Thanatopoiesis: The Relational Matrix of Spiritual End-of-Life Care

Dissertation

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By

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Abstract

Contemporary research practices in palliative medicine attempt to reduce, define, and study spirituality in end-of-life care with “scientific rigor” by isolating what counts as “spiritual.” Contrary to this move, informants from multisite hospice and bereavement spaces in this ethnographic study insist that encounters with death and dying lead to irreducible transformations that cannot be quantified or objectively defined. I argue that humans are irreducibly beings-in-relation (intimacy) rather than essentially isolated individuals (integrity), and thus “spiritual end-of-life care” necessitates attention to fluid, inextricably woven personal and relational processes. The thick social matrix of end-of-life scenarios supports the use of research methods and ethical models that acknowledge the contingent, particular, culturally embedded nature of humans as beings-in-relation. To that end, contemporary scholarship in the study of religion and feminist ethics can contribute much to debates about spirituality in end-of-life care.

This study specifically analyzes relational orientations between the living and the dead to illustrate complex transformations during mourning. Using Thomas Kasulis’s intimacy/integrity heuristic to analyze ethnographic interview texts, I argue
that the death of a beloved other ruptures relational boundaries and destabilizes the mourner’s imagined relation to the self, to the deceased, and to others. Narratives attest to oscillation among a range of wildly fluctuating relational orientations, yet suggest that internal relation to the deceased persists long after the death. Informants report intense affective dynamics akin to “labor,” yet these are interpreted as continued intimacy with the deceased. Esoteric experiences are framed tentatively, yet mourners see them as comforting “true signs” of connection to the deceased. Beliefs about death are speculative, personal, eclectic, and do not rely on participation in a religious tradition, yet all informants believe in “something,” most notably a belief in loving relation. These complex and fluid features of transformed relation in end-of-life care resist attempts to be objectified, reduced, contained, or isolated as is customary in scientific investigations.

Researchers in end-of-life spiritual care must be open to the inability of the human to be objectively and statically defined, reduced, bound, or understood in isolation from others in co-emerging cultural processes. These findings suggest that some feminist models are more suited to end-of-life dilemmas than principle-based ethical models. Principle-based ethics that construct the human as an independent, autonomous, and rational being fall apart in end-of-life settings where illness often renders the dying person unable to make decisions. The ethics of care assumes relation is ontologically basic to human life, and accept dependence and interdependence as realities in end-of-life scenarios, paving the way for collaborative decision-making in circles of care.
In the final analysis, what matters more than a precise normative definition of spirituality in end-of-life settings is the ability of caregivers to enter into internal relation with the dying person as someone who is inextricably embedded in expansive relational webs. Thus, I suggest that some of the most salient issues in spiritual care involve ways to cultivate capacities for deep listening, compassion, receptivity, and response-ability in caregivers.
Dedication

To Sande, Rita, and Peggy, my delightful group of companions in graduate school and members of the Fab Four.
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# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>ii</td>
</tr>
<tr>
<td>Dedication</td>
<td>v</td>
</tr>
<tr>
<td>Acknowledgments</td>
<td>vi</td>
</tr>
<tr>
<td>Vita</td>
<td>vii</td>
</tr>
<tr>
<td>List of Figures</td>
<td>x</td>
</tr>
<tr>
<td><strong>Chapters</strong></td>
<td></td>
</tr>
<tr>
<td>1. REIMAGINING END-OF-LIFE CARE IN AMERICA</td>
<td>1</td>
</tr>
<tr>
<td>Trends in Contemporary End-of-Life Care</td>
<td>4</td>
</tr>
<tr>
<td>Thesis</td>
<td>11</td>
</tr>
<tr>
<td>Literature Review</td>
<td>12</td>
</tr>
<tr>
<td>Medicine and Science</td>
<td>12</td>
</tr>
<tr>
<td>Humanities</td>
<td>17</td>
</tr>
<tr>
<td>Methodology and Overview of the Study</td>
<td>23</td>
</tr>
<tr>
<td>Description of Research</td>
<td>27</td>
</tr>
<tr>
<td>Limitations of the Study</td>
<td>29</td>
</tr>
<tr>
<td>Reflexivity and Positionality</td>
<td>31</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>41</td>
</tr>
<tr>
<td>Chapter Outline</td>
<td>43</td>
</tr>
<tr>
<td>2. RELATIONAL TRANSFORMATIONS AND DEATH</td>
<td>46</td>
</tr>
<tr>
<td>The Intimacy-Integrity Heuristic</td>
<td>49</td>
</tr>
<tr>
<td>The Intimacy Relation</td>
<td>51</td>
</tr>
<tr>
<td>“Sad Stories” - The Primacy of Affect</td>
<td>54</td>
</tr>
<tr>
<td>Somatic Knowledge</td>
<td>59</td>
</tr>
<tr>
<td>“True Signs” as Esoteric Knowledge</td>
<td>64</td>
</tr>
<tr>
<td>Broken Intimacy Relation – The Crescent Self of Mourning</td>
<td>69</td>
</tr>
<tr>
<td>Holographic Relation and Mourning</td>
<td>73</td>
</tr>
<tr>
<td>The Integrity Relation</td>
<td>78</td>
</tr>
<tr>
<td>Institutional: Colliding Relational Imaginaries</td>
<td>80</td>
</tr>
<tr>
<td>Irreparable Separation</td>
<td>83</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Lack of Cultural Space for Mourning</td>
<td>87</td>
</tr>
<tr>
<td>Conclusion</td>
<td>89</td>
</tr>
<tr>
<td>3. SUSAN’S STORY: “I CAN’T IMagine”</td>
<td>91</td>
</tr>
<tr>
<td>4. CATCHING THE WIND? THEORIZING SPIRITUALITY IN END-OF-LIFE SCENARIOS</td>
<td>112</td>
</tr>
<tr>
<td>Introduction</td>
<td>112</td>
</tr>
<tr>
<td>Exploring Meanings of Spirituality</td>
<td>115</td>
</tr>
<tr>
<td>Medical Approaches to the Study of Spirituality in End-of-Life Care</td>
<td>117</td>
</tr>
<tr>
<td>Religious Studies Approaches to Spirituality</td>
<td>126</td>
</tr>
<tr>
<td>Spiritual Vision Statement for Hospice</td>
<td>130</td>
</tr>
<tr>
<td>Narrative Themes Related to Spirituality and Religion</td>
<td>132</td>
</tr>
<tr>
<td>Separating Religion and Spirituality</td>
<td>133</td>
</tr>
<tr>
<td>Kyra’s Case Study</td>
<td>137</td>
</tr>
<tr>
<td>Crisis, Interior Experience, and Spiritual Journeying</td>
<td>141</td>
</tr>
<tr>
<td>Losing Faith and Questioning Beliefs after a Death</td>
<td>145</td>
</tr>
<tr>
<td>Conclusions</td>
<td>148</td>
</tr>
<tr>
<td>5. SPIRITUAL IMAGINARIES OF DEATH</td>
<td>152</td>
</tr>
<tr>
<td>Belief in Loving Relation</td>
<td>153</td>
</tr>
<tr>
<td>Unsure and Can’t Know</td>
<td>159</td>
</tr>
<tr>
<td>“Nothing More than Now” - Death as Limit</td>
<td>161</td>
</tr>
<tr>
<td>“A Happy Place” - Death as Certain Transition</td>
<td>164</td>
</tr>
<tr>
<td>Blending East-West Beliefs</td>
<td>168</td>
</tr>
<tr>
<td>On Healing: “Getting Conscious” of Holographic Relation</td>
<td>170</td>
</tr>
<tr>
<td>Jim’s Story</td>
<td>174</td>
</tr>
<tr>
<td>Mourning as Portal to Realizing Holographic Relation</td>
<td>177</td>
</tr>
<tr>
<td>Conclusions</td>
<td>179</td>
</tr>
<tr>
<td>6. END-OF-LIFE CARE AS RELATIONAL BLOOM SPACE</td>
<td>183</td>
</tr>
<tr>
<td>Summarizing the Study</td>
<td>188</td>
</tr>
<tr>
<td>Expanding the Intimacy/Integrity Heuristic</td>
<td>191</td>
</tr>
<tr>
<td>Re-Thinking Spiritual End-of-Life Care in America</td>
<td>198</td>
</tr>
<tr>
<td>A Resonant Death</td>
<td>201</td>
</tr>
<tr>
<td>Appendices</td>
<td></td>
</tr>
<tr>
<td>A. Research Process</td>
<td>208</td>
</tr>
<tr>
<td>B. IRB Documents</td>
<td>210</td>
</tr>
<tr>
<td>C. Demographics and Field Work Sites</td>
<td>213</td>
</tr>
<tr>
<td>References</td>
<td>217</td>
</tr>
</tbody>
</table>
List of Figures

<table>
<thead>
<tr>
<th>Figure</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. External Relations of Integrity (left) and Internal Relations of Intimacy (right)</td>
<td>25</td>
</tr>
<tr>
<td>2. Daoist Symbol for Yin-Yang</td>
<td>50</td>
</tr>
<tr>
<td>3. Self of Intimacy</td>
<td>52</td>
</tr>
<tr>
<td>4. Broken Intimacy or Broken Integrity</td>
<td>69</td>
</tr>
<tr>
<td>5. Buddhist Self</td>
<td>75</td>
</tr>
<tr>
<td>6. Holographic Wholes</td>
<td>75</td>
</tr>
<tr>
<td>7. Self of Integrity</td>
<td>81</td>
</tr>
<tr>
<td>8. Holding On</td>
<td>94</td>
</tr>
<tr>
<td>9. Cut Off</td>
<td>97</td>
</tr>
<tr>
<td>10. Containing Trauma</td>
<td>101</td>
</tr>
<tr>
<td>11. Heart, Harnessed for Carrying</td>
<td>103</td>
</tr>
<tr>
<td>12. Stages</td>
<td>104</td>
</tr>
<tr>
<td>13. Care Blooms as Clusters of Internal Relations</td>
<td>195</td>
</tr>
</tbody>
</table>
CHAPTER 1

REIMAGINING END-OF-LIFE CARE IN AMERICA

In an unlikely beginning, I start this account of my dissertation with a story about a trip I took to China, ostensibly to learn more about Traditional Chinese Medicine (TCM). What I realized on this trip is that dying can and does unfold differently in other contemporary cultures. After a career as a nurse psychotherapist working with dying people, first during the AIDS epidemic during the 1980s and 1990s, and later with cancer patients, I returned to the university in hopes of understanding dying practices in contemporary American culture.

During autumn 2004, amid coursework for my degree, I traveled to Hefei Anhwei Province China with five American advanced practice nurses and several martial arts teachers. We shadowed traditional Chinese medical doctors at one of the two remaining TCM hospitals in Hefei. We toured the pharmacy and herbarium, where giant ginseng roots mixed with animal parts and rare minerals are used in endlessly complex herbal formulations attempting to harmonize the patient’s condition. We experienced and observed traditional therapies such as cupping, moxibustion, acupuncture, twuina massage, and foot reflexology. We discussed the elusive concept of qi, or life energy, in TCM in classes given by the medical school
faculty. We visited the outpatient clinic where medical students inserted acupuncture needles along energetic meridians for those who came for care, one woman with a bag of squawking chickens in tow. We observed manual adjustments that looked similar to Western chiropractic practice. We watched cupping, the application of glass jars adhered to bodies with suction in an effort to remove toxins. We saw tubs where patients soaked in herbal baths to ease discomfort. We observed doctors and nurses massage patients for what seemed to be quite luxurious amounts of time by American standards.

I was assigned to travel around the hospital with Dr. X, who spoke English fairly well. I did not speak Chinese at all. Dr. X was cordial, informative, and politely answered my questions about traditional Chinese medical treatments. As we ended our tour on a unit of the hospital where some Western type medical technologies were integrated with TCM, we entered a room where a bedridden elderly man was surrounded by his family and friends. It appeared to me that he was very ill, thin, breathing slowly, unconscious, and he was hooked up to a dark brown liquid intravenous solution. I imagined he was dying or close to death. I turned to Dr. X and asked, “What do you do for people who are dying here?” He looked at me with a puzzled expression, and answered immediately, “We let them die.” I wasn’t sure if there was some kind of language barrier or cultural misunderstanding going on here. I eventually realized that my question seemed surprisingly curious to him. Isn’t it obvious? When people are dying, you let them die.
His answer seemed spontaneous, natural, calmly assured. As I write today, his words echo in my mind because they reveal an approach antithetical to my experience as an American health-care professional. I realized in subsequent reflection, that it is often in the presence of alterity, difference, or strangeness that we recognize our own habits and patterns of thinking-feeling-doing-being. In that moment, I realized that my previous experience as a nurse practitioner in post-HIV America (1980 to present) involved in the care of dying people and their families, was based on efforts to postpone death and prolong life at almost any cost. I began to think that in America the context for providing health care is one of prolonging life and evading, postponing, or even refusing inevitable conversations or discussions about debility, loss, and death. American specialist medical models do not treat the human body as a complete whole, and the context of cultural relations is mostly ignored. The thought that American health-care professionals could simply “let people die” seems out of the question.

Why? I wonder. What keeps dying from being treated as a natural end to life in America? What constitutes a good death? Is death a failure of organ systems in what amounts to a medical crisis, or is it a spiritual passage? How can dying people be mid-wifed into death peacefully with attention to what matters most to them and their circle of relations at the end of life? If dying is a spiritual passage, how is spiritual care envisioned? These questions guide the research for this dissertation.
Trends in Contemporary End-of-Life Care

I think doctors and health professionals need to take a cue from the public and realize that people don’t want to be tortured when they are dying. They don’t want to be tethered to machines. By and large they want honest compassionate communication. We need to get over our own anxieties about death and dying.

Mark, palliative care physician

This section surveys current issues in end-of-life care in America, in particular the problems of medicalized dying and a scientistic approach to studying spirituality. These problems are multidimensional and are related to scientism, the idea that scientific knowledge is the highest standard for all knowledge, and that decisions at the end-of-life should be made based on scientific knowledge and medical expertise. Scientism is the idea that science is the norm for all knowing. Medicalization implies the reduction of personal or social issues to medical problems, thereby giving scientific experts the power to “solve” them with medical means. Unfortunately, death and dying are not problems that medicine can solve nor that science can illuminate to any great extent. Death and dying pose existential questions for human beings. Hospice and bereavement programs espouse ideal practices that address the existential and spiritual aspects of death and dying. As such, this dissertation highlights narratives, discourse and practices found in hospice and bereavement spaces in order to show what can be accomplished using the ideals of relational care for the living person after (and in some cases before) the death of their loved one.

Problems in end-of-life care are confounded by fear of death or more precisely what I propose is a fear of losing relation. The belief that death brings a permanently
severed relationship between the living and the deceased can precipitate existential crises that involve anguish, sorrow, alienation, anger, fear, anxiety, and a host of other affective dynamics for those involved in encounters with death and dying. Unexamined beliefs about death and fear of permanent loss of relation on the part of patients and families, combined with indiscriminate medical imperatives to save or prolong life, can prevent candid conversations about choices for peaceful dying. This complex set of conditions mutes debates about how to die peacefully with attention to what matters most to the dying person and their circle of relations. When end-of-life wishes are not discussed, there is a greater likelihood that a medical solution to human suffering is applied at the end of life in contemporary America. And this means that other kinds of personal, cultural, or communal parting ritual are eschewed.

The way dying happens in America in 2012 is rooted in a compelling history of medical innovation and research, public policy and sentiment, economics, and enactment of law over the last 50 years. End-of-life care dilemmas are undoubtedly related to exponential growth of biomedical technology and innovations in medical treatment during this time, and they are entwined with legal cases involving the right to refuse medical intervention and the right to choose death with or without medical assistance. According to William Colby (2002), author of *Long Goodbye: The Deaths of Nancy Cruzan*, there is a correlation between the medicalization of dying and development of various medical technologies used to prolong life and prevent death. Procedures such as cardiopulmonary resuscitation (CPR), pulmonary ventilation, gastric feeding tube nutrition, dialysis, organ transplantation technologies,
radical surgeries and amputation, and experimental clinical trials for therapeutic pharmacological agents are just a few examples of biomedical research and biomedical technologies that have extended life expectancy. The question is “What Kind of Life?” as medical ethicist Daniel Callahan asks in his treatise on “the limits of medical progress” (1990).

In America, hospices are typically places where conversations about death and dying are openly discussed. This study was undertaken to provide ethnographic “thick description” of relational orientations in multisite hospice and bereavement programming where attention to cultural contexts, religious or spiritual ritual, and belief are part of the hospice ideal. Though my argument is against medicalization of death and scientisitic study of spirituality in end-of-life care, my study was conducted specifically in hospice and bereavement spaces as particular kinds of end-of-life care. Both are spaces of mourning, but they are qualitatively different. Hospitals, particularly intensive care units, may be more likely to use medical ritual such as CPR and other heroic measures at the end-of-life. In hospice care, the patient eschews heroic measures and opts instead for palliative or comfort measures as death approaches. Therefore, while I am arguing against medicalized dying wherever it may occur, the narratives collected here valorize hospice philosophy as a counterpoint to end-of-life settings where avoidance and denial of death as well as the dominance of medical ritual reign.

A push toward medicalization is also occurring in contemporary bereavement care. At the time of this writing, the American Psychiatric Association (APA) is
contemplating a change in it’s diagnostic and statistical manual. The proposed
counters include making a diagnosis of abnormal grief reaction for someone who has
“symptoms” of sadness longer than two weeks after a death of another. The DSM V,
includes a provision for diagnosing the person who experiences grief lasting longer
than two weeks after a death as having a “major depressive episode.” This move
threatens to treat grief, which may be a nearly universal human expression of love and
loss, as pathology. Sadness, a basic human emotion becomes “abnormal.” As a result,
grief is labeled as mental illness, increasing the likelihood that psychotropic
medication will be prescribed for the person in mourning. Vincent Hevern suggests
that this move by the APA is tantamount to “getting closer to pathologizing everyone.”
As Dottie, a mother whose daughter died of Gulf War Syndrome said, her doctor
prescribed anti-depressant medication, but after a while she discontinued this
medication under supervision of the doctor. She told the doctor “it seems to me you
should be sad because your daughter has died,” referencing the effects of emotional
numbing or elimination of sad affects that occur with anti-depressant medications.

In a circular conundrum, this APA action may be tied to insurance company
reimbursement regulations that require a medical diagnosis in order to pay for
prescribed medication. Physicians who diagnose illness have a better chance of being
reimbursed by health insurance companies for their time. Patients who are diagnosed
with illness obtain insurance reimbursement for medication expenditures. Another
critique I make in this dissertation involves the move to make chaplains “experts” at
spiritual care and become the sole consultants for providing spiritual care. Though I
am philosophically opposed to the “specialist” model of care, I understand that in order for chaplains to be reimbursed for their services, our health care system requires a “diagnosis” and care plan. Thus, the issues described in this dissertation are complex and related to multiple processes at play, such as economics and contingent political agendas of various groups, which ultimately affect health care policy and practice.

Attention to the hospice ideal includes discussion about comfort as death approaches. Debates about balancing quantity and quality of life are prominent in hospice and palliative care. Perhaps the most salient topic in current end-of-life care is the imperative to have “the conversation” with loved ones and health-care providers about how one wishes to spend the last days and months or even years. This is a relational issue. When conversations about end-of-life treatment are not discussed and even sometimes when they are, medical ritual can become the default at the bedside of the dying person.

Further, there is a move in American medicine to balance the overuse of medical interventions at the end of life spearheaded by those who are interested in “spiritual care” in medicine and see dying as a spiritual process. Like many, I interviewed, Mark, a palliative care physician, said he understands that people don’t want to be “tortured at the end of life” and die “tethered to machines.” Palliative care services and hospices offer alternative options for those who desire a less medicalized death. This study suggests that spiritual care is care that considers the relational context of the dying person.
Attention to the relational context of medical care is coming to the fore in contemporary medicine. Beach and Inui (2006) acknowledge that three recent movements in medical practice in the U.S. have been identified. They describe a pre-1960s “doctor-centered” care based on the preferences of the physician. In a swing toward correcting power imbalances in the patient-doctor dyad, doctor-centered care was followed by a movement called “patient-centered care” in medicine in the 1970s and 1980s. In 1994, a task force funded by the Pew Fetzer Health Professions Commission declared that “relationship-centered care” should be considered to reflect the value of relationships in providing medical care.

It is clear that there is a move toward acknowledging the importance of relations in the provision of medical care, but the concurrent rise of a “medical expertocracy” (Hartzband & Groopman) and a push for “evidence-based medicine” (Goldenberg) also prevail in contemporary American medicine. Evidence-based medicine is an extremely popular approach toward medical decision-making based on generating probabilistic medical knowledge about what is likely to work based on outcomes research. According to Maya Goldenberg, evidence-based medicine seeks to rid medicine of its “faulty intuitions and untested customs” by “elevating the scientific rigor of the discipline to improve patient care” (p. 46). Evidence-based medicine leaves the particular body, the sphere of relationships, and clinical intuitions based on internal relation with the patient or family out of the care equation.

The absurdity of trying to practice evidence-based medicine in end-of-life care comes into play when attempting to define “spiritual care” based on statistical outcome
measures. How do you ask a dead person to evaluate the care they received? How do you measure spiritual outcomes of care for the family? What constitutes spiritual care? What counts as “spiritual interventions” in end-of-life care? Can you predict norms for spiritual care given the particularity of people and their beliefs and practices at the end of life? These are the very conundrums that the special cases of death and dying present to scientific research and medical practice models. This dissertation specifically critiques the idea that spiritual dynamics can be isolated from other cultural processes, and therefore can be studied apart from the complex and particular nature of human spirituality. Indeed as will be discussed later in this work, the idea that humans can be defined is antithetical to the thinking of some philosophers including Jean-Luc Marion, who argues that scientific reduction of the human being comes at the cost of profound dehumanization. The idea that science is the norm for all knowing may be behind efforts to study spirituality with “scientific rigor” as recommended by Christina Pulchalski et al. (2009) in their recent white paper on spirituality in end-of-life care. In this report, spiritual care becomes “specialized” care that is provided by chaplains. Evidence-based and expert-based medical models suggest that scientific research and expert knowledge are the ways that health-care decisions and treatment should be guided and these models leave the dying person and their families out of the conversation about how to die in peace.
Thesis

Birth and death are only medical in a nonessential way. They are essentially personal, spiritual, existential aspects of our reality, and they are medical only because we’ve discovered over time there are risks that can mitigated. I think that the medical system does have a role to play [at the end-of-life], but it’s important that we understand the fundamental existential, spiritual, complex aspects of death, and that we don’t treat it as merely a medical problem.

Mark, palliative care physician

Given the intersection of narrow methods of scientific inquiry into spirituality in end-of-life care and the complexity of relational transformations in spaces of mourning, my thesis is as follows: Contemporary research practices in medicine attempt to reduce, define, and study spirituality in end-of-life care with “scientific rigor” by isolating what counts as “spiritual.” To the contrary, ethnographic narratives collected from informants in multisite hospice and bereavement spaces suggest that encounters with death and dying lead to irreducible transformations that cannot be quantified or objectively defined. Using Thomas Kasulis’s intimacy/integrity heuristic to analyze the interview texts, I argue that humans are irreducibly beings-in-relation (intimacy) rather than essentially isolated individuals (integrity). Thus “spiritual end-of-life care” necessitates attention to fluid, inextricably woven personal and relational processes. I assert that spiritual end-of-life care is inseparable from holistic care that attends to the ever-changing relational flows between and among human beings who encounter death and dying. The spiritual implies movement within, between, and across imagined relational boundaries, and this is the primary idea I want to foreground in this study. This fluid way of constructing the spiritual comes from
approaches in the humanities and is in opposition to the impulse in scientific research that reduces, objectifies, bounds, defines, and thus renders the spiritual a stagnant and impotent thing. The remainder of this introduction provides a literature review from medicine and the humanities, a methods section, an overview of the study, an introduction to Kasulis’s intimacy/integrity heuristic, key terms, and a chapter outline.

**Literature Review**

The review that follows covers selected literature in medicine and the humanities. I briefly look at the complex forces that impact how dying is enacted in medical settings contemporary America. Literature from the history, philosophy, and theory of religion is reviewed for conceiving the spiritual in end-of-life care.

**Medicine and Science**

The indiscriminate use of medical intervention at the end of life is highlighted by the 1995 SUPPORT study that exposed “the alarming extent to which aggressive life-prolonging measures were still being used in medically futile situations or when unwanted by patients” (Hastings Center Report, 2005, p. 2). Repeated multisite SUPPORT research studies basically concluded that hospital patients are likely to die in pain and with the use of heroic medical measures despite their wishes against lifesaving measures such as CPR. John Lantos, a pediatrician and medical ethicist discussed cardiopulmonary resuscitation (CPR) and other kinds of medical ritual at the end of life (Lantos, 1995, p. 22):
CPR is our culture’s desperate dance around the bed of a dying loved one.... It is used profligately in cases where it is unlikely to be beneficial, because we have so little else to offer.... Until we come up with alternative rituals, other ways of dramatically affirming and valuing the lives of people who are sick and dying, we will need these rituals badly, even if (or perhaps especially when) they are mostly symbolic.

Based on the findings from the original SUPPORT study, in 1996 the Hastings Center, the Soros Foundation’s Project on Death in America, and the Robert Wood Johnson foundation began a series of initiatives to “change the culture of death in America” by spending nearly $171 million to study the problem between 1996 and 2004. Hastings Center founder, bioethicist, and physician Daniel Callahan suggested a three-pronged plan that involved professional education, institutional change, and public engagement with death and dying. A report from a repeat SUPPORT multisite study headed by physician Joanne Lynn notes the dismal failure of suggested interventions. She concluded:

A second phase of [SUPPORT] revealed even more disturbing findings. The researchers designed a special intervention using nurses to facilitate communication between patients and health-care professionals, provide more accurate assessments of how long a terminally ill patient might live, and provide the patient and family with a means of expressing their wishes regarding treatment, including pain control and heroic measures such as resuscitation. Despite the diligence of the nurses and other members of the health care team, the intervention failed to change the circumstances of death. For example, the amount of time patients spent in the intensive care unit before dying was unchanged, and reports of pain did not decrease. About a third of the families lost most or all of their savings caring for the patient. (Hastings Center Report 2011, p. 6)

It was suggested in this repeat study that better communication of personal choice, such as writing advanced care directives that describe end-of-life wishes, is not
improving the quality of dying in American hospitals. Lynn concluded that the entire medical system and popular culture should be reformed, creating a “default glide path” for the dying patient (Lynn et al., 2000, p. 219). The idea that American medical and popular culture must change to improve end-of-life care is a tall order, yet at least Lynn et al. is in touch with the limits of specific end-of-life interventions played out against the backdrop of intractable and complex cultural patterns. In 2005, the Hastings Center, an institution founded by Callahan that focuses on medical ethics and bioethics in America, reported that, even after 10 years since the findings of the SUPPORT studies, too many Americans still receive poor care or experience “bad” dying without palliation or dignity. Their main recommendation for improving end of life is to (Hastings Center Report, 2005):

... put less emphasis on specific medical decision making concerning the individual patient and instead foster shared decision making and communication among patients and loved ones. The new collective approach toward end of life embraces the reality that people die as they live – in a web of complex relationships. (p. 1)

One contributor to the 2005 Hastings Center report, Yale University law professor Robert Burt, suggests that “applying the autonomy framework in end-of-life decision making has had little practical effect and involves much fictitious posturing” (p. 3). The report advocates approaching end-of-life care from a collective rather than individualistic perspective, involving family members, patients, and health-care team members in discussions. Authors of the report call for reexamining assumptions about autonomy, quality of life, trust, family dynamics, and the motivations of professionals and lay people at the end of life. According to this report, the overarching challenges
to improving end-of-life care lies in three main areas—educating and motivating health-care professionals to perform effective approaches to death and dying; reaching across class, race, economic, religious, and cultural divides to eradicate feelings of mistrust, exclusion, and inequality; recognizing that dying is an interpersonal affair that does not occur in isolation.

Hospice and palliative care research addresses the spiritual aspects of dying, yet current studies seek to reduce “spiritual care” to something separate from care in general. I wondered how spiritual care is conceived and enacted in American hospices where meanings about death and dying are negotiated on a daily basis and death is treated as a human transition or passage. This research in part looks for what counts as “spiritual” in hospice and bereavement care.

The history of the hospice movement in America is entwined with a “conscious dying” movement, the beginnings of which were perhaps fueled by Dr. Elizabeth Kubler-Ross and her popular book, On Death and Dying (1968). In 1973, the modern hospice movement was introduced to the U.S. from England by Dame Cicely Saunders. It is estimated that, at the time of this writing, approximately 30% of deaths occur under the auspices of hospice care, and these deaths occur in homes, nursing homes, and free-standing hospices. The exponential growth of hospice may be a response to the desire for a non-medicalized death that takes place at home with consideration that death is a natural part of life. Growth may be equally attributable to Medicare coverage of hospice care or, in some hospice programs, no cost for bereavement care up to 13 months following a death, making it affordable for all.
Larry, a hospice volunteer, criticizes the reluctance of the medical community to treat
death as a part of life. He hails the work that hospices do to reverse this idea.

I understand it to some degree that the medical profession tends to treat
you as a medical problem to be solved rather than a human being who
is going through a life experience, at this point a death experience. A
recent article in the New York Times talks about the reluctance of
doctors to talk to tell a patient, “Well, we’ve done all we can. Now
how do you want to live out the rest of your life?” It says that doctors
are, really many of them, uncomfortable in that situation. And what I
think is so interesting to me about hospice is that everyone from the
doctors right down through home health aides or whomever simply take
the patient the family from where they are and begin to try to move
them to deal with the issues that are a part of the end of the life, some
of them important, some of them minor. But whatever these
individuals need, they try to do that, and try to solve their problems or
help them deal with those issues. And this, to me, is just such a major
part of the hospice philosophy and theory.

Presently we are in the midst of a right-to-die movement in contemporary
America, perhaps fueled by public sentiment that sees a takeover of the end of life by
medical authority and practices. The overuse and misuse of heroic medical treatments
at the end of life have compelled citizen action groups such as Compassion in Choices
and Last Acts to work toward “taking back a death of your own” and away from the
likelihood of an over-medicalized death. Documentaries such as Consider the
Conversation and How to Die in Oregon follow the debates about dying in America at
this historical juncture. Further criticism of the present medical system is targeted at
physicians who, for various reasons, do not have conversations with those who are
approaching death.

In Letting Go: What Medicine Should do When it Can’t Save Your Life, a piece
recently published in the New Yorker magazine, physician and writer Atal Gawande
suggests that outdated tactics of providing unlimited end-of-life medical interventions are costing patients, families, and health-care professionals precious time, energy, and financial resources. The facts about exorbitant medical spending in the last six months of life have fired these debates with vehement opposition from some sectors of the population about limiting spending at the end of life. The inflammatory rhetoric of “death panels” was successfully used by opposition to President Barack Obama’s health-care reform bill, arguing that a requirement for physicians to discuss advance care planning with patients would limit “personal freedom” for heroic medical treatments at the end of life. Countless television programs, radio shows, and popular docudramas such as Michael Moore’s *Sicko* reflect public interest in these social problems that are part of larger debates about access to and affordability of quality health care for all Americans. End-of-life ethics figure prominently in these debates especially because 78 million members of the baby boomer generation are entering the medical system with chronic disease and facing end-of-life issues. Amid debates about access to health care and end-of-life care, the issues include the exorbitant costs of end-of-life medical treatment that prolong quantity, yet may not impact quality or may actually decrease quality of life.

**Humanities**

Hospice and palliative care spaces are spaces of mourning where intense relational transformations take place for all involved. According to many scholars in the humanities, spiritual issues are relational issues and thus understanding relation is
a key component of providing spiritual care at the end-of-life. Scholarship from the humanities provides important ways to think about spiritual issues in end-of-life care. This section surveys selected frames from the humanities that shape this project.

The narratives in this study reflect the suffering and transformation that follows a death. Lorna talks about all-encompassing transformations following the death of her 13-month-old daughter in this piece of autobiographical writing for other bereaved parents. She says:

And so it began; the ordeal of grieving, the incongruous event of outliving my child, the transition from innocence to complexity. Life never again looked simple. My eyes, my ears, and my heart all sense now with a different understanding of what lies beneath the veneer of our daily lives.... I woke up empty. Priorities changed. All I wanted to do was talk about Sarah, but I felt that it wasn’t OK. It was the beginning of a personal transformation. I got older, but Sarah stayed forever young. As unbelievable and uncomfortable as this may seem, there are gifts to be taken from such terrible losses. As I look back, I can’t quite fathom from where the strength, the inner sense, the intuitive survival came. If you try to bypass grief, it just moves ahead to the next fork in your road, confronting you, pushing you to walk through its maze. And when you come out you are changed – forever, profoundly, unalterably changed. I can admit this now while I never would have believed it or understood it 26 years ago: the change can be a good thing.

Lorna’s words reflect the enormous transformations that can occur after the death of a loved one. Stories like Lorna’s, collected in this study, can be termed what religious studies scholar Thomas Tweed called “teleographies” or narratives that grapple with the temporal and spatial limits of human life. His references to suffering and joy are very relevant to dying and the end of life, a time when those involved are at once mourning and celebrating relation. Tweed views religion as “confluences of
organic-cultural flows that intensify joy and confront suffering by drawing on human and superhuman forces to make homes and cross boundaries” (p. 54). Tweed’s theorizing of “sacroscapes” as secular spaces that involve confluences of cultural flows, applies to hospices where medical and religious discourse and praxis intersect. His discussions of humans as “crossing boundaries” and “making homes” have many applications in hospice care and bereavement settings. These tropes reflect the medieval origins of hospices (from hospes) as a places of hospitality, spiritual journeying, and respite care where host and guest come together.

An important philosophical source for understanding encounters with death comes from the work of Buddhist scholar David Loy. Loy’s brilliant monograph *Lack and Transcendence: The Problem of Life and Death in Psychotherapy, Existentialism, and Buddhism* surveys common questions among Western psychology, Buddhism, and existential philosophy in their approaches to life and death. Loy considers possible sources of human suffering that constellate around death, loss, and the desire for transcendence. He suggests that our real repression or fear is not sex as Freud theorized, nor death as many existential philosophers have suggested. An assumption I borrow from Loy is this—our fear and anxious attachment to life, along with dreams of immortality and dread of death, are symptomatic of a deeper desire to actualize a sense of self that is genuine and authentic, a self that wants to transform its anguished lack of being into something genuine and real in the present without projecting the problem of being into the future. Even if the fear of death represses something, Loy postulates that this fear is preferable to facing a lack of being in the now. A focus on
time allows for a focus on lack in the present moment, and a focus on a separate self results in groundlessness and suffering.

According to Loy, Buddhism does not place life/death and self/other in dualistic opposition. Loy argues that Buddhist philosophy deconstructs the duality of life and death and centers consciousness in the present and the relatedness of things. Meditation or other ritual practice that grounds the self in a net of interdependent relations, ends the problem of loss and lack by developing awareness that we are firmly rooted in expanded webs of relation. If, in Loy’s terms, nothing is lacking now, then “the issue of immortality loses its compulsion as the way to resolve our lack, and whether or not we survive physical death in some form is no longer the main point” (p. 28).

This foundational philosophy underlies the burgeoning use of Buddhist meditation practices in contemporary hospice and bereavement settings. Although a full treatment of this phenomenon is beyond this work, Buddhist thought and syncretically appropriated Buddhist practices such as meditation are reinvigorating end-of-life care in America. Buddhist meditative approaches to death and compassionate presence practices with the dying are based on awareness of the both the contents and dynamic flow of consciousness in the present. Bringing conscious awareness to bear on body-felt experiences, affective dynamics, and relational bonds lends a kind of vitality to the experience of living that is often missing when humans are attached to projecting the self into past or future scenarios. This kind of awareness affirms a full picture of interdependence that does not end with a death of a loved one.
It may lead to consideration of intimate bonds with others as foundational for end-of-life decision-making.

Historian of religion Caroline Walker Bynum’s scholarship on medieval eschatology is referenced in this project for what she calls “affective spirituality.” She proposes that affective dynamics, specifically desires for union or reunion, figure largely in western Christian beliefs about death. Bynum also draws attention to shifting historical conditions and contexts that shape definitions of spirituality. Personal and relational metamorphosis is a central concern in her writings about female medieval mystics.

Transformation is also the focus of Susan Kavaler-Adler, a neo-Kleinian psychotherapist, who writes about mourning as a developmental process and spiritual odyssey. In *Mourning, Spirituality and Psychic Change*, she unabashedly asserts that spirituality is a real concern when healing from grief and loss. She understands healing as an ongoing process that necessitates entering the cave of suffering, opening the mourner to further vulnerability and wounding. This dissertation draws dually on Kasulis’s construct of the intimacy relation and Kavaler-Adler’s analysis of mourning as the product of affective, somatic, and cognitive dynamics that involve the spiritual heart of the person. By the spiritual heart I mean the matrix of compassion and wise understanding that either withers or expands in response to loss and grief. Metaphors of the heart abound in these narratives and in images found in bereavement spaces. Kasulis (2008) and other contemporary Buddhist scholars and practitioners have written about cultivating the “mindful heart” noting the inseparability of reason and
emotion in human endeavor. Joan Halifax and other Buddhist practitioners talk about the necessity of compassion as a relational imperative between caregiver and receiver in end-of-life care.

For theorizing care, caring, and caregiving, feminist philosophers Nel Noddings and Eva Feder Kittay are cited in this dissertation. Noddings states that relation, rather than autonomy, is ontologically basic for human beings. She asserts that care implies affection and relation together, making care a type of internal relation. Kittay suggests that both the caregiver and care-receiver benefit from the caring relation. Unlike proponents of principle-based deontological ethics, she acknowledges that debility, dependence, and unequal power relations are part of caregiving scenarios. Because the dying person is increasingly dependent and at the center of a circle of care, the concept of care is important when theorizing relational bonds at the time of death. As an ethical model, the feminist ethics of care includes attention to particularity, relation, affection, interdependence, and dependence. As such, it deserves as much consideration as ethical models that favor autonomy and independence as principles for end-of-life decision-making. I use Noddings’ (1984) simple definition of relation as “a set of ordered pairs generated by some rule that describes the affect or subjective experience of the members” (p. 4). According to Noddings, this means that human encounter and affective responses are basic facts of human existence.

Philosopher of religion Hent de Vries, in his edited work Religion: Beyond a Concept, suggests that contemporary ritual can encompass “the things, words,
gestures, affects, effects, symbols, sensations, silences, powers, and practices that phenomenally manifest in both religious and secular contexts and help to chart unexpected connections” (p. 17). In his efforts to theorize religion, de Vries concedes that in both religious and secular discourse, human experiences that stand out in their intensity, their near absoluteness, and transcending qualities are those that often matter most. This dissertation is about such experiences as they are spoken by informants and heard by me.

Methodology and Overview of the Study

As detailed in the literature review, many scholars who study the history, theory, ethnography, and philosophy of religion attest to the historical and cultural embeddedness of human experience. They suggest that the spiritual is about personal and relational transformations—processes that are not amenable to understanding with the positivistic gaze of science. To illustrate the irreducible personal and relational transformations that occur in end-of-life care, this dissertation focuses on narratives that describe the complex relational matrix of grief and mourning that is found in end-of-life care settings.

During the research process, I engaged in a variety of ethnographic fieldwork observations and conducted interviews in multisite hospice and bereavement spaces. I read a range of readings from religious studies scholarship and current medical literature about spirituality in end-of-life care. One article stood out as a paradigm of what I wanted to argue against: the quantitative analysis of spirituality. Specifically, a
recent white paper on spirituality palliative care by Pulchalski et al. is emblematic of much medical research in that it engages the scientific paradigm and advocates quantitative methods of inquiry as ways to produce knowledge.

When it comes to studying spirituality in end-of-life care, however, this paradigm seems less helpful than others to describe and interpret the thick relational matrix of end-of-life settings or to interrogate the complexity of the term “spirituality.” The writings of Thomas Kasulis, a philosopher of religion, reflect on relationship as a key dimension of spirituality. To map complex relational transformations between the living and the deceased, I use the I/I heuristic developed by Kasulis, as detailed in his book *Intimacy or Integrity: Philosophy and Cultural Difference*. The I/I model is used to help us think philosophically about human beings and their relations to others. As a heuristic, the I/I model is simply a tool for organizing, interpreting, or engaging in philosophical analysis. This model, described in detail later in Chapter 2, offered me a flexible way to engage my own thinking about a range of relational orientations between the living and the dead.

The I/I heuristic looks at recursive relational cultural patterns out of which a whole analysis of culture can be constructed. Kasulis identifies two basic relational orientations to describe how human beings predominantly think about the self and his/her relations to others and the world—relations of intimacy and relations of integrity. The intimacy relation is characterized by overlapping or porous boundaries that allow each participant in the relationship a kind of innermost, sometimes
unspoken, understanding and affection. The integrity relation is characterized by solid inviolable boundaries of autonomous people related by some external connection.

These basic relational imaginaries are graphically represented in Figure 1. In the illustration, $a$ and $b$ represent two relatants in a dyad. $R$ is the way that the two people are related. In integrity-based relations, boundaries are imagined as solid, and independent people are connected by something outside them. In intimacy-based relations, boundaries are porous and interdependent people are related in overlapping internal relation.

![Figure 1. External Relations of Integrity (left) and Internal Relations of Intimacy (right)](image)

Kasulis, Thomas. *Intimacy or integrity: Philosophy and cultural difference* (p. 37). Honolulu.

To trouble a simplistic view of relationship in end-of-life care, this study focuses on how living mourners think about their relation to the deceased. Analysis of this relational dyad is used as an example of the complex relational matrix of end-of-life care. I argue that relational transformations are irreducible processes in that how mourners think about relation to the deceased is co-determinate with what they feel,
what they value, what they believe and hope for, and how they act within the context and contingencies of their particular expanded relational spheres.

How might we study the complexity of human relationships that coalesce around death and dying? Ethnographer of religion, Robert Orsi’s approach to studying relationship, belief, and religious practices are grounded in descriptive ethnographic methods. He defines religion as attending to relationships “between heaven and earth.” He suggests that symbolic others such as gods, angels, spirits, and ancestors have a primary place in discussing human relationships. This research was conducted using ethnographic interviews with a keen awareness of emerging narratives in the field. Ethnography, as an art of self-reflexive seeing, listening, and feeling deeply, is a worthy fit for describing the thick relational matrix of grief, loss, and mourning found in end-of-life settings. Following methods endorsed by ethnographer of religion Orsi and narrative medicine expert Rita Charon, the main research method was listening deeply to what the informants were trying to convey to me in the field. Engaging the ideas of medical ethnographer Rayna Rapp, I also tried to be cognizant of the thick social matrix of death and dying for informants and thus the complex relational landscape of end-of-life ethics. I was aware that the informant inhabited multiple spheres and histories of cultural relation including the familial, the religious, and the medical. Fieldwork experiences led me to research literature in the ethnography and philosophy of religion, and feminist philosophy, which further informed my research in the field. In the final analysis, a hermeneutic methodology was applied in that the
interview texts were read, studied, and contemplated in an effort to make meaning out of them.

**Description of Research**

The ethnographic interviews comprise most of the data for analysis. Sixty interviews were completed, transcribed, and then read and re-read closely, yielding more than 1,500 pages of transcribed text. On the macro level, the ethnographic field is broadly defined as spaces of mourning in one hospice and two bereavement programming sites in central Ohio. On a more micro scale, that is, at the personal level of informants, this work can be considered a relational analysis of mourning. Thus, the space of mourning has double meaning—both communal and personal—and these spaces are intertwined.

The study was conducted during a 2-year period (2009-2011) primarily at two fieldwork sites in Columbus, Ohio, a Midwestern American city. One site was a hospice/bereavement program that historically had religious affiliation with the Methodist church and is where I conducted my master’s research project. The other site was grief and bereavement programming at a major university medical center and research institution. During this 2-year period, I interviewed a range of informants both inside and outside these fieldwork sites. Individual interviews lasted about one hour or more and covered a variety of questions about relation to the deceased and beliefs about death. Interviews were digitally recorded and transcribed to supply the main data for analysis.
Sixty participants, forty women and twenty men, ranging in age from 19 to 86 years were interviewed for this study. Approximately 40 people are “lay” people, and 20 work in “professional” capacities in hospice or bereavement programming. One-third of the lay participants worked as volunteers in bereavement or hospice programming. At the time of the interviews, lay participants reported various lengths of time since the death, ranging from 2 months to 27 years. Deaths were from causes including cancer, congenital anomalies, heart disease, suicide, accident, war, and natural causes. Not all deaths were assisted by hospice care; some informants attended bereavement programming without having used hospice services. All participants had high school educations, most had bachelor’s degrees, many had master’s degrees, and four had doctoral or post-doctoral degrees. More than one-third of the participants identified themselves with various denominations of Christianity, including one from the Church of Jesus Christ of Latter-Day Saints. A little more than one-tenth identified themselves as Jewish. Two identified themselves as Buddhist and one as Muslim. Four participants denied any kind of religious belief, but two of these attend church for social reasons. The rest, about one-third, declared organized religion was not their path, despite personal histories with diverse religious affiliations. These informants claimed various beliefs about afterlife, reincarnation, or other beliefs about death.

As part of fieldwork observations, I attended many grief and bereavement support groups. During the time of data collection, I attended national and
international conferences on end-of-life ethics, hospice care, Buddhist approaches to end-of-life care, medical humanities, and the anthropology of death and dying.\textsuperscript{15}

**Limitations of the Study**

This ethnographic study was undertaken in hospice and bereavement spaces but critiques medicalization in other end-of-life care spaces. Because my purpose was to illustrate the hospice ideal and its rationale, a limitation of the study is that its narratives were collected exclusively from hospice and bereavement programming. A more comprehensive comparison of end-of-life spaces could be designed with attention to contingent cultures of medical care that are enacted in different end-of-life spaces. This study also could be enhanced by including narratives from the dying persons themselves, but as noted in the description of the study in Appendix A, permission for interviewing dying persons met with resistance at all levels of the research, hospice, and hospital institutions. A few narratives I designate as “nearing death” experiences from Angela, Stacy, and Nan add to the understanding of how difficult it is for the dying person to let go of human relationships in order to transition to death. Future studies will include narratives from dying persons themselves.

This dissertation alludes to but does not include thick description of ritual enacted in hospice and bereavement spaces, as they ultimately fell outside the parameters imposed by the present study. Nonetheless, it should be noted that the research included observations of ritual performed to restore or recreate internal relation between the living and the dead, or what I call healing ritual that differs from
medicalized ritual at the time of death. The idea that ritual in hospice and bereavement spaces creates internal relations between the mourner and the deceased is a fundamental finding from my fieldwork, yet the argument that the hospice ideal attends to restoring internal relation between the living and the dead is not supported as fully as it could be, since I did not include this data in the dissertation. A comparative study of medical end-of-life ritual and hospice end-of-life ritual is planned for future analysis. Description, contrast, and comparison of medical and spiritual or religious based ritual in the end-of-life scenarios might more fully illustrate the differences to the reader.

The sample of informants in this study also lacks racial diversity. A more detailed description of relational orientations and beliefs about death organized by differences according to race, class, gender, culture and ethnicity would add depth and nuance to this study. Though both the hospice and research university bereavement sites included health care services for a culturally diverse range of dying and bereaved people, those who came to grief and bereavement groups were more homogenous than the entire pool of persons served. This fact limited my access to a culturally diverse sample. Lack of cultural diversity in grief and bereavement groups may be due to many factors beyond the scope of what I analyzed in this study. These factors might include lack of funds or means of transportation to the groups, lack of information about the groups in particular communities, or use of other kinds of intervention to deal with grief and loss such as church, family or other social networks. I am aware that even though dying is a universally human fact, meanings of death are mediated by
culture, race, ethnicity and class, but this point may be lost because of homogeneity of the research sample. Though the spiritual imaginaries presented in Chapter 5 are particular, they are perhaps more similar in quality than a more diverse demographic would provide.

Finally, the critique of the scientistic study of spirituality requires a much fuller analysis and accumulation of supporting evidence than was possible within the parameters of this dissertation. More detailed analysis is needed to establish quantitatively a pattern of a superficial treatment of religion and spirituality in contemporary medical literature, including the efforts that the scientific medical community in general is making to universalize a definition of spirituality. A full critique of the scientistic study of spirituality as applied to end-of-life care also would include readings in the history and philosophy of science to fully critique the scientific paradigm, its methods, its proper application, and its limitations.

**Reflexivity and Positionality**

One important distinguishing difference between this ethnographic study and other medical end-of-life studies is that I acknowledge my own position as researcher. Indeed, ethnography can be seen as an intimacy-based method of scholarly inquiry because it relies on the affective/somatic engagement of the researcher overlapping with people, places, and things in the field. My background and life experiences shape my interest in cultural approaches to death and dying. The way I received these stories is filtered by my own experiences with dying people. As a self-reflexive act,
ethnography is a method of knowledge production that includes acknowledgement of personal and historical contexts and contingencies. My interest in death and dying can be traced through many kinds of life experience beginning in childhood to the present day. This section attempts to mark some of the more vivid life experiences that have propelled me into this work.

My first memory of death and dying is from sometime in the mid 1960s when I was a student at a Catholic grade school in the anthracite coal country of northeastern Pennsylvania. Mrs. Jones died. She was the mother of three boys who attended school with my siblings and me. The wake was in their home, just two streets away from ours. My mother prepped me about what to say to the grieving family before we left our house. I was to say that I was “very sorry for their loss” and to say a silent prayer at the casket. As I stood looking at Mrs. Jones in her light blue chiffon gown with tearful family standing around, I tried to muster up a prayer. But mostly I was overtaken with the atmosphere that in my memory, still defies description. The next day, as was the custom at our church, some of the grade school girls sang at Mrs. Jones’s funeral mass. I don’t remember this particular funeral very well, but I generally have fond memories of singing at the funerals that took place at church building next to our school, in row with the convent and rectory.

Singing at funerals meant that we left what we were doing in the classroom. It was a break from the tedium of the normal school routine. We would file over to the church following a nun in her flowing navy blue habit, and climb the narrow stairs to the choir loft, where the drama below was clearly visible in panoramic view. The
physical space of choir loft was a magical place for me with an old pipe organ and magnificent stained glass windows wedged into cramped gothic cut stone nooks. During funerals, clouds of incense wafted into the rafters of the loft, and we sometimes choked on the thickness of the smoke. Who knows how the eulogies and other elements of the liturgies influenced me as a child? But inevitably they must have. My friends and I enjoyed our time together singing, something we did outside of church too, learning popular folk songs of the 1960s on our guitars. At funerals we sang Gregorian plainchant, mostly from the Missa Angelorum, the mass of the angels. I can still sing some of the lines, including this central one that reflects a hopeful doctrine of the Catholic church on death: “may the angels take you into paradise.” Paradise. As a child, this seemed like a good place to go. Somewhere where there was no death and separation. A time and space where suffering did not exist.

Did I believe the doctrine of the church on death when I was a child? I cannot say for sure. I do know that the ritual, beliefs, and other cultural practices were part of a continually renewing spiritual foundation for my Irish Catholic family. It contained what seemed like comforting and quieting rituals for dealing with birth, life transitions, and death. Perhaps my interest in ritual comes from these early experiences. I think participation in ritual gave me an appreciation for what can be intensified, transformed, and/or released in community when death occurs. In our small town community, a religious-based social imaginary was spun. The narratives—grande and petit—about heaven, earthly conduct and death were reiterated at church, school, and home. Ritual that surrounded important life events such as births, deaths,
and marriages all took place in the church. By virtue of my birth into this community, I was taught to honor transitions throughout the life of its members with formal recognition, through formal rites and ritual. So, it seems natural that my pairing of death and ritual follows from some of these foundational personal experiences.

The idea that cultural beliefs and practices protect us from the terror of the reality of death rings true for me. The conceivers of contemporary terror management theory suggest that “cultures allow people to control the ever-present potential terror of death by convincing them that they are beings of enduring significance living in a meaningful reality (Pyszczynski, Solomon & Greenberg, 16).” I can say that my early indoctrination of religious belief through praxis did this for me. According to the aforementioned authors, culturally based symbolic vision and ritual can provide order, stability, meaning and personal significance for its members. Culture can provide answers to questions such as who am I? Where did I come from? What happens when I die? Today the answers to these questions are widely divergent in the America of 2012. And though what people believe and how they express those beliefs varies within geographical, cultural, and religious communities, I believe that knowledge about how death is particularly conceived and how dying is ritualized is essential information to have in end-of-life health care environments. I have also come to believe that memories of the death-bed scenario reverberate long after the death and can color the mourner’s affective and relational dynamics for long after the death.

In 1986, another series of events shaped my interest in dying and its dense cultural matrix. At the beginning of the AIDS epidemic, a dear friend of mine
contracted the HIV virus (human immunodeficiency virus, the virus that causes AIDS or acquired human immunodeficiency syndrome). Acknowledging his plight and many others who got diagnosed, I volunteered to work with the Columbus AIDS Task Force. The experiences I accumulated in the next five years of my life working with PWAs, or people with AIDS, greatly shaped both my personal and professional life. It seemed like the first time in recent history, or at least in my lifetime, that an epidemic of such devastating proportions had no effective medical treatment. Every person I worked with over my years as a support group leader died. Neither science nor medicine had answers for the (mostly) men that I worked with. Adding insult to injury, some families and churches alienated PWAs because of judgment about their sexual orientation. There was an assumption, with accompanying stigma, that AIDS was a “homosexual” disease. This soon proved to be erroneous, as all segments of the population became at risk for contracting HIV through various means of transmission including transfusion.

In essence, many people I worked with seemed outside the safety nets of medical treatment, and religious, familial, or cultural inclusion. They were on their own. And they were dying. Amazingly, what happened is that community was created from the ground up. The Columbus AIDS Task Force and the Ohio AIDS Coalition were formed by PWAs and others to offer community to those who wanted to face this disease and their unknown future together. Buddy systems paired volunteers with PWAs. Partners set up ways to offer services such as cooking, cleaning, errand running, and transportation to medical appointments. “Healing
Weekends” were held quarterly in Columbus and those from rural areas of the state met with doctors, social workers, massage therapists, and peers who could understand what they were experiencing. A well-oiled engine of altruism and volunteerism rolled ahead. I volunteered to run weekly support groups for PWAs and then eventually ran a group for teenaged family members of PWAs. We explored alternative healing methods and meditation hoping that anything might help. Often, a PWA started as a volunteer caregiver, and then as the disease worsened and physical impairment increased, he would become the cared-for. Despite the devastating loss of young lives, we all worked together to do what we could to lessen suffering on many fronts.

It was in the weekly groups with these men, their partners, and families that I got to know the anguish associated with premature, untimely, and often socially ostracized dying firsthand. The wonderful people I worked with taught me about how the end-of-life is a vitally important portion of a life fully lived. The dying process indeed seemed like a liminal space, a transition from one kind of existence into the unknown of death. I realized during this time that much important work can and does happen in this space for individuals and their circle of relations. Saying good-bye, leaving a legacy, reviewing a life, expressing doubts, fears, hopes, dreams, reconciling relationships, asking forgiveness, being forgiven—these seemed to be ingredients for dying with a modicum of peace. And though it is not always possible to control the dying process, I learned it is possible to create an atmosphere of compassion and security for dying to happen with as much peace as possible.
Many people in America were brought to their knees by the mystery and painful unfolding of dying too soon, without medical treatment that could reverse their fate. Sometimes this occurred in the absence of religious consolation and ritual or their family’s knowledge of their disease. Together, as volunteers, persons with AIDS, and partners, we literally created ritual for coping with what was going on with many of the people who came for weekly groups or quarterly weekend retreats. It was a time of discovery for me and an eye opening view of how death often comes unbidden and unwanted, leaving unfinished lives in its wake. Sometimes it was not possible to have face-to-face contact with those who mattered most to the dying person, so others stood in proxy, companioning the dying. I think it was also a testimony to the ability of a community of compassionate others to rally around those who needed help with everything from buying groceries, to securing health care, to writing wills. In the end, I think I learned that ritual around death and dying could be created and performed with neither efficacious medical intervention nor with the help of traditional religious praxis *per se*.

The experience of working with people who were HIV+ inspired me to work with others who were facing death or dying. My psychotherapy practice became limited to those with chronic or “terminal” illnesses, including people who were in various stages of cancer. For the next 15 years, I accompanied many people from diagnosis to death, sometimes not meeting their families until the final days or weeks of life when they were immobile and I would visit their homes. The stories I would hear about how medical treatment for their condition was unsatisfactory for the
“patient” stuck in my mind. What can be done when medicine can do nothing to prolong life or increase quality of life? Sometimes religious beliefs and practices were consolation for those I accompanied. But even if family, religion, and medical care provided support to the dying person, the existential crises that arose seemed to have no outlet but through words, hopes, dreams, tears, and deep silences. Hospice physician Michael Kearney writes about this dilemma in his first book *Mortally Wounded*. No human being escapes the finality of death and dying, though meanings of death are particular, and culturally constructed. From birth we are marked by the universality of dying. But the dying person can be attended compassionately, tenderly, and carefully as part of the human community.

My nursing practice became devoted to accompanying dying persons at the end of life. In 2000-2001, my parents died within nine months of each other. My father had aplastic anemia, a blood disease that took many long years to lead to his death. My mother died of lung cancer soon after. I read more about grief, loss and mourning. This time however, it was from a more personal point of view. I embarked on coursework in Buddhism, having a keen interest in Eastern philosophy since my first yoga class in college. The refreshingly honest assumption that suffering is part of the human condition seemed like a good place to start to understand conditions that might contribute to human suffering and how suffering might be eliminated. I realized I wanted to end my own suffering as well as those who were dying all around me. In the end, there was no difference between us. We were all approaching death. We had many of the same questions about life, death and relationship.
When my father was nearing the end of his life, one event in the hospital galvanized my interest in end-of-life ethics. He had become dependent on transfusions to keep his blood levels and energy up. Transfusions became more frequent, until it seemed he needed one almost everyday in order to function. During one of his last hospitalizations, as a few of my siblings and I stood around his hospital bed, the blood they were giving him was literally leaking from his body. I asked the physician what was happening. He led me into the hallway and told me that his weakened body was no longer able to hold the blood that was being administered. I asked what the prognosis was. Not answering my question, he said it was my father’s choice to continue treatment and that if I wanted to know anything more, I should ask him, something due to confidentiality laws and non-disclosure of patient conditions to family members. I was flummoxed. How could the doctor have inside, intimate knowledge of my father’s condition, but our family was not privy to this knowledge? In that instant, I was angry and felt completely shut out of what was happening. My father meanwhile, seemed not to understand much except that he did not want to die. What of other “patients” who have lost their ability to reason, think, or are completely unconscious as they near death? How can conversations that involve the patient (if possible), the family members, and the health care team be initiated so that decisions can be facilitated in consensus fashion? In 2005, the Hastings Center report *Improving End-of-life Care: Why has it been so difficult?* summarizes 20 years of end-of-life care initiatives and diminishes the place of patient autonomy and recommends shared
decision making in end-of-life scenarios. Dying takes place as life does, in webs of complex human relationships and this must be acknowledged during end-of-life care.

In retrospect, there was no one there to say that this was a sign of real deterioration in my father’s condition and that we would have to begin to make other kinds of choices and arrangements for his care. The palliative treatments were failing, and it was time to think about other ways to care for him. I wanted someone to relay this information to me and to my family in a compassionate manner. No one did. The futile transfusions continued that day, and even though he was my own father, I saw the waste of resources—precious time, money, and caregiving—that were spent on this suffering person to no avail. Perhaps the medical interventions were even increasing his pain and discomfort. Indeed the absurdity and sad futility of this scene haunts me. It is one of the reasons for this study. How can medical personnel do the best they can, communicate the projected efficacy or futility of further medical treatment, then bow out and let the person and family spend quality time together at the end of life? How can they make space other personal or cultural practices that might be enacted in the absence of medicine as the hegemonic ritual around the deathbed?

Dr. Atul Gawande talks about “what medicine should do when it can’t save your life,” the subtitle of a recent essay Letting Go in the New Yorker magazine. He states that contemporary medicine is good at “staving off death” with aggressive biomedical interventions such as chemotherapy, radical surgeries, organ transplantation, kidney dialysis, pulmonary ventilation, cardiopulmonary resuscitation, intensive care, and so on. But he laments that doctors do not know when to switch the
focus to improving the days that people have left to live. This sentiment is echoed by the palliative care and hospice physicians I interviewed for this research. One told me that “docs just don’t know when to stop” administering aggressive treatments. One of the problems in such cases, according to Gawande, is that “death is certain, but the timing is not.” Everyone involved in care of the dying confronts this uncertainty. According to Gawande, biomedical innovations have “rendered obsolete centuries of experience, tradition, and language about mortality, and created a new difficulty: how to die.” My trip to China in 2005 made me wonder if this new difficulty seems to be an American one, a culturally specific way of handling death with medical technology in hopes of taming, postponing, or preventing it altogether.

**Definition of Terms**

This section defines key terms used in this study. Some terms such as medicalization, scientism, intimacy/integrity, care, relationship, ritual, and religion have been briefly defined. Other terms explained below include thanatography, thanatopoiesis, mourning, affect, palliative care, hospice, spirituality, and spiritual imaginaries.

Thanatographies, or stories about or around death and dying, are what I call the narratives collected in this study. Thanatopoiesis is my word for the creative process encompassing potentially limitless transformations that emerge for the living person following the death of a beloved other. The term is inspired by ethnographer Kathleen Stewart’s (2005) writing on cultural poiesis and affective flows in the ethnographic
field. The etymology of the word lies in the Greek thanatos meaning death, and poien meaning creative making. In the broadest sense, thanatopoiesis encompasses a potentially infinite number of creative changes that can occur after a death. This work examines just a few. By thanatopoiesis, I mean the creative affective dynamics, spiritual imaginaries, and relational transformations that emerge from the death of a beloved other. In biomedicine, hematopoiesis refers to the production of blood cells. I would like to draw parallels, suggesting that death similarly produces creative holistic changes for the living.

Mourning is ultimately a relational process that is key to psychic transformation according to Kavaler-Adler. Her definition of mourning is one I have adopted for this work. Mourning is “a life long journey of connecting, internalizing, and letting go of external others, while integrating the symbolic meaning of the relationship with these others in the internal world” (p. ix). She asserts that mourning is a spiritual process that involves the heart as the psycho-physical locus of the person.

Affect refers to embodied relational resonances between the self and others. It moves within and between people and their environs. Affective resonances are part of describing internal relation in the I/I model and contribute to the ephemerality and indeterminacy of solid relational boundaries between the living and the dead.

In this study, spirituality is a relational construct. The etymological roots of the word “spirit,” from the Latin spiritus meaning “breath” and parallel to the Greek word pneuma with the same meaning, refers to the continual movement of affective energies that are reflected and refracted between and among human beings or between human
beings and supra-human powers. The spiritual is relational, imaginal, and moves.

These are the primary qualifiers I want to foreground in this study, in opposition to the impulse in end-of-life scientific research that reduces, bounds, and renders the spiritual, as discrete object, stagnant, and impotent. Spiritual imaginary is a phrase I use to refer to what informants believe, hope, dream, imagine, or fear happens at the time of death and/or beyond.

Palliative care is a medical specialty that focuses on alleviating suffering. From etymological roots in the Latin palliare, meaning to cloak, palliative care seeks to relieve the pain and symptoms of illness without having an underlying goal to cure. In 2007, palliative care became a specialty in American medicine after the SUPPORT studies’ results indicated that many people die in pain in U.S. hospitals. Hospice is a philosophy and model of care that involves an interdisciplinary approach to treating the dying person and their circle of relations. The emphasis is on comfort care and spiritual support through the dying process. Hospice staff members care for patients in their homes, nursing homes, or freestanding hospice buildings dedicated to care of the dying. Many hospice programs provide bereavement care following a death for family members of the deceased. Hospice care is a rapidly growing alternative to dying in hospitals in America, with almost 30% of dying now taking place in hospice care.

**Chapter Outline**

This section briefly describes the themes of each chapter. The content of each chapter relies on the interview texts and ethnographic field observations to support the
thesis that spiritual issues in end-of-life care are issues that involve internal relation between and among all involved in circles of caregiving and care-receiving.

Chapter 2, Relational Transformations and Death, begins with an in-depth explanation of the intimacy/integrity model. Narratives and interview texts are analyzed using Kasulis’s heuristic to call attention to the findings that relational transformations in mourning are dynamic, complex, and oscillate toward the intimacy orientation. In this chapter, I propose that affect, perception, and belief are inextricably woven components of shifting relation for the mourner.

Chapter 3, Susan’s Story: “I Can’t Imagine,” a case study that exemplifies the complex relational shifting that happens after the death of a loved one, presents visual representations of the personal and relational transformations that followed the death of her son in a mountain-climbing accident. Susan’s experiences of mourning are vividly captured by her artwork because she “had no words to describe this experience.”

Chapter 4, Catching the Wind? Theorizing Spirituality in End-of-Life Scenarios, addresses some themes on spirituality in the hospice/palliative care medical literature and in religious studies scholarship. I suggest that, like its etymological roots in the Greek *pneuma*, meaning breath, spirituality involves continual movement and is beyond our ability to capture scientifically. I suggest that petrifying a construction of spirituality, as is the recommendation of current quantitative palliative care literature, is antithetical to views of religious studies scholars who draw attention to the fluid, historically situated, relational nature of spirituality. I suggest that, instead
of prescriptive approaches to what counts as spiritual care, an ability to enter into intimate relation with those who present themselves for care may be needed.

Chapter 5, Spiritual Imaginaries of Death, describes spiritual imaginaries as the beliefs, hopes, and dreams about death as narrated by the informants in this study. In this chapter, I describe themes that emerged in the interviews regarding how the living imagine they are related to the deceased and for some describe the speculated location of the deceased. I suggest that spiritual imaginaries are further ways to construct relation to the deceased and use the intimacy/integrity heuristic to categorize certain spiritual imaginaries. Taken as a whole, these ideas about death may be reflective of contemporary American social imaginaries of death.

Chapter 6, End-of-life Care as Relational Bloom Space, summarizes the findings of this study and makes recommendations for rethinking spiritual end-of-life care. The title of this chapter refers to the limitless kinds of relational transformations between the living and the dead found in this study. I discuss how thanatographies might inform end-of-life ethics and how listening to the dying person and their intimate relations is one of the most important strategies for end-of-life decision-making. I consider models that guide practice, pedagogy, research, and ethics in end-of-life settings based on acknowledgment of the thick relational matrix of dying.
CHAPTER 2

RELATIONAL TRANSFORMATIONS AND DEATH

This chapter uses the I/I heuristic to map relational transformations between the living and the dead. To help explain my analysis of relational transformations, some of the basic tenets of the I/I heuristic are best covered here in the introduction. To elaborate the key terms of the intimacy/integrity heuristic, Kasulis (2002) draws on the Latin etymology of the terms. “Intimacy is making known (intimare) to a close friend (intimus/intima) what is innermost (intimus)” (p. 28). The intimacy relation is characterized by overlapping boundaries that allow each participant in the relationship a kind of innermost, sometimes unspoken, understanding and affection. Intimacy relations stress what is common between people rather than their independence. The intimacy orientation implies that two people “belong with” each other and contain each other in some way. A line from The Music Maker, by Sufi mystic and poet Jelal ad-Din Rumi illustrates this orientation. “Lovers don’t finally meet somewhere, they are in each other all along (Barks, 1997, p. 106).” According to Kasulis, intimacy is qualified having a personal rather than public objectivity, as having affective, somatic, and psychological dimensions, and as “dark,” or “esoteric.” Figure 1 represents the overlapping boundaries of internal relation characteristic of intimacy relations.
In contrast to the intimacy relation, the meanings of the integrity relation reflect the roots of the Latin *integritas* related to the word *integer*, meaning an inviolable, indivisible whole. The integrity relation implies some external relatant that connects each person’s integrity in a relational pair. The integrity orientation implies that two people “belong to” not necessarily “with” each other in a contractual way or through a formal declaration of legal of rights and responsibilities between people. Integrity is qualified by Kasulis as purely conceptual and intellectual, rational, bright, and public. Figure 1 represents the solid boundaries of external relation that are characteristic of integrity relations.

Kasulis concedes that relation is never purely one orientation or the other. He utilizes the Daoist the yin-yang symbol to illustrate the nature of bipolar relational shifting. Consider the intimacy relation as the dark ground of yin with a bright element of integrity, and the integrity relation as the bright ground of yang with a dark element of intimacy. This feature of the I/I heuristic makes it possible to account for oppositional, paradoxical, or shifting binary relational orientations in the mourner. Because many informants narrated shifting or paradoxical tensions in relational orientations during the interview, this feature of the heuristic is a practical one for analyzing relational flows in mourning. This feature of the model allows for describing a shifting “Dao of mourning relation.”

In a concise analogy that demonstrates the differences between internal relations of intimacy and external relations of integrity, Kasulis gives the example of sand, salt, and water in the ocean. For the external relation, he talks about the sand
and water. Sand is crystalline and water is liquid. Each has individual integrity. The essential nature of sand and water do not change in the ocean. Sand and water maintain their individual integrity and are connected in external relation by nature of their proximity as two elements in the spatial container of the ocean. To illustrate internal relation, Kasulis uses the example of salt and water in the ocean. Salt dissolves in solution in the seawater. Water and salt surrender part of their own integrity to become the saltwater in the ocean. The water is in intimate relation with the salt as their previous integrities dissolve into the single solution of seawater.

This analogy can be extended to how the mourner thinks of himself/herself in relation to the deceased person. Death of a beloved other results in ruptured or broken relation. If the mourner conceived of himself as an autonomous self of integrity, externally related to the deceased before the death, chances are that after the death relation might be imagined similarly. The integrity of the living person would remain intact. If affective dynamics like love and/or intimate understanding connected the pair in internal relation, however, then loss of the other necessarily transforms the self of the mourner. The mourner is forever changed by the death in ways that are eventually revealed in the mourning process. Later in this dissertation, I suggest that broken relation can be repaired through symbolic or ritual processes. This reparative process may be at the core of mourning ritual that works to bring the living into a present centered symbolic union with the deceased that is satisfying and is without lack or loss.
The Intimacy-Integrity Heuristic

In this section I explain how I used some of the basic tenets of the intimacy/integrity heuristic in detail. Remember, I am not claiming that the model represents the reality of relation for these informants. I simply use it as a way to engage thinking about how basic relational patterns might emerge during mourning. For my purposes, I see the model as illuminating three basic ways to think about relation in mourning—as an either/or binary opposition of intimacy or integrity; as a Dao of shifting relation; or as holographic, a deep internal relation to others and the world.

In this study, I associate shifting relational orientations with paradoxical tensions felt in the mourner. Informants told me they experience both separation from and union with the deceased, they have moments of emptiness and fullness, or they may feel an imperative to hold on and let go simultaneously. For example, the mourner may feel torn between the absence (integrity) and presence (intimacy) of the deceased. Yet representations of one mode of relating or another are deceiving, because, for absence to be conceived, presence is the unspoken correlate. Suffering intimates that one has felt its opposite in joy. Letting go implies something was initially given to hold. A danger of placing relational orientation into pure categories is that relation might be seen as static or unchanging. This is not what I found in the interviews. However, if relation to the deceased appears to have petrified into an unchanging orientation over time, this may be worth noting. For example, if the mourner remains stuck in an orientation of broken internal relation, without being able
to feel, this may be associated with a kind of incomplete or stunted mourning process.  

Thanatographies collected for this project suggest it makes sense to see relation as shifting with oscillating movement toward one binary pole or the other, keeping in mind that the opposite is contained within a holistic gestalt. Engaging the Daoist yin-yang symbol for analysis of shifting relation is a way to use the I/I model in a more dynamic fashion, identifying relational figure/ground shifting. As a graphic representation of intimacy in a Dao of mourning, consider the side of the yin/yang symbol that illustrates what has been called the “feminine” or dark yin ground with a bright white circle of opposing yang of the integrity relation. In a Dao of mourning relationship, consider the bright white background of the yin/yang symbol that represents yang or “masculine” qualities as ground to the dark yin circle as exemplary of integrity.

Figure 2. Daoist Symbol for Yin-Yang

This schema reveals a metaphysical bias that relation is holistic and can be seen as a coalescing of opposing tensions contained within a larger integrated whole.
These informants, at various times in the mourning process, see themselves as either primarily in union with (a ground of intimacy relation and porous boundaries) or as separate from the deceased (a ground of integrity relation with closed boundaries). The living person can sense paradoxical tensions of internal and external relation to the deceased simultaneously. The tension of these opposites forms a holistic gestalt because even when informants narrate extreme loneliness or isolation that I associate with external relation, intimacy is the ground of this figural external relation.

The Intimacy Relation

This section presents an overview of intimacy relations in mourning, weaving interview text and scholarship from various sources. This section explains the I/I heuristic in detail. First I attend to intimacy relations, the most common category I identified, with a focus on four identifying aspects: overlapping boundaries of internal relation, affective dynamics, somatic dimensions, and esoteric knowledge. These categories are interrelated, but each category is described separately in-depth.

As review from the chapter introduction, remember that in Kasulis’s schema, intimacy relations are characterized by affective, somatic, and esoteric kinds of knowledge. Boundaries are imagined as open, porous, or nonexistent. These qualifiers align with feminist philosophers’ accounts of internal relation as ontologically basic for human beings and agree with most informants’ experiences of relation to the deceased. The intimacy relation is characterized by overlapping or porous boundaries that allow each participant in the relationship a kind of innermost,
sometimes unspoken, understanding and affection. Refer to Figure 1 for the graphic of an internal relation dyad. The self of intimacy is imagined as a whole self, overlapping with other whole selves in internal relations. In Figure 3, \( a \) is the person at the center of overlapping relations with people \( b \) through \( i \).

![Figure 3. Self of Intimacy](image)

Kasulis, Thomas. *Intimacy or integrity: Philosophy and cultural difference* (p. 61). Honolulu.

Intimacy relations stress what is common between people and do not readily distinguish between the people involved in the relationship. The intimacy orientation implies that two people “belong with” each other and contain each other in ways that often defy logical explanation. The following interview excerpts illustrate the internal relations that mourners imagine between themselves and the deceased. The relatants in intimate or internal relation understand each other holistically, and to know a part yields knowledge of the whole person. Lexie described her relationship to Gabe, her partner who died, like this:
Our relationship was very intense, we talked about everything under the sun, we created art together, and our fights were just as passionate. As we went along, we couldn’t seem to stay away from each other. It was just a very close, honest, you know, heart to heart kind of relationship. And still to this day, he was the person that knows me best, knows the most absolutely dark secrets. We shared everything, more than a parent you know.

Another interviewee, Lewis, talked about how the death of his wife made clear to him the depth of affection they shared in life.

I probably learned about my own affection for Stella and how this... the ... I’m looking for the right word. I was going to say power, but that’s not right. I don’t know, how deep, maybe that’s the word, how deep my love was until [she died]. And I am grateful for that.

Stacy talked about how the death of her friend Betty changed her life. She acknowledges the intimate friendship they had but notes the impossibility of talking to her now. Stacy narrated a vision of her friend after the death, which seemed to affirm a coalescence of intimacy and separation simultaneously:

I think one of the hardest things was, I’d call her, we would call each other on the phone every 5 minutes if we’d think of something you know. I lost my confidante [tearing up]. Because you know there are some people you can tell almost everything to – and she was that person for me. And I’d like to tell her things now, but you know you can’t.

Celia talked about her connection with her husband who died:

He was my soul mate. He was the one person ... he was my best friend. He was a person I connected to, and I haven’t had a connection like that since then. Things we talked about ... I haven’t talked about with anyone else. So we just really had a strong connection. Umm, and surprisingly it was around spirituality. Yeah, he was very into spirituality. He was into trying new things and I was too, so we really connected on that level.
Rosa, a young college sophomore talked about the relationship she had with her father, who died from complications of a chronic illness:

Yeah, I mean it’s just affected every crumb of my life because my dad and I were so close. He was a central part of my day, like I would talk to him and he would call me while waiting for a doctors appointments. It’s like me, my mom, and my dad have always been very close. I think a lot closer than a lot of my friends are with their parents, and so yeah, it has really changed everything.

Similar references to the strong relational bonds between the living and the deceased run through the interviews. The intensity of affection, open boundaries, shared interests and experiences, and mutual understanding puts the mourner in internal or intimacy based relation with the deceased. The following section delves deeper into the affective, somatic and esoteric experiences that lead to designating relation as intimate or holographic for most of the informants in this study.

“Sad Stories” - The Primacy of Affect

Dottie, whose 33-year-old daughter Lee died from complications of Gulf War Syndrome, recounted in vivid detail the pain and suffering endured as her daughter’s health deteriorated. “Sad story. I think it’s a very sad story,” Dottie noted through her tears. After a death, imagined boundaries between the living person and the deceased, indeed between life and death itself, are laden with tremendous affective fluctuations in the mourner. Lewis, another informant, describes the physical reality of grief:

So those feelings that come with the memories often are kind of welling up sometimes to the point of tears. As I was saying before, it’s evidence – physical evidence that what I’m feeling, or what is going on, is not just intellectualizing about it. There’s a real emotional ... I don’t
know what the word is. There’s this reality to those thoughts and feelings that I have. A physical reality.

The entire world of the mourner is shifting. The body of their loved one is, of course, no longer present. Perception, affection, action, and imagined relation as aspects of being once oriented toward the deceased person, are in flux. Mourning, as a lifelong process of connecting with, internalizing, and letting go of external others while integrating the symbolic meaning of the relationship in the internal self, is in part about how relationship between the living and the dead is continually affectively negotiated and renegotiated. Lenore, an oncology nurse practitioner, talks about how the affective traces of grief and loss linger long past the death, saying “the amplitude doesn’t last. It settles. And yet, it never actually goes away.”

The history of the term affect in the last century can be traced in part to Sigmund Freud. Freud assumed that the ultimate cause of emotion is “psychic energy” of which the person may or may not be consciously aware. He often referred to emotion as “affects,” by which, according to Sheldon Solomon, usually meant a sensation or felt feeling or the conscious subjective aspect of an emotion (Solomon, 1998).

Contemporary scholars theorize affect as unqualified intensities or capacities to act and be acted upon. Emotion is selective activation or expression of affects. According to Patricia Clough, affects emerge from complexity in the lived present, are always emergent, and are intrinsically unstable. Affects may be seen as transitions
between states, and so are links to possible futures. Melissa Gregg and Gregory Seigworth (2010) write:

Affect is the name we give to those forces – visceral forces beneath, alongside, or generally other than conscious knowing, vital forces insisting beyond emotion – that can serve to drive us toward movement, toward thought and extension, that can likewise suspend us (as if in neutral) across barely registering accretion of force-relations, or that can even leave us overwhelmed by the world’s apparent intractability.

(p. 1)

They theorize affect as “found in intensities that pass body to body (human, non-human, part-body, and otherwise), in those resonances that circulate about, between and sometimes stick to bodies” (p. 1). Affect is “integral to a body’s perpetual becoming pulled beyond its seeming surface-boundedness by way of relation to, indeed its composition through, the forces of encounter” (p. 3). The affective capacity of the body is thus coextensive with the context or field of force relations.

One of the key features of relatedness is the sharing of affective states. Affect, relation, and spiritual yearnings are irreducibly entwined for these mourners. The mourning self, in renegotiating relational boundaries, flows with affective intensity between various modes of imagined intimate relation with the deceased person. The narrative excerpts cited in this section support the assumption that human beings are embedded in webs of affective relation that are often overflowing, uncontained, and overlapping. Feminist Christine Battersby posits a self that is permeated by otherness. In her model of self, “the boundary between the inside and the outside, between self and not-self, has to operate not antagonistically according to the logic of containment, but in terms of patterns and flow” (p. 355). The living person’s imagined relation to
the deceased other oscillates with varying degrees of boundary porosity and affective intensity. The instability of affect is coextensive with relational instability.

All of the narratives collected from the lay informants in this study contained an atmosphere thick with affective intensities. By far, tearfulness was the most common sign of affective flow in our interviews and informants confirmed that weeping and tears were sure signs of the affective dynamics of grief and loss. Brenna expressed the surprising upwelling of emotion after her husband’s death, when she said, “For a while after Don died, I just cried and cried and cried. I mean I was very prepared that this was going to happen but it brings up. It brought up emotions I didn’t expect to have.” Many informants told me similar stories about their shock, surprise, and lack of preparation for the affective intensity of grief, even though they intellectually knew that death was imminent.

Nicole, whose first child lived for only a very short time after birth, said this:

And just it’s like the deepest weeping. Afterwards I am mentally and emotionally and physically drained, because its just it I’ve never cried deeper in my life. It’s the worst pain I’ve ever felt.

In grief and mourning, the groundlessness of ruptured relation can precipitate a plunge into despair and depression or greater awareness that suffering and loss are universal problems that all human beings share. The ethnographic interviews suggest that mourning can be seen as a kind of affective labor. Kathleen Stewart writes (cited in Gregg & Siegworth, 2010):

Affect is the commonplace labor-intensive process of sensing modes of living as they come into being. Everything depends on the dense entanglement of affect, attention, the senses, and matter. Affect matters
in a world that is always promising and threatening to amount to something. Fractally complex, there is no telling what will come of it or where it will take people attuned. (p. 340)

As Stewart implies, affective dynamics hold both transformative potential and threat for the person who experiences them. The affective body-felt sensations and perceptions that come into being after the death of a loved one are like labor pains. Indeed, new configurations of the self and relation to the deceased are birthed during mourning. Louise, a bereavement staff member talked about this affective labor:

Grief has the potential to transform us in a way that nothing else can. From the bereaved person’s own perspective, when the pain becomes more than pain, as in childbirth ... more in the sense of labor, then it’s work. Then it has more a sense of meaning to it rather than just raw suffering.

Dottie describes this process as ongoing, even 8 years after her daughter’s death. “I just feel that I have coped with it as best as I possibly could have, but it still hits sometimes. It’s sort of like labor, you go along and go along, and then you get really get hit.”

In my analysis of the interviews, affect is what sometimes crosses, overflows, and ruptures solid boundaries between the living/dead or the living, others, and the world. Therese Brennan and other affect studies theorists have suggested that, as human beings, we do not stop at our skin. Indeed, our affective energies can be transmitted to others. According to Brennan, affects carry energy. I am more inclined to say that affects are energies. One can become attuned to the movement of these energies both inside the body and between the body and its outside environs. For example, love or anger can be seen as energetic outflows of affect across relational
boundaries that can be almost palpable to the sensitive receiver. Unqualified and unnamed embodied sensations and those affects that later get named as feelings, emotions, or moods are important sites of work for the mourner.

Because of the intensity of affective modulations, grief and mourning can be seen as liminal space and time where seeds of future relation are incubated. Thus, I agree with Stewart who suggests that complex affective energies hold unknown potential or threat. The intensity and threat of grief may be one reason that the topic of dying is left undisussed in our culture. In this study, many informants told me that although affective dynamics were sometimes perceived as painful, they also are visceral linkages of relation with the deceased, indeed confirmation that relation still exists. All informants I spoke with actually wanted to talk about their experiences of grief and loss. This should allay fears and doubts about whether or not to initiate conversations in end-of-life scenarios. The resonance or harmonics of shared affective dynamics is one reason that grief groups work as inclusive spaces for those who are new to intensely painful thoughts and feelings that follow the death of a loved one. Eventually, there is potential for realization of irrevocable internal relation to the deceased, opening the mourner to renewed internal relation with living others.

**Somatic Knowledge**

There were affective refrains of mourning in the interviews. How can I go on without this person in my life? Is life still worth living? Will I ever feel good, joyful, or happy again? Informants reported a range of emotions and experiences that
included shock, sadness, joy, love, fear, guilt, anger, helplessness, emptiness, and loneliness. The word “pain” was used by many and often connected to specific regions of the body. Sometimes emotion gave way to descriptions of bodily sensation embedded in a metaphor. Nicole, a mother whose first child was born prematurely and died, told me that “the emptiness is like a giant hole, and I’m caving in around it.” Larry told me that being overcome by emotion “seems to be universal” for the widows and widowers he has met since his wife died. Rosa told me “you can actually feel the pain. Grief is so physical.” She went on to say,

My whole body hurt. My lower back hurt. My upper back hurt. And it’s just like I feel the pain because I can’t always express it. Well maybe not because I can’t always express it, but I don’t even know why I’m feeling that way, you know? It’s just like there’s so much and it’s so complex.

This section discusses the body-felt visceral sensations that accompany grief and mourning, as told to me by informants in the field. Sometimes somatic experiences are associated with specific emotions. Other times the bodily-felt sensations are described as vague and framed speculatively. Dottie described her experience on a visit to her daughter’s grave as follows, “I couldn’t inhale. I couldn’t exhale.” Many informants mentioned specific bodily parts or functions in describing their experiences of grief. I quote Lewis in-depth because he was very articulate about the somatic aspects of his grief response:

Shakespeare has a line: “Tell me where his fancy’s bred, in the heart or in the head?” In the heart and in the gut [for me]. As much as I dislike that expression, and generally speaking I am not really interested in others’ “gut feelings” about anything, but that’s where they seem to come from. Certainly my chest, my heart, my gut. Certainly those. I
mean that is where this welling up comes from [sweeping his hands from his belly, through his chest, to his throat] and up into my throat. And tears. And those episodes of weeping. It was a kind of a residual physical sense in my head. Not painful, but not particularly pleasant either. A kind of sense of, not like a headache, but as if as if things swollen up inside my head are tight and full. It doesn’t last very long. And my mouth you know, and the weeping. Sometimes I know my mouth is contorted when weeping – at least it feels so. And those episodes of scrunching my eyes. But extremities? I don’t think so. Hands, feet, arms, legs, not so much. It’s the core at the core.

When I asked him if he could describe his “gut” feelings, he continued:

What is it like? [the gut feeling] I can’t give a metaphor, but it’s not unpleasant. It’s not painful certainly. It’s a feeling of fullness, well not fullness, but too much, where there’s too much, and it has to too much feeling, too powerful a feeling, too strong a feeling, too gut-wrenching a feeling. So it’s not like throwing it up, though it’s a form of externalizing. I suppose that feeling, once I’d had that sensation or those sensations – really combination of sensations – there’s kind of relief that follows.

Despite the painful bodily sensations associated with grief, informants expressed the sense that the body-felt affects put them in close contact with the deceased person. Phillipa, a social worker, who leads the infant loss support group said, “I think that people get so much out of talking about the deceased 7, 8, 9, 10 years later you know, because they don’t get to do it much, and in their grief they feel closest to that person.” Lewis reiterated this thought, saying that grief connects him to his deceased wife:

“I don’t want to give up grieving, it’s too important. It’s too important and some how I guess I fear if I give it up, forgetting is the next stage.”

For some informants, the gut wrenching rumblings of affect and the thoughts about loss of the other seem to meet and coalesce in the heart space, or what Kavalera-
Adler calls the “psychophysical locus” for the basic human capacity to love. The heart was a frequently used somatic metaphor. One informant, Lexie, describes the heart as the locus of grief, and her experiences leave her wondering and asking existential questions. She says:

It definitely feels very heart-centered. And it feels kind of like very freeing, very straight from truth. You’re not fooling yourself. It’s true emotion, true knowing. And in the really painful times with the crying, even though you’re going through it, it’s very cathartic. It’s almost primal. It’s a release. It’s a longing…. and big questions come up, like what do we really know?

Nan uses heart imagery and the metaphor of heaviness. “Yeah. My heart is heavy you know, and also for the first time in my life I feel old. I really feel old and I’ve never felt that way before.”

Several informants talked about sensations in the throat, chest, and lungs. Like Dottie’s excerpt discussed earlier in this chapter, many narratives contain reference to the lungs and difficulty in breathing. They describe these as real physical experiences. For example, Sam noted:

One of the first feelings would be, yeah, in the back of the throat. The top of the back of the mouth would feel very painful like as if you swallowed an ice cube or something, or like instead of a headache, it’s in the throat and the neck. Saliva would be very salty you know, and you’re just overcome with grief. And you can’t speak. You can’t scream. You can’t do anything. You know you’re just in shock. It’s just really like you’re between here and there. Like you’re alive and half dead. Half and half. Half in heaven and half on earth. And the shallow, shallow breathing, feeling like you can’t breathe.

While Sam makes a connection between the somatic experiences of grief, two other informants make a similar connection but also note that Eastern medical
practices associate the lungs with grief. Lorna had experienced the death of her daughter 28 years prior and her father’s death more recently. When anyone would inquire if she was a parent, she recalled, “I completely remember the feeling in my throat and my chest.... And this unbelievable pressure, pressure in the chest, and not closing off of the throat, but a lump in the throat. And I remember when my father died, my lungs. I just had all this congestion in my lungs.” She recalls, “I was seeing an acupuncturist at the time, and [he said] the lungs are the seat of grief. And it was just so amazing to me that the week my father died, I just had all this congestion in my lungs. How interesting is that?”

Rosa, a young college student, attended a yoga class to help her through the “physical pain” of grief. She talks about going to yoga class to work on supporting and opening the chest area:

We did restorative poses where she had us work with our chest. You know in Oriental medicine when you’re grieving, the lung is the weak organ. I knew that, but I had never really thought about it. It’s sort of like a metaphor because when you are grieving you’re like this [hunching her chest inwards] sort of like protecting yourself and you’re not really breathing right, so when we were doing these poses we would stick our chest out.

From these and other narrative excerpts, it seems clear that the pain of loss is felt on a visceral level in the body. The affective intensities seem to congeal in or through the gut, the heart, lungs, throat, and head. It seems that beneath or coextensive with fully formed emotions named and expressed by people in mourning, there is a pool of indeterminate, unqualified kind of affective energy that is “alongside” emotion. These energies may or may not be named.
Rituals practiced in hospice and bereavement care promote reflective body-felt awareness, so that the mourner can discern the amorphous energy of affective and somatic dynamics. The mourner becomes consciously aware, remembers, acknowledges, and can eventually express their grief in symbolic form. Many informants told me that the experience of the death a loved one is beyond words. For many, affects are un-nameable. Susan, a mother who lost her son in a mountain-climbing accident, told me that art made it easier to express what words could not. Angela, an art therapist, told me as she motioned with her hands downward from her head, to her heart, to her gut, that “art moves a person from here [head] to here [heart] to here [gut]. And then it all comes out.” For some informants like Susan, art was used as a process that made affects conscious. Using art as a ritual process enables creative expression of affects that can transform relation to the deceased.

“True Signs” as Esoteric Knowledge

We scattered her ashes, and the moment we scattered those ashes the sun came out and the wind came up. I don’t know. We were in the mountains. They get wind a lot I guess, but it wasn’t sunny until we scattered the ashes. I can see it even now. Of course, there were golden leaves because it was October in the mountains, and it was a fall day, but the leaves even made a noise! I could not intellectualize that away. At the restaurant we walked in, there were 10 or 12 midshipmen from [her daughter’s] naval academy on their way to Morgantown, West Virginia, to play hockey. You know they always make sort of they make their presence known. They are in uniform and polite, so I thought that was a true sign, it just had to have been a true sign.

Dottie, on sensing closeness to her daughter
Kasulis characterizes dark or esoteric knowledge as having a foundational basis that is not obvious or logically understandable even to those involved in the intimate locus. Knowledge often is gained or transmitted in a non-discursive way. Intimate knowledge is gained through praxis allowing the participants in intimate relation to have “inside” knowledge. This dynamic was observable as informants interpreted signs from the deceased in ways that only they could, having lived with or known the deceased intimately for so long. The accounts of what I call “out-of-ordinary boundaries experiences” support the personal verification of very subtle inner states of knowing that may not be publicly or empirically verifiable. These experiences were relayed to me by informants, often hesitantly, with a prelude that went something like, “I’m not sure what was happening, but this is what I felt/saw/heard/intuited” in a certain moment. I was very cognizant of including this kind of information or knowledge in my notes and analysis. I treated each informant as an expert on their own mourning process and relational orientations. It seemed to me that some of the most subtle and difficult to describe experiences contained the most power, awe, mystery, and wonder for the informants.

I was also careful not to deny the validity of such experiences, even though I did not usually understand what they meant to the informant unless they explained it to me. It was clear these held poignant meaning for them because of the affective modulations that emerged during the narration of the story. These affective modulations included a change in voice tone, quality, dynamics, or volume. Sometimes silence or long pauses and stammering or searching for words
accompanied the telling. Often tears and weeping emerged in such moments during the interviews. Out-of-ordinary boundary experiences appeared to contain an element of surprise or even delight for the informants. I concluded that mourning frequently is accompanied by confusion on cognitive, affective, and sensory levels, leaving the informants to wonder, as Lewis said, “What is going on here?” Many health-care workers might label these experiences “pathological” if they did not listen for cues of intimate knowledge, meaning knowledge that is not publicly verifiable, and contains esoteric, affective, and somatic components.

The “out-of-ordinary boundaries” experiences often involved wildly fluctuating emotions and affective, sensory, and perceptual experiences that the mourner connected to their loved one. They involved hearing, seeing, sensing, or feeling the presence of the deceased other. These experiences were often interpreted by the mourner as communication from the deceased. The way informants made meaning from these experiences varied, but most believed that contact was made to reassure them that the deceased person was watching over them, ensuring them that they were OK, or that they were still connected to them on some level. Lexie described such an out-of-ordinary boundaries experience that occurred on the evening of her 40th birthday:

I was just low at that point in my life. I was thinking I wish you were here to hang out and make dinner, and this music box starts playing out of the blue! [she plays music box for me] And I’m like, “Thank you, Gabe.” It was super cool. I’m like alright, thank you, happy birthday to me!
There were many out-of-ordinary boundary experiences narrated in the interviews. Sheri and her daughter, who died in a car accident, had a pact to communicate with each other via falling stars if anything happened to one of them. One night, when Sheri was particularly lonely and missing her daughter, she observed a shower of falling stars and was ecstatic about the feeling of closeness to her daughter. Another informant, Chloe and her husband, visited family in Wales with their dying infant. They took the child to a park in Snowdonia. One night after his death while watching a movie scene filmed at the same park, coins on their kitchen counter started rattling in a jar. Chloe took this to mean that her son was connecting with them and acknowledging their time together:

James Bond was running around those streets, and they drove past the lookout point that we went to with Peter. And the coins in this jar jumped. I just felt like it was Peter saying, “Mom, pay attention. Look! Look. Do you remember this?” It happened not once or twice, but three times. Both Ben and I heard the same thing and said, “What’s that?” I mean maybe it was something on the outside of the jar juggling, but I want to believe that it was Peter moving the coins in our house.

Some of these esoteric experiences happened in dreams or in dream-like states between sleeping and waking. Stacy talks about resting and sensing a visitation from her friend:

I was lying there in my recliner early in the day, and all of a sudden I didn’t exactly open my eyes, but I sensed Betty coming toward with me with someone else. I could make out Betty. I didn’t want to open my eyes, but I wanted to see what was going on. When I finally opened my eyes there was this white cloud, and it was like swoosh they were gone!
Tatti told me that she was having some maintenance problems on the front of their house, and when she was napping one day she got up to look out the front window to see her husband walking away from the house in his leather jacket. She interpreted this to mean he was checking up on her and the house. During our interview Rosa told me about a visit to her father’s grave on the day of his birthday:

I was really upset, saying this is your birthday [crying] and you should be here. So I was like I just want a sign that you are still here. I can’t even explain what happened. But this is the first time I have ever had any sort of... I saw something that I think was energy. I had been asking my dad, “I just want to know that you’re here.” I saw these... it was like these little waves or things and I was trying to touch it and it was all around me. I could see them all over. And I felt all of sudden, there was a tree and it just seemed it like it was popping out, not like physically, but I was noticing it more. It was just very present, and I felt like, “Oh my gosh I just tapped into something.” I felt like he was there. I was so upset when I got there, but when I left I was smiling cause I really felt like, oh my gosh, this is really here.

Many other informants had stories of unexplained phenomena that they connected to the presence of their deceased loved one. In the grief groups, those who did not have vivid dreams or sensations of presence seemed to seek them after hearing others talk about such experiences. In general, the signs were seen as messages and were interpreted as ranging from comforting to ecstatic reminders of relation to the deceased. Only Lewis said that a dream of his wife left him with “gooseflesh” and that it was not particularly uplifting. These experiences cannot be publicly verified or understood by the informants, yet their powerful affective pull and sensory reality leaves a strong impression.
**Broken Intimacy Relation – The Crescent Self of Mourning**

The broken intimacy relation is a dominant relation for informants in this study. In Kasulis’s description, broken internal relation creates a gap for each relatant in the dyad. In Figure 4, broken internal relation results in missing parts of the self. Broken external relation allows for continued integrity of the independent self.

![Diagram of relationship types]

**Figure 4. Broken Intimacy or Broken Integrity**  
Kasulis, Thomas. *Intimacy or integrity: Philosophy and cultural difference* (p. 59). Honolulu.

After a death, the living person may believe that part of the self is literally missing. Many informants gave accounts of feeling incomplete, having a “hole” in the
self, and feeling “empty.” It was such a common somatic metaphor that I emphasize this relational orientation as the crescent self of mourning. Represented by a half moon, the informant believes that part of the self is dead or missing. They feel diminished, fragmented, and partially present to themselves and others. They seem unable to feel connection to the deceased and to the part of the self that was in relation to the deceased.

The crescent self is named for the poem by Emily Dickinson, *A Crescent Still Abides*, written on the occasion of the death of Judge Otis Lord (whom Dickinson is thought to have loved, although he proposed marriage to her and she refused) in 1884 (Kirby, cited in MacKenzie & Dana, 2007):

> Each that we lose takes part of us;  
> A crescent still abides,  
> Which like the moon, some turbid night,  
> Is summoned by the tides.  
> (p. 130)

Kirby interprets Dickinson’s words to mean that the mourning self is inevitably and irrevocably transformed by the death of a beloved other. Part of the self is encrypted, walled off, or goes missing, and we are subject to “violent reconfiguration” (p. 30). We are wounded. Feminist philosopher Judith Butler (2004) suggests that this wound “testifies to the fact that I am given over to the other in ways that I cannot fully predict or control. It is not as if an ‘I’ exists independently over here and then simply loses a ‘you’ over there, especially if the attachment to ‘you’ is part of what composes who ‘I’ am” (p. 46). Eve Sedgwick (1999) adroitly captures how one might
feel when intimate relation is broken in *A Dialogue on Love*, a memoir about her life with cancer:

Love is a matter of suddenly, globally, knowing that another person represents your only access to some vitally transmissible truth or radiantly heightened mode of perception, and if you lose the thread of intimacy, both your soul and your whole world might subsist forever in some desert-like state of ontological impoverishment. (p. 168)

Several informants describe broken relation as a terrifying and sorrowful state of being bereft of joy or pleasure, as if the other person, as Sedgwick implies, was their connection to certain affective states. Nan said the death of her partner “sucked the joy out” of her life. Several members of the infant loss support group spoke of “emptiness” and the “hole inside” since the death of their infants. Nicole, whose infant daughter was born prematurely said, “I know for me, I’ll have episodes where it’s almost like there’s a giant hole, and my body is caving in around it. I could just physically curl up into a ball. There’s no getting rid of that pain. It’s awful. It’s like a baseline now, always having that part missing.” Jen’s infant daughter died, and she said, “It’s just the feeling you’ve gone through so much, and now the emptiness.” Shannon’s infant daughter died of congenital anomalies. She talked about filling the emptiness:

I filled it [the emptiness] with cake that’s why I have this! [pointing to her stomach] When you talk about the emptiness and the loneliness, I joke about filling it with cake, which I really tried hard to do, but it didn’t work. At first I filled that space with anger. I was pissed at everyone and everything especially God. F-U you know. I was very upset, and very mad, and I filled that space with anger. And then I started filling that space with funny, like I really love life! And I really love laughing all the time, and I really love just being goofy, and having
dance parties with my 3 year old to goofy music. It’s hard to get there, though.

Diane refers to the ephemeral traces of emptiness saying, “I personally don’t think there’s anything you can do for it to really go away. You know you just never know when it comes, and you just never really know when it goes. It just lingers with you.” Diane’s words echo Lenore’s quote noting that the amplitude of sorrowful affects lessen, but they never really go away. Affective traces linger.

In summary, this section emphasizes that mourning, as primarily containing intimacy based relations, includes affective, somatic, and esoteric correlates. Several informants reported changes in the breath and breathing, many others said that grief seems to lodge in the heart. According to Kavaler-Adler, we consolidate the true self – the instinctive core of the self that feels real and can recognize and enact spontaneous needs for creativity and self-expression – in the space of the heart. In her view, it is this true self that allows emotional connection to others and the world. Thus, in mourning, broken intimacy with the deceased can disrupt the emotional connection to the self, to others, and to the world.

The crescent self of mourning is an iconic relation for these informants. It corresponds to Loy’s concept of “lack” and the inability to affirm what is real and authentic in the self and in relation to others. According to Loy, lack resolves when we feel genuine and real in the present, realizing we are embedded in a net of relations. According to Kavaler-Adler, to be assimilated into the self, relationship with the deceased must be symbolized through representation in new form. Emerging ritual in
hospice and bereavement spaces allows mourners to symbolically incorporate the other through creative imagination, somatic practices, and the arts, to transform the anguish associated with loss and regain access to a fuller, expanded self rooted in a net of relations. This kind of work in mourning allows the living person to move beyond the fragmented, diminished, and sensually impoverished stance of the crescent self toward a re-creation of internal relation with the deceased and others.

**Holographic Relation and Mourning**

The easy part is to say she is in my heart, and that’s the truth. But I mean I understand that my heart, like everyone’s heart – if they recognize it – it’s everything. It’s huge. Our parents are in us, our ancestors are in us, and everyone we love is in us. I’ve come to understand that in a much more universal way.

Jim

Holographic relation involves a metaphysics of inter-relationality. A holographic conception of the self involves self, others, and the world in a very deep intimate, internal relationship. Holographic relation is a deep expression of the intimacy relation and relies upon a specific metaphysics of inter-relationality. The etymology of the word *holographic* implies that the “whole” (*holo*) is “inscribed in” (*graphic*) each of its parts. In the holographic mode of relation, understanding a part yields understanding of the whole. Holographic analysis is recursively fractal, meaning that each part can be understood and analyzed only as reflective of the whole. In a holographic metaphysics, each thing relates to something else, and ultimately with everything else. Every part is in the whole, and the whole is in every part.
Kasulis gives the example of the DNA in each cell of the human body as a holographic blueprint of genetic expression for a whole human being. Each cell contains the template of the whole even as the whole contains each cell. A holographic conception of relation involves the self, others, and world in a deeply intimate, internal relationship. In this view, human experience is seen as the mutual expression of self and world, and nothing is separable from the co-emergence of self and world together. No “thing” exists in isolation. Everything exists as a whole set of interdependent internal relations. The separate, discrete, isolated self does not exist.

The holographic model of relation represents the Buddhist conception of reality. An important theoretical source for understanding holographic relation comes from Loy’s Buddhist scholarship. According to Loy, Buddhism does not place life/death and self/other in dualistic opposition. In Mahayana Buddhist cosmology, the concept of shunyata, or the emptiness of self, suggests the human self is an interdependent phenomenon. The Buddhist self is a self that is empty of independent existence. This self co-emerges with other conditions in flux. The Buddhist self, as Kasulis represents it in Figure 5, shows a as a person who has no independence from the relational processes b through i that constitute him/her. The Buddhist self is a nexus of interdependent processes in dependent co-production. In other words, everything that exists, including the self, comes into and out of being through dependence on other processes.21
According to Loy, Buddhist meditation practices can impart an understanding of a self that is holographically rooted in deep internal relation to others and the phenomenal world. Figure 6 depicts the holographic inter-relationship of holographic wholes. Each whole contains the inscription of all the other wholes in deep internal relation.
What follows is a beautiful analogy that illustrates holographic relation. The story of Indra’s Net from the Hua-yen school of Mayhayana Buddhism is a metaphorical way to express the Buddhist inter-conditionality of all phenomena (Francis Cook, cited in Loy, 1996):

Far away in the heavenly abode of the great god Indra, there is a wonderful net that has been hung by some cunning artificer in such a manner that it stretches out infinitely in all directions. In accordance with the extravagant tastes of deities, the artificer has hung a single glittering jewel in each “eye” of the net, and because the net itself is infinite in all dimensions, the jewels are infinite in number. There hang the jewels, glittering like stars of the first magnitude, a wonderful sight to behold. If we now arbitrarily select one of these jewels for inspection and look closely at it, we will discover that in its polished surface there are reflected all the other jewels in the net, infinite in number. Not only that, but each of the jewels reflected in this one jewel is also reflecting all the other jewels, so that there is an infinite reflecting process occurring.... It symbolizes a cosmos in which there is an infinitely repeated interrelationship among all the members of the cosmos. This relationship is said to be one of simultaneous mutual identity and mutual inter-causality. (p. 90)

In this holographic analogy of relationship, any sense of separation or lack, as described in Kasulis’s integrity relation or broken intimacy relation, is illusory. Suffering comes from the delusive nature of a separate ego self. If holographic relation is assumed between self/others/world, there is no separation that causes suffering. Yet, mourners intensely “feel” this separation or lack, and at times feel completely alienated or isolated from the deceased. Imagined relations of broken intimacy or integrity brought sorrowful affects as seen in most of the informants’ stories examined earlier in this chapter. Most informants describe intensely sorrowful and painful affects related to separation from their loved one. Only a few informants
hinted at holographic relation with the deceased. Jim, whose story is recounted in Chapter 5, is the sole informant who described deep holographic relation. Several others hinted at holographic relation. Sally articulated a kind of holographic relation to her twin infants who died 12 years earlier, “I feel like they are a part of me, that they are part of my soul now, more so than as any kind of separate beings with me. They are just integrated into who I am. I get a sense of being with the others [deceased relatives], but with them I feel like they’re more with me always—always and everywhere.”

Holographic relation was by far the most rare and seemed to be realized after much struggle, reflection, and inner work on the part of the mourner. And even for those who narrated holographic or internal relation with the deceased, this was only one orientation within a range of other relational orientations. For example, in Susan’s case study presented in Chapter 3, relation to her son oscillates among several categories within the interview. Shifting relation is captured in her artwork that graphically depicts the flux and flow of relation over time. David alludes to holographic relation paraphrasing a quote from C.S. Lewis (1961), “My grief was like the sky, it covered everything.” He reflected, “Like the sky, everything, virtually everything, reminds me of Estelle. A lot of things remind me in expected and in unexpected ways. And I’m grateful for those moments because they are like physiological evidence that this is not all just intellectualizing.”

College student Marla describes her relation to her deceased roommate as carrying her presence inside. “I think that it’s one of those things where there’s always
going be part of her inside of me. Everyone that loved Lindsay and everyone that Lindsay loved, I feel like there’s a part of her presence that she gave to them when she passed away, that you just kind of carry that with you for the rest of your life.” Brenna feels connected holographically to her husband, and expands this relation to God, everyone, and everything. She was with him at the moment of his death and said this:

I saw life force energy leave my husband’s body and seemingly dissipate, but really in reality, rejoin everyone and everything in the universe. And that’s what I believe, so I don’t believe he’s in any one place. That’s what I believe. That’s why it’s impossible for me to feel disconnected from him. I think that’s why it’s impossible for me to feel disconnected from God. To me it is like God is in everything and every place, and there’s no place that God is not. God is in me and that’s how I feel about God.

**The Integrity Relation**

The integrity relation assumes solid closed boundaries and constructs human beings as autonomous and independent, related by external means. When informants narrate irrevocable distance, isolation, loneliness, and separation from the deceased, the integrity relation comes into play. The opposing relational orientations of intimacy and integrity thus allow for highlighting moments of either deep connection with or extreme alienation from the deceased or others. This section presents three kinds of integrity relations found in the field. Some informants spoke about institutional constructions of integrity relations between themselves and the deceased. A few told me that they see themselves as irreparably separated from the deceased by the fact of death. And many more, like Celia, told me that there was little space for mourning in our culture. Although they wanted to talk about their loss, others did not want to
Celia lost her husband and a baby to death. She said:

I would like people to know how lonely it is. With each loss, I really feel isolated. I kind of reached out and told people what was going on, and people never reached back to me. The worst ones are the people who want to tell you, you know like when the baby died, all the relatives they all called me and they were like: “You’ll have another one.” And I’m like, what kind of thing is that to say? Or the people who say, “Oh, you haven’t let go yet” or “Yeah, you need to move on.”

As review, remember that in the I/I heuristic, the integrity relation implies some external relatant connects each person’s integrity in a relational pair (Fig. 1).

The imagined boundaries of integrity relations are the solid, inviolable boundaries of autonomous independent people related by some external means. The integrity orientation implies that two people “belong to” each other in a contractual way or through a formal declaration of legal of rights and responsibilities between people. Kasulis uses the example of marriage, which can be viewed as a legal integrity based relationship, and if it is dissolved, the law protects the individual rights of each relatant. When marriage is viewed as a love relation, it is more of an intimacy-based relation.

Integrity relations are qualified by Kasulis as purely conceptual and intellectual, rational, bright, and public. The defining characteristics of integrity relations imply that knowledge produced therein is publicly verifiable through empirical observation or logical reasoning. Public verifiability and rational thinking form the basis of authority in integrity relations. Legal justice that rests on public statement of law and adjudication based on clearly defined principles is the basis for
upholding a person’s inviolable boundaries and personal “rights.” Scientific knowledge can be considered integrity based in that it relies on public validation and replication of experimental findings and stressing an absence of affect in its methodology. Both of these integrity-based stances collide with the esoteric/affective/somatic dimensions, boundary interpenetration, and relational interdependence associated with intimacy based relations.

**Institutional: Colliding Relational Imaginaries**

Initially, I thought that the contrast between intimacy and integrity relational orientations would not be relevant in this study, because fairly early in the research I identified that nearly all informants seemed to be internally or intimately related to the deceased. However, when misunderstanding or conflict occurred between the informants and others in their world, it seemed that the others were imagining relation between the living person and the deceased differently—namely as an external relation of integrity. The self of integrity is represented in Figure 7, where $a$ is the person who is externally related to others $b-i$ in external relation.
Figure 7. Self of Integrity
Kasulis, Thomas. *Intimacy or integrity: Philosophy and cultural difference* (p. 60). Honolulu.

An important finding in this research is identification of the friction that results when opposing ideas about human beings and their imagined relation to each other collide at the end of life or after a death. For some informants, conflict, friction, or misunderstanding reigned when grieving family members were confronted with social institutions or cultural practices that defined the relation between the living and the deceased as one of external relation. Many informants in this study were shocked and angered by how insensitively the relation between themselves and the deceased loved one was treated after the death. What appears to be a major disconnect occurred in the way that relationship to the deceased was constructed in an external type of relation.

Several parents in the infant loss support group told stories about attorneys, insurance companies, hospitals, and employers who seemed to “not get it” when it came to the intense grief and suffering that accompanied the loss of their newborn child. Jeff spoke about a time limit on his insurance policy for infant death. “When
Jenna passed away, we got $500 for her life insurance. And if she would have lived until she was 15 days then we would have received $10,000. How do you put a timeline in terms of what you get? It was just irritating, I mean money has nothing to do with it, but what if there are people who are in a situation financially and their baby is 1 or 2 days away from making it to that milestone? And that just upset me. It was just disappointing.”

Wade, another father in the infant loss support group, talked about the irony of being solicited by attorneys on the TV in the hospital cafeteria. “They were running a commercial saying, ‘Have you had a cesarean section? If so, call so and so.’ I mean they were actually advertising to sue the hospital in the hospital! I mean it was like one-stop shopping. Wow, yes, she did have a cesarean section, and this guy who’s wanting our business, they’re actually soliciting us right here. Have your sandwich and sue. I mean it’s bizarre!” Drew, a father in the same group was irritated about getting letters from attorneys that said, “Hey I’m sorry to hear about the passing of your daughter, you know, but if you would like to sue or if you want to really see if things were really legit, then contact me.” Dave added, “It’s just insensitivity.”

Diane, a mother whose child was stillborn, was angry about several issues, including employee “maternity leave” benefits that were switched to “sick leave,” lack of insurance benefits, and the lack of birth certificate for her child. Through tears she said, “But I mean our insurance company, to which we pay monthly premiums you know, to them Matthew wasn’t even a life I guess. You know you don’t get a birth certificate. I had filled out all the papers for maternity leave and then there was an
email saying, “Uh, we need you to fill these papers out again because it wasn’t a maternity leave!”

In these scenarios, the human being is constructed in set of contractual agreements that specify certain legalistic parameters of personhood and relation. These constructions imply external relations between human beings. In these cases, if certain conditions of personhood are met, parents are entitled to certain amounts of monetary compensation from insurance companies, certain amounts, and types of leave time from employers, and even acknowledgment of human existence as in receiving a birth certificate. The general consensus of the group was that nothing could compensate them for the death of their child, who was in every case irreplaceable and precious to them beyond compare. The denial that a child even existed or that an intimate relationship was severed by the death infuriated these already bereaved parents.

**Irreparable Separation**

Very few informants seemed to swing toward external relation, in which the death was constructed as an objective fact that irreparably and irrevocably disrupts relation. To illustrate some of the most striking examples of external relation and mourning, I reference the writings of Jacques Derrida.\(^{23}\) Derrida (1995) has said, “Every other [one] is every [bit] other” (p. 82). His words describe the impossibility of really knowing another person because of the radical difference and uniqueness of each human being. In the collection of eulogies that he delivers in memory of his
friends, Derrida (2001) implies that we can never really know the object of our mourning. It may be that we are mourning someone or something other than the deceased. Or we may be mourning “nothing other than our very ability to identify our mastery over the other and over death, as we yield to a force that is not ours, a force that always exceeds the rhetoric of mourning” (p. 17).

Of his deceased friend Louis Marin, Derrida (1995) says, “He is completely other, infinitely other, as he has always been, and death has more than ever entrusted him, given him over, distanced him, in this infinite alterity” (p. 11). Derrida refers to death’s gaze, now interiorized as coming from the dead other:

Upon the death of the other we are given to memory, and thus to interiorization, because the other outside us, is now nothing. And with the dark light of this nothing, we learn that the other resists the closure of our interiorizing memory. Death constitutes and makes manifest the limits of a me or an us who are obliged to harbor something that is greater and other than them; something outside of them and within them. (p. 11)

Derrida suggests that the dead other exists in the imagination, in our memory, and cannot be expunged from it. V.N. Halloran (2005) interprets Derrida’s unbridgeable gap of experience between the living and the dead as one of objectivity and distance. Derrida can “remember the friendship with the dead person, but he can no longer be the friend to the dead that he was to the living” (p. 25). Death effectively ends the friendship with the deceased, who is “now nothing,” although he can remember the friendship. The relationship with the other effectively becomes frozen or petrified as it last stood in complete and permanent alterity. For Derrida, mourning becomes impossible because, if the other is interiorized or incorporated into the living
person, this displays infidelity to the absolute alterity of the other. For Derrida, death is affirmation of individuality—irreducible, irrevocable, and impenetrable integrity.

The overall findings of this study are in opposition to Derrida’s declaration of impenetrable external relation between the living and the dead. For these informants, internal relation is narrated before death, and for most it continues after death. For a few, relation oscillates toward solid boundaries during times of extreme loneliness and isolation. After interviewing more than 60 people in hospice and bereavement settings, it is clear that external relation applied minimally to these informants.

Three informants might be said to oscillate toward external relation as figural in the interview. Using words that mirror external relation, Lewis mentioned that his wife was “irrevocably and irreversibly” separate from him now. Larry essentially stated that each person dies alone, telling me, “There’s only one way to die, and that is by yourself.” Past memories of his wife are the ways she is related to him. Nate said that he has “absolutely no belief that Diana exists” for him to continue relation with in any way in the present, yet he cherishes her journals, photos, and conversations with his children about her. These men narrate a swing toward external relation, but all three displayed sorrowful affects about the deaths. All three are hospice volunteers who reach out to others in their grief. Their statements might be considered ways to acknowledge the coalescing of opposing tensions or integration of an internal/external paradox of relation between human beings. It is true that we are separate individuals who can die only our own death, but we are socially and affectively connected to others in intimate webs of relation. The narratives of these informants support a kind
of Dao of relation to the deceased, a relational gestalt that emerges over time, which contains a shifting dominant ground supplanted by an opposing figural motif. These narratives point to relation as part of a holistic metaphysics, variously encompassing oscillating polarities of separation-union and closed-open boundaries at different temporal nodes in the mourning process.

Some informants seemed to lean toward imagining their loved one was more separate from themselves before the death. Katherine and Lexie, whose loved ones both committed suicide, had somewhat difficult relationships before the death. Both reported having to decide whether to stay with their partner who appeared to be self-destructing or save and nurture their own selves. Both chose to separate from their partners. After the death of her husband, Katherine told me she could not remember the love and connection they had during their early marriage. She was numbed to any pain at his death and later realized she was numb to her own heart in the process. A weekend retreat that focused on role-playing and listening deeply opened her to her husband’s and her own pain again. Katherine and her husband experienced the deaths of two infant daughters early in their marriage, and she believes that his inability to move beyond these deaths contributed to the unhappiness that eventually led to his own suicide. Katherine alludes to the reality of fluctuating relational boundaries after a death. She narrates relation that moves from external, to internal, to deep internal in a Dao of mourning relation:

I think it feels like you are losing a relationship in the beginning, and that’s what it’s felt like to me each time. There’s a loss of the relationship initially, and then it returns. I think that’s the difference
between Robby and me and why I could go on and have a life. He felt like he lost his two girls, [choking up], and he said that to me many times, he said: “I see you’re going on. How can you do that?” And I said, “Because I feel like they’re with me. I don’t feel like I’ve lost them.” I know the gifts that I got from being with them even just for such a short time. I mean the first child was only 3 days old [when she died] and I was completely a different person for those 3 days, and ever after. I was a mother. I loved somebody so much [crying], and that was a gift to me that her dying cannot have taken away.

Katherine refers to “not having access” to part of her heart after her husband died. It might be said that until she “found her heart again” and was able to feel, she remained in external relation with her deceased husband:

I felt the part of my heart that was involved with Robby was pretty cold. I didn’t have access to that part in the way that I wanted. So I didn’t have a lot of grief, when he died. I mean I grieved a lot before he died. I was surprised at how my reaction was more shock, which is a part of grief I guess, but I never really had the grieving phase like the sobbing stuff. Never had any of that. I didn’t have a lot of that until last year when this happened [her role playing workshop]. But it felt fantastic. It felt great. I felt, oh here’s my heart again! It feels appropriate to feel sad about this now.

For Katherine, the shift from external relation to internal relation involved cracking the heart open. Rituals of remembering and involvement in a group that listened deeply to her pain allowed a freedom to feel love and sorrow again.

**Lack of Cultural Space for Mourning**

A meta-theme of these narratives is a lack of cultural space and time for grief and mourning in America. Even though Kendra, the hospice director told me that “9-11 put grief back on the map in America,” by which she meant there is more public awareness of loss and mourning, it was clear to me from the first interview that the
people who volunteered for this study wanted to talk, and talked with some urgency about their encounters with death, grief, and mourning. Many told me that they had trouble finding someone who would listen to them, yet the need to talk was strong. Several told me they volunteered for the study because someone “actually wanted to hear” what they had to say. Susan and Rosa told me they lost friends after the death because they did not want to hear about the death. Some enrolled in grief and bereavement service programs for the reason that talking about their loved one and their intense affective surges were sanctioned. Many thought grief was a private process, and that they had to stifle their urge to talk or ask for help. Katherine is someone who lost two infant daughters soon after birth due to heart anomalies. She stated that there is “no space for grief” in our culture:

So many people think that in the face of the death of someone really close that they’re supposed to be OK right away. It’s like well, we had the funeral last week and now I’m back to work. It’s culturally expected that we get on with it. Many people are not present to the painful riches that can come out of that completion process. The image I had of myself, especially with the girls, was somebody that wished that I could wear black sometimes. Not always, but I wished that I could’ve put on black when I felt vulnerable. We need something, but a lot of us don’t know ourselves what we need, because we don’t have those rituals. I mean most of the rituals around dying are done at the funeral, and that’s just the very beginning.

Katherine critiques the impulse to “get on with it” right after a death. She insists throughout her interview that there are “painful riches” that result from enduring grief and loss. Katherine implies, as Lewis says outright, that mourners are “invisible.” The suffering they endure is not visibly apparent to those around them, but when some mourners reached out to others, and there was no affective empathic
understanding of their grief, this further alienated them from the deceased and others. In Chapter 3, Susan’s Story: “I Can’t Imagine,” Susan recounts this dynamic, telling me that when others said they could not imagine her pain, she felt “intense isolation.”

**Conclusion**

This chapter uses the I/I heuristic to look at complex relational fluctuations between the living and the dead during mourning. The I/I model is useful for thinking about relation for many reasons. It helps to identify nodal moments of pure oppositional binary thinking about relation as intimacy or integrity based, for discussing paradoxical thinking about relation, for noting holistic shifts in a Dao of mourning relation, and for contemplating the mutual emergence of multiple relations in a holographic metaphysics. One general conclusion of this study is that because of affective indeterminacy and modulation, relational orientations move rapidly between and among a range of categories that are too complex, too dynamic, and too numerous for representation. So after careful analysis, I make these two claims based on my data from the field and use of the I/I heuristic: relation to the deceased is an affectively charged, wildly fluctuating, unstable category; yet these informants oscillate most frequently toward the intimacy relation as defined by Kasulis. Sorrowful affect that overflows into the interview space is the most salient dynamic in the narratives gathered.

The primacy of internal relations, affective dynamics, and somatic and esoteric based knowledge in the interviews designates these end-of-life spaces as cultures of
intimacy. As such, those who work or volunteer in these cultures may need competencies that include empathic awareness and imagination, deep listening skills, suspension of judgment about out-of-boundary experiences, tolerance for paradox and complex relational shifting, and patience with the time it takes to negotiate transforming boundaries between the living and the dead. Those who provide care in spaces of mourning might enter into internal relations with dying and bereaved people for a fuller understanding of how enhance end-of-life decision-making. Chapter 3 provides a case study that illustrates complex and rapidly shifting relational orientations between Susan and her deceased son. Because she uses art as a ritual process, relational transformations can literally be seen in her visual images.
CHAPTER 3

SUSAN’S STORY: “I CAN’T IMAGINE”

In August 2002, our life was shattered by the sudden death of our 19-year-old son. All events became “before” or “after.” Our life was cleaved by that moment in time. I was broken in my heart and in my soul. The pain in the first two years was so intense that I could hardly bear to be in my skin. Over time the searing pain turned into a deep well of sadness that stretched like a barren wasteland before me. Many people have carried us with their love and comfort, but the most frequent message of concern has been “I can’t imagine the pain, I can’t imagine how you do it.” Once I suggested to someone that perhaps they could imagine it if they thought about it. The response was a quick and adamant, “no, I can’t imagine it.” I feel intense isolation in those moments.

Susan Carlson, Artist’s Statement

This chapter presents Susan Carlson’s story in order to illustrate the complexity of relation during mourning. The above statement opens Susan’s collection of mixed media artwork created in the first seven years after her son’s death in a mountain climbing accident. It gives voice to the intense embodied suffering she felt in those years. Our interview was eight years after her son’s death. In what might be seen as important information to those who would understand the bereaved person, her words reference the “intense isolation” she feels when others “can’t imagine” her pain. I viewed Susan’s art show at the local Jung Haus art gallery. Hannah, a Jungian analyst and counselor at the hospice bereavement program told me about the show and
thought I might enjoy it. Follow me as I move between viewing the show and our interview, trying to understand Susan’s experiences through her words and art. The art images are followed by Susan’s brief written descriptions.

It was a rainy spring afternoon in the bustling Short North area of Columbus. I headed for the quiet side street where an old brick house has been converted to a community center that focuses on programming related to the writings of Carl G. Jung. I entered the living room study and wrote my name in the registry. My first encounter was Susan’s artist statement, followed by a vibrantly beautiful pastel drawing of yellow flowers entitled “Before.” In our subsequent interview on the day Susan took down the show, she told me this about the first painting:

I’ve been an artist as an avocation all my life and was making art you know at the time Ben died. And umm, so you know this was kinda like well, draw what you know, making flowers like the ones before. But this didn’t have any meaning at all to me. None whatsoever. I have said to people that that I will never draw that way again. That life is over for me. That doesn't mean I wouldn’t draw something beautiful but it won’t be as free and exuberant, because I’m not the same person as I was before, you know what I mean?

Susan’s words and art reflect the intense paradoxical tensions, the embodied affects, and the personal and relational transformations that mourners described. The tension between “before” and “after” the death is evident in the above textual excerpts. She later alludes to the imperatives to “hold on” and “let go” (Fig. 8). She feels divided between the “living” and the land of the “dead” (Fig. 9). She distinguishes between “thinking” and “feeling,” saying that life cannot be lived without “feeling it.” In “Containing Trauma,” Susan draws attention to how affects circulate from “outside”
to “inside” and somatically involve her head, heart and gut. Susan’s artwork illustrates these tensions graphically and lend another level of comprehension for the viewer.

Our interview gave rise to multiple relational oscillations between herself, others, and her son. It is apparent that Susan loved her son dearly. The affective modulations, somatic involvement, and an esoteric dream experience point to the internal, open boundaries of intimacy relation. Yet, Susan’s artwork shows how cut off she felt from both the living and her dead son. The boundaries between herself, others and her son sometimes appear to be closed in external relation like solid the line drawn between herself and the living in “Cut Off” (Fig. 9). Susan might be said to oscillate toward broken internal relation, or the crescent self of mourning in “Stages” (Fig. 5), where she represents of herself as fragmented and incomplete. Another piece, “Nest” represents her son “living inside” her again, intimating porous or dissolved boundaries that are imagined between herself and her son. Finally, in words that point to holographic relation, she imagines that her son is “everywhere.” In the following pages, I hope to give an idea of Susan’s experiences of grief, loss, mourning and “healing” through her words and art, highlighting the relational oscillations that punctuated our interview.

The gallery was empty and silent, except for me, and a volunteer who was doing some paperwork in another room of the house. As I observed the show in sequence, I started to feel a great sadness that overpowered me. My throat closed off. I wanted to cry. Perhaps I began to feel something of the intensity of Susan’s experience. Her words and images point to the all-encompassing transformations that
follow the death of a loved one. Susan told me that most children are loved, and that Ben was “very loved.” The postcard image that was used for advertising her art show had a strong emotional effect on me. Entitled “Holding On,” it shows a plain white plaster cast of Susan’s hands clutching a worn out cotton blue t-shirt—one that might have been worn by her son. She told me that in this piece she wanted to show:

Just that clinging. I mean you know that holding on, that intense gripping of wanting to hold onto your child—to any remnant of your child. I just felt that so strongly, like the grip onto this thing, and I wanted it in my hands to show that intensity of emotion, of what you want to hold onto.

Figure 8. Holding On
Carlson, Susan. *I can’t imagine: Artwork by Susan Carlson* (p. 8). Cincinnati OH. Plaster, cloth. 15”w x 6”h

Many parents cling to their children’s clothing indefinitely. It’s difficult for others to understand how long we can hold onto these precious items. It’s not pathological; it’s normal. They are sacred.
For me, this piece brought up the attempts that mourners make to keep the beloved other close. Several bereavement counselors told me that items like clothing, jewelry, or keepsakes from the loved one may be held onto indefinitely. In her description of this piece, Susan alludes to the sacred nature of these objects for the mourner. The scent, texture, the feel of the object, the possible energy imbued in the object, can be a sensory reminder of the person. Louise, a bereavement counselor told me that she advises her clients to go to the closet and “get the stinkiest sweatshirt” from the closet and put it in a zip-lock bag. This way it retains the strongest odor from the deceased person. Susan had heard of this and told me:

Yeah I have a very special one that is full of his sweat and smell that I keep under my pillow. So it keeps smelling. I didn’t put mine in a bag—I wish I had. But I smelled it and believe me it was really smelly! He played ultimate Frisbee on a 95° day, so it still salt stains all over from the amount of sweat. Oh my God it was stinky, but I loved it.

Later in the interview, in juxtaposition to “holding on,” Susan talks about “letting go” of her son like this:

I think I struggle with thinking about what’s the meaning of a person’s life? It is part of trying to spiritually absorb that you know? Like it’s easy to say we are all little grains of sand. It’s harder for a mother to say my child is only a grain of sand, you know what I mean? In some sense, I have to let go of Ben. This doesn’t mean I’ll never obviously forget about him or whatever, but I have to. I have to go along with this and just allow myself to just ... you know that’s the hard reality. This is real you know, and I have to live with it.

Susan perhaps alludes to the difference between losing someone in intimate relation—a mother losing a son—rather than an external relation, someone or
something separate, like “little grains of sand.” In truth, she will never forget her son, yet must let go and surrender to the reality of his death on another level.

Susan and I met for lunch at a corner restaurant near Jung Haus for the interview about a month after I viewed the art show. Susan arrived first and was waiting for me at an outdoor table. I realized when I saw her that she was about my age. I later came to know that her son was just a year younger than my oldest daughter. In another coincidence, Susan knew our best friends, a couple from Cincinnati whose children attended school with Ben. I realized in this interview that my own risk-taking daughter, who had gone scuba diving hundreds of miles off the coast of Australia around that age to see the Great Barrier Reef, seemed a lot like her adventurous son who went mountain climbing in the Great Teton mountains. The similarities were striking. They were close in age and temperament. They both took chances. I was identifying with Susan, knowing that there are no guarantees that our children will outlive us. The interview was emotionally heavy. I felt tears well up in my eyes several times as she spoke. Affective modulations were all over the place in our interview. It seemed I felt love, tenderness, pride, frustration, anger, anxious worry, and much more affectively exude from Susan during our time together.

In the early days after the death, Susan felt cut off from both her son and others in her world. When I viewed this piece, I imagined that the figure was her son, looking from beyond the grave at the living (Fig. 9).
In our interview, Susan told me that she is that figure on the threshold between life and death. She said this about the piece:

During maybe the first couple of years I had only a face to offer everyone. I had nothing else to offer them. They were over there. I was searching the land of the dead for my son. And all I had was.... I could just put a face through. They could talk to me and could look at me, but I wasn’t there. I was over in this other place.

And later in the interview:

After Ben’s death, I had no joy. I said to our rabbi, because I belong to a humanist Jewish congregation in Cincinnati, I said you know, I
dishonor life every day of my life. I dishonor it. I’m throwing it away just like that. Something so special, I throw it away because I’m like, ok I see it, but I don’t feel it. I just couldn’t feel that joy. For me, living it means you have to really feel it. If I don’t feel it, then I’m not living it you know? So it has to be honest. It can’t just be a thought.

In this interview excerpt and image, Susan seems to be saying that being able to feel fully alive and joyful is an important part of living. Living fully involves feeling, not just thinking. This quote calls to mind David Loy’s suggestion that the real issue humans have in the face of death (as opposed to repression or fear) is our inability to feel fully alive and to actualize a sense of self that is genuine and authentic. How does one live fully with joy while having knowledge of the brevity of life and feeling “searing pain” or “deep well of sadness” that accompanies death? Susan grapples with this very dynamic in her art and with her words.

The next piece I viewed was called “The News (Tryptich).” It shows three images that Susan did in response to hearing the news of her son’s death from the police officer who came to their home. The first segment shows neat cursive handwriting on lined paper with repetition of this phrase in black pastel: “There has been a fatal accident.” The second image includes the words “Yes, it’s true ... dead ... fatal” written in red lettering with orange shadows. The third image is a grayish black scribble with a very fine erratic circular scribble in the center. It took her almost five years after the death to compose this piece because she “didn’t want to hear those words.” Later Susan described doing this piece as part of working through the shock and trauma associated with her son’s death. In our interview she talked about the
earliest days after the death as “the yearning.” Her words reflect Kavaler-Adler’s idea that the spiritual aspects of mourning involve yearning for the lost other. She says:

Working through the shock and the trauma was part of the initial time in addition to grief. But I think those early days, maybe the first year or two really, we were just in this phase where ... I called it ‘the yearning’ where you’re dealing with trauma, you’re dealing with shock. I had a lot of physical kinds of symptoms you know. I really was just there. There was nothing else on our minds. It was on our minds constantly. All the time you know. Every second.

After a while, so as to cope, I had to sort of mentally hold his death out in front of my face all the time, because if I stopped for a minute and concentrated on something else like work and then I would come back to it, I would experience the trauma and the shock all over again physically. So it would always be with you, I thought, like if I can just have it out here, then I’m always remembering it – then I don’t have to have it smack me in the face again.

The loose borders between shock, trauma, and grief were themes for some informants. Susan says that becoming aware of the reality of the death involved constant conscious attention, otherwise she re-lived the trauma when she remembered.

Listening to Susan talk led me to ask her how she differentiates grief and trauma as two states of being:

I think with trauma you don’t have any control. Well you don’t have any control over grief either, but grief is like you know the ocean or the waves. You know the tide comes in and tide goes out and you’re tossed about in the waves. Trauma I see as a complete body experience that you have no control over. Maybe it just comes in ... like it smacks you suddenly you know? You’re sort of paralyzed. You can’t control what’s happening in your body, and then you’re kind of overcome by something that feels like it’s almost separate from you. Whereas grief feels more congruent—like it is you.

A very striking pastel self-portrait called “Containing Trauma” (Fig. 10) brings her words about trauma to life. This image graphically shows some of the affective
and somatic elements of her experience. For Susan, the trauma floods through the tubes from the dark corner depicted in the portrait and into her head, heart and gut. Susan said to me that when the clips are “on” the trauma can be managed, but that the trauma, coming from the dark corner of the piece, is nonetheless “always there.” If “just the right thing touches the trauma, the clips fly off and you’re kind of flooded again until you get your clips on.” Many informants, like Susan, mentioned the complete unpredictability of affective surges, likening the affective waves to sudden labor pains.
Figure 10. Containing Trauma
I can’t imagine: Artwork by Susan Carlson (p. 17). Cincinnati OH.
Pastel. 17”w x 24”h
I experience trauma differently than grief. It has its own physical, all encompassing way. When the wire is tripped, the clips fly off and the trauma floods into gut, heart, and head until you can restore order once again.

Exactly one year after our interview, Susan was a keynote speaker at a central Ohio conference on grief. Her show was displayed at the meeting. I was fortunate to be able to attend this conference and hear Susan explain her ideas about using art to
move through her experiences with the death of her son and field questions about her art. Susan’s art wonderfully translates the somatic embeddedness of grief, loss, and mourning. Like her image “Containing Trauma,” involvement of the head, heart and gut are common themes in the interviews done for this study. Many informants referenced these anatomical touchstones when talking about grief. In this study, another one of the most common narrated somatic metaphors is the heart in various states of wounding after a loss. In her talk at the grief conference, Susan mentioned that a hole in the heart is an “iconic metaphor” for parents who have lost a child through death. Several of the parents in the infant loss support group that I attended echoed this thought. Susan herself includes the heart in various stages of weariness and wounding in her art. She told me that her mixed media piece entitled “Heart, Harnessed for Carrying” (Fig. 11) expresses the way she tried to bandage or protect her heart as she “put it on” each day.
Another dramatic representation of the heart that is pierced and wounded is shown in the small acrylic sculptures of her torso entitled “Stages” (Fig. 12). Susan told me that she intended these objects to be held in your hand, like ancient artifacts in a museum. I hesitate to narrate much about these pieces, because they seem to speak for themselves.
As examples for this chapter on affective and somatic aspects of internal relation, these images reflect the deep psychic and physical wounding that can happen after the death of a beloved person. The missing parts of the whole person in these sculptures allude to the crescent self of broken internal relation, or the self that feels fragmented, missing, and incomplete.
One of the most poignant moments in our time together was the story that Susan told me about a vivid dream she had. As an example of esoteric knowledge, this dream cannot be publicly verified, but had real meaning for Susan. It has elements of an out-of-ordinary boundaries experience since it seems impossible to really talk to the dead, given the boundaries of human time and space. This dream was similar to other informants’ dreams about vividly real encounters with their loved one. And as other interviewees told me, it had the effect of being deeply meaningful, comforting, and immanently memorable for the dreamer.

I had a dream that he came back. He told me where he was, what he was doing, and all of this. I asked him what happened and he said: “You know it wasn’t your fault. It was just something stupid.” He told me he loved me. He was hugging me when I woke up telling me he loved me. [she gives more details of the dream] Oh, this was intense! It was like he was there. Like he’s real, yeah, this is real. And you know then he faded. He told me he loved me, and I was holding him, and he faded away, and that was it. But I woke up instantly and I was like: Oh my God! Oh my God! I had this other kind of experience. It was very, very deeply meaningful—still is. And I’m thrilled for it, that I had that dream.

This dream along with Susan’s narration of her love for Ben, and the somatic and affective changes after his death suggest an intimacy relation between herself and her deceased son. And at several times during our interview, Susan also alluded to a kind of holographic relation. When describing what she thinks about death, Susan said:

I believe that my son is compost you know, but that means he’s living again in nature you know, in other living things. And that’s very meaningful and important to me. I need to know that he’s not here, he’s not there, but he’s everywhere you know.
Another memorable piece of art from her show entitled “Nest” might connote a deep internal relation to her son. Inside a circular nesting of white material similar to gauze or an ace bandage, she has a color photograph of Ben smiling. The cloth material is sewn together with blue thread, holding the photograph in a kind of silvery white cocoon. Susan comments: “This is the place where Ben lives inside me again.” She says this is one of her “hopeful pieces.” It seems to say that her son is part of her now, the art work showing how Ben is symbolically incorporated into her self.

Yet, at other times in the interview, Susan seemed to oscillate toward a ground of external relation. The death was so painful, so disruptive, and so final that she wonders about if this mortal life is really all there is, and if so, what is the meaning of human life? Saying it is easy to philosophize about meaninglessness, this point of view does not help her as mother of a unique human being who is now gone. Describing an art exercise she did while working with an art therapist, she says:

And maybe it doesn’t mean anything you know. So, I sort of drew this sketch of a whole bunch of grass, and like I don’t know, like little debris on the ground and things like that, and then I cut out a tiny a cutout, one picture of Ben’s face, and I just put it down in the grass and the leaves with this thing. And then I showed it to the art therapist and she was like: “Yeah well what about this one?” And I said well you know “What do you make of it?” And she’s looking at it, and then all of a sudden then she sees him down there, but she couldn’t see him until a very long time—which was purposeful on my part. And I said: “Yeah maybe that’s all it is. You just fall back to the grass. You’re not really anything anymore, but just a little fade away down there and that’s it! That’s all.”

I think a lot about what’s the meaning of one individual person’s life. Like people say, “We want to remember Ben.” And do I want people to remember Ben? Or what happens to Ben? You know, the life he lived. And I think, then I struggle with, well what difference does it
make? Nobody’s going to know Ben. They can’t know Ben. You can talk about him a hundred times all day long. Up one side and down the other side, but you have to know a person, to know you have to know them. And there’s no way to know a person. People are only going to know aspects of him and these are all in some ways stereotypes of what people want to make of him you know. What do we want to make of this ok? And that’s not really knowing a person. I’m his mother you know. What do I want to do with my son in that sense? You know this person, this unique life that lived?

In these quotes, Susan mirrors Derrida on the subject of mourning. How can we know the other that is “nothing now” after the death? Derrida’s construction of mourning implies humans in quintessential external relation to each other. He states that it is impossible to really know another human being and that this radical alterity and difference render mourning impossible. For Derrida, if the deceased other is swallowed whole into the self (incorporation) or if the living person begins to love in themselves what was loved in the other (introjection), either dynamic erases the singularity of the deceased. Derrida suggests that both orientations are unfaithful to the unique and irrevocable difference of the other. Instead, if mourning is successful, Derrida says that it works to dialectacize death. Mourning begins an ongoing conversation about what death is. Thus, Susan asks “What do we want to make of this, OK?” She retorts that no one can ever really know her son. This relational orientation might be viewed as external, since it implies solid boundaries that prohibit a kind of global, somatic, and affectively “felt” intimate knowledge of the person after death.

What I have shown here is that Susan’s relational orientation to her son oscillates among several relational categories in our interview and throughout her art
images. Overall, her words and multimedia art images suggest internal or broken internal relation to her deceased son. Her art stunningly shows affective dynamics and somatic metaphors that capture her experiences of pain, trauma, and loneliness in mourning. She represents herself as fragmented, wounded through the heart, and missing body parts as in the crescent self of mourning. She narrates an exquisite example of an esoteric kind of out-of-ordinary boundaries dream where she feels very connected in the present moment to her son who comes to talk to her from another dimension. Susan alternately thinks of her son as being “everywhere,” as “nourishment for the earth,” and he “lives in” her now. These may be seen as references to holographic thinking about relation to Ben.

Yet, at times she oscillates toward a ground of external relation. She questions if she can ever know her son who is now deceased. What if he is nothing but a “speck,” a “fade away,” a separate “grain of sand” that is no longer? In one pastel piece, she teeters on the threshold between life and death, feeling almost dead herself, totally cut off from both her dead son and living people all around her. Her life is bereft of joy. Susan’s interview and artwork are examples of how much the mourner shifts orientation toward the deceased. At the time of our interview, it had been eight years since her son’s death, leading me to suspect that at least for some mourners, grief and loss are ongoing processes involving constantly shifting relational orientations toward the deceased. Resolution by stage or step-wise progression through phases seems unlikely from this point of view. Perhaps it is more likely that the mourner
cycles back to affective states, albeit at new levels of understanding and ability to withstand the intense affective dynamics.

Susan said in the interview: “I want to be at more at peace with myself but I don’t think I’m entirely there. I’m still struggling.” Her attitude is that the mourner must “fully experience wherever you are” and not deny the pain. One year after our interview at the grief conference I noted changes in Susan. She seemed more at ease, more confident. She spoke assuredly of the role that art has played in her life since the death of her son:

I’m just a person who cannot... I can’t absorb that kind of emotion without it coming out in some way. It’s just not my nature to do that. And I couldn’t. Words had no meaning to me. I mean I couldn’t explain this in words to anybody. And so I think showing the artwork, and allowing other people to understand, you know, feeling understood, and come to that level of pain has helped me to become more at peace, and feel more connected to people. And it has been through that connection that I've healed.

This interview excerpt points to how feeling pain, expressing pain, and being understood by others is how she has healed. Reaching out in her pain to connect is crucial to healing, as so many other informants told me. And it seems from her words, that healing is an ongoing process, perhaps never really complete. Susan also notes her inability to name affective states in grief and mourning. Her art is a vehicle for expressing what words cannot say. She recounts how it was difficult for others to understand the depth of what she was going through, but praised art for communicating at another level.

It’s very difficult for them [friends, others] to know what the right thing is to say. And so in some ways the art makes it easier for me because I
feel like ok, well, alright, I worked, now you can look at that, and now I
don’t have to talk about it!

Susan’s presentation to the central Ohio bereavement services community was
focused on the creative process and grief. She said that creative expression supports
healing and can improve resilience or the capacity to cope well under adversity. For
her, creating visual art is very different from using spoken and written words. She
suggested that using language is futile when attempting to express the intensity of
pain. She mentioned how creativity brings something new into being that can help
release, transmute, and communicate strong emotions. Her most sincere advice to the
gathered listeners was to help survivors “live it out” by listening and helping them
“trust the process” of mourning where experiences can be held over time and
understood as having positive meaning. The creative self, where “beauty arises,”
comes to “guide in healing.” She sees the creative act as an imperative for fully
experiencing and expressing the complexity and intensity of human encounters with
death and loss.

Susan has volunteered with several groups and organizations including
Compassionate Friends, a group of parents whose children have died by violent means.
She has guided art exercises and talks about her own journey with loss through death.
At the conference, she recounted a story about leading an art experience with a mother
who was having trouble taking her drawing of her murdered child home with her.
Susan talked to her about the feelings associated with the drawing, and the mother was
able to take it home, folded up, until she was able to look at it some time in the future.
Susan trusts that with time this will happen. She said that with art she is able to “trust that order” can be made from the chaos of death. I think Susan’s sensibilities about death, dying, grief and loss are exceptional because of her own willingness to plunge into the waters of grief and loss, fully experiencing what unfolds. In the end, I thanked her for sharing so openheartedly with myself, and with others who are learning about how to cope with the intense affective and relational dynamics associated with the death of a beloved other, especially when the death is that of a beloved child.
Everywhere I think. Everywhere. A spirit is, I mean, where is the breeze? Where is the wind?

Cindy, on beliefs about the location her husband after his death

Introduction

The ephemeral qualities of the breath or the wind are fitting metaphors to introduce this chapter on spirituality in end-of-life care. Spirituality is a word with etymological roots in the Greek *pneuma*, meaning breath. Like the literal act of human breathing that involves continual movement between humans and the outer world, as well as movement deep within the inner body-self, this chapter focuses on dynamic affective movement “within” or “through” and “across” or “between” people as dimensions of the spiritual. Kasulis suggests that spirituality “is felt as an inner resonance (2004, p. 2),” implying that spirituality can refer to this dynamic inner/outer movement of affective energies, within and across permeable boundaries of the self. For Cindy, her husband’s “spirit” is “everywhere,” like the wind. Her imagined
relation to him reflects movement and holographic relation. It implies an inability to reduce him or their relation or to an objectified thing suited for scientific study.

In this chapter and the next, I call attention to the dynamic affective and relational flows of humans as “beings in internal relation” in order to critique the scientistic study of spirituality in palliative medicine. The mourner, as a spiritual being, is described as a being in deep connection with the inner self, and in internal or holographic connection with others—living or dead. The intimacy relation involves overlapping or porous boundaries, and has affective, somatic and esoteric characteristics. Holographic relation implies reflective and refractive relation between the self, others, and the world in mutual co-emergence.

For the mourner, the crisis of death and the search for meaning that ensues provides a portal to realization of a self in deep relation with others and the world. Upon this realization, new and creative relationships are continually formed with the living as well as the dead. This transformational process, which I call thanatopoiesis, is “spiritual” in that it can open the mourner to a felt resonance with something within and beyond the separate self. As Jim said after the death of his wife, the moment he realized “we are always and everywhere connected,” that realization “changed everything,” and he was able to “empathize” with others beyond what he previously thought was possible. I argue that complex personal and relational transformations are primary dimensions of spirituality in end-of-life settings, and that spiritual care must attend to these transformations.
The purpose of this chapter is twofold. First I explore how spirituality is defined and studied by contemporary scholars in the study of religion and by selected authors who write on spirituality in hospice and palliative care. The second purpose of this chapter is to report relevant narrative themes that reflect understandings of the spiritual from the ethnographic interviews. These themes include a distinction between spirituality and religion, the identification of a “core” aspect of the self, death and dying as spiritual crises, reports of personal and relational transformations following a death, and metaphors of travel or journey. Kyra’s case study is presented as an example of how these themes played out after the death of her infant daughter. As Louise, a bereavement counselor, said in our interview:

People don’t deal with death without dealing with where they are in the world, what their relationship to ultimate—however they spell ultimate—realities are, what the sequencing is as far as cause and effect, and how that gets disrupted by death. All of these are spiritual issues.

Louise’s words call attention to how encounters with death and dying can force an existential crisis, often challenging one’s previously held beliefs and raising a host of questions about what it means to be human. At the limit of these questions lies the meta-question of transcendence. Does anything survive death? If so, will I ever see my loved one again? Answers to these questions are what I call spiritual imaginaries, or what informants hope, fear, dream or believe about death and continued relationship. These too are spiritual themes, but they are presented separately in the next chapter.
This chapter and the next are informed by historian of religion Carolyn Walker Bynum’s scholarship. Though her writings explore medieval Christian eschatologies, or religious beliefs about death, fascination with the question of human transcendence holds today. Bynum approaches medieval eschatologies through the lens of feminist scholarship. She pays attention to “affective spirituality” or the interwoven dimensions of human affect, relation, desire, imagination, and belief. I approach the narratives collected here in a similar fashion. These narratives may teach us about what it is to be a human being who encounters death and dying in contemporary America. This project continually asks: What is it to be a human being who encounters the death of another? And this chapter asks: What might spiritual discourse and practice in contemporary end-of-life settings reveal about what it means to be a human being encountering death and dying?

**Exploring Meanings of Spirituality**

This section looks at constructions of spirituality from selected end-of-life medical literature, from the religious studies literature, and from the hospice fieldwork. From the medical literature, I specifically analyze segments of an authoritative report from a national consensus conference charged with making recommendations for improving end-of-life spiritual care. Within the religious studies literature, I reference Bynum, Kasulis, Tweed, and Orsi, as well as philosopher of religion, Jean Luc Marion. Finally, I look closely at the “spiritual vision statement” from the hospice where my fieldwork was conducted.
According to Bynum (1982), spirituality is a word coined in the nineteenth century to designate the study of mystical theology, or the “stages of the soul’s ascent to union” (p. 3). She describes a more contemporary meaning of spirituality as “the study of how basic religious attitudes and values are conditioned by the society in which they occur” (p.3). In this section, I am cognizant of both meanings of spirituality. The first is about the “soul” seeking that is reflected in the spiritual imaginaries of the informants in this study. Nan, whose partner died after a long illness, says, “Spirituality is your soul seeking love.” Bynum’s second meaning is about how culture conditions religious values. In this section, I look at how a certain kind of medical-spiritual discourse is emerging in the culture of hospice and palliative care. I assert that hospice and palliative medicine appropriates spiritual discourse and praxis for purposes of expanding narrow biophysical views of human beings at the end of life. Yet, at the same time, strict adherence to scientific models of inquiry restricts and deadens the performative nature of the “spiritual” taken as a dynamic flow of affective energies within and between human beings.

In the following sections, I discuss how narrowly derived empirical conceptions of spirituality and spiritual care in palliative medicine literature might be augmented and enlarged by theorizing from selected contemporary religious studies scholars.
Medical Approaches to the Study of Spirituality in End-of-Life Care

Spiritual discourse is ubiquitous in contemporary American hospice and bereavement spaces. Attending to the spiritual aspects of death and dying, grief, and loss in end-of-life scenarios are uniquely important elements of the holistic hospice mission. Yet, according to physician Christina Pulchalski, attention to spirituality is a fairly recent concern in modern medical practice. Several issues concerning spirituality in end-of-life care are intensely debated in contemporary medical practice, research, and education. Some of these issues include conceptual clarity about spirituality, types and usage of spiritual assessment tools to identify spiritual distress, what counts as spiritual care and who can administer spiritual care, and scientific evidence-based outcomes of spiritual care.

These issues were addressed by a national consensus committee whose goals included identifying points of agreement about spirituality in health care, and making recommendations for improving the delivery of quality spiritual care at the end-of-life. The authoritative white paper on spirituality in end-of-life care was published in the Journal of Palliative Medicine. Improving the Quality of Spiritual Care as a Dimension of Palliative Care: The Report of the Consensus Conference by Pulchalski et al. presents the goals, process, and recommendations of the consensus conference. The article notes that among the critical issues raised in previous studies on spirituality in end-of-life care are “ways to increase scientific rigor surrounding spirituality and spiritual care research and practice” (p. 885). As is the practice in scientific exploration, the group prioritized the need for a “commonly accepted definition of
spirituality” to delineate their object of study. They agreed that “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” (p. 887). This definition acknowledges “connectedness,” suggesting that relationship is important in end-of-life spiritual care, yet recommends using scientific methods to study spirituality.

The second part of their goal statement seems less easily actualized. How can the quality of spiritual care in palliative care be improved? An elaborate set of recommendations and guidelines for improving spiritual care is presented in that report. It recommends using standardized spiritual assessment instruments to ascertain whether or not the patient feels spiritual distress. If so, declaring a spiritual diagnosis and formulation of a spiritual treatment plan is recommended. The document offers a complex model to implement delivery of spiritual care. In an effort to appoint chaplains as the gatekeepers of spiritual care and apparent experts for delivering spiritual care, board certification is recommended, as is referral to chaplains for spiritual issues. A list of possible spiritual health interventions covering such things as therapeutic communication and listening, mind-body therapies such as massage, performance of spiritual practices or appropriate rituals are given as examples of ways to provide spiritual care. Finally, the report addresses how to develop the capacity of palliative care staff members to be present to the patient who is dying or those experiencing loss at the end of life. In their recommendations, professional
development and education are encouraged in the areas of self-care, reflection, and contemplative practices.

The authors of the report are to be commended for tackling the topic of spirituality in health care, one that is marginalized and often forgotten by a strict focus on the biophysical status of the patient. However, their scientific approach to spirituality contradicts the very holism they seek to champion in end-of-life care. I agree that spiritual beliefs and practices at the end of life are critically related to the quality of living and dying. Attention to religious or spiritual beliefs and practices must be included in medical settings where death occurs. Yet, if beliefs are embedded in personal and cultural practices, as many informants in this study imply, then how can “spiritual” or “religious” well-being be separated from human well-being in general? The “spiritual” or “religious” adjective may not be necessary when taking about the human as a being in holographic relation.

I argue that categories such as spiritual care, spiritual assessment, spiritual research and spiritual outcomes are reductive based on understanding the spiritual human as a being in holistic relation. If a holistic metaphysics is assumed, then the spiritual dimensions of human beings cannot be separated from the whole human being as a process co-emerging with other interdependent processes. Therefore, care that splits spiritual well-being from material well-being is fragmented. And a fixed definition of spirituality that draws boundaries around what can be considered spiritual, limits its conception. Research that separates spiritual outcomes from other outcomes for human beings reduces spiritual processes from a holistic reality that
recognizes human beings as embedded in mutually emerging interdependent processes. In understanding the human as a being in holographic relation, spiritual distress cannot be separated from human distress. In other words, spiritual care is an integral and irreducible component of holistic care rather than a separate entity.

In contradistinction to the report, I argue that no “commonly accepted definition of spirituality (885)” exists, nor can it be possible given the diversity of human beings in unique end-of-life cultural contexts in America. Would it not be better to approach spiritual care by listening to what spirituality and religion mean (or do not mean) to those who are dying and their circle of relations? It seems to me that the last thing that is needed in contemporary end-of-life settings is a limited, static, petrified view of what counts as spirituality and spiritual care. Even if a person declares a specific religious affiliation, the findings of this study suggest that there are wide variations in personal appropriation of religious principles and practices. And what of those who declare no religious/spiritual belief but believe in something else, like NASCAR racing or Ohio State University football, or love, or rock and roll music? Are they outside the net of “spiritual” care? Louise told me a story about a husband who wanted to give his wife an unconventional Christmas gift while she was in hospice care.

Everybody said, “Don’t be silly dad, mom has Alzheimers disease. She’s not going to remember. There’s nothing she needs. Just be here with her.” But he worked hard and got a quartet from OSU to come and sing Christmas carols to her. This family had been big OSU fans forever. So this quartet sang Christmas carols and they were all dressed in their nice scarlet and gray. A lot of the songs she remembered because music cuts through Alzheimers. The last song they sang was
Carmen Ohio. This was 3 days before she died and she was able to hold her arms out for the O-H-I-O! You are not going to find that in any church, yet that’s deeply spiritual, deeply spiritual. It reinforced the couple’s relationship, the family’s relationship, and the family’s relationship with a bigger entity. And it created joy.

Contemporary religious studies scholars pay attention to the very relationships and joy-enhancing rituals of which Louise speaks. Hospice and palliative care discussions of the “spiritual” could be enriched and expanded by attention to affective dynamics, relational imaginaries, and the cultural embeddedness of the dying person. Religious studies scholars and theorists such as Bynum, Kasulis, Orsi, and Tweed attend to historical context, cultural relations and flows, and affective resonances between and among people as aspects of the spiritual. They acknowledge the position of the researcher as an important aspect of studying the spiritual as a process embedded in other cultural processes.

Two things strike me in the spiritual assessment and spiritual diagnosis portion of the report. First, it seems that the authors are unaware of their own religious or spiritual biases. The consensus report does not mention the positions of the authors. It contains a Judeo-Christian bias in certain segments, especially in the section on taking a spiritual history and designating a spiritual diagnosis. The relation with “God” is referred to as the relation that receives anger and blame for abandonment. I am not suggesting that this does not occur, indeed this dynamic is reported by informants in this study. But not every person believes in “God” or has a “faith” or attends “church” as signs of a spiritual life. Most informants in this study leave a deity out of their experiences of grief altogether, except for the infant loss group members, who were
younger on average and seemed to question more on a religious rather than existential basis.

There is a blind spot in the scientific method that ignores the positions and biases of the researcher. Ethnographic research would require researchers to declare their own positions in relation to religion and spirituality. Most medical-spiritual research presents a veneer of scientific objectivity, identifying an “object” of study, when from the standpoint of religious studies scholars, spirituality is embedded in other cultural flows. The report does not account for that. I suggest that close ethnographic analysis of spirituality in end-of-life care reveals complex, contested, contextual, and historically and culturally embedded views of religion and spirituality that are not easily separated from other cultural processes. This thick social matrix of spiritual discourse, beliefs, and practices goes unnoticed and unaccounted for in scientific methodologies.

Secondly, when spirituality is approached in a cookbook fashion, with a checklist of ingredients that make for assessment of a spiritually healthy person, then what of those characteristics that are not on the list? In delineating what counts as spiritual, the authors of this report are in some ways defining what should count as human. When entering a room of a dying person, instead of being acutely aware of what is happening, the spiritual assessment checklist dictates the direction of the interaction between patient and health care professional. In my reading I found over fifty spirituality assessment scales and no two were alike. These scales lump all that counts for spirituality into categories tested by the particular items on the research tool.
I suggest that attention to the paper checklist and form distracts from the real live person waiting to be engaged and listened to. And in moments when the person is most in need of a compassionate other, the list and the certified chaplain may not be available. In an immanent death situation or unexpected death, there is no time for “spiritual assessment” anyhow, nor can “evidence based outcomes” of spiritual care be solicited from a dead person.

The following quote illustrates some of the realities of human encounters with loss in clinical practice, requiring compassionate presence and the ability to listen even at unexpected times and in unexpected places. Sally told me this about her nights on the antepartum (meaning “before birth,” so she was with pregnant mothers) unit in the hospital after her twin babies died soon after birth.

I felt physically OK, but emotionally I was a wreck. And they put me in an antepartum room because they really didn’t know what to do with me. I’m sitting there sobbing in the middle of the night and the nurses would come in look at me take my temperature take my vital signs and say, “are you ok?” And I said no. And they would say, “Well, I’m sorry” and would walk out.

The reality is that sorrowful affective modulations in grief are common, yet can strike in an unpredictable fashion at inconvenient times, and in this case, on a hospital unit with healthy pregnant mothers where death is unlikely. When someone like Sally needs another person to be compassionately present to their suffering in a spontaneous or instantaneous way, what is needed is a mindful heart. Assessment tools, diagnostic categorization, and quantitative knowledge about spirituality cannot adequately prepare the listener for this work. This is work of the heart. It is work that requires
comfort hearing about sorrow, guilt, anxiety, anger, fear, and other strong emotions. It requires the courage to enter the cave of dark unknowing and witness the mysteries of death and dying with the other. It does not require answers, only patience and listening, and the willingness to engage in an exchange that offers a net of compassionate safety in the present moment. How different Sally’s hospital experience might have been if someone sat next to her bed at those critical moments in the middle of the night and simply listened to her.

The idea of increasing scientific rigor in the study of spirituality seems antithetical to holistic views of human beings who, according to philosopher of religion Jean Luc Marion, are irreducible and elude de-definition. The aim of science is to reduce, objectify, and quantify phenomenon and does so through production of solid boundaries of the object under study. It seems this methodology is mismatched for studying the fluid, impermanent, affectively charged and culturally embedded relationships that Bynum, Kasulis, Orsi, and Tweed would use to call attention to the religious or spiritual. The approach taken by the consensus conference participants in some ways assumes that a scientific understanding of the spiritual, as a distinct object, is possible. This is a bit hubristic. Overall, the report objectifies spirituality, fragmenting a holistic understanding of the concept and its performative nature. It denigrates spiritual distress as pathology. It moves spiritual well-being into the domain of specialist mediated intervention, namely board certified chaplains who are called as consultants. Assessment tools can distract caregiver attention from holistic
processes and compassionate responses in the present moment. Efforts to improve
spiritual care would be better served by cultivating the mindful heart of the caregiver.

For those who would offer care, what may be more important than conceptual
clarity about spirituality is the ability to confront the reality of suffering at the end of
life. Attention to suffering is a common thread in both medical literature and religious
studies literature. Suffering at the end-of-life is linked to a range of possible causes.
Four consensus committee members—Chochinov, Ferrell, Halifax, and Sulmasy—
publish widely on spirituality in end-of-life care. Betty Ferrell, hospice nurse and
author, posits that suffering at the end of life can come from lack of control, the
accumulation of multiple loss experiences, intense emotions, and thoughts about
mortality and separation. These factors are in addition to the possibility of physical
pain and discomfort. She posits that suffering at the end of life leads to existential
questions about meaning, purpose, value, and relationship. She suggests that many of
these questions do not have answers, and in fact remain unknowable, propelling the
asker into the realm of either mystery, wonder, and awe or hopelessness, fear, anguish,
and despair.29

Physician and bioethicist Daniel Sulmasy (2009) similarly asserts that illness
and impending death can lead to existential questions that include speculation about
ultimate horizons or transcendence. Psychiatrist Harvey Chochinov (2006) states that
spiritual issues at the end of life are related to understanding well-being, hope,
meaning, dignity, and transcendence and how they correlate with pain control, quality
of life and coping with loss. These authors represent just a few who write about the
“spiritual aspects of dying,” yet all but Chochinov, who takes an existentialist approach, seem to skim the surface of what is going on in the particular imaginary life of those who have lost someone to death. Though the palliative care medical literature acknowledges other dimensions of human beings beyond the physical, it seems to lack depth. And the impulse is to quantify and normalize the spiritual dimension of human beings, which is not surprising since those who write and do the research are trained in scientific methods. Even Roshi Joan Halifax, who most explicitly writes about Buddhist practices in end-of-life care, has joined forces with the Mind & Life Institute to study compassion scientifically by reducing “pro-social behavior” to brain states. Considering these moves to quantify spirituality and compassion and define the edges of what it means to be human, can anything outside those parameters be addressed or accepted? Marion critiques the tendency in medical science to objectify and normalize human beings, and argues for seeing the human as indefinable and exceeding any clear and distinct boundaries.

**Religious Studies Approaches to Spirituality**

Religious studies scholar Thomas Tweed suggests that culture and religion are plastic, contested and contextual terms that cannot be bound and therefore cannot be studied scientifically. In Tweed’s view it is not possible to construct or discover “cross-cultural spiritual laws” as is done in science when making interpretations of the natural world. Laws, hypotheses, explanations, control and prediction are “unrealizable goals” for those who are trying to understand cultural processes such as
religion. Instead of static bounded concepts, Tweed focuses on movement, relation, and position in his theory of religion to explain how religion helps people journey through life “crossing and dwelling,” or making homes and crossing boundaries. According to Tweed, “religions are confluences of organic-cultural flows that intensify joy and confront suffering by drawing on human and supra-human forces to make homes and cross boundaries (54).” This broad conceptual treatment of religion allows for all kinds of human activities to be considered religious, including, as we have seen, singing the Buckeye alma mater.

Hospices exemplify what Tweed calls “sacroscapes,” or places where religious and other kinds of cultural flows—such as medical practices—intersect. Here, the blending and mixing of various means to alleviate suffering come from both medical and spiritual or religious praxis. Thus, American hospices can be seen as medico-religious hybrid spaces that utilize teams of interdisciplinary professionals to respond to a vast array of human suffering that has its roots in physical, mental, emotional, social or spiritual pain at the end of life.30

Tweed acknowledges that many religions propose that death is not a barrier, but a transition. Religions produce representations of the end of life in what Tweed calls teleographies, or stories that confront the temporal and spatial limits of human life and map what is desired. This is true for most informants in this study. Desire plays a role in what they believe or hope about death. In Tweed’s view, religious ritual around death and dying works to heighten joy and ease suffering as human beings negotiate the limits of human existence. Tweed says religion is “a cascade of
mediators that transform and bring people closer to what was imagined as distant” (p. 158).

Therefore, in Tweed’s view, religious beliefs and practices have the potential to enhance internal relation to the deceased, who might be seen as someone now “distant” from the living. In other words, religious belief and praxis may transform broken relation and restore imagined internal relation to the deceased. How religions deal with the ultimate horizon of death can influence imagined boundaries between the living and the dead, but many of the informants in this study eschew religious belief per se. What happens when religion is not used as this kind of anchor for the living? What replaces religious beliefs about death? How do health care professionals attend to end-of-life care for religiously and culturally diverse populations?

I believe that in hospice discourse, spirituality has become an umbrella term that includes religious belief and practice, as well as affirming a universal inner essence of human beings deemed worthy of respect. One way of conceptualizing the differences between religion and spirituality is offered by Kasulis. He defines “essentialist” spirituality as prescriptive, as that which “arises from an intuition of an inner core of being that drives values, beliefs, and actions” (p. 5). He contrasts this with “existential” spirituality as descriptive, as that “appropriate label for what a person values, believes, and does” (p. 5). For example, the declaration of being “Methodist” or “Buddhist” can be a label that might identify personal values, beliefs and actions. Note that both conceptual definitions are described as variations of spirituality.
Some scholars who represent historians, theorists, or philosophers of religion debate the genealogy and usefulness of the term spirituality altogether. Ethnographer of religion Robert Orsi points to a “nomenclature” problem when distinguishing between religion and spirituality in popular American culture. He is critical of the term, suggesting that spirituality carries too many connotations and can therefore be used to support anything the speaker wishes. He states that “spirituality is a term crafted in this culture to designate the opposite of bad religion,” and is therefore “a disciplinary word built out of and for exclusion” (p. 188). He distinguishes between “true” or “good” religion and bad religion, stating that spirituality may be equated with good religion and the human capacity for devotion. Orsi asserts that relationship is a central concern of all “true” religion, and that religion is a “network of relationships between heaven and earth involving humans of all ages and many sacred figures together (2).” He notes that most religions acknowledge relationships with saints, ancestors, ghosts, gods, and other special beings. According to Orsi, these relationships contain the same complexities including the hopes, dreams, fears, misunderstandings, evasions, projections and denials that are contained in our everyday human relationships. Orsi’s conception of religion as a network of relations seems to resonate with what some of the informants in this study say about religion, but some use the same terms to refer to spirituality. Those informants who spoke of how religion helped them through grief talked of prayer and other forms of contact with sacred figures. Others talked to the deceased in a kind of spiritual conversation.
In one last nod to the applicability of religious studies scholarship in hospice and bereavement settings, I consider Tweed’s metaphors of travel and journey. Many informants used travel metaphors in their language. “Crossing over” and “passing on,” are two very common metaphors used by informants to designate dying. Other informants told me of dreams of traveling to see their loved ones at night in their dreams. Tweed considers affect, movement, relation, and tropes of travel in religious movements. The idea that hospices attempt to construct a safe “dwelling” or create sacred space for the dying and bereaved families as they “cross” boundaries into the unknown is also echoed in some hospice and bereavement care discourse. The next section presents a spiritual vision statement from the hospice where I did my fieldwork. It alludes to creation of a safe dwelling place, as well as other salient dimensions of the spiritual found in the religious studies literature.

**Spiritual Vision Statement for Hospice**

Hospice at Woodside believes that the very act of aligning ourselves with those entrusted to our care is spiritual in nature. Each team member values and nurtures a deep sense of self, while genuinely integrating that in relationships with all others, the universe, and that which is Greater. We mindfully live the present moment—and every moment—with a profound appreciation that all of life is sacred, and that the essence of each person must be held in the highest regard. Our competent team tends to the technical aspects of total comfort, knowing at all times that a deeper healing occurs simply by how we interact with each person. We know of the transforming power of this presence to others and to one another. The compassionate quality of our openness, unconditional acceptance and love provides the safety that softens hearts and allows each person to experience their greatness.
The spirituality of hospice care is as simple and as essential as breathing.

This statement is a rich example of spiritual discourse referring to the human being as an inner essence in relationship with others. The voice seems to be that of hospice professionals communicating what they do (care, appreciate, value, nurture, live in the present moment), how they do it (with openness, appreciation of the sacred, compassionate presence, unconditional acceptance, love), and what the outcomes of care might be (safety, soft heart, experience of greatness, healing, transformation). People are valued and nurtured. The statement is sufficiently vague to imagine that this happens for both caregiver and cared-for. The focus is on caring relation. Relationship extends to the far reaches of the “universe” and is seemingly inclusive of a Greater or “God” type of relation without saying so outright. Though “that which is greater” could mean many things, it could also mean something greater than the separate self. The care is holistic, ensuring “total comfort,” which possibly alludes to palliation of diverse kinds of suffering (biophysical, mental, emotional, social, spiritual) that can occur at the end of life. Healing is not really defined, but happens in relation with others. As a kind of moral code, all life is sacred and all people should be regarded highly. Compassion, unconditional acceptance, and love are the caring ideals. These elements place this vision statement in alignment with feminist philosophy and an ethics of care. The last line about attention to breathing is a nod to the roots of the word spirituality and intimates that spirituality is what literally vitalizes hospice care. This statement is a call to an ideal of care that acknowledges
relationships with others in a way that incorporates both immanent and potentially transcendent expression.\textsuperscript{31}

In sum, this statement is one that lends credence to a fuller picture of the human being than is afforded in strict biophysical constructions of human beings. It is an attempt to present a vision of care that goes beyond atomistic, biophysical reductions of human beings to acknowledge their webs of relationship. It also asserts that the present moment, mindfulness, and compassionate relationship are integral components of caring relation and healing.\textsuperscript{32} It intimates that hospice is a safe dwelling place for crossing the boundary of life into death. This statement resonates with Tweed’s ideas about religion in that it acknowledges movement, relationship, transformation, and is performative in nature. In other words, it describes what happens, what people do, and how the patient is approached in hospice care, rather than appealing to a set of definitions, dogmatic beliefs and specific religious practices.

**Narrative Themes Related to Spirituality and Religion**

This section summarizes the main themes in the interviews related to spirituality and religion. Relevant narrative excerpts are juxtaposed with selected literature that might be used to understand what informants said in the interviews. Separation of religion and spirituality is the first theme, though for some informants this distinction was blurred. Kyra’s case study calls attention to this dynamic. I also discuss encounters with death as a personal spiritual crisis, the trope of journey, and the theme of existential questioning that leads the mourner to question faith and
religious beliefs. Themes from the informants’ spiritual imaginaries are treated exclusively in the next chapter.

**Separating Religion and Spirituality**

The dying process always creates a spiritual situation. And with some folks, through that process they’re drawn more than ever before toward their religious background. And yet other people go away from it. Some people may come back to it if they’ve been away from it for awhile, and they find some comfort in that. But it’s almost like the spiritual piece is very large, and very big, and everyone has that. Then the religious piece I think is smaller, and is used differently depending on how that person is navigating their spiritual experience. I think dying is a spiritual experience. And you get all kinds of help along the way on that journey. Your religion might be one of those things, or it might be something you totally reject.

Kendra, hospice director

One general theme of spiritual discourse in the palliative care literature and fieldwork interviews is the distinction made between spirituality and religion. Kendra’s statement implies that spirituality is felt as a personal experience, and that religion may or may not be used by people to “navigate” their spiritual journey. These broad themes are present in much medical-spiritual discourse.

The following excerpt from a text designed for contemporary health-care professionals declares the conceptual separation of religion and spirituality. The reference to an “animating spirit” as well as “connectedness” or relationship with others is part of defining spirituality (Burkhardt & Nagai-Jacobson, 2002):

Spirituality is a broad concept, transcending religious boundaries. By virtue of being human, all people are spiritual, regardless of whether or how they participate in religious observance. Spirituality, as discussed here, is understood to be the essence of our being, the animating spirit or soul through which we know and experience connectedness with all
of life: with our Self, with Others, with Nature/Cosmos, and with the Divine or Sacred Source. Thus, spirituality is ultimately about relationships. Both giving and receiving care occurs in the context of relationship. (p. xiii)

The citation actually alludes to the distinction between what Kasulis identifies as “essentialist” and “existential” spirituality. She speaks of an “essence of being” through which human beings experience life and relatedness, or essentialist spirituality. This essence transcends religious boundaries, observances and practices, or what Kasulis terms existential spirituality. Sulmasy posits that religion and spirituality are related but conceptually different. He understands spirituality as “the ways in which a person habitually conducts his/her life in relationship to the question of transcendence” (p. 1635). A religion, by contrast, is a “set of beliefs, texts, rituals, and other practices that a particular community shares regarding its relationship with the transcendent” (p. 1635). Like Kendra, Burkhardt and Nagai-Jacobson see the spiritual as the broadest concept, and religion as more narrow. These distinctions read well on paper, but in reality, I found overall what people said about religion, spirituality, belief, and practice to be muddled and confused. The meanings of religion and spirituality seemed to overlap and be synonymous in some cases, and not in others.

In these interviews, I found numerous discrepancies between what informants said they personally believed and the official dogma of their declared religion. For example, both Buddhist informants said they were “not sure” they believed in reincarnation. Likewise, many informants who declared to be members of various
Christian religions declared belief in the possibility of reincarnation, or stated they had no belief in an afterlife. Several informants attended church services regularly for what seemed to be social reasons, while declaring that they were atheists. Others told me that their cultural roots were more entwined with certain observances and practices, rather than a strict set of beliefs. Nina told me “religion is more about tradition than prophets and sages.” She mentioned the “ceremonies” and “meals” that were part of her Jewish childhood as very important ways to connect with others. She shared with me the Jewish practices of sitting shiva and washing the body after death. As someone who managed a nursing home, she believed that personal and cultural practices should be honored at the end of life.

Overall, I found it very difficult to know what informants believed based on their religious affiliations. Eventually I abandoned my impulse to associate the informant’s declared religious affiliation with a certain set of orthodoxies or practices, since each person seemed to have a uniquely personal set of beliefs and practices that were or were not in fact related to their religion. Hannah, a bereavement counselor, alluded to this dynamic in her interview:

During bereavement some people throw out all aspects of the religion they were brought up with. I remember one women was extremely fundamentalist and that kept her grief at bay. It was like God loves me and everything is hunky dory, you know. She could not get to the grief, religion masked it. Some people just can’t use the religious symbolically. It’s hard for them to relate, they take it as dogma, they are angry, and they throw it out. So I try to help them reconnect in some way with their own beliefs. I think the dreams bring up their own religious core. It’s not what’s taught to them. The symbols may be from other religions that they weren’t raised with. They might be
Egyptian, or Hindu, or whatever they make up symbolically. So it’s where their psyche is coming from—not what they were raised with.

This finding has implications for enacting care in end-of-life settings because beliefs and practices may be much more personally and socially complex than a simple declaration of “religious affiliation” might imply. It also may justify a move in end-of-life care toward understanding religion as embedded in personal and cultural practices, rather than assuming the person has strict allegiance to a certain set of beliefs and practices. Likewise, discourse that assumes a norm such as a spiritual universal “core” in that is present in all people may make it easier to care “equally” for patients and families in clinical settings, though it might simultaneously obscure their actual differences in particular beliefs and practices.

In sum, I came to realize that end-of-life issues surrounding belief and ritual are part of a complex cultural matrix that cannot be reduced to “religion” for these informants. And it seems that religion and spirituality have different meanings for some, but are used interchangeably by others. Yet, as I will explore in the next chapter on spiritual imaginaries, all but a few informants had stories or dreams about what they hoped happens after death. And whether or not informants believed in a transcendent higher power or an afterlife, virtually all of them believed in *something*.

My narrow focus in this study is the relation between the living and the dead. However, the way that these informants imagine themselves related to other special beings and devotional figures leaks into the interviews at every turn. These interviews confirm the idea of the spiritual self as a self in context, as is theorized in
contemporary religious studies scholarship. Informants allude to relationships with saints, angels, God, ancestors, and spirits or ghosts. If religion is constructed as a network of relationships involving humans and sacred figures together as Orsi suggests, then how the mourner constructs the relation with the deceased may have much to do with construction of an expanded web of relations or a cosmology that includes a range of sacred or special relationships, of which they are a part. As the next section shows, Orsi’s and Tweed’s ideas about webs and flows of human and supra-human relations are extremely relevant for some informants in this study.

**Kyra’s Case Study**

In some narratives, it seemed virtually impossible to separate religion and spirituality. Kyra’s interview was full of references to the flow of affective dynamics between she and her infant daughter. She was grounded in beliefs and practices in her faith community, and refers to a wide range of religious figures. She and her husband Joe were very active in their Russian Orthodox Church where Joe was a deacon. Kyra credits support and prayers from their church community with helping them through the ordeal of their first child’s death. Unlike many other informants in the infant loss support group, Kyra “never lost faith in God.”

As horrible as this whole situation’s been there wasn’t ever a time where I doubted. There wasn’t ever a time that I felt abandoned. There wasn’t ever a time that I felt like that’s it, I’m done with you God. But I think a lot of that is from prayer from other people. And I think that’s from just having such a strong rooted faith. We were absolutely praying for a miracle and the thing that’s hard to accept, but what I can so easily recognize in the beginning is, it’s not that we weren’t given a miracle, I
mean she was born alive. We could hold her! We were ultimately given so much time with her compared to a lot of other people. But sometimes it’s hard to understand that just because you’re given a miracle, it doesn’t mean you’re going get the one you asked for. I can’t deny that we were given one, I just wanted more.

Kyra told me long stories about her Russian Orthodox faith. She credited her religious beliefs and practices with sustaining her through the darkest days after the death of her infant child. Her interview contained several references to esoteric knowledge. She told she heard the voice of her daughter Marina speak to her reassuringly:

I can specifically remember two times when I have just felt so sad and just so alone. And even though my husband was literally sitting five feet away, I was feeling so alone in my sadness. There was one time when I was sitting here on the couch and we already had the TV on the wall, so its not like the TV in the corner was distracting me, but for some reason, from that direction I could hear Marina saying “I love you mommy and it’s ok.”

She went on to say:

To me it’s not a paranormal ghost type a thing or like a weird science thing, to me it’s truly like a blessing, like a gift from God. I mean we truly believe in our church that God is seriously everything. So it’s not like a weird freaky science ghost thing. I believe its God’s way of comforting me. And kind of letting her speak to me in a reassuring way.

Kyra and her husband Joe planned to have their priest present in the delivery room to perform their infant daughter’s baptism right after birth. They introduced Marina, who was never opened her eyes and was kept alive on a pulmonary ventilator, to her ancestors by showing her pictures in neonatal ICU and letting her know that she was part of the family. They cropped her nails, cut a little lock of her hair to keep, bathed her, and said good-bye in a room full of relatives before the ventilator was
disconnected. They administered communion and wine into her mouth with a tiny eyedropper.

My husband’s biggest thing was like you know there was nothing we can do for her physically here on earth, but as her parents, we need to prepare her spiritually for the afterlife. And so it was very comforting to us that not only was she baptized but she also had first communion. I mean obviously she wasn’t going to get married you know or have any of the other sacraments, but she still had the ones that we could give her. I think its kind of one of those silent comforts that we did those things.

The religious rituals performed the week that Marina lived were very important to Kyra and Joe. But despite her strong faith in God and belief in an afterlife, Kyra was unhappy, and sometimes depressed and lonely. She explained to me that she wanted to feel at peace, but was “not OK” with her loss. She told me a story about baking communion bread one day, in a “reflective” state of mind, when she talked to one of the saints in the Russian Orthodox tradition. She wanted to feel the same peace that her husband was able to have about the death of their daughter and so prayed to St. Herman. She surrendered to her feelings and reached outside of herself, asking for help.

I was looking at the icon and was just kind of saying “St. Herman would you please help me? I really want to feel at peace with this. I mean I’m never going be completely ok with it, but I really want to be ok with it.” At the end of the day I felt such a calm and peace. And you know it’s not that the next day was I fine by any means, but it was just like I felt a little bit of understating of Joe’s grief process and why he was ok with things.

Kyra’s belief that this saint could help her may be part of why she felt more at peace in that moment. But other informants also told me that surrendering to
sorrowful affects, asking for help, and reaching outside of the self to others living or
death seemed to be part of their healing process. Hannah, a Jungian analyst and
bereavement counselor said this about surrendering to grief, “You’ve [grief
counselors] just got to be with the person [the bereaved] whoever they are and
wherever they go. I think primarily, a lot of my analytical practice on grief work at
some level, is about the ego’s need to surrender. That’s grief. That’s what it’s about.”
For some informants, when the person admitted they needed help, reached out and
connected with others who understood, then affective dynamics changed.

Kyra choose her daughter’s name based on hagiographies, which reflected her
imagined connection with her daughter before and after her death. She read a
description of the saints who shared her own and her daughter’s name, another sign
that they are connected, not in just “random ways,” but at a level beyond this life and
beyond this time in history. She read from a description of these saints lives:

The venerable women Marina and Kyra who practiced estheticism in
Syria in the 5th century lived in one cave for more than 50 years
continually abiding in strict fasting and prayer and died in peace in
about the year 450. So Kyra and Marina were together…….. I liked the
name Marina because it was like Marina and Kyra were kind of tagged
together in history in this story, basically you know as monks or nuns.

These quotes indicate that Kyra sees herself and her daughter as internally
related and part of a larger expanded web of relation that they share. These webs
include their families, their church community, a network of saints, and God all in
intimate relation. In Kyra’s spiritual imaginary of her daughter she is not suffering,
and gets to frolic and play, something she never did here on earth.
Heaven of course! Of course my daughter is in heaven. I mean no one knows what heaven is like, but when I like picture her, I always think of her as being this girl with blonde pigtails, running through a field chasing butterflies and picking flowers. And you know it’s a sunny day. That’s how I picture her just laughing, and being a little girl, just being carefree and having fun. I mean one thing that had bothered me, and I think it was because it was such a beautiful time of year when she was born, well, she was never outside and she never saw the sunlight.

Kyra’s narrative alerted me to the overlap between religious and spiritual beliefs and practices for some informants. In her narrative, the spiritual and religious cannot be easily separated.

**Crisis, Interior Experience, and Spiritual Journeying**

I said oh my gosh, now I’m starting to understand myself.... I started reading more and more and the whole process is always internal, and of course it’s not easy you know. Talk about the dark night of the soul! Well I’ve learned that first hand. But then I started to have insights, and what I also found out is often they would occur when I was in really great agony.

Jim

Particular stories that emerged in the narratives depict death, dying, grief and loss as painful crises on a spiritual journey. Jim goes on in his interview to describe an experience of feeling “pure love” in the midst of agony. Several informants told me of very particular spiritual experiences that included affective resonance with an expansive reality greater than the self. Some of these have been described in Chapter 3 in the section on esoteric experiences. In her description of a nearing death experience, Angela describes a very deeply “spiritual time” as a particularly personal experience that put her in connection with her deceased father and a larger reality that
she was unable to put into words. She was critically ill and given the last rites by a priest, before drifting into an interior experience that resulted in a sense of “peace,” “calmness,” and “serenity” that she can remember to this day.

One of the things I can remember he [the priest] asked is, “Do you feel like you are prepared?” I can remember after answering the question, he was saying some additional prayers, and all of a sudden I closed my eyes, listening to what he was saying and this image, this most beautiful, beautiful warm white light was present. I remember it was like this wing. I think it was like an angel wing and I can remember the texture of this wing. It was so real I could just reach out and touch it. It was really plush and it was layers and layers and layers of feathers and some parts were very white, and some had been around for a while. Not dirty, just a real sense of strength, but it was real thick. I’m not describing it the way I want to. I can’t even put it into words because it was so unbelievable! It was very thick and firm and strong. I think you kind of get the picture. That one was kind of half a heart shape. The other wing right beside it was this oval odd shape, and it was very transparent. It was almost like silk, almost sheer. And I could see right through it, it was so transparent a material.

Then all of a sudden I could remember that real thick, plush wing I remember a certain fluttering and I could actually feel it across my cheek and I could feel the breeze, and at that moment in time, I thought “that’s my dad” and I think in a way it was a depiction of me too and I’m not done yet. It was just a real sense of peace, and I know I just felt it was a very spiritual time for me. It was obviously a lot of time to be quiet and think and pray and sleep, but it was very, very much a very spiritual time. And still to this day, when I’m feeling overwhelmed with the world, I go back and think how blessed I was to have that experience and that the calmness, the serenity that I felt. It’s so easy to get caught up in this world and the busyness and frustration. Now I think each day is a blessing and sure things get crazy, but when I feel overwhelmed I go back to that time. I think that’s what a death experience can be like. Again it’s a solitary experience that, despite family members being around, it’s a personal journey in that you can either accept it or be angry. I feel like it’s a personal journey…what that’s like I can’t put it into words, but the images are very powerful for me. It was very sacred to me. I’ve told my kids but I don’t know if they will ever really really understand how powerful that time was for
me. So I don’t know how to describe it, but for me it’s still a very solitary experience.

Angela’s narrative excerpt calls attention to powerful images and perceptions, symbols and dream-like states that are part of an intensely “real” interior experience. The angel wing and the warm white light become sacred anchors of peace for her during a “spiritual time” on a solitary journey. I talked to many other informants who talked about life and death in terms of a personal spiritual journey. Tweed’s proposal that religion can be used for understanding movements, relations and positions of human beings as they journey through life “crossing (crossing boundaries) and dwelling (making homes)” can be called on to understand this story. Angela’s narrative contains affect, movement, relation, and the trope of travel. She was on the brink of death, but came back. During the crisis of illness she experienced perceptions that she had trouble explaining, but that were obviously very meaningful for her many years after they occurred. Other references to life as journey, and death as birth came from several other informants. Gay, a hospice volunteer said this,

My idea of death is more like the author of “Embraced By The Light.” I really see it as light, and that it’s a journey. And my idea is, I can’t let go of the fact that I will see my mom and dad, and you know, all the people that I expect to see. But I don’t I don’t expect this to be the end of my journey. And in fact, I expect life to continue someway somehow, you know? You chose this journey for some reason, and you’re going to go on, and there’ll be another journey. Yeah, the death is a new beginning.

The references to images are discussed in Susan’s case study, but many other informants spoke of images as part of their spiritual imaginaries. Lorna says this about how she maintained relation to her daughter:
I left Europe ten days after she died. I remember when I got on the airplane to come to the states I had a visualization of taking her and putting her into my heart so I could bring her back with me. Because I was leaving her there you know, and I had to bring her home with me somehow. I just lifted her up into my arms and I sort of placed her into my heart and that was it. And years later I did some therapy and the therapist did this guided visualization with me. I don’t quite remember what happened but I remember she had me create a room for Sara in my heart. I had told her about putting Sara in my heart and so she had me create this room for me to decorate. So yeah, I feel like she is always there. She just sits in my heart and I can sort of bring her out anytime I want.

Lorna used this visualization, as others did, to keep relation close.

Recognizing that biomedicine can only go so far in alleviating suffering with dying and bereaved people, hospice physician Michael Kearney engages the ideas of Carl Jung and ancient Greek medicine for spiritual work in bereavement settings. He pays attention to dreams, symbols, myth and ritual that support spiritual healing, noting that this is an injunction for both patients and those who work with them. In his monograph *A Place of Healing: Working with “Suffering in Living and Dying,* Kearney gives case studies from his work as a hospice physician that illustrate theoretical tenets of Jungian psychology and Aescleopian medicine. Kearney refers to both psychic inner space and outer spaces that promote deeper levels of experience to facilitate peaceful dying and mourning.

This section reviews some of the interior experiences of spiritual crisis that informants relayed in their interviews. These experiences contain esoteric, somatic and affective dimensions. They involve movement and travel across imagined
boundaries between life and death, and involve imagined internal relationship with others who are living or dead.

**Losing Faith and Questioning Beliefs after a Death**

I grew impatient with religious talk. Speak to me of God and I am afraid that you do not understand.

Lewis, paraphrasing C.S. Lewis, after the death of his wife

As I listened to the participants talk about how religion does or does not play a part in their mourning process, a range of ideas about religion and death emerged. For those who had strong religious beliefs, like Kyra, this foundation seemed to help her through the loss. For others, the death of a loved one forced them to consider whether their beliefs were valid and whether or not religious practices made a difference. Celia noted an abrupt pause in her spiritual practices after her husband died. She says, “I stopped praying. I stopped everything.” For some informants, nothing offered solace or consolation, even their previously held strong beliefs and religious practices. For Sharon, whose infant daughter died of congenital birth anomalies, she returned to church reluctantly hoping that she would find comfort, but did not:

I went to church for 6 months every Sunday faithfully with my daughter and husband and every Sunday I resented it. I resented God. I resented church. I was reminded of his abandonment of me and my situation! It was disgusting, despicable, and I can’t believe I did it. And it was just enraged every Sunday for a good 6 months. People acted like because you came back you to church that you were OK.

The following quotes from the infant loss support group contain a wide range of talk about religion and words that either hurt or helped. Lewis told me that God-
talk was not helpful for him. And when others spoke for God, this seemed to be very problematic for informants. The following quote draws attention to this, as well as how the death was experienced as part of a cascade of losses for Diane:

Diane: I told Don [her husband] I don’t think I believe in God anymore. And I don’t know that I believe in heaven. Maybe when you die that’s just it, and there are times when I vacillate between the two. It’s like another gap [meaning another loss for her] because it was such a part of me, a part of us, and now our relationship has changed, our faith has changed, and it feels like it just make you a different person.

I get jealous of people who say that God’s going to get them through it. They can rely on their faith. And I get really pissed at people who say: “oh there’s a whole plan” and “there’s a deeper meaning to this.” I love your father, but those were the first words Don’s father said to me. He said: “God just wanted her more than you did.”

Don: God has been used as a weapon.

Several parents in the infant loss group talked about how they hoped and prayed for miracles. Some, like Kyra, saw the birth of the baby as a miracle even if it was not the miracle they expected. Drew questions because he prayed and his miracle didn’t happen:

But that’s kind of how my feelings have changed spiritually. I don’t know. Our prayers, our miracle didn’t happen. So I don’t know. Do prayers help? I mean they didn’t for me or any of you. And we’re all good people. And that’s why I think I don't know that he [God] can really control what happens. Things happen, and maybe he’s there for you to help you through. But I don’t know.

Nicole says that in retrospect maybe she should have prayed for something different:

I knew from my pregnancy that she was going to be born early. I was really really sick with the blood pressure issues, and I’d been hospitalized a lot and it became a matter of when was this [the birth]
going happen? And so I always prayed for God to protect her. In hindsight I would have prayed that she live. But after talking to the doctors, I know that she didn’t suffer, so my prayers were answered. Not in the way that I expected, but I know that they were answered and she was taken care of. She lived for 10 minutes and she didn’t suffer.

The reality of suffering was like a thick affective fog in most of the support groups. This young mother hopes that her suffering will be rewarded by being with her daughter again someday “in the next life”:

We started talking about you know like how for instance, if you are Catholic, you look at the saints, and they are closer to God than we can ever imagine. They sold everything and became hermits or monks or nuns or whatever just to be closer to God. They didn’t prosper in this life. They suffered in this life and built up their reward someplace else you know. They prospered in the next life. And that’s what I’ve been clinging to lately. Like yeah, go ahead beat me up, cause then I’m going see her, right? I’m going to make it there with her right?

These narrative excerpts reveal that not all religious talk or practices are helpful during mourning. Some religious talk was experienced by the bereaved person as glossing the reality of suffering with platitudes that ignored the intensity of their feelings or denied the strength of relationship to the deceased. These quotes also show how death can cause the mourner to question previously held beliefs and doubt the efficacy of religious practices.

Spiritual discourse in hospice and bereavement may be a way to create distance from certain forms of religious dogma or religious talk that hurts. British sociologist Tony Walter suggests as much in his writing about meanings of the spiritual in contemporary palliative care. He says that “spirituality is a discourse used at the present time in the English speaking world by those who wish to move beyond and
distance themselves from institutional religion” (2002, p. 134). This may be true, when practitioners attempt to distance themselves from what Orsi calls “bad religion.” But nevertheless, when confronting suffering during mourning, it seems that some mourners intensely question their particular set of religious beliefs and practices. And others find comfort and solace in their religious beliefs and practices. End-of-life care may thus require careful attention to the particular interface between the mourner and their particular beliefs and practices, whether religious or not. In the next chapter, I turn to describing the wide range of spiritual imaginaries of death as narrated by these informants.

**Conclusions**

This chapter briefly explored selected meanings of spirituality from hospice and palliative care literature, the ethnographic interviews, and fieldwork. I supplemented these meanings with critical ideas about spirituality from contemporary religious studies literature. The mourner, as spiritual being, is described as a being in internal, holistic, or holographic relation—a being in deep connection with the inner self and internal connection with others living or dead. The death of a beloved other provides a portal to realization of holographic relation and can open the mourner to transformed relationships with others living or dead.

A vast amount of hospice and palliative care literature points to spirituality as a concept that is a placeholder for existential questions and human experiences related to meaning, value, and relationship. Thus, in some ways, the medical-spiritual discourse
of hospice and palliative care works to resist scientific reductionism, atomism, positivism in theorizing human beings by acknowledging affect, beliefs, practices and relationships. Yet ironically, experts within the medical community who seek to understand the human being at the end-of-life and improve the quality of care, overwhelmingly embrace quantitative scientific methods to study their “object.” Spirituality and compassion are reduced to objects of study, defined, given sure boundaries, thus rendering their conceptual status static and devitalized in end-of-life settings. I suggest that what is needed more than scientific rigor surrounding conceptual clarity of spirituality, is an ability to enter into internal relation with those in end-of-life settings. The cultivation of deep listening skills, compassionate presence, openheartedness, receptivity and responsiveness in end-of-life care is addressed in the conclusion.

As fraught as the literature on spirituality in end-of-life care seems, I see the burgeoning use of contemporary medical-spiritual discourse as an important contribution toward re-thinking, re-imagining, and re-contextualizing the human being in overly technological and scientific medical settings. The literature that addresses spirituality in end-of-life care seems to call attention to that which has been all but forgotten in biomedical technological settings that treat the physical body without attention to the humanity of the patient. If an assumption is made that all people possess a universal core worthy of respect, then attention and compassion in providing health care to all might be promoted regardless of differences in race, class, gender, and religion.
The study of spirituality in end-of-life care could be enriched by contemporary scholarship in the study of religion. Bynum’s attention to affective spirituality and religious eschatologies describe the human as a dynamic feeling, hoping, and seeking being in historical context. Tweed’s understanding of religion as confluences of cultural flows emphasizes the blending of religious or spiritual beliefs and practices with other kinds of cultural beliefs and practices—such as the confluence of medicine and religion in hospice care. Tweed’s attention to crossing and dwelling, alleviating suffering and intensifying joy in relation, is what the best holistic end-of-life care could do, making the milieu of dying a liminal dwelling place between life and the unknown. Orsi’s suggestion that relation with a whole realm of significant and sacred others can transform suffering for the mourner is a reminder to keep the religious or spiritual imaginary life of the mourner in focus at the end of life. Kasulis’s suggestion that spirituality is “felt” as an inner resonance, calls attention to the dynamic affective inner/outer movement that is described in these spiritual imaginaries. In sum, contemporary religious studies scholarship adds an affective and relational dynamism to the study of spirituality that is sorely lacking in hospice and palliative spiritual care literature. It acknowledges relational transformations evoked by encounters with death that are irreducible and indefinable.

This chapter suggests that instead of petrifying the concept of spirituality and medicalizing spiritual care, the emphasis for alleviating suffering in end-of-life care might instead be given to cultivating receptivity and open-heartedness in the caregiver. In other words, the ability to enter into an internal or intimacy-based relationship with
the care-receiver is, in my estimation, more important than agreement on any specific construct of spirituality. The agile caregiver is sensitive to particular occasions and contingencies that arise in the clinical setting. Through listening in internal relation, she is able to begin to assess where the care-receiver is in relation to existential questions, their comfort or pain level, their unfinished business in the realm of relationships, and whether or not they are at peace with what is happening. This stance requires great inner awareness on a visceral level as Kearney and Halifax suggest in their writings on healing and compassion in end-of-life care. The cultivation of self awareness, discipline, open-heartedness, compassion and wisdom together are key qualities needed for working with the dying person and their family. Chapter 6 will address the feminist ethics of care in hospice and bereavement settings and pedagogical strategies for cultivating these qualities in caregivers.
CHAPTER 5

SPIRITUAL IMAGINARIES OF DEATH

Spiritual imaginaries are what I call narratives that describe what informants say they believe, hope, dream, fear or imagine happens at the time of death and beyond. Spiritual imaginaries reflect the informants positioning of the deceased in time and space, as well as their relation to the deceased. This chapter reports how informants narrated their beliefs and imaginings about death. Sometimes these stories were in response to the question: Have your beliefs or imaginings about death changed since the death of your loved one? As I suggest in previous chapters, spiritual imaginaries of death are entwined with affective dynamics and reflect relational orientations between the mourner and the deceased. The wide range of spiritual imaginaries presented here contain beliefs woven with desire, longing, wishing, and hoping. They contain temporal frames that locate the deceased in the past, present, or future, and in spaces ranging from heaven to symbolic integration inside the very being of the mourner. Spiritual imaginaries describe locations of the deceased in time and space, and thus give clues to how the mourner constructs death and relation.

This chapter begins with the overall themes of the spiritual imaginaries of death. Each informant narrates relation to the deceased in a unique fashion, yet
certain themes emerge. The most prevalent theme is belief in loving relation—whether narrated as past, present, or future. A section is devoted to this theme as the crux of the spiritual imaginaries. Other themes are arranged into categories that include uncertainty about death and relation, no belief in an afterlife, certainty of an afterlife, and blending beliefs of a soul and reincarnation.35

The next section presents a brief discussion of healing as a process that involves ongoing relational transformations. Jim’s story is presented within this section. His narration of holographic relation with the deceased, others, and the world was the most rare spiritual imaginary and serves as the sole case study for this perspective. Finally, there is a section that proposes mourning as a portal to realizing internal or holographic relation.

**Belief in Loving Relation**

God is not necessary in fact, but the need to believe, is to my understanding, both a pre-religious and pre-political anthropological necessity.

Julia Kristeva (2009)

The spiritual imaginaries collected in this study support Kristeva’s notion that the need to believe is a human necessity. Virtually all informants believe in *something*, yet very few mention a belief in God in their death imaginaries. Several bereavement counselors noted this dynamic. Hannah says, “I think grief is spiritual because we are spiritual. I don’t think you can separate it. But I don’t think it is related to some other-worldly being.” Using the metaphor of fog as what separates life
from death, Louise, a bereavement counselor comments, “Well I think people can be atheists and deeply spiritual, and by that I mean, they would fit the criteria of no interest in a higher power of any sort, but they have a sense of connection that goes through the fog.” During a discussion about whether or not God can intervene in the suffering after the loss of a child, Connie, one of the mothers in the infant loss support group comments, “I have to believe. I mean if it’s not belief in a God, something keeping me sane.”

This section explores the idea that even though death imaginaries are framed very speculatively, the certainty of love and relation is a real and pervasive truth for informants in this study. This finding supports the crux of my argument—the mourner’s realization of loving relation to others living and dead constitutes the spiritual human being as a being in internal relation. The following interview excerpts all describe a belief in something, and though it varies from person to person, the belief revolves around the reality of loving relation with the deceased or others.

Cindy refuses to “make up a story” about what death is, but nevertheless believes that her husband’s voice “is still out there”:

I don’t know, and I don’t care that I don’t know because I never can. Nobody ever can. It [death] is metaphysical. It’s something impossible to know, so I’m not going try to figure it out. And I’m not going make some story up which I think Christianity has done. It’s something that’s amorphous. It has no body. It has no shape. But that that love I have doesn’t die because Alan’s dead. And there’s definitely a void, but the void is I don't have his body. I won’t hear his real voice again but his voice is still out there.
Tara believes in the continuation of relation to significant others in her life. She notes that relationships are transformed at death, but “do not end.” She says, “My parents are not here, close friends who have died are not here to talk with anymore, but they’re still alive in my heart. The relationship that I have with them is different, ok? So there’s a kind of continuation, but it’s wrapped in impermanence, change, flux, and flow.” The reality of transformed, but continued relation with the deceased is the most persistent theme in these imaginaries, though as I suggest later, there is much uncertainty about the possible location of the deceased.

For psychoanalyst Kristeva, the imperative to believe follows the fact that a person has been loved, and therefore, believes. According to Kristeva, because these informants know or have known love, they believe in the persistence of love. The narratives reflect belief in a range of things from the reality of “grief that connects” them to the deceased, to a sense of justice or “happiness” in an afterlife, to the idea that love persists after death in a “loving universe.” Their spiritual imaginaries blossom out of their love, hope and trust that they are connected. For Lewis, who says “there is nothing more than now,” and knows he will never see his wife again, he still believes that grief connects him to her. He says, “My grief that Estelle is gone, and my desire to hold on to grief is part of that package because I know that’s all there is. I believe that is all there is. I don’t know it, I just believe it.”

Cindy says she believes in loving relationships in a loving universe:

I think that that relationship has to do with love. I make separations between matters of faith, and matters of knowledge. I have no evidence of these things but I’ll believe them anyways so keep them over in the
faith pile. But I don’t think of it as a religious faith. I don’t have an idea of an anthropomorphic God. I don’t have that kind of Christian God saves you and God loves you thing. I think that God is the universe, and the universe is loving.

Nan believes she had the love of her life with Jill and will be with her again. Like some other informants, she doesn’t fear dying now. She says, “I feel like its ok to die now, you know whenever, it’s fine. I have had the love of my life, and now I’m just going on to hopefully love my family and friends until I can get to be with Jill again.”

Louise believes that the relational bond between she and her deceased father is still very real. For her, death is a “spiritual-emotional-relational” reality:

I mean I grew up on the east coast and we had fog a lot of the time. I knew just because I couldn’t see something it didn’t mean it wasn’t there. I really see the two realities [life and death] as like different sides of the same coin. The sad part about death is not having the channels, the comfortable channels of relationship when someone dies. But the presence, from my perspective, is still there and so I experience that bonding to be very real. I don’t have any physical description of it at all. It’s much more a spiritual emotional relational kind of reality for me.

Katherine trusts that her children who died were with her after their death:

I could feel their [babies who had died] presence sometimes, not even not always feel it, but I just trusted it. You know I didn’t have to have a lot of confirmation. I just trusted somehow that it was there. Sometimes I did have the sense of their presence but mostly not. Mostly just like my heart would be ok.

Lee believes in love despite her traumatic experiences on 9-11. After the story of her harrowing exit from the World Trade Center buildings, she told me, “I believe in love in any capacity in human beings. One of the hardest things is that you have to
be strong and vulnerable synonymously. And I love that. And well, I think we are all wounded. I think being wounded is healthy.”

Sally believes that her twin infants are together with other members of her family who have died. She says, “I do believe in some kind of other life. Whether it’s a heaven that looks like something, I don’t know. I don’t know the answer to that, but I do believe that they [her twins and mother, brother who have died] are together.”

Many narratives from parents like Kyra whose children died, believe that they will see their child again, and told me they will be “very disappointed” if that does not happen.

Stacy, a grief group facilitator, says she had to “come to grips” with what she believed during her near death from cancer:

We constantly say grief effects us physically, emotionally, mentally and spiritually. And that spiritual part of it for everybody is asking why did this happen? How did this happen? Why him? Why her? Why me? For some people the question is answered so quickly that they don’t even realize they’re asking it. Some people come from a religious background and they have definite ideas. Somebody like me who doesn’t take a religious side, I had come to grips with what I believed in.

Marla, whose college roommate died in a car accident, believes in “spirits” and that some part of the person “lives on”:

I didn’t just didn’t really think about it [death, until after her friend died]. I don’t believe in heaven and hell. But I believe in some form of ... not really not even an afterlife, but I believe in you know sprits and stuff like that. So I always thought that some part of the person lived on. I didn’t really think about how or in what ways. But I’m superstititious you know! I watch the ghost shows, you know what I mean? I believe it all!
Susan, whose case study is presented in Chapter 3, at one point in the interview says she believes her son is living again in nature, that he is “everywhere”:

I’m a Jewish humanist so spiritually I’m a very spiritual person, at least I consider myself to be, so it’s important to me. But it’s a very humanistic kind of spiritualism, and so you know, I believe that my son is compost. But that means he’s living again in nature, in other living things, and that’s very meaningful to me and important for my own self. I need to know that. So he’s not here, he’s not there, but he’s everywhere you know.

Brenna alludes to holographic relation with her deceased husband, God, and the universe, saying she believes her husband joined “everyone and everything in the universe. And that’s what I believe, so I don’t believe he’s in any one place. That’s why it’s impossible for me to feel disconnected from him. I think that’s why it’s impossible for me to feel disconnected from God.”

The last two imaginaries, along with others, seem to be attempts to articulate a holographic metaphysics or relation goes beyond the dyad of the mourner and deceased. These quotes construct the deceased as part of a larger whole, part of the earth and part of the universe. Jim’s statement that his wife is in his heart, “but if you understand what I mean by heart, it’s huge,” gives voice to a holographic relation with the deceased, others, and the world. Lewis said that “virtually everything reminds me of Estelle,” alluding to relation that continues in a global manner.

The narrative excerpts in this section call attention to how the living persistently believe in continued relation whether or not they believe in a deity or follow a prescribed religious path. Generally, the belief in love and relation continues
after the death of the other in a range of imaginaries. The following sections organize
spiritual imaginary themes into more distinct categories.

**Unsure and Can’t Know**

Well I don’t know. To leave the body I think it [dying] is truly a
surrender. I mean you shed whatever this is [pointing to her body], and
I wish I knew more about the physics, the layers of energy and all and
how it’s affected, but I don’t know physics. I mean there may be
reincarnation. I don’t know. You know if there’s reincarnation I
could’ve cycled back through already. I don’t know what’s going on. I
don’t know if people are in a better place. I don’t know if we stay in
separate entities. I don’t know if we merge into something or what it is.

Hannah, grief counselor

An equally pervasive theme in the wide range of spiritual imaginaries is that
informants speak very hesitantly, admitting that they cannot really know what follows
dying. Their imaginaries are framed very tentatively. They sometimes switch their
thoughts mid-sentence, at one moment sure, in the next breath, unsure. “I don’t know”
is said repeatedly, almost as a refrain. Virtually all death imaginaries are framed as
speculations. They are fluid constructions. Informants seemed to be creating them as
we spoke. And though most informants admit they do not know what death holds,
they have definite wishes, desires, hopes, and dreams about what happens. The
following excerpt is from Dottie, one informant of many that voices uncertainty tinged
with hope:

I sort of believe in the hereafter. I hope there’s a hereafter. Jay [her
husband] said to me one time: ‘Do you think there’s a hereafter?
Certainly I do, because it’s the only thing at this time that’s keeping me
from putting a bullet through my head.’ So I think there’s something. I
don’t know what it is, nobody knows what it is, but I think so.
Most informants admit that they cannot know what death holds, and their fluctuating ideas reflect this uncertainty. For Cindy, whose husband died suddenly of a heart attack, the death leads to existential questions about the nature of life. She says that as she sat with her husband in the emergency room she spent a lot of time thinking: “What is this? I was touching his arm and holding his hand that still felt warm. I felt like he was still holding my hand. I kept asking, What is death? What made the heart stop? What made the breath stop? And it seemed to me that there was something that makes that heart pump, and the breath has to do with spirit, and it really felt to me that his spirit was still there.” Cindy is one of many informants who are uncertain about death, but simultaneously propose a “spirit” or “essence” of the human being.

Some informants like Jim and Gay state that no matter what they imagine, what is most important is “doing the best we can” in the present. Jim says:

We are in this physical form now, and whatever the spiritual energy is the rest of the time ... maybe we come in and out of these forms or maybe we go into some other forms. I don’t know. Is there memory in that? I don’t know. And the point is this: Does it matter? What matters is doing the best we can with what we’ve got here and now.

Gay echoes a focus on present centered action, rather than belief. She says, “I don’t think God is too concerned about what we believe, he is more concerned with how we have lived our life.” Larry mentions that he is “open” to ideas about what death is, though nothing can be proven. He says, “I’ve heard all sort of theories, and I have friends of almost every faith from atheism to conservative Christian to Judaism.
I listen to them. I certainly respect their beliefs. And I am not so convinced of my own position that I’m not willing to concede that one or more of them may be correct, but at this stage, none of us is going to be able to prove it.” In general, most informants did not seemed convinced of the certainty of their beliefs about death, yet belief in continued loving relation prevailed in these narratives.

“Nothing More than Now” - Death as Limit

Another theme is a belief in death as either transition or limit. There are only five individuals who were adamant about their belief that death is a final limit with no continuation of any kind. These individuals are such a minority that they stand out from the rest. The following interview excerpts are from those who speculate that “nothing” follows this life. Susan and Alice are counted in the group of informants who voice multiple ways they imagine their loved one since death, but oscillate toward belief in death as a limit. In these three excerpts that follow, informants speak from their rational mind. Lewis actually says it’s not “rational” to count on reunification with his wife:

I have a certainty that there is no more to our existence than this frame in which we find ourselves, this mortal coil. My conviction has been increased, it has been strengthened [since his wife’s death] that there is nothing more than now. To me it’s not a comforting thought, it’s so bizarre, it’s not reasonable or rational to live your life alone without a wife or whomever counting on some reunification in some other realm. I don’t mean to say it’s a waste of time to look that way, but it doesn’t appeal to me. I wouldn’t want to do that. That would be like denying that Estelle was gone because she’s in another room and soon you will be there too—you’ll be together again. It doesn’t seem to honor the loss of the person.
In this imaginary, Lewis cannot conceive that his wife is spatially in “some other realm” or that he will see her again. His relation to her is lived through memories and recounted in his daily journal where he reviews their life together, numbering each day since her death. He draws, posts genealogy findings, copies old photographs, and speculates about grief and loss in his journals. He believes that the temporal now, without his wife is the only way to approach “this mortal coil,” a phrase from Shakespeare’s famous soliloquy that contemplates the meaning of life, death, and the tumultuous world of mortals. Now is the time, here is the place, and she is not here now. Yet, this narration of external relation is complicated by the notion that memory brings relation into the present moment, suffusing the mourner with sensory and perceptual cues that can bring the deceased close again. So, even though these informants narrate a kind of external relation to the deceased, memory can call relation into present experience.

Larry “can’t get his thoughts around” the concept of an afterlife:

You know for those individuals who believe it, I think it’s wonderful. But for me, I think it just too egotistical to think that there is much in the way of a afterlife, so that’s really not a part of my personal philosophy or theology. Well I think [at death] your physical body shuts down. To the extent that there is afterlife, I think it is in the people who have had contact with you during your lifetime, and to the extent that they have either good or bad memories of you. Yeah, that perhaps is something of an afterlife. But I just can’t really get my thoughts around the concept of an afterlife as in heaven or hell or anything similar to that.

For Larry, his “personal philosophy” does not include belief in an afterlife. However he sees memories of the deceased as “something of an afterlife.” In this kind
of afterlife, the deceased lives on in the memory of those who knew them, making it a kind of internal relation.

Nate’s “mind” doesn’t work toward perception of an afterlife:

I have no perception of afterlife. No knocks on people that do! I mean, I just don’t. And so that’s my view. She certainly is not gone from my mind. It’s not that she’s in God’s loving arms and I will, when I die, I will not meet her. That is just not how my mind works. I look at death as that is the end of that life. You know there can be all sorts of memories of it. There can be writing of it. I have any number of pictures. I have some travel diaries that she kept from our travels that I like to read through. And she kept notebooks on some things of interest to her. I keep all of those, so that’s where she is. But I have absolutely no concept of an afterlife in any sense that we’ll meet again someday. Only up here [pointing to his head], fond memories remain.

Nate views death as the end of a life. He has no “perception” or “concept” of another time and place where he will meet his deceased wife. Yet, for Nate, his wife is present now through his reading of her journals and diaries. His relation to her consists of “fond memories” in his mind.

All three of these men narrate spiritual imaginaries that represent a swing to external relation, since the deceased person is rationally described as non-existent, with no hope of reunion. Yet, all showed sorrowful emotion and cried in the interview, perhaps validating internal relation to their deceased wives. They had no hope of future reunion with the deceased, but a present-centered internal relation was engaged through memories for these informants. Stacy, facilitator of the widow/widower support group, states that despite no belief in an afterlife, she considers that mourners still have a spiritual relationship with the deceased. She says, “Even if your spiritual beliefs are that there is no afterlife, that there is nothing—you
know, you die and that’s it—there is still a spiritual relationship. There’s an ongoing relationship because you can think back, and say: ‘What would she have said in this situation? ‘What would he do?’ ‘What would he tell me?’ So even if that person can’t give you anything new, you still have a spiritual relationship.”

“A Happy Place” - Death as Certain Transition

Most of the informants who narrate certainty about their belief in an afterlife describe hopes for reunion with their loved ones. They describe places of peace, love, happiness, justice and beauty. Here are a few examples of those who were certain that something continues after life. Wade is one of the few informants who combines a belief in an afterlife with belief in God:

Well I certainly have a strong belief in Jesus Christ and the hereafter. I just look at it as a place where Dan will be healthy [tearfully] and he’ll be out of that cotton-picking wheel chair. I would give anything to be able to help him out of that chair! Carolyn will be there, well again, not with all the problems that she had for the last 5 years of her life. I look at it certainly as a very happy place be reunited with my folks, and my two sisters who have predeceased me. I don’t know what it will look like particularly, other than I think it will be a happy place, a chance to be reunited with family and friends.

In this imaginary, Wade sees a hoped-for future place and time of reunion with his deceased relatives. His relationship with his wife is narrated in the past and future. But he also told me that when he volunteers at hospice, he talks to her in the present, especially when he is in the hospice room where she died.

Nan posits a place of learning that follows death where she “will be glad” that she has no physical body. She says, “I think death is just going on to another place.
You’re not going to have a physical body, and you are surrounded by love and kindness, and it’s not difficult. I mean you just learn, you go on, and time is different. And you wait for your loved ones. You revel in the ones that are up there with you or down there—wherever. Maybe they’re in the next room.” Nan imagines that time and space are “different” in this “other place” where you will see your loved ones. The architecture of her afterlife settles on a kind of parallel place—maybe the deceased are in “the next room” rather than in a higher or lower position.

Like Nan’s belief in no physical body, some informants spoke about death as a release from the suffering that was encountered in life. In Lexie’s narrative, she speculates that Gabe her partner has moved on from the suffering he endured on earth as someone addicted to alcohol. In her imaginary, he knows more than he did as a mortal being and he watches out for her. She speaks of him in the present tense, and talks to him often, intimating an internal relation in the present, though obviously looking forward to a different kind of relation after her own death.

I see pain and suffering in terrible way, but I see death like almost a birth or a graduation you know. I feel like he knows all the truths now. Even though he really trusted me and loved me when he was here, he knows even more now, and I think he will in any way he can kind of watch out for me a little bit. And if he’s not at the gate or whatever when I arrive I will be very angry! You better greet me there! I think there are good and beautiful things that we can’t even imagine, that’s what I hope. And I tend to believe in reincarnation but I’m not sure, I’m not sure.

Lexie thinks there are “beautiful things” that we cannot imagine. The trope of birth is juxtaposed with death. She is one of the many informants who speculate about reincarnation.
Like Lexie, most informants who voice a belief in reunion in some transcendent future seem to be highly invested in seeing their loved ones again, and for some, their fear of death is transformed into hope. Chloe, whose 4-month-old son died of a brain tumor, said:

This really helped me to connect to some kind of spirituality of the next life. I’m just not afraid of death anymore. I used to be absolutely terrified of death. When Peter was super sick every night, I’d go to sleep holding his hand thinking, “Am I going to wake up and he’s going be gone?” But now I see that death is an opportunity to be reunited with my son. It’s kind of like the nicest thing you know, I’m going see my son again.

Sam and Nan actually contemplate what their loved ones might be doing wherever they are now. Nan mentioned that she talks to Jill saying not to worry about her, and “I know you have things to do.” Sam speculates on what his father might be experiencing or thinking. This rare perspective seems to be a kind of imaginal empathy with the deceased and involves dialogical thinking. Sam is a blind adult who lived with his father and was very close to him. Our interview was four months after his father’s death:

A bad day would be the feelings of wanting to be with him, but you know you can’t be. Or just the certain feelings of sadness or emptiness and loneliness, and then at the same time wondering: Does that person feel the same as I do? Do they feel more sad than I do? How are they feeling? And you know trying to grasp at their feelings. I think considering how strong a man he is, I am sure he is doing quite well. Wondering how he feels, I would imagine his feelings are just as strong there – wherever he is spiritually – as you know here on earth.

Stacy, a bereavement counselor who almost died during cancer treatment many years ago, combines ideas about a life review, meeting others on the other side, levels
of spirits, time, and reincarnation in her spiritual imaginary. She thinks that if you are isolated on earth, this is true on the “other side” too:

I believe in a very complicated system of contracts and reincarnation. I believe in the light. I believe very, very, very strongly that no person dies alone. They may be alone on this side, but they’re not alone on the other side. I believe that whomever they need to be there with them—whether it’s someone they’ve known, or some sort of teacher—is there. And I think that on that other side, of course time is gone. So that’s very different. I do believe in a life review. I would be surprised if there’s not. And I think that’s when we go “Oh, now I get it!” I think they get to step back. I don’t think they have ultimate knowledge. I don’t think they’re suddenly privy to everything.

Stacy’s spiritual imaginary includes the idea that life and death are a series of ongoing transitions from “this side” to the “other side.” Time is “gone” and the space is populated with others who are there to help the person make the crossing. And though knowledge is not “ultimate,” there is understanding that surpasses our present abilities. She goes on to say:

I think there are probably different levels of spirits, enlightenment, if you will. Not a dumber/smarter, but just more or less experience. Yeah, an openness. I think that on the physical plane some people have more awareness that we are all connected, whereas some people have awareness that they’re isolated very much inside their bodies, and I think that’s true on the other side as well.

Informants like Kyra, Wade, Nan, and Chloe and others are sure of reunion, and these imaginaries of death are tinged with hope and longing. They are emotionally invested in the belief that an element of the human being continues in some other time and space beyond this life. Some, like Stacy, Nan, and Katherine, believe there is learning involved in the journey within and between lives. The next section presents a few of the narratives that blend a “soul’s” journey with reincarnation.
Blending East-West Beliefs

At least half of the informants use the words “soul,” “center,” “core,” “energy” or inner “essence” to refer to a central aspect of the human being. The theme of reincarnation was less prevalent than reference to a soul, but it came up in at least six interviews. These informants mix beliefs about an inner essence or soul with the possibility of reincarnation. They relay imaginaries that involve an ongoing journey of a self through time and space in relation with others. Though reincarnation is an appealing idea to these informants, no one seems to understand how it works. The following excerpts give examples from Katherine and Lorna, two informants who combine belief in a soul and reincarnation.

Katherine, who lost many family members to death, including her first two children, is also a yoga teacher. She says:

Who am I? I’m just this ... I was going say being-ness, a kind of entity, but entity is maybe even more form than I mean, but some essence that has things to learn. I don’t know. I don’t think the rapture, like I’m going leave my clothes and shoes behind. I think that it has nothing to do with my body. But I mean I’ve had many experiences in meditation and in asana where you know I’m in touch with a ... what seems to be a universal energy, a sense of just life. You know I feel like I’m a part of that, maybe more easily a part of that, if I don’t I have a body, but I don’t know. I don’t know.

In this imaginary, Katherine identifies an “essence” that has something to learn in relation to something greater than a separate self. She says she is part of a “universal energy” and doubts there is a body in death. Katherine says, “the yoga idea of reincarnation and the Buddhist idea of many lifetimes, again, I have no idea if this is
true, but it makes sense to me intellectually. And it agrees with my experience up to a point. I like the open-heartedness of it and the possibilities.”

Like Katherine, Lorna combines ideas about a soul and reincarnation in her spiritual imaginary. She says she believes “the soul is separate from the body” and wonders if the souls of the deceased helps the living through grief:

I do have the sense that we don’t just die when we die. The body certainly does, but it feels like to me likes there’s a spirit that persists, and I don’t know in what form or in what way, or for how long, or does this hover and watch us and get us through grief? I don’t know. I don’t know what happens. But it does feel like something persists.

Lorna’s narrative contains speculation about reincarnation and the confusion about how it might work. The confusion voiced in the following excerpt from Lorna is present in several interviews:

I really had a sense of my dad being around for a number of years then suddenly I didn’t. There was a much more powerful sense that they were really there at a certain point, and then that maybe they entered another body, so they weren’t so available. I’m really not sure of course. I hope that their souls are there waiting for me! It is the thing I would love most, to be able to be with them again. But I sort of think it is a very Western thing to think about the soul. I mean even if there are souls still out there, they are not going to talk like I’m talking now. They are going to be the souls of a million years. Their souls are a million years old kind of thing. So, I feel like there is something other, but I don’t know what it is.

Some informants read books about Eastern religion and Eastern philosophical ideas about death. Hannah incorporated these concepts into her practice as a grief counselor:

I like the whole take on death from The Tibetan Book of the Dead. The person that is grieving goes into the Bardo, the land of the dead too, so they’re dead. Everything they had interest in they no longer do, they
can’t fix it, they don’t like it, they keep trying and nothing works. Memory is not good, focusing is not good, they’re just kind of zombies. So I think they go into the land of dead in a certain way. They go through a period of time, liminal time, and that’s soul time, outside of time and space. So that would be something you could call spiritual.

In summary, the narrative themes discussed in this section reveal diverse spiritual imaginaries. Most informants admit that they cannot know what death holds and their fluctuating ideas reflected this uncertainty. Some informants live as if relation is still intact. For these informants, the affective resonance between the living person and the deceased is lived in the present. For others, the relationship is lived through memories. For others, relation is hoped for in a transcendent future. Virtually all imaginaries affirm belief in loving relation that continues despite the death, and this belief is not dependent on a deity or adherence to a religious tradition.

**On Healing: “Getting Conscious” of Holographic Relation**

The mourner comes to feel the inner presence of the loved one, no longer an idealized hero or a maligned villain, but a presence with human dimensions. Lost irreversibly in objective time, the person is present in a new form within one’s mind and heart, tenderly present in inner time without the pain and bitterness of death. And once the loved one has been accepted in this way, he or she can never again be forcefully removed. (Cantor, cited in Hockey, Katz, & Small, 2001, p. 32)

This section briefly discusses the idea that healing in spaces of grief and mourning involves realization of internal relation to others living or dead. The bulk of these narratives suggest that the diminished self of broken relation that feels fragmented, lonely, and partially present can be transformed during grief and
mournings. Healing loss involves the workings of a mindful heart that eventually realizes ongoing internal relation with the deceased or holographic relation through the deceased. Healing can be conceived as an affective resonance, an ongoing realization of internal relation within deepest levels of the self and between the self, others, and the world. Susan made reference to the ongoing nature of healing as well as the movement outside herself when she told me, “I want to be more at peace. I just don’t think I’m there yet, though it is through sharing my artwork with others that I’ve healed.”

The word “healing” is a complex and contested term. Its meanings are “rarely well-defined in contemporary American usage” according to Linda Barnes and Susan Spered, who discuss the construct at length in their edited book, Religion and Healing in America. Stacy, a grief group facilitator attests to the multiple meanings possible for the word healing in bereavement settings, preferring to say transformation rather than healing, “I would imagine that a lot of people would not want to use the word healing. I have always kind of bristled at that word. For some people it’s absolutely ok. Other people are afraid that if they say they’ve healed that it means that they’re better off. The best you can say is there is some transformation going on.” Phillipa, a social worker who leads the infant loss support group, says, “Do they heal? I think the bitter goes away.” Lewis completely rejected the word healing, saying he “does not want to heal” if healing means he would not remember his wife, and he could not feel the grief that comprises a bittersweet reminder of their relationship. Though healing has vague connotations, and its meanings should be excavated for each person who uses it, in this
section I explore some meanings about healing and mourning based on the literature and interviews.

Kavaler-Adler suggests that healing is always an ongoing process that involves the spiritual heart of a person. She sees the human capacity for love as “having a spiritual form of energy experienced through yearnings for another” (p. 7). In mourning, keeping the heart open to all that enters—including rage, doubt, guilt, and terror, as well as feelings of delight and love—is a process that involves the pain of loss and regret. These dark emotions can be a means to crack the heart open, potentially uncovering joy in relatedness and a release of affective energies for the mourner. For Kavaler-Adler, healing grief involves continual opening to further wounding and vulnerability. It requires the ability to feel the affective energies that come from wounds connected to relationship with others. For Hannah, a grief counselor, healing means “getting conscious” which requires holding the tension of polarities:

Healing? That’s hard to explain. I don’t think healing necessarily means somebody is going to get better. Maybe it’s getting conscious; it’s an attitude shift, connecting with your core probably. Trusting that there’s a process going on, not that this is an end result, and I’ve got to get to a certain place in order to be right. And I also think grief goes into every other developmental aspect of a person’s life. You cannot separate them out. So I think as a Jungian. We get conscious by opposites, and holding the polarity there. So it can’t be all good, it can’t be all happy and blissful, you have to have all sides in order to get conscious.

In the following quote, Lorna affirms that healing happens, even for those in most difficult circumstances following the 9-11 tragedy. Lorna volunteered as a grief
group facilitator for widows who lost husbands on that day. She believes in a human “need” to heal though she cannot say how it happens:

I believe in healing because those women healed! I mean they were this amazing group of women. We began the group 5 weeks after 9-11. I mean that first week was the most unbelievably intensely painful, you know, numbed. I mean there were women pregnant with babies, there was a woman that had a 2-month-old, there was a woman with a 6 week old. They brought their babies to the first meeting breast feeding you know, a couple weeks later one gave birth. You know it was just unbelievable. One woman had lost her husband and her bother-in-law, so the two bothers had died you know. So these women have somehow come through the trauma, their internal vision of what had happened to their husbands. You know their imaginings. They were able to move on somehow years later. They got through it. And that 9-11 group just spoke to me about the power of healing, the ability, the need for us to somehow heal, and that we do it. I don’t know how we do it, but I know that we do it.

Part of my fieldwork for this study was spent observing what I call emerging ritual for grief and mourning. Though it is beyond the scope of this dissertation, the ritual practices I observed were ways to re-create internal relation between the living and the dead. Emerging ritual in hospice and bereavement spaces provides various communal practices using art, quilting, memorial jewelry, music, death photography, electronic media, yoga, camps, and support groups. These practices are used to symbolically repair broken relation between the living and the dead. Some informants like Jim tried many different ways to heal after the loss. The following case study presents excerpts from Jim’s story, the narrative about his continual spiritual quest after his wife died.
Jim’s Story

One of the most vivid interviews that I did was the one with Jim, who describes his “spiritual journey” as a transformative one that includes the process of mourning his wife’s death. He tried remarriage, yoga, psychotherapy, reiki, and meditation among other things to deal with the changes in his life after his wife died.

When I ask how he thinks about his wife now, he answers:

The easy part is to say she is in my heart and that’s the truth. But I mean, I understand that my heart, like everyone’s heart, if they recognize it, is everything. It’s huge. Our parents are in us, our ancestors are in us. Everyone we love is in us. I’ve come to understand that in much more universal way.

Jim’s words refer to realization of a deep internal or holographic relation to his wife. He describes conscious realization of an inner resonance with others and the world, though said that this realization was born of great suffering. At one point on his journey, after “reading more and more” he realizes “Oh my gosh, I’m starting to understand myself. The whole process is always internal, and of course it’s not easy. Talk about the dark night of the soul! I’ve learned that first hand. But then I started to have insights, and what I found is they would often occur when I was in really great agony.”

Jim also told me about a “satori” experience as he sat in a coffee shop one day with his friend:

I experienced absolute love, absolute love. I knew it was going on. I could hear the cars on the streets and other things, but I was right there just feeling absolute love. And I remember my stomach just started just vibrating. But what was happening, what was going on is that I was feeling this absolute joy! I was completely aware of the other people in
the room, and coming from here from my stomach and solar plexus area, was an ironic feeling of laughter. And the irony was I said: ‘This has been here all this time. This love, this absolute love we’re made of, what we’re created of and that changed everything. Once you experience that love, I don’t believe, I know.

Jim’s realization that we are “made of love” was a pivotal point on his “spiritual journey.” He tells me about another experience, one of feeling union with the world as he hiked in a park:

Yeah, we’re all part of the same thing. It’s unity. It’s oneness. I felt this for the first time a year ago when I was walking in Slate Ridge. It was early May and it was just a green undercover that was growing. I was just walking on this trail like I normally did and I walk fairly slowly because there’s so much to see, to feel, to hear, and everything else. It’s marvelous, when I was just told to look to the right. And I looked to the right and there were all these trees, and there was no difference between them and me. No difference at all! And I remember thinking that now I understand the talk about subject and object. I never quite understood that. The subject-object separation is duality, me and them. We’re always separate from them. And that’s why so many people suffer because they think we are separate from everything you know? People who are environmentally conscious have this sense we’re all in this together.

Jim went on to start a volunteer support group for caregivers and used his “insights” to help others who were struggling with caring for dying loved ones. He notes that he cannot really explain “what is going on,” but knows that transformations are ongoing:

What I’ve been learning is that here and now is the only thing we have. How I see myself recently is like this: I’m in this space and there is no going back. There’s nothing there. I’m in this white space, ivory white space and there is no future. I’m just right here and I’m not sure what is going on, but I know there’s some transformation going on again in me, but what it’s telling me is just maybe I am right here in this very moment.
Jim is the one informant who is totally focused on the present moment. For him, all relation coalesces in the present, and he is connected to everything and everyone. One of his greatest insights came when he was taking a reiki class:

I told my heart I love it! I love you. And it was like wow! And then it came to me: this is where true understanding comes from. It’s when the mind and the heart are working together you know. And what I discovered in this class for an example, is I’m letting my heart lead me—whereas in most of my adult life it was always my head leading—project management, big project programs, and all that stuff. Now it’s this, and I should say that I realized the brain is the tool to help my heart to do what it wants to do.

Jim narrates holographic relation that includes deep awareness of the self, nature, and others as inextricably connected. To him, suffering means thinking you are “separate.” True understanding comes from “the mind and heart” working together. He tries to express his idea that relation to his wife is part of a larger relational matrix that includes nature, his ancestors, and others. He realizes, in his satori experience that human beings “are made of love.” But these insights are born of great agony and suffering. Jim’s words point to an ontology of the mourner as a being in holographic relation who experiences love, suffering, and joy in relation. However, realization of holographic relation was rare as those who said nothing follows death. Holographic relation was alluded to interviews with Brenna, Susan, Lewis, and Sally, yet none of these informants seemed as articulate as Jim in describing their experiences.
Mourning as Portal to Realizing Holographic Relation

In mourning, encounters with finitude and change are central dilemmas for human beings. In his essay about the Greek philosopher Heraclitus, philosopher Patrick Miller suggests that encounters with the limits of human life present us with a choice between transcendence and immanence as a way to reconcile the death of the other. According to Miller, Heraclitus laid foundations in Western philosophy for taking the immanent road. In his aphorism “the same you cannot step into the same river twice.” Heraclitus seems to draw attention to the instability of both the self and the world in which the self exists. The death of the other highlights this very instability. Changes occur on the level of self and at the level of relation with the deceased and others. In mourning, the living person has an opportunity to realize that both self and other are unstable, changing, and impermanent categories in flux, emerging simultaneously within larger more expansive flows of relation. In other words, reflection on death of the other can provide a portal into holographic experience of the self and others as processes in mutual unfolding.

The issue of fluctuating relational boundaries between the living person and the deceased, as well as the living person’s own interior experience and experience of a “core” self are salient themes in these narratives. Healing, from etymological roots in the old English haelen, is a way of talking about wholeness. The Greek holos, implies similar meanings, incorporating the whole. The mourner in holographic relation has transcended opposing relational orientations or paradoxical tensions of grief to glimpse that state of being where relation has no center and no boundary. Aids for
entering this kind of relation to self/others/world, might include the use of symbol or ritual to move beyond the painful paradoxical pulls that tear the mourner into fragmented pieces.

Yet, as so many in this study suggested, entering the sorrowed disorder, chaos, confusion, or interiorized time of darkness is necessary for reentering the world reenergized and reawakened, ready to give outwardly to someone or something greater than the isolated self. The intense affective labor of grief and mourning births new potentials for intimacy and holographic relation with others and the world. The realization that the “riches” (Katherine) that have been “discovered” in interior experience by the mourner “has been there all along” (as Lewis and Jim noted) is an interesting commentary. For the volunteers in these hospice and bereavement spaces, the practice that heals is giving selflessly to others in various ways. For this group of individuals, as Jim so eloquently expressed in his story, questions of transcendence—as Loy suggests—lose their appeal, since “the mind is there to do what the heart tells it to do” and what matters most “is how you live your life here and now.”

Eventually, conscious mourning can lead to feeling whole within and yet part of and drawn to engagement with a larger whole. Pure holographic relation that imparts an experience of completely dissolved individual boundaries defies discursive description—though some informants tried. This rare relational orientation seems to me the pinnacle of spiritual grounding and resonant relatedness. Understanding holographic relatedness seems more suited to creative expression through symbol, dream, image and metaphor. The image of Indra’s net as a shining field of jewels
reflecting and refracting light is one way to visualize the interconnectedness and mutuality of human beings. Jim’s account of his “satori” experience in the coffee shop is an example of his awareness of holographic relation, or as Buddhist sages describe enlightenment, the moment when the wave knows it is the ocean.

**Conclusions**

The belief in love and relation as some kind of spiritual truth or imaginary, lies at the crux of my arguments about loss and mourning. The transformations that propel mourners from broken relation to realization that they are beings in internal or holographic relation, are irreducible, non-hierarchical, and elude definition. And so, I agree with philosopher Jean-Luc Marion who suggests that trying to define the human being is an impossible task. Marion argues for a negative anthropology that would “protect the human by insisting that it lacks definition” (Carlson in de Vries, p. 828). Such a stance contests scientific methods that objectify and reduce humans. Marion’s stance would leave the seminal questions of this dissertation dangling. “What is it to be a human being who encounters death and dying?” And, “what is it to be treated like a human being who encounters death and dying?” are unanswerable for Marion who says, “Every definition imposes on the human being a finite essence, following from which it always becomes possible to delimit what deserves to remain human from what no longer does” (Carlson in de Vries, p. 829).

Yet, for the purposes of finding new ways beyond medicalization of dying in contemporary American medical settings, I find myself affirming and emphasizing the
relational dimensions of human beings, as an argument against the strict use of biomedical ritual that is so frequently imposed at the end of life. Spiritual discourse and practice is a corrective move from the scientific reduction of human beings in contemporary end-of-life care. There is no guarantee, of course, that other kinds of ritual would be more satisfying to the patient and their circle of relations, though powerful narratives from these informants in hospice spaces bear witness to the possibility of peaceful dying without undue medicalization. Kyra’s inclusion of baptism and communion for her dying infant daughter, and the singing, listening, reminiscing, forgiving, hoping, praying, or cradling the dying person with touch that I observed in my fieldwork seem more akin to gentle midwifing the dying into the unknown.

Caught up in the loss of a loved one, the mourner is brought to their knees with paradoxical affective energies, longing, and confusion that literally play out in the body. They are unwillingly thrown into the realm of the unknown, the mysterious, perhaps confronting the shadow side of life that contains our fears, and more importantly according to Loy, our feelings of lack and the suspicion that we are not real or not authentic. For many of these informants, the disorientation that follows commences a search for meaning and for what is true despite the loss through death. Whether or not religion is called upon to make sense of death and dying, these informants need to see the sacred or significant nature of the deceased person.

The need to believe in some form of continuing love and relation is present in all of these narratives. For most, continual transformation of relation to the deceased
is an ongoing process that lasts the rest of their lives. For a few, relation is severed with no hope for reunion, though relation continues through memories. For others, relation blossoms as the mourner realizes that suffering cracks open the heart, allowing them to share with others the tender care that was shown them by the deceased or others in caring relations earlier in their life.

The ethnographic narratives collected in this study indicate that spiritual imaginaries of death are diverse, dynamic, particular, and personal. Spiritual imaginaries rarely correlate with the official dogma of the informants reported religious affiliations. They demonstrate that relation to the deceased fluctuates wildly among relational boundaries that are perceived as closed (external), porous (internal), or completely dissolved (holographic). The spiritual imaginaries contained within these narratives verify Kristeva’s “incredible need to believe” as a necessity for human beings. Although most spiritual imaginaries of death are framed speculatively and hesitantly, all informants expressed some element of belief or deep intuition of loving relation to the deceased in the past, present or future. In the majority of these narratives, the need to believe supersedes rational thinking that concludes there is a finite end to relationship. The belief in “something more” is difficult to describe discursively. These very complex dynamics make the task of predicting spiritual distress, prescribing spiritual care and documenting “evidence-based spiritual outcomes” almost impossible. Indeed, the spiritual is a chimera. Although sought and desired, like the wind, it is illusive and impossible to capture in its fullness, complexity, and power.
The spiritual imaginaries presented in this chapter support the idea that the mourner is primarily a being in internal relation, whose interior experiences of receiving loving affection (through a range of memories, perceptions, signs, ritual, practices) allow for internal relation to the deceased. Realization of internal relation to their loved one, even in death, may lead to a blossoming movement toward others and the world in a new way, revitalized by the irrevocable relation that continues with the deceased person. In this way, the death of the other can be a portal into realization of internal or holographic relation with others and the world.
CHAPTER 6

END-OF-LIFE CARE AS RELATIONAL BLOOM SPACE

This dissertation begins with a critique of two aspects of end-of-life care in contemporary America: the medicalization of dying which reduces the universal event of death to a medical problem; and the scientistic study of spirituality, which objectifies, reduces, and isolates the “spiritual” from other aspects of human experience. The research findings support the thesis that humans are irreducibly beings in relation (intimacy) rather than essentially isolated individuals (integrity), and that spiritual end-of-life care necessitates attention to fluid inextricably woven personal and relational transformations. Opposing medicalization of dying and scientism within spiritual care research, these narratives and fieldwork observations collected in hospice and bereavement spaces support the following ideas. Death and dying are “complex,” “spiritual,” and “relational” human processes that evoke existential suffering and intense transformations in mourners. Spirituality is primarily a relational construct, and as such, the study spirituality in spaces of mourning may necessitate attention to irreducible relational transformations for those who encounter death and dying. Taking a cue from Tweed, the best end-of-life spiritual care would
attend to these relationships, and confront the suffering and enhance the joy inherent in them, as human beings travel through life “crossing and dwelling.”

This chapter is divided into four sections. The first section summarizes the interviews using direct quotes from various informants in an attempt to give an ontological description of the mourners I encountered in this study. The next section summarizes the study and highlights findings. The second section discusses the applications of the I/I heuristic in spaces of mourning, and is used to theorize end-of-life medical practice settings as cultures of intimacy. The last section makes recommendations for end-of-life care practice, pedagogy, research, and ethics based on the findings of this study.

**An Ontological Description of Mourning**

The story of this dissertation has to do with the shocking un-grounding and boundary rupturing of the mourner when the loved one dies. The living person feels as though they have “lost their moorings” or like the “north star is gone.” The embodied intimate loving relationship with the deceased is forever changed, and the ensuing time can involve a painful pursuit of restoring relation to the deceased. The “dark wet heavy woolen blanket of grief” bleeds into the whole life of the living person, where “everything is different” and “nothing will ever be the same.” All attempts to restore relation, as it was previously known, are futile. The avoidance of feeling or repressing the sorrowful affects does not seem possible for most of these mourners. There are only “temporary distractions” that divert the person from the painful labor of grief,
which comes in waves, unexpectedly and unbidden. Among other contradictory and bewildering feelings, the mourner may feel paradoxical tensions of anger/gratitude, suffering/joy, absence/presence, and holding on/letting go. Wild relational swings between these polarities are possible, generally described here as oscillation between internal and external relation to the deceased.

Mourners are confronted with mystery, the unknown, and the inexplicable. Some mourners told me at a certain point in the process, they wanted to follow their loved one “into the land of the dead.” Many lost their fear of dying since they believed that someone waits for them on the “other side.” Most informants could touch their deepest feelings of grief long after the death, dispelling any theory that grief and mourning are able to be “resolved” or “healed.” More likely relational orientations continue to fluctuate over the lifetime of the mourner.

A kind of searching for what was lost can cut the mourner off from their inner self and the self that enjoyed relation to the deceased, leaving only a crescent self. Part of the self is missing, since loving relation with the deceased was lived without boundaries and with an intimate kind of knowing between them. The “emptiness,” the “loneliness” cannot be “filled” with anything that works to restore what has been lost. The “hole in the heart” is an iconic image for this missing part. Searching and wishing and hoping for future relation keeps some mourners in a future oriented temporal frame. When loss becomes lack, mourners feel fragmented or can feel reduced to a fraction of themselves. There is suffering. There is dissatisfaction with life. There are
intense affective rumblings that erupt in body-felt sensation giving rise to moods and emotions, though at the somatic level, affect seems indeterminate and neutral.

Meanwhile, some informants report “true signs” of communication from their loved one in various forms of sensory perception from dreams, to visions, to hearing the voice of the deceased. These signs are interpreted as comforting and impart a feeling of closeness and continued relation with the deceased. Though not everyone had these experiences, they were very meaningful. Ritual that symbolically incorporates internal relation with the deceased can move the mourner past binary tensions and paradoxes of grief and loss, toward a harmony that can be actualized when boundaries are porous, the heart is cracked open, and the mourner feels (with the mindful heart) an understanding that human beings universally share suffering and joy in relation.

David Loy posits that death presents us with something greater than the fear of death and that is that “I” am not real. A fragile sense of self, blown around by forces beyond control of the mind, seeks security, affirmation, to know that it is real. The desperate efforts to stop the groundlessness that occurs with death of a loved one fail miserably. If the mourner avoids feeling, “grief waits” to present itself at “another fork in the road.” Though all change is a reminder of life’s inevitable fluctuations and impermanence, the death of a beloved other is perhaps the most powerful reminder. It is fruitless to “try to keep the heart from breaking.” With surrender to the sorrowful affects of grief, weeping and crying become cathartic energetic releases. At the gut level, these affects appear to be neutral movements. They are visceral reminders of
fluctuation and change, and deep connection to the deceased. When the mourner surrenders to the intense affective dynamics of grief, they let go into the process. They experience their utter groundlessness, and the absence of any fixed nature of things. By surrendering to groundlessness and impermanence, new possibilities for relation emerge as the heart is cracked open. In effect, they say yes to life and what has transpired. Ironically, some discover a deeper internal connection to the deceased, and others, noting that this relational bonding, like the connection between the jewels in Indra’s net, “was there all along.” Some informants broke through this phase of the mourning process only to find that relation to the deceased was never really lost. The “bitter goes away.” Though this can take “a long time.”

For those who begin to see the self in the other and the other in the self, a new kind of blossoming relation emerges, one that realizes we all experience suffering, that we all experience crises, that “we all have a 9-11 in our lives.” When lack comes to an end, so does the problem of meaninglessness. There are endless opportunities for being receptive and attentive to the suffering of others. The volunteers in this study became wholeheartedly engaged in accompanying the suffering of others who were undergoing the process they had just been through. They found meaning in their own suffering and were able to be compassionate or “suffer with” others who asked for help with the dying and bereavement processes. They are able to reflect and refract light, in holographic relation, as a jewel in Indra’s net. By accepting the ground of a net outside the separate self of mourning, they were embedded more securely. A few realized they are the net with no center and no edge.
In sum, the affective dynamics of grief are embodied, intense, and indeterminate. Spiritual imaginaries of death are varied, speculative, and framed hesitantly. Sensory out-of-ordinary boundaries experiences are perceived as real, but may be unreliable. Relational orientations of the participants toward the deceased loved one oscillate rapidly, confounding stable categories of pure internal or external relation, and calling into question mourning relation without affective dynamics. Thus, when relational orientations are seen as unstable and rapidly fluctuating categories, when affective dynamics are indeterminate, when spiritual imaginaries are speculative, and when perceptual experiences are unreliable, then the time of mourning is qualitatively diffuse and full of potential. Mourning is indeed what Stewart calls a “bloom space” that resonates with potential and threat.

**Summarizing the Study**

This study was undertaken in order to understand end-of-life spiritual care. Ethnographic interviews, fieldwork observations, and medical and humanities literature were analyzed. The interviews and fieldwork were conducted in hospices and bereavement spaces where meanings about death and dying are negotiated on a daily basis in American culture. Here, as many informants told me, dying is seen as a “natural part of life,” and is a “spiritual passage” that evokes great existential suffering and questioning for those who encounter it. In these spaces, deathbed scenarios resonate long after the death for the living. Ritual, as enacted in the hospice ideal, attends to the complex relational matrix of dying and may provide greater potential to
create peaceful transitions, rather than indiscriminate use of futile medical ritual that can cause further suffering. In the final analysis, “spiritual” care is care that which acknowledges and responds to the patient as a being in context, embedded in ever expanding webs of relation.

Chapter 2, Relational Transformations and Death, presented some of the potentially limitless relational transformations that follow the death of a beloved other. Using the I/I heuristic to think about relational changes during mourning, I suggest that most of these mourners continue in internal relation with the deceased, though this relation oscillates wildly and contains particular affective, somatic, and esoteric components. Physical, emotional, and spiritual yearnings for the other are inexorably entwined for the mourner, suggesting that scientific study of spirituality that reduces spirituality from other dimensions of human experience, at least for these informants, is a failed endeavor. The primacy of internal relations in these interviews suggests that these spaces of mourning may be cultures of intimacy. As such, caregiving based on findings in these end-of-life settings, may suggest a need to attend to complex and particular internal relations between the living and dying/deceased.

Chapter 3, Susan’s Story: “I Can’t Imagine,” presented a case study that illustrates the rapid relational oscillations and transformations between herself as the living, and her son, the deceased, during mourning. Her story supports the idea that relation is painfully ruptured at the time of death—especially in traumatic deaths—and continues to fluctuate long afterwards. Broken internal relation, an iconic relation in these narratives of mourning, is graphically illustrated in Susan’s artwork, a medium
that can capture what “words cannot.” Art as ritual process and “sharing with others” who can imagine the pain of loss is how she “healed.” Her story is a basis for recommending that empathic imagination is a skill that caregivers may need to cultivate in order to understand the emotional life and needs of those in their care.

In Chapter 4, Catching the Wind? Theorizing Spirituality in End-of-Life Scenarios, I suggested that medical-spiritual discourse attempts to expand narrow scientific views of human beings and humanize end-of-life care. Yet, positivistic quantitative methods seem unable to capture the thick relational matrix of spirituality or end-of-life care. Research methods from the study of religion may be more suited to exploring existential end-of-life questions. Ethnography may be a way to “intimately” study relational flows, culture, belief, ritual, and the contingent contexts of human beings by entering into internal relations in the field. Hermeneutics offers a way to explore the meanings of interview texts and other discourse encountered in end-of-life settings. Religious studies scholars suggest ways to interrogate the culturally and historically embedded meanings of religion, spirituality, and death. Many informants in this study describe death and dying as involving personal and relational crises on the journey of life. Many call on supra-human relationships to sustain them through the crisis of the death. Some retain their religious faith, though others lose faith and question previously held beliefs. Recommendations based on these findings indicate that end-of-life care might include careful attention to the particularity of belief and practices for individual patients and families, despite what might be declared on patient assessments.
Chapter 5, Spiritual Imaginaries of Death, discussed the diverse beliefs, hopes, dreams, and fears that informants narrated about death and relation to their deceased loved one. Beliefs about death are diverse, personal, particular, and do not always follow the declared religious tradition of the informant, nor do they necessarily include a deity. This chapter suggests that even though death imaginaries are framed speculatively, belief in the certainty of loving relation may be a real and pervasive truth for all informants in this study. Internal relation dominates these narratives. External relation and holographic relation to the deceased are rare. For those who experience the diminished and fragmented self of broken relation, healing is defined as an ongoing process of realizing internal relation, until the deceased loved one is simply “part of” the living person and can never be removed.

These findings can be used to make recommendations for improving end-of-life care, and these are explored in the last section of this chapter. But first, I explain how the I/I heuristic could be used in American healthcare for thinking about relation in spaces of mourning and beyond.

**Expanding the Intimacy/Integrity Heuristic**

In this section, I discuss how the I/I model can be further adapted to understand relation in spaces of mourning such as end-of-life settings. Chapter 2 already adapted the I/I model for thinking about relational transformations between the living and the dead. Broken internal relation is described as an iconic relation in mourning, and the
crescent self that feels diminished, fragmented, alienated and lonely may be why these mourners presented themselves to bereavement programs for help. In contrast to the diminished crescent self of mourning, certain narratives themes are supportive of a category that describes an expansive “blossoming self of mourning.” This mourner imagines or feels that boundaries between themselves and the deceased have ruptured, and are porous, open, or completely dissolved.

In a movement parallel to the transformation of imagined boundaries between themselves and the deceased, boundaries between themselves, others, and the world are cracked open. They enter into internal relation with others. This stance was exhibited by many informants, including Stacy, Jim, Lewis, Lexie, Susan, Katherine, and others who experienced a death then later volunteered with others who were suffering. In the process of staying with their own pain and suffering, it seems they discovered inner strength, resilience, patience, and open-heartedness—and were then ready to accompany others going through similar circumstances.

Informants described the outpouring of care toward others as a spiritual process. As Jim said about encountering his wife’s death and then starting a center for other lay caregivers, “You’re learning and finding out what you have inside you that you didn’t know you had, and that’s part of my spiritual growth of course.” Stacy, a hospice volunteer who visits four bereaved persons regularly, told me that she was always apprehensive about death, yet she is able to face it now. She says, “I think I have more compassion now, more a spiritual sense.” Lexie, whose partner died from
alcohol abuse, now leads a suicide awareness group at a local bar. She speaks of the way living through the death and volunteering with others has changed her:

I look at the world more mysteriously and positively now. Instead of saying, “This is bad,” I ask, “Well how much did you learn from it?” and “How much deeper is your life now?” and “How do you live it?” and “Look how much easier you’re able to connect to people.” I was the shy person that never spoke, and now I can talk to anyone!

Larry, who works as an attorney, volunteers at hospice events and also gives time to families doing “ordinary things” like helping with laundry, errands or housecleaning. He says “I don’t go into it with any preconceived notions of what I ought to do, sometimes simply being there doing the ordinary thing is as much as part of therapy as something more intense.” These narratives suggest that some mourners are able to turn the painful experiences of grief into a process that gives meaning to their own life through helping others. Surrender to the groundlessness of their own grief, then reaching out to help others, may bring awareness that they are more fully grounded in a net of compassionate relation. Relation, that for some like Lewis and Jim, was “there all along” but they had never noticed.

Blossoming relation was evident in the hospice volunteers. The blossoming self overflows the fragrance of realized internal or holographic relation—scenting or suffusing the relational field with understanding that all human beings share experiences of suffering and joy in relation. In this vein of thinking, Judith Butler (2005) suggests that mourning can be a catalyst for community rather than isolation. Through grief, community with the living is born. In a certain sense, “loss makes a
tenuous ‘we’ of us all.” Grief reveals “the thrall in which our relations hold us. We are undone by each other. And if we’re not, we are missing something” (p. 22).

The informants in this study overwhelmingly comment on the caring they experience as part of hospice philosophy and practice. They say this is what attracted them to work or volunteer in hospice or bereavement services. Larry talks about the intimate relationships that are formed in hospice caregiving:

I think one incident that I will always remember is that they sent one of the home health aides in to let me have a little respite and run some errands and so forth. When I came back and stepped in the house I heard laughter! My wife and the home health aide were chatting as if they had been lifelong friends. And I thought, this is not sarcastic laughter in the face of death, this is just two human beings connecting.

Larry refers to the intimacy that is present in caring relation, saying that this “strange and unusual” relationship cannot be quantified. He says, “I think this is just part of the hospice philosophy, and you can’t really quantify it. It’s hard to even try to describe it, but I believe that this is the kind of thing that develops out of the experience of two people being together in this situation.”

In this study I identified clusters of intimate relation that occur in circles of care surrounding the dying person and their family/friends. I call these “care blooms.” Care blooms are overlapping intimate relation between and among caregivers and the dying person. Hospices include interdisciplinary teams of caregivers who ideally practice a caring ideal. In this study, I want to broaden the circle of care beyond health professionals to include family, friends, community members, volunteers, or basically anyone who exhibits caring toward the dying person. Figure 13 graphically represents
a person in need, such as the dying person or the bereaved person, at the center of a circle of internal relations. The care-givers enact open or porous boundaries between themselves and the care-receiver. Care blooms could also be envisioned as holographic modes of relation (Fig. 6). Like the metaphor of Indra’s net, it is possible to characterize care blooms as clusters of mutually caring relations that involve infinite reflection and refraction.

Figure 13. Care Blooms as Clusters of Internal Relations
Kasulis, Thomas. *Intimacy or integrity: Philosophy and cultural difference* (p. 96). Honolulu.

I envision care blooms as relational bonds based on a feminist ethic of care.

This relational model is informed by the work of feminist philosophers Nel Noddings and Eva Feder Kittay. Noddings (1984) defines caring as a relational ideal that
“springs from two sentiments: the natural sympathy human beings feel for each other and the longing to maintain, recapture, or enhance our most caring and tender moments” (p. 104). Care might also be considered a virtue or a value, but for my purposes, I use care as a way to connote an ideal relational practice.

Noddings states that caring relations are not contractual, eliminating them from Kasulis’s category of integrity, and suggesting that caring is an example of internal relation between human beings. Care is a relational ideal involving the outward flow of affect across permeable boundaries. According to Noddings, those in caring relations are reciprocally dependent, meaning the cared-for makes significant contributions to the caring relationship. Kittay echoes this idea in her comparison of justice based and care based ethics in biomedicine. She acknowledges that in care ethics the self is a self in relation, and that dependence, difference, and vulnerability are accepted as qualities of moral agents. The self is inextricably related to others in relations that constitute a formative basis of their desires and identities.38 Kittay notes that the aim of moral relations in care ethics is to foster or preserve connections and to serve what Carol Gilligan called “affiliative relationship.” These ideas support use of the feminist ethics of care as a model in end-of-life scenarios where, internal relation between the dying person and the family is ideally preserved or enhanced in order to promote peaceful dying.

Noddings posits that caregiving requires that the person caring possesses a non-selective, receptive mode of attention as well as exhibit an outflow of energy toward the other. She also notes that caring relations are often not natural, nor are they
always equal in power dynamics. As such, caring requires a continually renewed commitment to attention, receptivity, and response-ability between relatants. This has implications for the continual development of caring cultures in American medicine. Ethical practice may depend on constant renewal of the caring ideal. This study in many ways presents the hospice ideal as one that involves clusters of internal relations among the dying patient, the family, and others in ever-expanding relations of care. I understand that this ideal is not always found in practice for many reasons that are beyond the scope of this dissertation. Erosion of the caring ideal is occurring in the current climate of American health care. The caring ideal I explore in this dissertation is threatened by trends toward profit-driven privatization of hospices and hospitals that previously operated as charitable institutions, as well as by commodification of care that exploits affective labor (see Dean-Haidet, *Narratives of Women Healers*, 2007).

Noddings’s ethic of caring is rooted in internal or intimate relation. “Relations, not individuals, are ontologically basic,” she says in *Caring*. Indeed internal relation and affection are necessary conditions for caring to occur. Noddings suggests that the caring ideal is constructed from the fact and memory of tenderness. So in a sense, when a caregiver feels or expends an outflow of energy toward the cared-for, she may be relying on a kind of holographic caring matrix that reflects and refracts tenderness and empathic affection among relatants. In this sense, caring is a holographic relational dynamic that moves beyond a strict focus on the self of the caregiver, and may be reflected from all others who have shown or show care to those caring or cared-for. The harmonious overlap of feminist ethics of care and the I/I heuristic can
be used for conceiving care in all American healthcare contexts, beyond exclusive use in end-of-life settings.

**Re-Thinking Spiritual End-of-Life Care in America**

This section makes suggestions for end-of-life care practice, pedagogy, research and ethics based on the findings of the study. The dominance of internal relations found in these spaces of mourning, suggest that the way to teach about dying may be to engage learners in reading, discussion, or praxis that allows them to empathically identify with actual or potential others who express the joy and sorrow inherent in end-of-life relationships. The findings suggest that deep listening and reflective practice are skills for those who would work with suffering and dying. Though listening in end-of-life scenarios is often difficult because it reminds the listener of their own mortality, it can crystallize the realization that we are all together in what we bear as human beings.

Practice with listening can be honed through reading, writing, or sharing stories about death and loss in supervised classroom or clinical settings. The creative techniques of Rita Charon, who has conceived the field of narrative medicine, are wonderful exercises in reflection and develop skills listening for close reading of the patient narrative. Her parallel chart exercises pair the patient narrative with the narrative of the health care worker who reflects on clinical scenarios to better understand what is happening relationally in the care giving/receiving dyad. Narrative analysis and ethnographic research are two models that assume inter-relationship, and
attend to position and affect. Thus, based on these findings, narrative and ethnographic research methods may offer more depth and less reduction when studying the complex relational matrix of end-of-life care.

Other tools such as meditation, are used by Joan Halifax at the Upaya Being with Dying Project to allow the novice or seasoned health care worker time and space to become quiet and observe what emerges when suffering is embraced as part of living and compassion is cultivated as a response. Mindfulness meditation can give insights into the relatedness of things and support the outward flow of caregiving without becoming drained or exhausted. When the caregiver feels firmly rooted in a web of relations, there can be a sense that suffering and joy are shared human experiences that contribute to the vitality of living. For Loy, this means that questions of transcendence lose their meaning, and the authentic person blossoms fully in the present moment as the only moment.

Cultivating the mindful-heart is something that can be taught those who would accompany the dying. According to Kasulis, immersion in a practice that transcends the ego and engages community nurtures both cognitive and emotional sensitivity. Many volunteers in this study did just this. They gave selflessly of their own time and energy to those who needed help with the overwhelming job of caring for the dying. For someone who approaches caregiving as a spiritual practice, qualities such as awareness, receptivity, compassion and responsiveness are cultivated along the way.

The feminist ethics of care are built on such ideals in human relationships. Such models affirm and support human interdependence. Based on the findings,
ethical models that acknowledge human interdependence and dependence may be more suited to end-of-life care than currently popular principle-based deontological ethical models that stress rational thinking, autonomy, and beneficence or what is “good.” In end-of-life scenarios, what is good depends on the position of the desiring person. Multiple actors have multiple positions, and feminist models acknowledge the power and knowledge differentials that often operate in biomedical settings.

The deteriorating physical body of the dying person lies at the center of end-of-life care. The dying person is eventually completely dependent on others. Especially when there is an absence of narrative, for example when the patient is an infant or is unconscious, then those who encircle the patient in relation must make decisions about treatment. This is a huge dilemma in contemporary end-of-life settings where biomedical technology is often employed to keep someone alive beyond their ability to decide. In these scenarios, communication within the entire circle of caring relations is suggested. Feminist models of care affirm internal relations like the ones found in this study between and among human beings, and thus are recommended for end-of-life decision-making. In summary, the complex and impermanent relational transformations that occur in end-of-life care, require attentive, responsive others who have developed a mindful heart and are courageous enough to enter into internal relation with suffering others—knowing that all are connected in expansive webs of relation. This can be called spiritual care, but it need not be. Relationship-centered care is another way to talk about spiritual care for those who may not like connotations that come with words like “spiritual” and “healing.”
**A Resonant Death**

The narratives collected in this study construct the end-of-life as a fertile time of affective and relational blossoming that resonates long after a death. As such, the time of death is an important moment for all involved in the circle of care. Referencing how death is observed in other times and cultures, Komatsu Yoshihiko writes (cited in Heisig, Kasulis, & Maraldo, 2011) about the event of death within a temporal flow that could expand to embrace others as well. In medieval Western historical contexts, as reported by Bynum and Aries, death was not reduced to just the event of dying. People lived with death in a kind of intimate bond. Komatsu contrasts a death of intimacy with a death of integrity (cited in Heisig, Kasulis, & Maraldo, 2011):

Like a vibrating string evoking a series of resonances to make a single sound, one person’s dying was shared with those in the surroundings to make a single death. The “resonating death” was altogether different in nature from the “individually confined death” of today in which death is reduced to the event of dying and thought to belong only to the one actually facing death. (p. 1240)

A death of integrity occurs for independent individuals on a solitary journey. A death of intimacy is one where dying is shared in intimate bonds between those who surround the dying person, yet the dying is felt as a holographic resonance through expanding relational fields. Death, in this view, is not alienation in which one’s individuality is lost, but a change of relationship that resonates within a holographic whole.
Endnotes

1 Indeed, as it has at other times in Western history. See Philipe Aries, The History of Dying, The Hour of Our Death, Western Attitudes toward Death, and Carolyn Walker Bynum’s The Resurrection of the Body and her other books that deal with medieval Christian eschatology.

2 Of course, not everyone has the opportunity to plan for a good death. Sharon Kaufmann in her ethnography of dying in American hospitals. ...and a time to die (2005) suggests we have come to expect a kind of taming and triumph over death, as if it can be disciplined by biomedical means. But in 2011 America, the baby boomer demographic, 78 million strong, is headed for a death in the next 20 years that will be more likely due to a chronic or debilitating disease rather than the infectious and acute diseases that killed people a century ago. For those who have the time to contemplate it, and the advanced notice that death is immanent, the “good death” may be a possibility. Though it is a contested and contextual phrase that has individual meaning for individual people, it’s philosophical import dates back at least to the Greeks. In Plato’s Phaedo, the dialogue on Socrates death suggests that the best way to prepare for death is to live with the life long awareness of it. Socrates is released from life to death in a peaceful manner because he has prepared and practically releases himself. What is a good death? Recent studies suggest a good death may be one that is attended by compassionate others and a dying process that allows time for reconciliation, forgiveness, legacy giving, celebration, saying good-bye, letting go, and other rituals of leave-taking. My concern is that dying, whenever possible, be a peaceful experience for both the dying person and their circle of relations.

3 An in-depth discussion of high profile cases such as those of Terri Schiavo and Nancy Cruzan are extremely relevant to American end-of-life policy and medical treatment, as is the movement for physician assisted dying that is legally enacted in the state of Oregon, but these are beyond the scope of my discussion here. Please see the Lifetree website for a biased, but nevertheless comprehensive history of the hospice and right to die movement in the U.S. since 1963.

4 The SUPPORT study was started in 1989 and continued for 15 years with funding from the Robert Wood Johnson Foundation. This multisite study which was conducted to Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment, concluded repeatedly that patients who die in hospitals often die in pain and without their wishes for final medical treatment being honored. Sharon Kauffman studies this phenomenon in her ethnography of dying in American hospitals called ... and a time to die. At this writing, it is estimated that 50% of deaths in the US occur in hospitals. About 30% occur in nursing homes, and 20% take place at home. Hospice care covers home and some nursing home deaths.

5 Indeed the etymology of the word hospice (hospes) refers to a place where host and guest reside together. Early medieval Christian hospices were places where travelers could find food and lodging during their travels or on pilgrimage. Later charitable hospices cared for the sick and dying. The modern hospice movement began in England under Dame Cicely Saunders and moved to America in the late 1970s. Saunders said she wanted a place where the spiritual aspects of dying were acknowledged and honored. American hospices have tripled in number in the last 10 years. Part of this growth is due to Medicare coverage for the financial burden of hospice care, and part may be due to a kind of death awareness movement that stresses benefits of conscious dying and planning for what is personally meant as a good death.
A peripheral concern of this study is to describe ways that some emerging ritual in bereavement spaces enables the meaning of transformed relation with the dead to be symbolically felt or known by the living. A planned future direction for study focuses on cultural variations of ritual beyond medical variations in end-of-life care.


See Appendix A for a summary of the research process including more detailed description of fieldwork.

See Appendix B for the interview questions, consent forms, recruitment scripts, introduction letters, and other IRB documentation.

The lay informants represent a range of occupational interests, including businessmen & women, engineers, attorneys, teachers, homemakers, computer programmers, college professors and others. The professional group includes nurses, social workers, physicians, art therapists, music therapists, chaplains, bereavement counselors, artists, pet/equine therapists, and administrators.

Class and economic strata of the informants are unknown to me, although there was minimal racial diversity in this group. Three informants were black females, the remainder of the informants were white males and females. This may reflect class or race discrepancies in use of hospice/bereavement programming in this particular locale or general use of hospice services. Representatives at both fieldwork sites told me that their services are utilized by diverse cultural groups, although most of the grief support groups lacked cultural diversity. Future studies should seek to increase diversity among informants. See Appendix C for more demographic information on these informants.

I read several grief memoirs and illness narratives that inevitably deal with dependence and debility of the body. I initially wanted to include this literature in the study, but the sheer magnitude of the fieldwork and interview texts prohibits including these sources at this time.

Complicated mourning, or what Freud called melancholia, may be seen as a process of becoming “stuck” in the integrity orientation, bereft of emotional energy for the self, the deceased, or others. Susan told me she felt “numb, cut off, unable to enjoy life.” Therese Rando and other contemporary grief theorists have defined complicated mourning as failure of six “R” processes in mourning. The bereaved person does not recognize the loss, react to the separation, recollect and re-experience the deceased and the relationship, relinquish old attachments to the deceased and the old assumptive world, readjust to a new world without forgetting the old, and reinvest emotional energy in new things. However, this study is against attempts to phase, stage, compare or pathologize grief and mourning, or otherwise provide a template for engaging the person who lives in the midst of loss and death, other than to listen deeply to all that they wish to say. I suggest that a wide range of responses to death are natural for contemporary mourners. I further suggest that mourning that seems stuck or frozen, and does not allow the person access to affective energies of the self or others is just another response to the death.
A full treatment of Freud’s work is beyond the scope of this dissertation, but, for my purposes, some interesting formulations about what is now known as affect occurs in Freud’s work.

In his pre-psycholanalytic writings, contemporary scholars assert that Freud embarked on a project with the intention of explaining how mental content can be excluded from consciousness (1895), or what is now known as “A Project for a Scientific Psychology,” contemporary interpreters (Smith in van de Vijver & Geerardyn) suggest that one of the aims of his project was to elaborate a physicalistic model suggesting that mental states are brain states. According to Solomon and Smith, Freud abandoned this project because of the limitations of neuroscience in his day.

The work on mourning and object relations done by Freud, Melanie Klein, Ronald Fairbairn, D.W. Winnicott, John Bowlby, Colin Murray Parkes, Stroebe & Schut, Tony Walter, Therese Rando, Kavaler-Adler and others is beyond the scope of this dissertation, although readers are referred to the review of grief theory by Neil Small, as well as Kavaler-Adler’s excellent book on mourning for further reading. One aspect of this literature to consider is the psychoanalytic terminology of Freudian psychology and the differential meanings that apply. Concepts such as libido, cathexis, complexes, melancholia are part of the specialized language of psychoanalysis and have meanings that have been used to pathologize or normalize grief and mourning responses in the past century. I would like to move beyond a normal/pathological antimony of grief and mourning and simply identify a range of possible responses to loss of a beloved other. However, I am interested in the work done by theorists and clinicians regarding the relation between previous relational trauma and wounding through loss. Although I did not ask for a history of loss or trauma from informants, many started their narration with a story about the first or most profound loss they had experienced in their life. More recent research on grief and mourning in the social sciences in the last 15 years acknowledges “continuing bonds” with the deceased. Silverman and Klass posit that this theoretical shift marks a transition from a Freudian approach to grief and mourning that recommended decathexis or withdrawal of attachment from the deceased other in favor of making new libidinal attachments in the present. However, Small suggests that two Freudian legacies of mourning have survived the test of time—projective identification and elements of attachment theory. The “continuing bonds” theory of grief first proposed by Klass, Silverman, and Nickman (1996), following clinical observations that support continued relation with the deceased, does not specify what kind of attachments or relational bonds continue between the mourner and the deceased person. This research proposes a range of imagined relational bonds that continue after a death, therefore supporting diverse kinds of “continuing bonds.”

I responded to the sorrow of these informants. I would wake in the middle of the night hearing their words, seeing them cry, wondering which quotes to use amid the huge depository of language that I have digitally recorded. I have absorbed these stories in my very bones. Perhaps because the inception of this study came months after my own parents died, I was grabbed by the interviews. I could identify with the pain and sorrow of each person with whom I talked. For a time, my eyes watered constantly while I was collecting field observations and conducting interviews. I consulted an eye doctor to no avail. After visiting a friend who suggested that I might be “taking on the sorrow” of those I interviewed, I came home and allowed my tears flow freely. She was right. I had picked up or identified with so much sorrow and pain, or perhaps was anticipating the day that comes for all of us when a loved one dies, that I seemed to be having a grief response of my own.

Several contemporary Buddhist teachers and scholars highlight holographic relation in their writings. The Vietnamese Buddhist monk Thich Nhat Hahn talks about “interbeing” as the expression of interdependence and the idea of no separate self. He uses an example of a sheet of paper containing everything in the universe. “If you are a poet, you will see clearly that there is a cloud floating in this sheet of paper. Without a cloud, there will be no rain, without rain the trees cannot grow, and without trees we cannot make paper. The cloud is essential for the paper to exist. If the cloud is not here, the
sheet of paper cannot be here either.” He talks about the sunshine that allows the trees to grow, saying the sunshine and the trees “inter-are.” He goes on to talk about the logger who cuts the trees being dependent on wheat to make bread that sustains him. The logger’s parents are connected to the sheet of paper since they are related to the logger’s existence. And so he concludes that “everything co-exists with this sheet of paper ... as thin as this sheet of paper is, it contains everything in the universe in it.”

22 Most stillborn infant deaths are recorded as “fetal death” in the U.S. Presently in Ohio, a “birth certificate” is not issued for a stillbirth until after a “fetal death” certificate is issued. Parents may apply to the Ohio Department of Health for the free “commemorative certificate of stillbirth” that classifies the infant as a “fetus.” Many parents nationwide object to this “definition” of their child. According to Joanne Cacciatore, psychologist, mother of a stillborn infant, and founder of MISS, a volunteer organization devoted to helping families who have experienced the death of a child: “Stillbirth, for decades, has been overlooked and disregarded as the number one mechanism for child death. Estimates range from 25,000 to 39,000 stillbirths annually in the U.S. That is approximately 83 per day or 4 per hour. Stillbirth takes the lives of more infants than all other causes of deaths combined! Yet, these numbers have gone virtually unnoticed. Reports about national or state rates for "infant mortality" do not include stillbirth rates. Stillborn babies, despite gestational age or viability, are labeled "fetus" and are not regarded by public health departments, statisticians, or some researchers as an infant death. This attitude has been the driving force behind the complacency toward stillbirth in society.” The MISSing Angels is a group devoted to raising awareness of stillborn death. Pointing to dis-membering discourse and practices, Roland Barthes is quoted on their website: “Language is legislation, speech is its code. We do not see the power which is in speech because we forget that all speech is a classification, and that all classifications are oppressive.” Update: March 6, 2012 Iowa unanimously passed a law that provides parents with a birth certificate as well as a death certificate for a stillborn birth. The new nomenclature is Certificate of Birth Resulting in Stillbirth (CBRC).

23 Derrida is a continental French philosopher who has written extensively on many ideas (death, religion, hospitality, and mourning) contained in this dissertation. He writes on the impossibility of mourning, the aporia (or impassible gap) that death presents to the living, the politics and ethics of hospitality toward others who are strangers, religion as containing ideas about passage to responsibility, and the limits of rationality when imagining one’s own death.

24 See Lisa Miller’s Heaven: Our Enduring Fascination with the Afterlife (2010) for an interesting history of heaven and compilation of human death imaginaries.

25 Bynum analyzes the worlds of female Christian mystics to elaborate affective spirituality by carefully studying their imagery and metaphors. She calls attention to such words as love, teach, serve, mother, nurse, womb, and feed and their connotations in religious writings (1982). She ponders the affective qualities that are contained in human experiences of wonder, awe, inspiration, as well as encounters with ghosts and miracles to discuss their role in human transformation or metamorphosis. Bynum (2000) is interested in what eschatologies, or concerns about death and the ultimate destiny of human beings, (from Greek eschatos, meaning furthest or last), reveal about theories of the human person. She notes that in medieval contexts (1995) the body was not separated from the mind, heart, and soul—an idea that resounds in hospice literature.

26 A discourse in J.G.A. Pocock’s terms is “a complex structure comprising a vocabulary; a grammar; a rhetoric; and a set of usages, assumptions, and implications existing together in time and employable by a semi-specific community of language-users for purposes political, interested in and extending sometimes as far as the articulation of a world-view or ideology” (Pocock, cited in deVries, 2008, p. 791).
The turn toward holistic medical care and inclusion of spirituality is a trend that interestingly correlates with exponential growth in medical biotechnologies, resulting in increased medical treatment options meant to prolong life or increase quality of life for human beings. The corpus of loosely defined “complementary” and “alternative” therapies (or CAM, meaning complementary and alternative to the dominant biomedical therapies) that have emerged in the last forty years may be a reaction to increasingly high tech medical treatments that leave the patient in need of a balancing human touch. Indeed, the birth of “bioethics” as a multidisciplinary field of inquiry has developed in this same thirty to fifty year time period. Both the CAM and the bioethics movements might be seen as efforts to rein the unwieldy power of biomedicine gone unchecked and unbalanced.

A full description of the article is beyond the scope of this chapter, but readers are referred to the journal for the complete report. The Consensus Conference was sponsored by the Archstone Foundation in California, whose mission is “to contribute toward the preparation of society in meeting the needs of an aging population (archstone website).” The 40 conference attendees were invited national interdisciplinary leaders in palliative care.

My caveat to her observations is that these existential questions cannot be answered with certainty, but dialogue about what matters most to the dying person or mourning family members is of utmost importance in end-of-life ethics. Indeed, communication about how a person wishes to spend their last days and hours is essential information for the health care team. So despite some questions being “unanswerable,” I submit that conversation about individual values and speculations about purpose and meaning in life should be engaged.

In recent history, the modern hospice movement as founded by Dame Cicely Saunders in Great Britain in the 1960s, traveled to the United States in 1978. It is interesting to note that Saunders coined the phrase “total pain” to signify suffering that may have roots in multiple processes for human beings. In her years working as first as social worker, then as nurse, and finally as physician, she observed that pain and suffering at the end of life could be caused by physiological, mental, emotional, social, or spiritual dynamics. Her legacy was to address what she called the spiritual dimension of dying in specialized end-of-life care.

I note British sociologist Tony Walter’s (2002) critiques of spiritual discourse as “a burdensome discourse to those who object to the term and the implications of improving or treating spirituality” (pg. 134). He further asserts, “Spirituality is a discourse used at the present time in the English speaking world by those who wish to move beyond and distance themselves from institutional religion.” I might add that spiritual discourse also works to distance health professionals from reductionistic, atomistic, positivistic biomedical discourse. Thus spiritual discourse can be seen as a contestation of some biomedical and religious orthodoxies. I accept Walter’s view, and note the oversaturated meanings of the word spirituality, yet realize that some third type of language is needed to encompass end-of-life suffering in ways that resist the reduction of humans to physiological entities, as well as ways to move beyond the damaging rhetoric of fear and exclusion that is present in some religious discourse.

Although it is probably not intentional at this previously Methodist-based hospice, the use of terminology that might apply to Buddhist philosophy is striking to me. The ideal of compassionate presence is aligned with Buddhist philosophy and praxis. The focus on expansive relational ties could be references to interdependence. The references to mindfulness could refer to meditative awareness in the present moment. Garces-Foley suggests that the language of Buddhism was appropriated by humanistic and transpersonal psychology in the United States from the 1950s onward, and that Buddhist practices have reinvigorated end-of-life care. The acknowledgment of suffering as a part of human existence, the mutual expression of self with other interdependent processes, the call to
compassion, and mindful awareness of the present, make Buddhism a fit for working with dying. The
one sign of Buddhism that is not represented in this vision statement is that of no-self. In fact, an inner
“deep sense of self” or what might be called the soul in Western philosophical traditions is instead
referenced. This blending of East/West approaches to questions of human existence, suffering, and
death are also present in many informants’ spiritual imaginaries which mix a soul’s journey with
reincarnation.

33 Kearney draws on Jungian principles and practices that emphasize engagement of myth, symbol,
dreams, and images to engage what Jung called the “transcendent function.” According to Carl Jung,
images are the primary language of the psyche. The image and symbol making capacity of the psyche
are deep structures that can constellate a uniting symbol that transcends opposing elements that emerge
consciously or unconsciously in the human psyche. Jung further asserted that the individuation
process, or movement toward wholeness, is catalyzed by approaching death or metaphorically any loss
or transition to an unknown realm of experience.

34 Remember that I already stated the theme that informants’ death imaginaries do not necessarily match
the dogma of their declared religious tradition in the last chapter.

35 In future analysis, a taxonomy for categorizing the location of the deceased in time and space, noting
relational categories from the I/I heuristic could be constructed with these imaginaries. Each spiritual
imaginary could be analyzed for the temporal and spatial frames and how relation is constructed
between the living and the deceased.

36 She suggests that the need to believe is rooted in two experiences for human beings. The first is the
equivalent of Freud’s oceanic feeling, or feelings of intimate union with the mother/world (rooted in
pre-linguistic, pre-oedipal life). The second is confirmation of identity or “I” consciousness by some
beloved authority, the father/world, that acknowledges “I” exist (rooted in post-oedipal life and
language).

37 According to Miller, this statement has been misquoted to read “you cannot step into the same river
twice.”

38 An extensive treatment of feminist philosophy and care ethics is beyond the scope of this work, but
readers are referred to Noddings, Kittay, Joan Tronto, and Virginia Held to learn more about the
distinction between justice and care based ethics. Virtually all of these authors refer to the seminal
work done by Carol Gilligan, a pioneer who set the stage for the development of a feminist ethics of
care.
APPENDIX A

Research Process
The research process began when I was granted permission to interview people in bereavement programming at the hospice. I wondered if approaches to grief would be different in a major public medical center with no history of religious affiliation, and so received permission to collect data at the second site, which was the university medical center bereavement programming. However, the initial response to my requests for interviews at both sites was very slow. This necessitated opening the study to others outside the intended fieldwork sites. That being said, only thirteen participants are from outside these two fieldwork sites. Almost all of the lay informants come from the hospice site because of various difficulties finding informants at the medical center.

I used what is sometimes called the snowball technique for recruiting informants. In other words, anyone who heard of the study or was recruited by those who knew of the study became informants. Some hospice/bereavement programming staff members generously allowed me to observe their grief support groups after they had gotten permission for my attendance from the participants. I recruited most informants by attending grief groups run by the hospice, announcing the study there, and asking for volunteers. I also put an introduction to the study in two hospice newsletters to attract potential research participants. Interested participants were asked to call me to receive a questionnaire and set up an interview. Initially, I distributed a questionnaire to those participants who agreed to be in the study. From the returned questionnaire, I received their phone number with approval to call them to set up an interview. After about half of the questionnaires were in, I abandoned this method, since the information gleaned in interviews was much more comprehensive than that from the paper and pencil survey. The interviews took place in various settings. For those who volunteered or worked at hospice, most often the interview took place there. One phone interview took place with the only out of state participant.

A fairly large segment of the group (over one third of informants) started out as bereaved individuals then became lay, professional, or volunteer workers in the area of death, dying, grief, and bereavement. I think this speaks to the degree to which the death of a beloved person is a transformative event. The response from this group was significant in that they recognized how death had changed them personally and relationally. Most of the volunteers had utilized hospice services for their loved one who died and went on to become volunteers after a time of waiting. This dissertation has really become their story in many ways. They were eager to share the story of their own experience with death and dying and give examples of how formative it was in their own life.

National bereavement research reports that only about 15% of individuals use bereavement services after a death, so this population is somewhat unique. Perhaps some informants self identified as needing help during the transition after a death. Others were referred to bereavement services by hospice or hospital staff because they seemed at risk for “complicated bereavement,” a term I discuss in the body of the dissertation.
APPENDIX B

IRB Documents
III. Interview Questions
For people who are enrolled in or have previously participated in Hospice or Bereavement Services

IRB Protocol # 2009BO265
Kate Dean-Haidet RN MSN MA, Investigator
Today’s Date:

Your Background
Name
Sex
Age
Occupation
Ethnic group
Religion:
Time since the death/deaths

1. Can you tell me about your relationship with your deceased loved one?
2. How has the death affected you?
3. Since the death, what do/did you struggle with most?
4. What helps/helped you most through the time after the death?
5. Do you think/feel/sense you are still connected to the deceased person?
6. If so, would you be willing to share a story about your connection with the deceased?
7. Have your beliefs or imaginings about death changed during the time of bereavement or since the death of your loved one?
8. Is there anything else that you would like to tell me?
VI. Interview Questions for Bereavement Services Staff Members

IRB Protocol # 2009BO265
Kate Dean-Haidet RN MSN MA, Investigator
Interview Questions for Hospice/Bereavement/Grief Group Staff Members

Today’s date

Your Background
Name
Sex
Age
Occupation
Ethnic group
Religion:
Time since the death/deaths

1. Can you tell me about your relationship with your deceased loved one?
2. How has the death affected you?
3. Since the death, what do/did you struggle with most?
4. What helps/helped you most through the time after the death?
5. Do you think/feel/sense you are still connected to the deceased person?
6. If so, would you be willing to share a story about your connection with the deceased?
7. Have your beliefs or imaginings about death changed during the time of bereavement or since the death of your loved one?
8. Is there anything else that you would like to tell me?
APPENDIX C

Demographics and Field Work Sites
60 Total Taped Interviews

40 females
20 males
40 lay people (L)
20 hospice professional (P)
14 hospice volunteers (V)

<table>
<thead>
<tr>
<th>#</th>
<th>Name</th>
<th>Type</th>
<th>Role/Function</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sonya</td>
<td>P,V</td>
<td>music therapist at medical center</td>
</tr>
<tr>
<td>2</td>
<td>Alice</td>
<td>L</td>
<td>college senior, friend died</td>
</tr>
<tr>
<td>3</td>
<td>Marla</td>
<td>L</td>
<td>college senior, roommate/friend died</td>
</tr>
<tr>
<td>4</td>
<td>Dena</td>
<td>P</td>
<td>bereavement services coordinator, MSW</td>
</tr>
<tr>
<td>5</td>
<td>Brenna</td>
<td>L</td>
<td>retired businesswoman, husband died</td>
</tr>
<tr>
<td>6</td>
<td>Tessa</td>
<td>V</td>
<td>Threshold Choir director</td>
</tr>
<tr>
<td>7</td>
<td>Kendra</td>
<td>P</td>
<td>hospice director</td>
</tr>
<tr>
<td>8</td>
<td>Lora</td>
<td>P</td>
<td>Bereavement Services Counselor, MSW</td>
</tr>
<tr>
<td>9</td>
<td>Dottie</td>
<td>L</td>
<td>mother, daughter died of Gulf War Syndrome</td>
</tr>
<tr>
<td>10</td>
<td>Tina</td>
<td>L</td>
<td>homemaker, husband died</td>
</tr>
<tr>
<td>11</td>
<td>Gina</td>
<td>P</td>
<td>hospice chaplain</td>
</tr>
<tr>
<td>12</td>
<td>Tara</td>
<td>V</td>
<td>college professor, Buddhist chaplain, hospice volunteer</td>
</tr>
<tr>
<td>13</td>
<td>Nan</td>
<td>L</td>
<td>retired, partner died</td>
</tr>
<tr>
<td>14</td>
<td>Hannah</td>
<td>P</td>
<td>Jungian analyst, artist, bereavement counselor</td>
</tr>
<tr>
<td>15</td>
<td>Nina</td>
<td>L</td>
<td>retired nursing home administrator, mother died</td>
</tr>
<tr>
<td>16</td>
<td>Kyra</td>
<td>L</td>
<td>young mother, infant daughter died at 7 days old</td>
</tr>
<tr>
<td>17</td>
<td>Lexie</td>
<td>L,V</td>
<td>hospice volunteer, partner died</td>
</tr>
<tr>
<td>18</td>
<td>Lee</td>
<td>L</td>
<td>9-11 survivor, makes memorial glass jewelry</td>
</tr>
<tr>
<td>19</td>
<td>Lorna</td>
<td>L,P,V</td>
<td>daughter died, 9-11 support group volunteer leader</td>
</tr>
<tr>
<td>20</td>
<td>Sally</td>
<td>L</td>
<td>former ER health-care professional, baby twins died</td>
</tr>
<tr>
<td>21</td>
<td>Isabel</td>
<td>V</td>
<td>professional photographer, NILMDTS volunteer</td>
</tr>
<tr>
<td>22</td>
<td>Louise</td>
<td>P</td>
<td>bereavement counselor</td>
</tr>
<tr>
<td>23</td>
<td>Louise</td>
<td>P</td>
<td>bereavement counselor</td>
</tr>
<tr>
<td>24</td>
<td>Katherine</td>
<td>L,V</td>
<td>yoga teacher, husband died, 2 infant daughters died, volunteer</td>
</tr>
<tr>
<td>25</td>
<td>Miranda</td>
<td>V,P</td>
<td>artist, quilter, bereavement counselor</td>
</tr>
<tr>
<td>26</td>
<td>Monica</td>
<td>L,V</td>
<td>retired, volunteer, husband died</td>
</tr>
<tr>
<td>27</td>
<td>Melody</td>
<td>P,V</td>
<td>harper, hospice volunteer</td>
</tr>
<tr>
<td>28</td>
<td>Lena</td>
<td>V,L</td>
<td>retired, nursing home volunteer, husband died</td>
</tr>
<tr>
<td>29</td>
<td>Gay</td>
<td>P,V</td>
<td>retired teacher, counselor, hospice volunteer, Stephen Minister</td>
</tr>
<tr>
<td>30</td>
<td>Cindy</td>
<td>L</td>
<td>graduate student, husband died, widownet blogger</td>
</tr>
<tr>
<td>31</td>
<td>Nell</td>
<td>P</td>
<td>director Healing Journeys for Children, MSW, equine therapist</td>
</tr>
<tr>
<td>32</td>
<td>Tatti</td>
<td>L</td>
<td>retired, husband died</td>
</tr>
<tr>
<td>33</td>
<td>Phillipa</td>
<td>P</td>
<td>Infant Loss Support Group Facilitator, MSW</td>
</tr>
<tr>
<td>34</td>
<td>Rosa</td>
<td>L</td>
<td>college student, father died, yoga for grief class participant</td>
</tr>
<tr>
<td>35</td>
<td>Sheri</td>
<td>P,V</td>
<td>yoga teacher, teenaged daughter died</td>
</tr>
</tbody>
</table>

214
Infant Loss Group Parents - 15 people, couples whose babies died within 4 months of birth

**Informal Interviews**
- Mary & Curt - artist & videographer, baby daughter died, grief group facilitator, now do memorial videos for families of dying
- Donald, hospice physician
- Harry - retired, wife died

**Age range**
19 years to 86 years old

**Educational Levels**
high school diploma to post doctoral degrees

**Kinds of Death**
cancer, congenital anomalies, accident, suicide, heart disease, war, and others

**Religions Represented**
23 Christian
1 Mormon/Church of Jesus Christ of the Latter Day Saints
20 Undeclared or none (but this group had various beliefs in afterlife, reincarnation, continuance of soul, spirit, or essence of the human being)
7 Jewish
4 No affiliation or belief
2 Buddhist
1 Muslim

**Fieldwork Groups Observed**
American Academy of Hospice/Palliative Care Medicine, Wash DC, 2010
American Society for Bioethics & Humanities meeting, Wash DC, 2009
Central Ohio Conference on Grief, 2010, 2011
Grief Share session at Etna United Methodist Church
Healing Journeys for Children Debriefing Group, major medical center
Hospice Memorial Service—N Broadway United Methodist Church, Woodside Hospice
I Love You Lindsay Facebook Page, memorial page
Infant Loss Support Group Woodside Hospice
Marmon Valley Art group, part of “Good Grief” Group, major medical center
Marmon Valley Horse Camp part of “Healing Journeys for Children,” major medical center
Mommies of Angels You Tube Video done by Infant Loss members, 2009
NIH Summit on End-of-Life Research, Wash. DC, August 2011
Now I Lay Me Down to Sleep (NILMDTS), infant death photography, Newark OH
Ohio Hospice & Palliative Care Organization conferences 2009, 2010
Older Widow/Widowers Support Group Maple Grove Methodist Church, Woodside Hospice
Steps Toward Healing, general grief group at Woodside Hospice
Threshold Choir, four meetings at Columbus Mennonite Church
Widownet.com
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Kasulis, T.P. (2010). From the love of wisdom to the wisdom of love: Re-envisioning our philosophical foundations of interrelationship. Lecture given at Gustavus Adolphus College, St. Peter, MN.


