..." She was stunned and I had her full attention. "God is horrible," I said, "*at taking orders.*" She laughed hard. I continued, "Margaret, I've tried to teach God how to take orders. I really have. I've screamed, and yelled, and threatened—it just doesn't work. God shows no interest to learn."

We became instant friends.

That short conversation helped alleviate her existential pain for a little while. But when I returned the following week it was back.

"I'm ready to go. Why won't God take me? I hate just laying here and waiting ..." Margaret complained.

"Look you're dying. But, you're not in pain, you're in a comfortable bed, you're safe and warm, and the people who love you most are caring for you. At this time of life it just doesn't get any better than this. Quit your bitchin."

After the momentary shock on her face disappeared, she laughingly said, "Thanks, I needed that." Margaret was a bulldog after all.<sup>73</sup>

During our conversations I suggested Margaret might consider blessing her family members uniquely as a way to not only pass the time being bedbound but also as a legacy that would outlive her. Even though a lifelong church member, she had no idea of how to

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<sup>73</sup> Grewe, 153-4.

craft or impart such a blessing. I realized the sad truth that you cannot give what you have never received, and thus the idea for the seminar began to take shape. I wanted to help people have a safe place to receive a blessing and practice giving one.

The concept of a blessing has a spiritual foundation and thus requires a soul connection. But as I soon discovered, the term *soul* can be very problematic.

### **Soul Searching**

The nurse had called to tell me Mario was actively dying and his caregivers asked if I would come. I'd been visiting Mario once or twice a month for nearly a year, and in all that time I'd never heard him talk. He was a short man with a long European nose and waxy skin, and his glassy eyes always had a faraway look, as though he were somewhere else. On several of my visits, when I arrived and introduced myself (which I always did), he extended his hand for me to shake. That was the only response I ever got from Mario to indicate he even knew I was present.

Mario was living his final days in an adult foster home. When I arrived at the home, Mario was lying in his bed staring out the window on his left, with that familiar faraway look. He was snoring loudly, yet his glassy eyes remained wide open.

I pulled a rocking chair close to Mario's bed so I could silently pray for him. But after I got settled in, it struck me how bizarre the whole scene was. I guess Mario liked Perry Como music, because the caregivers had a Perry Como CD playing on a boom box next to Mario's bed. As I sat down, Perry was belting out, "Hot-diggity, dog diggity, boom what you do to me ..."

I began looking around Mario's room for clues to who this little man with the faraway look really was. The first thing I noticed was a huge picture of John Wayne. It was an oil painting on black velvet. On the bureau was a framed photo of a young man in a military uniform, circa World War II. The man in the photo (I assume it was Mario) reminded me of Radar O'Reilly from TV's *M\*A\*S\*H*. He looked so full of hope, so full of promise. On the wall above Mario's bed was a small, cheap, plastic crucifix.

“Hot-diggity, dog-diggity, boom, what you do to me.”

As I sat there trying to pray for Mario, looking at his vacant stare and the waxy shell that was his declining body I thought, “When does the soul leave the body?” Looking at Mario, I wondered, was he in there? I mean, was that animated spark that made Mario uniquely Mario, his soul, still inside his body or had it already left? Did it leave long ago, hence the vacant far-off stare?<sup>74</sup>

What is the soul anyway? So many people talk about the soul and just assume we all understand what is meant by the word. Is it that animated spark of the Divine so many people believe we all have? Is it the *imago Dei*? Are the words *soul* and *spirit* interchangeable? When does the soul leave the body? What happens to it after it leaves the body? These are the kinds of questions you ask if you want to start a fight. But when you're a chaplain and someone is dying and the family wants to know the answers and you're supposed to know the answers—it can all be kind of daunting.

### **Defining the Indefinable**

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<sup>74</sup> Ibid., 54 ff.

Anticipating conclusions to be drawn from current neurological research into spirituality (which some have dubbed *neurotheology*), Nancey Murphy, professor of Christian Philosophy at Fuller Theological seminary, asserts humans have no invisible immortal soul at all. She argues for a non-reductionalist physicalism—her language for purely biological beings but capable of experiencing the Divine.<sup>75</sup>

While her reasoning has not been widely embraced, one aspect of her argument is very convincing. Murphy points out that it is impossible to know exactly what the biblical authors were trying to communicate when they used their words for “soul” and “spirit” due to the later inculturation of the Semitic Christian experience with Greek philosophy.<sup>76</sup> Augustine powerfully fused Plato’s concept of an invisible immortal soul that is liberated from the body at death with the biblical teaching.<sup>77</sup> Later, Aquinas developed an elaborate hierarchy of powers of the soul based on the logic of Aristotle.<sup>78</sup> Murphy insightfully suggests that the biblical authors probably had no such concepts in mind when they first utilized words for “soul” and “spirit” and we are left to read such texts anachronistically. She concludes that the Bible does not offer a

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<sup>75</sup> Nancey C. Murphy, *Bodies and Souls, or Spirited Bodies?*, Current Issues in Theology (Cambridge, UK ; New York: Cambridge University Press, 2006), 145-147.

<sup>76</sup> *Ibid.*, 12.

<sup>77</sup> John P. Lizza, *Persons, Humanity, and the Definition of Death* (Baltimore, Md.: Johns Hopkins University Press, 2006), 41.

<sup>78</sup> Murphy, 15.

*partitive account* of what it is to be human (i.e., body, mind, soul, spirit) but rather that we are psychophysical unities.<sup>79</sup>

Murphy's notion of psychophysical unities fits nicely with the thinking of another contemporary philosopher, John Lizza. In his *Persons, Humanity, and the Definition of Death*, Lizza argues for the "the psychophysical integrity of the person."<sup>80</sup> He states that the traditional view of "a person is a *terra animate* or, as Paul Ramsey has put it, 'an embodied soul or an ensouled body,' makes no distinction between the class of human beings and the class of persons."<sup>81</sup> Lizza then proceeds to nuance the idea of person into three meanings. I find his third meaning, "substantive meaning" of *person*, to be most compelling when thinking of soul.

"... the existence, individuality, and identity of persons as substantive entities that essentially have a mind ... Personhood in this sense is what makes a particular person what she is and differentiates her from all other persons."<sup>82</sup>

What Lizza calls "the mind" I understand to be interchangeable with the term "soul" as it is used in common vernacular. The idea that our soul is what is distinctive about us is foundational to my own understanding.

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<sup>79</sup> Ibid., 21-22.

<sup>80</sup> Lizza, 179.

<sup>81</sup> Ibid., 34.

<sup>82</sup> Ibid., 40.

Lizza also observes that “what is deemed essential to the nature of a person or human being may vary with different metaphysical, ethical, or other cultural beliefs.”<sup>83</sup> This hints at another belief I hold about our souls—they are shaped in part by our experiences and our relationships. Perhaps no one has so concisely asserted that our soul is in part shaped by others as Martin Buber, who writes, “Man becomes an I through a You.”<sup>84</sup>

Bioethicist Micah Hester believes, “While biological, physiological beings are *uniquely* situated, no organic mass should be mistaken for a “self”; it takes social processes to create an individualized ‘self’ ... Community, then, is constitutive of and prior to the self.”<sup>85</sup> Here the term self is yet is another common expression for the soul. While I agree with the idea that our souls are shaped and can grow or evolve, the term *self* can be problematic. Jung differentiated between the ego (the center of personal consciousness) and the Self (the psyche as a whole.)<sup>86</sup> But then there are Buddhists who are adamant there is no “self” and any idea of “self” is simply an illusion.<sup>87</sup>

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<sup>83</sup> Ibid., 32.

<sup>84</sup> Buber and Kaufmann, 80.

<sup>85</sup> D. Micah Hester, *End-of-Life Care and Pragmatic Decision Making : A Bioethical Perspective* (Cambridge ; New York: Cambridge University Press, 2010), 24-25.

<sup>86</sup> James A. Hall, *Jungian Dream Interpretation : A Handbook of Theory and Practice*, Studies in Jungian Psychology by Jungian Analysts (Toronto, Canada: Inner City Books, 1983), 11.

<sup>87</sup> Thich Hạnh Nhất, *The Heart of the Buddha's Teaching : Transforming Suffering into Peace, Joy & Liberation : The Four Noble Truths, the Noble Eightfold Path, and Other Basic Buddhist Teachings*, 1st Broadway Books trade pbk. ed. (New York: Broadway Books, 1999), 133-36.

At this point it is becoming apparent that defining the term “soul” is a bit like trying to define a chameleon—while it is changing colors. Parker Palmer cuts through all of this soul clutter and cogently writes,

Philosophers haggle about what to call this core of our humanity ... Thomas Merton called it the true self, Buddhists call it the original nature or big self, Quakers call it the inner teacher or the inner light, Hasidic Jews call it a spark of the divine. Humanists call it identity and integrity. In popular parlance, people often call it soul.

*What we name it matters little to me, since the origins, nature, and destiny of call-it-what-you-will are forever hidden from us, and no one can credibly claim to know its true name. But that we name it matters a great deal. For “it” is the objective, ontological reality of selfhood that keeps us from reducing ourselves, or each other, to biological mechanisms, psychological projections, sociological constructs, or raw material to be manufactured into whatever society needs—diminishments of our humanity that constantly threaten the quality of our lives.<sup>88</sup>*

I particularly resonate with Palmer’s emphasis that soul is what makes us human.

### **The Wild Animal**

Of all the soul descriptions I have encountered, none is as captivating as that put forward by Thomas Merton, who compares the soul to a wild animal.

The inner self is precisely that self which cannot be tricked or manipulated by anyone, even the devil. He (the true self) is like a very shy wild animal that never appears at all whenever an alien presence is at hand, and comes out only when all is peaceful, in silence, when he is untroubled and alone. He cannot be lured by

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<sup>88</sup> Parker J. Palmer, *A Hidden Wholeness : The Journey toward an Undivided Life*, 1st ed. (San Francisco, CA: Jossey-Bass, 2008), 33.

anyone or anything, because he responds to no lure except that of the divine freedom.<sup>89</sup>

The soul is a *wild animal*. Something about Merton's metaphor simultaneously attracts and scares me. For so many years I have tried to trap and kill my wild animal because it frightened me—it's uncontrollable. I don't know where it will lead. Is this wild animal the dark side, the shadow that Jung talks about?

As I have sat with dying persons like Mario, they have given me the space to explore these questions directly and graciously allow me to admit the truth that no one really knows what the soul actually is. Oh, I know, many have strong opinions about it—opinions taught by forceful preachers or inspiring writers or out-of-the-body experiences. But the bottom line is none of us really knows for sure. The dying have reminded me that I must hold very lightly to my own strong opinions about this question and humbly acknowledge I might be wrong.

So where does all this leaves us? I propose a functionalist use for the term "soul" and *not* a metaphysical one. (This avoids getting far afield into unanswerable explorations about the afterlife.) When I write about the Soul's Legacy, I am using the term "soul" to mean all of one's values, morals, dreams, hopes, doubts, insecurities, experiences, wounds, fears, successes, loves, wisdom, ego, id, suffering, pain, persona, authentic self—the totality of one's being. In my usage it is the composite of a person's genetics, life experiences, and distinctive qualities. I agree with soul expert Thomas

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<sup>89</sup> Thomas Merton, *The Inner Experience : Notes on Contemplation (I)*, ed. Patrick Hart (Trappist, KY: Cistercian Studies, 1983), 5.

Moore's conclusion, "Soul is the font of who we are."<sup>90</sup> Therefore, for my continued work and dissertation when I use the term "soul" I simply mean what that thing is that makes me me and you you.

### **What's Your Story?**

Most of the current models employed today to help ameliorate existential suffering at the end of life utilize some form of what is termed a "life review."<sup>91</sup> Most notable among them are Harvey Chochinov's *Dignity Therapy* and William Breitbart's *Individual Meaning-Centered Psychotherapy*. More than a simple reconstruction of the facts of one's life, these therapies aim at unearthing the core values and meaning which lie underneath to be excavated and shared with loved ones. They aim, in an intentionally non-religious manner, to uncover the soul.

As I will argue, our souls are shaped by our life experiences, our interactions with significant others, our cultural worldview, and our concept of the Sacred. In our effort to understand ourselves, to connect with our soul, we integrate a life narrative from these four elements.<sup>92</sup> The poet Christian Wiman reminds us, "existence is not a puzzle to be

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<sup>90</sup> Thomas Moore, *Care of the Soul : A Guide for Cultivating Depth and Sacredness in Everyday Life*, 1st ed. (New York, NY: HarperCollins, 1992), xviii.

<sup>91</sup> Eugene C. Bianchi, *Aging as a Spiritual Journey* (New York: Crossroad, 1992), 171.

<sup>92</sup> Michael Steger, "Experiencing Meaning in Life: Optimal Functioning at the Nexus of Well-Being, Psychopathology, and Spirituality," in Paul T. P. Wong, ed. *The Human Quest for Meaning : Theories, Research, and Applications*, 2nd ed., Personality and Clinical Psychology Series (New York: Routledge, 2012), 165.

solved, but a narrative to be inherited and undergone and transformed person by person.”<sup>93</sup>

This work creating a meta-narrative for the meaning of our lives is much like printing a photograph by the old color separation process. The idea was, in order to print a color picture, the photograph had to be separated into four different colored sheets of acetate; cyan, magenta, yellow, and black. Looking at each sheet separately, a person could see only a partial view of the picture. There were many blanks and missing pieces. Only when the four sheets were piled on top of each other did the whole picture become clear. The combination of those four separate sheets made possible an infinite variety of color for the finished piece. So instead of four different colored acetates, we pull together our personal lived experiences, bits reflected to us from the people in our lives, pieces from our culture, and our personal transcendental beliefs to portray our life story—all for the purpose of making sense (meaning) out of our experiences and existence.<sup>94</sup>

The stories we weave together from these various strands of information are usually tragic ones. As Dr. Margaret Mohrmann has observed in her book, *Medicine as Ministry*, tragedies come in all shapes and sizes, minor and major, but they all have three things in common: they are sad stories; they have flawed heroes; and they represent conflicts of good and evil.<sup>95</sup>

We are each the hero in our own tragic story.

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<sup>93</sup> Christian Wiman, *My Bright Abyss : Meditation of a Modern Believer*, 1st ed. (New York: Farrar, Straus and Giroux, 2013), 91.

<sup>94</sup> Hudson, 129.

<sup>95</sup> Margaret E. Mohrmann, *Medicine as Ministry : Reflections on Suffering, Ethics, and Hope* (Cleveland, Ohio: Pilgrim Press, 1995), 69.

Tragic heroes trying to figure out why we are alive and what it all means.

### **Old Blue Eyes**

As I sat weeping next to Jack's just deceased body, what I missed most was the playful glint behind those beautiful blue Irish eyes. They truly were the window to his kind and gentle soul.

He had been a strapping young lad from Michigan camping in the Grand Tetons when Marcia and her family arrived for their vacation. Jack and Marcia hit it off straight away and, in fact, Jack followed Marcia's family back to California. He simply showed up on her doorstep and never left. That was sixty-seven years ago and part of the story Alzheimer's had erased from Jack's memory bank.

Also gone was a lifetime of working for the forestry service, raising two loving daughters, untold hours fishing, and traveling the country with Marcia in their little camper. Bedbound for the last several years of his life, as his body ever-so-slowly diminished so did a lifetime of memories and even an awareness of who he was.

What did not diminish, however, was that playful kindness in those deep blue eyes. Always present to the moment, Jack loved to laugh and tease. After months of visits and simple conversations Jack could vaguely remember my face but not who I was or why I was there. Most of the time I simply told Jack his own life story. It all started naturally enough. On one of my first visits, those blue eyes looked like a deer's caught by headlights as Jack told me he couldn't remember who he was or why he was still here. So I just started to remind him. As I told him his own life story, those blue eyes began to

water and relax. When I told him he was a good man and had lived a good life he smiled. That mischievous Irish grin captured my heart.

Over the months Jack taught me so much about living in the present moment. That's all we really have anyway. With him, the present was all there was. He taught me how lost we can get when we forget who we are, when we forget our story—and how important it is to have good friends and loved ones to remind us. He also taught me about emotional investing. Because of the love he had deposited into others throughout his ninety-plus years of living, he earned great dividends and was able to benefit from those investments when it was needed. His memory bank may have been depleted, but his emotional and relational accounts continued to thrive.

The night before he died, Marcia and their daughter Lynn were up caring for him and got no sleep. The next afternoon, Marcia had just lain down to get some rest in the next room. She told me she really didn't sleep—she called it being in a “twilight zone”—when she saw a golden luminous ball suddenly appear on the door of the bedroom. She was thinking, “Is that Jack's spirit?” when Lynn came in to tell her that Jack had just passed away.

Was that luminous golden ball that manifested on Marcia's bedroom door Jack's spirit as she believes? Was it the divine spark that animated the playful glint behind his beautiful blue eyes? I don't know. But what I do know is that my own life has been incredibly enriched by simply spending hours with a good man, basking in the glow of his love with and for Marcia, and having the distinct privilege of re-telling this kind man with the beautiful blue eyes the story he actually lived.

## **We Are Family**

Research now tells us that Jack actually began to craft his story, as we all did, within the first days of life. Studies show that newborn infants, within the first four days, “can monitor the behavior of others and react as if they had innate expectations regarding rules of interpersonal interaction.”<sup>96</sup> Therefore, one of the primary and most significant sources we use to create our life story comes from our experience within the nuclear family.<sup>97</sup> It is the family, the first group of “others,” who begin to reflect back to us who we are in the world. This familial influence goes far beyond our feelings of being loved and accepted, as we also learn important family myths, learn our place within a hierarchical structure of power, and are named.

It is within the nuclear family that we are taught “myths surrounding particular family members” and our place in the larger world.<sup>98</sup> These “family stories become part of our own personal self-definition.”<sup>99</sup> Research shows “the position we occupy within the sibling constellation of our nuclear family of origin foreshadows our expectations of ourselves and others.”<sup>100</sup> This sibling position directly affects our choices in building

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<sup>96</sup> E. Nagy, "Innate Intersubjectivity: Newborn's Sensitivity to Communication Disturbance," *Developmental Psychology* 44, no. 6 (2008): 1779.

<sup>97</sup> Evans, 7.

<sup>98</sup> B. John Hagedorn, "Counseling with Families," Barry K. Estadt et al., eds., *Pastoral Counseling*, 2nd ed. (Englewood Cliffs, N.J.: Prentice Hall, 1991), 198.

<sup>99</sup> Robyn Fivush, Jennifer Bohanek, and Marshall Duke, "The Intergenerational Self: Subjective Perspective and Family History," Fabio Sani, ed. *Self Continuity: Individual and Collective Perspectives* (New York: Psychology Press, 2008), 141.

<sup>100</sup> Edwin H. Friedman, *Generation to Generation: Family Process in Church and Synagogue*, The Guilford Family Therapy Series (New York: Guilford Press, 2011), 54.

social relationships most significantly upon our future mates.<sup>101</sup> Therefore, who we are is influenced by not only our genetic code *but also by* the learned patterns of behavior transmitted to us in the primary social network that surrounds us.<sup>102</sup>

Particularly influential is the name we are given and its meaning. In addition to our given name, the label we are identified by in the family unit, being referred to as a “clown,” the “hero,” or as a “black sheep,” has a lasting effect and is deeply resistant to change.<sup>103</sup> These labels often exert a major influence over our life choices for many years and they help form the lens by which we see ourselves. The power of these labels is one of the reasons people sometimes experience discomfort at family reunions or funerals. Regardless of how we may have grown or changed over the years, when we are reunited with people who have been in important part of our lives they often continue to reflect back to us who we once were but not who we are now.

Sometimes these early family experiences can help set the stage for a life that is rich and meaningful, and at other times, like for my friend Amos, they can set the course for rough waters.

### **Upon Further Reflection**

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<sup>101</sup> Ibid.

<sup>102</sup> Augustus Napier and Carl A. Whitaker, *The Family Crucible*, 1st ed. (New York: Harper & Row, 1978), 50.

<sup>103</sup> Friedman, 37.

Nurse Pam could hardly contain her laughter as she told me our new patient Amos wanted to see me. Amos didn't fit the usual profile of a hospice patient wanting spiritual support.

My first visit lasted an hour and a half and felt like a test. Amos dropped more F-bombs and smoked more cigarettes than I could count. I learned he'd spent a lot of years in prison, had knifed several folks, was an enforcer for mobsters, and liked to read detective stories. When he saw he couldn't scare me off, he eased up.

Over the next several weeks he told wild stories from his life and introduced me to colorful aphorisms like "Don't let your alligator mouth overload your humming bird ass."

I introduced him to Jack Reacher (the hero in the Lee Child mystery books).

He told me about how hard it was growing up. How his father used to beat him, then, when he was ten, his dad just up and left. Amos shared on his twenty-first birthday he got drunk, found his dad, and beat the shit out of him. "Greatest day of my life," he said.

Now, underneath all the F-bombs, cigarette smoke, and stories of prison life, Amos had a softer side. He told me how he had met Rena (his now deceased wife) and how his love for her changed him. "Until I met her, I never did anything that wasn't selfish ... But she taught me how to love. She taught me how to think of others. She taught me how to be kind."

His disease process worsened, and as Amos couldn't walk anymore or do anything but read his crime novels, his frustration grew more intense. One day as we were talking, Amos was again bitching about his life, his crummy apartment, and the fact

that he was dying and I just interrupted him. I don't know why but I just began to tell him what he had taught me over the weeks. I told him how moved I was by his love for Rena and how it gave me hope that it's never too late to change your life. As I went on he looked like a little kid in rapt attention. Better, he looked like a flower whose petals were opening up in time-lapse photography. I was simply reflecting back parts of him that he had trouble seeing anymore. It eased his pain, for a while.

Amos became a good friend and a great teacher. Amos taught me the power of positive reflection.<sup>104</sup>

### **The Shaping of Our Worldview**

In addition to our nuclear family, the other powerful reflection we assimilate into the work of crafting a meta-narrative of who we are and why we are comes from our culture. Cultural messages and mores act as powerful lenses by which we comprehend reality. Religious studies pioneer Ninian Smart writes, "What people believe is an important aspect of reality whether or not what they believe is true."<sup>105</sup> For Smart, the study of religions and cultural beliefs are what he terms "worldview analysis"<sup>106</sup> and comprises such elements as experience, ethics, beliefs, ritual, and institutions.<sup>107</sup> These

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<sup>104</sup> Grewe, 115-6.

<sup>105</sup> Ninian Smart, *Worldviews : Crosscultural Explorations of Human Beliefs*, 3rd ed. (Upper Saddle River, N.J.: Prentice Hall, 2000), 1-2.

<sup>106</sup> *Ibid.*, 2.

<sup>107</sup> *Ibid.*, 4.

often unseen elements exert incredible influence over the ways in which we experience and interpret reality.

In one of the more popular TED Talks, Ed Pariser describes what he calls “filter bubbles.” He points out how Google, Yahoo, and other search engines all utilize filter bubbles to try and intuit what the searcher is actually looking for when she or he types in a topic to be searched. All of the Internet search engines track the most frequently visited websites by each customer and then create, via an algorithm of filters, returned data from a search query. Pariser argues while this may serve advertisers paying the search engines, it limits our freedom to learn. These engines are simply reflecting back to us what we already know and have interest in. This example is simply a microcosm of what our culture does for and to us. Culture is a master filter of how we interpret reality.

In a slight variation of Smart’s elements of worldview analysis listed above, a brief look into four components I deem essential to crafting our understanding of reality is necessary. They are in no particular order: geography, social habitus, mythology, and ethics.

### *Geography*

The actual physical space in which we live is a major contributor to our self-understanding. This idea is underscored by the often quoted line of Jose Ortega y Gasset, “Tell me the landscape in which you live and I will tell you who you are.”<sup>108</sup> The physical terrain (i.e., mountains, plains, ocean, and desert) and climate (hot, cold, rainy,

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<sup>108</sup> Jose Ortega y Gasset quoted in Belden C. Lane, *Landscapes of the Sacred : Geography and Narrative in American Spirituality*, Expanded ed. (Baltimore, Md.: Johns Hopkins University Press, 2002), 20.

and dry) where we dwell play a significant role in our choice of careers, and, as I have argued, our life role is major factor in our experience of meaning. In a very real way the natural geography of where we live reflects back to us who we are in this world and how to be in this world.

The importance of geography upon our self-understanding has been highlighted by the research of folks like Oscar Handlin, who found in describing the archetypal experiences of Eastern European immigrants on American soil in the late nineteenth century,

‘I was born in such a village in such a parish’—so the peasant invariably began the account of himself. Thereby he indicated the importance of the village in his being; this was the fixed point by which he knew his position in the world and his relationship with all humanity. Human existence is heavily dependent upon such fixed points; they enable one to “dwell” in the world with meaning.<sup>109</sup>

What Handlin and others have discovered is that our literal roots, where we come from geographically, helps shape our self-understanding and view of the world in very profound and often unseen ways.

To go one step further, in his *Landscapes of the Sacred: Geography and Narrative in American Spirituality*, Belden Lane asserts, “However we conceive of the multifarious environments we build, and to whatever extent they appear contrived or unpretending, they inevitably define our individual and communal identity.”<sup>110</sup> The natural environment we live in helps shape our souls and our souls help shape the

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<sup>109</sup> Ibid., 34.

<sup>110</sup> Ibid., 8.

artificial environments we create. “Who we are, in other words, is inseparably a part of where we are.”<sup>111</sup>

### *Social Habitus*

Our worldview is not only shaped by our physical space, but by our social space as well. The instinctual search for tribal identity we need to create our life story has been identified and studied cogently by Pierre Bourdieu, among others. Bourdieu describes this very human activity as habitus.<sup>112</sup> It is that drive within us to identify ourselves as Democrats or Republicans, Dodger or Yankee fans, lovers of opera or country music. We actively seek out others who are like minded and will reflect back to us the “we” we want to be or want to become.

Bourdieu asserts, “Human beings are at once biological beings and social agents who are constituted as such in and through their relation to social space.”<sup>113</sup> By social space, he means the invisible set of relationships that translate into our physical space.<sup>114</sup>

At this point of the discussion, we can compare social space to a geographic space within which regions are divided up. But this space is constructed in such a way that the closer the agents, groups or institutions which are situated within this space, the more common properties they have; and the more distant, the fewer.<sup>115</sup>

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<sup>111</sup> Ibid., 6.

<sup>112</sup> Pierre Bourdieu, "Social Space and Symbolic Power," *Sociological theory* 7, no. 1 (1989): 14.

<sup>113</sup> Pierre Bourdieu, "Physical Space, Social Space and Habitus," Vilhelm Aubert Memorial lecture, Report 10, (1996): 11.

<sup>114</sup> Ibid., 12.

<sup>115</sup> Bourdieu, "Social Space and Symbolic Power," 16.

This social space is constructed upon “several fundamental powers: economic capital (in its different forms), cultural capital, social capital, and symbolic capital.”<sup>116</sup>

For Bourdieu, “habitus are the generative and unifying principles” with which we interpret our life.”<sup>117</sup>

Habitus are the structured structures, generative principles of distinct and distinctive practices—what the worker eats, and especially the way he eats it, the sport he practices and the way he practices it, his political opinions and the way he expresses them are systematically different from the proprietor’s corresponding activities / habitus are also structuring structures, different classifying schemes classifying principles, different principles of vision and division, different tastes. Habitus make different differences; they implement distinctions between what is good and what is bad, between what is right and what is wrong, between what is distinguished and what is vulgar, and so on, but they are not the same. Thus, for instance, the same behavior or even the same good can appear distinguished to one person, pretentious to someone else, and cheap or showy to yet another.<sup>118</sup>

These “affinities of habitus” form the basis for whom we love and whom we hate, who are our friends and who are our enemies, they even help determine whom we will marry or partner with—they have power over all of our relationships.<sup>119</sup>

This project of creating a social space is not only an individual enterprise but a collective one as well.<sup>120</sup> Habitus not only help define our sense of place but also the

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<sup>116</sup> Ibid., 17.

<sup>117</sup> Bourdieu, "Physical Space, Social Space and Habitus," 15.

<sup>118</sup> Ibid., 17.

<sup>119</sup> Bourdieu, "Social Space and Symbolic Power," 17.

<sup>120</sup> Ibid., 18.

sense of place of others.<sup>121</sup> For Bordieu, the essential point is that these social categories become real and symbolic differences and create a very real language of their own.<sup>122</sup>

“The social space is indeed the first and last reality.”<sup>123</sup>

### *Mythology*

In his classic text, *The Hero with a Thousand Faces*, Joseph Campbell gives the following multifaceted understandings of the term *mythology*.

Mythology has to be interpreted by the modern intellect as a primitive, fumbling effort to explain the world of Nature (Frazer); as a production of poetical fantasy from prehistoric times, misunderstood by succeeding ages (Müller); as a repository of allegorical instruction, to shape the individual to his group (Durkheim); as a group dream, symptomatic of archetypal urges within the depths of the human psyche (Jung); as the traditional vehicle of man’s profoundest metaphysical insights (Coomaraswamy); and as God’s Revelation to His children (the Church). Mythology is all of these.<sup>124</sup>

Cultural myths help encode for a society what is and what is not acceptable behavior by its members. They are deeply held narratives about what is important for the life of the individual and the community and what constitutes right from wrong.

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<sup>121</sup> Ibid., 19.

<sup>122</sup> Bourdieu, "Physical Space, Social Space and Habitus," 17.

<sup>123</sup> Ibid., 22.

<sup>124</sup> Joseph Campbell, *The Hero with a Thousand Faces*, 3rd ed., Bollingen Series Xvii (Novato, Calif.: New World Library, 2008), 330.

Working in an often invisible way, myths act as an interpretive lens by which we make mundane and important life decisions. They are the scaffolding to what we aspire to be. They help us define our place, our role in society. But as Campbell warns, if we disregard the cultural myth we will be “broken-off” and become “simply nothing—waste.”<sup>125</sup>

For example, one of our foundational American myths centers on the idea of individualism. Innumerable movie scripts, songs, and novels portray the hero bucking a whole system to declare his or her independence. From John Wayne to Rambo, from the early pioneers to modern day self-made-millionaires—we Americans highly value the rights of the individual, often over that of the community at large.

Now this mythological ethos of individualism has significant consequences on our end-of-life care and the numerous ethical issues involved with this care. This becomes our next field of cultural examination.

### *Ethics*

The import of the American mythological ideal of individualism has significant ramifications on our ideas about the delivery of healthcare. Ethics are the ideals we utilize in order to live in harmony with one another and are aids in arriving at the best possible solution for difficult situations. Bioethics are the specific tools healthcare providers utilize. These bioethical tools include ideas of autonomy, paternalism, beneficence, non-maleficence, and justice.

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<sup>125</sup> Ibid., 331.

The English word “autonomy” is derived from combining two Greek words that essentially mean self-rule. Historically “two conditions are essential for autonomy: (1) liberty (independence from controlling issues) and (2) agency (capacity for intentional action).”<sup>126</sup> Since the 1960s, autonomy has become the all-powerful controlling ethic in modern North American healthcare. As Beauchamp and Childress assert, “Respect for autonomy is not a mere ideal in health care: it is a professional obligation. Autonomous choice is a right, not a duty of patients.”<sup>127</sup> This approach, a direct consequence of our cultural mythological ideal of individualism, has greatly contributed to the current ethical crisis on end-of-life issues. Men and women are now making choices for themselves that heretofore only God could legitimately make: when and how human life comes to an end.

On the opposite end of the ethics spectrum is the concept of paternalism. At the heart of paternalism is the idea that a wiser, more objective “other” make important decisions on behalf of the patient. This was the ruling ethic in North America prior to the 1960s. Doctors, in a *Father Knows Best* fashion, often made decisions for their patients, deciding in some cases not to fully inform patients concerning the extent of their disease or options available to them. This was generally not motivated by a malicious intent to injure people, but rather an approach to not add further heartache and suffering to the afflicted. The concept of paternalism was informed by two other ethics. The first is beneficence.

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<sup>126</sup> Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics / Tom L. Beauchamp, James F. Childress*, 4th ed. (New York: Oxford University Press, 1994), 58.

<sup>127</sup> *Ibid.*, 63.

Beneficence refers to an action done to benefit others; benevolence refers to the character trait or virtue of being disposed to act for the benefit of others; and the principle of beneficence refers to a moral obligation to act for the benefit of others.<sup>128</sup>

Simply stated, healthcare providers have an obligation to do only good for their patients.

The other informing ethic of paternalism is non-maleficence. “*Primum non nocere*: Above all [or first] do no harm.”<sup>129</sup> With this ethical imperative it becomes very important how one defines harm. Harm has traditionally been understood to mean “thwarting, defeating, or setting back” the patient’s interest.<sup>130</sup> But who decides what that is? The issue between autonomy and paternalism really comes down to who decides what is best for the patient. It is an issue of control.

One other ethical consideration to be added to the mix is that of justice. “A very inclusive understanding of this right requires that everyone have equal access to every treatment that is available to anyone.”<sup>131</sup> At the current time, the issue of justice is one of the most hotly debated in the field of healthcare. On the one hand, the intrinsic American ideal of fairness would dictate that every person should have the same opportunities to the best healthcare. On the other hand are the economic realities of this impossibility. These are generally argued on a utilitarian basis. Utilitarianism counters: Why should a society spend limited resources on those who cannot contribute back to the welfare of the general good (society)?

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<sup>128</sup> Ibid., 166.

<sup>129</sup> Ibid., 113.

<sup>130</sup> Ibid., 116.

<sup>131</sup> Ibid., 244.

The interaction of these classic ethical ideals form the criteria by which most modern bioethical decisions are made. But there is one more aspect of the medical decision-making process to be considered before looking at how Christian beliefs contribute to this process. Brian O'Toole has insightfully identified four different ways people synthesize the above values in making ethical decisions: the principle approach, the consequences approach, the virtue/character approach, and the moral sentiment approach.

People who take the principle approach rely on a set of fixed principles like the Ten Commandments or the Golden Rule to make decisions. "For a principle-oriented person, an action or decision is right or wrong regardless of the consequences."<sup>132</sup> Those who use the consequence approach are more concerned about the likely outcomes. "People using this approach often ask such questions as, What's the bottom line?"<sup>133</sup> With the virtue/character approach (which according to O'Toole includes most clergy) the weight is on the integrity and responsibility of the decision maker. This approach examines intentionality and motives. Finally, people who employ the moral sentiment approach rely heavily on their feelings to make an ethical decision. These feelings are directly tied to personal interactions and a relationship with the patient.<sup>134</sup> O'Toole suggests that many ethical controversies are really the result of communication problems. People at odds are often communicating ethical ideas from these competing approaches.

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<sup>132</sup> B. O'Toole, "Four Ways People Approach Ethics. A Practical Guide to Reaching Consensus on Moral Problems," *Health Prog* 79, no. 6 (1998): 40.

<sup>133</sup> *Ibid.*, 41.

<sup>134</sup> *Ibid.*, 42.

I deal with the practical implications of this interplay between social space, mythology, and ethics on a daily basis. Possibly the best example of this existential distress for the dying I serve is captured by the experience of “feeling like a burden” to others. Remember, as Joseph Campbell warned, “if we disregard the cultural myth we will be “broken-off” and become “simply nothing—waste.”<sup>135</sup> So many of the patients I visit are terrified of losing their autonomy, violating our national myth of independence, and creating hardship for their social space. They experientially feel like “a nothing, a waste,” and often these feelings are the result of their own mental constructs of reality.

### **What’s Your Net Worth?**

As I was sitting with Frank at the Memory Care Facility waiting for my laptop to boot up so I could get an electronic signature from a facility care giver to prove to my boss and the Medicare folks that I really was sitting next to Frank at said Memory Care Facility, I received an ominous message from the Universe on the screen: “FATAL ERROR—YOUR LAPTOP WILL NOT COME OUT OF HIBERNATION.”

On one level those words meant another ten minutes in the discomfoting Memory Care Facility (after a manual shutdown of the damn laptop) waiting for the re-boot so I could obtain the coveted signature proving I really was with Frank.

On another, I wondered if this was some sort of divine commentary on my situation, as I was with a terminal patient whose memory was certainly in permanent hibernation. Regardless of the message’s intent, I simply sat with this hard-of-hearing,

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<sup>135</sup> Campbell, 331.

severely demented, and uncommunicative little man with the wavy white hair in a wheelchair. As I sat, I really started to look at him. To truly see him.

Underneath the bright green and yellow Oregon Ducks sweatshirt covered with crumbs from the morning's breakfast and the matching green and yellow Ducks hat, sat a peaceful little man clutching a soft pillow to his face. Frank had been a devout Baptist for most of his life, serving as an elder and deacon for more than fifty years.

While Frank's heart beat just fine, his memories and his soul had vanished nearly seven years before. As a result, this little man with the wavy white hair has little value in our culture. Oh, his biological organism is safe and well cared for, but for the most part Frank's just put off to the side, out of sight, in a memory care unit with many other breathing, vacant bodies. So as I was sitting with Frank, silently praying for him as the laptop sorted through its millions of codes to restart, I heard a deep male voice (emanating from the little boom box in the common room) begin to sing, "Jesus loves the little children ..."

I recognized the song—and as I sat praying for Frank I was serenaded by the words,

*Everything is beautiful in it's own way.  
Like the starry summer night, or a snow-covered winter's day.  
And everybody's beautiful in their own way.  
Under God's heaven, the world's gonna find the way.*

I began to wonder if in some crazy way Frank's dementia was a gift? Did it protect him from the suffering so many of the folks I visit endure?

In our materialized, capitalist culture we have turned human beings into commodities. A person has value and worth so long as they can produce and purchase. We esteem people based on their ability to make money, spend money, or both. For

example, people can be big jerks, but if they make or spend a ton of money we give them great respect, honor, and attention. On the other hand, someone who can do neither we ignore. Consider the plight of the homeless, the disabled, those on welfare, or the financially destitute dying—we make them invisible.

Many of the folks I visit who realize they are no longer productive and useful suffer terribly—feeling as though they are leeches to their family and friends. Did Frank’s dementia shield him from this existential and societal pain?

I left these thoughts that had sidetracked me once again from my assigned task and began praying for Frank. Lately, when I’ve been with uncommunicative folks warehoused out of sight from our highly productive world, I have taken to praying the last Beatitude taught by Jesus. A reading of the text from Matthew 5:11-12 I particularly feel a closeness to renders the words of the Master so,

“Blessed are you when your life is sucked out, you’re dislocated, and classified as a waste of time for my sake ... Rejoice and be glad for great is your reward in the Heavens. It is a sign of the prophets to intensely feel the disunity around them.”<sup>136</sup>

Seems Jesus values a human being’s net worth differently than we do. I wonder who’s right?

*And everybody's beautiful in their own way.  
Under God's heaven, the world's gonna find the way.*

## **Of Gods and Men**

The final element to explore in the work we do to create our life story involves our concept of the Divine. Centuries ago John Calvin posited that "without knowledge of

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<sup>136</sup> Bourdieu, "Physical Space, Social Space and Habitus," 70-2.

self there is no knowledge of God . . . and without knowledge of God there is no knowledge of self.”<sup>137</sup> Whatever our beliefs about transcendence, they play a crucial role in our understanding of ourselves and our place in the universe.<sup>138</sup> Kenneth Pargament argues that our search for meaning, community, and self are transformed when they are imbued with a sacred dimension. Further, he asserts that this sacred aspect should involve “dynamic change” both internally and externally.<sup>139</sup>

I use the terms God concept, Divine, and transcendence interchangeably, and I simply mean the way in which we understand our connection with something larger than ourselves.<sup>140</sup> Our God concept may be informed by sacred texts like the Bible or the Qu’ran, or by beliefs in such things as astrology, philosophy, and paranormal experiences. Wherever we draw our beliefs about the transcendent from, researchers have identified eleven primary God concepts that affect our self-understanding: Benevolent, Wrathful, Omni, Guiding, False, Stable, Deistic, Worthless, Powerful, Condemning, and Caring.”<sup>141</sup> Recent studies have also shown that people with a positive God image are

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<sup>137</sup> John Calvin quoted in Mark A. Kunkel, "God Images : A Concept Map / by Kunkel, Mark A...[Et Al.]," *Journal for the Scientific Study of Religion* 38, no. 2 (1999): 193.

<sup>138</sup> Richard L. Gorsuch and Ana Wong-McDonald, "A Multivariate Theory of God Concept, Religious Motivation, Locus of Control, Coping, and Spiritual Well-Being," *Journal of Psychology & Theology* 32, no. 4 (2004): 319.

<sup>139</sup> Robert A. Emmons and Cheryl A. Crumpler, "Religion and Spirituality? The Roles of Sanctification and the Concept of God," *International Journal for the Psychology of Religion* 9, no. 1 (1999): 18-19.

<sup>140</sup> Michael Steger, "Experiencing Meaning in Life: Optimal Functioning at the Nexus of Well-Being, Psychopathology, and Spirituality," in Wong, ed., 175.

<sup>141</sup> Ibid.

more self-directed, cooperative, and securely attached, while those with a fearful God concept are more likely to exhibit psychological distress.<sup>142</sup> These findings portend assessment and treatment possibilities for spiritual care providers working to help troubled clients gain an improved self-esteem and better sense of well-being.<sup>143</sup>

Current findings reveal “that self-regarding attitudes influence God-images. A believer selects a ‘god’ that is consistent with power-related (locus of control) and evaluative (self-esteem) self-images.”<sup>144</sup> The bottom line is that our understanding of self is a major determinant in our selection of God image. It seems Merton was right after all when he wrote, “Our idea of God tells us more about ourselves than Him.”<sup>145</sup>

### **Spiritual Safaris**

When I first met Erika she was lying on her bed, talked nearly non-stop for an hour, and was easily tearful. She lived in a modular home that was crammed to overflowing with stuff. There were books and knick-knacks everywhere and trails through the maze of brick-a-brack for her little white yappy dog to explore.

Erika was a Theosophist (a semi-religious practice begun in New York City during the late nineteenth century). Theosophists attempted to marry comparative religions, science, and philosophy into a comprehensive life practice. Their motto was

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<sup>142</sup> Ibid., 148.

<sup>143</sup> Ibid., 22.

<sup>144</sup> Peter Benson and Bernard Spilka, "God Image as a Function of Self-Esteem and Locus of Control," *Journal for the Scientific Study of Religion* 12, no. 3 (1973): 298.

<sup>145</sup> Thomas Merton, *New Seeds of Contemplation*, Shambhala Library (Boston: Shambhala, 2003), 17.

“There is no religion higher than truth.” A major teacher of this life practice was a man named Djwal Khul, whose writings (after his demise) were claimed to have been telepathically transmitted to his secretary, Alice Bailey. There is great speculation as to who really authored the ideas of Theosophism, Djwal or Alice.

In addition to Theosophism, Erika had also explored the writings of Rudolph Steiner, an Anthroposophist (a little more spiritually mystical than Theosophists), who started the Waldorf schools. Erika shared stories about traveling to Europe in her twenties and while in Paris, realized she had been there before “in another life” and had walked down the Champs Elysées to a guillotine. She told me she hoped she was ready for “the great adventure” (as her teacher Djwal Khul referred to death). During her monologue, Erika wept several times as she explained to me that she was emotionally very sensitive.

Living with Erika in her stuffed little modular home was her daughter Jasmine, who waited dutifully on Erika’s every whim. Erika also had a son (eighteen years older than Jasmine) who lived in Montana and ran a gun shop / liquor store combo. Erika and the son had been estranged for many years.

Now, I had heard from Erika’s nurse that Erika and Jasmine did not get along well. It seems Jasmine felt deep resentment for all of the time, attention, and money Erika had invested in her own spiritual pursuits, thus neglecting her role as mother. In fact, Jasmine ended up mothering Erika for most of their lives.

The day before my last visit to Erika, her nurse told me that Erika and Jasmine had a wonderful reconciliation and Jasmine had come to understand on a new level her mother’s deep need for acceptance. It was a profoundly grace-filled experience for both of them.

When I arrived the next day Erika was nearing death and I asked her if she felt there was anything she needed to do before she died. She replied, “Let’s get quiet for five or ten minutes and see what surfaces.” So we sat quietly for ten minutes or so. Erika held my hand during this time. After the quiet, Erika asked me, “Is there anything else I need to do?”

I replied, “I don’t think so ... you’ve been a seeker your whole life ... you’ve devoted yourself to your spiritual development ... you’ve done well.” Erika visibly relaxed and thanked me. I also reminded her about the loving exchange she had with Jasmine yesterday as evidence of spiritual work. We talked about the miracle of love, grace, forgiveness, and acceptance ... the more you give them away the more you get. For the first time in my two visits, Erika looked peaceful.

I remember another hospice patient named Darla. She told me that every weekend, she and her husband travel 165 miles each way to go to church. They belong to a small strict Christian sect. They drive up on Saturday night so they can be there for early “instruction” (training to become a full member) before the regular worship service on Sunday mornings. They stay for Bible study in the afternoon, then Sunday evening service, and spend the night before returning home on Monday morning. According to Darla, they do all this because they “want to be saved.” *Saved* is a religious code word for being accepted by God. Darla shared, “My biggest fear is not being in God’s will.”<sup>146</sup>

Erika and Darla were two spiritual seekers from two very different faith traditions both aching for the same thing—acceptance. This acceptance stuff is a big deal. We all are driven by it—sometimes to extremes. Some of the most devout patients I have

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<sup>146</sup> This story is from Grewe, 63-4.

encountered are terrorized by the idea they have not done enough to please God. Their god concepts were a source of fear and punishment and profoundly shaped their worldviews.

Now this is contrasted by a passage from theologian Karl Rahner, who spoke about “the totality of humanity which God will never allow to escape from his love.”<sup>147</sup> Another spiritual seeker with very different worldview.

So the question is, how is my god concept shaping my worldview?

### **Death Saves Us**

Before I detail the Soul’s Legacy seminar that is the basis of this dissertation, one more theoretical foundation piece needs to be laid. It is an idea existentialist psychotherapist Irvin Yalom has succinctly posited, “Although the physicality of death destroys man, the idea of death saves him.”<sup>148</sup> His point is that consideration of our dying actually enriches our living. Based on the insights of Heidegger and his own experience in counseling patients, Yalom asserts that often an impending awareness of death frees us from the tedious details and annoyances of everyday life and can liberate us to engage life more richly, savoring each experience precisely because it is passing and finite.

Working with numerous cancer patients Yalom observed startling shifts and deep personal growth as a result of their physical crisis. He lists most notably:

- A rearrangement of life’s priorities: a trivializing of the trivial

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<sup>147</sup> Karl Rahner and John Griffiths, *Prayers and Meditations : An Anthology of the Spiritual Writings by Karl Rahner* (New York: Seabury Press, 1980), 26.

<sup>148</sup> Irvin D. Yalom, *Existential Psychotherapy* (New York: Basic Books, 1980), 30.

- A sense of liberation: being able to choose not to do those things that they do not wish to do
- An enhanced sense of living in the immediate present, rather than postponing life until retirement or some other point in the future
- A vivid appreciation of the elemental facts of life: the changing seasons, the wind, falling leaves, the last Christmas, and so forth
- Deeper communication with loved ones than before the crisis
- Fewer interpersonal fears, less concern about rejection, greater willingness to take risks, than before the crisis.<sup>149</sup>

These observations align with my own experience working with dying patients during the past ten years. It is interesting to note that several of the most important spiritual figures over the past millennium, like Francis of Assisi and Ignatius of Loyola (who founded the Jesuits), had dramatic spiritual awakenings as a result of life-threatening experiences.

Another important aspect of Yalom's work lies in his discoveries about our defense strategies to cope with the existential anxiety concerning death. One of the two primary defense strategies he has identified is what he calls "specialness." By this he means a hyper-individuation whereby an individual believes herself/himself to be so special as to be impervious to death.<sup>150</sup> In its most extreme forms,

The individual oriented toward specialness and inviolability (and striving toward emergence, individuation, autonomy, or separateness) may be narcissistic; is often a compulsive achiever; is likely to direct aggression

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<sup>149</sup> Ibid., 35.

<sup>150</sup> Ibid., 117ff.

outward, may be self-reliant to the point of rejecting necessary, appropriate help from others, may be harshly unaccepting of his or her own personal frailties and limits; and is likely to show expansive, sometimes grandiose trends.<sup>151</sup>

In my work with the dying, these traits (not in extreme forms) are very common and lead me to believe that Yalom's diagnosis of *specialness* can be applied not only to individuals but our culture as a whole. The American idolization of individualism, our obsession with looking young, our compulsions towards achievement and violence—all can be understood in Yalom's schema as one grand cultural denial of death anxiety.

And what is his suggested therapy for death anxiety? To simply face it. Based on the Stoic philosophy “Contemplate death if you would learn how to live,”<sup>152</sup> Yalom works with his patients on what he calls death awareness. By looking at death directly, he asserts, you can actually ameliorate its anxiety.

Yalom is not alone on this insight. Poet Christian Wiman puts it succinctly (as poets tend to do), “Death is here to teach us something, or to make us fit for something.”<sup>153</sup> Eugene Bianchi asserts that death is *a* if not *the* major theme of all the world's religions, stating, “death is the great hub around which religions circle.”<sup>154</sup> And Erich Lindemann adds,

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<sup>151</sup> Ibid., 152-3.

<sup>152</sup> Ibid., 163.

<sup>153</sup> Wiman, 105.

<sup>154</sup> Bianchi, 142.

If you can begin to see death as an invisible, but friendly, companion on your life's journey, gently reminding you to not wait until tomorrow to do what you mean to do—then you can learn to *live* your life rather than simply passing through it.<sup>155</sup>

This idea, the contemplation of death as a key to living richly, was vividly portrayed to me in the life and death of my dear friend Rudy.

### **A Requiem for Rudy**

Rudy was a devout atheist who regularly attended the first Presbyterian Church. Actually, that's where we met, sort of. It's not that Rudy was looking to convert from atheism—he just loved to sing, and being in the Presbyterian choir gave him a chance to share the beauty of his deep bass voice.

The pastor was out of town one Sunday and had asked me to preach for her. The next day Rudy knocked on my office door at the hospital. After a brief introduction I thought he had come because he had been captivated by the brilliance of my sermon. I soon discovered he was on a mission and this interview was a test.

During the sermon I had mentioned I was a hospice chaplain. Rudy had come to check out my views on advance directives and set me straight if I didn't see things as he did. His wife had died after years of dementia and the toll it had taken on him and his children (both emotionally and financially) caring for her body long after her mind, memories, and anima had vacated was devastating. After retiring from a distinguished career of psychiatry, Rudy now spent his days working to help people plan for their death. He had experienced firsthand the importance of making your preferences known

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<sup>155</sup> Erich Lindemann quoted in Hudson, 95.

about the kind of medical care you would and would not want to have done if you could no longer communicate for yourself. I passed Rudy's test.

He became a dear friend and mentor. Rudy was one of those rare individuals who seemed to have shed his ego and passionately enjoyed his living. Well into his nineties, he continued to learn, to read, to sing, to travel, and to enjoy the pleasures of sex with his beloved partner. Rudy was simply alive while always having his dying in view.

The week before he died he called me to his home and asked if I would give the eulogy at his memorial service. After pointing out the incongruity of praising an atheist in a Presbyterian church—I humbly agreed. He chuckled and handed me a file folder containing what he wanted me to say. The folder contained the distilled data of his richly lived life: his resume, his accolades, and his distinguished achievements. All facts. But what was missing from the folder was the delight he exuded when learning new discoveries about how the brain works, the passion in his eyes as he shared his thoughts about living and dying, the joy on his face while singing in a choir. What was missing from the folder was the way he made you feel special when you were with him.

Early on in our relationship Rudy sent me a letter in which he quoted Johannes Brahms from one of the pieces he loved to sing, "The German Requiem." Words Rudy's life made very real.

*"Lord, make me to know the measure of my days on earth,  
to consider my frailty that I must perish."*

## **Summary**

In this chapter I have presented the philosophical, psychological, and theological issues surrounding the existential distress experienced by many elderly folks at the end of

life. To help minister to these numerous issues, I assert it is vital to help senior adults reflect on what they have learned in their living to be of lasting value in order to pass these treasures of the soul on to their loved ones.

To begin this process we explored what is meant by the term “soul.” In this paper I do not use *soul* in a metaphysical sense but rather in a more functional way. I use *soul* to mean all of one’s values, morals, dreams, hopes, doubts, insecurities, experiences, wounds, fears, successes, loves, wisdom, ego, id, suffering, pain, persona, authentic Self—the totality of one’s being. In my usage it is the composite of a person’s genetics, life experiences, and distinctive qualities.

Next we examined the major project of the soul, the construction a life narrative. This life story helps us discern our sense of meaning and our place in the world. These goals are accomplished by weaving together our actual lived experiences with the reflections we receive from our significant relationships, our culture, and our concept of the Divine.

Considerable space was devoted to the cultural reflection (worldview) aspect in building our meta-narrative and its constituent parts: geography, social habitus, mythology, and ethics.

Finally, I presented a discussion of how a direct confrontation with the existential reality of death can offer the impetus for living a more engaged life.

As I struggled at the beginning of this chapter to help Margaret with her existential distress, I was searching for a spiritual approach to help ameliorate her suffering. In my own struggle to help Margaret and numerous others like her, the biblical concept of imparting a blessing to surviving loved ones emerged. These sentiments

capture the heart of what this qualitative case study is really about. My goal is to create a spiritually based program to help people become less afraid of dying and more engaged with living. Frederic Hudson offers an important insight to this end.

Older adults have seen the face of death in every life transition they have traversed. They have lived with the unknown, the sense of helplessness, the futility of loneliness, the lack of a future. And each time, they arrived at new strength, fresh vision, and hope. Perhaps our transition experiences throughout our lives are rehearsals for our dying—our greatest resources for living with our ultimate unknown, over which we have no control.<sup>156</sup>

My hope for this seminar, to be presented now in detail, is to help aged persons draw upon the resources—those that have helped them to survive and thrive in life—to support them on the final leg of their journey and to pass these jewels on to those who love them.

### **The Soul Legacy Seminar**

In my years working as a hospice chaplain, I have seen the existential issues addressed in the previous two chapters played out again and again in the lives of dying patients. The great difficulty is that these issues are not only complex and multilayered, but all too often the people I serve no longer have the physical stamina or mental acuity to adequately wrestle with them.

Therefore, my plan is to develop a mechanism to help senior adults begin to address these inevitable existential concerns long before the diagnosis of a serious or life-threatening illness. To this end, I have developed a five-week seminar to aid senior adults

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<sup>156</sup> Ibid., 203.

in the process of crafting a soul legacy to have as a foundation for their eventual end-of-life process and a gift to be passed onto surviving loved ones.

A corollary aim of the seminar is that those participants who upon reflection of their life are dissatisfied with their soul's legacy will still be able to make changes by investing in meaningful experiences and relationships while they have the health, time, and energy to do so. Research has shown that if we can help people experience an increased satisfaction in their living, this will mitigate an excessive anxiety in their dying.<sup>157</sup>

The way I presented this concept to prospective attendees was by sharing that they probably have a financial will to disperse monetary assets at their eventual time of death, but what about their soul's assets? Who will inherit those, and how? And just as a financial will can be modified every few years, so too can their soul's legacy be adjusted and modified as life and relationships warrant. This seminar is simply an opportunity to begin the process of crafting such a legacy of the soul.

Additionally it was shared that the soul's legacy does not have to be a written document. Some people struggle with finding the right words and are simply not comfortable or skilled in the use of words. Therefore, the legacy of the soul can be anything that communicates wisdom acquired over a lifetime of living and love for specific individuals. Example of these will follow shortly.

What follows is a description of the seminar as it was experienced by over thirty senior adults in the spring of 2015 at three different venues. The following chapter will offer reflections and analysis of the seminar as a qualitative case study.

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<sup>157</sup> Yalom, 208.

## **Week One: Connecting with Your Soul**

Prior to the first session, participants were given a handout (Appendix A) with the instructions for bringing a Soul Print Box containing five or so items to help reveal their souls.

As we met for the first session our time began with a reading of the following piece by Henri Nouwen to help create the kind of open and safe space for our sharing times together. Nouwen describes this idea beautifully when he writes about hospitality.

Hospitality is not to change people, but to offer them space where change can take place. It is not to bring men and women over to our side, but to offer freedom not disturbed by dividing lines.... The paradox of hospitality is that it wants to create emptiness, not a fearful emptiness; but a friendly emptiness where strangers can enter and discover themselves as created free; free to sing their own songs, speak their own languages, dance their own dances; free also to leave and follow their own vocations. Hospitality is not a subtle invitation to adopt the life style of the host, but the gift of a chance for the guests to find their own.<sup>158</sup>

This was followed by a brief discussion about our agreement to confidentiality of what was shared in the group and to offer acceptance to each other and the ideas shared.

After each person shared for about five minutes what they brought in their Soul Print Box and why, the session concluded with the following meditation. The participants were asked to sit comfortably, close their eyes, and listen reflectively.

I recently took a class called “Living with Dying.” One of the folks in the class was a retired minister and he shared a thought I have been turning over ever since. He said *grief* is the pain we feel when something is ripped

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<sup>158</sup> Henri J. M. Nouwen and Robert Durback, *Seeds of Hope : A Henri Nouwen Reader* (Toronto ; New York: Bantam Books, 1989), 36.

from our lives and *grieving* is the work of re-stitching our lives back together without that piece.

Now, as we've discussed, all of us create a life narrative of who we are and what our life means. We stitch this story together using pieces of our experiences, our family's influence, and the values of our culture. When a major thread in our self-narrative is ripped out our story begins to unravel.

For example, I'm a husband, a father, and a chaplain. If my wife were to die or we got divorced, I would no longer be a husband. There would be a hole in my self-narrative. A hole that would hurt. Grieving is the work of re-stitching a life narrative together without that piece as husband. Now I was a husband—and that influence will remain—but I would no longer be husband. I would have to begin a new chapter in my story without that piece. The same is true with the loss of a job. If I were to get fired and could no longer be chaplain, who would I be? What new story would emerge?

Our lives are shaped to a large extent by these griefs we experience *and* the grieving work we do to cope, much the way a sculptor shapes a statue.

There's an apocryphal story told that Michelangelo had a most unusual approach to sculpting. Upon selecting a stone, all the other artisans in Florence would make sketches of their intended finished product and then begin to hammer away shaping the slab into their image. Not Michelangelo. It was said that upon receiving a block of marble, he would just sit and stare at it for days. He would walk around it. He would glide his hands over it—to feel it. He seemed to peer into the stone's very core. Then, without any ceremony (or sketches) he would simply pick up hammer and chisel and begin to hack away. You've seen the results.

When asked what the inspiration for his unique approach was, Michelangelo simply stated that he looked to find the beauty that already lay inside the stone, and he just wanted to set it free. His work with chisel and hammer was one of liberation. He didn't create masterpieces—he set them free.

That's what grace does—it sets us free. Free from our delusions. Free from our inflated sense of importance. Free from being the center of the universe.

But as theologian Belden Lane warns, "... grace rarely comes as a gentle invitation to change. More often than not it appears in the form of

an assault, something we first are tempted to flee.”<sup>159</sup> Grace hammers away at our rough edges sculpting us into more compassionate human beings. This aspect of grace is never fun, but it is necessary for authentic spiritual growth.

The process of being sculpted hurts like hell. While in the throes of a grief you often feel like you can’t see your way out, you can’t find a firm place to stand, and you fear it will never end. But it does. Joseph Campbell is the famous mythologist who studied religious and cultural stories from all over the world and he discovered, “One thing that comes out in myths, for example, is that at the bottom of the abyss comes the voice of salvation. The black moment is the moment when the real message of transformation is going to come. At the darkest moment comes the light.”<sup>160</sup> Falling into the well of grief, enduring the dark night of the soul, and emerging as a wiser, gentler person is all part of the human experience. It’s what helps make us human.

Expanding on Thomas Merton’s description of the soul as a wild animal that was on your assignment sheet for this week, Parker Palmer shares the following insight.

“Like a wild animal, the soul is tough, resilient, resourceful, savvy, and self-sufficient: it knows how to survive in hard places. I learned about these qualities during my bouts with depression. In that deadly darkness, the faculties I had always depended on collapsed. My intellect was useless; my emotions were dead; my will was impotent; my ego was shattered. But from time to time, deep in the thickets of my inner wilderness, I could sense the presence of something that knew how to stay alive even when the rest of me wanted to die. That something was my tough and tenacious soul.

Yet despite its toughness, the soul is also shy. Just like a wild animal, it seeks safety in the dense underbrush, especially when other people are around. If we want to see a wild animal, we know that the last thing we should do is go crashing through the woods yelling for it to come out. But if we will walk quietly into the woods, sit patiently at the base of a tree, breathe with the earth, and fade into our surroundings, the wild creature we seek might put in an

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<sup>159</sup> Belden C. Lane, *The Solace of Fierce Landscapes : Exploring Desert and Mountain Spirituality* (Oxford ; New York: Oxford University Press, 2007), 32.

<sup>160</sup> Joseph Campbell and Bill D. Moyers, *The Power of Myth*, 1st ed. (New York: Doubleday, 1988), 39.

appearance. We may see it only briefly and only out of the corner of an eye—but the sight is a gift we will always treasure as an end in itself.”<sup>161</sup>

Parker Palmer shares he became keenly aware of his soul when he was suffering through a bout of depression. Psychologist Thomas Moore suggests this is not uncommon. He writes, “... soul appears most easily in those places where we feel most inferior.”<sup>162</sup>

I suggest we reflect on this concept for the next few moments. Get comfortable in your chair and if you’re willing close your eyes. For our meditation, I’m going to ask that you try to remember a time when you felt inferior, weak, afraid. Where were you? How old were you? What did it feel like? What part of your body feels the experience most?

Now with that feeling in tow, let’s take a walk into the forest Parker Palmer described. Notice the trees ... the fallen leaves along the path ... sunlight casting beams through the branches ... listen to the quiet. You spot a safe place to sit, and comfortably ease to the ground. As you sit quietly, feeling so vulnerable and afraid and alone ... you simply wait. Breathe with the earth. Rest.

Can you see or sense or feel that Someone or Something appear that helped you through that difficult time? That Someone or Something that made you feel so not alone. Is this your soul? Is this God? Is this presence strong ... loving ... kind? Do you trust it?

Sit with it.

If you sense that presence with you now, you might want to simply place the palms of your hands together as a reminder to yourself of what this feeling is like ... being with your protector. Let the sensation of the skin on your hands touching each other remind you of what it feels like being with your protector ... your strength.

Thank the presence for being there with you. Thank it for being trustworthy.

Now after that presence has departed, you can just sit and relax for a moment. Enjoy the sensation of feeling safe. Enjoy the sensation of feeling loved.

When you feel like it, you can slowly see yourself get up and begin to causally emerge from the forest ... feeling energized, secure.

When you’re ready ... you can open your eyes.

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<sup>161</sup> Palmer, *A Hidden Wholeness*, 58-59.

<sup>162</sup> Moore, 51.

At the conclusion of the reflection, participants were given the homework assignment for the next class (Appendix B). They were to think about their lives and plan to share for about five minutes a meaningful story from their past at the next session.

### **Week Two: Connecting with Your Story**

As this session began, a presentation was offered that explained the overall plan of the seminar. Each week, a different element was being introduced that would facilitate the creation of a soul legacy project. I utilized the metaphor of making a stew to this end. The different components we would explore each week (i.e., our soul, our story, our relationships, our God concept, and our feelings about finitude) would all contribute, like vegetables in a stew, to our end product. Each person's creation would be unique, but hopefully nourishing to themselves and those they love. The goal of simply beginning the project was highlighted, with no expectation of a completed legacy by the conclusion of the course.

It was also made clear that the soul legacy did not have to be a written document. This was done to alleviate the stress on those who do not have comfort or facility with words. While the goal is to communicate the wisdom gained over a lifetime of experiences and learning, it was suggested this communication could take any number of forms. Examples given included: a scrapbook, a painting, a piece of woodwork, jewelry, a book of favorite recipes, or a collection of favorite songs. The aim is to communicate, in a very personal way, the treasures of the participant's hearts.

As an introduction to the sharing of stories participants prepared for this session, there was a brief extemporaneous presentation on the importance of the concept of

*reflection* (see page 14 of this dissertation). The main idea offered is that we can only understand ourselves by being in relationship with others.

Finally there was a brief discussion on the importance of *story* in our understanding of who and why we are—and that our self-understanding *story* is created by our lived experiences, our family role(s), our culture, and our image of the Divine. This *story* is also reinterpreted many times over the course of our lives as new experiences and learning warrants.

The time of story sharing was opened with a reading of Mary Oliver’s “When Death Comes”:

When death comes  
like the hungry bear in autumn;  
when death comes and takes all the bright coins from his purse

to buy me, and snaps the purse shut;  
when death comes  
like the measles-pox

when death comes  
like an iceberg between the shoulder blades,

I want to step through the door full of curiosity, wondering:  
what is it going to be like, that cottage of darkness?

And therefore I look upon everything  
as a brotherhood and a sisterhood,  
and I look upon time as no more than an idea,  
and I consider eternity as another possibility,

and I think of each life as a flower, as common  
as a field daisy, and as singular,

and each name a comfortable music in the mouth,  
tending, as all music does, toward silence,

and each body a lion of courage, and something  
precious to the earth.

When it's over, I want to say all my life  
I was a bride married to amazement.  
I was the bridegroom, taking the world into my arms.

When it's over, I don't want to wonder  
if I have made of my life something particular, and real.

I don't want to find myself sighing and frightened,  
or full of argument.

I don't want to end up simply having visited this world.<sup>163</sup>

At the conclusion of the story sharing session the following quote from Gabrielle Roth  
was read as a closing benediction.

In many shamanic societies, if you came to a shaman or medicine person  
complaining of being disheartened, dispirited, or depressed, they would  
ask one of four questions.

When did you stop dancing?

When did you stop singing?

When did you stop being enchanted by stories?

When did you stop finding comfort in the sweet territory of silence?

Where we have stopped dancing, singing, being enchanted by stories, or  
finding comfort in silence is where we have experienced the loss of  
soul.<sup>164</sup>

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<sup>163</sup> Mary Oliver, *New and Selected Poems, Volume Two*, 1st ed. (Boston, MA: Beacon Press, 2004), 8.

<sup>164</sup> Gabrielle Roth ~ *The Four-Fold Way: Walking the Paths of the Warrior, Healer, Teacher and Visionary*, <http://www.elephantjournal.com/2012/07/in-many-shamanic->

### **Week Three: Connecting with the Divine**

Prior to the third session, participants were given the assignment to reflect on their image of the Divine and bring representative items of that image to share with the group (see Appendix C).

This week's session began with a brief explanation on one of the end goals of this seminar, namely the development of a program for churches and other faith communities to help senior adults begin crafting a soul legacy. I also shared how current work in this area being done by psychiatrists generally disregards religion. It was acknowledged that not everyone finds religion meaningful but some people do. There was also given a disclaimer that the concluding meditation for today's session, taken from Christian Scriptures, was by no means an intent to convert anyone, but rather an effort to make this program useful for church groups.

I also gave a brief reminder of the premise shared last week, that what we weave our life story from is: our experiences, our family role(s), our culture, and our concept of the Divine. To further explain my thinking, I used the metaphor of the computer operating system that runs in the background on our computers. Whether it's Microsoft Windows or an Apple, without the operating system that is running unseen in the background, none of our computer programs will run effectively. Similarly, our experiences, our family role(s), our culture, and our concept of the Divine all run unseen in the back of our minds as we create our life story. What we are working at is reflecting

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societies-if-you-came-to-a-medicine-person-complaining-of-being-disheartened-dispirited-or-depressed-they-would-ask-one-of-four-questions/.

on these elements to evaluate if they are helpful in creating our life story or if they need to be adjusted.

This was followed by a time of the participants sharing their images of the Divine.

After the sharing, there was a brief discussion and I closed this portion of our time by reading the following quote from Thomas Merton, “Our idea of God tells us more about ourselves than Him.”<sup>165</sup>

Week three’s session concluded with the following meditation. The participants were asked to sit comfortably, close their eyes, and listen reflectively.

Close your eyes and imagine Judgment Day. Imagine the Last Day. Imagine the Great White Throne, the sea of glass, the four and twenty elders. Everyone who has ever lived is gathered together in a great hall for final judgment. A massive sea of people stretched beyond eyesight. One by one, as a person’s name is called out, the great crowd of humanity parts and allows the person called to step forward and approach Almighty God. Each stands before God, all alone and looks God right in the eye. Eyeball to eyeball with God.

After a period of time you hear your name called. As the crowd parts you get your first glimpse of God. The Almighty seated on a great throne. Behind is the emerald-like rainbow. There is the sea of glass—and the four and twenty elders—and those four living creatures with eyes everywhere buzzing and hovering over the scene. Peals of lightning emanating from the throne. When you look at God, what do you see? What do you see?

When you’re ready ... you can open your eyes.

After the meditation, the remainder of the time was spent debriefing about the experience.

#### **Week Four: Connecting with Others**

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<sup>165</sup> Merton, *New Seeds of Contemplation*, 17.

Prior to the fourth session, participants were given instructions asking them to prepare a blessing for a classmate at the next gathering (see Appendix D).

This week's session began with little introduction, and a chair was placed in the center of the circle where the recipient of the blessing was to sit. The blessing was told to look into the eyes of the one they were blessing.

After each person received their blessing, the remainder of the time was spent debriefing about the experience. I concluded this session with the following quote from Henri Nouwen,

Small signs of friendliness can create much joy, and small disturbances between people much sadness, while the “great events” of the day often do not touch us so deeply. An unexpected note from a friend or the passing remark from a co-worker can make or break my day emotionally, while inflation and recession, war and oppression do not touch my emotions directly.

But how little do we use this knowledge? How seldom do I do this? Still, I realize that every time someone says, “I appreciated your remark” or “You really helped” or “You really fit in here”—I feel my inner life being lifted up and the day seems brighter, the grass greener, and the snow whiter than before.

Indeed the great mystery is that a small, often quite immaterial gesture can change my heart so much. The way to the heart always seems to be a quiet, gentle way.<sup>166</sup>

### **Week Five: Connecting with Mortality**

There was no homework assigned prior to the last session.

As we met, there was a brief disclaimer that the final exercise was a meditation on our own dying. The purpose of the reflection is not to frighten, but rather help us awaken to the wonder of our lives and consider how we really want to use the gift of time remaining to us.

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<sup>166</sup> Henri J. M. Nouwen, *Mornings with Henri J.M. Nouwen : Readings and Reflections* (Ann Arbor, Mich.: Charis Books, 1997), 62.

The Nine Contemplations that follow offer a way to explore the inevitability of death and what is important to us in the light of our mortality. The practice asks us to question what we are doing in our life at this very moment and to see what is important for us to do in order to prepare for death. The contemplations come from Atisha, an eleventh-century Tibetan Buddhist scholar, who systematized the method for generating an enlightened mind. This practice is based on the work of Roshi Joan Halifax and Larry Rosenberg.

### **Meditation: The Nine Contemplations**

#### *The Practice*

Find a comfortable place to sit. Make sure that your body is relaxed and calm. If you want to, close your eyes. Let your mind settle. Bring your attention to your breath. There are nine contemplations that remind us about the nature of life and death. Please consider them deeply.

#### **1. All of Us Will Die Sooner or Later**

Even though it may be difficult for you to realize that someday you will die, there is no question that you will be met by death sooner or later. There is no way around it. No one can prevent death; death is the outcome of birth. It is inevitable.

Not a single sentient being—no matter how spiritually evolved, powerful, wealthy, or motivated—has escaped death. The Buddha, Jesus, and Muhammad did not escape death, nor will you and I. All the gifts of your life—education, wealth, status, strength, fame, gender, friends, and family—will make no difference at the moment of death. In fact, many of these circumstances can make dying harder because we hang on to them. Death lends a sense of profound equality to us all.

Look at your life. What are you doing right now that will help you die? Please consider this, and observe your response to this question. Then remind yourself, “Death is inevitable. I, too, will die.” Repeat this statement to yourself. On the in-breath, “Death is inevitable.” On the out-

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<sup>167</sup> This meditation is based on the work of Larry Rosenberg, *The Nine Contemplations of Atisha*, ed. Roshi Joan Halifax, <https://www.upaya.org/dox/Contemplations.pdf> (accessed August 8, 2015).

breath, “I, too, will die.” When the mind wanders away from this contemplation of the inevitability of death, call it back. Do not lose the opportunity to realize that you cannot avoid your death. You might resist by drifting in thought or turning to fantasy. Bring your attention back to this contemplation—that you will die, that each being precious to you will die, that each person and each creature now on earth will die.

Watch what the mind may do to escape this very simple fact. Death is inevitable. Can you face this truth? Can you feel it in your body, your blood, your bones; can you know it in your breath? The inevitability of death pervades every cell in your body. Please do not forget this. Death is inevitable; this is the first contemplation.

### **2. Your Life Span Is Decreasing Continuously**

Your life span lessens every moment that you live. There is the moment of your birth, and then the time of your death. Life flows for better or worse between these two points of change. Your movement toward death never stops. Every breath you take in and give out brings you closer to this destination that we call death. Every word that you speak, every thought that you have brings you nearer to death. Every step that you take brings you closer to your so-called final resting place.

As you consider that your life span and that of all living beings is ever decreasing, notice what comes up in your mind. If the mind attempts to divert you, call yourself back to this truth that your life is limited. Recognize this. See it clearly. Perhaps appreciate what you have now, and that there may be no tomorrow.

In light of your life’s ever decreasing span, what are you doing with this precious life now to live life fully and to support a sane and gentle death? Do you appreciate this life? What are you doing to help others? What will give your life meaning and the lives of others meaning in the light of life’s briefness? Please ask yourself these questions as you remember that your life grows shorter each second. This is the second contemplation.

### **3. Death Will Come Whether You Are Prepared or Not**

Life is short, and most of us will meet our death without having strengthened our awareness of our true nature. How much time do you now spend training, strengthening, and stabilizing your mind? When death comes, do you think that you can negotiate with it for more time?

Someone once said that we have 1,300,000 thoughts every day. How many of these thoughts are you even aware of? How many of these thoughts are about liberation from suffering and death? How often do you remember that, indeed, death will come? How often do you turn your

mind toward the commitment to prepare for death? Death is merciless. It has no discrimination. Up until the time it comes, if we are wise, we will be mindful of death.

Please ask yourself: How do you spend your time? What really is important for you to do with this precious human life? We spend so much time eating, drinking, grooming, playing, working, sleeping. We conduct business, make and spend money, and tend our relationships. When we are dying, we might wonder, "What have I done with my life?" Most of us are doing so little to prepare ourselves for death. This contemplation, reminding us that death will come whether we are prepared or not, encourages us to take care of life now and prepare for death.

In light of the truth of your ever-decreasing life span, how do you want to spend your time, your energy, your resources? Is there a way that you can truly benefit others and yourself? What kind of practice will strengthen your mind? What can you do to wake up in this life? Is your capacity to give attention to the mind and body in this moment adequate to meet the challenge of dying and death?

You can ready yourself right now. Watch your mind. Does it avoid facing the fact that death will come regardless of whether you are prepared for it? Before going on this journey, please make the best arrangements possible. Prepare yourself for going to this destination that we call death. Consider the third contemplation that death will come whether will come whether or not we are prepared.

#### **4. Your Life Span, Like That of All Living Beings, Is Not Fixed**

Think of the many beings who died this day. How many of them really thought they were going to die today? There is an essential uncertainty about the time of your death. Do you really think that you know how much time you have left? Please consider this.

Death can come at any moment. You could die this afternoon; you could die tomorrow morning; you could die on your way to work. You could die in your sleep. Most of us try to avoid the sense that death can come at any time, but the timing of death is unknown to all of us.

Can we live each day as if it were our last? Can we listen to one another, relate to one another, as if there is no tomorrow? Are you ready to die? Abide in the cycle of your in-breath and out-breath, remembering that death can come at any moment. You do not know how long this life span will be. This is the fourth contemplation.

#### **5. Death Has Many Causes**

There are so many ways to die. The causes of death are infinite. You can die because of a storm or an accident; you can die of cancer, heart

disease, diabetes, old age, and so forth. You can die of fear or a broken heart. Even if you have been diagnosed with a so-called terminal illness, it may not be the cause of your death.

Watch what your mind does when you contemplate the truth that death can come through so many doors. Do you try to avoid this thought, or are you able to consider the possibilities? There are many conditions that bring death, and the forces that sustain life are few. All life ends in death, one way or another. Consider this fifth contemplation that death has many causes.

### **6. Your Body Is Fragile and Vulnerable**

When you are young, you may feel as if you will live forever. Growing older, seeing other people die, you may know differently. Life hangs by a breath. Breathe in. After this next exhalation, consider the possibility that you might not be able to inhale. When the wind has gone from your nostrils and the breath no longer enters your body, then your life span has ended, and you will die.

Look deeply at the truth of this. Say to yourself, “This life is so fragile and is completely dependent on my breath. Breathing in, my life depends on this inhalation. Breathing out, my life depends on this exhalation.” Can you allow yourself to really know that your life is hanging by a breath? Inhalation, “My life depends on this in-breath.” Exhalation, “My life depends on this out-breath.”

The beating of your heart, the activity of your brain gives life to your life. A heart attack or a stroke can bring you down in an instant. An accident, a moment of violence, a mistake can bring your life to a surprising and rapid end.

Consider how vulnerable this body is. What does your mind do when you remember this? Does knowing how vulnerable and fragile you are turn your mind toward living? Does it deepen your experience? The sixth contemplation is a reminder to consider this human body. Your life is literally hanging by a breath.

### **7. Your Loved Ones Cannot Keep You from Death**

It is only natural to turn to friends and family at the time of your dying. However, the people whom you love cannot keep death from you, and these strong attachments may produce sorrow and clinging, which make dying more difficult. Your loved ones are essentially helpless and powerless in the face of your dying. No matter how kind and adept your friends might be, ultimately they cannot prevent your death. There is nothing they can do for you at the moment of your death. Death will simply prevail. Look at this deeply.

Since your friends will not be able to stop death from taking you, ask yourself, what really is going to help at the moment of your death? Your loved ones cannot keep you from death. This is the seventh contemplation.

### **8. At the Moment of Your Death, Your Material Resources Are of No Use to You**

Imagine yourself on your deathbed. You are growing weaker and more frail by the moment. You have spent your entire life earning money, accumulating material possessions. You have a beautiful house, a nice car, jewelry, and fine clothes. On the threshold of death, what good are these things to you?

Every single penny, every single item must be left behind. Houses, bank accounts, art objects, fine wines, beautiful clothing, expensive jewelry—all the comforts that you worked so hard for—you have to leave behind. They will be utterly useless to you when you are on the threshold of death. In some sense they are worse than useless. They are impediments to fully surrendering to death. In order to die in peace, you will have to let go of everything. In considering this, can you see yourself clinging to these things that make up part of your story and identity?

Consider that all your cherished objects, all your money, will be in some way or another redistributed at the time of your death. Everything that you have accumulated over so many years will be given away to friends and relatives. Some of it may end up in a thrift store or a junk pile. You can take nothing with you.

Now ask yourself, "What is a sound investment to make in this life?" What will be really important at the moment of my death? Material possessions will not help. On the in-breath consider this. On the out-breath know what it is to release the breath and attachment to all that you possess. This is the eighth contemplation; that your material resources will be of no use to you at the moment of your death.

### **9. Your Own Body Cannot Help You at the Time of Your Death**

You have spent so much time working on your body—feeding it, watering it, exercising it, dressing and undressing it, beautifying it, enjoying and not enjoying it. You may spend hours just thinking about your body, viewing it in a mirror, evaluating its appearance, trying to make it look younger and more beautiful. Then what happens? It dies on you anyway.

Since your conception and birth, this body has been your constant companion, sometimes a friend, sometimes an enemy. You have experienced so much pain in it and so much pleasure. You treasure it. You despise it. And at the moment of death, you lose it.

This is not to say that you should neglect this body. You should take care of it. Although you are not your body, the care you give your body may make a difference in your practice and your relationships.

At this moment can you feel your dependence on your body, your attachment to your body? Can you see how holding on to your body at the time of your dying might torment you?

Imagine what it might be like just before you die. You realize suddenly that you are losing your money, your friends, your loved ones, your status, your job. And at the moment of your death, in an instant, you will also lose your body. Consider this. Abiding in the in-breath, abiding in the out-breath, remember that even your body cannot help you at the time of death. Can you understand how others may feel who are facing their deaths? Why there is so much fear, so much clinging to life, such anger in anticipation of giving up life? Can you feel compassion for yourself and for others?

What is really important for you in light of this truth that we cannot hold on to this body when we die? What can you do to prepare yourself to face your death and to skillfully help others face theirs? What can you do to prepare? What can you do to strengthen your awareness and your capacity to surrender to death? What can you do to make it more possible to really be present for yourself or another who is facing the loss of everything at the moment of death? The ninth contemplation reminds us that our body will be of no use to us at the moment of our death.

These are the nine contemplations: Death is inevitable. Our life span is decreasing continuously. Death will come regardless of whether we are prepared for it. Human life expectancy is uncertain. Death has many causes. The human body is fragile and vulnerable. Our friends cannot keep us from death. Our material resources cannot help us at the moment of death. And our own body cannot help us at the time of death. Consider these truths.<sup>168</sup>

(At the end of the meditation created by Roshi Halifax, I added a tenth contemplation asking the participants to once again go back to the forest from the

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<sup>168</sup> Roshi Joan Halifax, *The Nine Contemplations of Atisha* (Louisville, CO: Sounds True).

exercise we shared in week one. The focus here was to contemplate if the Divine presence we experienced then will also be accessible to us on the death bed.)

The meditation concluded with the following insight from Henri Nouwen:

Am I afraid to die? I am every time I let myself be seduced by the noisy voices of my world telling me that my “little life” is all I have and advising me to cling to it with all my might. But when I let those voices move to the background of my life and listen to that small soft voice calling me the Beloved, I know that there is nothing to fear and that dying is the greatest act of love, the act that leads me into the eternal embrace of my God whose love is everlasting.<sup>169</sup>

After the mediation, the remainder of the time was spent debriefing about the experience and the seminar.

This detailed description of the sessions comprising the Soul Legacy seminar provides a context for understanding the results, presented in the next chapter, of what the thirty-four participants in my qualitative case study experienced.

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<sup>169</sup> Nouwen, 107.

## Chapter 4

### The Soul Legacy Seminar Experience

*Remembering that I'll be dead soon is the most important tool I've ever encountered to help me make the big choices in life. Because almost everything—all external expectations, all pride, all fear of embarrassment or failure—these things just fall away in the face of death, leaving only what is truly important. Remembering that you are going to die is the best way I know to avoid the trap of thinking you have something to lose. You are already naked. There is no reason not to follow your heart. —Steve Jobs<sup>170</sup>*

The assignment for week two was to either tell a story from your life or write a fairy tale about your life. Jenny wrote a fairy tale.

The fairy tale was about a mother lion that had an infection and wanted to help her cubs by sharing her life story. As the infection grew the mother lion needed to rely on others for help and this was very hard for her, as she had always been so self-sufficient.

The mother lion was very proud of her cubs, both of whom eventually fell in love with other lions and got married, having cubs of their own. The mother lion was happy for them but sad because she wouldn't be part of their lives much longer due to the infection. She relished her cubs, teaching their cubs grandmother's life lessons and story. "It was like a dream come true," she shared.

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<sup>170</sup> From a prepared text of the commencement address delivered by Steve Jobs, CEO of Apple Computer and of Pixar Animation Studios, on June 12, 2005, at Stanford University, <http://news.stanford.edu/news/2005/june15/jobs-061505.html>.

Jenny concluded by sharing, "I'm losing my memory ... I have early onset Alzheimer's, so I tell my children my stories while I can remember them. I so want them to hold onto my stories and lessons."

### **The Participants**

Jenny was one of thirty-four folks in this pilot study designed by the author to help senior adults create a unique soul legacy to be passed on to surviving loved ones. The participants were residents of the Rogue Valley in southern Oregon and experienced the five-week seminar in the spring of 2015 at one of three venues: a United Church of Christ congregation (UC), an American Baptist Church (AB), or a Continuing Care Retirement Community (CC). The locations were chosen for their diverse theological worldviews; the UC congregation is more liberal, the AB congregation more conservative, and the CC is a secular community. Details of the participant demographics follow in Table 1.

**Table 1. Participant Demographics**

	UC ( <i>n</i> = 13)	AB ( <i>n</i> = 10)	CC ( <i>n</i> = 11)
Gender (female), %	53.8	60	82
Age <i>M</i> (range)	67.69 (57-80)	67.6 (51-84)	78.73 (55-93)
Level of Education			
High School	2	3	5

College	3	3	4
Master's Degree	6	3	1
Doctorate	2	1	1
Level of Income			
< 25K	2	3	2
25-50K	4	5	2
50-100K	6	-	4
>100K	1	1	2
Working	4	3	-
Retired	9	5	10
Disabled / Unemployed	-	2	1
Married	5	5	1
Single	2	-	1
Divorced	2	1	2
Widowed	1	2	7
Spirituality			
Christian	8	7	7
Agnostic	1	-	2
Eclectic	4	3	2
Advance Directive, %	83.3	80	82

*Note: All participants were Caucasian*

The sample size was determined by several criteria including: age (over fifty), commitment to be present at all five sessions, a desire to do the reflective work involved,

and a willingness to complete the necessary preparation for each weekly session. Along with the author, the pastor of the American Baptist Church and the director of pastoral services at the Continuing Care Retirement Community determined the senior adults best suited for the project. Potential participants were given a detailed explanation about the concept of the project (see Appendix A), and informed consents were obtained by the author at the initial session of each seminar.

### **Measures**

The Soul Legacy Seminar was designed by the author and included anonymous pre- and post-seminar questions (see Tables 2 and 3) in the following categories: feelings about death and dying, life's meaning, and an ability to share feelings with loved ones. A coding system was utilized to ensure the survey tool was anonymous and it was developed to track any movement or influence as a result of the seminar on the listed categories.

**Table 2. Anonymous Pre-Seminar Survey Questions**

<p>The thought of death and finality causes me to feel? The thought of my own dying process causes me to feel? One of the most meaningful periods of my life was when? When I think of how I have lived my life I generally feel? When I remember difficult life choices I have made I feel? I find it (?) to communicate my feelings to my loved ones. If I could, after my death I would come back to haunt: <input type="radio"/> More than three people <input type="radio"/> Two people <input type="radio"/> One person <input type="radio"/> No one <input type="radio"/> I don't think about it</p>
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**Table 3. Anonymous Post-Seminar Survey Questions**

The thought of death and finality causes me to feel?  
 The thought of my own dying process causes me to feel?  
 One of the most meaningful periods of my life was when?  
 When I think of how I have lived my life I generally feel?  
 When I remember difficult life choices I have made I feel?  
 I find it (?) to communicate my feelings to my loved ones.  
 If I could, after my death I would come back to haunt:  More than three people  Two people  One person  No one  I don't think about it  
 Please indicate by circling the response closest to your view.

<b>Soul Print Exercise</b>	Really Meaningful	Kind of Nice	OK	Too Schmaltzy	Embarrassing
<b>Story Sharing Exercise</b>	Really Meaningful	Kind of Nice	OK	Too Schmaltzy	Embarrassing
<b>Honoring Each Other Exercise</b>	Really Meaningful	Kind of Nice	OK	Too Schmaltzy	Embarrassing
<b>Soul in the Forest Reflection</b>	Deeply Moving	Food for Thought	OK	Too Schmaltzy	Made Me Uncomfortable
<b>God Image Reflection</b>	Deeply Moving	Food for Thought	OK	Too Schmaltzy	Made Me Uncomfortable
<b>End of Life Reflection</b>	Deeply Moving	Food for Thought	OK	Too Schmaltzy	Made Me Uncomfortable

Please list one or two things you really liked about the class.  
 Was there something you did not like?  
 What was a major take-away for you from this class?  
 What suggestion(s) would you make to improve the class?  
 Any other comments?  
 \_\_\_\_\_

## **Procedure**

The study was approved by the Institutional Review Board of Pacific School of Religion in Berkeley, California, and was also approved by representatives of the three host sites. All fifteen sessions (five at each site) were conducted by the author. Every effort was made to create a respectful, open space for honest sharing. Each session began with a short reflection based on the theme of the class and then participants were invited randomly to share what they had prepared for the class. Participants were encouraged to not share beyond their own comfort level and could opt to skip their turn if so desired. During the sessions the author took written notes of the experience and made audio recordings for further analysis.

At the outset of the first session the pre-seminar survey question forms were collected and the goals of the seminar were reiterated. For the first session of each class, “connecting with your soul,” participants were encouraged to bring various items that held special meaning for them. Numerous items were presented, including photographs, pieces of art, poems, natural artifacts, books, music, and jewelry—each with a story of what made the item meaningful. In the second session, “connecting with your story,” participants brought forward formative stories from their lives (two persons opting to write a fairy tale about their lives instead) with about 30 percent of the participants using a written narrative. In the third session on “connecting with the Divine,” various symbolic items were shared, which included mostly photographs of loved ones or nature, prayers, and other religious artifacts. The fourth session focused on “connecting with others” and participants brought tokens to give to the person they had selected to honor in

the group. The final session, “connecting with your mortality,” required no preparatory work for the participants.

Analysis involved using the in-depth approaches of case study analysis suggested by Robert Yin and Robert Stake: (a) data was collected and analyzed without preconceived expectations in the hope of providing workable insights and further understanding for future research;<sup>171</sup> (b) multiple sources of evidence were gathered to address construct validity of the research;<sup>172</sup> (c) the analytic strategy employed was the development of a case description to identify patterns and complexities in the findings, and the researcher worked to develop ideas and theories based on accounts and experiences of the participants;<sup>173</sup> (d) cross-case synthesis helped ensure the conclusions drawn were not too rigid and resistant to future contradictory data;<sup>174</sup> and (e) finally data source triangulation was employed to ascertain if the experience yielded the same results in different times and spaces with different participants.<sup>175</sup>

In addition to facilitating all of the seminars, the researcher transcribed the audio recordings of the sessions and analyzed each transcript. Patterns in themes were clustered

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<sup>171</sup> Robert K. Yin, *Case Study Research : Design and Methods*, Fifth edition. ed. (Thousand Oaks, CA: Sage Publications, 2014), 42.

<sup>172</sup> *Ibid.*, 45.

<sup>173</sup> *Ibid.*, 139-40.

<sup>174</sup> *Ibid.*, 164.

<sup>175</sup> Robert E. Stake, *The Art of Case Study Research* (Thousand Oaks: Sage Publications, 1995), 112-3.

together and themes and subthemes were labeled utilizing the participants' own words or quotations. This report summarizes the experience of the thirty-four participants.<sup>176</sup>

**Results: Survey Data**

**Table 4. Significant Data from Pre- and Post-Seminar Surveys**

	UC	AB	CC	Total		UC	AB	CC	Total
Pre-feelings about death					Post-feelings about death				
sad / scared	8	4	2	<b>14</b>		2	2	1	<b>5</b>
peaceful / good	4	5	8	<b>17</b>		9	6	7	<b>22</b>
Pre-source of meaning					Post-source of meaning				
family / marriage	4	6	5	15		3	3	4	10
work / service	6		2	8		1	1	2	4
trials	2	2	3	7		4	3	2	9
spirituality	2	1	1	<b>4</b>		1	2	5	<b>8</b>
Pre-feelings					Post-feelings				

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<sup>176</sup> This chapter was modeled on J. Cohen-Mansfield et al., "Wisdom of Generations: A Pilot Study of the Values Transmitted in Ethical Wills of Nursing Home Residents and Student Volunteers," *Gerontologist* 49, no. 4 (2009).

about life					about life				
grateful	4	1	3	<b>8</b>		6	2	4	<b>12</b>
good	6	6	4	16		6	6	5	17
sad	2	2	4	8		1	2	2	5
Pre-feelings about life choices					Post-feelings about life choices				
good	10	6	7	23		9	8	4	21
bad	2	3	2	7		1	2	1	4
ambivalent	1	1	2	<b>4</b>		3		6	<b>9</b>
Pre-share feelings with family					Post-share feelings with family				
easy	4	5	6	15		6	5	8	19
hard	5	2	3	<b>10</b>		3	2		<b>5</b>
ambivalent	4	3	2	9		4	3	3	10

*Note:* UC ( $n = 13$ ), AB ( $n = 10$ ), CC ( $n = 11$ )

The most significant results from the pre- and post-seminar surveys are presented in Table 4 and will be discussed in the following paragraphs. A “UC” denotes reference to the United Church of Christ seminar group, an “AB” indicates a reference to the

American Baptist Church seminar group, and a “CC” corresponds to the Continuing Care Retirement Community group.

Of the thirty-four people who participated in the study, fourteen indicated on the pre-seminar survey as feeling either “sad or scared” when considering their death or finality. At the conclusion of the five weeks, that number decreased by 64 percent to five. Most of the movement came from the UC group, with a decrease from eight to two. Similarly, in the UC group those who felt “peaceful or good” about the prospect of their death jumped from four in the pre seminar survey to nine folks in the post-seminar survey, an increase of 125 percent.

On the question concerning where people found a sense of meaning, the most interesting result was an increase of 100 percent (from four to eight) in the area of spirituality. Most of that movement came from the CC group, a group not affiliated with a worshipping community.

Two questions on the survey addressed how participants felt about their lives. The first spoke to how they felt about their life in general and the second on how they felt about the difficult decisions that they had made. The results show an increase in “gratitude” of 50 percent (from eight to twelve folks) and a decrease in the number who felt “sad” about their lives from eight to five. Surprisingly, the number of folks who felt “ambivalent” about the hard choices they had made in their lives increased from four to nine, with most of that increase coming from the CC group.

And finally those who before the seminar stated they found it “hard” to share their feelings with loved ones decreased by 50 percent, from ten to five, after having participated in the class.

## **Results: *Themes from Each Group***

### *UC Group*

All of the group members from UC Group were members of the church. The UC church is a progressive community that is open and affirming on the issue of gay rights, and is composed of mostly middle class Caucasians, politically leaning left, who highly value education. Interestingly, only eight of the thirteen participants self-identified as Christian. As this is the home congregation of the author, all of the participants knew the researcher prior to the seminar. The classes were held in a newly acquired and refurbished education room on Sunday afternoons immediately after the church service. The room itself was mostly sterile, and simple folding chairs were placed in a circle for the sessions.

*Week One Themes.* The focus of this session was to help participants connect with their *souls*. Not surprisingly ten of the thirteen group members (77 percent) referenced the importance of their families. After this, the most prevalent themes were art / creativity / beauty (46 percent) and work (46 percent) and were followed by the influence of books (38 percent), and spirituality / the Divine (at 31 percent). These themes are represented by the following responses:

- This is a letter from our oldest son thanking his parents for how we raised him; this letter I would never, never part with ...
- This is a letter I wrote from camp as a child to my mother and she saved it; it shows my creativity and free spirit ...

- This is an email from a friend, my first friend. I was a lonely isolated kid and got a scholarship to an art class where I met my friend ... his friendship changed my life dramatically. In college we were roommates ... he is a pianist and I sing; we did recitals ...
- I enjoyed recognizing the past ... this is a pin that was my mother's from the American Businesswoman's Association—she had no college education but she was very strong ... and this pin is my nursing pin ...
- This is a picture of the fuel station where my dad worked, his and mom's ashes are buried there ...
- This feather I found on vacation and it reminds me the importance of staying on the path I learned from a Lakota Shaman ...
- This book was written by wife. This book is how we met at a conference ...
- This is a gold ring from Father when I turned eighteen with a crest of my family clan ...

And finally, this is a poem one of the participants wrote and shared at the session:

#### Ode to My Soul Print

My soul print box has been a process. I bring it symbolically empty from an outward observance. It is filled with air, atmosphere, ambiance, it is filled with my breath, the vibrational energy, pulsations, rhythms of my soul life lived and living. My soul print is a work in progress, an art form evolving. Here inside my soul print box expressions of multi-dimensional souls surrounded by, instilled with a cosmic cadence, a galactic frequency, a world soul's heartbeat. My soul box draws with enlightenment, en-dark-en-ment, the star filled night sky, the sun filled blue sky. My soul print lotus emerges from rich deep filled moist mud source, ever moving from darkness to light source, always alchemically altering legacies,

inheritances, from ancient and historical patterns. Weaving essential truths into secular and sacred stories. My soul print winds my labyrinthine path with humor, insight, grace. Questioning, soul searching, sounding, past, present, future, simultaneously, in a precious eternal spacious presence. My soul print awaits that curious creative impulse to be.

It is noteworthy that during the time of sharing, seven of the thirteen participants cried, and four of them were men.

*Week Two Theme.* The focus of this session was to help participants connect with their *stories*. During the time of sharing three of the participants cried, and without question the major theme that emerged was the overcoming of difficult trials in life leading to greater growth, and was referenced by every participant. Here is a sampling of the responses:

- I got fired from my job ... friends helped me find work, they were tough times but I experienced great growth that forged my life themes: relationship with God and inner strength. The four lessons I want to pass on to my kids and grandkids are: 1. when faced with daunting experiences, don't give up, 2. never underestimate the value of friends and family, so nurture those relationships beyond all else, 3. maintain faith in yourself even when outside forces seem to be against you, 4. and nurture your faith in God. I'm still wrestling with what I am doing now—is it really worthwhile?
- I want to pass on, "to thine own soul, spirit, heart, and self be true." I want the loving support of my family and I will give it to them.

- I want to pass on the importance of equality in career and volunteer work, the value of process in decision making, to be inviting and inclusive, to value diversity and hear all voices.
- I want to pass on the value of overcoming interior self-doubt.
- I have a second chance; two years ago I was diagnosed with cancer, it still feels surreal, I didn't feel sick, it felt like I was in a dream. It was terrifying. I did chemo, the cancer experience has without a doubt been the greatest gift in my adult life. Amazing. I had lost sight of my dreams, I had been divorced, had to take care of a mother with dementia, difficult teenagers at home, unhappy at my job. After the diagnosis I felt so incredibly loved. I felt it would work out fine. My spirituality blossomed, in addition to chemo I did alternative therapies and changed everything I could change in my life—the way I eat, the way I think, the way I pray, the way I relate to people. I turned around. My treatment ended last summer, now it is time to start living the rest of my life. It feels like every day is a gift, and I want to consciously choose how my life is lived ... my kids were supportive ...
- I don't worry about getting it right, now ... my parents were slaves of duty ... but I experienced grace ...
- I was a large baby born with asthma (fear of being alive) and nearly killed my mother. My father deserted us for a time ... it was a Catholic hospital and it almost came to her life or mine. She had postpartum depression and was institutionalized. Then mother had a religious experience ... I've

learned that children need help with transitions ... I've either worked with children or old people, helping old people write their life stories. At end-of-life it is our job to make sense of our life story, I want to help people do this ... I hope I have a better way out than I had a way in ...

*Week Three Themes.* The focus of this session was to help participants connect with *the Divine*. Eleven folks (85 percent) spoke of the importance of nature. After this, the most prevalent themes were religious symbols (46 percent), and music and people were (tied with 31percent each). These themes are represented by the following responses:

- God is the power behind all of creation, I once spent a night on a hill ... that night was a place of extreme darkness but of great power. A piece of that power came down through me and into my hands ... it was a life changing experience. I felt like I touched the face of God ... it was a dazzling darkness ... I realized we're all interconnected and when I am aware of that I am aware of the presence of God.
- As A GI I went to Chartres Cathedral ... stepping through the doors into this vast dark space was overwhelming. It was lit by shaft of sunlight through the window, a pool of rose colored light, in this huge space ... hearing the Gregorian chants ... I felt so contained in this vast space ...
- I watched a video of the Big Bang ... what caught me was the inclination of matter to group together ... we are all intimately connected and when I

see a bird fly, and remember that these are atoms that joined together  
...that's me ...

- I grew up in a Mennonite home and never heard the words heaven or hell  
... I had a night sky in my bedroom and that was God ... in the mornings  
I'd hike up a mountain and feel everything in the universe pouring into me  
...
- I see God in images that when I look at them, I lose my self ... pictures of  
the night sky, the Milky Way, pictures of a forest, and when I helped my  
step daughter give birth ... the miracle of birth ...

*Week Four Themes.* The focus of this session was to help participants connect with *others* and was based on an experience of honoring someone else in the group. This was a very joyous session with a lot of laughter and a lot of celebration. A chair was placed in the center of the circle of chairs and the honoree sat in the chair while the blesser spoke words of affirmation to the blessee. Participants chose to honor the other they had selected in a blind drawing based on the themes of the blessee's work / service to others (38 percent), overcoming of life's trials (31 percent), and creativity (31 percent).

Here is a sampling of the sharings:

- I thought a lot about your soul sharing, shameful, painful, beautiful story with us, your beauty, you remind me of a pearl ... the ragged rough grain of sand that becomes a pearl ...so I want to honor your transformation because I feel when a person can hit bottom and come up with tools and

grace and beauty they can reach out and pull someone else up with humility and beauty like no one else can ...

- The words that come as I think about you are calm, caring, patient, thoughtful, both as in kind and in a pondering way, peaceful and connected, you look to find God in the eyes of another person, and that's what you represent to me ...
- You bring compassion, but the important modifier is effective compassion, many of us think we are compassionate, but your compassion has a wide ranging effect on the whole community ...
- Your fight with cancer shows your courage. My gift to you is a heart rock I got from a hike in Arizona. I knew it was yours when I drew your name because it has roots, and lines, and cracks, and real life ... and it shows your strength and solidness ...
- When I first met you at church I was in awe, I saw you as dependable, and as a leader, and I was a little afraid because I didn't recognize the softness you have ...

In the debrief time after the sharings, one of the participants noted that it was much more difficult to receive the blessing than give it because the receiver is not in control of the process. Most of the participants heartily agreed with this observation.

*Week Five Themes.* The focus of this session was to help participants connect with their *mortality*. During the debrief time after sharing a thirty-minute mediation based on the dying process (*The Nine Contemplations of Atisha*), only two themes emerged: the

mystery of death, and stories of being with loved ones who had died. Here are three of the responses:

- "We are spiritual beings having a human experience." I've had that experience for the past several years and this meditation deepens that. The other thing is that whenever someone close to me has passed on there's always a mysterious quality about that, they've had a precognition about it. My father and I had a great conversation the night before he died, and when my ex-husband died a year or so ago we slept through that ... it was so mysterious. There is more than we can know, most of the time I kind of like that ...
- I am thinking what can I leave for the ones I love, and that is a serious question for me because I see my four sons investing for this kind of thing and I want to leave them something spiritual and I don't know quite how to do that ... and if they have any guilt because of how I raised them ... then I'm sorry ... and I might ask them if they do ... do I need to ask forgiveness?
- What I got out of this class is to continue really enjoying the physical things we have now, like washing my hands, the feeling of warm water on my hands, or hearing the little bird up in the tree when I'm walking. These physical things are what I will miss most ... and being aware of them and not taking them for granted ... the beautiful gifts we are given. I know I'll see my family again, in a different way, but we'll miss this earthly experience ... the other thing I got out of this presentation was how much I

want to more completely organize things and write letters to my children, and make arrangements to get rid of my stuff ... I still have my mother's stuff ... she loved it so much that I feel bad about giving it away but I'm paying every month to keep it in storage ... I want to get rid of my stuff to make it easier for my children.

### *AB Group*

Unlike the UC Group three of the ten participants in the AB Group were not members of the congregation and were strangers to the rest of the group. The AB church is a more theologically conservative community that is not open and affirming on the issue of same sex unions, and is composed of mostly middle class Caucasians, politically leaning right, who highly value traditional biblical standards. Though this is not the home congregation of the author, all of the participants knew the researcher prior to the seminar mostly as a guest speaker for fill-in pulpit supply. The classes were held in a well-worn, rather large fellowship hall on Saturday mornings. The room itself was mostly sterile and participants sat on chairs around plastic tables for the sessions.

*Week One Themes (Soul).* All ten of the group members (100 percent) referenced the importance of their families. After this, the most prevalent themes were work / service to others (46 percent) and the Bible / Jesus (38 percent). These concepts were followed by the influence of books and music (33 percent). Four of the folks who shared cried during their presentation; all were female. Here are some of the sharings:

- My grandfather's watch ... out of all the kids he gave it to me. It set a tone for me that I should feel about myself as he did, he always carried this watch ...
- My mother's Bible. She bought it with her last few dollars from a door-to-door salesman. It was special to her and what she taught me. I loved finding what she underlined, a flower from my wedding was in it. And this is a little dress I wore as a child, my aunt kept it and it reminds me of love, because my aunt kept it, my mother made it for me and my aunt persevered it ...
- A diorama from my sons as a memory when were out camping, and crèches from around the world. One of my first crèches was from working as a missionary in Guatemala. I keep the crèches up all year long, because each of us has a year-long journey ...
- This is a gift CD from a daughter about how she can turn to me for strength ...
- I bought a motor home because I value my freedom, not fancy, a symbol to me, my wife didn't understand why ...
- This is a picture of my father ...he invested time in me. He was a Methodist minister. I have Parkinson's ... I've taken my brain for granted all of my life and now it's going ...

*Week Two Themes (Story).* During the time of sharing two of the participants cried and again the major theme that emerged was the overcoming of difficult trials in

life leading to growth. This was referenced by every participant. Additionally, with this group, the importance of family (66 percent) and Divine Providence (66 percent) were also significant. Here are portions of three of the responses:

- It was a great shock to me and my family—I was married for twenty-three years, and my husband left. He left me a note. I had to figure out what I was going to do with my life, my sister invited me to live with her in CA, I knew the Good Lord was with me, my two daughters came with me, I got a job, we moved on, but stayed in touch, then came the divorce papers; I made a decision on my own, he was doing all the telling. I took my independence, so I got the divorce ... I picked that story because it was a shock, in those days you didn't get divorced. I didn't know what to do. I was lost and survived it. I'm here and I'm happy ... I can see where the Good Lord was working in it ... the Good Lord worked, I didn't see it at the time.
- Why am I currently the way I am, because I was a troubled person. I was desperate for positive change, dysfunctional family, absentee parents, middle of three boys, because of insecurity and lack of supervision led to "malevolent teasing among us." Think of Columbine shootings and *Lord of the Flies* by Golding. My ability to function in the world was impacted mentally, physically, emotionally, and spiritually by all of this. Therefore my life has been spent in trying to heal ... one of the saving graces for me at age twenty-one I found solace in asking Christ into my heart and at

thirty-two I came closer to Christ when meeting my wife who was a Christian ...

- At seventeen I had cancer ... that changed my life. I went through cobalt treatment for over a year. I wanted to graduate so I stopped treatment. They told me I wouldn't survive, so I told them to cut my leg off. They did. I was the only one in my family to graduate. I'm ornery ... I wanted to chase the rainbow and have done that all my life. I've travelled the world. I've been a problem solver, I've made and developed prosthetics for others and had my own businesses ... I'm always looking for a challenge. When I get knocked down I always get back up ...

*Week Three Themes (the Divine)*. It is not surprising that this theologically more conservative group shared they find God in Jesus and the Bible (60 percent). After this, the most prevalent themes of where participants felt connected to God were in nature (50 percent) and with people (40 percent). These themes are represented by the following responses:

- I see God in his work, and the beauty of the landscape, and flowers, I don't see him ... I see what he has done ...
- I feel God closest to me in the springtime when I'm out digging in the dirt, just by myself in my garden, in the silence, vegetables from seed to mature plants, water and rain, all the natural things, the quiet of a first snowfall, fire, a flame in the fireplace ...
- God is relational and we see aspects of God in one another ...

- We're connected to something higher ... the relational aspect ... Rainbow Acres speaks to me, it's a ranch for mentally disabled people. I got the hook out there. I spent a month out there ... something about the smiles of those people, there is this love there, they just love me so much ... when I got home I was driving and saw a man flipping the bird to a little lady who was driving too slow it was so jarring to me after being at Rainbow Acres ... I just started to cry.
- Images don't help me connect with God, my authority to connect with God is the Bible which says that God is Spirit who connects to my spirit ...
- I'm not so visual, I'm more of a feeler, I see God in everything I look at, even the wall, the paint, but I feel most connected when I'm doing things for others ...

*Week Four Themes (Others).* Again the experience of honoring each other was a very joyous session with a lot of laughter, clapping, and celebration. The group sat around the tables and the blesser was asked to look into the eyes of the blessee as the words of affirmation were spoken. Participants chose to honor the other they had selected in a blind drawing based on the themes of the blessee's faith (40 percent), work / service to others (30 percent), and overcoming of life's trials (30 percent). Here is a sampling of the sharings:

- I've seen you at church for a number of years but I really didn't know you, this class has opened my eyes...

- I didn't know anybody here when I showed up, but I did notice your smile. Seeing that I was a stranger you asked if you could help, you saw that I was limping a little bit, I saw your heart. Later I learned that you lost some of your leg due to cancer when you were fourteen ...you've said numerous times, "I don't know why things haven't worked out the way I wanted but I've been doing the best I can," and I thought isn't that all of us? We try the best we can ... One thing I've noticed about you is your body language is always open, you're open and inviting, not guarded. You're a friendly person, and you listen when other people speak, and that is a great skill. When I think of you I think of a Japanese saying, "fall seven times and get up eight" ...
- I wanted to come up with one word, so I came up with nurturer because you like to see things grow and thrive. You nurture relationships with others. I thought back to the items in your treasure box and one was particularly poignant, the little dress that you wore as a child and that your aunt kept for you. That represents how you maintained that long-term relationship and how you nurtured it ... and then I thought about how you nurture your relationship with God in so many ways ...
- My wife and I call you "precious." I met you on your first day at here at church and fell in love with you instantly. You love to help people. To me that's quite a feat. You help the down and out, you reached out to the less fortunate folks near the church, you see the positive in everything, you always have a smile and a hug, and I love you very much ...

*Week Five Themes (Mortality)*. During the debrief time after sharing the thirty minute mediation based on the dying process (*The Nine Contemplations of Atisha*) only two themes emerged: what happens in the afterlife, and the importance or lack thereof of material possessions. The first person to share after the meditation stated, “I don't believe in dying. I believe in reincarnation. I know I've had at least seven lives, through regression hypnosis. I don't believe I'll leave this world ...”

This comment opened up a passionate discussion by many of the devout Christians in the group to assert their beliefs about the afterlife based on Scriptural interpretation. After the researcher intervened and redirected the group back to reflections on the mediation, the discussion focused on the importance of material possessions in our lives. Here is a sampling of that conversation:

- When you talk about material things, after you die they mean nothing ...  
Once my parents died I had to dispose of everything. I feel like I've been preparing to die ever since ...
- For me material things don't matter ...
- Yes they do, because if you don't take care of them the kids will argue about who gets what (discussion by many about preparing to dispose of things to avoid family fights) ...
- When you're younger you try to acquire more, when your older you want peace, disposing of things can bring you peace ...

- Parts of the reflection point out how many treasures I have will end up in a garage sale. Parts of it were very poignant and parts very humorous, I think that's how life is ...

Finally, when speaking about the seminar overall one person stated, “You normally don't get an opportunity to talk about these things ...” And another added, “Your kids won't talk about these things with you...”

### *CC Group*

Nine of the eleven members of this group lived at the Continuing Care Retirement Community and knew each other socially (the community houses over one thousand residents), while the other two lived locally. The CC group was older and more affluent than the previous two groups. It was also a mixture of progressive and conservative thinkers from various faith backgrounds. The author knew only three of the participants prior to the seminar as he was a guest speaker from a previous class offering on death and dying. The sessions were held in a small education room with many colorful maps decorating the walls on Tuesday mornings. Simple folding chairs were arranged in a circle for all of the sessions.

*Week One Themes (Soul)*. Ten of eleven the group members (91 percent) referenced the importance of their families. After this, the most prevalent themes were spiritual or religious references (73 percent), work / service to others (55 percent) and creativity (46 percent). Here are some of the sharings:

- My box contains stories ... all my treasures are in my heart. I read a story called the "Paradox in Healing" and intuitively knew I shouldn't do the chemotherapy ... I read another line from a poet "no need to survive" and I knew I didn't have a need to survive, which bothered my son ... this is a picture of an oak tree with not one straight line in it. I knew that tree had survived many things. If that tree could do it I can do it too as long as I don't have to be straight ...
- If a hurricane came I'd take all physical stuff, but what shaped my soul, God gave to me, my parents shaped my soul ...
- This dried rose petal is from a rose my mother found out in a field when I was in third grade. She thought the rose was dead but she revived it and has continued to travel with us. It was sixty years old when we found it, she told me this was your rose, and even though it has thorns on it it's beautiful, it still blooms ...
- These are tapes of my mom's stories. Many people think a legacy is money or property, but I am rich because I have my mother's legacy recorded on these two tapes ...
- This birth plate has my name on it. My mother was prejudiced but I was named after a black nanny ... I've always tried to help other people, I became teacher ... my husband was a Presbyterian minister and he was Chinese ... when I told my parents, it didn't go over well and my dad wouldn't walk me down the aisle or let me wear the family wedding dress.

They did come, which was amazing. I knew it wasn't right what they were thinking ... it was wonderful marrying someone of a different culture ...

*Week Two Themes (Story).* During the time of sharing three of the participants cried and again the major theme that emerged was the overcoming of difficult trials in life leading to growth (73 percent). Additionally this group referenced work / serving others (55 percent) and the importance of family (36 percent). Here are portions of four of the responses:

- What is the legacy I want to leave my children? To know where I came from, to know where I am going ... I'm the fifth child of eight, great genes, grandparents strong, God-fearing people who expected that of us ... I was a happy kid, didn't care about being the smartest or prettiest, just floated along ... dated until I met my husband, I loved him with respect, he was a man's man, treated me like a queen. We had seven kids in ten years. I got to participate in the miracle of creation ... I love my kids, love my husband, but it was very hard. It was then that I learned to trust in God, I knew that God was with me. The legacy I want to leave my children is this, to know God, to love God, to do your best, to be responsible, and to work hard, do the best you can and then charge ahead.
- In junior high kids were unkind, they called me "kike" and "Jew girl." I was Baptist, I was Arab-American, and I looked Jewish. Mom was Irish from the South and dad was Syrian and Lebanese, first generation. He fled persecution. Mom told me one day you'll understand ... Mom put notes in

my lunch every day through college ... she died from a stroke. Twice she spoke to me "I go away and I love you." She died in my arms ... We promised each other we'll never be alone.

- The theme of my life is "I was the only woman." In high school glee club, science class, it was hard work keeping up with boys. In seminary Old Testament class ... they had to bend the rules so I could get ordained ...
- I was going through a divorce, one holiday I just decided to do something for others so I went down to the hard core of LA to a mission to help serve meals. That helped me a lot about understanding other's problems ...

*Week Three Themes (the Divine).* This highly creative group shared they sense the Divine most profoundly in nature (64 percent), in their religious symbols (46 percent), and in others (family and friends) and art (at 36 percent each). These themes are represented by the following responses:

- Since I am not a person of faith, the closest I can come to the Divine is miracles. I do believe in miracles. I think everything I encounter is a miracle—the presence of the Universe, the presence of life, another miracle is that we can understand some of it, how the universe began, how light works, how gravity works ...
- This was a challenge for me, because when I was growing up in a Baptist family, images were verboten ... twenty years ago I had a sabbatical at Ghost Ranch, the landscape is striking. I saw the images and symbols in nature. I was grieving the death of my father, he had been sick a long time.

I was so astounded that while I was there by myself this grief came out. I would be walking and crying, and then I remembered, "Blessed are those that mourn for they will be comforted..."

- My daughter gave me this Kenyan art piece. It is all one piece. It symbolizes God for me because it is all connected ... everyone, everything is twisted together but it is beautiful, all of this put together is one, this tangle comes out in this beautiful and connected way ...
- My connection with God is in solitude ...
- I have had a strange progression of the images of God or the Divine given to me because they were always exclusive and that bothered me. My own experience was always inclusive. At some point, not recently, I put the two things together. It enlarged my sense of God because everyone's "My God" was exclusive and carried so much baggage. So this bowl of water is what I call "the All" or "Infinity" and this little sponge is me. (She placed the sponge in the water). So this is me in the infinity ... I am in the water and the water is in me ... and other people are also sponges in the water "the All."

*Week Four Themes (Others).* Again the experience of honoring each other was a very joyous session with a lot of laughter, clapping, and celebration. A chair was placed in the center of the circle of chairs and the honoree sat in the chair while the blesser spoke words of affirmation to the blessee. Participants chose to honor the other they had selected in a blind drawing based on the themes of the blessee's work / service to others

(64 percent), overcoming of life's trials (27 percent), and faith (27 percent). Here is a sampling of the sharings:

- I luckily chose you, even though you may be in physical pain, you always ask others how they are; even though you are grieving you help others in their grief ...
- You shared your greatest joy is walking with folks through their struggles, and you do that now ...
- You have shown me something of yourself in this class that I haven't seen before. I've only seen you in the gym. Our spirituality must affect our behavior, and I have seen your interactions in the gym are beautiful and important ... I have written a haiku for you because you bring joy to everyone ...
- What impacted me from what you shared was the bowl of water and the universe being in us and us being in the universe ... you have shown us the universe in you, the stars and black holes, but besides grace the other quality I see in you is wisdom ...
- You are precious ... You are the gift that keeps on giving, compassion, caring for others, you comfort and sooth others on their journey, thank you for touching me with yourself ...

*Week Five Theme (Mortality).* During the debrief time after sharing the thirty minute mediation based on the dying process (*The Nine Contemplations of Atisha*) only one major theme emerged—forgiveness. Here are some thoughts from that conversation:

- If your conscience feels clean, and you feel good about yourself, what else is there?
- This is work. A lot of people are afraid of this work, forgiving themselves. Forgiveness is hard work but it is a good work. I want to keep short accounts, I have made my peace with people, and let them know how I feel. I forgave my ex-husband. We try to avoid these things but in my practice I go into these feelings,
- 
- Why do we stay stuck on people who have hurt us, why we can't we move on?
- We need to forgive ourselves, that is the hardest ...

**Table 5 Session Themes**

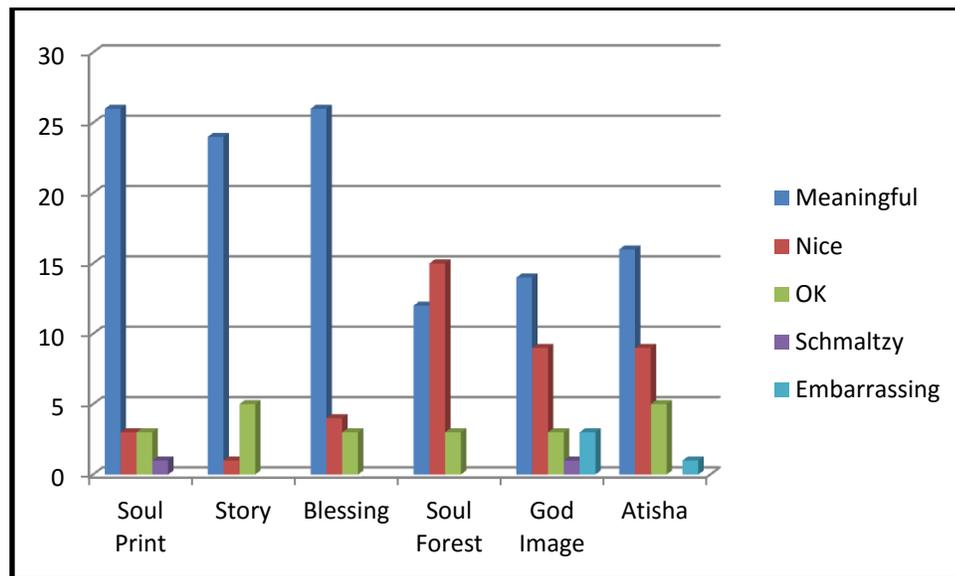
	UC	AB	CC
Soul			
Family	77%	100%	91%
Art / Creativity	46%	-	46%
Work / Service	46%	46%	55%
Religious	31%	38%	73%
Books / Music	38%	33%	18%
Story			

Family	15%	60%	36%
Work / Service	8%	10%	55%
Spirituality	-	60%	18%
Overcoming Trials	100%	80%	73%
Divine			
Nature	85%	50%	64%
Art / Music	31%	10%	36%
People / Family	31%	40%	36%
Religion	46%	60%	46%
Blessing Others because			
Overcoming Trials	31%	30%	27%
Work / Service	38%	30%	64%
Faith	-	40%	27%
Creativity	31%	10%	9%
Mortality			
Mystery	*		
Being w/ Loved Ones	*		
Afterlife		*	
Possessions		*	
Forgiveness			*

Note: Items marked by \* indicate this theme was mentioned most by participants in the session.

### Results: Participant Evaluations

Figure 1. Participant Evaluation of Seminar Exercises



The figure above illustrates the participant's feelings about the six exercises in the seminar. The Soul Print, Story Sharing, and Blessing exercises were very successful. By contrast, the three guided meditations were not nearly as popular.

*Please list one or two things you really liked about the class.* On the Post-Seminar Survey twenty-two of the thirty-four participants (65 percent) indicated what they really liked about the seminar was getting to know others at a deeper level. What follows are portions of their comments:

- I really liked getting to know and experience everyone. I really liked getting in touch with the deep feelings of what I have loved in my life—it helps me let go of everything else. (UC)
- It pushed me beyond my comfort level in terms of sharing my personal experiences and the experience of others. Class 2 (story sharing) was the most difficult. (UC)
- The diversity of all attendees, respect shown for attendees with different perspectives. (AB)
- Getting to know new people / getting to know myself better. (CC)
- Loved the feeling and knowing the spirit of everyone. (CC)

*Was there something you did not like?* Most of the negative comments spoke to the guided meditations as evidenced by Figure 1 above. Other comments included:

- I had to get past sharing deeply with people I don't know or trust yet. But I am grateful for the outcome. (UC)
- The guided meditations were hard to follow. Other people were often difficult to understand. (UC)
- I found it hard to disclose—talking about myself—I hide in others' stories. (AB)
- The last exercise (Atisha) I needed more pauses between the different sections and more contemplation. (CC)

*What was a major take-away for you from this class?* The major take-away (50 percent) listed on the surveys involved making a greater effort in preparing one self and one's family for their eventual death.

- Accelerating my getting my affairs together, sharing deeply my feelings with my kids, and helping to ensure I'm the author of my life as long as possible. (UC)
- Getting to know others at this level of sharing. (UC)
- Wounding—I realized more deeply how painful my early negative experience was. (AB)
- Death is fine. (AB)
- To share with my family how I treasure them. (AB)
- Made me do a lot of thinking through the week—reminiscing and forming conclusions for further "work." (CC)
- Living each day to the fullest. (CC)
- Keep searching. (CC)

*What suggestion(s) would you make to improve the class?* The most surprising aspect of the project was how deeply the three groups bonded. By far the majority of comments and suggestions revolved around continuing to meet together. The pastor of the AB church informed me that five of the seven members from his congregation that participated in the seminar have told him they wish we were still meeting as a group. Additionally, I know of two sets of participants (paired from the blessing exercise) that still meet regularly for coffee, more than six months after the conclusion of the class.

- I wish class could go on a little longer. (UC)
- Fewer people in the classes (five to eight). (UC)
- A workbook, list of sources you used, ideas on further exploration to follow up. (UC)
- Talk more about God and Jesus. (AB)
- I would shorten it to four weeks by consolidating some of the exercises and meditations. (AB)
- More classes. (AB)
- Maybe end with lunch together. (CC)

*Any other comments?*

- I found it hard to be deeply engaged. The successful individual exercises didn't add up to a whole for me. How do I strengthen my soul? (UC)
- Great class. It really got me thinking of meaning and ways to be present in the moment and to also think about what I might need to do or start thinking to be completely at peace with my own death. (AB)
- We did become a community. (CC)
- The workshop nudged me to question my seeming need for outside validation, not that this hasn't been a life-long journey with this question. It does seem that I keep on getting the opportunity to struggle with it again ... until I "get it." (CC)
- Choosing to relate a short story about me made me realize how little of that life is known to my children. My husband and I did not share our

early life with them. They learned he was on that Washington march only right before he died. Thank you for alerting me to this omission. (CC)

- Before we knew what had happened, we spoke to one another of our histories, deepest thoughts, and desires. Why, sometimes, people, previously unknown to each other, would leave a meeting arm in arm, conversing warmly and smiling, clearly symptoms of spontaneous detachment from the grid. Such exhibitions of freedom and good will may very well be contagious or infectious or both. (CC)

And finally I received this note from Jenny, whose story was shared at the beginning of this chapter.

After the losses that I have had since coming to the CC, your "Soul's Legacy" came at the perfect time. Since my husband died and I have been diagnosed with early Alzheimer's, I have focused a lot of my children and my husband's children. How can I help them? How can I support their dreams before I can no longer do so? What do I want to pass on to them? This group has really focused on these questions. I want to pass things on to my family before I die or can no longer remember their names. I felt empowered to move from a cottage to a small apartment so that I could give special items to all of my children now as opposed to later. (CC)

## **Discussion**

It has been noted by other researchers that doing the preparatory work for projects such as writing an ethical will or creating a soul legacy can often be cathartic.<sup>177</sup> This study certainly bears out that observation as evidenced by the number of participants who cried during their group sharing presentations.

This author prefers the concept of a soul legacy to ethical will for several reasons. First, the term “ethical will” is confusing. When most people hear the word “ethical” they think of the values and mores that are culturally agreed upon, not an individual’s personal life ethic. Secondly, the term “will” directly implies a reliance upon words, and many people feel inadequate in the primary use of words for communicating their deepest feelings. It was presented and stressed in the seminar (that is the basis of this study) that a soul legacy can transcend words and be offered in a variety of ways: art, music, a scrapbook, a piece of woodwork, a photograph, a piece of jewelry, etc. Finally, at the heart of a soul legacy is the emphasis of passing on a personal blessing to a loved one. This blessing includes words of particular affirmation for the blessee and a small token gift to memorialize the event.

Contemporary research and my own experience have shown that deeply troubling existential issues are normative at life’s end. As an effort in alleviating this soul suffering, the Soul Legacy Seminar was created to offer senior adults, and their faith communities, tools to help cope with this inevitability. The five weekly themes comprising the basis for the Soul Legacy Seminar (connecting with your *soul*, connecting with your *story*, connecting with *the Divine*, connecting with *others*, and connecting with your *mortality*) were chosen to aid in participants’ engagement with self-understanding and provide an

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<sup>177</sup> Ibid., 533.

opportunity to reframe how they view their own lives. This self-reflection will hopefully then become the basic material to eventually be passed onto surviving loved ones.

It is my intention that in addition to advance directives, POLSTs (Physicians Orders for Life Sustaining Treatments), financial wills, and funeral plans,—that a soul legacy be considered an important element in end-of-life preparations.

*Study Strengths.* A unique aspect of this study is that it was done in groups. Most ethical will research has involved personal interviews with senior adults. This is one of the first projects studied where participants engaged this type of life review process in a group setting. The group format facilitated several positive benefits for the participants: 1) it afforded group members the opportunity to learn from each other on how to craft their own soul legacy, 2) it offered a nurturing environment to explore terrifying existential concepts such as death and meaning in relative safety, and 3) it provided the opportunity to experience a personal blessing in order to be able to give one.

Irvin Yalom has asserted that, “If a therapist is to help patients confront and incorporate death into life, he or she must have personally worked through these issues.”<sup>178</sup> It is believed that ten years working as a hospice chaplain, companioning with more than a thousand patients who have died, has helped prepare the researcher to conduct this study. The importance of creating an open, honest, and safe space for the participants to explore the often frightening existential issue of their own death cannot be overstated. In all of the sessions with the participants, and in the subsequent analysis of

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<sup>178</sup> Yalom, 205.

those sessions, every effort has been made to present death as a very normal and natural event.

*Study Weaknesses.* —The present study was hampered by several limitations. First was the sample size. Thirty-four total participants from three pilot groups does not make for a substantive study. Second was the lack of ethnic diversity—all of the participants were Caucasian. There was some slight cultural diversity in terms of theological and political views between the three groups, but basically all the participants were older, white, middle class residents of southern Oregon. Third, this is one of the first pilot studies of senior adults working on a life review process in a group setting. Fourth is the inability to discover if the participants actually completed the process of creating a soul legacy. This simply requires further research. And finally, the researcher’s naiveté should be noted, as this is his first research project.

*Conclusions.* One of the major aims of the study was to determine whether doing a life review process, in a group setting, with the aim of crafting a legacy of the soul for loved ones might alleviate existential distress concerning the issue of death for senior adults. As evidenced by the anonymous pre- and post-seminar surveys, this aim was achieved. Prior to the seminar fourteen participants indicated they were either “sad” or “scared” when considering their own mortality. That number decreased to five after completion of the seminar, a decrease of 64 percent. Additionally, those who stated they had difficulty in communicating their feelings to loved ones decreased by 50 percent (from ten to five). Another important outcome was the increase in participants’

ambivalent feelings about their life choices, which more than doubled (from four to nine). This ambivalence is seen as significant because it is effective in coping with existential issues and becoming more comfortable with uncertainty, and it speaks to the honest reflection on the part of the participants.

The most surprising aspect of his project for the author was the deep bonding that took place among participants in the three groups. This was a thoroughly unanticipated outcome. My original intention was simply to aid senior adults reflect upon their own lives and possibly reframe significant events in order to experience more peace in their latter stages of life. The overwhelming desire by a majority of participants in each of the groups to continue meeting was unexpected.

In reflecting on this unanticipated outcome from the project, several possibilities suggest themselves. First, the groups naturally achieved what Carl Rogers has identified as necessary conditions for a growth-promoting atmosphere in human development: 1) there was a transparent genuineness exhibited by the participants in the groups, 2) a non-judgmental, “unconditional positive regard” gifted each participant with the feeling of being accepted, and 3) the groups afforded an empathetic understanding to the members.<sup>179</sup> While not intentionally built into the design of the seminar, this atmosphere, achieved by each of the groups, had a significant influence on the outcomes measured.

The second contributing factor to the group bonding that occurred may well be the power of story sharing. As referenced earlier in this dissertation, story creation is a major project of the human experience. It appears that story sharing (in an atmosphere described above) promotes fertile soil for a deepening of relationships. Both of these

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<sup>179</sup> Carl R. Rogers, *A Way of Being* (Boston: Houghton Mifflin Co., 1995), 115-17.

observations warrant future exploration and intentionality as I continue to present and craft this seminar.

The Soul Legacy Seminar project, therefore, does demonstrate the value of creating a nurturing group environment to aid senior adults in the self-reflective work necessary for crafting a soul legacy as a means of alleviating their existential fear of death.

## Chapter 5

### Conclusions and Further Explorations

*It is only in the face of death that man's self is born.*<sup>180</sup> —St. Augustine

More than seven years ago I moved to Ashland, Oregon, to become the chaplain for a small community hospital and hospice. Professionally alone, I sought companionship and advice in an online chat room for chaplains. Members of the group were quite active in dispensing advice and opinions on a variety of topics. I remember one day, in frustration at my own inadequate efforts of offering spiritual care for dying patients experiencing existential distress, I posted a question asking what others in the group did to help patients reframe a sense of meaning when bedbound and nearing death.

No one responded.

No one.

Then I really felt alone.

That experience, and the feeling of inadequacy in ministering to my dying patients, ignited a desire in me to learn how to help people cope more effectively with existential distress. This project is the fruit of that search.

#### What Did I Learn?

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<sup>180</sup> St. Augustine quoted in Yalom, 30.

Over the past three years I have been working on this doctoral project, one of the major lessons I have learned from both my studies and my hospice patients is the power the stories we create about our lives have in our experience of reality. I have argued that we create those stories out of the elements of lived experiences, our family roles, our social *habitus*, and our concept of the Divine. My work has been to create a mechanism for senior adults to explore how we work to create these meta-narratives in the hopes of empowering them to intentionally author their own endings. The aim of this effort is based on an observation by psychoanalyst Irvin Yalom, “a sense of fulfillment, a feeling that life has been well lived, mitigates against the terror of death.”<sup>181</sup> My goal has been to help senior adults in the last stages of life search for what they have found to be meaningful and beautiful in their lived experience as a means to alleviate existential distress.

But I also propose to go a step further by suggesting that sharing these treasures of one’s soul with loved ones actually increases both their beauty and their meaning. This is really not a new idea, but rather an ancient one. In religious circles, it has been traditionally referred to as a blessing. Sadly, in our post-modern, post-Christian era, this concept has been lost. My aim is to bring back the power of the experience without the religious trappings that are so off-putting to contemporary people.

My focus has been to work with senior adults who are neither on palliative care nor hospice care. The reasoning is that patients in either of those services can be compromised by pain, mental acuity, and/or fear. Additionally, by working with this pre-illness population, the hope is those adults who—after doing the self-reflective life

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<sup>181</sup> *Ibid.*, 208.

review exercises I propose—feel remorse that they have not discovered sufficient soul treasures, will still have the time and ability to create some.

The other significant area of my learning has been a deepened understanding of the existential issues that terrify us all. To this end, Irvin Yalom's work has been extraordinarily influential. Two of his insights that significantly shaped the scope of my doctoral project deal with the idea of healing. First, he suggests that by simply confronting the existential ideas of death and meaning, not trying to avoid them or solve them but by simply confronting them, we can alleviate their sting.<sup>182</sup> Second, he also asserts that it is the therapeutic relationship that heals—the connection between real, honest, human beings sharing the same existential angst.<sup>183</sup> Therefore, I set out to create a group atmosphere where people could address these issues head on, in safety, and together. The result was my pilot project.

The group process is an outgrowth of my own experience in five units of Clinical Pastoral Education (CPE) and the Small Process Group element that is crucial to that form of education. In those groups from my chaplaincy training days, we were able to learn from each other and find deep emotional support as we faced our own fears of inadequacy. Additionally, the group concept afforded the opportunity for participants to actually practice both giving and receiving a blessing.

Dr. Yalom has not been my only teacher on the insights of existential distress. Weekly, I encounter hospice patients for whom this is not simply a theory but a lived reality. Patients like Robert.

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<sup>182</sup> Ibid., 14.

<sup>183</sup> Ibid., 5.

## **The Wisdom of Sisyphus**

The highlight of my week was hearing Robert say, “Hi Fred.”

I couldn’t quite figure Robert out. He was a kind man living in a body that was just worn out. From the stuff in his room at the Adult Foster Home I knew Robert loved his family, the Pittsburgh Steelers, and the Blues Brothers.

His son told me that Robert used to play the drums and sing in a rock band. He’d always loved music and, like another musician, Woody Guthrie, Robert was dying of Huntington’s disease. He’d lost most of his muscle control, his little body spasmed awkwardly, and he struggled mightily just to get a word or two out.

Every time I’d visit I always asked if he was in pain. He always said, “No.” I asked him about the care he received, “It’s good,” he replied. Any complaints? “No.”

Sitting there praying for Robert, watching him spasm awkwardly, and seeing the peace in his eyes—I thought about Sisyphus.

A few months earlier, in an effort to broaden my horizons, I ordered a series of lectures from The Teaching Company on existentialism. The idea is you get to listen to great college lectures on a particular topic without having to read the textbooks, take the tests, or write the papers. (That’s my kind of class.) The lectures came on CDs I listened to in the car while driving around visiting my patients.

I have to admit, the week I was driving around visiting dying patients and listening to insights in the car about the very depressing existential philosophy of Albert Camus was not the best choice I’ve made. But I was captivated by Camus’ take on Sisyphus.

If you remember your Greek mythology, Sisyphus was the man who got stuck for all eternity rolling the big rock up the hill, only to have it roll back down every time he got it up there. For me, Sisyphus is Exhibit A of *futility*. Not so for the very depressing and existentialist philosopher Albert Camus. For Camus, Sisyphus was a hero.

In his essay “Myth of Sisyphus,” Camus wrote that Sisyphus loved rolling that big rock up the hill because it reminded Sisyphus that *he was alive*. The feel of the cold stone on his face, the heavy weight pushing against the muscles in his arms and legs, the air his lungs inhaled to muster the energy to move that big rock all told Sisyphus *he was real and he was alive*. And for Sisyphus that was enough. That was better than not being.

So as I sat next to Robert praying for him I would think about Sisyphus. Somehow Robert had made peace with his decaying physical condition. It’s my worst nightmare—being trapped in a body that won’t work. But Robert didn’t complain or show any sign of annoyance. He was always pleasant and kind. As I say, I couldn’t quite figure Robert out.

Maybe like Camus’ Sisyphus, Robert simply loved being. Maybe he knew that one day soon enough he would be gone from this “mortal coil.” (That’s a phrase Hamlet used when he too was considering “to be or not to be.”) Maybe Robert discovered the secret of just enjoying each moment of life he has been given regardless of the circumstances?

I don’t know. But I can tell you Robert sure made me feel very special when I would walk in his room and see him struggle so to simply gurgle out, “Hi Fred.” He made me feel very glad to be alive.

Learning from great teachers like Yalom and Robert has helped me make peace with my own existential distress. And this is crucial if I am to be of any help to my patients, for as Elisabeth Kübler Ross so famously observed, “In the long run it is the persistent nurturing role of the therapist who has dealt with his or her own death complex sufficiently that helps the patient overcome the anxiety and fear of his impending death.”<sup>184</sup>

### **What Will I Do Differently?**

While I feel my doctoral project was highly successful and there were significant outcomes (which were addressed at the end of the previous chapter), there are some things I plan to do differently as I proceed with the Soul Legacy Seminar.

First, I would like to more formally establish group agreements as a way of promoting an atmosphere of growth for the participants. Having witnessed firsthand how powerful the group dynamic was to the experience, it is very important to establish a safe and accepting atmosphere that has universal buy-in from the outset. The agreements I envision are as follows:

- We will be respectful.
- We will speak our truth in ways that respect other people’s truths. Our views of reality may differ, and being respectful means we will not interpret, correct, or debate what others say. We want to speak from our center, so we will use “I” statements, trusting people to do their own sifting.

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<sup>184</sup> Elisabeth Kübler-Ross, *On Death and Dying* (New York: Scribner, 2003), 59.

- We will not trash others. This is not the forum to discuss or complain about politics, our church, our family, or our co-workers.
- We will not try to fix, to save, to give advice (unless asked), and we will not attempt to set each other straight. This one is hard but it is vital to welcoming the soul, to making space for the inner teacher.
- We will not toot our own horn. Is what I want to share for the benefit of the group or self-serving?
- We will observe deep confidentiality. What is shared in this space and time is confidential.
- We will be present as fully as possible. This means really listening to what others have to share and not planning what I want to say while someone else is speaking. We will refrain from side conversations.
- We will invite others to share, not demand it. Be free to speak or not speak and know that you do it with our support.
- We will attempt to respond to each other with honest, open questions. (Some examples are: “What did you learn from that experience?” or “What did you mean when you said you felt sad?”)
- We will not judge each other.
- We will honor silence. Silence is a gift in our noisy world, and a way of knowing in itself. We will treat silence as a member of the group. We will

take time to reflect on what has been shared without immediately filling the space with words.<sup>185</sup>

I will also discontinue using the “soul in the forest” and “face of God” guided meditations. The “soul in the forest” meditation was not very well received in any of the pilot groups. The “face of God” was acceptable in the more theologically conservative AB group, and I will keep it as an option for more biblically based groups in the future. Instead I plan to work in an exercise based on the theme of forgiveness, which was not really addressed in the pilot groups. Additionally I will also explore adding an exercise on a participant’s nuclear family experience while growing up (like sharing your family nickname or family role). I also plan to work in an option of having participants write their own eulogy or obituary to share with the group.

### **For Further Exploration**

Beyond what I have just suggested I am hopeful others will take some of these ideas and develop other avenues to research in what appears to be fertile soil for discovery. For example, I would like to pursue how we might follow up with seminar participants to ensure they actually complete crafting some form of soul legacy to pass on to loved ones. Research needs to be done with participants of other ethnic, cultural, and religious backgrounds.

My primary hope is that the Soul Legacy Seminar might be found very useful for senior groups in faith communities. The significant outcomes of the pilot group study

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<sup>185</sup> A number of these suggestions are influenced by a workshop I took presented by The Sacred Art of Living and Dying Center located in Bend, Oregon.

bode well for such an application. The deep bonding of the groups, participants making friendships, parishioners getting to know each other more intimately, and a lessening of existential distress are all benefits any church senior group would welcome.

I also see a clinical application for the seminar. Numerous medical inpatient and outpatient clinics struggle in caring for patients who are wrestling with existential issues and the medical staffs are not trained or equipped to adequately deal with them. These patients are often medically non-compliant and absorb precious staff time. I wonder if having a chaplain or trained social worker facilitate a Soul Legacy type of seminar for these patients might be a more cost effective way to improve outcomes?

Finally, I can even foresee an application for pastors helping churches die in peace. In our day and age, mainline churches are steadily declining. I believe groups can suffer from existential distress just as individuals do. Developing tools for pastors of dying congregations, to aid in a peaceful, gracious, and loving end of a faith community is becoming a greater need.

## **Conclusion**

In this dissertation, I have attempted to blend the two important avenues of learning that inform my practice of hospice chaplaincy; the theories developed by trusted therapists and the stories of the patients I serve. Dame Cicely Saunders, who founded the modern hospice movement, has written,

The answer to the question of the preparation for this kind of work is that *you learn the care of the dying from the dying themselves*. But only if you look at them with respect and never merely with pity, and allow them to teach you. It is they who show us that the fear of death is overcome. Seeing this, we, too, can come to the place [where] ...“we cannot know what is beyond the end of our

days, but we can enter into an order of things which can make us say, 'I'm not afraid.'"<sup>186</sup>

This is the gift bequeathed to me by the more than one thousand souls I have had the honor to companion with to the Great Beyond. It is a gift I treasure. It is a gift I hope to offer to the unnumbered souls I will walk with until my own time of departure.

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<sup>186</sup> Cicely Saunders, The moment of truth: care of the dying person. In: Leonard Pearson, *Death and Dying: Current Issues in the Treatment of the Dying Person* (Cleveland,: Case Western Reserve University, 1969), 78.

## Appendix A

### Soul Print Exercise

Of all the soul descriptions I have encountered, none is as captivating as that put forward by Thomas Merton, who compares the soul to a wild animal.

The inner self is precisely that self which cannot be tricked or manipulated by anyone, even the devil. He (the true self) is like a very shy wild animal that never appears at all whenever an alien presence is at hand, and comes out only when all is peaceful, in silence, when he is untroubled and alone. He cannot be lured by anyone or anything, because he responds to no lure except that of the divine freedom.<sup>187</sup>

For this exercise we will search for our “wild animal” by making a Soul Print Box.

Put in five things that matter most to you.

Possibly the greatest value of the Soul Print box comes from the process of making it. In spiritual searches, process is often the most important thing. Let’s view your Soul Print Box as a treasure chest of sorts, which makes filling the box a treasure hunt. In a treasure hunt, the two words are inseparable—to find a treasure you must hunt for it, and if you hunt, you will surely find a treasure. The very process of “boxing” your soul print—pulling together the significant signs of your soul—will help reveal your soul print. If you take the time to search for your home for soul print articles, you will be making the time to search for your soul. And if you hunt, you will surely find.

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<sup>187</sup> Merton, 5.

What do you put in your Soul Print Box? Love letters, family heirlooms, photographs, favorite quotes, and your own soul print reflections on life. If any items are too big, represent them with an object or write them on a slip of paper.<sup>188</sup>

Another way to think of it is to imagine a hurricane is about to hit your home and you have just fifteen minutes to grab what is most important to you before you evacuate. What do you grab?

Bring your box to our first session and plan to share for about five minutes with the rest of the class on why these things are so important to you.

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<sup>188</sup> Marc Gafni, *Soul Prints : Your Path to Fulfillment* (New York: Pocket Books, 2001), 24.

## Appendix B

### Story Telling Exercise

For next week's session, plan to share part of your life story. You'll have about five minutes. You can use the following questions taken from the work of Frederic Hudson and Harvey Max Chochinov as a springboard for your sharing.

- What is your current *plot* (the principles and reasons that explain why you are the way you are)?
- What are the dominant patterns or *themes* of your story?
- What are the most important roles you have played in your life (e.g., family roles, vocational roles, community service roles)? Why are they so important to you, and what do you think you accomplished within those roles?
- What are your most important accomplishments, and what do you feel most proud of or take most pride in?
- Who is included in your cast of characters?
- What were the chapters of your story and how did they transition?
- What are the major turning points of your story and how did you change?
- When did you feel most alive?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your family?

- What do you like most about your life now? What do you like least?
- What would be the title of your story?<sup>189 190</sup>

### **Fairy Tale Exercise**

Or if you prefer, write a fairy tale that describes your life. (This one is especially good if you have a particularly pressing problem right now.)

There will be three parts to your fairy tale:

1. *The description of the problem.* Do this using a symbolic language, using animal (wolves, bears, etc.) or other fairy tale characters (princesses, shoe cobblers, knights, or kings). Let your current situation provide the inspiration, but as soon as you can, move away from your conscious awareness of the problem and let the story take over.

2. *The magical intervention.* Let your imagination come up with a magical solution—whether that's a potion, the arrival of a new character with special powers, a change in the weather, whatever comes to mind.

3. *The happy ever after.* Describe what it looks like when the problem is resolved.<sup>191</sup>

On the back of the instruction sheet was included the following piece from Parker Palmer and Marcy Jackson on story sharing.

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<sup>189</sup> Hudson, 54.

<sup>190</sup> Chochinov, 71.

<sup>191</sup> This idea was taken from the work of Dana Gerhardt at <http://mooncircles.com/>.

## Ego Stories & Soul Stories<sup>192</sup>

Parker Palmer and Marcy Jackson, © 2012

<b>Ego Stories</b>	<b>Soul Stories</b>
<ul style="list-style-type: none"><li>• Are stories told for the sake of self-promotion, as when we apply for a job</li><li>• Focus on life's high spots when we have been successful and affirmed</li><li>• Try to portray us as in control or in charge of our lives</li><li>• Are often linear stories of continuity and consistency, stories that have a resolution</li><li>• Are highly crafted stories that leave our important things</li><li>• May ignore or falsify certain information by "spinning" the facts</li><li>• Are always told in prose, and sometimes involve numbers</li></ul>	<ul style="list-style-type: none"><li>• Are "the story beneath the ego story," the one with the thread of truth running through it</li><li>• Honor shadow as well as light, suffering as well as gladness</li><li>• Are often stories of twists and turns when our best-laid plans were undone by the unexpected</li><li>• Allow us to integrate the fragments with the whole</li><li>• Are unafraid of change, fear, loss, failure and shame, or mystery, passion and ecstasy</li><li>• Are sometimes told in poetry, music, or art</li></ul>

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<sup>192</sup> Parker Palmer and Marcy Jackson, "Ego Stories and Soul Stories, © 2012, found on Clear Path Counsel website, [http://www.clearpathcounsel.com/files/4313/3029/8683/Ego\\_Stories\\_Soul\\_Stories.pdf](http://www.clearpathcounsel.com/files/4313/3029/8683/Ego_Stories_Soul_Stories.pdf) (accessed 10/6/2015).

<ul style="list-style-type: none"> <li>• Are stories that do not sustain us in times of suffering</li> <li>• Are stories we tell at a party when someone asks, “What do you do?”</li> </ul> <p style="text-align: center;"><i>“Produce! Get results! Make money! Make friends! Make changes! Or you will die of despair!”</i></p> <p style="text-align: center;">Chuang Tzu</p>	<ul style="list-style-type: none"> <li>• Are stories that we can hold onto in the hardest of times</li> <li>• Are the stories we want the people we love most to know</li> <li>• Are the stories we are most likely to be reliving when we are awake at 3:00 AM or when we die</li> </ul> <p style="text-align: center;"><i>“Joy and sorrow aren’t two different feelings for it. It attends to us only when the two are joined.”</i></p> <p style="text-align: center;">Wislawwa Szymborska</p>
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## Appendix C

### Meditation on the Divine Connection

For next week's session, plan to share some photographs, art, or images of whatever connects you with the Divine—images that remind you of the immanence of the Divine.

Below is a photograph Thomas Merton (who was, in addition to being a world famous monk, also a photographer of note) entitled, "The Sky Hook" and which he later wrote was "the only known picture of God."



You'll have about three minutes to share your images with the rest of the group and explain why they help you connect with God.

## Appendix D

### Blessing Exercise

As part of our effort to discover our life's meaning we want to affirm each other's gifts. To this end you will draw the name of a class member and then reflect on *one* characteristic or attribute that person possesses that enriches our whole community. For example, maybe the name you draw is a person who is "dependable," always following through on their promises, or possibly they are "justice oriented," always looking out for the under-privileged. The idea is to notice this beautiful trait in one of our colleagues, and then you will have an opportunity to bring it forward to the group in a time of sharing. Plan to share for two or three minutes about what it is you see in this person that you admire, and why. You can write something out or speak from your heart. What matters is that your sharing about the honoree is authentic and honoring. Also, try to find a small token (something from around your home, or a small craft you make, or an inexpensive, under \$5 gift) to represent this attribute you see in your colleague and give to them to remember this moment of acknowledgement. No one is to be left out.

To recap, you will draw the name of one of our classmates and then prepare prior to our next session:

- spoken words
  - expressing an important gift the recipient brings to our community
  - offering an active commitment to see that gift accepted and nurtured
- a small token to remember

## **Appendix E**

### **Participant Permission for Thesis Project Research**

Fred Grewe

Project: *The Soul's Legacy*

Pacific School of Religion

Spring, 2015

My name is Fred Grewe and I am a Doctor of Ministry candidate at the Pacific School of Religion in Berkeley, CA. As part of the final requirements for fulfilling my degree, I plan to conduct a series of five-week seminars aimed at helping senior adults discover and pass on important life lessons and values to their loved ones in the form of a written legacy.

You can help further my research by participating in one of these experiential five-week seminars to explore a variety of topics, including getting in touch with your soul, blessing others, and spiritual reflection on the important stories from your life. My overall goal is to help you identify life lessons and values and commence the development of your written legacy by the end of the course. Each seminar will be will last for 90 minutes and limited to 10 to 12 participants. In addition, attendance will be mandatory for each of the five sessions. There will be homework assignments each week to be shared in the class.

Throughout the five weeks, I will be collecting your verbal and written comments on specific topics and issues as well as soliciting your feedback about

the effectiveness of the course. I will collect your comments and feedback in a variety of ways, including taking written notes, tape recording each seminar session, and asking you to complete and hand in anonymous pre- and post-seminar surveys.

### Protection of Confidentiality

Though the other participants in your five-week seminar and I will know your identity, I will take all reasonable measures to preserve your confidentiality outside of this group by:

- Asking each participant to sign a covenant of confidentiality in regards to the comments of other group members.
- Removing your name and/or other identifiers from any quotations or references to personal comments.
- Providing you with the opportunity to review and/or amend or remove any personal comments or quotations used in my final project prior to its submission.

### Professional Referral upon Request

Discussing issues related to the end of life can sometimes be troubling. As the sole researcher for this study, I'm unable to provide you with counseling services but will upon request provide you with a list of referrals to professional counselors in this area with whom you can schedule confidential counseling sessions.

### **Voluntary Withdrawal from the Study**

*Throughout the five-week seminar, you will always be free to only share what is comfortable for you and to not answer any specific question or questions. You can also back out of the study at any time and/or request that none of your personal comments or quotations be used by notifying me via email and/or writing.*

While I will retain all intellectual and commercial rights to the shared materials (copyright), I freely consent to give you access to the materials pertaining to your comments or quotations to cite or quote for your own use. I can be reached at 541-708-0183 or at fred@fredgrewe.com.

*Thank you for your participation!*

### ***Participant Confidentiality Agreement***

I (print name) \_\_\_\_\_ voluntarily and with understanding consent to participate in Fred Grewe's doctoral project pertaining to end-of-life issues and developing the soul's legacy. I understand that I am free to not answer any specific questions(s) and that I may withdraw from the project at any time. I also understand that though my identity will be known to other seminar participants and Fred Grewe, any written reporting of my participation in this project, including any attributions of personal comments and quotations, will be entirely anonymous and confidential.

\_\_\_\_\_ (initial) I agree to be tape recorded for the purposes of this research project.

(Please sign here) \_\_\_\_\_ (Date) \_\_\_\_\_

**Course Description: “The Soul’s Legacy: Discerning Your Life’s Meaning and Passing It on to Your Loved Ones”**

This will be an experiential five-week class to help senior individuals begin crafting an ethical will—what you have learned or found important in life—that you might want to pass on to your loved ones. The goal of the class will be for each participant to have begun working on their particular soul’s legacy by the end of the course. Topics to be discussed will include: getting in touch with one’s soul, blessing others, and spiritual reflection on important stories from one’s life. Each course will be limited to 10 to 13 participants, and attendance will be mandatory for each of the five sessions. There will be homework assignments each week to be shared in class. Permission forms will be designed satisfying Pacific School of Religion’s standards for research projects involving human subjects.

I am aware of the range of emotions and reactions involved in the kind of introspective reflection this project may illicit and will do my best to be respectful and circumspect about my respondents’ involvement and reactions.

Due to the possibility of emotional distress involved I will make a referral list of professional counselors available to any workshop participant who may need it. Because I will be facilitating the study and have a conflict of interest, I will be unable to serve as one of these referrals. Additionally, subjects will be free

not to answer any particular question or to not participate in any particular exercise.

Participants will benefit from participating in the research by being afforded the opportunity to reflect on the meaning of their life, with peers offering objective feedback and observations. Additionally, participants will also be offered practical suggestions on how to more effectively communicate their affection and appreciation for their loved ones.

### **Instructor Biography**

Fred Grewe is a Board Certified Chaplain (Association of Professional Chaplains) with a Master's Degree in Pastoral Care from the Aquinas School of Theology in St. Louis and an ordained Congregationalist minister working for Providence Hospice. He is currently working on a doctoral degree on end-of-life care at Pacific School of Religion in Berkeley, CA, and this class will form the basis of his thesis.

### **Course Outline:**

#### WEEK ONE: Connecting with Your Soul

- Soul Print exercise developed by Marc Gafni

#### WEEK TWO: Connecting with Your Story

- Dignity Therapy exercise developed by Harvey Chochinov

WEEK THREE: Connecting with the Divine

- Meditation exercises developed by Fred Grewe

WEEK FOUR: Connecting with Others

- Blessing exercise developed by Fred Grewe

WEEK FIVE: Connecting with your Mortality

- Nine Contemplations of Atisha exercise developed by Joan Halifax

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