

PSYCHOSPIRITUAL TRANSFORMATION THROUGH CHRONIC ILLNESS:
AN INTUITIVE INQUIRY

by

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A dissertation submitted
in partial fulfillment of the requirements
for the degree of Doctor of Philosophy
in Psychology with a concentration in Transpersonal Psychology

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February 5, 2014

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Abstract

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The purpose of this research was to understand the subjective experience of psychospiritual transformation among people who have lived with chronic physical illness for at least 7 years, beginning in early to mid-adulthood. I define psychospiritual transformation as a profound change in the core ways in which we function, see ourselves, and relate to other beings in the world. I used the intuitive inquiry research method because it provides an interpretive structure for exploring subtle topics of psychospiritual development close to this researcher's own life experiences (I have lived with Type 1 diabetes for 22 years and fibromyalgia for 7 years). This method included (a) an inward examination of my own experience and perspective on the topic, (b) an analysis of 8 previously published autobiographical narratives, and (c) a reflection on my own shifts in understanding of the topic in light of relevant literature.

In my theory of psychospiritual transformation through chronic illness I describe a process of change over time, touching upon a fuller range of transpersonal human experience and development not present in previous studies and theories on this topic. These cyclical moments include (a) an initial physical crisis and the shock of diagnosis, (b) an attempted return to one's previous lifestyle and a search for a cure; (c) losses and the disintegration of the self; (d) slowing down/inward focus; (e) mourning losses; (f) fear and helplessness at uncertainty; (g) confronting one's shadow while learning self-observation and self-compassion; (h) integral self-care from one's own body consciousness; (i) new lifestyle and an expanded sense of self; (j) integration of inner opposites and revisiting previously unresolved issues; (k) paradoxical movement between

surrender and will; (l) embodied attention and joy, with a greater appreciation for the spiritual dimensions of the self and the world; (m) a sense of interconnection with the world and compassionate service for others; and (n) living in the moment with gratitude and acceptance of impermanence.

Dedication

To all people who suffer from chronic illness. May you find joy, meaning, hope, appreciation of the moment, and light within the darkness.

Acknowledgements

I would like to thank all of the people who have helped me during these past years of my dissertation process, especially family and friends. I am also grateful to the authors of the narratives that I analyzed in this study; these allowed me to reach a greater understanding of the topic. Thank you to my chairperson, Dr. Nancy Rowe, for your patience, insightful accompaniment, and motivation. Thank you to Dr. Ilka List and Dr. Kevin Krycka for your valuable input on my research.

Epigram

God, give us grace to accept with serenity the things that cannot be changed, courage to change the things that should be changed, and the wisdom to distinguish the one from the other.

~Reinhold Niebuhr, The Serenity Prayer (1943/2012, p. 695)

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Chapter 1: Introduction

Chronic illness can be a shocking wake-up call to the fragility of our bodies and our lives (Loffer, 2000; Metzger, 2004; Spencer-Benson, 2003; Taylor, 2003). One may experience a range of overwhelming, sometimes horrible, physical sensations and emotions that one never imagined possible (Butterfield, 2011; Fennell, 2001, Goodheart & Lansing, 1997; LeMaistre, 1995; Register, 1999; Ruhl, 1995). When illness does not go away, life is forever altered in a myriad of ways, forcing one to abide rigorously by the body's needs and shed ways of living that have become damaging or impossible (Cole & Hopkins, 2006; Fennell, 2001; Goodheart & Lansing, 1997; Ironson et al., 2002; Ruhl, 1995). As days become months and years, some people with chronic illness may struggle to find meaning in living with this perplexing, relentless, invisible burden (Butterfield, 2011; Fennell, 2001; Goodheart & Lansing, 1997; LeMaistre, 1995; Register, 1999; Ruhl, 1995). Some may easily fall into despair and depression, becoming a broken body and spirit living at a survival level, a shell of one's previous life (Butterfield, 2011; Fennell, 2001; Goodheart & Lansing, 1997; LeMaistre, 1995; Register, 1999; Ruhl, 1995).

However, other people seem to emerge from this ordeal with the uncanny patience, serenity, wisdom, and nonattachment usually found only among saints, mystics, and truly enlightened beings (Butterfield, 2011; Cole & Hopkins, 2006; Loffer, 2000; Ruhl, 1995; Spencer-Benson, 2003; Taylor, 2003). Surely, no one who lives with chronic illness is a stranger to suffering, pain, and darkness, but some individuals somehow find *brightness* (Butterfield, 2011; Cole & Hopkins, 2006; Loffer, 2000). They may live in sync with their own body and soul in a way that is foreign, and perhaps inaccessible, to people who enjoy good health (Metzger,

2004). In this sense they experience a transformation that no one would *willingly* undertake minus the illness (Kabat-Zinn, 1993; Kramer, 2003; Metzger, 2004).

This dissertation is an attempt to understand the life stories of those people who have been transformed by a chronic illness. I believe that these insights are valuable to people who live with an illness, to those who love and accompany them, and, perhaps, to anyone with an appreciation for being present to the movements and needs of body and spirit along one's path of development. I gathered data from eight previously published autobiographical narratives of people who have lived with a chronic physical illness for at least 7 years. I attempted to lean into these experiences so that I might witness, feel, understand, and tell. As the reader's tour guide, I engaged in this inquiry from my own path of living with Type 1 diabetes for more than half of my life and, during the past 7 years, with fibromyalgia (a central nervous system disorder mainly characterized by pain throughout the body, cognitive impairment, chronic fatigue, and sleep disturbance), transparently showing and working with, for what they are, my own biased perceptions, ideas, experiences, and shifts on the topic. I am aware that the findings of this study do not necessarily represent how all people experience chronic illness; in a sense this research is biased because it is based on narratives from people who found meaning and understanding in living with a chronic illness and felt inspired to write their stories. This research was a transformative experience for me on many levels, and I hope that it will also be so for the reader.

I engaged in intuitive inquiry (Anderson 2004a, 2006, 2011) to understand the process of transformation through chronic illness within a hermeneutic circle that includes (a) an inward examination of my own experience and perspective on the topic, (b) an outward movement in analyzing 8 people's published experiences, and (c) an inward return to reflections on my own shifts and changes in understanding in light of this new data and the relevant literature. In this

sense, intuitive inquiry invites the researcher to mediate a dialogue between his or her self, the research participants, and the wider cultural understandings of a lived experience. With the researcher as both the lens and the instrument of inquiry, I used a series of rigorous intuitive research techniques adapted to my own intuitive style.

Transpersonal Relevance of the Research

As painful and as difficult as illness may be, it can sometimes help us to awaken previously undeveloped qualities, perceptions, sensibilities, and abilities (Loffer, 2000; Metzger, 2004; Mindell, 1985; Strachan, 1992). It may be a catalyst toward healing core psychological issues, living with greater presence in the body, learning key life lessons, and cultivating a greater sense of purpose and life mission (Hillman, 1996; Ironson et al., 2002; Metzger, 2004; Mindell, 1985; Spencer-Benson, 2003; Strachan, 1992; Taylor, 2003; Walsh, 1990). One may experience chronic illness as a kind of forced embodiment or spiritual practice quite distinct from a path of personal ego development (Hart, 2000; Kabat-Zinn, 1993; Metzger, 2004). Illness has been called the Western path to enlightenment, a phrase that characterizes these experiences as comparable to the excruciating physical endeavors that ancient spiritual seekers willingly undertook for the sake of their own spiritual development (Kabat-Zinn, 1993; Kramer, 2003; Metzger, 2004). Illness can be an indication of overall psychospiritual imbalance and a teacher for aligning ourselves with our own soul, which perhaps mysteriously *chooses* this challenge in a movement toward wholeness (Hillman, 1996; Newton, 1994, 2000, 2004; Walsh, 1990). In this study I define psychospiritual transformation as a profound change in the core ways in which we function, see ourselves, and relate to other beings in the world (Coburn, 2006; Gaynor, 1999; Hart, 2000; Imber, 1994; Metzner, 1986).

Justification

Sufferers of chronic illness and the professionals and loved ones who support them find few references for understanding the transformative potential of illness from real-life experiences. Stories of people who have experienced an internal transformation through their illness seem limited to vague, distant legends of gurus, mystics, and shamans. Furthermore, few theoretical reflections shed light on the way that this embodied process may unfold over time, including their progression through common stages, cycles, shifts, and challenges and the experience of the key factors that contribute to transformation and healing (Ruhl, 1995).

Psychological literature on illness offers therapeutic approaches for helping people cope with illness (Fennell, 2001; Goodheart & Lansing, 1997; LeMaistre, 1995) and explorations of typical responses to illness over time (Goodheart & Lansing, 1997; Register, 1999; Ruhl, 1995), but rarely proceeds from exploration of deeper and more pervasive aspects of transpersonal psychospiritual development. Research on transformation through illness has focused mainly on the *effects* of surviving a life-threatening illness late in life (Cole & Hopkins, 2006; Spencer-Benson, 2003), personal healing in association with the dying process (Williams, 1995), and experiences with specific illnesses (Ironson et al., 2002; Loffer, 2000; Taylor, 2003), rather than on the experiences common to people who live with any of several types of chronic physical illness over greater periods of time.

Definition of Terms

In this section I will briefly define my own understanding of several key terms to be used in this study. I include these here in order to maximize the clarity of this study. A more in-depth discussion of these and other terms can be found in Chapter 2: Review of Literature.

To expand on my aforementioned definition, *transformation* relates to many aspects of one's life (including the psychological, spiritual, physical, social, etc.) and is an on-going process of development (Braud, Dufrechou, Raynolds, & Shroeter, 2000; Coburn, 2006; Hart, 2000; Imber, 1994). This process involves paradoxical movements between surrender and will (Hart, 2000), uncovering and reconciling dialectical opposites or conflicts, and discovering and integrating shadow aspects of the self (Coburn, 2006; Hart, 2000; Metzner, 1987). As we transform, we become more aware of the spiritual dimensions of the self (including our own uniqueness and potentials) and less identified with an ego self, while, at the same time, feeling a greater connection to the world on multiple levels (Hart, 2000; Imber, 1994; Maslow, 1999). Transformation may be catalyzed by limits on external freedoms and may move us toward greater presence, openness, and inner freedom (Hart, 2000).

I regard healing as a process similar to transformation, the former term referring to a phenomenon that is often mentioned in relation to a specific illness, psychological wound, or trauma (Mehl-Madrona, 2003; Metzger, 2004). I define healing also as a profound change in core ways of functioning, but with an emphasis on the resolution and integration of core wounds or conflicts that had previously limited one's integral well-being or development (Ingerman, 1991; Loffer, 2000; Mehl-Madrona, 2003; Metzger, 2004; Spencer-Benson, 2003; Taylor, 2003). Although transformation and healing can be rather synonymous, I think of healing more in terms of moving beyond a point of stuckness, or, a chronic, pervasive, one-sided way of being, toward greater balance and an expanded sense of self (Loffer, 2000; Mehl-Madrona, 2003; Metzger, 2004; Spencer-Benson, 2003; Villoldo & Krippner, 1986). One may heal from a specific conflict or issue but continue to transform in other ways. Both transformation and healing comprise a

process of aligning one's own body and psyche with the soul (Mehl-Madrona, 2003; Metzger, 2004; Villoldo & Krippner, 1986).

Among illness experiences, healing is often contrasted with the idea of a cure, or, the resolution or elimination of physical symptoms (Lerner, 1993; Mehl-Madrona, 2003; Metzger, 2004; Remen, 1993). A state of either illness or cure can be subject to observable data. A cure is often the sole purpose of Western medicine. Given these definitions, experiences of healing and a cure may be quite distinct and independent, as one may live one without the other (Lerner, 1993; Mehl-Madrona, 2003; Metzger, 2004; Remen, 1993). In this dissertation I have focused on people's experience of transformation, or, perhaps, healing, regardless of whether they have experienced any degree of a cure.

I herein use, as my operational definition of *intuition*, "a subtle sense perception that conveys direct insight into future possibilities or circumstances that cannot be experienced through the ordinary five human senses or analytical reason" (Anderson, 2007, p. 1). Intuition interacts with the senses, the rational mind, the imagination, and our communication with the world around us. It is manifested in a variety of ways, and, with attention, people can become more familiar with their own unique intuitive ways of knowing and develop practices to maximize their intuitive insights (Anderson, 2007, 2011).

Research Questions

This dissertation process was guided by the main research question, the nature of the topic, and my own characteristics as a researcher. My main research question was *What is the subjective experience of psychospiritual transformation among people who live with chronic physical illness?* I sought to understand this phenomenon over a period of at least 7 years.

I was also interested in the following secondary questions in exploring specific aspects of the main research question: (a) In what ways do the selected authors feel that they have been transformed by their illness experience? (b) How do the authors interpret their illness? Has it changed the way that they *experience* their bodies? (c) How do the authors of the selected autobiographical narratives find *meaning* in living with chronic illness? (d) What do the authors consider has contributed to their transformation process? (e) How have the authors indicated that they modified their lives as a result of their illness? Rather than approaching this study with hypothesized answers to the above research questions, I tried to remain as open as possible to the emerging data.

Method

I used intuitive inquiry to do this research because it allows access to unconscious, intuitive knowledge and experience about a topic that is very close to the researcher (Anderson, 2004a, 2006, 2011). Intuitive inquiry is an effective way of explaining the universal through particular experiences (Anderson, 2004a, 2011), which factor allowed me to relate the findings to a broader understanding of living with and transforming through chronic illness. Throughout this research process, I used my own intuitive strengths, which include feeling through my body; empathic identification; access to unconscious material through writing, dreams, movement, and shamanic journeys; and detecting and combining multiple aspects of a phenomenon from internal and external sources. I have developed some of these intuitive strengths through my embodied experience with illness, and I have also been trained in shamanic practices.

Potential Contributions to Transpersonal Psychology

Although this research is primarily directed at sufferers or survivors of chronic illness, I hope that the findings may also help transpersonal psychologists and other mental and physical

healthcare professionals to understand and assist such patients in their transformation process. In the end, I hope that this research project will enrich and bridge the respective fields of psychology, spiritual guidance, and holistic healing.

I believe that this research project is innovative and important because I attempted to reach an in-depth understanding of the embodied process of transformation through chronic illness, from other people's experiences and my own, while drawing from theories of transpersonal psychospiritual development (Hall, 2000; Hillman, 1996; Jung, 1939/1983, 1928a/1983; Maslow, 1999; Ruumet, 1997, 2006; Wilber, 1999). Rather than researching a time-specific experience, phenomenon, or state, I used intuitive inquiry to understand an inner process that occurs over a great period of time (more than 7 years); in a sense, I attempted to understand a *sequence* of experiences or phenomena within a process. Since the topic itself regards a subjective narrative, I, appropriately, drew research data from autobiographical narratives and expressed my new theory of psychospiritual transformation through chronic illness as a composite narrative. I juggled the complex challenge of contemplating both the specific issues or moments of this story and the overall process involved in the transformation. In order to do this, I gathered data from authors who had already contemplated and written about their own process. To the best of my knowledge, I am the first researcher to use intuitive inquiry to understand a process over time and to draw data from previously published autobiographies. I also contributed methodological innovations to intuitive inquiry and research in psychology through my own unique ways of knowing and being in the world, which, at the same time, are also universal. Specifically, I believe that I have contributed innovations for researching embodied aspects of psychospiritual growth and healing.

In general, this research proposal coincides with Sofia University's global research foci in terms of "spiritual experiences and qualities that serve the global community" (Anderson & Braud, 2006, p. 2). This study is also a way to honor global wisdom psychologies and multicultural ways of knowing. These findings promote tolerance, authenticity, truth-telling, and understanding.

In the following chapter I will present a literature review of the relevant theories and research findings related to psychospiritual transformation and healing through chronic illness. In chapter 3 I explain the research methods used in this study that include providing an overview of intuitive inquiry and a discussion of validity. Each of the subsequent five chapters mirrors the five cycles of intuitive inquiry. In chapter 4, or Cycle 1, I explain my relationship to the research topic and my intuitive style. In chapter 5, or Cycle 2, I present my own lenses for understanding the research topic prior to data collection and my research procedures for defining and articulating these lenses. In chapter 6, or Cycle 3, I present the results of this study, or, the main themes that have emerged from the 8 participants' illness narratives, and my research procedures for arriving at these themes. In chapter 7, or Cycle 4, I present my new understandings of the research topic and the process through which these emerged. In chapter 8, or Cycle 5, I integrate my new understandings of the research topic with the empirical and theoretical literature and offer a discussion of my methodological contributions of this study to the field of transpersonal psychology.

Chapter 2: Review of the Literature

How do people experience psychospiritual transformation through chronic illness?

Transpersonal spiritual perspectives of lifespan development (Anderson, 2004b; Hall, 2000; Hillman, 1996; Jung, 1939/1983, 1928a/1983; Kegan & Laskow Lahey, 2009; Maslow, 1999; Ruumet, 1997, 2006; Washburn, 1995, 2003; Wilber, 1993, 1999), illness (Grossinger, 1980; Mehl-Madrona, 2003; Metzger, 2004; Mindell, 1985; Newton, 1994, 2000, 2004; Strachan, 1992; Walsh, 1990), transformation and spiritual growth (Braud et al., 2000; Carpeneto, 1997; Coburn, 2006; Esbjörn, 2003; Gaynor, 1999; Hart, 2000; Imber, 1994; Metzner, 1986, 1987), and healing (Achterberg, 1987; Horrigan, 2003; Ingerman, 1991; Mehl-Madrona, 2003; Metzger; Villoldo, & Krippner, 1986; Yeh, Hunter, Madan-Bahel, Chang, & Arora, 2004) can provide an overarching framework for understanding this process. At the same time, empirical findings on psychospiritual transformation and healing related to illness (Cole & Hopkins, 2006; Krycka, 2000; Spencer-Benson, 2003) and chronic illness (Ironson et al., 2002; Loffer, 2000; Ruhl, 1995; Taylor, 2003) and conceptual proposals on the process of living with a chronic illness (Butterfield, 2011; Fennell, 2001; Goodheart & Lansing, 1997; LeMaistre, 1995; Register, 1999) can elucidate more subtle, vivid details of what this experience may be like.

Transpersonal psychologists contemplate multidimensional aspects of human beings in relationship with the universe within the context of a spiritual journey, or a process of becoming, beyond ego consciousness (Hillman, 1996; Jung, 1939/1983, 1928a/1983; Maslow, 1999; Newton, 1994, 2000, 2004; Ruumet, 1997, 2006; Walsh, 1990; Washburn, 1995, 2003; Wilber, 1993, 1999). Illness and physical symptoms can also be understood within this broader context of development (Hillman, 1996; Mindell, 1985; Strachan, 1992; Walsh, 1990). Physical symptoms may be viewed externally and rather objectively, as they often are in modern

medicine, through empirical and quantitative measures. They can be grouped and characterized by general diagnoses with corresponding causes and treatments. However, the *meaning* of illness within one's own process of lifespan development is subjective and multidimensional (Ruhl, 1995). Illness may be understood within the context of psychological wounds and needs, cycles of ordering and disordering, social and global phenomena, natural processes of growth and maturation, and callings or initiations to new stages or aspects of development (Hillman, 1996; Jung, 1939/1983, 1928a/1983; Metzger, 2004; Newton, 1994, 2000, 2004; Ruumet, 1997, 2006; Walsh, 1990; Wilber, 1999). It may be difficult for us to contemplate the overall meaning and pattern of illness within the context of our greater path, because we are often firmly living or perceiving from our immediate bodily sensations and ego needs and wants.

A Transpersonal Understanding of Development and Illness

Since the goal of my study was to understand the subjective experience of psychospiritual transformation through chronic illness, in this chapter I will explore both theoretical and empirical literature related to this process. Many of the authors cited in this section offer theoretical understandings of illness within the process of human development (Campbell, 1949; Dennehy, 1987; Grossinger, 1980; Hillman, 1996; Metzger, 2004; Mindell, 1985; Newton, 1994, 2000, 2004; Strachan, 1992; Walsh, 1990). These perspectives are positioned *from the outside looking in* and are complementary to the way that people who suffer from chronic illness may subjectively understand their own experience.

Several authors have pointed to the potential role of illness in contributing to psychospiritual development. Counseling psychologist Michael Newton (1994, 2000, 2004) wrote of the soul willingly *choosing* the physical body (from a limited set of choices) with which one incarnates. He based his assertion on data from hundreds of hypnotherapy past-life-

regression sessions. Newton argued that, although each lifetime is not predetermined, the soul chooses (based on previous but limited information) a set of life conditions, including a body and personality, that will appropriately combine with and challenge the soul in working on specific areas of development toward its further evolution across lifetimes. Newton pointed out that, in some cases, the soul deliberately chooses a life with illness in order to develop these qualities and make its contribution to the world.

Psychologist James Hillman (1996) argued that, as is consistent with understandings common to world spiritual traditions, we come into the world with an inherent way of being and that symptoms may be a crucial part of revealing a person's unique calling or destiny. Hillman explained that symptoms are literally "a combination of accidental happenings" (p. 34), neither good nor bad, that coalesce into an image that shines and wants to be seen. Hillman urged readers to revalue symptoms and their invisible intentions as belonging not "first to disease but to destiny" (p. 34). However, Hillman pointed out that "it is impossible to see the angel unless you first have a notion of it" (p. 108), thus emphasizing the need for instruction in looking beyond what our sight tells us.

Psychologist Roger Walsh (1990) emphasized that growth is not fluid or smooth but rather is often accompanied by psychological stress, transitions, and turning points. He argued that this stress is usually mirrored in the body and that physical symptoms may be part of an initial shamanic calling, or a developmental opportunity, whose refusal can result in a worsening physical condition or even death.

Similarly, psychologist Arnold Mindell (1985) claimed that bodily symptoms, illnesses, and dreams all carry important information about the manifestation of the unconscious. He argued that illness is a compensating function of a one-sided conscious attitude *necessary* to the

person at an unconscious level. Mindell stressed the value of analyzing physical symptoms as a piece of information in attempting to become more whole while also alleviating the symptoms:

Feel your symptoms, pick up your signals and integrate them now into your life. If you are lucky healing will occur. If you are even luckier, you will begin to grow. Even if your chronic symptoms do not disappear, they become friendly allies ushering you into a phase of existence in which you behave as a whole and congruent person in the midst of a rich and meaningful life. In any case sickness can be a stroke of luck. It's a dream in the body; use it to wake up. (pp. 69-70)

Both Mindell (1985) and psychologist Virginia Dennehy (1987) referred to dream images and symptoms as beginning messages within a psychophysical process toward integration and wholeness. Mindell also cautioned against regarding an illness as directly corresponding to or being caused by a single psychological issue, arguing that the physical and the psychological are interactive. Thus, a chronic illness can be related to several psychological problems at different moments throughout one's life, just as certain psychological issues may interact with the body in different ways.

Mindell (1992) also explained that one's physical and psychological processes interact with processes outside the individual self, including environmental, social, hereditary, and cultural factors. In his concept of *fields*, he argued that every feeling, thought, movement, and encounter is simultaneously an inner and an outer event. Dramatic outer events can shape our inner world, and we may feel these fields through multiple channels, senses, and experiences.

Consistent with Mindell's (1985, 1992) theory, psychologist Alan Strachan (1992) suggested that symptoms are priceless *gifts* that may guide one throughout life in recognizing and living in accordance with one's deepest truths and destiny. Strachan cited Mindell (1985, 1992) and Jung (1964, 1966, 1969, 1976) in referring to childhood dreams as manifesting life patterns, adult illnesses, and one's basic *life myth*, because the early unconsciousness represents the wholeness of the personality before the ego filter is more fully developed.

Psychologist Jerry Michael Ruhl (1995) argued that, since all types of symptoms are part of one's developmental process, their meaning can be understood from several perspectives and levels. He pointed out that "other levels of meaning, such as situating the illness within a personal life story and relating the illness to a patient's central purpose, are often ignored or negated" (p. 158). Ruhl suggested that, "by approaching illness with a mythic or religious attitude, a patient may learn to accept and accommodate forces greater than the individual will and thereby connect to more encompassing and enduring levels of nature's hierarchy" (p. 159). Ruhl cited mythologist Joseph Campbell's (1949) idea of accepting one's own woundedness and working with one's fate: "In the search for meaning, the sufferer may be thrown into an archetypal experience beyond meaning. This involves a view of suffering from other than the ego perspective: it involves a sense of the 'not I,' the unconscious, or the Divine" (Ruhl, 1995, p. 159).

Anthropologist Richard Grossinger (as cited in Achterberg, 1987) referred to disease as "the place where all other crises and necessities of the organism come together. It is the most intimate writing of the turbulence and changes of life on the single bodies and collective body of the biosphere" (p. 13). Similarly, writer and storyteller Deena Metzger (2004) referred to illness as a manifestation of both the person's soul and a society's ills.

Metzger (2004) argued that illness is a "breakdown [or a] necessary ordeal that reveals meaning and leads to our transformation" (p. 7). She explained that illness is the necessary breakdown in order to undermine the destructive aspects of our lives and to "receive the spirit" (p. 7). Metzger further argued that a person who suffers illness and who learns this task can become a healer: "We learn our most powerful medicine through our bodies and lives. The medicine person suffers a common jeopardy and often carries medicine exactly as the vehicle for

an affliction that will provide us with needed teachings” (p. 4). Metzger argued that an illness experience may help us to forget who we are (in terms of the ego self), more readily identify a call from spirit, and live more presently in the body: “Illness has become the spiritual challenge and trial that leads to enlightenment in our society. It has become our hero’s journey. It calls us on to the sacred path. It provides the ordeal that allows for transformation” (p. 14). Both Ruhl (1995) and Metzger emphasized the importance of seeing the mythic and archetypal levels of illness and healing as an opportunity for personal and social change.

The authors in this section refer to the wide variety of causes of physical illness and its possible contributions to psychospiritual development (Campbell, 1949; Dennehy, 1987; Grossinger, 1980; Hillman, 1996; Metzger, 2004; Mindell, 1985, 1992; Newton, 1994, 2000, 2004; Ruhl, 1995; Strachan, 1992; Walsh, 1990). I consider these ideas complementary to the way that sufferers of chronic illness experience their lives. Taking into account unconscious and social factors in the development of illness and in the process of meaning-making can widen and enrich our understanding of the subjective experience of illness without belittling or demeaning it. Although some of the authors sometimes consider illness to be a calling toward wholeness or a higher level of development (Dennehy, 1987; Grossinger, 1980; Hillman, 1996; Metzger, 2004; Mindell, 1985; Newton, 1994, 2000, 2004; Strachan, 1992; Walsh, 1990), I believe that it would be too reductionist to argue that sufferers of chronic illness *cause* their own illness or that their continued physical symptoms can be necessarily attributed to their refusal to acknowledge a calling, unconscious factors, or their own “medicine” (Metzger, 2004, p. 1). This extreme position would unfairly and exclusively charge sufferers of chronic illness with the task of a superior level of human development and erroneously assume that they are the only people who have not completely integrated their own corresponding unconscious material and callings.

Similarly, any type of human tragedy or challenge can potentially contribute to one's psychospiritual development. I suggest that the phenomenon of chronic illness is more complex and multilayered than it is characterized to be by this reductionist perspective, and I am more interested in understanding the way that people subjectively experience their own process with chronic illness rather than providing theoretical arguments for why they are sick and how they should live this experience.

Transpersonal Models of Embodied Lifespan Development

In this section I will briefly outline ideas and models of transpersonal lifespan development to provide a wider framework for understanding psychospiritual transformation through chronic illness. By *transpersonal lifespan development* I mean the general way that we experience growth throughout our lives, including the multidimensional ways in which we change and shift (Ruumet, 1997, 2006). The subjective experience of psychospiritual transformation through chronic illness outlined in this study also, in turn, provides a specific, unique experience of development that can inform and give greater detail to the more general models of transpersonal lifespan development.

Transformation and lifespan development are related to psychologist Carl Jung's (1939/1983) idea of individuation, which he used "to denote the process by which a person becomes a psychological 'in-dividual,' that is, a separate, indivisible unity or 'whole'" (p. 212). "Individuation means becoming a single, homogeneous being, and, insofar as 'in-dividuality' embraces our innermost, last, and incomparable uniqueness, it also implies becoming one's own self. We could therefore translate individuation as 'coming to selfhood' or 'self-realization'" (Jung, 1928a/1983, p. 418).

Jung (1944/1983) used the term *the self* to describe the individual psyche, which includes both conscious aspects—or, the ego—and unconscious aspects. “The self is not only the center but also the whole circumference which embraces both consciousness and unconscious; it is the center of this totality, just as the ego is the center of the conscious mind” (p. 422). For Jung (1928a/1983), “the self is our life’s goal, for it is the completest expression of that fateful combination we call individuality” (p. 422).

Jung (1952/1983) claimed that “if the individuation process is made conscious, consciousness must confront the unconscious and a balance between the opposites must be found” (p. 328).

Conscious and unconscious do not make a whole when one of them is suppressed and injured by the other . . . Both are aspects of life. Consciousness should defend its reason and protect itself, and the chaotic life of the unconscious should be given the chance of having its way too—as much of it as we can stand. This means open conflict and open collaboration at once. That, evidently, is the way human life should be. It is the old game of hammer and anvil: between them the patient iron is forged into an indestructible whole, an “individual.” This, roughly, is what I mean by the individuation process. As the name shows, it is a process or course of development arising out of conflict between the two fundamental psychic facts. (Jung, 1939/1983, p. 225)

Jung (1934/1983) considered *personality* to be an achievement of the second half of life manifested by “definiteness, wholeness and ripeness” (pp. 18-19).

If the unconscious can be recognized as a co-determining factor along with consciousness, and if we can live in such a way that conscious and unconscious demands are taken into account as far as possible, then the center of gravity of the total personality shifts its position. . . . This new center might be called the self. (Jung, 1929a/1983, p. 19)

Jung observed that, when we begin to embrace the unconscious in our individuation process, we begin to understand and confront the persona, the shadow, the anima/animus, and other archetypes that emerge from the collective unconscious.

For Jung (1929b/1983) “the persona is a complicated system of relations between individual consciousness and society, fittingly enough a kind of mask, designed on the one hand

to make a definite impression upon others, and, on the other, to conceal the true nature of the individual” (p. 94). “One could say, with little exaggeration, that the persona is that which in reality one is not, but which oneself as well as others think one is” (Jung, 1934b/1983, pp. 420-421). In order to engage in the individuation process, one must begin to understand the construction of one’s persona and one’s truer nature beyond it.

According to Jung (1939/1983), one also confronts the shadow, which “personifies everything the subject refuses to acknowledge about himself and yet is always thrusting itself upon him directly or indirectly –for instance, inferior traits of character and other incompatible tendencies” (p. 221). “The shadow is that hidden, repressed, for the most part inferior and guilt-laden personality whose ultimate ramifications reach back into the realm of our animal ancestors” (Jung, 1951/1983, p. 422). Jung emphasized that, on closer examination, the shadow “does not consist only of morally reprehensible tendencies, but also displays a number of good qualities, such as normal instincts, appropriate reaction, realistic insights, creative impulses, etc. (sic)” (Jung, 1951/1983, pp. 422-423)

According to Jung (1939/1983), the unconscious also contains the anima (in men) and the animus (in women), or, unconscious female and male personalities of which we are “generally quite unaware” (p. 221). He argued that “the animus and the anima should function as a bridge, or a door, leading to the images of the collective unconscious, as the persona should be a sort of bridge into the world” (Jung, as cited in Storr, 1983, p. 415). With the shadow and the anima/animus, one is confronted with and engages with aspects of the unconscious that are in contrast to one’s conscious identity or ego. During the individuation process, one integrates these opposites, bringing them into consciousness. Jung (1952/1983) emphasized the importance of consciously engaging in the individuation process:

The difference between the “natural” individuation process, which runs its course unconsciously, and the one which is consciously realized, is tremendous. In the first case consciousness nowhere intervenes; the end remains as dark as the beginning. In the second case so much darkness comes to light that the personality is permeated with light, and consciousness necessarily gains in scope and insight. The encounter between conscious and unconscious has to ensure that the light which shines in the darkness is not only comprehended by the darkness, but comprehends it. (p. 328)

Jung (1928b/1983) also theorized about four natural human functions: *intuition*, *sensation*, *feeling*, and *thinking*. He argued that we learn to use the function or functions that have become most natural, easy, or habitual, while the unused ones remain “relatively unconscious, and, hence, unused, untrained, and undifferentiated” (p. 63). The functions are complementary pairs (intuition vs. sensation and feeling vs. thinking), as we use one in favor of its opposite. Our personality is substantially based on our primary function, the subsequent order in which we begin to access the other three functions, and our dominant attitude of *introversion* or *extraversion*. Hence, for Jung, striving for wholeness or unity entails bringing to consciousness all four functions and moving beyond the most habitual one(s).

Jung’s ideas of individuation (1939/1983, 1928a/1983), the persona (1929b/1983, 1934b/1983), wholeness and the self (1928a/1983, 1944/1983), the integration of the shadow (1939/1983, 1951/1983), the anima/animus (1939/1983), and psychological functions (1928b/1983) all provide important insights toward understanding the process of psychospiritual transformation through chronic illness during a person’s lifetime. I have applied these concepts to the discussion of my own model of this process in chapter 7 and in my discussion of its relationship to Jungian psychology in chapter 8.

Other lifespan development theorists (Erickson, 1980; Fowler, 1995; Hall, 2000; Keen, 1979; Maslow, 1999; Ruumet, 1997, 2006; Wilber, 1999) agreed on a general premise that people must move through certain stages or conflicts in order to proceed to higher levels of

development. They mentioned that these stages do not imply a linear process in which people definitively progress from one stage to the next but represent cyclical growth in which one may partially or temporarily *regress* to previous ways of being, revisiting certain inner conflicts in new and different ways. Living with a chronic illness can create unique life challenges, thus triggering specific instances of the application of these developmental models.

Transpersonal theorist Ken Wilber (1993, 1999) outlined a hierarchical model of human spiritual development that included nine stages and three components of consciousness. He broke down these stages into three major ones: the *prepersonal*, the *personal*, and the *transpersonal*. For Wilber the *prepersonal* stage exists before the development of the ego, consisting of id and psychic aspects, both of which remain at an unconscious level. The *personal*, or *egoic* stage, is associated with self-consciousness, overcoming self-alienation, and finding a personal calling or meaning. The *transpersonal*, or *superconsciousness*, stage is the discovering of Spirit as Spirit, transcending personal boundaries and needs to attain a higher level of human transcendence. Since the first and the third major stages do *not* have ego development as their primary characteristic, Wilber argued that they are often confused. He claimed that many psychologists have been guilty of the pre/trans fallacies, either elevating the prepersonal to the transpersonal or dismissing the transpersonal as prepersonal.

Wilber (1993, 1999) argued that these stages are structurally different and build on previous ones. He explained that few people reach the highest of the nine stages of transcendence and that these are much more integrative, because they include certain qualities from the lower stages. Wilber argued that human beings develop simultaneously in all areas. While some structures are rather permanent (such as sensations, cognition, space-time conceptions, and motor skills), not all lines of development (such as affect, morality, sense of self, and interpersonal

relations) develop in a uniform or parallel way. Still other structures are transversal (or ever-present), enduring, or even transitional. For Wilber, the *spiritual*, having to do with ultimate concerns, is always present in all stages, but can also be thought of as a higher stage.

Transpersonal philosopher Michael Washburn (1995, 2003) also outlined developmental stages, differentiating these as between egoic and transegoic stages. Washburn (1995) argued that life begins with a profound connection to a deep psyche, or Ground, but that, as our energy increasingly focuses toward the outside world, a separate self emerges that is mainly closed off from the energy of the Ground, a phenomenon that results in a primal alienation. Washburn explained that, as the child moves away from the symbiotic union with the mother, he or she eventually develops an *ego self* that is more associated with the head, while it regards the body as an object. He explained that, in midlife, one often begins to focus more inwardly in integrating or getting in touch with the Ground. Washburn (1995) explained that “the ego asserts its independence and develops itself in repressive disconnection from Ground [but then] undergoes a regressive return to the Ground (regression in the service of transcendence)” (p. 10).

Wilber (1999) refuted Washburn’s (1995) ideas that the Ground is *unrestrictively present* in infancy and that one completely *loses* touch with it in the ego stage, arguing that one would, thus, cease to exist. For Wilber, one need not regress to pre-egoic stages to connect with the Ground, as this connection in the transegoic state is qualitatively different than is that in this early phase.

As a complement to the aforementioned models of psychospiritual development, educators Robert Kegan and Lisa Laskow Lahey (2009) presented a theory of mental development in adulthood. They mentioned three qualitatively different, discernibly distinct plateaus in mental complexity: (a) the socialized mind, (b) the self-authoring mind, and (c) the

self-transforming mind. According to Kegan and Lahey (2009), “development does not unfold continuously; there are periods of stability and periods of change. When a new plateau is reached we tend to stay on that level for a considerable period of time” (p. 15). Additionally, they maintained that each new level contains and expands upon the mindset of the previous stages.

In the socialized mind, wrote Kegan and Lahey (2009),

We are shaped by the definitions and expectations of our personal environment. Our self coheres by its alignment with, and loyalty to, that with which it identifies. This can express itself primarily in our relationships with people, with "schools of thought" (our ideas and beliefs) or both. [In the self-authoring mind,] we are able to step back enough from the social environment to generate an internal "seat of judgment" or personal authority that evaluates and makes choices about external expectations. Our self coheres by its alignment with its own belief system /ideology/ personal code; by its ability to self-direct, take stands, set limits, and create and regulate its boundaries on behalf of its own voice. [In the self-transforming mind,] we can step back from and reflect on the limits of our own ideology or personal authority; see that any one system or self-organization is in some way partial or incomplete; be friendlier toward contradiction and opposites; seek to hold on to multiple systems rather than projecting all but one onto the other. . . . Our self coheres through its ability not to confuse internal consistency with wholeness or completeness, and through its alignment with the dialectic rather than either pole. (p. 17)

Kegan and Lahey's (2009) theory of adult mental development describes the process in which one assimilates beliefs inherited from one's social group, develops one's own beliefs from one's own experience, and then can step back and transparently see the construction of one's own beliefs and embrace opposites and contradictions. In many ways this theory may mirror and help us to understand the process of psychospiritual transformation through chronic illness as one begins to focus on one's own feelings, sensations, and beliefs emerging from one's physical experience with illness. Later, in the self-transforming mind stage, one may come to see the construction of one's own self-authoring ideas and become open to contradictions, opposites (such as aspects of the unconscious), and the limits of these beliefs in making sense of one's illness experience.

I resonate with psychologist Hillevi Ruumet's (1997, 2006) helical model of psychospiritual development as a useful framework for understanding life-long embodied transformation. This model has an integral focus that takes into account psychological development, inner experience, interpersonal relationships, emotional healing, and dynamics between Ego and a true Self.

Ruumet's (1997, 2006) model is consistent with Jung's (1928a/1983) notion of individuation as a process in which one becomes whole, embracing one's own uniqueness and different aspects of the self—in a sense, “coming to self-hood” (p. 418). Jung (1934a/1983) differentiated between *ego* development and *true* self-development, a crucial aspect of the helical model. Ruumet based her model primarily on her clinical experience as a psychotherapist and spiritual guide and has recognized the complex, multiple aspects of human beings (such as the spiritual, physical, psychological, social, etc.) that may be developing at different rates. Despite one's mastery in certain areas, undeveloped aspects that one has bypassed in previous stages may resurface, calling for a more integral growth.

For Ruumet (1997, 2006), people tend to work simultaneously, and sometimes rather haphazardly, with conflicts and issues vital to different stages. In this sense, development is neither linear nor “neat” (Ruumet, 1997, p. 8). Indeed, her two-dimensional diagram of human development consists of a spiral transected by a vertical line. She illustrated the stages as numbered points along the vertical line as it intersects with the spiral, moving upward from 1 to 6. Thus, numbers one and six cross at the outer points of the spiral, while points three and four coincide with the spiral's center. This diagram illustrates the cyclical relationship between certain stages (I-VI, II-V, and III-IV) born of retracing similar issues in a qualitatively different stage. Ruumet characterized people in the first three stages, or centers, as *in-laws*, in relationship

with whom one takes for granted one's own cultural conditioning as universal reality. People principally in stages IV to VI can be thought of as *out-laws* because they have developed a wider view of reality that takes them beyond the assumptions of their cultures.

Ruumet (2006) explained that we live from a particular center as a kind of "center of gravity [or] home base" (p. 19) for what could be a period of several years, or even the rest of our lives. Our center gives us a basic goal, perceptual biases, and a span of consciousness that expands as we move through successive stages. According to Ruumet, a move from one center to the next is

transformational, and entails major shifts in consciousness. The expanded worldview resulting from this requires a total realignment of all our conceptual categories, guiding mythologies and neuroses. A genuine transformation of this kind does not involve rejecting or devaluing preceding home Centers, only revitalizing them. Some things are left behind, some are refurbished to fit the space of our new "home." (pp. 19-20)

I have in the next pages briefly outlined each stage or center and its respective transition elements for growth. I have therein also emphasized the embodied aspects of development for each center, which I have drawn both from Ruumet's (2006) work and psychologist Rosemarie Anderson's "*The Body Map of Human Development*" (2004b), the latter of which mainly refers to psychologist Brian P. Hall's (2000) similar stage model.

In Ruumet's (1997, 2006) *Physical/Survival Center* stage, one is concerned with basic physical needs in the service of safety and survival. One's motivations are based primarily on the pleasure principle and, therefore, involve reacting with fear of authority. This center is not inherently related to early aspects of cognitive development, nor is it necessarily exclusive to children. For Ruumet (2006) and Anderson (2004b), it is related to a grounded vital self in helping us to tackle the work of the world and the challenges of adulthood, with feeling physical safety, and with dealing with and feeling comfortable in the material world. In this center, one

lives undifferentiated from the body and experiences self-protection, alertness, survival, and pleasure.

In Ruumet's (1997, 2006) *Center Two: the Emotional/Kinship Center*, one at this developmental stage focuses on need, greed, and attachment, responding mainly from insecurity and a fear of lack. Control issues emerge, along with a need to feel loved, cared-for, and accepted and for a sense of belonging. Emotional and social self-preservation is the main focus. In this stage, one's "wings are clipped" (Ruumet, 1997, p. 12) according to the size deemed appropriate by the social and family environment, this clipping placing limits on inner development and/or outer levels of achievement. One experiences family love as dependent and conditional, and, thus, feels the Divine, by extension, as an all-powerful parent (as based on an environment that produces rewards and punishments), an image sometimes ranging anywhere from a boss to a supportive mother. When this center is life-affirming, it gives us basic emotional security (feeling loveable and able to love), comfort and sensuality in the body, good social and relationship skills, and a solid sense of place in the social order of the universe. One in this stage may especially feel the need for comforts, material security, and a human connection through sexuality, mainly for pleasure and emotional bonding.

Somatically, one may live in this center with a "heightened sensitivity to the opinions and feelings of others" (Anderson, 2004b, p. 5), often striving for reciprocity, approval, physical self-worth, and competence. Lack of a sense of external approval may result in a rejection of one's own body and physical appearance. This center may also be characterized by pleasure in physical movements and challenges around self-care and anxiety (Anderson 2004b; Ruumet, 2006).

In Ruumet's (2006) *Center Three: Apotheosis of the Ego* stage, one's goal is "making it" (p. 48) in the world in terms of whatever the given culture defines as success. One's social skills and relationships are at this stage placed in the service of personal power goals--even that of learning to control others to get what one wants. One strives to create what the mind envisions. However, in an earlier work, she has noted that, while we build ego strength and competence at this level, "on the negative side, we may become arrogant, grandiose, persona-driven, egotistical, or worse, actively destructive to those who challenge our power" (Ruumet, 1997, p. 13). The ego "thinks of itself as separate, sovereign agent of its own will, king of its own domain, with the assumption that it can and should set its own terms and control its own destiny" (Ruumet, 2006, p. 48). In this stage, one experiences God, or the Divine, more as love than as a parental figure. These first three stages, according to Ruumet, are more predictable from childhood to adulthood, with many people remaining in the third one because the general culture supports its values.

Eventually, according to Ruumet (1997), this Ego inflation becomes an obstacle to genuine growth:

Until something "wakes up" people immersed in this Egoic identity and experience (and God certainly finds ingenious ways to do this), they are unlikely to seek spiritual direction. It becomes more likely to happen as the limits of Ego and its version of power are reached, for example, through mid-life disillusionment with the things that were supposed to guarantee happiness. (p. 14)

Ruumet (1997, 2006) argued that, during this crisis, one may be ready to put ego values aside and set a new life course grounded in spirit rather than in ego-self. The shift from centers III to IV can mean an intimidating encounter with the unknown, or even an "[ego] dethronement if not yet death" (Ruumet, 2006, p. 57) in moving from the personal to the transpersonal. Peak experiences and breakthroughs may occur, but the Ego attempts to co-opt these moments and push forth the process as a personal quest.

The body may reflect this center's goal of mastery, success, and strength through a need to appear invulnerable, thus precipitating a process in which one becomes susceptible to stress-related symptoms and diseases (Anderson, 2004b). At this center one seeks to stretch one's own strength and capacities, molding the body to fit the Ego's ideals in focusing more on self-evaluation than on the approval of others (Anderson, 2004b; Ruumet, 2006).

Ruumet's (1997; 2006) *Center Four: the Aloha Waltz* represents the heart energy. One comes to see the common Divine essence in every human being in moving from a base of *power* (Center Three) to *love*. In this Transpersonal Passage from III to IV, "the ego must yield to Self, personal power to capacity to serve as a higher purpose, and judgmental self-righteousness to tolerance and compassion" (Ruumet, 1997, p. 15). One begins to use the skills and capacities developed in previous centers in the service of the heart.

Ruumet (1997) commented that mid-life crises are often invitations to the "IV-III waltz" (p. 15) or the "Aloha Waltz" (Ruumet, 2006, p. 65) and that this transition is one of the most difficult. She remarked that this passage is not necessarily easier for women than for men (Ruumet, 2006), as she had originally thought (Ruumet, 1997), but tends to be more subtle for women. Suddenly, more is not enough, as "a subtle, growing, insistent feeling may then come upon us that feels like homesickness for a place or a something we do not know but have a deep, vague feeling will finally make us happy" (Ruumet, 2006, p. 65). We begin to witness our own behavior and inner process, as well as that of others with greater compassion, as we now see what the ego is doing. This can begin a process of deconditioning from the negative patterns with which we once identified.

According to Ruumet (1997, 2006), in the Aloha center, one becomes more generous and empathetic toward both others and self. Recognizing the needs of others and the self is no longer

an either/or issue but a basic cognitive shift to a more flexible stance. One develops greater respect for a variety of traditions and beliefs. A sense of community and impulses to service arise from a sense of love rather than from ego power. Divine energy is less personified and is experienced more as Love found in all beings. A person living this fourth stage may find it necessary to revisit issues in the previous stages, such as unfinished emotional business and personal power issues, in order to avoid slipping back into self-righteousness or service in function of ego.

According to Ruumet (1997), only after one is well into the Aloha center can one see how the “wake up call” (p. 16) that stimulated a move beyond egoic power was related to a higher source, as well as partly to one’s own unconscious intentions (Ruumet, 1997, 2006). Ruumet argued that it is as if the Self *arranges* this wake-up call, resulting in a kind of ego death or emptiness, which may also be experienced as an identity crisis.

In Ruumet’s (1997, 2006) fourth center, one develops increased awareness of a mind-body continuum, including the interplay of emotions, stress, physical symptoms, and sensations in one’s overall well-being. Anderson (2004b) commented that during this stage “we want to feel more centered and grounded in our bodies and in the realities of life because we now understand that all life circumstances have the potential of being opportunities for growth” (p. 10). One is generally more affectionate, open, and accepting (Ruumet, 2006). If one is not careful, this goal of heartfelt service through good works may lead to neglecting one’s own physical needs and falling into stress-related symptoms and illnesses (Anderson, 2004b; Ruumet, 2006).

The move toward *Center Five: The Descent Tango* is like “finding and following our unique ‘Star of Destiny’ so that we can live our life as an expression of and gift of the Divine” (Ruumet, 1997, p. 17). In this stage one finds one’s own voice through a new level of

unconventional and *noncompetitive* creativity for its own sake that may not bring social rewards within one's lifetime. This new way of being may be contrary to one's likes, profession, and a previous sense of self: "We create as we go along, directed by an inner impetus that we may have difficulty trusting or understanding, and the outcome is unpredictable" (Ruumet, 2006, p. 89). One may encounter self-criticisms, as well as judgments from others, in response to these unexpected changes.

In the move from the fourth to the fifth center, one solidifies his or her "capacity and enthusiasm for compassionate and non-judgmental self-witnessing" (Ruumet, 2006, p. 95) and more easily avoids being swept back into old ego perceptions, habits, and strivings. One experiences a greater freedom to choose and a capacity to shed conditioned ways of being that no longer support one's authenticity in the present.

Ruumet's (1997, 2006) Descent Tango is related to the Emotional/Kinship center (II), and one at this stage may need to revisit old issues and fill in gaps related to social and relationship skills, intimacy, sexuality, early wounds, and irrational fears. According to Ruumet (1997, 2006), if one attempts to bypass these issues, they may become detrimental to growth, as one may slip back into previous stages. In this fifth stage, the ego must maintain its proper role as "the Soul's helper to outer world tasks" (Ruumet, 1997, p. 19). However, development along spiritual and psychological axes may not be in sync. One may be compelled to reframe one's own life history (to the self and to others) from this new perspective, owning it all in the presence of the Divine. For this reason, grief is a major theme of this stage and depression may be a sign of a need for emotional work (Ruumet, 1997, 2006).

Ruumet's (1997, 2006) fifth center is also characterized by intense yearning for Divine connection, often with confusion and frustration as to its form of realization, as previous

practices may seem one step removed from this direct experience. One senses the Divine more through nature as mother, de-emphasizing dogma, and may no longer feel at home in one's spiritual tradition. Mystical or paranormal experiences outside the in-law logic are quite common at this stage, as one may gain a greater understanding of past events that were previously unclear. In general, the Descent Tango means "a sense of coming home to ourselves, and this brings an inner peace that is a relief from the emotional twists and turns of the Tango" (Ruumet, 2006, p. 107).

The presence and nonattachment of Ruumet's (1997, 2006) fifth center enable one to feel joy in the body; the body is an integral part of this flowing self-expression and participation in the world in a way that seems beyond the individual self. One may develop a sense of mystery and paradox in appreciating the intrinsic uniqueness of every being and every moment, including one's own embodied experiences. At this center one must be careful not to neglect aspects of the physical self and the physical world in favor of these flow experiences (Anderson, 2004b; Ruumet, 2006).

The few people who inhabit *Center Six: Embodying Spirit* are usually considered spiritual teachers and mentors (Ruumet, 1997, 2006). One is fully aware, at this stage, of the nondual nature of the Divine, because such dichotomies as mind/body, spirit/matter, and sacred/profane seem to dissolve into a *Oneness of being*. In this stage one also revisits core issues from the physical/survival center (I), doing the work of return:

The leftover issues in this center relate to our physical incarnation, including sickness, death, physicality, possessions, and the fact of impermanence in general, and the paradoxical emptiness and fullness of Being in particular. It means learning to "die" long before we actually die physically, learning to maintain our equanimity through all the losses and changes of life (the "little deaths"). It means honoring and fully inhabiting our mortal body even as we live in Spirit, and overcoming our arrogant superiority toward the Earth and the feminine that we inherit from our Western patriarchal culture. (Ruumet, 1997, p. 20)

In this inner union of all opposites in Ruumet's (1997, 2006) sixth center, an understanding similar to Jung's (1928a/1983, 1939/1983) theory of individuation, one experiences an integration of body, mind, emotions, and spirit, without egoic attachments to any of them. Physically, this center is characterized by a sense of joy, ease, presence, trust, and connectedness with all things, as one harmonizes with the surrounding beings and circumstances. Distinctions are *dissolved* between spirit/matter and my body/the universe (Anderson, 2004b). We also develop an appreciation for the body's deep wisdom in guiding us but may feel frustrated by the body's needs (Ruumet, 2006).

Ruumet (2006) described *Center Seven: The Transpersonal Journey* as containing all of the previous ones, as it is "not really a Center at all, but a condensation of many advanced stages of transpersonal development up to non-dual realms transcending all images, polarities, and descriptors" (p. 131). Ruumet (1997, 2006) also commented that, due to many factors (including gender, personality, natural preferences, and cultural factors), we tend to move more easily through certain centers than through others, often gravitating toward and staying in stages where we feel most comfortable. For instance, she pointed out that women tend to stay in Centers II and IV, while men usually feel more at home in Centers I, III and V. We tend to move too quickly through centers that we find difficult, bypassing key issues that may limit us when moving into other stages. Ruumet (1997) remarked that "failed transitions can be tragic, even lethal" (p. 23). She mentioned how a refusal to hear the inner call to the next stage may result in depression, psychopathology, personal and career consequences, and even soul loss. Ruumet suggested paying attention to the roads not taken and the emotional skills not fully mastered at each center. The experience of living with a chronic illness can present unique challenges and limitations for moving through each of Ruumet's stages.

As a complement to the above models, psychologist Vipassana Christine Esbjörn (2003) has made an important contribution to understanding the embodied aspects of spiritual growth. She explored the relationship between the body and spirituality among 12 diverse women spiritual leaders. Esbjörn concluded that women who live a spiritual path go through a cyclical dialectical process of *dis-identification* and *re-identification* with the body. Many of her secondary themes mirror and shed light on the embodied aspects of Ruumet's (1997, 2006) model, especially the shifts to centers Five and Six. These themes included (a) embodiment as a purposeful choice; (b) permeable boundaries between the world, the self, and others; (c) fluid self-reference not fixed in the body; (d) sexuality as an integral part of embodiment; and (e) physicalized intuition in the body. In this intuitive inquiry, Esbjörn described her own growth as going beyond a dichotomous understanding of the body and spirit while discovering new ways of combining and perceiving ideas.

Similarly, spiritual director Gloria Carpeneto (1997) did a phenomenological study of the embodiment of spirituality among 4 women during their middle years. Her emerging themes also mirror Ruumet's (1997; 2006) fifth and sixth centers: (a) interweaving spirituality in their lives, especially in "being-bodily" (Carpeneto, 1997, p. iv); (b) a different experience of time and a sense of open-endedness; (c) a different sense of spatiality and motility, as the body can be an opening into space; (d) a felt experience of spirituality coming more to the surface; (e) the importance of suffering and brokenness; and (f) powerlessness to put into words the experience of Being, as it becomes problematic, more mysterious, or not so easy as before. Carpeneto pointed out that, in general, her participants reported their spirituality as becoming more *tangibly felt*. She also pointed to a more ambiguous and paradoxical understanding of the dualistic

polarities of such aspects as spirit/matter, being/doing, sacred/profane, and speech/silence in this increasingly embodied sense of spirituality.

Transformation and Healing

Several authors address the concepts of transformation and healing in a manner consistent with understandings of the transpersonal perspectives of psychospiritual development.

Psychologist Ralph Metzner (1986) distinguished between transcendence and transformation, clarifying that *transcendence* refers to going beyond, reaching a higher state, or rising above something, while *transformation* implies changes in patterns, structures, and functions of the psyche. He associated transformation with *fire*, as patterns are dissolved, purified, or remade, impacting the core of the self. Building upon Jung's (1939/1983) theory of the transcendent function as a union of opposites, Metzner (1987) argued that the notion of dialectic opposites and their reconciliation is a central common element of transformation in all spiritual traditions, especially around the following three pairs of opposites: (a) balance of male and female energies, (b) reconciliation of good and evil, and (c) the integration of human and animal consciousness. In a manner similar to Jung's, Metzner (1987) claimed that a key to transformation is recognizing these dualities in ourselves and finding ways to transform the opposition to a state of either complementarity or peaceful coexistence.

In response to recognizing the difficulty of explaining these complex experiences in nonordinary states, Metzner (1987) characterized transformation in terms of two core metaphors: (a) an awakening and (b) the journey. In *awakening* we may experience normal consciousness as a dream-sleep state and gradually move to a more enhanced objective state. As in Jung's (1939/1983) theory of individuation, the *journey*, for Metzner, refers to an ongoing process of personal transformation that implies leaving one's home, family, culture, or world in search of

healing knowledge toward wholeness. This metaphor may also imply either a *return* or a series of *cyclical movements*.

Psychologist Tobin Hart (2000) discussed transformation as (a) both an outcome and a process, (b) changing self-structures, (c) a dialectic between will and surrender, (d) recognizing and integrating unconscious shadow aspects of the self, (e) greater inner freedom catalyzed by limits on external freedom, and (f) increased presence resulting in freedom from fixed ego perspectives and patterns. According to Hart, either destroying, purifying, or shedding aspects of the self allows us to expand our perspectives and identity rather than to continue living through old lenses. *Lenses* refer to one's core ways of perceiving and experiencing the world. Lenses are related to the basic structure or pattern of one's personality. As in Ruumet's (1997, 2006) fifth center and in Jungian (1939/1983) theory, Hart also argued that we must develop appropriate ego strength, but without ego fixation, reworking the ego to align it with the rhythms of newly emerging aspects of the self in the world. Hart argued that these constant deaths of old ways of being are the fertile ground for creativity.

For Hart (2000), transformation involves a dialectic between *will* and *surrender*. Paradoxically, it requires intention and agency combined with receptivity and openness. Hart argued that will, without surrender, prevents us from trusting in the unknown, while surrender, without will, results in complacency, in negating our own responsibility: "These are the yin and yang, or the masculine and feminine principles that underlie human growth throughout the life span" (p. 158), and one of these may be stronger than the other at a given point in our lives.

In characterizing transformation as greater inner freedom catalyzed by less external freedom, Hart (2000) pointed to stories of "radical freedom in the midst of complete external restriction" (p. 160), including self-induced practices and conditions outside one's control, as

with the advent of illness. He explained that, when we stop searching for freedom in external things, when that path is forcibly cut off from us, we may begin letting go and looking for inner resources to find meaning and freedom. Hart argued that, when we limit our typical choices, we become more aware of ego-generated resistances or reactions, an awareness that may even lead to *exposing* and *dissolving* a fixed self.

Lastly, Hart (2000) characterized transformation as an increased presence in the moment and held that this involves freedom from fixed perspectives of time and space: “Our self as a centerpoint of perspective becomes more fluid and may seem to recede altogether” (p. 163). Hart noted that “this perspective moves from a single vantage point to multiple perspectives” (p. 163), an *aperspectival* awareness beyond notions of subject and object.

Braud et al. (2000) characterized transformation as marked by the qualities of *persistence*, *pervasiveness*, and *profundity*. They explained that transformation touches many aspects, or areas, of one’s life and is deep and significant. In parallel with understandings developed by Jung (1939/1983) and Ruumet (1997, 2006), Braud et al. emphasized that psychospiritual development is an ongoing process, rather than a time-limited event.

The above concepts of transformation are also related to Maslow’s (1999) idea of *self-actualization* as exploring formerly unrecognized levels of humanness. Maslow (as cited in Coburn, 2006) also characterized this phenomenon as an

ongoing actualization of potentials, capacities and talents, as fulfillment of mission (of call, fate, destiny, or vocation), as a fuller knowledge of, and acceptance of, the person’s own intrinsic nature, as an increasing trend toward unity, integration or synergy with the person. (p. 21).

According to the author, self-actualizing people live less from self-centered needs and are more motivated by the intrinsic nature of things, including the potentialities of people and things.

Maslow emphasized that this process is often accompanied by peak experiences in nonordinary reality.

Healing, which is similar in its effect to transformation, is a concept usually mentioned in relation to a specific illness, psychological wound, or trauma. Several authors agree that healing occurs only with a dramatic change in lifestyle and the healing of all of one's relationships, including connection to a Great Spirit, family, the society, the planet, and past ancestors (Achterberg, 1987; Mehl-Madrona, 2003; Metzger, 2004; Villoldo & Krippner, 1986). This constellation of personal changes implies restoring the natural perfection and beauty to what has been disrupted or the essential, intrinsic harmony of the universe. Health, or healing, is something that must be maintained through integral daily practice in all areas of one's life.

Metzger (2004) distinguished between healing and curing: "While cure rarely transforms us, healing is a practice; it becomes a way of life. This is its offering to us" (p. 7).

Healing is not necessarily restoring the original condition. It is not returning to paradise. Healing is helping to align the individual with the trajectory of the soul. Healing is the field of beauty through which the details of the larger purpose of an individual's current life in relationship to his/her own history, ancestors, spirits, the present, the future, and global healing are revealed and enacted. (p. 17)

Spiritualists interviewed by Villoldo and Krippner (1986) stressed an awareness of the continuity of life as an essential aspect of healing. Other authors stressed the importance of a client's positive beliefs or expectations of healing (Harner & Doore, 1987; McClenon, 2002; Villoldo & Krippner, 1986). Shamanic authors also emphasized the intrinsic healing power of engaging in communication with the spirit or sacred realms in expanding one's view of the self and one's work in the world (Ingerman, 1991; Metzger, 1987; Villoldo & Krippner, 1986) and the act of someone doing work on one's behalf (Horrigan, 2003). Similarly, Sally Owen (2001) pointed out that healing often depends heavily on one's belief system and that these beliefs may

change when one enters into alternative healing practices. She noted changes in beliefs and relationship patterns as common curative factors in the process of healing from illness. Susan Vose (1998) also concluded that altered states of consciousness play a significant role in emotional healing within several forms of alternative healing.

Yeh et al. (2004) cited the following key principles of indigenous healing: (a) selfhood as relational and contextual with regard to other living beings; (b) a heavy reliance on the use of communal, group, and family networks for supporting, reconnecting, and resolving problems; (c) the common use of spiritual and religious beliefs and traditions within healing processes; (d) healing ceremonies performed by shamans on behalf of the person; and (e) healers tending to work integrally with aspects of body, mind, and spirit in helping to restore harmony in human relationships or harmony with internal or external forces. Yeh et al. explained that this harmony is often thought of in terms of the greater collective good, as sometimes individual autonomy can create disharmony.

Lewis Mehl-Madrona (2003), a Native American medical doctor and psychologist, argued that healing, in contrast to a *cure*, is more holistic, broad, subjective, and intentional, with a movement toward wholeness and balance in living in right relationship. He pointed out that healing may or may not mean that one becomes *free* of illness. Mehl-Madrona claimed that it is possible to recenter ourselves even with respect to suffering a disease, changing the way we see ourselves so that suffering has *meaning* and *purpose*.

Mehl-Madrona (2003) explained that he has learned the following ideas from traditional Native American healers about the healing process: (a) the importance of harmonic relationships between the patient and other living things; (b) acceptance and surrender of one's body in maintaining a passionate desire to be healthy but without demands or obsessions; (c) a focus on

the present rather than an obsession with the past, letting go of feelings of guilt and anguish about the future; (d) belonging to a community of hope, allowing one to participate in a collective energy to sustain one through difficult times; (e) transcending blame (of self and others) in understanding the conditions that allowed the illness to come about and finding a new direction; (f) a spiritual dimension to one's life, including a regular spiritual practice; and (g) a profound change in becoming a different person, even celebrating a kind of funeral for the death of the old self. Mehl-Madrona explained that each person has his or her own healing power and must find his or her inner healer to reach a point of peacefulness, dignity, and meaning. He emphasized that healing has no end and that the healer's role is in helping the patient re-create stories about the self and the possibility of healing.

Mehl-Madrona (2003) also outlined the following important factors for healing: (a) accurate and realistic appraisal of one's physical condition; (b) belief that healing is possible, visualizing a healing story that incorporates an understanding of how one became ill; (c) a focus on progress, even the "small successes to build faith" (p. 221); and (d) a meaning in life and suffering, and, with this, a *joy* in fulfilling this life purpose. Mehl-Madrona characterized the experience of being healed as feeling a sense of (a) unity with all things; (b) the presence of a higher power or something guiding one's life; (c) surrender and acceptance; (d) greater joy in everyday life; (e) emotional and physical presence; and (f) realism, satisfaction, and humor. With these aspects comes an increased quality in relationships, intimacy, forgiveness and nonjudgment.

Shamanic Explanations of Illness

In a shamanic understanding of illness, our health in general is affected by all that is in and around us, including our physical environment, genetic makeup, karmic influences, past

ancestors, past and current diet, family dynamics, our intentions, the social context, and beings in other dimensions of reality, many of which we cannot perceive through ordinary states of consciousness (Horrigan, 2003; Ingerman, 1991; Villoldo & Krippner, 1986). As the multiple dimensions of reality are inherently related, shamanic traditions explain that disincarnate spirits are in constant contact with human beings and the rest of the physical world (Horrigan, 2003; Ingerman, 1991; Villoldo & Krippner, 1986). However, as in our social world, not all spirits are wise, benevolent, or holy, and some may be quite destructive (Achterberg, 1987; Horrigan, 2003; Ingerman, 1991; Villoldo & Krippner, 1986). At the same time, illness is not simply something that happens *to us* or enters from *without*, but rather is something that emerges from a loss of personal power that may leave us vulnerable to intrusion (Achterberg, 1987; Horrigan, 2003). Reciprocally, all of our thoughts, intentions, and actions influence our personal power and state of health, and this state of health can be thought of in several aspects (physical, emotional, spiritual, etc.).

Based on their field studies with Asian and South American indigenous shamans, Villoldo and Krippner (1986) characterized a shamanic view of the multilevel causes of illness in terms of (a) biological or physical events; (b) psychological (or experiential) factors; and (c) the spiritual (or metaphysical). The authors considered these ideas to be reconcilable with an allopathic worldview.

Sandra Ingerman (1991), a counseling psychologist, shamanic practitioner, and author of the groundbreaking book *Soul Retrieval: Mending the Fragmented Self*, explained three classic, and sometimes interrelated, causes of illness from a shamanic perspective: (a) power loss, (b) soul loss, and (c) spiritual intrusions. In power loss, a person loses his or her power animal or guardian spirit. In an interview with Horrigan (2003), Ingerman explained that symptoms of

power loss may be chronic suffering from illness, depression, misfortune, and suicidal tendencies that leave one's immune system vulnerable.

Ingberman (Horrigan, 2003) explained that

when we suffer emotional or physical trauma, there is a possibility that a piece of our soul, a piece of our essence, escapes into non-ordinary reality—either the Lower World, Middle World, or Upper World—where it's safe and waiting outside of time for somebody to retrieve it and bring it back home to the body again. When you lose your full soul, you die. (p. 78)

Ingberman (Horrigan, 2003) commented that during a shamanic journey she becomes aware of the location of the lost soul part and proceeds to journey to this place in nonordinary reality for its retrieval. Ingberman (1991) differentiated this perspective from a psychological view of disassociation in which the split-off parts remain in the person's *individual* unconscious.

Ingberman (Horrigan, 2003) explained that *where* the soul part has gone is of vital importance to the shaman, as it “may be trapped in a fearful place” (p. 20) or may dwell in a more pleasant place where it chooses to stay. The author pointed out that soul loss in modern times is often caused by a *chain of soul loss* in which people who are disassociated from themselves commit horrible acts toward others as a reaction to their own soul loss (Ingberman, 1991; Horrigan, 2003).

Ingberman (Horrigan, 2003) explained that symptoms of soul loss may include (a) disassociation; (b) difficulty in staying present in the body, or a sense of *observing* one's own life rather than fully *participating*; (c) continually attempting to fill voids through external things; (d) immune deficiency problems, including chronic illness, depression, and suicidal tendencies; (e) having been chronically ill as a child; (f) gaps in memory after the age of five, sensing that one has blocked out significant traumas; (g) struggle with addictions; and (h) difficulty in moving on in one's life after losses such as divorce or the death of a loved one.

According to Ingerman (Horrigan, 2003), in a *spiritual intrusion* a person has an opening or void in the body and something comes in to fill it. She explained that spiritual intrusions come from negative thought forms, such as anger, either from one's self or from other beings, including both embodied and nonembodied beings (Horrigan, 2003; Ingerman, 1991). This misplaced energy can result in symptoms of *localized* pain or illness associated with a specific body part or chakra (Ingerman, 1991). All people can create localized intrusions in themselves or in other people, especially if we *send* anger rather than *express* it (Ingerman, 1991). One may heal from an intrusion when a shaman extracts it and returns it back into nature (Horrigan, 2003; Ingerman, 1991).

People may also be affected by *possessions from disembodied beings*, especially if one has already experienced significant soul loss (Horrigan, 2003; King, 1987; Villoldo & Krippner, 1986). Usually, after a person dies, he or she moves to the Lower or Upper World. However, if he or she suffered a traumatic death, the soul may not know that it is dead and may stay in the Middle World by going into another person's body (Ingerman, 1991). In which case, according to Ingerman (Horrigan, 2003), "the shaman still has to do the work of convincing the possessing soul that it is dead, that it will be happier in the other world, and that it's time to move on, and then psychopomp it to another world" (p. 79). This involves safely assisting the soul in moving to its appropriate place. The spiritists interviewed by Villoldo and Krippner (1986) added that the entering spirit may trigger in the host person similar symptoms of physical, psychological, and spiritual imbalance that the person suffered before or upon death. Entire families may be affected by these spirits, but frequently only the most sensitive person (often the youngest) directly manifests symptoms (Villoldo & Krippner, 1986). The spiritists explained that these symptoms are frequently in the form of chronic, serious illnesses beginning at an early age (Villoldo &

Kippner, 1986). Intrusive spirits are often attracted to people who have “open windows” into the spirit world and several spiritualist healers recommend that, as part of their healing process, patients be trained to control the “opening” and “closing” of psychic channels, discriminating between the lower destructive and the higher enhancing forms of spiritual communication (Villodo & Krippner, 1986, p. 10).

In addition to intrusions from spirits and soul loss, spiritist healers also explained that illness could be caused by a sudden initial contact with traumas from one’s own past lifetimes, particularly around a shocking or painful death (Villodo & Krippner, 1986). In this sense, many of our thoughts, intuitions, actions, and habits could be unconsciously influenced by communication with the spirit world.

Empirical Findings on Psychospiritual Transformation and the Psychospiritual Benefits of Experiences in Nature

In the rest of this chapter I review empirical findings on experiences related to the process of psychospiritual transformation through chronic illness. I first explore research on psychospiritual transformation in general and then, in the following section, review literature more specifically related to chronic illness experiences. In this section I also touch upon research concerning the psychospiritual benefits of experiences in nature, many of which are related to the process of psychospiritual transformation.

In a quantitative and qualitative study, psychologist Dana Gaynor (1999) concluded that transformation experiences are associated with developmental stages in cognitive processing, including an expanded awareness of (a) implicit relationships in the universe, (b) aspects of the self, (c) new connections in various aspects of the universe, and (d) being part of a greater universal order. Psychologist Jeffery Imber (1994) did a heuristic study of experiences of

psychospiritual transformation that illuminated the lived experience of 8 research participants. Imber explained that psychospiritual transformation is about “opening up one’s psyche to powers both transcendent and immanent to oneself” (Abstract). Consistent with Metzner’s (1987) and Hart’s (2000) theories, Imber related transformation to letting go of former ways of being in the world while encountering a deeper reality with the self and nature *beyond* ego power in relating to a spiritual dimension of life.

Imber (1994) described core themes of psychospiritual transformation that included these understandings: (a) it is an ongoing process; (b) its relation to the healing of core issues; (c) its requirement of moving beyond cultural scripts; (d) an opening of the heart to a transcendent dimension triggered by catalytic events; (e) a feeling of belonging and connection to something transcendent; (f) its involving an experience of emptiness and breaking with ego-identity and worldview; and (g) its requirement that expressing this deeper spiritual self involves detachment from the ego-identity and one’s current social role. Other core themes referred to *the results of transformation*, and included (a) a sense of being an instrument of God in service to others, (b) an increased contemplative dimension to life and a sacramental participation in the world, and (c) an experience of joy and freedom.

Psychologist Merry Coburn (2006) defined transformation as a “significant change in a person’s functioning characterized as expanded self-understanding, a connection with Spirit, and a commitment to service” (p. iii). Coburn referred to transformation in a more operationalized sense, with the first two aspects mirroring Hart’s (2000) dual aspects of transformation and a third one referring to a more *externally* manifested characteristic. She referred to transformation both as a *process*, in terms of cycles of descent and rebirth, and as a more integrated and expansive *level* of psychospiritual development. In her research findings, Coburn concluded that

this process includes moments of darkness, crossroads, descent, experiencing compassion, retrieving an embodied self, rebirth, and a sense of coming home. She suggested a connection between nature-based experiences and psychospiritual changes.

In findings related to this idea, several researchers have shown evidence of the contribution of nature-based experiences to psychological well-being. Kaplan and Kaplan (1989) concluded that people experience the following restorative benefits when spending time in nature: (a) pleasure or satisfaction, (b) support of human functioning (both physical and cognitive), and (c) recovery from mental fatigue. The authors cited four levels of this third aspect of restorativeness, with each level requiring increasing levels of quality of the environment and duration: (a) clearing the head of distracting mental fragments; (b) the recovery of direct attention; (c) cognitive quiet to face important cognitive matters or worries that would otherwise be ignored and generate significant internal distraction; and (d) deep reflections on one's life, priorities and possibilities, actions, and goals. This latter level could especially favor a process of psychospiritual transformation.

The following researchers also cited the relationship between experiences in nature and aspects of psychological well-being, all of which can play a contributing role in one's process of psychospiritual transformation. Hartig, Evans, Jamner, Davis, and Garling (2003) concluded that walking in a natural setting helped to reduce blood pressure (which reduces stress) and anger while increasing positive affect. In van den Berg, Koole, and van den Wulp's (2003) study of 114 participants, the researchers concluded that viewing natural environments improved mood, concentration, and affective restoration. Similarly, Mayer, Frantz, Bruehlman-Seneca, and Dolliver (2009) concluded that people exposed to natural settings showed an increased attentional capacity, the capacity to reflect on important aspects of their lives, and less

undesirable public self-awareness. Mayer and Frantz (2004) suggested a positive correlation between connectedness to nature and subjective well-being, while, in her quantitative study among university students, counseling psychologist Cassie Comeau (2012) concluded that connectedness to nature was significantly (albeit weakly) related to the following specific factors of wellness: thinking, emotional awareness, leisure, love, and nutrition. Finally, Paul Marsh (2008) analyzed qualitative data to determine the following components of participants' spiritual development from nature experiences: (a) transcendent experiences, (b) increased awareness, and (c) a sense of fulfillment. Other major benefits from nature experiences included reflection, tranquility, the capacity to focus, and appreciation of beauty, all of which contributed to participants' sense of spiritual meaning.

Conceptual and Empirical Literature on Chronic Illness Experiences and Transformation

In this section I will review conceptual proposals and empirical literature on people's experience of living with chronic illness and transformation. In her book *The Chronic Illness Experience: Embracing the Imperfect Life*, Cheri Register (1999) wrote about her own and other people's lived experiences with diverse illnesses such as multiple sclerosis, epilepsy, asthma, and diabetes. She emphasized that living with chronic illness is often a kind of invisible phenomenon, not very obvious or understandable to others, and is a constant act of strength, survival, patience, and active choices.

Register (1999) mentioned the following characteristics of the initial phase of chronic illness: (a) symptoms that come and go over a period of time; (b) attempts to explain away symptoms through psychological causes; (c) false or partial diagnoses; (d) strained relationships with others from these prolonged, unexplained symptoms; (e) changes in mood and personality; (f) determination to eliminate symptoms by changing habits and behavior; and (g) both relief and

grief in determining the disease. She maintained that one's initial reaction to diagnosis can be varied, including its being felt as horror, dread, shock, no reaction at all, anger, fear, or an overwhelming hope for a cure.

Register (1999) noted people's common experiences when illness became a chronic situation, including (a) frustration of not getting better; (b) negotiation with the illness and trying out several treatments; (c) the difficulty of coping with uncertainty; (d) cycles of false hope and frustration; (e) a deep mourning of the loss of health, which can feel like a death; (f) a realization of the impossibility of returning to one's old life in terms of diet, activities, or hobbies; (g) constant fatigue, discomfort, or pain; and (h) anxiety about anticipating the next attack or relapse.

Register (1999) emphasized the sense of *loneliness* in living with chronic illness and the difficulty of making emotional connections with others about this difficult experience. She also mentioned other key issues in chronic illness experiences, such as (a) difficulties with one's body image; (b) dependency on others; (c) dealing with family members' range of attitudes; (d) changes in sexuality and sexual activity; (e) deciding with whom to share more intimate details of how one is feeling; (f) identity crisis because of changes in roles, activities, and bodily sensations; (g) letting go of the illusion of total control, despite improving one's self-care; (h) the stigma of blame and unsolicited advice from others; (i) the challenge of finding proper health attention; (j) nondirected anger; and (k) depression arising from the pain that isolates. Register pointed out that depression among sufferers of chronic illness is often manifested through rebelliousness, tiredness, or frustration because of their lack of energy to sustain relationships or even take care of themselves.

Register (1999) also suggested keys for *healing* among people who suffer chronic illness, including (a) defending one's right to feel and to live within one's own physical possibilities without self-judgment (contrary to attempts to react heroically or prove one's self-worth by ignoring one's illness), (b) cultivating increased body consciousness in noticing daily and cyclical patterns, and (c) applying active patience in riding out the waves of pain or discomfort until they pass. Register pointed out how even suicidal thoughts can become a gift to treasure in knowing that living with chronic illness does involve a daily decision to choose life. She explained that living with chronic illness may sensitize one to suffering in the world and may motivate one to engage in passionate service to others.

Psychologist Darcy Butterfield (2011) used *The Book of Job* as a metaphorical guide for explaining the six stages of the emotional process of living with chronic illness: (a) illusion, (b) chaos, (c) alienation and guilt, (d) despair, (e) transformation, and (f) individuation. These stages were also based on Jungian (1939/1983) theory and her personal experience in living with multiple sclerosis.

In Butterfield's (2011) first stage, *illusion*, one's state of relative health is interrupted, as "serious illness catapults the individual into a world not previously conceived of or endured" (p. 44). In this first stage, one over-identifies with one's *persona* to the detriment of a more integrated self and often takes for granted one's health and/or good fortune, even attributing them to one's own will.

In Butterfield's (2011) second stage, the *chaos* state, one experiences pain, uncertainty, anger, and frustration at not being able to participate in the world as one had before, along with social stigma or a sense of being an outcast. One attempts to deny one's condition, clinging to

one's ego accomplishments and previous identity, despite possibly having received dream messages that should obviate denial:

When faced with the physical and emotional demands of serious illness, the now alienated ego is often overwhelmed with vivid and startling dream imagery. Dreams are a natural pathway to the unconscious and often contain material that the ego is unable or unwilling to realize. (p. 51)

In the stage of *alienation and guilt*, one experiences a physical, emotional, and spiritual crisis, including a sense of alienation and abandonment (Butterfield, 2011). One also experiences a questioning of one's faith and worth, guilt, and a confrontation with one's own shadow.

In the *despair* stage, one experiences depression and shock and is unable to imagine a future or see a way out of the relentless pain (Butterfield, 2011). Struggles with suicide can represent "a desire to engage in the great unknowing and could serve as a gateway to wholeness" (p. 63). This despair can eventually lead to a psychic shift toward wisdom and transformation.

In the stage of *transformation*, Butterfield (2011) wrote,

Job's anger and suffering propel him across the line from ordinary ego consciousness into the depths of the unconscious where rich imagery enables a contact with the Self. . . . In the dark night of the soul, one is confronted with the ineffable. Jung referred to it as the divine darkness of inner opposites. . . . Trickster embraces contradiction and offers a solution to rigid duality. He demands one be able to sit with the dance of opposites. (pp. 67-69)

Regarding Butterfield's (2011) *individuation* stage, she reminds the sufferer, "Job has become whole through his encounter with Self and the conscious assimilation of the unconscious feminine" (p. 72).

For chronic illness clients, the surprise of a new set of symptoms can always be viewed as a setback but if one engages in depth psychological work of individuation the client may be ennobled to undertake regular journeys that build resilience and facilitate personal growth. . . . Desire and despair are aspects of appetite. (pp. 78-79).

Butterfield (2011) used Jungian (1939/1983) theory to understand the general process of psychospiritual transformation or individuation in the context of living with chronic illness.

However, she offers little detail of the specific experiences of each of these stages and the key aspects (other than dreamwork) that contribute to growth or movement throughout the stages.

In the book published by the American Psychological Association, *Treating People With Chronic Disease: A Psychological Guide*, Carol Goodheart and Martha Lansing (1997) mentioned the following five common problem sources during people's experience with chronic illness: (a) distance in interpersonal relationships; (b) dependence; (c) disability or disruptions in achievement; (d) disfigurement, impairing body image or integrity; and (e) anxiety and fears of death. They outlined the following major factors that may influence the way that people respond to these problems: (a) the nature of the illness, (b) the person's coping style, (c) the social image of the illness, (d) the visibility of the illness, and (e) the person's life stage. According to Goodheart and Lansing, three common themes typically emerge among people with chronic illness, including (a) decreased self-esteem associated with body image; (b) mourning or loss; and (c) negative effects of physical, psychological, and social discomfort.

Goodheart and Lansing (1997) outlined the following stages of a person's response to chronic illness, beginning with initial onset:

1. *Initial response that something is wrong.* This may include denial, long periods of suffering before seeking medical attention and/or diagnosis, and a shock of trying to make sense of the disease.
2. *Awareness of chronicity,* in which physical symptoms are not resolved. This response is often accompanied by fear (sometimes of death), denial, grief at the end of a past healthy self, and difficulties in relating to others. These difficulties are intensified by negative family or social reactions, such as denial, blame or rejection, especially when the illness is vague, or considered socially unacceptable.

3. *Disorganization*, in which one feels a profound disturbance and loss provoked by the illness, especially in terms of routines, quality of life, family relations and responsibilities, work, energy, pain, and the ability to rest. One may experience fear and a profound psychological disorganization when symptoms return suddenly after remission (sometimes resulting in anger, frustration), or a feeling of unfairness at having the disease.

They face the internal loss of a familiar sense of self, function, and identity, and they may be faced with external loss of support or contact with important other people at work, in the social milieu, or even among family members. (p. 38)

In response to these losses, some people become withdrawn, isolated, and depressed. The authors explain that, at this stage, people experience a natural tendency toward self-absorption with the body, often with confusion and self-doubt as to whether these new physical sensations are *really* happening.

4. *Intensified wish for a cure*, focusing on a return to the “normal” or “old self” in terms of a physical and psychological identity (p. 39). People tend to seek more information and alternative forms of assistance and treatment, even embarking on a spiritual quest. Some people experience the illness as a punishment or a test and may attempt to repent or bargain in order to be healed, a tendency especially found among people who suffer from more threatening diseases.
5. *Acknowledgment of helplessness: I cannot change what is wrong*. In this stage, usually after many ups and downs, one comes to the realization that life will never be the same again. Profound depression is common, even after a healthy and necessary grieving. This acknowledgment does not imply that people passively accept being ill or cease to take

care of themselves, but rather that they draw on internal strength to face what cannot be undone and the corresponding losses.

6. *Adaptation: How can I live with what is wrong and is changing my life?* Arriving at and developing at this stage depends on many factors, including the capacity for creative adaptation, the severity of the illness, and the availability of social support. Keys for success at this stage include the following: working on issues of loss; accepting necessary lifestyle changes; and dedicating energy to enjoyable and worthwhile activities without feeling guilty, frustrated, or depleted.

Goodheart and Lansing's (1997) stages focus mainly on describing how chronic illness sufferers come to accept their own physical and ego limitations while continuing to live in a reality dominated by ego strength. In my view, these stages fall short of portraying the *full* range of exceptional human development. I suspect that the above stages are mainly based on people who were in the beginning years of their chronic illness experience and who were primarily at centers II or III of Ruumet's model (1997, 2006).

JoAnn LeMaistre (1995), a clinical psychologist and a multiple sclerosis sufferer, outlined six stages of one's emotional reactions to illness: (a) crisis, (b) isolation, (c) anger, (d) reconstruction, (e) intermittent depression, and (f) renewal. In the *crisis* stage the person is "seriously ill and very frightened" (p. 10), while events, and even time itself, seem confusing from this disorientation. "The sick person's energies are directed inward toward healing, and controlling panic" (p. 10), and the person and his or her family begin to experience a fear of the unknowable future.

Regarding the *isolation* stage, LeMaistre (1995) noted this phenomenon:

In time, the acute nature of the illness may abate. But total recovery does not occur, and the illness persists. . . . There is so much uncertainty about the future that the patient may

not be able to sleep at night and may seem restless and distracted during the day. The lack of an expectable future constitutes a major assault on one's self-image. . . . During the isolation stage, patients look inward and experience many negative feelings about themselves. (pp. 12-13)

According to the author, patients begin to believe that no one can understand the devastation of the losses and this isolation most troubles patients who have been the most independent.

LeMaistre explained that one of the emotional barriers to asking for help is a strong feeling of guilt about having a disease. She cautioned that blame must not play a part and that talking about feelings with others is a very important way to break the isolation.

In the *anger* stage, LeMaistre (1995) explained,

The sick person has been suffering severe upset, terror, anxiety, and helplessness. Add to this the sense of injustice, unfairness, and senselessness of being struck down by a disease, and the result may be a rage reaction of tremendous proportions. Often the target of this rage is the patient himself or herself. . . . The commonly experienced feelings of despair may result in contemplation of suicide. . . . With the feeling that their underlying problems cannot be solved, along with the belief that they themselves are the culprits, many patients suffer intense unhappiness. . . . This flirtation [with suicide] may also represent a way to regain control when one's body, one's feelings, and the emotions of one's family seem out of control. . . . The only effective control is striving toward emotional health. (pp. 13-14)

She recommended that the patient take back control in small steps and develop a "task-oriented" (p. 14) response.

In the *reconstruction* stage, LeMaistre (1995) says that

the sick person may now be feeling much stronger physically or may have had enough time to begin mastering new living skills. . . . Moods are happier and the difficulties seem a bit further away. In short, the sick person is learning the possibilities and limits of his new competences . . . it is a reconstruction of the sense of oneself as a cohesive, intact entity. The reconstruction takes on many concrete aspects, such as the development of new skills, but the most important value is emotional. When a customary pattern of living has been shattered by illness, the patient fears that he or she is no longer recognizable as a whole being. It is the reemergence of a positive self-image that constitutes reconstruction. (pp. 15-16)

LeMaistre explained that, although patients often feel devastated by recurring symptoms, each experience with trusting and succeeding is a building block toward reconstruction.

In the *intermittent depression* stage, LeMaistre (1995) offered that

the elation associated with new skills can give way to new feelings of despair as the patient recalls how much simpler it was to do routine things the old way. Nostalgia and grief may combine to produce sadness and discouragement.

Seeing a doctor, who confirms your intuition that your condition is not improving or is worse, often leads to depression. . . . It may be best to seek counseling during these difficult times as a way of shortening their duration and providing new understanding of what all the feelings of loss are attached to. New understanding brings new resilience; it does not make the losses go away.

Intermittent depressions seem to combine two feelings. One is the awareness of loss of function that occurs several times a day in the course of ordinary living. . . . If the awareness of loss arouses a distinct image of what life would be like if the amputation had not occurred, and if this fantasy has strong emotional meaning for the person, depression is very likely. This image of how you would be without the illness I call the *phantom psyche*. . . . It is the self-punishing mechanism whereby the chronically ill person continually erodes his or her own self of self-worth and competence. . . . "If only" statements . . . contain harsh judgments of worthlessness.

Self-esteem increases proportionately to successful experiences of independence and purpose. . . . The phantom psyche—those unrealistic expectations you have for yourself—cannot compete with the heady gratification of hard-won success. (pp. 16-17)

In LeMaistre's (1995) renewal stage,

The losses, and the sadness they cause, never go away entirely. Rather there is a sense of lingering regret for all the capacities that have been lost. A person who has mastered the technique of using a wheelchair can feel very proud of this achievement and know full well that this device is essential for retaining an active life. But the person does not have to like it.

It is not necessary to like or to resign yourself to the compromises you need to make to get on with living. It is only necessary to acknowledge that changes in lifestyle and skills have to be made. Acknowledging that your skills are different from your preillness days is not the same as "adjusting" to illness. There is no surrender involved, only growth—the creation of new options through new means.

If you have a chronic disease, you need not be emotionally handicapped if you continually strive to be able-hearted. . . . Even if you feel in the grip of hopelessness, you are behaving in an able-hearted way by any expression of interest in another. Shared interest and compassion is what establishes meaning and purpose in life. (pp. 18-19)

LeMaistre emphasized that the creation of renewal comes from the experiences that teach us not to waste the present on fearing the future.

LeMaistre's (1995) stage model focuses on cognitive development in coping with the physical changes of illness. She does not mention broader aspects of psychospiritual transformation reflected in Ruumet's (1997, 2006) model or the Jungian (1939/1983) theory of individuation that may emerge in people's experience in living with chronic physical illness, such as feeling an interconnectedness with all life or embracing previously hidden unconscious aspects of the self.

In my view, the following model presents a more complete perspective of psychospiritual development in relation to chronic illness experiences. In *The Chronic Illness Workbook*, social worker Patricia Fennell (2001) described the following core realities of chronically ill people: (a) onset (dramatic physical changes akin to a physical and emotional earthquake including grief, denial, and painful recognition of changes); (b) rejection; (c) loss of self, including pain, and loss of certain abilities or changes in relationships; (d) role changes (for the person as well as other family members); (e) identity confusion, sometimes even around the idea of whether one is sick or not, depending on the way one conceptualizes illness; (f) cultural stigmatization, along with all of the misconceptions that people may have of the illness; (g) hindrances in normal physiological or social development; (h) disbelief and suspicion on the part of others; (i) clinically induced trauma; and (j) loneliness, loss and withdrawal. Fennell illustrated the changing, and often *cyclical*, nature of chronic illness, as people may experience extremes between relative stability and worsening symptoms. Chronic illness may create not only constant suffering and changes in lifestyle, but also disabilities, either constant or recurring, which often affect people in profound, yet subtle, ways invisible to others.

Fennell (2001) outlined a Four-Phase descriptive and prescriptive model for rewriting “the story of you and your illness,” (p. 7) caring for one’s self, and living a meaningful and fulfilling life:

1. *The crisis phase.* At initial onset of disease one may experience confusion, self-doubt at ambiguous uncertain symptoms, loss of physical and psychological control, fear of being different or becoming stigmatized, isolation due to physical difficulties, and the uncertainty of conflicting advice. This crisis phase may be abrupt or occur gradually over a long period of time without a clear diagnosis. Keys for moving out of this stage are (a) containing the crisis, (b) recognizing and permitting one’s own suffering, and (c) revising one’s personal narrative.
2. *The stabilization phase.* This phase is characterized by relapses, instability, and recognition of some patterns of the disease and attempts to establish an appropriate treatment or lifestyle. People commonly experience frustration and guilt in attempting to assert a previous lifestyle, an intense desire and search for a cure, and resistance to major life changes. Fennell outlined the following keys to this stage: (a) achieving stability, (b) restructuring one’s life according to physical needs, (c) committing to a period of monastic life of self-care without overextension, and (d) regarding one’s own suffering with compassion.
3. *The resolution phase.* Fennell explained that, in this phase, one *releases* the search or hope for a cure and builds a new life, making room for the illness with all of its limitations, treatments, and lifestyle changes. One becomes aware of relapses or crisis when one tries to return to the self and lifestyle that prevailed for one prior to the onset of illness. This leads to a greater realization of impermanence at this irreversible change.

Thus, grief is a natural part of this phase. Identity crises are common at this point as people tend to question their own self-worth and will to live, withdrawing into their own feelings of despair and vulnerability. In this phase, one searches for a new, authentic self and meaning in this suffering. Key to this phase are (a) maintaining insight; (b) honestly analyzing losses, while engaging in active grief; (c) respecting one's own suffering without dismissing it; and (d) developing meaning toward constructing a new self. Creative expression may be particularly helpful in identity exploration and in dealing with emotional material.

4. *The integration phase* is a moment in which one integrates the parts of the old self (before the onset of disease) with a new self. This phase may be experienced only for brief periods. One begins to organize life, and a support network, based on this identity and the realistic conditions of the disease, as one also rethinks one's enjoyments and abilities, for a more *complete* life in which illness is only one aspect. One conserves energy and realistically takes into account boundaries and limitations, striving for a personal best without external comparisons or judgments. The illness experience also becomes part of a larger philosophical or spiritual framework.

Although Fennell's (2001) model may provide useful insights into the process of transformation through chronic illness, it is not based on empirical research, nor does it address broader aspects of psychospiritual development. This model focuses on changing notions of the self, toward wholeness. *The resolution phase* is related to a breakdown of the ego in adopting a lifestyle more suited to bodily needs, while actively engaging in inner work on issues of acceptance and grief. The final *stabilization phase* touches upon aspects of Ruomet's (1997) "IV-III waltz" (p. 15) as one moves beyond wishful cures and acknowledges a sense of

emptiness in stripping away who one was. This realization helps one to see that this identity is not the whole self. The final phase represents the return work, embracing new, unique creative aspects of the self, and is similar to Ruumet's (1997) Star Center (V) and Jung's idea of the integration of opposites (1939/1983).

Psychologist Kevin Krycka (2000) wrote of a common *splitting of experience* among people with illness when there is a division between the patient's view and understanding of illness and the doctor's perspective, especially when the doctor does not understand or respect this view. He argued that this can be psychologically devastating for the patient and lead to disembodiment. Krycka wrote that embodiment contributes to a "deeper understanding and lasting change" (p. 71) with regard to the illness experience, arguing that a "growing body of work suggests that as people distance themselves from the wisdom of the body-mind unity, a gulf opens wherein experiences are disintegrated" (p. 71).

Clinical psychologist Jerry Michael Ruhl (1995) used a hermeneutic research method based on written patient narratives to explore both ways in which serious illness disrupts lives and patterns of illness response, and he grounded this study "in the belief that illness is not just a physical disease but includes the psychological experience of the sufferer as well as the broader context of family, culture, environment, and cosmos" (p. ii). He concluded that there are four primary psychological responses to illness, each of which may be appropriate according to the person's context and timing: (a) regression, (b) maintenance, (c) transformation, and (d) transcendence. His analysis was based on written accounts by people with disabilities and chronic illness.

In characterizing these illness responses, Ruhl (1995) emphasized that they should not be used to *categorize* or *judge* people in terms of stages, as each person and illness is completely

unique and cannot be understood outside of her or his particular context. Ruhl added that, while these responses should not be used to prescribe the “right [way of being ill, they] can be used as doorways into each patient’s experience of illness” (p. 211). Ruhl expressed his belief that “a response should have the potential to change as the patient and circumstances change [and, thus, it may be appropriate to ask,] ‘Is the patient stuck in one response or can the process unfold?’” (p. 211).

According to Ruhl (1995), in *regression*, the self is diminished by illness, and one focuses on self-preservation at the expense of willful control. One may feel helpless, dependent, and debilitated and play the role of a compliant, passive, and grateful patient, even resorting to a kind of *infancy*, or child state. One is expected to follow the treatments, “get better” (p. 179), and then revert back to one’s previous social responsibilities. Ruhl explained that the majority of people who suffer illness temporarily respond with regression but that some may incorporate it into their identity and personality and have difficulty in making this transition back to an independent life. He argued that the medical model of the doctor healing the passive patient favors this response. Regression also implicates an alienation of the body, or a part of the body, from the idea of the self (Sacks, 1984; Ruhl 1995), especially if one cannot see or feel it or if it is not functioning properly.

Ruhl (1995) explained that this response “often includes psychic deflation accompanied by feelings of anger, self-pity, or depression. The patient may feel less than what he or she really is, incapable, left behind, excluded from the flow of daily life” (p. 183). One may also experience periods of inflation, or narcissistic gratification, and frustration in wanting to go back to the “old self” (p. 184). According Ruhl, people may cyclically return to the regression

response throughout their illness experience, at least as a short-term solution, taking a step back from daily life and focusing on physical survival.

Ruhl (1995) explained that, in the *maintenance* response, one sees the illness as *separate* from the self and seeks mastery over it in attempting to adapt and maintain the pre-illness self-organization. This often involves “denial and minimization of the potency and impact of the illness” (p. iii) and of the emotions that emerge with it, as if nothing has occurred. Ruhl explained that this response may be conscious or unconscious, sometimes lasting for many years, in which one *denies* information and experiences that threaten the idea of the self. According to the author, this can result in a sense of *disembodiment* and overintellectualized detachment from one’s own thoughts and feelings in discussing one’s conditions abstractly. Wounded parts are repressed and segregated from a sense of self. These parts may include the experience itself, an organ or limb, or pain.

Ruhl (1995) concluded that the maintenance response is exacerbated by social pressure to return to a normal life, observing that chronic illness sufferers often respond to an external expectation to get better with shame or guilt and “may attempt to compensate for physical deficiencies by overtaxing other aspects of the self. Models of heroic overcoming are held up to the chronically ill and disabled as examples to be emulated” (p. 192). This response of society implies personal weakness or lack of character among people who remain ill while regarding individual will as “potent and effective” (p. 186) in determining one’s fate. Ruhl suggested that the maintenance response strategy may be inadequate and inappropriate for people with chronic illness, because they must accommodate themselves to the illness, which is a task “requiring major changes in self process” (p. iii).

In Ruhl's (1995) *transformation* response, the illness is integrated into a major reorganization of the self. Ruhl maintained that, although transformation can occur with *any* illness, it is particularly important for those who suffer *chronic* illness or *ongoing* disabilities. This creation of a new self implies recognizing the reality and implications of one's illness and grieving losses, as Ruhl likened this response to a kind of *death* of the pre-illness self. This response may be characterized by loneliness, bitterness, and withdrawal strongly related to consciousness and fear of death and to individual pain and sickness that no one else can truly feel. Ruhl argued that the key to transformation is *incorporating* illness into the self and seeing its liabilities and possibilities. It "requires an honest appraisal of what one has lost to illness" (p. 200), a process that begins in the body, but that spreads to other areas of life.

According to Ruhl (1995), in the transformation response, people often report a loss of innocence and invulnerability based on the recognition that future plans can be broken and tomorrow is in doubt. Among children and young people, the "losses involve what never will be" (p. 201), and one's sense of self may be more *intertwined* with the illness experience. When illness begins in adulthood, "a self-structure is already in place, involving habitual ways of perceiving and interacting with the world that are suddenly lost" (p. 201). Many people, both children and adults, face the difficulty in forgiving themselves for supposedly being defective, and may even experience self-loathing, cursing, or hating their body, especially when physical limitations are more obvious to other people. This new self that emerges may trigger a reassessment of values and a new meaning, or central purpose. Ruhl explained that transformation is not an *event*, but rather a *process* accompanied by grief, fury, and constant adjustment:

One never fully adjusts to a life-changing illness. Individuals frequently spiral around the illness, taking in its reality a bit at a time, yearning and returning to their old self identity

as best they can, bumping up against limitations, and only gradually integrating the illness with the self. There are periods of relative balance, stability, interspersed with frustration and despair. Transformation is not tidy. (p. 204)

In Ruhl's (1995) *transcendence* response, the illness disruption is integrated, and one's identity shifts *beyond* the body and ego: "Illness can be a rite of passage in which one may heal, not only physically, but also heal into a new understanding, a deeper experience, a heartfelt compassion or even a transcendent vision" (p. iv). Transcendence involves a broader circumference of identity, including the family, the social, and the transpersonal. One stops trying to wrestle with and *beat* the illness and lives in mystery with joy, appreciation, and a sense of interconnectedness in recognizing a force greater than individual will. One may begin to see the divine in everyday acts as universal love is illuminated in all. Ruhl argued that, for many people suffering from chronic or terminal illness, the central issue becomes "finding a balance between resisting and opening, fighting and surrendering, willing and accepting. When it becomes clear that there is some measure of fate or destiny in everyone's life, a deepening of self is possible" (p. 210).

Ruhl (1995) provided an in-depth analysis into the complex response patterns among people who live with illness. I agree and identify strongly with many of Ruhl's findings, especially in the responses of transformation and transcendence as complex, lonely, spiraling processes. The findings are presented as vivid stories that elicit sympathetic resonance. These response patterns are not necessarily *sequential* stages in development, but, like Ruumet's (1997, 2006) centers, they may be useful for understanding shifts in one's "home base" (Ruumet, 2006, p. 17) in living with chronic illness. However, it also seems to me that one may move to different response patterns from moment to moment. The transformation and transcendence responses

generally reflect several themes addressed by other authors on transformation and healing and Ruumet's (1997) movements between centers, beginning with "the IV-III waltz" (p. 15).

However, I also find several key limitations to Ruhl's (1995) study. First, it does not explain shifts in response patterns over time within the person's developmental process. I believe that the research method of analyzing existing written texts had several limitations, including the absence of contextual information on participants, other possible response patterns, and a more in-depth exploration of what contributes to these responses.

Other studies explored experiences and results of psychospiritual transformation directly related to experiences with illness, including current chronic illness and bouts with life-threatening illness that were eventually overcome. In the first representative nation-wide study on spiritual transformation, Tom Smith (2006) reported that approximately half of Americans report experiences of spiritual or religious change. The leading causes of this change are normal religious activity and having had a serious problem, most often an illness or accident (to self or someone else) or the death of someone close. The specific aspects of these changes were found to be (a) strength of faith, (b) changes in character (for example becoming more understanding or helpful), and (c) a halt to self-perceived bad habits.

Brenda Cole and Clare Hopkins (2006) researched experiences of spiritual transformation among 253 people diagnosed with cancer during the previous 2 years. They noted spiritual changes in four domains: (a) perceiving life through a more spiritual worldview, (b) focusing on more spiritually oriented goals versus trivial matters, (c) acting with greater compassion in relationships, and (d) experiencing a changed sense of self in seeing one's own life as sacred.

In a study of spiritual transformation among people diagnosed with AIDS, Gail Ironson, et al. (2002) reported changes in behavior, beliefs, values, priorities, and views of self.

Correlations with spiritual transformation included a greater sense of purpose in life, a more positive view of God, and a greater adherence to HIV medications. The most common antecedents to spiritual transformation were found to be (a) a near-death experience, (b) receiving a positive HIV diagnosis, and (c) stopping drugs or alcohol in a moment of extreme crisis.

Psychologist Shirley Lyn Loffer (2000) performed a study with women who experienced a sense of transformation and meaning through their long-term experience with rheumatoid arthritis, a systemic and progressive degenerative illness. Among her metathemes, Loffer outlined (a) a return to the self, including the examination of old beliefs and behavior, embracing novel experiences of self, and rediscovering abandoned aspects; (b) taking necessary control over one's life; (c) making connections and building support; (d) gaining perspective on one's journey, including cultivating acceptance, hope, and optimism; and (e) sharing one's learning with other people who suffer chronic illness. As in Ruumet's (1997, 2006) fifth center of the Descent Tango, these findings speak of a return to previous ways of being, exploring old wounds, finding new meaning in perceiving one's life as a whole, and moving outside of an ego identity. Asserting greater control over one's life may indicate previously uncultivated ego strength (third center) commonly bypassed by women who are in centers four or five (Ruumet, 1997). Sharing with others may speak to universal connection, love, and service to others in Ruumet's (1997, 2006) fifth center.

Psychologist Rosemarie Elaine Taylor (2003) reported transformation and self-healing among people who suffered long-term panic attacks. She concluded that all coresearchers had moved from ego experience to eventually accepting and integrating panic attacks and their associated altered states of consciousness into an expanded sense of self. Participants reported

increased authenticity, sensitivity, desire for a spiritual path, and compassion, with an improved self-image. Taylor also mentioned a discovery of turning points and self-management skills and with the recognition of potential benefits of their illness. These altered states, a deep spiritual desire, and an understanding of self beyond ego identity coincide with experiences of Ruumet's (1997, 2006) fifth center.

In her interdisciplinary doctoral dissertation, Frances Marylou Spencer-Benson (2003) conducted heuristic research on the essence of transformation through the survival of a life-threatening illness, focusing on the redefinition of participants' beliefs, values, and worldview. The research participants had already recovered from life-threatening illness at the time of the interview and, thus, were speaking in retrospect about the effects and experience of illness. Participants were mostly Canadian Caucasian women from a Judeo-Christian background who had suffered cancer.

In her results Spencer-Benson (2003) emphasized the importance of sharing these stories as an integral part of the participants' healing process. Important aspects of the transformation experiences included learning to love the self, awareness of others and everyday experience, self-awareness, a sense of purpose within their disease and living in sync with one's self, a sense of illness as a gift or a "wonderful experience," (p. 135) that acts as a catalyst to make one healthy . Spencer-Benson reported that "disease previously understood as something to avoid was embraced as producing riches that intensified and expanded [participants'] consciousness" (p. 135).

Spencer-Benson (2003) emphasized the multidimensional aspects of healing, remarking that "the participants in this study turned inward and discovered a path that led to healing in many ways other than physical well-being" (p. 146). Spencer-Benson argued that the study lends

credible evidence to the idea of “power within illness—personal power claimed by the participants in moving them from a place of fear of disease to a place of celebrating disease as the catalyst that led them to enter into a transformative process” (p. 147).

I am critical of Spencer-Benson’s (2003) attitude of attributing the participants’ physical cure and transformation to the power of *their own will*, as she mentioned that “they transcended a serious illness” (p. 144), an idea consistent with Ruhl’s (1995) maintenance response. I believe that Spencer-Benson’s results were rather one-sided in describing illness as a “great gift” (p. 136) while giving little attention to the difficulties, a focus that I believe emerges from retrospective interviews with people who no longer suffered from an illness. I believe that an illness is more complex than simply a gift or a celebration, but is something that emerges as part of an imbalance that one must try to understand and learn from. It may be limiting to think of an illness as giving one something, in order to move further along toward transcendence, and then disappearing when one finally understands it. Spencer-Benson does not explore the process of transformation as it occurs over time in terms of common issues or stages.

The above studies reflect the influence of (uncured or unresolved) chronic illness on psycho-spiritual development. Common issues include (a) moving toward a more expanded sense of self beyond ego identity; (b) identification with broader aspects of life beyond the individual self; (c) a greater sense of meaning and purpose; (d) desire for a spiritual path beyond previous life goals; and (e) a greater sense of surrender, hope, and optimism (Butterfield, 2011; Cole & Hopkins, 2006; Fennell, 2001; Ironson et al., 2002; Loffer, 2000; Ruhl, 1995; Spencer-Benson, 2003; Taylor, 2003). Some of these areas of growth may be part of life-long cycles of development experienced by people who do not suffer from chronic illness. For some people, chronic illness served as a kind of catalyst for psycho-spiritual development, although it would

be rather one-dimensional to conclude that illness was the *sole* factor in contributing to this growth. It is also plausible that other forms of crisis and suffering (other than illness) can similarly influence psycho-spiritual development.

Nearly all of the literature in this chapter reflects the idea that the process of transformation and healing is *complex, subjective, and multi-dimensional* (Braud et al., 2000; Coburn, 2006; Gaynor, 1999; Hart, 2000; Imber, 1994; Mehl-Madrona, 2003; Metzger, 2004; Villoldo & Krippner, 1986). In the end, the process of psychospiritual transformation through chronic illness is about the person's life-long journey, perhaps the soul's journey, within one's place in the universe. Moreover, the movements and layers of the self are perhaps too incomprehensible for us to understand. In the end, the self and the world around us may be one and the same.

Chapter 3: Research Method

In this chapter I will present the research method that I used in this study. This presentation entails (a) a general overview of intuitive inquiry and my rationale for using it as my principle research method; (b) an outline of the five cycles, or methodological steps, of intuitive inquiry; (c) a discussion of validity; (d) my research questions and participants; (e) selection criteria for the autobiographical narratives of this study; and (f) delimitations and limitations of this study. In the five subsequent chapters I will present my work with each of the five cycles of intuitive inquiry for this study, including a description of my procedures and the conclusions of each cycle.

Introduction

Any process of transpersonal transformation can be subtle, complex, multidimensional, and highly subjective. The life-long experience of living with a chronic illness is especially totalizing, involving *all* aspects of the self and of one's life (Butterfield, 2011; Fennell, 2001; Register, 1999; Ruhl, 1995). It cannot be set aside as an isolated piece to be analyzed. The overall process is practically impossible to access, understand, characterize, or adequately convey in words, even to one's self. Even phrases such as *my body got sick*, *my illness*, or *what my body is demanding from me* reflect the inadequacies of language in articulating this embodied phenomenon that, because it is illusive, cannot be reduced to a physical experience. This experience is also beyond a single, temporal moment. It is a broad painting that cannot be felt or seen from each individual brushstroke. A true depiction of this experience is more than a series of descriptions or events but is the result of a somehow deeper, more subtle, artistic perception of the whole of our being across time. In the capturing of the essence of this experience, the line between science and art becomes blurred, their distinction less relevant.

Understanding the process of transformation through chronic illness requires multiple ways of knowing in allowing both the participants *and* the researcher to access inner experiences involving spiritual, physical, and psychological shifts. It calls for a qualitative research method that transcends linguistic skills and word-based rationality in collecting, analyzing, and presenting data. Although the researcher's personal qualities are of critical importance in all phases of any qualitative study (Amlani, 1998; Anderson, 2004a, 2011; Mertens, 2005), this topic demands special kinds of sensitivities, perceptions, empathetic capacities, and expressive skills. In the end, who the researcher *is* is inseparable from the research question, design, analysis, and report of any study.

Intuitive Inquiry

Psychologist Rosemarie Anderson (2004a, 2006, 2011) developed intuitive inquiry to meet the challenge of understanding subtle, complex characteristics of psychospiritual development that are close to the researcher's own life experiences, concerns, and unique inspiration. She developed this method throughout the 15 years of her research and dissertation supervision with graduate students at the Institute of Transpersonal Psychology. In recent years, intuitive inquiry has been further used and enriched through doctoral research on a variety of topics (Carlock, 2003; Coleman, 2000; Dufrechou, 2002, 2004; Esbjörn, 2003; Esbjörn-Hagens, 2004; Hill, 2005; Hoffman, 2003, 2004; Manos, 2005; Phelon, 2001, 2004; Rickards, 2006; Unthank, 2007). Intuitive inquiry combines intuition with intellectual rigor in a process that often results in the transformation of not only the researchers' ideas about a topic, but their personal lives (Anderson, 2004a; 2006).

Intuitive inquiry is designed to give a structure to a full hermeneutic process of interpretation, from the selection of the research topic, reflection on one's ideas about the study,

and data analysis and interpretation, to the presentation of findings (Anderson, 2004a, 2006, 2011). In designing this method, Anderson drew upon her years as a qualitative and quantitative researcher and was informed by an integration of feminist theory and research, heuristic research, focusing, classical hermeneutics, phenomenology of the lived body, and Gendlin's "thinking beyond patterns" (Anderson, 2011, p. 17). Anderson (2011) argued that intuitive inquiry is a *science* because it involves rigorous methods and the careful documentation of intuitive insights or contents, along with their respective context and modes (visual, auditory, proprioceptive, kinesthetic, etc.). In using this approach, she stressed the importance of the researcher's familiarity with his or her own intuitive style, which will enable him or her to use or create methods that will more accurately access insights (Anderson, 2004a, 2006, 2011).

Intuitive inquiry invites the researcher to explore and make explicit his or her own preliminary lenses in viewing the research topic prior to data collection (Anderson, 2004a, 2006, 2011). These lenses represent both how the researcher *views* the topic and *what* he or she sees. The preliminary lenses are defined based on one's own personal beliefs and experiences and a thorough literature review. After completing the data analysis, the researcher refines, expands, or modifies these original lenses through an inner dialogue, highlighting intuitive breakthroughs. These new lenses are discussed in light of relevant theoretical and empirical literature and the general social context of the topic.

Intuitive inquiry can be an important method for *theory-building*, in both exploring new theories and refining existing ones (Anderson, 2004a, 2006, 2011; Unthank, 2007). Intuitive inquiry encourages the researcher to develop a *big picture perspective* rather than a reductive one, exploring conceptual shifts and changes (Anderson, 2004a). The five cycles, or methodological steps of intuitive inquiry, can reveal the construction of theory through

disciplined imagination, deliberate introduction of diverse aspects of thinking from multiple paradigms, and the following of intuition wherever it goes as it moves through these steps (Anderson, 2011). The paradoxes in these cycles become opportunities as the researcher works with tensions, oppositions, and contradictions (Anderson, 2011).

Intuition in Intuitive Inquiry

Rosemarie Anderson (2007) defined intuition in the following way:

Intuition is a subtle sense perception that conveys direct insight into future possibilities or circumstances that cannot be experienced through the ordinary five human senses or analytical reason. When an intuition is sensed, one often feels as though one is tapping into a collective or unconscious source of wisdom that requires a diffuse awareness rather like a dream state while awake. However, as a subtle sense, intuitions often flutter out of sight as though vanishing into the background of awareness at the precise moment that the focused, rational mind “kicks in” searching for the intuition’s meaning. To “capture” meaning, intuitives often learn unique means to “navigate” between diffuse or dreamlike perceptual states and analytical reason and reflection.

In everyday language, the word intuition is a blanket term often used to describe any insight inexplicable in ordinary terms. Yet, to the individual experiencing an intuition, intuitions are in themselves quite palpable as distinct yet subtle perceptions into the nature or reality of things as they are. That said, it is important to recognize that intuitions manifest in highly variable forms from individual to individual. An intuitive solution to a problem may be seen as an image, heard as a song or voice, sensed as a gut feeling or inner knowing, distinguished in a gesture, found expressed in nature or surrounding circumstance, and in many other forms. Over time, the unique ways that intuitions manifest can be refined with attention and practice because people learn what works for them uniquely and what does not. (p. 1)

Anderson also (2011) outlined five types of intuition in terms of practical manifestations in the creative process of research and in daily life:

1. *Unconscious, symbolic, and imaginal processes*, embedded in an interaction with nature from our own biological, psychological, and historical context, including visionary experiences, dreams, archetypal experiences, and dialogue with symbols. In this sense, inner and outer sensations and insights often become blurred.

2. *Psychic or parapsychological experiences* as direct and unmediated ways of knowing often related to one's personal connection with the phenomena or person, including telepathy, clairvoyance, and precognitive experiences.
3. *Sensory modes of intuition*, involving not *only* the five main senses but subtle forms of "kinesthesia (sense of movement in space); proprioception (sense of orientation in space); and a visceral sense arising from sense receptors in the organs and tissues of the body" (p. 24).
4. *Empathetic identification*, in which one may call upon a variety of senses in knowing about the person or object of study. "What is observed yields itself to our knowing. There is no intrusion, no object, and no subject" (p. 25).
5. *Through our wounds*, as personal openings of compassion to the world often mirroring wider cultural needs for healing.

In the next chapter I will describe my own intuitive style, drawing upon the above concepts and typologies, because my intent is to align my research procedures as closely as possible with my natural intuitive style, in order to maximize my insights.

An Overview of the Five Cycles of Intuitive Inquiry

In *Cycle 1* of intuitive inquiry as explained by Anderson (2011), the researcher explores his or her research motives, relationship to the topic, target audience, and specific intuitive skills and style:

A researcher identifies a topic based on his unique interests and passions. In intuitive inquiry, in order to clarify and refine the identification of a topic of study, the intuitive inquirer selects a text or image that repeatedly attracts or claims his attention and relates in a general—and sometimes initially ambiguous way—to his research interests. (p. 31)

The researcher engages with the text or image through meditation and intuitive knowing, in order to further explore subtle aspects of the topic and of the researcher's relationship to the topic.

Anderson explained that, at the end of Cycle 1, the researcher defines the research topic and question(s) and proceeds to design the specific research procedures for the subsequent cycles.

In *Cycle 2* the researcher explores his or her own personal values, assumptions, and understandings about the topic, while also reviewing a range of relevant literature (Anderson, 2004a, 2011). The end result of Cycle 2 is a series of lenses, usually less than a dozen, that are both “a way of viewing a topic and what is seen” (Anderson, 2011, p. 31). In intuitive inquiry the researcher *acknowledges* these lenses, rather than putting them aside, and invites their change and refinement throughout the research. According to Anderson (2011), this dialectical process gives the researcher feedback that invites discernment and self-scrutiny. Anderson remarked that many intuitive researchers are often surprised at what they discover about their own deep beliefs about the topic. Cycle 2 also includes exercises for selecting theoretical, empirical, literary, or even historical texts that may help the researcher further explore and refine his or her lenses. These texts may include insights from philosophical writers, teachers, or clinicians, beyond conventional literature reviews (Anderson, 2011). After exploring a variety of novel perspectives, the researcher reviews and prioritizes this list of preliminary lenses, placing them in full scrutiny in the research study (Anderson, 2011). Preliminary lenses need not be presented in a written list form, because Anderson encouraged researchers to explore more creative ways of expressing and presenting lenses. For example, psychologist Katherine Unthank (2007) presented her preliminary lenses as a trauma theory which she later refined in her new lenses.

Cycle 3 consists of choosing sources and their selection criteria; collecting data; and preparing descriptive, summary reports of findings prior to a more in-depth interpretation (Anderson, 2004a, 2011). Traditional empirical research is often largely limited to this cycle. Although most intuitive researchers have collected original data through interviews or stories

from participants, some studies have included data from participants' artistic expressions (Hill, 2005; Hoffman, 2003, 2004; Manos, 2005; Rickards, 2006) and embodied writing (Dufrechou, 2002, 2004) and one an analysis of contemporary mystical texts (Carlock, 2003). Summary reports have included thematic content analysis and verbal portraits of participants (Anderson, 2011).

Cycle 4 focuses on how the researcher has changed, or what he or she has learned from the research project in terms of the original lenses presented in Cycle 2 (Anderson, 2004a, 2011). In Cycle 4 the researcher interprets the data, drawing forth general themes and new ways of understanding the topic, including intuitive breakthroughs and patterns (Anderson, 2011). Anderson (2011) explained that “perhaps more than in any other cycles of intuitive inquiry, the researcher’s familiarity with his or her intuitive style is key to the success of Cycle 4. Knowing how one’s intuitive process works makes it easier to cultivate and invite breakthrough insights” (p. 54).

In *Cycle 5* the researcher integrates understandings from Cycle 4 with the empirical and theoretical literature examined in Cycle 2, commenting on the significance and relevance of the study in broader terms (Anderson, 2004a, 2011). Anderson (2004a, 2011) emphasized that each cycle of intuitive inquiry is accompanied by both internal data known only to the researcher *and* externally verifiable data (see Table 1).

Table 1

A Summary of the Five Cycles of Intuitive Inquiry

| Cycle | Purpose | Main activities | Result of the cycle |
|-------|--|---|---|
| 1 | Explore one's research motives, relationship to the topic, target audience, and intuitive style. | <ul style="list-style-type: none"> ▪Select a "text" ▪Intuitively engage with it ▪Design the study | <ul style="list-style-type: none"> ▪Definition of research topic and questions ▪Researcher's clarity on his/her relationship to the topic and initial ideas about it ▪Initial design of research procedures. |
| 2 | Explore and articulate one's values and assumptions about the topic. | <ul style="list-style-type: none"> ▪Intuitively engage with one's ideas about and ways of viewing the topic ▪Review relevant literature (including non-conventional sources) ▪Synthesize initial lenses ▪Present lenses appropriately | A set of initial lenses that reflect the researcher's ideas about and ways of viewing the topic |
| 3 | Collect and synthesize new research data | <ul style="list-style-type: none"> ▪Clarify appropriate sources and their selection criteria ▪Collect data ▪Prepare initial summary reports of the data | Summary reports of the data using the most appropriate means |

Continued

| Cycle | Purpose | Main Activities | Result of the cycle |
|-------|---|---|---|
| 4 | Engage with one's own changes and learning with regard to the initial lenses | <ul style="list-style-type: none"> ▪Engage in deeper data interpretation using one's own intuitive style ▪Rigorously document intuitive insights Articulate general themes and understandings | <ul style="list-style-type: none"> ▪Revised set of lenses on the topic reflecting the researcher's growth and learning ▪Researcher's reflections on his/her personal change and the research process |
| 5 | Integrate Cycle 4 understandings with relevant literature and the general context of the topic. | <ul style="list-style-type: none"> ▪Discuss new interpretations in light of relevant literature ▪Develop ways of promoting the readers' sympathetic resonance with the topic ▪Reflect on the greater significance of the research in light of current cultural understandings of the topic | <ul style="list-style-type: none"> ▪Ways for the audience to engage more closely with the topic ▪Discussion of the significance of the research for the relevant fields of study and the culture in general |

Validity

I am ensuring validity through a high level of *detail* and *transparency* throughout the entire intuitive process so that the reader may clearly understand and judge my own steps of analysis. This documentation is consistent with Anderson's (2004a, 2006, 2011) guidelines for

validity in intuitive inquiry. The reader will become familiar with my own intuitive style and lenses in determining whether the described procedures were adequate to support the reported conclusions. In addition to rigorous and transparent documentation, I am following Anderson's (2011) suggestions in acknowledging my own subjectivity, voice, bewilderment, and mistakes in moving toward personal change and integration.

Mertens (2005) explained external validity of qualitative inquiry in terms of the *transferability* or *generalizability* of research findings to another social group. However, in intuitive inquiry, Anderson (2006) explained that external validity “concerns the value of the reported findings to the receiving audiences, over and above whether findings demonstrate generalizability to other situations in the conventional sense” (p. 41). She added that, “for the purposes of intuitive inquiry, validity refers to the capacity of a study and its report as a whole to render added value to human life” (p. 44).

Anderson and Braud (2011) explained that

Lincoln and Guba (1985), and many others after them, have argued that the concepts of internal validity, external validity, reliability, and objectivity, *as these are defined and measured in quantitative research*, are not appropriate for qualitative inquiries that use different approaches and have different aims, and that there is a need to reconceptualize these in more suitable ways. For qualitative research purposes, Lincoln and Guba reframed these four features as *credibility*, *transferability*, *dependability*, and *confirmability* respectively, and they suggested several techniques that can be used by qualitative inquirers in order to enhance each of these four features. (p. 290)

Anderson (2004a, 2006) and Anderson and Braud (2011) proposed *resonance* and *efficacy validity* in determining the external validity of intuitive inquiry studies. Anderson (2006) defined *resonance validity* as the “capacity of a study and its findings to produce sympathetic resonance in readers” (p. 42) and further explained that

sympathetic resonance is a psychological principle akin to well-known resonance principles in the physical realm. The essential feature is that if two structures or systems are very similar in nature, an activation or disturbance of one will be faithfully mimicked

or mirrored in the other. . . . This resonance /similarity idea, when extended into the psychological realm, can be used as an indicator of the *validity* of an investigator's findings. If what is discovered about an experience of one person (or group of persons) also applies to another person (or group of persons), as revealed by the latter's resonance with or mirroring of those findings, then this similar response affirms the findings' validity. Psychologically, resonance is revealed by responses such as "yes, that feels or rings true for me as well," "yes, that is how I have experienced it," or "yes, that is the nature of my own experience." Resonance can have intellectual, emotional, bodily, or intuitive aspects. The degree and extent of such resonance (or nonresonance or even antiresonance) reactions can indicate the degree of accuracy, fullness, or generality of certain findings.

A resonance panel provides a systematic, formal procedure for assessing sympathetic resonance. Carefully selected individuals, who were not involved in the original research study, are presented with the findings that were generated in that study, to determine their degree of resonance (agreement) with those findings. (p. 301)

At Anderson's (2006, 2011) suggestion, I formed a resonance panel of people who live with chronic physical illness to determine their level of resonance with the Cycle 3 composite story that I generated based on the 8 autobiographical narratives.

Anderson and Braud (2011) referred to *efficacy validity* in terms of changes in the reader (as well as in the researcher and the research participants) as a result of encountering the research findings. They argued that a report is high in Efficacy Validity if it promotes compassion, transformation, depth of understanding (about the self, the topic, and the world), a sense of knowing the researcher personally through clarity and authenticity of writing, and inspiration toward action and a new vision of the future.

Unthank (2007) also emphasized validity through storytelling, which, as consistent with Creswell's (1998) use of the concept, she defined as "an expression of an authentic experience" (p. 70). Unthank (2007) argued that storytelling is "at the heart of intuitive inquiry because stories are close to lived experience as we relay that experience to ourselves and to others" (p. 70). She described storytelling as introspection within a disciplined practice and the researcher as mediating from the space between first- and third-person accounts of lived experience.

Research Questions

My research procedures for this intuitive inquiry were guided by the main research question, the nature of the topic, and my own characteristics as a researcher. As I stated in chapter 1, my main research question is: *What is the subjective experience of psychospiritual transformation among people who live with chronic physical illness?* I sought to understand the way that this process unfolds *over time*.

I was also interested in the following secondary questions in exploring specific aspects of the main research question: (a) In what ways do the selected authors feel that they have been transformed by their illness experience? (b) How do people within the selected autobiographic narratives interpret their illness? Has it changed the way that they *experience* their bodies? (c) How do people within the selected autobiographic narratives find *meaning* in living with chronic illness? (d) What do people within the selected autobiographic narratives consider has contributed to their transformation process?) (e) How have the authors indicated that they modified their lives as a result of their illness?

Data Collection and Selection Criteria

I analyzed 8 previously published autobiographical narratives by people who have lived with a chronic physical illness. I originally contemplated interviewing people who have experienced psychospiritual transformation through chronic illness, but, as I envisioned this conversation, I realized that a 1-hour interview with even the wisest and most articulate participants would be limited and would not allow the person to more fully explore his or her in-depth experience over a period greater than 7 years. I thought of myself, and I realized that I could much better articulate my experience of psychospiritual transformation if I was allowed time to write about it at my own pace rather than required to speak during an interview. I decided

that the best way to more fully explore this topic would be to read book-length autobiographical narratives by people who had lived psychospiritual transformation through chronic illness and who had taken the time to reflect upon and write about their experience. I used the following criteria for selecting these narratives:

1. The narrative contains the author's explanation of his or her process of psychospiritual transformation through chronic illness.
2. The authors of the narratives have been living with a chronic physical illness for at least the previous 7 years, which they consider has strongly impacted several aspects of their lives.
3. The authors believe that they have been significantly transformed through their illness experience, as loosely consistent with my own definition of transformation;
4. The narrative is at least five full pages in length.

The narratives could have been written or recorded with the assistance of a second author or an editor, by my criterion. I attempted to select 8 narratives that reflected diversity in terms of types of illnesses, age, gender, ethnicity, and socioeconomic background so that the conclusions of this study might be applicable to a wide audience of people who live with chronic physical illness. A chronic illness experience may sometimes be similar to the inevitable aging process. However, since it is my hope that this study may also be helpful to younger people who live with chronic illness, I attempted to include narratives by people who have been living with a chronic physical illness since prior to mid to later life.

Delimitations and Limitations

This study may be limited by my own intuitive and expressive abilities and by the authors' articulateness, memory, time and energy, and their capacity to engage in and share their

insights on their own process. In addition, the audience's level of resonance with the authors (in terms of lifestyle, illness, and other factors) could be a limitation for this study's broader social impact. The group of authors may not be very representative of the general population of people who suffer from chronic illness in terms of several possible characteristics, including type of illnesses, age, ethnic and cultural background, geographic location, and spiritual practice.

Chapter 4: Cycle 1

Consistent with my research method, in this chapter I will present my work with Cycle 1 of this intuitive inquiry. It entails (a) a description of my intuitive style, (b) an explanation of my relationship to the topic (the process of my life experience with chronic illness), and (c) my engagement with a personal text to stimulate an initial inner dialogue about my research topic.

I began my work with Cycle 1 in 2007, and, through this process, I slowly began to formulate my research questions, target audience, procedures, and my initial ideas and experience about the topic of psychospiritual transformation through chronic illness. In general, the writing of my dissertation proposal was a substantial part of my Cycle 1 work as I began to explore more formally what I had experienced about the topic, what I wanted to learn, and what others had written about it. The target audience I wish to reach with my dissertation is people who live with chronic illness and, secondly, the people who love them and who professionally care for and accompany them. My review of literature would help to inform the creation of my Cycle 2 lenses.

I had initially planned to research the experience of psychospiritual transformation through chronic illness and shamanic healing because of the strong impact of shamanic healing and personal practice on my life. However, I eventually realized that my true interest was the subjective experience of psychospiritual transformation through chronic illness and that, for me, shamanic healing was one of a series of experiences within that overall process. Any exploration of the impact or experience of shamanic healing by people with chronic illness would need to be tackled in a separate study. Throughout 2008 and 2009 I searched for participants through shamanic websites, and, after I had found no one who fulfilled my research criteria, it was thus

confirmed to me that I needed to reduce the focus of my study. Therefore, in 2010, I redesigned my dissertation proposal

My Personal Experience with the Research Topic

In this section I will explain my relationship to the research topic so that the reader may begin to understand my approach to and lived experience of psychospiritual transformation through chronic illness and its influence on the subsequent cycles of this research, especially in the formulation of my Cycle 2 lenses.

I have lived with diabetes mellitus for 22 years, since its onset in early 1992, when I was 19 years old. Living with this seemingly invisible burden of illness has been a major part of the way I live and know from my body, my own spiritual journey, and my subsequently being drawn to study transpersonal psychology and healing during the past 13 years. With my condition, I experience constant and dramatic metabolic changes in my body, and I practice a sometimes rigorous self-care regimen in order to maintain balance, including blood sugar monitoring, exercise, and several insulin injections throughout the day to cover the four small low-carbohydrate meals.

Illness was quite familiar to me from birth and throughout my childhood. I became diabetic at a time when I was in the midst of a spiritual emergence, which, at the time, I interpreted as a call to become a Jesuit priest. In the prior and subsequent months I experienced several mystical, unifying experiences that seemed to allow me to transcend space and time, especially through the extreme, solitary moments of fasting and sleep deprivation, mystical experiences in nature, and writing. During this time, I was often quite oblivious to my own physical needs and sensations, and I felt empathy toward other people's and the world's suffering, a feeling accompanied by an overwhelming sense of guilt and responsibility. My

boundaries were opened, and everything seemed to flow in and out of me with little discrepancy, but I paid little attention to my physical needs. I was enthusiastically involved in volunteer services to the poor and student retreats and prayers.

Just one month prior to my developing diabetes, a close friend and peer at the university took his own life, and I felt devastated, as if part of me wanted to die with him. During that same month I also received a series of vaccines prior to my end-of-the year university service trip to Guatemala, injections that would soon play havoc with my immune system. My return to the cold winter of Chicago after this unique spiritual experience with orphans and nuns in the rural highlands seemed jarring to me, while my relationship with my family became strained. All of this was an implosion for my body and my blood sugar rose to five times its normal level, seemingly overnight. I also later learned that my life-long immunity problems might perhaps be partially attributed to my father's exposure to the dangerous chemical herbicide Agent Orange prior to my birth during the Vietnam War.

My initial experience of diabetes was rather numbing. I did not react very much at all. I was in shock, but I cannot say that I was devastated, because I did not fully comprehend what diabetes was. I had no idea then how insulin injections would change my life. I just wanted to feel better and get on with my life again, and I was trying not to miss too many days of classes. The 10 days in the hospital felt like *no time* or a space outside of time that I inhabited while everyone else continued with their lives. People visited me, and the experience seemed like being at my own wake.

When I returned to school, my life was different. I had to inject myself with insulin, check my blood several times every day, and follow a rigorous diet. I carried containers of foods such as cottage cheese, beans, and vegetables, and a glucometer with syringes and insulin. I felt

weighed down. Before this diagnosis, I would simply do or eat whatever I felt like, often following my impulses without paying much attention to my body. Now I was grounded, and I had to pay attention to certain limitations and laws of the physical. I felt that I was now sick as a permanent condition, yet I vowed not to let this condition stop me. I began to walk a difficult learning path through the body, often battling against this limitation. I felt damaged and inferior to others.

I thought that, by taking insulin, I could ensure that my problem would go away, but my difficulties were just beginning. I had to learn about insulin dosage, carbohydrates, and exercise and to balance these during each day. I was focused on philosophy and theology, music, and saving the world. Taking care of myself seemed very boring and selfish and just plain outside of my understanding. My head seemed to operate in terms of poetry, symbols, impulses, and intuition. This new grounded, rational routine of healthcare seemed to take me in an opposite direction, and I resisted.

With diabetes I felt as if my body was somehow turned over to authorities. The doctors had given me a strict diet and insulin regimen, and I was not to make changes. Diabetes, I was told, is a manageable illness, and, when things were not going well, it was implied to me that *I* was not managing it properly. I often felt guilty and ashamed when my blood sugar was too high, and I tried to hide it. I became more aware that I habitually used food to deal with my emotions. My condition was so bewildering to me that I did not even want to try to explain it to others. I felt traumatized, as if I was sentenced to living in this personal hell from which there was no escape. Since I felt ashamed that I could not control my blood sugar, I was too embarrassed to seek professional help.

I felt cut off from my previous body and life. This also occurred at a moment in my life when I had begun to distance myself from my family, and, 5 months after my diagnosis, during the summer of 1992, I moved to an apartment near the university on the other side of the city, thus isolating myself to begin this new stage of my life with an illness. I reacted to my diagnosis with disbelief and then with shame and guilt at this punishment that had been placed on me. I thought of myself as carrying a cross, just as Jesus had done. Part of me felt that my existence was now validated with this new suffering, and, yet, at the same time, I felt terribly alone and burdened by this invisible prison with a life-sentence. I was reluctant to talk about my experience with others, because I felt that I had brought this condition upon myself.

Throughout that first year with diabetes, I often felt very tired and with little energy, and I felt isolated because taking care of myself seemed to leave me with little time and energy to interact with others or to participate in extracurricular activities. Ten months after my initial diagnosis, I felt I was on the verge of suicide, and I searched for ways to reach out to others, so I eventually contacted a psychotherapist through the university.

A semester of psychotherapy sessions in 1993 helped me greatly and was followed by a two-year semi-regular process of spiritual direction. I felt I was being resurrected, and I incorporated self-care into this new identity instead of trying to run away from my body and my limitations. I began to value my strength as a survivor of illness, and I focused much of my energy upon study and political activism around poverty and homelessness. I felt more empowered when I channeled my energy into social issues because I largely felt powerless at changing my physical health. Although I did do the minimum of taking care of myself through injections and diet, I thought of my body more as a machine that I needed to keep running so that I could continue to do my important, interesting activities. I often ignored my integral needs and

lived from impulses, binges, and sleep-deprivation. I was largely hiding my illness from others and from myself because it was still painful for me to face my own physical limitations.

At 22, upon finishing my undergraduate degree in philosophy and sociology, I left my native city of Chicago to live as a full-time volunteer in Guatemala, working with rural communities displaced by military repression. In the year prior to leaving I began to take better care of myself because I realized that I needed to be healthier if I was to survive in a third-world country and do what I wanted to do in life. I became more conscious that chronic illness did not just mean having to do things to take care of myself that others did not but was also about having my future possibilities cut short. I was searching for a meaningful spiritual and community connection and more militant political by silencing my self-image as a fragile, helpless man that seemed to be reinforced for me following my diabetes onset.

My experience in Guatemala during those first years was mainly of militant political activism in the midst of poverty, danger, pollution, and intense bonds and camaraderie. I seemed to be living on the paradoxical edge of hope and fatalism, alienation and community in the face of suffering and repression. I found myself adopting the culture of those around me—of self-sacrifice—sometimes trying to pass myself off as a healthy person, but I soon realized the importance of sticking to my healthcare regimen of diet and exercise. I found that my two or three daily walks helped to calm me. In the face of such suffering in Guatemala, I came to value my own life, and I discovered the simple joy of eating pure natural foods and walking in nature in this temperate climate. Taking care of myself became a joyous spiritual practice. I often felt just as committed to my self-care as to my work because, for me, they were both an expression of active love for life and equally valuable.

By 1998 I reached a crisis. The travel, long office hours, and dangerous urban conditions were taking a toll on my body and spirit. I felt tired and burned out, and an intestinal infection and a prolonged bout with malaria convinced me that I needed to make changes. I became conscious that I have a compromised immune system and that I needed to take better care of myself. In many ways I also felt a spiritual call *home*. I allowed myself to follow some of my passions that I had come to ignore, such as enjoying restful time in nature, journaling, cooking, drawing, reading fiction and metaphysics, watching movies and baseball games, and doing simple self-care activities. I cut back on my work and travel, creating a greater balance in my life and bringing in more emotional support, as well as community. Even in my work as a popular educator, I began to move more from political organizing to issues of personal identity and healing, especially with men. I began to accept my body as it was and to create a lifestyle based more on my physical needs and passions rather than trying to adapt to what I thought others wanted from me. Within this process I also discovered the joy of living more in sync with my body in a more natural way. I was less inclined to feel that I was fighting against limitations, and I went along for the ride of high and low blood sugar even if I did not always feel in control.

In 1999 I met my future wife, and she immediately filled a great gap in my life—love, playfulness, support, and optimism. This soon led me to an encounter with Mayan spirituality, her culture. Months later I met an indigenous shaman/healer who would continually attend to me for my healing and guidance, not only in relation to my diabetes, but in helping me to become more open to my own spiritual journey and gifts. Much of this shamanic work was based on the sacred Mayan calendars and “nawal” system, an ancient oral tradition for understanding the cosmos and essential energy of the person. It was then that I began to see my illness more in relation to my family and ancestors, my life mission, diet, and life lessons. I felt a shift from

seeing myself as a flawed, weak, inferior person who shamefully had to suffer from both a divine and self-induced punishment, to a broader understanding of myself as a carrier, inheritor, and sensitive receptor. I began to see my illness as a challenge that I was given, or that was *bestowed upon* me to bring balance and healing to myself and the world.

Through sacred traditional fire ceremonies and divination practices, this shaman indicated to me that I was to be trained in his tradition as a shaman/healer for my own healing and life mission, an extremely *rare* invitation to a non-Mayan person. I undertook and completed this training with him during 2000-2001. I continue to practice my role as an *Aj'jiq* or *carrier of the day* in performing ceremonies or offerings for the healing and well-being of other living people, spirits, and the natural world, and for my own personal health and guidance.

During 2001, near the end of this initial training, I experienced a major physical and emotional crisis. I experienced intense panic attacks and diabetic peripheral neuropathy, a constant tingling and needle-like pain in my hands and feet, which doctors told me was a result of *irreversible* and *incurable* nerve damage from the diabetes. Walking and even touching telephones or electric appliances was painful. I felt devastated at the thought of my future possibilities being cut short by a painful, crippling condition after so many years of diligent self-care. At that time I also felt trapped by my demanding consultant work with an international NGO and largely overwhelmed and unprepared for the responsibility of my shamanic work. While I was excited by my future studies and a career in transpersonal psychology, this seemed so far away from my dreadful reality in Guatemala City.

After 6 months of recurring crises, my wife and I both received powerful precognitive dreams leading us to a Mexican spiritist in Mexico City, who subsequently cured me of neuropathy through a spiritual surgery similar to those described by Villoldo and Krippner

(1986), a painless physical incision in the area of my pancreas. The neuropathy disappeared, and I was assured by the group of healers that the diabetes, in time, would also be completely cured. After a 40-day recovery and self-care period, I experienced greater physical balance and a new sense of mission and purpose. I lived life more calmly and with greater gratitude. I became more conscious that life is fragile, and I was thankful for this second chance.

In 2003, my wife, infant daughter, and I abruptly fled Guatemala due to threats to our physical safety. These dangers arose from the political nature of my work with people who had survived military repression. We were alerted to these dangers mainly through dreams, synchronicities, and signs from fire ceremonies (from our own and from those of other shamans). We followed the guidance of a powerful elder shaman who directed us to the city of San Cristobal of Chiapas, Mexico (just 3 hours north of the Guatemalan border), where we continue to live today. At nearly the same time, I began my doctoral studies in transpersonal psychology with the Institute of Transpersonal Psychology. After years of enduring a dangerous, polluted city, I began my new life as a father and a graduate student in this small, sometimes touristy town surrounded by mountains and forest. The doctoral program satisfied my deep needs for spiritual growth, community, intellectual inquiry, contact with global spiritual traditions, professional development, and a kind of return arc to the U.S., including aspects of my own language and culture.

In my studies I began to more fully explore the emotional factors surrounding my illness onset. I also began to become aware of and express the extent to which diabetes impacts my life. It was very important for me to allow myself to become aware of my own pain in living with this condition. I also developed the practice of mindfully witnessing my body, my emotions, and the world around me, and I began to feel more at ease, in awe, and appreciative. I began to realize

that my journey with illness had given me great gifts of grounded awareness and self-compassion and had strengthened my sensitivity and love in working with others. In 2005 I began to explore literature related to chronic illness experiences, and, for my masters integration paper, I designed a series of psychospiritual practices for people who suffer from chronic illnesses that were based on Native American cosmology.

From 2005 to 2007 I met a series of alternative healers, doctors, and shamans who treated me and emphasized to me that my diabetes cure was within reach. With the support of a shaman, I recovered several soul parts that I had lost throughout my life, especially during my childhood. I also received spiritual healing for my own damaged organs. I felt happy and whole in an important way. These changes generally included (a) greater physical presence, joy, and sensitivity in my body; (b) a deeper sense of self-worth and self-acceptance; (c) a greater willingness to defend and care for myself, especially my physical needs; (d) a greater sense of purpose in my illness; (e) a sense of wholeness and serenity, living less from a sense of lack or wanting outside myself; and (f) the increased physical healing of my pancreas. With this calmness, I was more readily able to halt destructive impulses, habits, and emotions that once seemed to control me. I felt that I had recovered my body in a major way, including awakening myself to a complete range of joys and sensitivities.

In 2007 I also made a dramatic dietary change, eliminating carbohydrates such as sweet fruits, dairy, lentils and beans, pasta, bread, soybeans, and rice, all of which had been a staple of my diet. For the first time since I was 17 years old, I began to eat animal protein on a regular basis, especially fish and chicken, and this finally helped me to stabilize my blood sugar and reduce my insulin dosage. I tried to completely eliminate my need for insulin by eating small meals and doing vigorous exercise. In the end, my weight went down to about 110 pounds (my

lowest since about age 13) and I was more physically fit, but I was not able to live without insulin injections. By 2007 I let go of that desire, which sometimes bordered on obsession, accepted my body as it was, and decided to inject the necessary insulin to eat what I needed to. I realized that, during most of the previous 15 years, I had lived with a constant fear of high blood sugar and would generally walk vigorously three times per day (following each high carbohydrate meal). I began to realize how much this fear ruled my life and how much this routine limited me, especially in spending time with others. I felt I was now listening more to my body and feeding myself what I needed.

At the end of 2007 my wife and I separated, and I eagerly began a new chapter in my life, as my five-year old daughter spent half of her time living with me. During 2007 I began to feel bothersome and puzzling symptoms of joint stiffness, especially in my shoulders, elbows, knees, and hips. At first, it was not so painful, but my joints made loud cracking noises, and I needed to do a series of stretches and movements just to feel comfortable. This new condition emerged as I began to feel anxiety and stress while working on my dissertation proposal. In hindsight, I can see that, while I felt passionate about my courses, as I moved into my dissertation, I began to feel inadequate and unworthy of the doctorate title and my future professional life.

At the beginning of 2008, my dissertation research had been approved, and I also worked part-time in editing and as an assistant in the masters curriculum and course design. I adopted a healthier diet, and, for the first time in my life, I began to consume a substantial amount of raw organic vegetables and seeds to go along with fresh fish and fruits. I felt that I was learning how to eat for the first time. I focused my energy on researching about health and nutrition and finding the healthiest foods in my town.

I spent much of the year still battling my sugar addiction, and, under moments of stress, I binged on snacks of flour and sugar. I often felt I could not control my actions, and the results were devastating for my body. I come from a family of strong addictions (alcohol, sweets, and cigarettes) and overindulging in food was something I learned from an early age. Now that I was spending so much time alone, I felt that nothing was keeping me from going over the edge. I also realized that I had not fully processed the grief and loss from my separation and that this was impacting me in many ways. After my 36th birthday, at the end of 2008, I was finally able to give up sugar and flour without any relapses.

Throughout 2008 the pain and stiffness in my body intensified. During this time I also felt anxiety and pressure about advancing in my dissertation, and it was difficult for me to find a way to begin. I had no idea what was going on in my body, and I tried to take care of myself by eating as healthfully as I could and exercising, but I was getting worse. By the end of the year I stopped going out, because I could no longer sit comfortably in a chair, I felt a heightened sensitivity to cold, and most clothes irritated me. My muscles and bones were bothersome to me, especially on my back, shoulders, and hips. I would go to stores to try on clothes and the clerk would nod and comment that a garment fit me well, but, in another 5 minutes, the clothes would become unbearable. My left hand would freeze up on me, socks were bothersome to me because of the sensitivity in my skin, and I had a strong constant need for air and water.

By 2009 I seemed to be spending all of my time stretching, walking, balancing my blood sugar, and in bed resting from body aches and so much exercise. I felt a constant fatigue and a drop in energy. My left hip and my shoulders were always uncomfortable, and I felt frustrated that I could not completely open them. I rapidly lost fluidity in my gait, and walking was always painful and no longer provided relief. I experienced a dramatic reduction in my mental

capacities, and I had intestinal difficulties. I could no longer go out for long walks in the forest or along the river because of my discomfort, limited mobility, and mental confusion. I began to feel very sad and confused. I had thought I was going to be living a new chapter in my life with vigor and happiness, but now I felt so limited, so very old and decrepit. I felt ashamed to be with others, because I felt I had no way of explaining what was happening with me. During the previous 17 years the rules of the game had become clear to me about keeping my blood sugar balanced, but now I had no idea how to break through this pain and fatigue.

I consulted frequently with my homeopathic doctor, and I wanted to know what was happening with my body. Blood tests revealed many fluctuations in my body, and he explained that I was going through a physical crisis with atypical consequences of diabetes, rather than a new disease, and that my nervous system was severely compromised by my immune system. My doctor suspected that my emotional difficulties and the vaccines I had received in 1991 were playing a central role in provoking these symptoms.

By this time I began to spend less time with my 6-year old daughter, partly out of her decision to live mostly with her mother, but also because I was becoming too sick to care for her and spend meaningful time with her. Amidst the fatigue and need for stretching, I could no longer sit and play with her. This loss saddened me greatly. I felt that I was losing so much in my life: my physical comfort, the ability to walk and be out in the world (which I so enjoyed), the ability to work and concentrate (and earn a living), and my social life. I sank deeper into the physical pain without a clear idea of what was happening or how to improve. I felt that I was dying.

After a visit from my parents in August of 2009 my physical nightmare escalated. I could not properly eliminate liquids, with my lower legs and feet suddenly swelling, and the pain in my

body flared up throughout my left side (from head to foot). Sleeping became difficult. Fatigue weighed heavily on me. I could barely walk, and I experienced dizziness, headaches, and pain, especially if I was in a moving vehicle. I constantly felt an intense coldness in the left side of my chest and in my head behind my eye, as if I had two pieces of ice inside me. I always felt cold. I dreaded the moment of sundown, and my only relief was wrapping myself in sweaters, a hat, and a scarf and drinking hot water. My joints felt like they were made of ice. I had never experienced anything like this before. I had once enjoyed my athleticism, but now I could not even do a squat or a push-up or lift my arm over my head. I felt I had lost a vital aspect of who I was. In the previous years I had led an active life and had been walking 90-120 minutes per day, but now my body and my life had drastically slowed down. My stomach constantly bothered me, and I could no longer even think straight.

By the beginning of 2010, I rarely left my apartment, as I began to contract with taxi drivers to run my errands and buy my food. Walking to the corner was nearly impossible. My weight ballooned from my lack of movement and overeating. I could not even bring myself to get out to a doctor, as unbelievable as this sounds to me now. I found myself in this dark lonely cave and realized that I had let myself go. I was in shock at my physical changes and I was attempting to escape because I did not know how to face them. I wrestled with suicide, especially at the worries over my economic survival and my despair of ever recovering my health. I wanted a release from the pain. The thought of my daughter was one of the main motivations for me in deciding to try to live. I prayed for guidance and healing.

By mid-2010 I sought medical attention, and, over the next months, I slowly began to improve, but I realized that the solution would not be magical or simple. I knew that I was up against something over which I had no control, and I resigned myself to pray for healing. I kept

my intention to recover my health and to be open to whatever might help me. I gave thanks for all that I had, despite my sadness and despair in not knowing if I could recover. I felt a strong connection with my grandmother and my deceased family members as I remembered the sense of love and protection I had felt as a child. They often visited me in my dreams with calming images.

All that was left for me to do was humbly move forward and seek help, although I was often confused about where to begin. I sought more information and I learned much from books and websites. With the guidance of my doctor I tried many alternative healing therapies, including Reiki, osteopathy, massage, crystal healing, guided meditations, magnet therapy, and acupuncture, and even sought diagnoses from allopathic doctors. All of these practitioners were puzzled by my symptoms, and I was often told that I was generating my own pain and that I did not have an illness. I experimented with dietary changes. None of these therapies led me to major health improvements. Eventually psychotherapy became an important part of my healing journey in helping me to work through much of my early childhood traumas and my recent life changes. I became more conscious of my need for communication and intimacy with others.

I accepted the uncertainty of my body and began to feel a deeper sense of calm despite my discomfort. I began to accept my losses and let them pass. The calm turned to strength and security in who I am and in finding meaning in my process. I began to see my challenges as a process of learning and growth beyond this lifetime. For the first time in my life, I learned to live alone with a greater sense of self-love without depending on a partner or feeling anxious. I began to live more from a place of tranquility and hope in beginning to trust that no matter what happened everything would be alright, even if I did not know what this alright would be like. While I could no longer enjoy vigorous walks in nature, I opened myself to other joys, such as

listening to music and reading. Rather than expecting someone to cure me, I began to think of myself more as my own healer or healthcare manager. I learned much more about my body, nutrition, and alternative health, and I began to develop a clearer sense of what I needed in order to be well.

Although I held the intention of finding out what was happening with my body and healing myself, I tried to move forward with my life as best I could and to adjust to my body as I was. The nature and cause of my health problems was still a mystery to me. While I desperately wanted to know the name of my condition so that I could better understand my situation, I learned to also patiently wait for this news to reveal itself when the time was right. I focused more on dealing with my immediate situation rather than on my losses, especially my economic situation and my dissertation, which were creating stress in my life.

At the end of 2011, I participated in a *family constellation therapy*, a group therapy (originated by Bert Hellinger), in which each participant invites the group to occupy the roles of the people and issues related to one's problem in order to release and resolve profound tensions within and between people and to reveal to the subject a previously unrecognized systemic dynamic within the family that spans previous generations (Cohen, 2006). This therapy was helpful to me in recognizing and dealing with my own emotions and the family issues influencing my diabetes onset and my recent symptoms. I was able to transform some of my habitual emotional responses that were limiting me, and this therapy has sparked a healing of my relationship with my parents and brother. Since this therapy I have also focused my intention on reducing my physical pain and discomfort and concentrating more on my dissertation. Throughout 2012, as I focused on reading the autobiographical narratives, I gained greater

strength and flexibility through stretching, yoga, and cardiovascular exercise (when my legs were able to do so), and I was able to get back down to a healthy weight.

During these years I also experienced several extremely low blood sugar episodes, sometimes resulting in confusion and loss of consciousness for several hours. It has been a challenge for me to live through these moments, especially because I am usually alone, but I have learned to surround myself more with a support network, take precautions, be more conscious of my physical signs before I get too low, and, more importantly, ride out these moments of confusion with calmness, trust, wonder, and focused concentration. While unconscious, I have often brought myself out of hypoglycemic episodes by eating fruit. I have come to see myself with self-love and compassion in recognizing my own strength and presence in living with my daily physical challenges.

In 2012, I became interested in cellular therapies as a viable form of healing, and I prayed to connect with someone who could help me. By the end of the year I encountered a clinic that works with stem cell therapies and other cellular therapy, and, in 2013, after several injections, I began to experience some physical improvement. I have also focused on better balancing my blood sugar in the interests of avoiding sharp drops and loss of consciousness.

As I was concluding my dissertation draft in December of 2013, I became aware that my condition is called fibromyalgia, a central nervous system disorder, or "central sensitization syndrome," caused by neurobiological abnormalities that produce physiological pain, cognitive impairments, and neuro-psychological symptomatology (Ngian, Guymer, & Littlejohn, 2011, p. 6). Fibromyalgia is characterized by chronic widespread pain and allodynia (a heightened and painful response to pressure) and the term literally means muscle and connective tissue pain (Ngian, Guymer, & Littlejohn, 2011). Its exact cause is unknown but is believed to involve

psychological, genetic, neurobiological and environmental factors (Maletic & Raison, 2009; Geoffroy, Amad, Gangloff, & Thomas, 2012). Other symptoms include debilitating fatigue, sleep disturbance, and joint stiffness (Hawkins, 2013). Fibromyalgia is frequently comorbid with psychiatric conditions such as depression and anxiety and stress-related disorders such as posttraumatic stress disorder and is estimated to affect 2–4% of the population (Buskila & Cohen, 2007; Schweinhardt, Sauro, & Bushnell, 2008), with a female-to-male incidence ratio of approximately 9:1 (Bartels et al., 2009).

With this diagnosis I at first felt saddened in becoming more conscious of the widespread and systematic damage to my body and being reminded of the intense pain and discomfort I have endured in these recent years. I felt compassion for myself for all of my losses. I now understood my frequent loss of consciousness during hypoglycemic episodes, short-term memory loss, and difficulties in concentration. I then seemed to move beyond the emotions and began to enthusiastically watch videos and read about natural alternatives and treatments for improving my health through dietary changes, nutritional supplements, detoxifying myself of contaminants in foods and healthcare products, and practicing contemplative activities. I am attempting to change the unconscious thought patterns and emotions that are contributing to the pain and physical limitations. The clarity of my diagnosis has been a great gift, as I now better understand my illness process and how to change course. I have a firm belief that my health will significantly improve in the near future. With this positive intention and optimism, information, healers, and treatments seem to be crossing my path, ranging from medical doctors to mediums and transpersonal healers. I feel happy at feeling the light at the end of this crippling physical crisis and thankful for my growth and learning.

Meanwhile, it has still been difficult to bear the discomfort, fatigue, and interrupted sleep. With the uncertainty of how I will feel the next day, I try to take life one day at a time. I sometimes find myself mourning the days when I felt comfortable, could walk great distances and move with ease, and had more energy. Walking is still usually painful and uncomfortable, and I need to spend much time stretching throughout the day to be minimally comfortable and to sit for short periods. I usually cannot bear to wear much more than shorts and a sleeveless t-shirt. My daily routine of cooking, cleaning, injecting, checking blood sugar, stretching, and resting often takes up most of my time and energy. I sometimes still feel a prisoner of my body's limitations.

But I am thankful for my daily experiences, passionate about living my life in the moment, and hopeful about my future. I do what I can and focus on positive intentions. I know that life will always be filled with a certain degree of uncertainty and difficulty, and I trust that things will work out and I will be able to deal with what may come, knowing that my life's challenges are part of my spiritual growth and that somehow I am making a contribution to the world.

My Intuitive Style as Informed by My Illness Experience

My intuitive style and my experience with diabetes and fibromyalgia are intertwined, and shape me as a researcher, from my general approach to the specific research procedures. In this section I will attempt to describe my ways of being and knowing (which may, of course, differ greatly from other diabetics' experience) so that the reader may understand and assess the rationale behind my proposed research procedures.

Diabetes mellitus, or Type 1 diabetes, is a metabolic illness in which my pancreas does not produce sufficient amounts of the hormone insulin to receive and break down foods for their

proper intake into my body. Type 1 diabetes typically emerges among children, adolescents or young adults and is found in approximately 1 in every 400 to 600 people under the age of 20 in the US (American Diabetes Association, 2007). I cannot simply consume foods without previous external injections of insulin, and this dosage must match the food that I am consuming in terms of its timing and amount. Of course, foods vary greatly in their impact on my blood sugar. In living with this illness, I must carefully regulate my food and insulin intake. Brisk aerobic exercise, for at least 10 minutes at a time, also helps the pancreas to use the injected insulin and, thus, metabolize the food.

Without insulin injections, or with insufficient insulin in my system in relation to my food consumption, especially in terms of carbohydrates, I have an *excess* of sugar in my blood resulting in symptoms of overall heaviness and fatigue; an irritable or grouchy mood; difficulty in concentration; discomfort, especially in regard to physical contact; excess thirst; oily skin; and an unpleasant sensation of heat and fullness. The opposite extreme, too much insulin or exercise relative to my carbohydrate consumption, can bring my blood sugar to a dangerously *low* level, producing sometimes very distressing physical symptoms of general metabolic acceleration, heart palpitations, shaking, coldness, confusion (with less oxygen to the brain), irritability and annoyance, faintness, shortness of breath, cold sweating, lack of circulation to the hands and feet, and even loss of consciousness or normal awareness.

A healthy pancreas produces insulin rather involuntarily, upon demand according to food consumption, maintaining blood sugar levels within normal ranges, even despite moderate levels of overeating and fasting. In nondiabetics insulin is secreted in just the right amount when it is needed throughout the day. The insulin I inject, however, is released according to its own chemical composition as it interacts with my body. Thus, in order to maintain my blood sugar

level at normal levels and avoid these extreme symptoms I mentioned above, I must regulate my food consumption and exercise to match the release of insulin that I am injecting, quite the reverse of that experienced by nondiabetics, whose pancreas produces insulin according to what they decide to eat.

Thus, keys for me are (a) accurately calculating, based on previous experience, the proper combination of insulin dosage, exercise, and foods, in order to live as closely as possible in sync with my natural physical needs; (b) perceptively reading my physical signs to know when I am moving into either extreme of high or low blood sugar, in order to make the necessary adjustments; and (c) the will and discipline to act in avoiding these extremes. In general, during the course of a day, I eat four low-carbohydrate meals, do about 30 minutes of biking or walking (when I can move my legs well), do a daily yoga practice, inject 6-8 times, and check my blood sugar about six times (before meals, sleep, exercise or when in doubt).

Living with diabetes encourages me to be present in each moment and objectively take into account the many variables of a situation so that I can make appropriate decisions to meet my needs. I sometimes have little margin for error, as seemingly minor lapses, such as engaging in unconscious eating (eating too much of inappropriate foods), skipping meals, miscalculating insulin, or getting inappropriate amounts of exercise (as much as 5 or 10 minutes' difference in a walk) can all trigger uncomfortable extremes in my blood sugar level. Moreover, minor changes in my daily routine (such as not being able to walk outside, changes in sleeping patterns, or limitations on food access) can provoke challenging adjustments. Paradoxically, the more my sensitivity to my blood sugar level grows, the more I feel the discomforts of the extremes of the highs and lows. At times, the personal organization efforts and anxiety involved in properly

regulating all of these factors in order to avoid these sometimes overwhelming symptoms is much more taxing on me than are the physical discomforts themselves.

In terms of my own ways of knowing and being in the world, living with diabetes gives me a heightened sensitivity to my own inner sensations and the way I am responding to and interacting with a variety of external factors, including foods, temperature, light, sound, the social environment, and so forth. I am also aware of how my emotions and thoughts influence and interact with my body. A significant aspect of my daily functioning is being attuned to my subjective inner sensations and systematizing them so that I can make sense of the data in order to make decisions for my well-being. At the same time, I pay attention to more objective, external, rational data, such as through the use of my glucometer to measure my blood sugar, paying attention to the passage of time in calculating the time lapse since my insulin injection and investigating the carbohydrate levels of foods. In general I am constantly analyzing the *overall* effect of these many varied factors on my blood sugar. A significant part of this discernment process is simply recognizing what is happening, accepting it without judgment, and making the necessary adjustments. For all of my previous experience, each situation is unique, and I must be open to discerning what is happening, no matter how surprising, bewildering, or distressful it may seem to me. In order to engage with my intuitive insights, it is vital for me to accept, trust, and honor my way of being and knowing

My physical condition also gives me a unique sensitivity to changes in cyclical time. I tend to focus my attention on changes in my body and in the world around me, especially the natural cycles, from daily changes (cycles of the moon, the sun, temperature changes, etc.) to broader periods. This is perhaps one of the reasons why I am drawn to the Mayan cosmology,

with its focus on cyclical time and the movement of the sacred calendars for indicating the energetic essence of each day within repeating cycles.

For me, intuition is usually manifested very physically and internally. To *know* something, I must touch it or sense what it is like to *feel it* in my body, much more than seeing it (visual), hearing it (auditory), or thinking or reading about it (verbal or conceptual). I am quite sensitive to my own imbalances. I tend to feel strong inner proprioceptive reactions to people, often resonating with or mirroring their situation in a deep, interpretive way.

Frequently, insights come to me through dreams, when moving (especially when walking outside), in darkness, and when in nature. These intuitive insights tend to be proprioceptive and auditory, many times with outer movements interacting with my inner world. I easily feel overwhelmed by the senses, especially sounds. Thus, stimulants around me can halt intuitive insights if they feel too close or intrusive. I dwell comfortably in quiet natural settings, and, in this type of setting, I often feel much more open to my body and the world.

My intuitive insights often emerge in an embodied way, sometimes through inner sensations that brew and percolate throughout the body and rise out from my heart area like running water or blood. I feel and witness many varied aspects, including inner and outer stimulants, converging and flourishing in my body in a moment of clarity. I feel a *gelling*, as things seem to hang physically together in space. It is a synthesis, and I say, "*That's it!*" I focus less on separate details as my intuition goes to the heart, often synthesizing and filling in the gaps between things. I often see things both as *wholes* and as the mingling combinations of distinct parts, very much like a swirling collage or a salad. The parts do not *cease* to be what they are, but the whole yields a unique, qualitatively different, and rich plate.

When I allow this intuitive way of knowing to flow, I witness and honor in a non-oppositional way, without trying to control what emerges. I use this *combining skill* in both perceptive and active ways. For instance, I may receive and sit with a multitude of sensory and inner information or different points of view, or make evident conflicting elements, tensions, patterns, and specific heterogeneous aspects of a whole. This skill helps me to become aware of and appreciate the unique, complex composition of each individual thing. I may begin to glimpse the role of each complementary part in contributing to the equilibrium of the greater whole, seeing all things *at once* and recognizing what is lacking, weak, or out of balance. It also helps me to perceive individual elements within a greater context.

In *expressing* my intuitive insights, I am quite aware of the limits of words. I tend to write too much, because I often feel that I cannot accurately convey my ideas. The way I express best (and understand other people's ideas best) is through images, symbols, or glyphs that express something that does not have a fixed meaning, or, rather, a single thing packed with levels of illusive meaning that can be understood from many different angles and contexts. These elements, images, or symbols tend to be more meaningful to me if they are somehow *interrelated*, as this conveys to me a sense of relatedness, context, and wholeness. For example, I tend to resonate with maps, diagrams, cyclical illustrations, models, and mixes of colors. Examples of these include the Native American Medicine Wheel (Cohen, 2003), the Enneagram (Maitri, 2001), the chakra system (Avalon, 1974), Ruumet's (2006) Helical map of human development, symbolic cards, or numeric or statistical descriptions. This kind of material deeply moves and entertains me, and I can often find varied meanings each time I engage with it. I tend to find difficulty in understanding and engaging with lists of verbal ideas, because I often find them flat, disconnected, abstract, or limiting. When expressing and reading in words, I prefer

very short phrases that invite various shades of meaning. I usually have little patience for, or interest in, the details of long descriptions.

Engagement With a Personal Text Related to the Research Topic

When I was initially writing my dissertation proposal in 2007 I explored many texts related to my topic until I focused on a dream that I had experienced in March of 2006 in which I was mindfully dying by leaning into physical suffering. Shortly afterward I journaled about this dream:

I was struck by a very lucid dream in which I was doing a meditation for dying (cross-legged on the floor and leaning all the way forward). Many years went by in the dream and I did lean forward into death and died as a very sacred, willful act in the face of overwhelming physical suffering. I am very aware of the experience (of pain and death) and being an extraordinary witness to many years of time flowing before me, as is common for me in many of my dreams.

I leaned into the pain and kind of went *through* it to death. I was in simple robes and a long beard in a dark, barren room with dirt floors which I knew was many miles away from other people. I was accompanied by Jesus in the beginning (of the dream), but in the end I was an elder and teaching my daughter the meditation (now a 3 year-old child but an adult in the dream), but urging her not to use it until her time had come. I die in the dream and it is extremely peaceful and expansive. I awake in the middle of the night after this dream experience in this position and it takes me several minutes to convince myself that this is my reality.

I think it is about the way I am leaning into my physical difficulties instead of resisting, really welcoming the way that some low blood sugar episodes sometimes bring me to the threshold of death. I don't resist this possibility of death in these near-death experiences of late, but my daughter is the main reason I choose to stay, as my unfinished business. She is 3 years old and is very interested in death (especially when we see dead animals on the street, which is not infrequent here). She is very accepting of death and even seeing animals eat others. (Baltazar, 2006, p. 1)

During a 6-week period I practiced an internal dialogue with this dream text and then I articulated the following insights on my topic. Many of these reflections are quite personal, in touching upon my own healing needs and challenges and the ways in which I am experiencing transformation, joy, and difficulty in relationship to my illness. Some of the following reflections

also served as seeds for further developing my preliminary lenses on the topic beyond my own personal experience:

My illness is here to *break* me, or at least *part* of me. Transformation is about breaking attachment to core aspects of the personality, including will, inertia, impulses and wants. I am challenged to simply do what the body wants and needs, what the spirit is guiding me to do.

I am learning to *lean into* what is coming, what is pulling me, and awaiting me rather than squirming away and trying to flee back to a comfortable space. I am completely captivated by where I am going, leaning in with a smile, relating to something that is paradoxically both *outside* and *within* myself and *forgetting* who I am. I am leaning more fully into my body and discovering new, subtle nuances of needs, sensations, pleasure, and balance. I am more in-tuned with my body's overall rhythms and needs beyond maintaining a stable blood sugar level. I am recovering my body with all its pain and joy.

Healing is about simultaneously honoring and caring for *all* parts of my self (from specific limbs and organs to soul desires) and giving special attention to those that have been damaged or abused. It is important to compassionately *witness* each of these aspects without judging or blaming myself for these wounds.

The illness that I carry has meaning and purpose, for both my own soul *and* the world around me, which in the end, is a false dichotomy. I am a *soul*, not just a finite human body. I firmly believe that I have lived for hundreds or even thousands of years and I will continue living beyond this body. I put the diabetes in this perspective. My soul *chose* this illness as a test, to gather strength, healing, patience, centeredness, etc. Perhaps my soul has even *repeatedly* chosen bodies with physical illness to learn these lessons. The illness will pass, but maybe not in this lifetime. By living with illness I am developing faster as a soul. I will outlive the illness and later understand more. If I can release the darkness of the illness in this lifetime, then after death it can be transformed and planted back into the Earth, blooming into a beautiful rose. If it remains as darkness, it will continue to grow and produce suffering after death.

As I am developing as a soul I am leaving a great contribution to the world, not only to my immediate family, but also through my own writing, research, and the lives of the people I touch. After my physical death I will be able to help others in different, more *powerful* ways.

This journey is about *crossing over*, *wanting* to go into another dimension of reality or state of being. It is like a pilgrimage to a threshold, to cross over and come home. I am happy and smiling, called to be here. I am saying my last goodbye to the world and I only want my daughter, Sara, to be here. I have great trust in her in accompanying me. I am fasting, waiting to ascend or fade away but with anticipation and joy. It is a *long* process of waiting. I feel like a pregnant woman who goes away with a midwife to a sacred isolated place to give birth. I am going off to die. I sit down to try again, this may be it—no, not this time. I get up and walk around again. Joke with Sara again, if I were a smoker I'd have a smoke.

I experience poignant moments when things become clearer with expanded perception. I get *way out there*. There are sudden dramatic turns in which I glimpse something that had been unattainable.

Living with an illness is like compassionately taking care of a small child, as when I am with my daughter. Simply being *present* and living with *love* and *attention*. I find pleasure in taking care of everyday needs and nourishing myself. I am also more sensitive to the needs of others around me and take pleasure in caring for them. Self-care can be quite an absorbing task, but it is a kind of *service* to my own soul and to the world. I am learning to enter into a relationship of give and take with the universe, rather than just consuming.

I begin to suffer and become bitter when I see self-care as a waste of energy. I continue to confront a sense of guilt and worry that I should be doing other things, such as earning money, advancing more quickly in my studies, or doing more for others. These ideas emerge when I begin to compare my situation with other people or my own ideas about how I *should* be. Illness is a question of perspective. It is just *being* and being with the body when it does what it does. Our judgment of the experience places our condition in a category.

The rules are so *different* for me, and I must accept this in order to compassionately heal myself. Every infinitesimal, microscopic task and decision can be so *difficult*, but the more challenging the deeper the healing these bring, like a soft spot on a baby's head that is not a *weakness* but something that needs nourishing because it is still forming. I find meaning and *celebration* in these moments.

Bodily presence is both *involuntarily* and a something I *will*. When I am surrounded by many people and sensory distractions, or simply "out in the open" away from my home, I easily move out of my center and I feel like I "*lose*" my body. I feel disconnected and I tend to do things that put my well-being at risk.

Paradoxically, my self-care brings me to greater *isolation* as I more rigorously defend my individual needs and boundaries, while at the same time it leads me to a greater empathetic spiritual *connection* with the Earth and other sufferers of illness. Being present to my physical sensations can be quite absorbing and it is difficult for me to focus on things outside of my body or engage in the world. I am often indifferent and closed to the needs of others and unwilling to sacrifice any degree of personal comfort. I often feel the presence of other people to be an invasion, a hazard to my self-care. It disturbs me that I often feel that relationships are not worth the effort.

Illness can be a channel through which one both *is* and *does* one's life work in the world. At the same time, *over-identifying* with an illness condition as a transitory context of the soul's embodied path can *stifle* growth because we can hide within the illness and not see or assume other aspects of the self and one's life work.

I feel a tension between wanting to *heal* my own wounds and issues vs. wanting to be *cured* of the diabetes. Sometimes I feel that my life mission is to live with the diabetes and obey what is being asked of me and other times I feel that my path is to do everything I can to physically overcome the diabetes. I live in a tension between surrender and will, acceptance and persistence. In surrendering I am willing my will to stay out of the picture, like holding down a powerful, restless dog until it becomes still enough to receive its medicine. I get glimpses into a physical cure but I am sometimes not sure if this is just

self-deception. My hope is shifting, not so much in a cure, but hope that someday I *will feel more whole and at peace even with the illness.*

My body is a *prison*. I find *joy* and *freedom* in this absolute captivity. Nothing else left to find. Nothing can “save” me from my own embodiment nor do I have a need to flee. In this barren prison cell I sing my spirit and connect to something beyond myself. It is an invisible, heavy load that I must carry always. It turns into a constant, unseen dance. I show up and am present with it, rocking back and forth with the world, just sit here on the edge of the fence. By being present here I travel, I can know *all*. I can displace myself across time and space. Time travel is *real* and part of my soul essence. I am an *explorer*.

Illness is not *all* pain and suffering. I am old and grey with grey colors but I can see the subtleties of the world. These joyous visions are invisible to others but they look *vibrant* to me. I experience great simple joys in my body in just walking, eating, cooking, being outside, even feeling hunger and sleepiness.

I have a particular illness in which my symptoms are always changing and there is much I can do to influence it, so it is not simply giving in and “going with the flow” but being *proactive* or even one step ahead to try to keep myself balanced. The anxiety and worry is sometimes worse than the physical sensations I am trying to avoid. It is difficult for me to feel at ease and to trust.

I worry about finding a way to continue to engage in my necessary self-care (which I willingly do) while also doing meaningful work with others, including finding a way to earn an *income*. It is part of a hope that all aspects of my life will be fully aligned and balanced (economic, physical, spiritual, service toward others, etc.). (Baltazar, 2007, pp. 1-3)

Chapter 5: Cycle 2

In Cycle 2 this researcher explores the literature on the topic and generates a series of preliminary lenses about the topic that represent both how the researcher *views* the topic and *what* he or she sees. According to Anderson (2011), “The goal of Cycle 2 of intuitive inquiry is the articulation in words of the researcher’s personal values, assumptions, and understanding of the research topic as preliminary interpretive lenses prior to data gathering” (p. 39). The preliminary lenses are defined based on one’s own personal beliefs and experiences and a dialogue with texts from the literature review (Anderson 2004a, 2006, 2011). After completing the data analysis of Cycle 3, in Cycle 4 I refined, expanded, and modified the Cycle 2 lenses through an inner dialogue, highlighting intuitive breakthroughs.

Cycle 2 Procedures

My exploration of Cycle 2 has proven to be the most elusive. I felt very frustrated and confused in attempting to generate my ideas about the process of psychospiritual transformation through chronic illness because this experience is so multidimensional and all-encompassing. How can I articulate the process of a life’s evolution when it is something that I am in the midst of and just beginning to understand? How can I theorize about something that amounts to no less than my *entire* adult development? How can I separate my transformation through illness from other aspects of my life experience?

I worried about being able to do this vast topic justice and be able to clearly articulate all of the important aspects of what I had been experiencing and/or reading about. I felt that I could not truly hold all aspects of this process in my mind in order to articulate it adequately. While I experienced one aspect of transformation through illness at a given moment, in another moment

of my life another very different aspect emerged. The aspects of transformation seemed infinite and multilayered and their sequence was not necessarily fixed but more recurring and cyclical.

To begin the process of generating my Cycle 2 lenses (in 2008) I slowly reread my literature review and my dialogue with my personal text of Cycle 1. I wrote down my main research question in a notebook, and I continually asked it, to myself: *What is the subjective experience of psychospiritual transformation among people who live with chronic physical illness?* I tried to carry this question with me throughout my waking and sleeping hours. I wrote down ideas of my Cycle 2 lenses as they emerged. I tried not to edit or even engage with them but simply wrote them down as they came to me. I wrote down my dreams, and, when ideas emerged that seemed to inform my Cycle 2 lenses, I dialoged with the dream text. I also engaged in a series of meditations, walks, and visits to natural sites in order to generate ideas in different states.

I wrote my ideas in a notebook in the form of short phrases (mostly 8 to 30 words) or in prose. I often found that, when I was engaged in these exercises, the act of writing seemed to activate my rational mind and interrupt my flow of ideas, so I began to speak my ideas into a hand-held cassette recorder during my daily activities and even allowed myself to do movements, often somatically acting out the transformation process. I even found that I often generated much more lucid ideas while in a hypoglycemic state, ideas that could not occur to me during an ordinary state.

While I was attempting to map out the Cycle 2 lenses, my own life story continued to emerge. It was difficult for me to separate what I have experienced from what I think other people experience in psychospiritual transformation through chronic illness. I kept asking myself, “Do most people experience transformation in this way?” I was being careful not to

project my experience onto my ideas about what I thought people tend to experience, but it seemed a slippery slope. I came to the conclusion that I needed to explicitly write my story of transformation, put it aside, and then attempt to articulate my Cycle 2 lenses. I wanted to include my story so that the reader (and I) may more clearly see what my experience of psychospiritual transformation through chronic illness has been like (my biases) and how this context is influencing the way I see the topic. I also wanted to tell this story to use it as a fertile ground for developing my lenses, although I tried to keep in mind that my chronic illness experience may be quite different from those of other people, for many reasons, especially in terms of my illness type, personality, gender, and ethnicity.

Rosemarie Anderson (2011) remarked that the most developed procedure for Cycle 2 is that the researcher engages in an imaginal dialogue with an important set of texts related to the topic in order to generate a series of lenses. I used my own story and texts from my literature review as texts for helping me to generate my own lenses. Anderson also suggested another option in which the researcher recruits a friend who is knowledgeable on the topic to interview him or her so that the researcher may articulate what he or she believes about the topic. This idea did occur to me, but I could not find an English-speaking friend who was knowledgeable on my topic.

I planned to continue to generate my ideas for Cycle 2 lenses until I felt that I had reached saturation or that the ideas were beginning to repeat themselves, but I never felt that I had completely expressed all of my ideas. I generated several dozens of pages of notes and 7 hours of audio-recorded ideas during a period of more than 2 years, all of this while I was living through my most difficult physical challenges. The volume of ideas became unmanageable. I began to undertake the overwhelming task of revisiting these ideas and attempting to synthesize, edit, and

order these aspects. As I read through the ideas, other ideas occurred to me about which I was unsure whether *they* had been recorded; thus I wrote the new ones down, and the process seemed never-ending. I felt that I was never able to wrap my mind around the entire process or set of ideas about psychospiritual transformation through chronic illness in one sitting. I also had several computer files written about my lenses, and it was frustrating and confusing for me to not be able to see them all at once. I tried to cut out the ideas and stick them on the walls of my apartment, but the pieces of paper became too numerous to handle.

I tried to enter these ideas into the computer and combine ideas that seemed similar. At first, the ideas seemed disconnected and haphazard, but eventually a process seemed to take shape. After immersing myself in these ideas over a period of several months, I began to write down the aspects of transformation through chronic illness as a kind of narrative, much like my own story. I could not transcribe every idea that I had recorded during the previous years. In a sense, these had all been living inside and around me, and I put the papers and tapes aside and tried to simply sit down and let them flow onto the computer. My ideas were clear to me and the writing flowed quickly. I did this final writing over a period of perhaps 1 month. Then I went back and tried to combine, edit, and synthesize as best I could. I spoke the ideas aloud to gauge how much they resonated with me.

With some aspects of the experience of transformation through chronic illness, I definitely felt that there was a sequence, with some occurring before others within a process. Other aspects had no specific moment or sequence and seemed to occur repeatedly, cyclically, or gradually, and I was unsure how interdependent they were with other aspects of the experience. I have arranged them generally in the order in which I believe they may occur, but the order may

not always be essential. Still other aspects of the experience seemed more like a characterization or the results of transformation in the person rather than specific moments of the process.

I sought to express my Cycle 2 lenses in a concise, understandable, and manageable way, perhaps even using symbols or a graphic to map out this process. However, as I went about this task, I found that I could not express the multidimensional aspects of this complex experience in a simplified way without losing important ideas. My Cycle 2 lenses are not a few concise independent ideas but rather a story or description consisting of a series of detailed aspects of the experience of psychospiritual transformation through chronic illness. When I had completed this set of lenses, it was difficult for me to feel satisfied. I felt that the lenses were too extensive and wordy. I tried to reduce and synthesize as much as possible, but, in the end, I realized that I was allowing my internal critique to judge what lenses are *supposed* to look like. My Cycle 2 lenses perhaps are not pretty, flashy, or concise, but, in the end, and most importantly, they represent how I was understanding the process of psychospiritual transformation through chronic illness (at that particular moment) and, however long and descriptive they may appear, they fulfill the purpose of Cycle 2. It was difficult for me to walk away from these edited lenses because I kept feeling that I had more ideas about this experience that I had not included or articulated. However, I realized that I had to let my research flow and trust that my main ideas were expressed.

I numbered the ideas in the narrative of my Cycle 2 lenses so that I might more easily go back to these during Cycle 4. I worked on Cycle 2 beginning in 2008, but when I redesigned my study at the end of 2010, eliminating the focus on shamanism, I refocused my lenses specifically on the process of transformation through chronic illness. Thus, I worked on my Cycle 1 personal narrative and my Cycle 2 lenses throughout 2010 and 2011 (during my most intense physical

challenges), producing a final edit of my Cycle 2 lenses in January of 2012. At this time, prior to beginning my Cycle 3 data collection, I also wrote an accompanying piece outlining what I had learned or ways that I had grown as a result of my illness experience. I updated and edited my personal narrative in 2013.

My Cycle 2 Lenses

1. Chronic illness emerges as a crisis that builds over time. This process may occur on many different levels or dimensions, including the personal (emotional and physical), the family, hereditary or ancestral inertia, environmental, and so forth. It is a crisis that builds and eventually comes to a culmination or breaking point while it manifests as an illness, as if one too many drops are added to a glass and the water spills over. There is a change in the body beyond the point of return. One feels this as an overwhelming, negative, confusing experience involving intense pain or trauma. The onset of this process may be gradual or rather sudden.
2. One may feel an initial shock in becoming aware of the diagnosis of this illness. Reactions may vary and may include relief, shock, or denial. One may experience a period of confusion before reaching a clear diagnosis. If one had been suffering from puzzling symptoms, it may be a relief to be able to put a name or gestalt on one's condition. This diagnosis may, however, feel like a powerful blow to one's identity. One may feel that one is/was *myself* and now is, supposedly, *a patient with this illness*. One may feel labeled or with one's identity negated. It may feel like a death and having crossed over to a new life. It may take a long time for the news of this diagnosis to sink in or for one to believe it. During this initial onset of illness, especially if one is hospitalized, one may feel like a non-person in a *no space* and *no time* miasma during

this transition period. One may feel a certain death of this previous life and fear and uncertainty regarding one's future life. One's future vision of one's life can seem suddenly to be in doubt or to have been taken away.

3. In this initial onset of illness one may need to focus all of one's energy on physical survival. Other worries or priorities may seem to fade, and one is seemingly at the forefront of this physical struggle and more conscious of the fragility and preciousness of one's life and health. One becomes aware of what is important in one's life, and one feels motivated to be able to live these important aspects.
4. When potentially chronic illness first occurs, it is a period in which medical authorities intervene and take charge. One receives treatment, new information, and orientations for lifestyle changes. At the beginning of this process, one applies these instructions literally without first-hand knowledge, to a certain degree, trusting in this care and even suspending one's own knowledge or judgment.
5. It can be a bewildering, even shattering, experience to find that one's body is no longer what one knew it to be. This change in the body creates a shift, or even a shattering, of identity.
6. One feels that one's life has been interrupted, threatened, and forever altered. One comes to the realization that one has a chronic illness and that this condition will not be reversed. One may initially react with denial, escapism, or hopes of a cure. One eventually comes to accept this circumstance and realizes that one does not have control.
7. This initial period of crisis eventually turns into a relatively more stable period.
8. After the onset of illness, one feels an attachment to the previous sense of self, including one's physical experience, lifestyle, relationships, and even status. One feels a degree of

resistance toward one's new condition and continually attempts to recover this previous sense of self. One feels a certain degree of denial of one's condition, especially throughout one's initial experience with illness, and attempts to continue to be who one was, yet wanting to make changes in order to feel good.

9. One eventually begins to feel a split or rupture between who one used to be and one's current bodily situation. One may even feel a sense of *no self* in comparison with one's previous life or with other seemingly healthy, active people, especially of one's age group. One experiences a kind of transition of identity: the death of the previous sense of self, perhaps a sense of an imposed identity from the illness diagnosis, and a *no self*, prior to gradually creating a newer, expanded sense of self. One eventually becomes aware that one's self is beyond the particular condition of one's body and that one's previous sense of self was limited. Paradoxically, one completely identifies with the body during specific moments in order to become *no one* again, thus releasing this identification with one's previous sense of self. One realizes that the body and illness are embodied aspects of the self rather than thinking of *I* as a mental or egoic self relating to or *having* a body or an illness, as if they were separate entities.
10. One feels a sense of loss and mourning in relation to bodily changes. This is a recurring or cyclical process that one continually confronts throughout one's life with chronic illness. Although change and loss are part of all people's lives, one experiences unexpected, atypical, and/or accelerated physical changes and losses as distinct from more common losses related to the aging experience. One experiences a kind of shock in losing what one never expected to lose and experiencing unanticipated physical changes. These losses may lead to recurring bouts of depression or even to a sense of alienation

from others. A key to transformation is to consciously mourn and to let go of these losses while beginning to appreciate the opportunities for new experiences in one's present.

11. Eventually one develops greater awareness of one's physical self and greater familiarity of these new symptoms in being able to care for one's self beyond, or in conjunction with, the knowledge and treatment prescribed by the medical community. It is a process in which one becomes acquainted with this new body, more knowledgeable about one's illness, and, thus, more adept in taking care of one's self.
12. Inevitably, moments of acute crisis reoccur, and one must seek treatment and/or take actions. During some moments, one must sometimes focus all of one's attention on self-care or survival. These moments lead to increased wisdom about one's self, in all dimensions, and one's illness. One begins to accept that acute crisis is always a possibility in one's life. One takes precautions to avoid acute crisis but, at the same time, surrenders to this uncertainty. One develops increased awareness and appreciation of the fragility and ever-changing nature of life. One learns to appreciate the moment and to humbly live more in the present.
13. By taking care of one's self, one values the preciousness of one's life and of life in general. One may confront difficulties in self-love and self-acceptance, but one eventually comes to committedly love and care for the self matter-of-factly without emotion or judgment, as if one were caring for any other living being worthy of attention and love. One musters the necessary will in order to survive from moment to moment.
14. One continually feels a sense of gratitude and grace at simply being alive.
15. One becomes more aware that health, or well-being, is a fleeting, multidimensional phenomenon that takes into account many aspects of one's body in the world (physical,

emotional, social, mental, sexual, contact with nature, etc.). One attempts to become healthier in more integral, balanced ways and becomes aware of the many ways in which one was unhealthy prior to developing an illness. Despite one's illness, one becomes healthy in many other ways through shifting or transforming self-destructive ego tendencies.

16. One develops a more integral way of taking care of the self. One seeks greater information and incorporates alternative healing therapies as needed as a complement to medical treatment. One develops a greater knowledge of the self and of the healing process and plays an active role in one's self-care. One develops a more intuitive sense of what one needs for one's integral well-being as based on one's experience rather than exclusively on external sources. This intuitive sense may involve an awareness or cultivation of transpersonal ways of knowing.
17. One lives with fear about one's possible future complications or deterioration with the illness. These fears are also cyclical. One may feel that one's future has been taken away, and it may be difficult to find hope for the future. One may eventually learn to live each moment while accepting the possibility of these potential complications by recognizing one's own fears, expressing them with others, and learning to live and appreciate the present. One learns to accept that one does not have control of what may occur in life and lives with an increased sense of trust.
18. One becomes conscious of the importance of one's intentions and mental health in the face of physical illness. One is more conscious that, although one may not control what happens in the body, one may indeed decide upon one's state of mind.

19. One experiences acceptance and forgiveness of self and others for one's condition. One releases feelings of guilt, blame, anger, or shame in relation to illness, and one simply accepts what has occurred and what is.
20. One develops a unique form of spiritual practice, perhaps even exploring and incorporating a variety of traditional and nontraditional practices. One may even feel that living with a chronic illness is, in itself, a spiritual practice of living in the present and caring for life. One's experience with illness can open one to unique forms of spiritual practice.
21. One feels a genuine sense of joy and thankfulness in being alive and embraces one's experiences with chronic illness.
22. One develops meaningful relationships or a sense of community with other people/beings. One finds that a supportive family or community can often be essential to one's integral well-being and that this is a reciprocal blessing of the relationship.
23. One develops an increased sense of interdependence with the world around one, including family, social relations, the natural world, and so forth. One values spending time in the natural world as an important source of harmony, calmness, healing, and insight.
24. One's experience with chronic illness leads one to continually confront the core conflicts or issues of one's personality or ego structure. One becomes more aware of how these have played a major role in one's physical condition and throughout one's life. Working on these core ego issues is essential to a sense of transformation, and this can lead to a greater sense of spiritual growth and serenity. One is conscious that a true sense of

healing involves this freedom, and one develops greater self-compassion and self-understanding.

25. Transformation through chronic illness involves both surrender and will. One becomes conscious of the many things that are outside one's control (including, to a certain degree, one's physical condition) and humbly accepts these. At the same time, one must often muster a great degree of will to survive in the world. One develops a greater sense of discernment of what one can control and what one cannot and accepts this distinction.
26. One discovers ways of making contributions to the world through and with, and not in spite of, one's illness. The illness experience is an integral part of who one is and one's sense of mission in this world. One develops a deeper appreciation for one's own unique gifts and talents and finds a way to manifest these to the world and for one's self in one's everyday life, perhaps even toward a new kind of unique vocation. One feels a greater sense of empathy and compassion, and this motivates one to contribute to a greater good in the world. One's illness experience directly or indirectly relates to one's newfound role in the world. Paradoxically, one feels that, by taking care of one's self, one is, at the same time, taking care of and serving the world. One envisions one's contributions to the world that can occur or be extended beyond one's lifetime.
27. One develops an increased awareness and appreciation of the self and of the surrounding world, perhaps even at times collapsing this dichotomy. This realization may include an increased awareness of one's physical sensations, emotions, spirituality, and relationships. One develops an increased awareness of nature, people, and the social world on a deeper level than one had before. This awareness develops toward empathy, love, and compassion for self and fellow beings.

28. This process is generally consistent with the process of human development in transpersonal psychospiritual development models such as Ruumet's (1997, 2006) helical model and the development of one's Jungian (1928b/1983) functions. The experience of chronic illness can accelerate, facilitate, or stimulate certain stages or areas of development, while, at other times, these may stagnate or be fraught with obstacles. Living with illness challenges one to confront the shortcomings and challenges of one's personality. One becomes more grounded in the everyday world and develops one's previously weaker or less-developed functions and abilities.
29. One develops a sense of openness, surrender, and hopefulness concerning the future, even despite a worsening physical condition. Transformation involves an increased acceptance of one's inevitable death and a consciousness/belief that one is a spiritual being beyond one's physical existence.
30. One perceives how one's struggles with chronic illness have become a blessing for the self and others in the world that can foster integral healing and well-being. One is conscious that personal transformation is a continuous never-ending process and that one looks upon these further challenges with openness and willingness that is focused toward one's integral development and the good of the world.

Chapter 6: Cycle 3

According to Rosemarie Anderson (2011), the creator of intuitive inquiry:

In Cycle 3, the researcher (a) identifies the best source(s) of data for the research topic, (b) develops criteria for the selection of data from among these sources, (c) collects the data, and (d) presents a summary report of data in as a descriptive manner as possible. (p. 45)

Cycle 3 Procedures

I came to the conclusion that the best sources for understanding the process of psychospiritual transformation through chronic illness are in-depth autobiographies by people who have lived this experience (see discussion of this conclusion in chapter 3, in the Data Collection section). This experience is a process that occurs during a period of several years, and I needed to find people who had reflected deeply about their lives and had articulated their process over time. I had a clear vision of the kinds of stories I was looking for, and it was easy for me to formulate the selection criteria. I wanted to find people who had lived with diverse illnesses from a variety of contexts.

I prioritized young people because I felt that the experience of becoming ill at a relatively young age (20s and 30s) would be a more dramatic and life-changing experience than would the advent of such an illness at an advanced age. Living with and accepting an illness at a younger age would be more challenging and life-changing because the authors would be forced to deal with many issues of physical change and accompanying spiritual issues at a much earlier age, with less life experience, than would most people. Moreover, people who have lived an experience of transformation through chronic illness from a younger age would have much wisdom to share with people who begin the process later in life. I also did not want to focus on autobiographies of people who had lived with illness since early childhood because I felt the

process would be qualitatively different from that of a person who developed illness as an adult.

I was eager to find this group of authors and immerse myself in their stories.

In 2011, I began to search for these autobiographical narratives through online bookstores. It was not easy to find appropriate narratives for this study. I used many key words to do my search and read hundreds of book descriptions. Surprisingly, very few books fulfilled my criteria. I found many self-help books for curing or living with illness, but very few written by people who had *lived* with chronic illness. Many others featured people who had been cured of an illness or had beaten cancer. It was quite difficult to find authors who simply told their story of chronic illness without trying to put forth a healing method or a set of religious or spiritual practices. I searched for people who simply narrated their struggles with chronic illness and who felt that they emerged from this with a sense of transformation, wisdom, or change, but without trying to present their lives as exemplary.

I found nine full-length books and one book of a collection of stories by people with chronic illness and disabilities. These were the *only* books I could discover that I felt fulfilled my selection criteria. I began the process of reading these stories in January 2012 after completing my Cycle 2 lenses and personal narrative.

I began the reading process very slowly. The stack of books was on my living room desk as I did my daily chores and exercises each day. I simply allowed them to dwell in my space for a while and I observed my own excitement at becoming immersed in their stories. When the time came to begin to read the first book I chose the one that most strongly drew my attention. I also generally started with the shorter narratives and proceeded to the longer books in order to advance more quickly in this process while also varying the sequence by gender and illness type.

This was the way I chose each new book, and I did not dwell much on why I chose each one or why each book chose *me*.

When I began reading each book I treated this moment as a sacred encounter with a life experience. I slowed down, gave thanks for this opportunity, saluted the person, and asked the universe to allow me the necessary capacity to comprehend this story and articulate a representative summary to my audience in order to contribute to our greater understanding of this sacred phenomenon. I felt as if I was hosting a month-long visit from a new friend who came to tell me the intimate details of his or her story.

I read each book very slowly and wrote down extensive notes in a notebook. I did not try to interpret or theorize about the experience but simply tried to take it in and focus on summarizing what the person was telling. Since most of the stories were approximately 150 pages in length, I needed to faithfully capture the principle moments of each person's process. I spent approximately one month or more with each story. On separate pages in my notebook I also wrote down my own feelings in response to the narrative and the issues or experiences that resonated with me from my own life.

After reading each story, I wrote a detailed summary on computer, including significant quotes, before beginning the next book. I tried to stay as faithful as possible to each person's words about their experiences rather than using my own terms or concepts. By November of 2012, I had read and summarized 7 full-length books and 1 shorter narrative. The summaries were quite lengthy, totaling 33 pages of single-spaced type, followed by another eight pages of notes about my own learning and reflections in relation to each story. These summaries are like condensed books and are comparable to raw interview data. In this dissertation I am including a reduced summary of each person's story.

Although I had originally planned to read 12 illness narratives, I stopped after 8 because I realized that I had generated a large volume of notes on the process of psychospiritual transformation through chronic illness. The stories were extensive, and I still had two more book-length narratives that I could have read, but I decided to stop after 8. Due to my physical challenges, my capacity for sitting for extended periods was limited and it would have taken me another 2 to 3 months to complete the reading. I knew that I had already generated more than enough material to work with in contemplating a shift in my Cycle 4 lenses.

After I completed each of the 8 individual summaries, I proceeded to write a composite story that represented their process in general. This proved to be nearly as complicated as writing my Cycle 2 lenses. My intention was to synthesize and articulate the main themes that emerged from the stories. I first tried to cut phrases from the summaries and combine them into themes, but this proved to be too voluminous. I slowly reread the summaries several times and focused on the main moments of each of the stories, circling key words. From these main, repeating themes I began to reconstruct a story. I became aware that I was afraid to write this composite story out of concern that what I was writing would not be faithful to the participants' lives. I meditated about the main topics of this process, holding the intention of allowing these moments to come forward. After immersing myself in their stories, to a certain extent, I put them aside, distancing myself from the volume of notes in order to express onto the computer a synthesis of what had been in and around me.

After I wrote a draft of the composite story, I then went back to the narrative summaries to make sure that each person's significant moments had been incorporated into the story. I noticed that I was projecting some of my life story into the composite story, especially feelings of shame, and I tried my best to eliminate these. I used the narrative summaries and my extended

notes as a reference to improve the composite story, eliminating elements that were not present in the summaries and adding elements until I felt that the authors conveyed to me that their voices had been heard.

Description of the 8 Authors

The 8 authors (5 women and 3 men) have lived with a variety of chronic illnesses for a significant period of time. On average, the authors began their chronic illness at age 35 and, upon writing, had lived with illness for an average of about 14 1/2 years. The average age at the time of their writing was approximately 50. Seven of the 8 authors continued to live with chronic illness at the time of writing while 1 person (Manguso, 2008) had experienced a remission 4 years prior to writing. Six of the 8 authors had experienced significant and rather sudden physical symptoms at the very beginning of their illness onset and subsequent diagnosis.

All of the 8 authors lived in the United States throughout their illness experience. Although not all of the authors explicitly mentioned their place of birth, all but 2 of the authors expressed that they had lived in the US at least since their childhood. Concha Delgado Gaitan (2009) is from Mexico and had moved to California at age 7, while Carmen Ambrosio (2010), who was from the West Indies, had moved to the US at approximately age 17. Adan Williams (2008) identified himself as African American, Delgado Gaitan as Latina, and Ambrosio as a West Indies native, while the rest of the authors were unspecific about their ethnic identity (although from their author photos one may suspect that they have European origins).

Six of the 8 authors identified themselves as heterosexuals and one as homosexual, and one person was unspecific as to sexual preference. In terms of marital status or partnerships, 4 of the authors mentioned that they had lived with a partner during most or all of the illness

experience narrated in their books, 3 had lived mostly without a partner during this time, and 1 person did not specify that information.

The 8 authors have generally been accomplished writers and professionals. Two of the authors hold Ph.D.s and have authored multiple books on their research, while 4 others have published creative written pieces that include novels, poems, and essays. All of the authors, including the 2 whose narratives represent their sole publication to date, have had an interest or academic background in writing (journalism, creative writing, ethnographic research, etc.). Seven of the 8 authors earned at least a bachelor's degree, while 1 person did not specify.

Table 2

Descriptive Table of the Narrative Authors

| Author | Illness | Age at illness onset | Age at the time of writing | Number of pages of narrative |
|--------------------|---|-------------------------|----------------------------------|------------------------------------|
| Dean Kramer | Multiple sclerosis | 33 | 52 | 149 |
| Adan Williams | Human immunodeficiency virus (HIV) | 25 | 45 | 11 |
| Carmen Ambrosio | Multiple sclerosis | 31 | 50 | 153 |
| Sarah Manguso | Chronic idiopathic demyelinating polyradiculoneuropathy (CIDP) | 21 | 34 (remission at age 30) | 184 |

continued

| Author | Illness | Age at illness onset | Age at the time of writing | Number of pages of narrative |
|---------------------------------|--|-------------------------|----------------------------------|------------------------------------|
| Phillip Simmons | Amyotrophic lateral sclerosis (ALS) | 35 | 42 | 154 |
| Concha Delgado Gaitan | Systemic lupus erythematosus (SLE) | Approx. 45 | Approx. 60 | 180 |
| Floyd Skloot | Chronic fatigue syndrome (CFS) | 41 | 48 | 173 |
| Marguerite Guzmán Bouvard | Interstitial cystitis | 50 | 69 | 7 and 140 |

Dean Kramer's Narrative

In her book *Life on Cripple Creek*, Dean Kramer (2003) wrote about her experience of living with multiple sclerosis (MS) and chose to sometimes call herself a “cripple” (p. 2) because she considered it an appropriate description for her physical condition, despite her sometimes widely varying symptoms. Kramer, who was 52 years old at the time of this writing, was diagnosed with MS at age 33 and began to feel intensified symptoms in her early 40s.

When Kramer (2003) was diagnosed she reacted with denial, speeding up her life in order to forget her illness and to prove that she could still be physically active. She was scared and angry and tried to seize control, blaming herself and others for the illness onset. Kramer rejected and disowned body parts that had changed.

Kramer (2003) sank into an “abyss” (p. 144) and was forced to confront her own psychological issues that she had always carried but had avoided. She accepted that her health was declining and that her body was changing. Kramer sought to educate herself and the people around her on MS and sought the services of a psychotherapist. She struggled with her own self-judgment and compared herself to others when she was no longer able to do things that she felt were important. Kramer fell into grief, mourning her own losses, especially the activities that she enjoyed and that she had closely associated with her own identity.

Kramer (2003) entered a process of detachment from her previous self, embracing new activities to which her body had led her. She eventually chose to be more present, to simply *be* and observe. Kramer became more open to these new activities and to the newly emerging self. She discovered new gifts and qualities.

Kramer (2003) lived with constant uncertainty of her changing symptoms and came to accept this as a way of life. A key step for her was accepting herself as she was. She lived with stillness of mind and body and came to appreciate it, valuing simply living in her body, observing and honoring it as part of the world, and accepting her limitations and relinquishing the idea of controlling her body and her situation.

Kramer (2003) came to understand how her emotions and external factors influence her physical health and began to observe her own body, eventually developing a greater understanding of the cycles of changes in her body. She made a conscious decision to shift her attitude in response to her illness, accepting herself and her situation for what was happening. Kramer embraced self-compassion and self-forgiveness without judgment, letting go of negative values that were no longer helpful to her. She began to conserve her energy for activities that she enjoyed, and this allowed her to make meaningful connections with others.

A period of solitude was helpful to Kramer (2003) in facing her psychological issues, observing and accepting her body, and rebuilding a new lifestyle based on her new physical self. Time in nature was also extremely important to her as she learned to observe herself within nature in a much more detached way, while developing a greater sense of serenity and acceptance. Humor also helped her to accept, enjoy, and live with her current situation.

Kramer (2003) came to identify herself based on her strengths in the here-and-now, embracing new-found gifts and qualities that she tried to use to make contributions to others, especially those with MS. She felt a greater balance between solitude and community as she valued meaningful relationships with others, especially with other MS sufferers and with a friend or partner, a reaching out that she felt at a certain point was now more possible after this period of solitude. Other factors that were helpful to Kramer included a good relationship with a doctor, support from others, and the use of appropriate technology.

Adan Williams' Narrative

In his article *Pas de Deux with Mister D*, Adan Williams (2008) told his story of transformation from living with the human immunodeficiency virus (HIV). He had been diagnosed at age 25, 20 years prior to writing his story. With his initial diagnosis, he was in shock and felt that his comfortable life had been rudely and abruptly pulled out from under him. Williams felt confusion, denial, and in a “surreal haze” (p. 109) upon realizing that his life would be changed forever. Upon receiving this news, he had felt betrayed, lost, humbled, and ashamed. He felt that he had somehow thrown away the precious gift of life that he had been given and wanted to protest this injustice. Williams was initially told by doctors that he would not live to be 30 years old. “My consciousness had radically shifted, and what I had once understood to be a

secure reality no longer had any ground to stand on” (p. 109). He felt that he was now living in uncertainty.

Despite the negative message from doctors and the media that he was doomed to die, Williams (2008) decided that he did not want to die and that he wanted to live his life to the fullest. He prayed to God to be shown a way to thrive in the face of this illness. Williams experienced the silence of a deeper inner light in knowing that his life was not ending and that his true work was now beginning. The mantra that he credited with saving his life and sustaining his being was: “I honor the Lord who dwells within me” (p. 110).

With this illness Williams (2008) valued his own life more and felt more motivated to live his life with love. He reached a new understanding of his interconnection with all life: “The more I love and invest in life, the more life will love and invest in me” (p. 111). Williams shifted away from his previous belief that life had owed him and he attempted to value living from the heart in every aspect of life, detaching from dreams of wealth and fame and adopting the vocation of teaching as a form of service in sharing with others what he had received in life. Williams also did volunteer work for reforestation so that he could contribute to life, thus putting forth into the world his desire to live a healthy life.

With the motivation to live his life to the fullest before dying, Williams (2008) travelled to other countries. He even visited an island in pursuing a dream image of finding a brick of gold under a field of pineapple trees and then sharing it with the world. He did find this brick of gold on that island in the form of a wide-eyed child that represented for him his reconnection with his own happy, unwounded inner self. In his journey with illness, Williams (2008) felt a strong sense of gratitude, a peace of mind, a renewed appreciation for simple pleasures and time in nature and with loving people, and a faith that life can be well:

My disease has taken me much deeper into life than I ever would have gone without it. My disease has been my teacher, making me a better and truer human being. Though I would not wish it on another, and though I wish it might be otherwise for myself, my disease has been a gift to me nonetheless—a gift whose origin I believe is divine, and whose inner lessons I have yet to fully recover. . . . Even so, certainly I know this much it has taught me: wherever I go, I am in my own home. As frail as my body may be, illness strengthens my spirit. (p. 118)

Williams (2008) commented that he felt that God dwells in his heart as love and that he expresses this love as gratitude. He commented that he is more aware that things are beyond what is seen on the surface and that he feels a greater oneness with all.

Carmen Ambrosio's Narrative

Carmen Ambrosio (2010), a 50-year-old woman, narrated her story, *Life continues*, to portray the period since she was diagnosed with multiple sclerosis (MS) at age 31. She is from the West Indies and moved to the Midwestern US when she began college in 1977. In 1991 Ambrosio began to feel unexplained symptoms of numbness in her fingers and toes and midsection before finally receiving this diagnosis.

Ambrosio (2010) initially reacted with shock at the news that she would eventually become crippled. She then responded by reaching out to loved ones, researching information on MS and its possible treatments (from a wide variety of allopathic and alternative sources), and adopting a healthier lifestyle in order to delay symptoms, despite conflicting information regarding that possibility.

In the years to come, Ambrosio (2010) dealt with many odd new symptoms and endured constant pain, confusion, frustration, and intense side effects from medications. She experienced a sense of helplessness, hiring and firing doctors and adopting a more proactive, holistic approach to healing that combined allopathic and alternative approaches.

Ambrosio (2010) responded to her symptoms by listening to her body, waiting, resting, and honoring limits. She learned to surrender and to accept the unpredictable pain. The author lived with confusion and constant uncertainty, even the specter of possible death, but focused on living in the here-and-now and reminded herself that it could be worse and that life continues. Ambrosio accepted the losses of what she was no longer able to do.

Ambrosio (2010) learned the difficult task of asking for help and built a support network, including mutual support from other MS sufferers. She especially appreciated emotional support, listening, encouragement, and laughter.

This uncertainty sparked Ambrosio's (2010) spiritual search, especially of Eastern religions in which she embraced acceptance, self-awareness, and impermanence. She adopted a spiritual practice of meditation, yoga, breathing, chanting, and singing. Ambrosio became aware that, in order to deal with MS, she had to eliminate negative thoughts and emotions and become more mindful, joyful, compassionate, and accepting. The author felt that she needed to introduce laughter and joy into her life to get past the pain and regain hope.

Ambrosio (2010) maintained a sense of humor and positive intentions and waited for answers to the meaning of her suffering. She also made provisions for her possible worsening condition, letting go of future plans, yet also developed a new career based on her new limitations and lifestyle and her newfound interests, gifts, loves, and wisdom. Ambrosio experienced a profound sense of gratitude for her gifts, health, inner voice and guides, and support from others. She became more conscious of the opportunities to learn from everyday experience and tried to live in the moment and enjoy life.

Sarah Manguso's Narrative

Sarah Manguso (2008) was ill from ages 21 to 30 with a severe form of chronic idiopathic demyelinating polyradiculoneuropathy (CIDP), an autoimmune disease in which her body was producing antibodies in her blood that were destroying her nervous system, resulting in chronic paralysis of her extremities and difficulties in breathing. She also experienced severe depression until age 30. Upon publishing her memoir at age 34, *The two kinds of decay*, the author considered herself to be in good health.

Manguso (2008) had experienced sudden onset, with symptoms of weakness, paralysis of her extremities, and difficulties in breathing. Manguso had endured an extremely painful and uncomfortable medical procedure for more than a year that involved massive blood withdrawals and the reinfusion of her blood with (cold) plasma replacements. This four-hour procedure was performed more than 50 times during this first year through a permanent line that was inserted into her chest and that resulted in intense cold within her body and a metallic taste sensation.

It took Manguso (2008) several months to get a proper diagnosis, and during this period she experienced uncertainty. Her illness is rare and unpredictable and her symptoms were atypical and often dismissed by doctors. Manguso experienced changing degrees of paralysis and, although she could often barely move, she resisted using a wheelchair because she did not want to give up hope of recovery. She was conscious that she was suffering permanent damage and that she would continue to need this painful procedure. Manguso learned to live with her fear of death and fully accepted this possibility. She was disappointed at being continually told by doctors that she would get better soon and that she would no longer need blood replacements. However, one night in the hospital, she awoke with fright to find that her central line had again been inserted.

Manguso (2008) reflected that her illness was a kind of unconscious self-destruction that may have either triggered or been caused by her suicidal depression, noting this relationship, or parallel, between physical and emotional processes in her health. After this 1st year Manguso saw a new neurologist who opted for a more sustainable treatment for her, without blood replacements, that consisted of steroids and gamma globulin infusions. She improved greatly, gaining increased mobility, but experienced dramatic side effects of loss of reflexes and sensory deficiency. After this central line was removed from her chest after this 1st year, Manguso noted, she became aware of the mystical power of sexual intercourse to help her heal emotional needs.

During her long, painful treatments, Manguso (2008) noted that she had learned to simply pay attention and be in the moment without anticipating the next one. She noted that the “worst part of being sick was not having energy to feel powerful and fast. Not enough energy to run away” (p. 110). She felt a sense of helplessness in accepting that she could not control or will her body to health.

Manguso (2008) took steroids and prednisone for the next 4 1/2 years, which saved her, yet poisoned her with serious side effects, including mood disorders, pain, fatigue, and weight gain. Having survived and recovered from illness became a central part of her identity. Manguso felt bitter, spiteful, furious, jealous, negative, and in possession of a sense of entitlement. She commented that, for a few years, this pervasive sense had made her “a worse person [and that it had cost her much more effort to lose the] mean air that inflated it” (p. 137).

After an unexpected surgery, Manguso (2008) had experienced a steroid-induced psychosis that left her with severe aches, fatigue, and depression for 5 months. She experienced a loss of hope that she would ever get well, and, after evincing suicide intentions, she was admitted to a locked hospital ward. Manguso felt that her life was already over and that she had nothing

left to lose, but, despite this conviction, she radiated mercy, discovered prayer, and found true community. The depression eventually triggered another CIDP relapse, and she returned to the hospital.

Manguso (2008) recovered from her last acute relapse of CIDP at the end of 1999; she stopped taking steroids, lost weight, and felt healthy and lean for the first time in nearly 5 years. She later came to an acceptance of her illness history and developed a sense of pride in having endured. Manguso considered her (9-year) illness a part of her continued life-long growth rather than an isolated aspect of this period. She was going through many other life issues and struggles as a young adult, and it was impossible for her to identify what was related to illness and what was not.

Seven years after her CIDP remission, Manguso (2008) explained, she still lives in uncertainty, since part of her still acts as if the disease will come back tomorrow. She has not made any major life commitments (partner, career, home, car, etc.) because she does not feel that she will be able to live a stable, healthy life. At the time of her writing, she tried to take nothing for granted and believed that all could be taken away from her at any moment. Manguso emphasized that illness happens over a long period of time, not just in the moments in which we feel it emerge and it becomes acute.

Manguso (2008) learned to pay attention to each moment and believed that this is all that we truly have. She summarized this for herself in the following way:

To pay attention is to love everything.

To see the future as *brightness*.

Everything that happens is the last time it happens. We see things only as their own fatal brightness, and there is nothing after that brightness.

You can't learn from remembering. You can't learn from guessing.

You can learn only from moving forward at the rate you are moved, as brightness, into brightness. (p. 184)

Phillip Simmons' Narrative

Phillip Simmons (2000) narrated his 7-year experience with amyotrophic lateral sclerosis (ALS), popularly known as Lou Gehrig's disease, which began when he was 35 years old. He explained that ALS is a "degenerative and ultimately fatal neurological condition with no effective treatment and no cure" (p. 2), and he died 2 years after completing his book, *Learning to Fall: The Blessings of an Imperfect Life*.

When Simmons (2000) was diagnosed and felt his health declining, he decided to spend his time in a cabin with his family in the New Hampshire mountains, the place of his childhood summers. He noted that his fuller consciousness of his impending mortality was his "guide to being more fully alive" (p. x).

Simmons (2000) reacted to his illness by focusing on loving and accepting himself and treating others with kindness. He felt blessed to still be alive in the face of a dire, fatal diagnosis. Simmons sought self-knowledge, knowledge about his illness, laughter, time with his family, and time in nature. He counted his blessings, or the good things he had in his life, despite pain and weakness, and he began to notice the beauty around him. He tried to be present in his life and felt that he was gaining the present even as he was losing his life.

After his diagnosis Simmons (2000) sought the services of shamans, priests, psychotherapists, bodyworkers, and several alternative healers. He practiced mindful walking, and falling on his face cured him of complacency and pride. Simmons began to accept all that befell him as part of his place in the natural order. When the author accepted his present condition, he was able to set aside his fear and discover love and compassion as his highest human endowments.

Simmons (2000) found freedom when he accepted that one day he (and we) will lose everything, including our very lives. He became conscious that he was moving into something beyond his control and that this is a universal phenomenon in which we “fall” (p. 11) from ego, such as when we fall in love. Simmons wrote that he fell into passion, terror, vulnerability, joy, compassion, emptiness, “into oneness with forces larger than ourselves. . . . We fall, at last, into the presence of the sacred, into godliness, into mystery, into our better, divine natures” (p. 11).

Simmons (2000) felt that it was his duty to simply continue to face loss, grief, pain, and debility. He came to accept all things, both good and bad, recognizing that both joy and suffering come from God. Simmons tried to seek God not only as solace during suffering but as the suffering *itself* and, with this, tried to mindfully attend to all that was broken in his life with compassion and generosity. The author found God in the imperfect and was called back to a world he was rediscovering. He came to appreciate that he had not a perfect life but a *full* one.

Simmons (2000) attempted to be present in his body, yet he was conscious that his body was transitory and that his true home lay elsewhere. He became aware that he could reach this future perfection only by being present in the body in the moment. Simmons began to feel more at home with the people around him and felt more whole when he contributed to making a “house of peace” (p. 48) in the present moment for himself and those around him. The author found joy in building this unfinished house.

Simmons (2000) tried to become “a wild thing” (p. 52) in simply doing, without thinking, reflecting, or analyzing. He tried to simply be present yet observe himself with total self-acceptance. With practice, this wildlife presence began to allow Simmons to simply *be*, without judgment, doubt, and criticism. Being both *in* and *out* of the world brought calmness to his life,

and Simmons felt that he was returning to his true self and living more fully “in the midst of soul” (p. 61).

It was helpful for Simmons (2000) to both live in solitariness and engage in relationships with others. The “holy quiet” (p. 67) of contemplative business (any kind of simple, creative calming activity) helped him with self-understanding which enabled him to share with the world his gifts rather than his obsessions. Quiet time calmed him, emptied him of ego, and allowed him to be less fearful, less conflictive, and ready to contribute to relationships.

Simmons (2000) learned that suffering is an activity of the mind, and he was sometimes able to maintain inner calm while withstanding physical harm. He became conscious that his inner calm could help him to eliminate other forms of suffering in his life, such as fear and anger, and that this helped him to dissolve inner conflicts and create more possibilities in his life. Simmons valued learning to “walk in the mud” (p. 87) as a way of grasping truth through pain and sorrow. He felt connected to the world, feeling that all comes from a common source, and he began to see the world through the eyes of an unconditional lover of the world.

Simmons (2000) experienced his illness as receiving the joy of an empty box, as he received the gift of simply being present and living with loving presence. When he became increasingly disabled, he learned the difficult task of nondoing, not simply sitting still, but calming the mind and coming back to the emptiness of breath. He expressed that he felt thankful for his good fortune to return to the place of his boyhood summers.

Simmons (2000) learned to live with unexpected loss and to accept that his previous life was forever out of reach and that life is, in any case, beyond our control. He found that if he could be present to his true home within, then, no matter where he went or what happened to him, by returning to his highest nature, he would always be at home in the place he had never

left. He learned to live in the paradox of striving toward goals and yet letting them go without trying to force things too much. Simmons found that, “dwelling in the present moment, in the face of everything that would call us out of it, is our highest spiritual discipline. More boldly, I would say that our presentness is our salvation; . . . [it is] our gateway to eternal life” (p. 145).

Concha Delgado Gaitan’s Narrative

In her book *Prickly Cactus: Finding Sacred Meaning in Chronic Illness*, Concha Delgado Gaitan (2009) narrated her 15-year story of living with systemic lupus erythematosus (SLE), a chronic autoimmune disease that caused her pain and partial paralysis. When she experienced initial debilitating symptoms (fatigue, joint pain, fever, and weight loss), Delgado Gaitan felt shock, confusion, and anger: “The person that I was disappeared,” (p. 7) and she felt a stranger to herself without having the language to explain what was happening to her. In the 2 weeks prior to her diagnosis, she experienced uncertainty and worry, and, upon hearing the diagnosis, she went into denial. Upon further research, Delgado Gaitan discovered that there was neither cure nor effective treatment for her illness, and she worried that she would never be well again.

Delgado Gaitan (2009) realized that she had dedicated her life to social change and academic achievements but had never learned to take care of herself. Being sick went against her self-image of being productive and independent, and she resisted acceptance of her state. Delgado Gaitan experienced exhaustion and pain in her muscles and joints for years, until she learned key lessons. Despite months of intense symptoms, she continued to work and to take drugs to mask the pain, because she felt that illness was a sign of weakness. She believed that her body existed to serve her, and she tried to control it, as she did with everything else in her life, but realized that, in regard to this illness, she could not. Delgado Gaitan realized that she was in

denial, and her fears began to control her. She had to face life without the physical strength that she had relied upon and identified with and was forced to use crutches.

Delgado Gaitan (2009) experienced mental confusion and loss of memory, and she lost track of time. She felt empty, fearful, and without her strongest allies: a strong body and a sharp mind. Her past and present felt distant to her and she was often at a loss as to what to do. The author shared that, in these times, she most appreciated the support from family and friends (especially financial support) and laughter. Delgado Gaitan experienced the gift of becoming more conscious of her body, yet experienced the uncertainty of not knowing whether she would get better. She was afraid of losing her identity as an able-bodied person, resisted thinking of herself as disabled, and worried about other people's expectations of her.

A big step in this process for Delgado Gaitan (2009) was surrendering to rest. She felt that the voiceless part of herself that wanted to rest was screaming through the pain. She eventually began to see herself more in terms of her capacities rather than her restrictions, and, with this, she began to experience hope. Delgado Gaitan finally suspended her own self-judgment about her mobility and stamina and used a power wheelchair to conserve energy and do what she enjoyed. She connected with a community of disabled people and focused on the strong part of herself, thereby discovering that she was more than her body and sharp mind. The author became aware of the importance of a loving community to her healing, and she learned to call upon others for help.

Delgado Gaitan (2009) learned to meditate and became aware of the connection between spirituality, her emotions, and her immune system, and how her compulsive work habits worked against her healing. She learned to appreciate herself, confront her fears of the future, and prioritize practicing spirituality in everyday life by living in the present; listening to the body;

and making time for rest, exercise, and meditation. She also began to try alternative and holistic therapies.

Delgado Gaitan (2009) reconnected to her heritage of Catholicism and Buddhism to find sacred meaning in daily life, embracing and committing to old and new forms of self-care and learning to express gratitude. She discovered the importance of speaking about her illness and healing in order to create external support and healing in her life and to access the healer within. Through study and work with a spiritual guide, Delgado Gaitan acquired a whole new framework for healing beyond what she had known prior to becoming ill. She learned to speak about illness and about healing internally and also to reach out to others toward building community. At the beginning of her illness experience, she had been trying to heal her body so that she could continue to use it as an instrument of ego, but this focus shifted, as she later came to believe that health *is* her life's work.

Delgado Gaitan (2009) found ways to live with her pain and to simplify her life. She allowed herself to express the hidden feelings that she had previously thought of as bad, thus integrating parts of herself that had been denied and allowing her immune system to heal. She expressed forgiveness of self and others, felt a closer connection to her inner spirit, and believed that healing was possible. In a moment of sudden crisis, Delgado Gaitan would set about letting go of her fears and being simply present in the flow of life, where she experienced oneness with Spirit and the world. Her body became her teacher, as she unlearned destructive habits and learned to quiet herself, because she wanted to heal not just her body but her soul, in reaching a place of wholeness and peace. Delgado Gaitan cultivated the practice of prayer, alone and with others, and learned to *listen* rather than simply demand. Through prayer she began to trust, and this made her feel stronger. Music, singing, and laughter were also vital to Delgado Gaitan's

healing in respect to taking the time do things that she enjoyed. She explored new ideas and practices for healing both mind and body, and these became important aspects of her life.

Delgado Gaitan (2009) drew upon her inner faith to deal with physical and financial insecurity, pain, loss, and fear. She set limits in her work life and adopted a one day at a time approach to her life, even seeing flare-ups as opportunities for growth. She continued to use allopathic treatments but combined them with alternative treatments that allowed her to feel stronger, more peaceful and optimistic, and more connected to her own energy and to others. Delgado Gaitan became her own health guru and sought and found a holistic doctor to help her manage her own health regimen (acupuncture, Tai Chi, herbs, and energy healing) and take responsibility for her health.

Delgado Gaitan (2009) found that her self-esteem and identity were now less dependent on her physical strength, and she experienced an expanded self-identity that included more aspects of herself (both the light and the dark), as she learned to feel and express emotions without judgment. She reached out to others, breaking her own rules of self-sufficiency, and the presence of community in her life was essential to her healing. Her health improved as she integrated body, mind, and spirit. Delgado Gaitan embraced death and the emptiness she felt upon losing her job but recreated her career as an independent writer from her own abilities, interests, and health situation. By becoming open to the destructible nature of her body, Delgado Gaitan became open to the indestructibleness of her inner power. In order to heal, she needed to retrieve her family and cultural strengths.

Delgado Gaitan (2009) looked inward and

came to believe that in illness lies its own cure. Pain has a voice. If we listen we are given instructions on how to move in the direction of healing. . . . Getting healthy became full-time work, not only because of the chronic nature of the illness, but also because health is

not an end but a process, an adjustment of a whole life through spirituality, community, and recreation. (p. 175)

She experienced an expanded sense of healing beyond fixing physical symptoms, learned to quiet herself and listen to what illness was telling her, and even learned to trust herself beyond her physical strength. Delgado Gaitan found that how she perceived herself, those around her, and her physical environment influenced her overall health, and she became more conscious of her spirit, body, and mind, and especially of her own power.

Delgado Gaitan (2009) became conscious that she is never alone and felt more connected to Spirit. She felt a greater sense of control over her health by taking charge of it herself rather than depositing this control into the hands of a doctor and became her own strongest advocate, researcher, manager, and caretaker. She felt empowered when she began to make decisions about her body and her life. Delgado Gaitan found peace within and realized that miracles happen when we are free from fear. She moved from impatience and separateness to gratitude, oneness, paying attention to bodily messages, and balance. She commented that illness helps us to discover who we really are and to travel down roads on which we would not have gone.

Floyd Skloot's Narrative

Floyd Skloot (1996) became suddenly ill with Chronic Fatigue Syndrome (CFS) at age 41 and finished his narrative, *The night side*, nearly 7 years later. The author experienced the onset of illness while he was apparently, for all intents and purposes, at the peak of health (he was running 7-8 miles each morning and over 2,000 miles per year). He suddenly began to experience symptoms of tiredness, disorientation and incoherence, body aches, a viral infection, and memory loss. Skloot felt that his power had suddenly been stripped from him, as he wrote that it was like "being estranged from my normally reliable mind. . . . as though it had walked

out on me and left no forwarding address” (p. 4). He tried to force himself to beat it by pushing harder, but, after more than 40 days, he could barely move, and he sought medical attention.

During a 5-month period, Skloot (1996) took several medical tests with many specialists until he finally reached a clear diagnosis. “I was probed, biopsied and drained. . . . About the only thing the medical practitioners seemed not to be doing was listening to me” (pp. 9-10). Skloot’s nightmare continued past these initial procedures of diagnosis: “For months, as I continued to get worse, I was shuttled from specialist to specialist” (p. 59). “Bad as the diagnosis was—a disease that could neither be treated nor cured—I wept with relief at having a name for it” (p. 12). He explained that it was difficult to arrive at a diagnosis because little was known about the disease at this time (the name of the illness does not reflect the vast array of symptoms) and because it cannot be diagnosed by technical means.

After his diagnosis Skloot (1996) eventually experienced stages of denial, fear, anger, and, later, acceptance. Especially during this initial period, he emphasized the importance of support from family, friends, and colleagues from work. Following diagnosis, Skloot tried every known treatment for CFS, including alternative treatments, but, after 15 months, he had exhausted all options without any improvement.

Skloot (1996) spent a lot of time resting, and, 8 months after his initial onset, he could begin to read. He changed the way he enjoyed baseball, his lifelong hobby, from playing it to a more passive modality, and this helped him to change other areas of his life and cope with having a disabling and chronic disease. Baseball also helped Skloot to jog his memory and to feel satisfied about something instead of just feeling sad about his losses. No mental and physical movements were second nature to him anymore, and his engagement with baseball helped him to redefine his relationship to the past and to open a path to the future.

Skloot (1996) lost a sense of physical power, a significant loss, as he had previously felt infused with capacity, which had given him great confidence and had felt vital to his way of being in the world. Upon the date of his completing his narrative, onset was still a mystery to him, it still mattered, and he was still trying to understand and accept it.

After living with chronic illness for a while, Skloot (1996) began to become much more conscious of his body. His life had slowed down, he had much time to think, and much of his attention was now on the body. He began to live (rest, eat, and move) according to his own bodily rhythms rather than as based upon schedules, plans, and what others wanted from him. Illness also changed the way he dreamed, and, in most dreams at this time, he was lost in a fog. Skloot (1996) expressed his sense of illness through a dream in which he was running a never-ending solo race without a clock, a finish line, observers, or fellow runners:

I look up, but there is no colorful banner arcing across the road, no clock to read, nobody alongside cheering. I raise my arm to check the time, to be sure I haven't miscalculated, but my watch face is blank and so I look ahead again. It's true. There's no finish line. I only know of one thing to do. All my years of running tell me this: relax, dig down, keep going. (p. 56)

After losing his capacity to lead his busy life and do simple everyday tasks, Skloot (1996) felt an ambiguity in his sense of self.

All of a sudden, I can't do what I never had to think about doing. Never mind the daily 6 miles, what about can I walk to the corner? When I can't work anymore because I can't concentrate, can't add or spell, can't remember, CAN'T THINK, I must wonder if it's even me anymore. (p. 56)

Skloot (1996) began to call upon the deep wisdom he had learned from his childhood in order to make sense of his illness experience. He learned to observe in wonder, knowing that there are forces greater than his self acting upon him in the world. Skloot came to the conclusion that it all has its own power and reasons beyond our will and control, and he embraced this trust. He observed the world around him over great periods of time, as he had done as a boy, and grasping

this essential truth of the world allowed him to avoid despair in a way that he could not have done through normal observation.

Skloot's (1996) struggle with illness prompted him to seek his own emotional healing:

It was almost as if I could not begin to heal until I had grasped certain truths about myself, though I had no idea what those truths might be. . . . But I was beginning to believe that healing, on the one hand, and making myself well, [and] *curing myself*, on the other hand, might be totally different things. Intuitively, I had known that I must start with the first places, especially the narrow island in the Atlantic where I grew up. . . . I knew as if through my own body that healing comes from within, that there are always tests and to pass those tests you had to dig deep down, had to find resources in the very fabric of self. (pp. 74-75)

Through his experience with illness Skloot also felt motivated to be less selfish and give the best of himself in his relationships.

Throughout his first 5 years with illness, Skloot (1996) had thought of his health crisis in purely physical or medical terms, but he soon found himself seeking emotional healing from a renowned German Divine Mother and surprised himself when he asked her to "*Help me to see how it all fits together*" (p. 100). Soon afterward, he became aware that his life-long recurring nightmares represented the childhood abuse from his parents, and he dealt with this by writing a novel. Skloot noted a sense of spirituality in "living everyday life closely. It is not necessary that much happen, except the finding of greater awareness" (p. 104).

Skloot (1996) used both allopathic and alternative healing modalities in his daily self-care, along with home remedies that he claimed "serve as a kind of mortar between the bricks of Eastern and Western medical practice that provide me shelter during illness" (pp. 117-118).

Skloot noted his confusion in discerning which (often conflicting) home remedies and treatments to use but says he often went with the advice that

it's worth a try. . . . And of course, I am often tempted to do nothing at all. That is sometimes offered to me as the soundest advice. Do nothing. Surrender to your illness in order to defeat it. Stop searching for a cure and be healed. (pp. 123-124)

Skloot commented that, after all he has learned and lived with in regard to healing and the mind, “the mysteries only grow deeper” (p. 121).

Skloot (1996) commented that, even after 7 years, he was still struggling to understand the major life changes he has experienced as a result of his illness:

It is very confusing to be chronically ill. . . . I have been cut off from my past as an athlete, as a member of the work force, as a vital human being. Family relationships and friendships have altered. Whether I have sinned or lived wrong, expended too much or held too much in, deserved my virus or was stricken arbitrarily, my life has been changed utterly. This is difficult to grasp even now. (p. 121)

He wrote that “One of the most frustrating aspects of long-term, chronic illness is the confusion created by relapses” (p. 166) and his uncertainty of whether they were brought on by an alteration in his health-care regimen. Although he mentioned that his own constant, uncomfortable symptoms have led him to consider even the most bizarre remedies, Skloot tried not to become obsessed with researching and experimenting with healing options, “not allowing the stress of such uncertainty to exacerbate symptoms. It is enough to make a person sick” (p. 122). He maintained a sense of wonder at his own mysterious process of illness and healing, which may or may not be a result of his own efforts. “But as the contradictions deepen, as what works and what does not work develops its own strange rhythm, I feel as though I have learned to approach the dance of hope and despair with high style” (p. 131).

Skloot (1996) noted a change in the way that he sensed, thought, and wrote:

During those first years, I was there the whole time; I was experiencing and sensing and feeling—eventually even thinking—but all I could do was store things up. It was a kind of enforced accumulation of knowing, and when I began to write again, a few minutes a day on a good day, it no longer seemed possible to write as I had written before. (p. 136)

As a writer Skloot could no longer approach his material with an overview, but rather was required to work from small pieces at a time. He commented regarding this change that, “In some ways, I don’t recognize my writing any more” (p. 139).

While living with illness Skloot (1996) experienced a different sense of time, especially in feeling disconnected from daily activities that he had previously engaged in. He began to turn inward and, after 1 year, noticed how slowly time seemed to pass, yet at the same time felt that it had gone by so quickly, as if it were one long day. “For the last five years, I have lived out of time almost entirely. . . . Strangely enough, I’ve come to see my disjunction with the traditional concept of time as liberating and vital to what little writing I can do” (p. 140).

Paradoxically, the way to take control of time is to let it go altogether. . . . Solitude became a kind of chamber in which my separation from time and the world of measured change made sense. . . . Soon I learned to eat when I was hungry and sleep when I was tired. It is not that appetite changes in chronic illness, it is that being chronically ill provides an opportunity to become aware of appetite and how it works. (pp. 154-155)

Time turns out to be a truly inner phenomenon . . . time was in fact a measure of how I experienced my self moving through my life. I began to look at my illness in a new way: it had not taken time away from me, it had given time back to me. (p. 156)

Lengthy illness isolates people, turns them inward, makes them reconsider identity. . . . Illness not only gives them the context but eventually demands that they do such wondering. (p. 142)

Skloot (1996) noted the changes in his lifestyle, wardrobe, and appearance since becoming ill and that, by virtue of his losing his hard, lean body, “it seems like my armor is gone” (p. 151). After being a “lifelong city boy” (p. 152) he learned to live in the country and love it and to move, speak, and listen more slowly and consciously. “Now I conserve, I loiter, I move as in a dream. . . . But [out] of this necessity has come a whole new way of being in my life. . . . Something different and vital has emerged” (p. 152).

Skloot (1996) also came to appreciate classical music rather than fast music to sing along to, to pass the time, or as background noise to accompany him in his activities:

Sometimes music took me to the very center of my experience, to the conflicts I was feeling about all that had changed in my life, the vortex of emotions. But sometimes it took me outside myself altogether, into a realm of pure sound, where there could be peace. . . .

Without what music taught me I might not have known how to grasp that the score my body had followed for life was totally rewritten. . . . Music has taught me my being could still contain harmony, if I could only hear the whole thing through. (pp. 153-154)

Skloot began to appreciate touch as a powerful healing force in his life, and this feeling of connectedness to others was the beginning of rediscovering erotic love after he had believed that it would no longer be possible, due to his illness. “Of course, I could not miraculously function as though my central nervous system and immune system were normal again. But I found that Eros is a remarkably restorative force, life-affirming and optimistic” (p. 157).

Skloot (1996) explained that transformation was not just coping with but being able to “accept the opportunities illness brings us and do something with them” (p. 158). He commented that, although he had to stop doing many activities, new possibilities began to take shape in unexpected ways, such as appreciating paintings, nature, music, communicating with other people who were ill, eating more natural foods, and writing about his experience. “Finding the places within that illness cannot reach, and learning to honor them, can help transform the bed of thorns that is illness” (p. 159). It was also important to him to play baseball again in his own limited way, respecting his body’s limitations.

Marguerite Bouvard’s Narrative

In her book *Healing: A Life With Chronic Illness*, Marguerite Bouvard (2007) narrated how she had become ill in 1987, at age 50, with interstitial cystitis, an inflammation and deterioration of the bladder lining. She began experiencing nocturia and was tired during the day,

due to her interrupted sleep. Bouvard thought that it would pass, and, after her diagnosis, she continued to work as a political science researcher, while in a state of denial. She tried to negotiate with her employer and lessened her workload, but, even after a sabbatical, she was never able to return to her previous life. Bouvard explained that her story is of rebuilding her life from chronic illness and that she was “deeply involved in the grieving process with its phases of denial, disorganization, and acceptance” (p. 1).

Bouvard (2007, 2008) continued to experience intense bouts of spasms and pain. “I left the planet of so-called normal people, who take for granted the ability to go through the days without overwhelming fatigue, and entered a new world.” (Bouvard, 2008, p. 83). During her initial weeks of acute pain and sleeplessness, frustration and exhaustion were like new guests in her home. Like a willow tree, Bouvard bowed beneath the wind, her spirit both grazing the earth and touching the sky. The author observed her own emotions, allowing time for her demons to walk about freely.

After experiencing denial and numbness, Bouvard (2008) felt first grief and then disorganization. She realized that, for her, the loss of her health was similar to the loss of a loved one, and she felt lost in a fog of exhaustion, “as if behind a glass wall” (p. 84). After leading a busy, stimulating life, she was now at home, sleepy, and barely able to continue her professional writing. Bouvard acknowledged then that life is “different than it once was, but it’s a life” (p. 84). She continued on a physical and emotional roller coaster with very dark periods, but she was able to rise again.

Bouvard (2007) commented that, at the onset of her little-understood illness,

I felt disoriented, as if I were floundering. It seemed as if I were back at school trying to learn important subjects for survival without a teacher, or traveling in a new country without a map. In retrospect, while I was seemingly moving backward, I was actually taking leaps into the future. As I coped with the physical problems of my condition, I was

simultaneously taking the risk of redefining myself, a risk I might never have taken if [I] had remained healthy and continued rushing through my days without the opportunity for prolonged inner reflection. (p. 2)

Bouvard (2007, 2008) struggled to make a life for herself while dealing with a debilitating and unpredictable illness. She allowed her vulnerabilities to speak, just being and trusting that, after her letting go, renewal would follow. Bouvard (2008) commented that the “important part of healing is facing the tremendous anguish one endures during and after these bouts of acute symptoms” (p. 82).

Bouvard (2007, 2008) continually felt cycles of powerlessness and sadness that she felt she had to deal with in solitude. She sought excursions in nature, especially by the sea, to bring her back to calmness and strength, “for only in acknowledging and experiencing our own weakness can we become strong again” (Bouvard, 2008, p. 82). Bouvard (2008) also faced her own fears of death and further illness: “They are invisible, but very rich moments when all our forces are marshaled and, although suffering, we are intensely focused and alive” (p. 82).

After such periods, I turn to nature, to its calming pace, losing myself in a world that transcends our small egos and my own frailty. In society, my limitations often seem to relegate me to the margins; here I become part of the ocean’s vast expanses. (Bouvard, 2008, p. 84).

Bouvard (2008) commented that, as with others of life’s difficulties, “illness is an invitation to explore the inner spaces, the depths of ourselves and our possibilities” (p. 84). She discovered new meaning, especially during long periods that she spent alone. Battling her condition was “very demanding of the soul” (p. 84) and proved to be a tedious, never-ending job. At other times, through meditation, she felt a sense of spaciousness in which boundaries and limitations melted away.

Bouvard (2007, 2008) experienced a sense of gratitude and counted her blessings each day. Before her illness, she had noticed what was missing but after its onset focused more on

what was present, and, with this, came to see and cherish the world around her. “Now I have come to see the presence of the Creator shining in ordinary events of daily life” (Bouvard, 2008, p. 85). She stopped *doing* and suspended self-judgment: “I take the day as if I were a child again and let time flow around me like the surge of waves” (Bouvard, 2008, p. 86).

Along with living in the present, Bouvard’s (2007) “most effective medicine” (p. 2) was continuing to honor her interest of activism but expanding and revising it to accommodate her physical condition. This was a key for her to live hopefully and well, as she maintained a sense of wonder in everyday life and transformed her lifestyle.

Journaling was important to Bouvard (2008) in pouring out her inner storm and allowing her true self to unfold. In her time in nature, she was able to gain a deeper understanding of life in and around her and to regenerate herself. Bouvard became a quiet, invisible observer of herself and the world around her, walking around and taking in life with her entire being, forgetting about her own inner crisis and losing herself in the elements and people. She learned to savor life slowly, just *being* rather than focusing on accomplishments, and, with this, regained a sense of serenity.

When Bouvard (2008) felt herself being forced into a prison by her illness, she looked out at the ocean and saw herself “journeying within the boundless reaches of our common humanity and the inexhaustive spaces of the heart” (p. 87). At the end of her narrative, Bouvard (2007) came to the following conclusion about her own changes:

I see meaning in circumstances others might find frightening, see myself in the process of transformation, see a continuity beyond my own small episode on this earth. . . . If it often seemed as if I were walking in the dark, this search has nevertheless brought me to a profound realization of the divinity within me and around me, to a reality that is vast and invisible. I have found this insight to be the gift that comes from accepting the terms of our journey. (pp. 139-140)

Composite Story of 8 Narratives

The following narrative represents my attempt to construct one condensed story based on the common experiences reflected in the 8 authors' stories. Rather than simply list common themes, I believe that it was important to conserve the sequence of the narratives. I chose the name Marjorie as the protagonist of this composite story simply because it was the first woman's name that occurred to me (5 of the 8 authors are women), and I believe that the name is not important. Although I do not wish to exclude or discount the male authors' experiences, I felt that it would be more manageable and concrete to assign a sex to the composite protagonist.

Illness onset. Marjorie felt an initial shock of becoming ill at the age of 35. She began to feel sudden, debilitating symptoms that she had never felt before, and, with this, felt shock, confusion, fear, shame, and anger. Marjorie reacted with denial, as she did not fully accept that this could be a lasting illness, and she tried to continue her normal daily activities until this was no longer possible and eventually decided to seek medical attention.

With these new symptoms, Marjorie felt a dramatic change in her body, and this created great confusion and uncertainty. Her life was suddenly put on hold, as she felt strong symptoms and had to undergo an immediate treatment that despite its apparent urgency, did not provide much relief or resolution.

Confusion, uncertainty, and frustration. Marjorie felt confusion and uncertainty about what was going on with her body and how long this would last. It was difficult for her to understand this new and foreign experience of her own body and to express her understanding of it to others. Marjorie felt shame in not functioning as she normally had and was met with disbelief by some people in her life, especially by the medical community that was trying to diagnose and treat her. She observed her own sometimes obsessive tendency to monitor her own

physical changes in an attempt to understand what was happening in the face of something that was unknown and out of her control. Marjorie's symptoms were sometimes dismissed by medical professionals, and she often felt that she was not being listened to. She felt frustrated.

Shock of diagnosis. When Marjorie received a clear diagnosis, she learned that she has a serious illness that is incurable, rare and unpredictable, only partially treatable, and would most likely lead to continued deterioration of her body. She was shocked by this diagnosis and feared her possible future bleak circumstances that, according to her doctor's explanation, included becoming crippled or being limited to a wheelchair. Marjorie felt that her life had been rudely and abruptly pulled out from under her. She felt confusion, denial, and in a surreal haze over the information that her life would be changed forever. She felt that she no longer had a secure reality or ground to stand on. Marjorie reacted to her diagnosis with denial, shocked that she might become crippled, as if something had been taken from her. She was scared and angry, tried to control, blamed herself and others, and even rejected and disowned body parts that had changed.

Despite this bleak diagnosis, Marjorie also felt some relief in learning about what was going on with her body and having a name or a language to describe and talk about her condition. She felt a certain validation of her own experience upon receiving the diagnosis. Although this illness was not something she could equate with her own self-identity, she was aware that the way she now experienced her body definitely felt different from how it had before. Marjorie began to feel afraid of the possible future implications of having this illness.

Adaptation to illness chronicity. Marjorie responded to this emergency by reaching out to loved ones, researching information on her illness and its possible treatments, and adopting a healthier lifestyle in order to delay symptoms, despite conflicting information in that regard. She

wanted to get a glimpse of what might be awaiting her. In beginning to undergo this new treatment, Marjorie felt that she was entering unknown terrain and that, in a sense, she was submitting herself to the medical authority that was prescribing this treatment.

Marjorie chose to seek more information on her illness and other ways of promoting her well-being in more holistic ways, changing some aspects of her diet and lifestyle. She felt that obtaining more information gave her greater control over her life. During this time Marjorie also reached out to family and friends, and their support was important in getting through this emergency period, helping her to take care of many practical life issues while she eventually transitioned to a lifestyle change.

Fear of the future and gradual acceptance. Marjorie's visions and plans of her future life were now up in the air, and, to a certain extent, she felt that they had been shattered. She could no longer take for granted that she would be well in the future, and this sometimes created a great deal of fear and anxiety. Marjorie worried about one day becoming crippled, living with greater pain, losing vital mental and physical functions, and dying an early death. She was afraid, and she resented that her future had been unfairly cut short.

Marjorie was forced to accept that her health was declining and that her body was changing. She dealt with many odd new symptoms, enduring constant pain, confusion, frustration, and intense side effects from medications. Marjorie at times endured painful and uncomfortable medical procedures. She experienced a sense of helplessness and a kind of desperation in trying to get well by whatever means she could.

Marjorie began to more fully accept her own impending death and the uncertainty of life and her fears around these realities. By expressing her fears, she began to live more fully in the present and to surrender. By being aware of her own finite existence, Marjorie became more

motivated to live her life from the values that were most important to her. She learned to live with her fear of death, began to more fully accept this possibility, and focused on living in the here-and-now. Marjorie responded to her symptoms by listening to her body, waiting, resting, and honoring her limits. She accepted and surrendered to the unpredictable pain.

Helplessness before uncertainty and chronic symptoms; new lifestyle. Marjorie was disappointed at being told by doctors that she would get better soon and then finding that she did not, and sometimes experienced trauma when symptoms returned. She often experienced self-judgment and compared herself to others. Marjorie resisted using a wheelchair and other supportive technologies because she did not want to think of herself as a cripple or to give up hope of recovery. One of the most difficult aspects of her experience was living with the uncertainty of recurring, changing symptoms, which often included fatigue. She realized that her illness was neither something that would simply get better or go away nor something that she could control. She often felt helpless in this situation, and she had to let go of her sense of control and simply follow or adapt to what was happening in her body, often giving in to her need to rest and slow down.

Fatigue was a constant part of Marjorie's life, and it presented her with many everyday challenges. She moved very slowly and observed that simple everyday activities would tire her out for long periods—especially trips, sleepless nights, or any extraordinary efforts. Marjorie needed to take time to recover and rest and had to negotiate with her supervisors at her job until she eventually needed to let it go and find work that was more suitable to her condition. Marjorie was saddened to have to leave a kind of normal life of work and activity.

It was difficult for Marjorie to accept the uncertainty and unreliability of her symptoms. Her body had changed, but part of her difficulty with accepting this change was that her

symptoms were inconsistent. Marjorie was constantly adjusting and dealing with physical changes or continuous cycles of relapses and improvements. She began to simply live each day as it came and realized that each moment is a gift.

Obsession with a cure. Marjorie felt a kind of desperation in reaching toward the possibility of curing her own physical symptoms and sought and experimented with a wide variety of treatments (both allopathic and alternative) and diet and lifestyle changes beyond the original medical treatment she had been given. She quickly became aware of the many potential levels and aspects of well-being that these treatments offered beyond enjoying a functioning body.

Losses. Marjorie attempted to continue her previous lifestyle and activities, and, when she could not, either because she was not physically able to or because she had to undergo her treatments, she felt sad and frustrated, and she often judged herself and compared herself to others. She felt that she had lost part of herself and her life and was forced to be in a *no space* or *no time* while other people continued to live their normal lives. Marjorie began to lose activities and roles that were related to her own personal identity and that largely seemed to make her who she was. She became saddened at these losses and mourned them.

It was often difficult for Marjorie to accept her body as she was, and she felt saddened by her new appearance and loss of physical abilities. Marjorie felt that she had lost who she was, as if she had lost her own sense of identity. She especially lamented the loss of her physical activities, such as sports. She began to painfully accept these losses without knowing whether she would ever regain them. Marjorie realized that she could deal with these losses only by allowing herself to feel the pain and to grieve over them rather than by trying to avoid

acknowledging them. Marjorie slowly began to let go of blame and judgment and to lovingly accept herself as she is, despite her limitations

In addition to dramatic physical symptoms, Marjorie also experienced mental limitations or lapses. Her normally reliable mind would, sometimes rather abruptly, stop functioning. Marjorie would sometimes forget ordinary things or names, not be able to think or talk, or lose consciousness. Some of these instances were frightening to her, because she felt a sense of helplessness in abruptly losing vital functions that she associated with her own sense of self, and this also made it difficult for her to work. Marjorie tried to conceal these limitations, but she eventually accepted them without judgment and had to make the necessary provisions and precautions in living with them. She began to feel an intense sadness at these debilitating symptoms that were out of her control. She could no longer simply try to continue her life as usual and needed to deal with her own intense emotions surrounding this dramatic change in her life. Only after Marjorie accepted her physical changes did she begin to look for ways to deal with her condition. This cycle of acceptance and adjustment would recur many times throughout her illness experience.

Body consciousness. At the same time, Marjorie became much more aware of her body in observing and attending to her physical sensations instead of living in distractions or absent-mindedly willing the body to achieve her plans or goals. She learned to simply be in the body and become more present, becoming aware of physical changes in the body in a way that she had never paid attention to or had never before come to appreciate.

Greater awareness of the (natural) world around her. Marjorie learned to slow down, and, with this slowing came self-awareness, along with a greater awareness of her external world, especially the natural world. She began to find connections with natural places and

beings, and these moments of contact and observation helped her to feel more serene, hopeful, humble, and connected with the world. Marjorie learned to be in and observe the natural world, and this allowed her to observe herself with greater detachment and serenity. She felt as if she was living on the same ride with the rest of the world, and this gave her a greater sense of calm and trust. She began to feel that there was meaning in her journey, even if it was often difficult.

Emotional self-awareness. Marjorie became painfully aware of how her own mindset, lifestyle, and life-long emotional issues have, indeed, been obstacles to her own physical health and that she must work on changing these, if she was going to begin to heal herself. Her body could no longer afford negative thoughts and emotions. She realized that these emotional issues were also influential in the onset of her illness, along with other physical, environmental, and hereditary factors that she would never completely identify or understand. Marjorie became more conscious of the unhealthy aspects of herself and her life, perhaps present since early childhood, beyond the physical problems of her body. She felt motivated to more fully examine her own unhealthy emotional aspects and to deal with them toward her own deeper healing, even if she could not be physically well again.

Pursuit of emotional/spiritual healing. Marjorie pursued this emotional healing in a variety of ways through seeking the guidance of a person (teacher, spiritual guide, or psychotherapist) and by exploring spiritual practices both alone and in a group (such as breathing exercises, meditation, yoga, journaling, prayer, walking, reading spiritual texts, and simply spending quiet time alone). She eventually adopted a kind of modest personal spiritual practice of things that were most meaningful to her, and these would change over time. Many times her most important spiritual practice would be simply doing nothing, in the interests of listening to and attending to her body.

Marjorie became more aware of her finite life and began to reevaluate her own values and actions, attaining in that reevaluation the motivation to live more from love and her passions. She wanted to focus on things that were meaningful and important and wanted to make a difference in the world. Marjorie felt motivated to give the best of herself to her relationships and to the world.

Letting go of preoccupation with her illness onset. Marjorie sometimes found herself dwelling on how and why she became ill. On one hand, it was important for her healing to understand the unresolved emotions and lifestyle issues that may have contributed to her illness onset. However, on the other hand, this illness onset, which also came about from factors that were outside her control, remained an unresolved trauma that she continually dealt with. It was a continuous challenge for her to simply accept the reality of her situation and to live in the moment with gratitude. Marjorie was more at peace with herself when she finally let go of any blame of herself or others for her illness.

Seeking support from others. Marjorie began to reach out to others for support, especially her friends and immediate family. She was grateful for this immediate support when she first experienced symptoms, but, as her symptoms became more constant, Marjorie disliked the idea of being dependent upon others. She tried to continue to be independent and sometimes went to great lengths to conceal her change from others, especially her coworkers. Marjorie eventually realized that she must begin to ask for and receive support from others as a daily part of her life. It was difficult for her to accept that she sometimes needed help, especially during moments of emergencies or flare-ups. She began to realize that she is interdependent with others. Marjorie also realized that she enjoyed strengthening her social relations with others beyond what they had been prior to her illness experience.

Letting go of an obsession with a cure. Marjorie focused her intentions on getting well, yet, paradoxically, realized that becoming obsessed with physical healing would often create more stress and exacerbate her health. She eventually let go of this strong desire and decided to accept whatever might occur with a kind of detachment, acceptance, and gratitude.

Appreciation of her own journey. At times Marjorie felt an angry sense of self-entitlement, as if the world somehow owed her, and she sometimes felt envious of healthy people who had full use of their bodies. Part of her wanted others to be aware of her pain and loss in the prime of her life, and what she felt was unfairness in being burdened with physical difficulties that other people her age did not seem to be facing, when she felt she should be enjoying an exciting career and social life, finding a partner, and making her way through her life. Through prolonged periods of solitude, this angry sense of entitlement eventually subsided in favor of a quiet, humble acceptance and personal pride in knowing that she had endured her greatest life challenge and survived. All of her other life accomplishments paled in comparison to this invisible sense of growth that she knew she was experiencing. Perhaps most people would never understand what she had endured, but her own awareness of her journey was enough for her.

Marjorie continually dealt with economic worries, especially during periods in which she could not work and in which she was faced with extensive medical bills. It was a challenge for her to find ways to resolve this situation, and economic support from family and friends was often essential. In general, Marjorie became more adept at making decisions about her well-being in ways that she had never done before. She felt more empowered and responsible in facing her economic fears, and a key for her in doing this was learning to trust that all would be well and being thankful for what she had. Marjorie embraced new activities and ways of being

and this gave rise to a new sense of identity, including new joys and attention to talents or interests that she had not been previously aware of.

Learning to simply be. By simply experiencing her physical symptoms, Marjorie lived more fully in the present rather than in relentless plans and activities. One of the most difficult things about living with an illness was that she no longer had the energy to feel powerful and fast in her body. Marjorie realized that, before, when she could remain active and busy, it had given her a sense of strength, control, and capacity in moving through life but that now she was conscious that her body was beyond her control. With these sometimes overwhelming symptoms, Marjorie entered a kind of quiet solitude from which she could not easily escape. She eventually began to settle into this quietness and simply *be*, for what seemed like the first time.

Marjorie's solitude allowed her valuable time for reflection, observation, and creativity. In these solitary moments of intense pain, she felt at the edge of life, marshaling all of her forces to stay alive, and, with this, felt intensely alive and somehow accompanied. Marjorie found herself breaking many of her own unconscious habits and personal rules about how she was to be in the world, and she realized that this breaking was important for taking care of her body and finding greater freedom in her way of being. In tapping into her own inner strength to survive in the midst of this solitude, Marjorie found herself revisiting some of her early childhood interests, hobbies, and cultural and/or family heritage and spiritual traditions related to her place of origin. This helped her to feel a sense of support, calling upon them for help, happiness, and strength to deal with her physical challenges while also discovering new meaning of these sacred aspects of her early life in her historical present.

With this loss of previous activities and sense of identity, Marjorie also began to discover new, quieter activities. She came to value stillness, and, with this, more calming or less active

activities that she had not previously pursued, such as music and observation of nature. Her identity was expanding, and she realized that she was more than who she had *thought* she was. Marjorie became conscious that she was a being or spirit beyond her own physical body, and this realization gave her a sense of comfort, meaning, and hope.

Marjorie came to value her own inner strength and an inner voice or intuition in guiding her toward greater healing. She knew that surviving and living with this illness was one of the greatest personal accomplishments of her life and that it was now an important part of her identity. Marjorie was aware of her own battle scars and looked upon them no longer with either shame or arrogance but with a quiet pride in knowing that these experiences had allowed her to grow and become who she is.

Recognition of unresolved needs. Marjorie learned to listen to her own symptoms, to begin to understand her own unacknowledged needs that seemed to be speaking through her illness, and to take care of herself in a more integral way. She became aware of her own unconscious self-destruction and its impact on her body. Marjorie was conscious that healing is an internal state of joy, hope, and gratitude that cannot be provided by an external remedy. Despite continued symptoms, Marjorie did witness some degree of her own physical and inner healing when she addressed these unresolved needs.

Appreciation of beauty in and around her. Marjorie became more appreciative of the beauty in the people and the beings in the world around her. She learned to be more present to all things in her life.

Deeper self-appreciation. Marjorie found a way to honor and live her own passions and joys, albeit in modified ways, despite her physical challenges, and this was a powerful way for her to find meaning, hope, and renewed vigor. She came to value herself for her own unique

inner beauty and gifts beyond her physical condition and realized that who she truly is cannot be diminished by illness and that, on the contrary, by stripping away the more transitory roles and characteristics that she had associated with her identity, she was able to perceive or witness the more vital aspects of her being.

Importance of partnership. Although Marjorie spent much of her journey with illness as a single adult, partnership was also very important to her in providing emotional and physical support. It was valuable for her to live part of this journey alone, experiencing solitude yet feeling a connectedness with the world around, before establishing a partnership. Because Marjorie lived long periods of intense pain and discomfort, fatigue, new symptoms and side effects from medication, and the malfunctioning of several body parts and organs, she had come to believe that erotic love could no longer be possible, at least not in the way she had experienced it before. Finding a partner was difficult, since she was not able to go out much and participate in social spaces to meet new people. Thus, establishing a loving connection with a partner (and when possible, experiencing an erotic connection) was important for Marjorie not only to feel loved and supported, but to reconnect with her own sense of vitality and desirability after she thought that it had been lost. Physical touch was an important part of her emotional healing and in feeling intimately connected to another being.

Integral self-care. Marjorie developed a greater sense of responsibility for her health and saw herself more as a proactive manager of her own health rather than as a patient. She took on a more active role in pursuing a variety of allopathic and alternative healing therapies in order to contribute to her physical, spiritual, and psychological well-being. Marjorie often faced the difficult dilemma of deciding which therapies to use at any given moment but became more attuned to intuiting what she needed and observing that these needs constantly changed. She

developed much greater knowledge of her body and of physical health in general. Marjorie felt a greater sense of personal power and became more conscious that power and healing come from within and can be sustained through her own intention. Taking care of herself became an integral part of her everyday life as a vital part of the way she lives her love for herself and the world, which, in the end, are one in the same. Although she once considered her own healing or self-care as a kind of distraction from her important everyday tasks, she now considers it her spiritual practice and a vital part of her mission in the world. When she became ill, part of Marjorie felt that her life was ending, but finally she could see that her true work was now beginning.

Marjorie decided to act with greater self-compassion and self-love. She learned to set limits and to conserve energy, giving herself permission to not do activities that were now too difficult and instead to spend time pursuing things that she was passionate about or that provided her great joy. In the end, she realized that joy and laughter were vital to her physical and overall well-being and were just as important to her as her medical treatment. Humor helped her to live in the moment and to see her situation from a wider perspective.

Greater emotional self-awareness. In general, Marjorie felt a greater calmness and serenity. She still experienced strong emotions in her everyday life, but the difference now was that she was able to more calmly witness and accept them with self-compassion and find healthy ways of expressing herself. Marjorie became aware of how her emotions can impact her physical health, and she became much more adept at transforming these into more positive intentions of love for herself and the world. Marjorie has by now also been able to more fully understand how her emotions are related to the life-long issues of her own personality, and she is conscious that emotional work is part of a never-ending process of healing and growth.

Compassion toward others. In general, with Marjorie's illness experience, she became more compassionate toward the suffering of others. She became more empathetic, less judgmental, and conscious that other people are suffering in their own ways and dealing with their own inner issues. When she had the simple opportunities to engage in service to others, it was rewarding to her. Marjorie experienced a meaningful connection with other people who live with the same chronic illness or other illnesses, and this became an important source of community and mutual support. She became aware of how her experience with illness allowed her to make contributions to this community either through writing or in direct contact with others.

Pragmatic use of technology. Although Marjorie resisted the use of a cane and a wheelchair because she did not want to see herself as a handicapped person, she eventually overcame her resistances and began to pragmatically use the latest technology and medication available to her in order to function in her daily life, these amenities allowing her to conserve energy, live more comfortably and independently, and dedicate her energy to meaningful activities. She reminded herself that using this technology did not mean that she would lose who she is.

Acceptance of impermanence/death. By witnessing the changing nature of her own body that was beyond her own control, Marjorie began to accept the impermanence of her physical body and find sacred meaning by living in the present. Paradoxically, Marjorie focused on her own positive intentions for the future, and yet, at the same time, began letting them go in accepting that they might never come to pass. Marjorie discovered a sense of freedom in knowing that she will one day lose everything. She became aware that we are all moving toward something, without control, and this realization helped her to live more in the moment. She

began to realize that, with this movement, we will never really lose, because we cannot lose our being, despite losing our bodies.

Sense of gratitude. Marjorie felt a sense of profound gratitude for all of the beings in her life and for all of her experiences, including the difficult ones. She developed a greater sense of trust and openness and an acceptance of the future. Marjorie would continually return to this sense of gratitude and trust when facing difficult times. She discovered the value of prayer, not only in reaffirming and focusing her intentions, but also in attempting to listen to and understand the answers that she received from the universe, even if the response was not what she had asked for. Marjorie realized that both joy and pain come from the universe and are gifts or parts of the natural order of the world.

Sense of interconnection. Marjorie felt a greater connection to all life and to the universe in general as part of a universal journey. She realized that, despite further physical deterioration and even death, she will never lose this connection with being or life, because it is ever-present and dwells within and around her.

New lifestyle based on strengths and passions. Marjorie eventually adopted a lifestyle based on her strengths, gifts, passions, and wisdom and saw herself more in terms of these positive aspects. She found a way to make a living and make an important contribution to the world, not in spite of her illness, but rather by integrating this aspect of herself.

Resonance Panel

After completing the composite story, I sent it to representatives of my target audience, people who live with chronic illness, in order to verify their level of sympathetic resonance with the findings of the narratives. I found people through informal contacts. Similarly to my recruitment process with the authors whose narratives I read during this study, I sought people

who fulfilled the following two criteria: (a) persons who have been living with a chronic physical illness for at least the previous 7 years, an illness which they consider has strongly impacted several aspects of their lives; and (b) persons who believe that they have been significantly transformed through their illness experience.

I asked the three resonance panel members to answer multiple choice and open-ended questions about (a) the degree to which the findings resonated with their own experience, (b) which specific aspects resonated with or contradicted their experience, and (c) their personal experience of reading these findings in terms of their own shifts or emotional responses (see Appendix A). The resonance panel members sent me their responses via e-mail communication.

According to Anderson and Braud (2011),

the aim of the analysis and presentation of resonance results is, of course, to indicate if and how the various resonators responded to various aspects of the original study's descriptive findings. These resonance results can be summarized and presented either quantitatively or qualitatively or in both forms, and they can be presented in both overall and individual formats. The researcher could indicate degrees of resonance to various study findings—either quantitatively (by summarizing Likert-scale outcomes) or qualitatively (by indicating whether all, most, many, some, few, or no members resonated to which original study findings). . . .

Different panel members would be expected to feel differently about different aspects of the original findings. The researcher would report indications of both central tendencies and variability of resonance results. (p. 301)

I do not know the name of the illness that the first resonance panel member suffered from. The first person resonated strongly with the composite story, especially with the following aspects: shock, anger, and self-blame at the initial diagnosis; confusion and uncertainty about treatments; shame and self-comparisons with others; experience of the body feeling different or changed; searching for healing information and entering new terrain in trying several alternative therapies; denial of one's condition, as it took 2 years for her to accept the chronicity of her illness; self-judgment and trying to pass herself off as a healthy person; living a constant cycle of

acceptance and adjustment; confrontation with her life-long emotional issues and consciousness that she needed to heal in order to become truly whole; spiritual practice and development (rooted in the natural world) becoming the ultimate vehicles for her healing; importance of living more in the present (with joy and laughter); body awareness in order to become cognizant of unhealthy patterns and make changes; becoming more communicative about her needs; challenge of finding work more suitable to her physical condition; a sense of solitude and being outside her previous social life; an expanded sense of self, especially when in nature; greater knowledge about her own body, and intuiting from within rather than depending on external views from doctors; sense of greater inner strength; beginning to address her unresolved needs since prior to becoming ill; healing as an internal state of hope, joy, and gratitude; becoming more appreciative of beauty in herself and around her; greater compassion for others; attributing her survival to grace and feeling a sense of gratitude and trust; transcending self-judgment; a greater sense of connection to life; and adopting a new life based on passions, strengths, and personal wisdom. She did not resonate with the loss of mental and physical functions and the grief over these, economic worries due to illness, the use of supportive technology or support groups, and worry about the potential terminal nature of her illness.

The 2nd resonance panel member suffered from a chronic environmental contamination illness. The 2nd person also resonated strongly with the findings (despite significant differences in the events of her own illness story), especially with the following aspects: initial shock of becoming ill and attempting to continue her normal daily life; confusion and uncertainty about her unpredictable, dramatic physical changes; search for information and the sense of entering unknown terrain; support from others during emergency period and then a more stable period; loss of vital aspects of self and a sense of no time; importance of accepting her body and then

adjusting; awareness of multiple levels of health; dealing with her own emotions in response to her debilitating symptoms; awareness of her own unhealthy life-long emotional issues and confronting these; greater self-understanding; adopting a personal spiritual practice; a sense of peace and healing through experiences in the natural world; difficulty in accepting her need for help; fatigue and a need to adjust her career; challenge of surrendering and dealing with uncertain symptoms; setting limits and conserving energy; loss of vital functions and sense of self; expressing fears and anxiety about her uncertain future and this helping to open her to her own intuition and gifts in the present; greater sense of empowerment, responsibility, and presence; embracing quieter activities and an expanded sense of self; listening to the body and focusing on healing without becoming obsessive; greater knowledge of her body and of healing; valuing her own inner strength and intuition; addressing unresolved needs since prior to becoming ill; becoming more appreciative of beauty; honoring her own unique gifts and passions; reconnecting with her desirability; and compassion toward others and meaningful connections. In general she experienced intuition and growth in transpersonal awareness. She did not resonate with denial of her condition, self-comparisons with others, shame and self-blame, a sense of helplessness, and economic worries. She never believed that her condition was incurable and always felt that she could change her condition through her own mindset.

The 3rd resonance panel member suffered from epilepsy; she also felt great resonance with the composite story. She especially resonated with the following aspects: initial shock of becoming ill after being in optimal health, including disbelief, sadness, and fear; denial that this condition could become a lasting illness, as it took more than 1 year to accept it; questioning of why it was happening; strong uncertainty and fear of future attacks; shame and attempt to hide her illness from others; anger and sadness; continuous cycles of acceptance and adjustment; her

fear lessened with she accepted her illness, expressed her emotions, and talked with others who suffer the same illness; despite acceptance, a strong desire for the illness to be gone; a sense of helplessness with symptoms outside her control and difficulty expressing this to others; bodily awareness and learning how to prevent future attacks; awareness of her own life-long emotional difficulties and an attempt to make changes; spiritual practice and nourishment, especially through time in nature, writing, dancing, and time with friends; returning to what helps her to feel balance; importance of positive thoughts; confronting economic worries; challenge of dealing with loss of mental functions; importance of prayer and paying attention to her own emotions; the idea of health as an internal state of joy, hope, and gratitude. She did not resonate with the struggle of asking for support from others and accepting the losses associated with physical changes, since her illness is primarily neurological.

With the results of this resonance panel, I concluded that the sequence of issues that I described in the composite story, based on the 8 illness narratives, would produce a high level of sympathetic resonance among people who have lived with chronic illness. All 3 resonance panel participants also commented that reading this narrative was meaningful to them and helped them to become more aware of their own process with chronic illness.

Chapter 7: Cycle 4

According to Rosemarie Anderson (2011), the creator of intuitive inquiry,

In Cycle 4, the intuitive inquirer refines and transforms the preliminary interpretive lenses developed in Cycle 2 in light of his engagement with the data gathered in Cycle 3. Cycle 2 lenses are modified, removed, rewritten, expanded, etc. –reflecting the researcher’s more developed and nuanced understanding of the topic at the conclusion of the study. (p.53)

Cycle 4 Procedures

Throughout the year and a half that I spent exploring the new Cycle 3 data, the autobiographical narratives, I became aware that my understanding of the process of psychospiritual transformation through chronic illness was growing and expanding. I felt that I had a much fuller and more detailed idea about this process, while, at the same time, my consciousness about my own process also expanded. The order of the experience of transformation and the interrelationship between these moments became clearer to me.

After completing Cycle 3, I slowly reread my Cycle 2 lenses, allowing myself to circle interesting words and write notes to myself. I quickly realized that many of my original ideas were underdeveloped. I was not necessarily in disagreement with the lenses, but they had not been fully explained. Moreover, the ideas in these lenses were not clearly separated by topics or moments, as they seemed to be jumbled together without a clear understanding of the process. The process that I had mapped out still seemed dense and out of focus, as if the camera lens could not clearly show what was happening. With some lenses I simply felt that the order was wrong. I could see how much of what I had written was based more on my own experience and I had not fully explained the experiential process over time. In many of the lenses I also sensed that I was rigidly stating what happens rather than qualifying my ideas of what may be happening and the process of how it unfolds.

As I read through the Cycle 2 lenses, I found myself jotting down notes about the major moments within the process and giving names or titles to these such as *shock of diagnosis*, *losses*, *change to a healthier lifestyle*, or *surrendering into the experience*. I wrote several pages of notes about the process as I was attempting to depict the shape of the story, much as would a sculptor. Throughout Cycle 4 I often felt like a sculptor, sometimes trying to solidify an invisible movement for which there is no visual reference. Although I had tried to sculpt this process in Cycle 2, I was now finding these ideas to be more like an unfinished lump of clay jumbled together without a clear enough form.

I then proceeded to read my Cycle 3 composite story and write notes to myself about this data. I found that nearly all of this much more detailed story was relevant to the lenses and I wanted to incorporate these ideas into my Cycle 4 lenses to add much needed vividness and shape to my vision of the process of psychospiritual transformation through chronic illness. Again, I wrote down extensive notes and I became conscious of this long, dense story. I still wanted to sculpt or paint a picture of the distinctive moments of the process. Now the moments seemed to be stepping forth in a way in which they had not been clarified in Cycle 3.

I also reread my literature review of the topic. This revisit was very inspiring to me, because more than 5 years had passed since I had read many of these sources. My original literature review, which I had done during 2007, represented my first in-depth intellectual and academic exploration of the topic of psychospiritual transformation through chronic illness, and this acquired knowledge gave me a wider point of reference beyond my personal experience. Since then I had put the literature review aside, and I had lived a much more intense, debilitating, and solitary experience with chronic illness and had read and analyzed detailed autobiographies

on the topic. I was now approaching my literature review from a very different place in my life and with a much wider perspective.

As I began to read through my literature review, I felt that my new notes, my Cycle 2 lenses, and the Cycle 3 composite story were now becoming overly extensive. I felt that it was time to begin to write out a new set of Cycle 4 lenses rather than to incorporate my new notes into the original Cycle 2 lenses. I needed to map out what I now believed the process of psychospiritual transformation through chronic illness was like. I did this fairly quickly, as the ideas were very present to me, and I wanted to get them down. I asked myself “What are the key moments of the process?” At this point I put aside all notes and simply wrote about my understanding of this experience. Over the next several weeks, I flushed them out, adding detailed explanations and adding moments that were missing. I then went back to my notes on the Cycle 2 lenses, my Cycle 3 composite story, and the literature review and incorporated missing pieces or bits of wisdom from these sources, making sure that I had not left out important ideas. I felt that I could now graphically and soundly tell this story.

At other times during this process, I often set aside the Cycle 3 composite story and the literature and opted to simply try to feel in my body what this process of psychospiritual transformation is like, allowing myself to visualize, feel, or call to mind the major moments of this journey from my personal experience and readings. At many times during my daily life, ideas occurred to me, and I wrote them down. I also incorporated ideas from my dreams.

During this time I also felt an even stronger desire to listen to songs and watch films that somehow related to this experience of going through a challenge, hardship, or life-changing experience and emerging forever changed and with a sense of presence, gratitude, wonder, and trust. Rather than acting as distractions, these explorations helped me to stay in touch with my

experience and ideas and to better express them while feeling as if in the company of others who are going through something similar. My yoga practice also helped me to stay more focused in my body and to maintain greater concentration.

Cycle 4 Lenses

In this section I will outline the process of psychospiritual transformation through chronic illness as I now conceive it. I do this through a series of paragraphs, each of which has a title that describes its main idea. This process is cyclical, and one may encounter many of these moments repeatedly in different ways throughout one's illness experience. Although I attempted to put these moments in a general sequence, many of these are often occurring simultaneously, sometimes as if they are parallel areas of development. Some people may experience some of these moments in a different order, depending on many individual factors.

I divided this process into four main moments: (a) an unwilling beginning to this journey, (b) leaning into the experience/consciously taking this journey, (c) expanded sense of self and new lifestyle, and (d) the return arc/integration. I have found that psychospiritual transformation through chronic illness is both a process and a result; thus, some aspects of the third and fourth moments refer to characteristics of this changed state.

Moment 1: An Unwilling Beginning to This Journey

Initial crisis. One begins to feel sick, and this could be gradual or rather sudden. One experiences symptoms that one had never felt before. The symptoms build, and one realizes that this is a major physical crisis, because something is not right. One experiences intense pain and discomfort, confusion, and surprise. One focuses one's energy on immediate physical survival. One reacts with denial and feels that one's life has been interrupted. One suddenly feels vulnerable.

Diagnosis. One receives initial medical attention and, eventually, a clear diagnosis, which may occur a significant period of time after experiencing symptoms. Until the time of diagnosis, one experiences a great deal of confusion about what is happening with one's body. One feels shock at the news of illness, and it is a blow to one's self-image and future expectations. One wishes to know what will happen in the future, and a previous sense of security has been shattered. Feeling ill was already a shock itself, but, with the news of this illness and all of its implications, one feels even more vulnerable and as if something has been taken away. One tries to deny it, and the news of this illness does not sink in immediately although one may feel an internal clarity in knowing that this diagnosis is true. One may feel disbelief, outrage, anxiety, and/or numbness, or simply be overwhelmed. The news of the diagnosis may be a blow to one's identity, as being a person with this illness has not yet become incorporated into one's sense of self. To some degree, one also feels relief in having a name for this condition, feels that one has gained a greater understanding of what is happening in the body, and even feels a kind of validation of one's experience, especially if one felt discredited by others.

Initial emergency period. One receives medical (and/or alternative) attention and attends to one's physical survival during this initial emergency. It may take a while to receive effective treatment. During this initial crisis one seeks information on what is happening and on what to do, and loved ones may offer support. One wishes to know what may happen in the future. One may feel some physical improvement, or at least greater stability, especially in knowing what the treatment and lifestyle changes consist of and to what degree they may help. One adopts a more practical approach, at this time, of going through the minimal actions and adjustments to take care of one's self without necessarily comprehending or accepting the

chronic nature of illness. Confusion may persist, despite some initial answers, as the diagnosis and treatment may create more uncertainty about the future.

Attempted return. After this initial crisis, one attempts to return to one's "normal" previous life, despite the persistence of acute symptoms, pain, or fatigue. But one cannot continue as before because one's body is different. One may spend a significant period of time trying to continue one's previous lifestyle and may take careful measures to conceal one's illness to others, especially to one's peers, in attempting to "pass" as a "healthy" person. Symptoms are recurring and one feels confusion about how to continue. In one's attempted return it may take a while for one to recognize this reality. One may feel shame, guilt, or simply *less* than others or less than one's *previous self* and this physical change may be painful to recognize. One must adjust to this change and the treatment itself may be causing intense physical symptoms. One begins to realize that this condition is not going away and that one's body has changed profoundly in ways that one still does not understand. One feels anger in having to adapt to this new condition.

Search for an escape. Albeit with resistance, one begins to make minimal lifestyle changes, seek more information and alternative treatments, and perhaps even ask for help from others, in an attempt to restore one's health and avoid future decline. One tends to consider the illness and the body as something separate from the self and an entity that one must manage or control. One seeks to escape from this situation and may begin a desperate search to restore one's health but may often return to one's previous habits, diet, or lifestyle. One may at times develop an obsession with becoming cured of illness, believing that one can beat it.

Losses/disintegration. One is confronted with losses of physical and mental functions and abilities, or even changes in one's appearance, and these can lead to other losses in terms of

activities, roles, or status. With this loss of energy and physical vitality in the body, one loses a sense of power and control in one's life, and one feels more vulnerable. One feels that one is losing vital aspects of who one is or was, and, at times, this can feel devastating. One continually faces self-judgment and comparisons with others or with one's previous sense of self. One may even begin to reject body parts or physical aspects of the self that one now deems undesirable. These changes can also trigger changes in roles and relationships, and this may mark the beginning of a process of adjustment for all. One experiences confusion and fear of what is happening in the body and an uncertainty about one's future. One does not know to what extent these losses can be recovered and may deny the gravity and/or permanence of one's condition. One may resist using medication or technology that creates lifestyle changes or present visual reminders to others or to one's self of one's changes.

Moment 2: Leaning into the experience /consciously taking this journey

Slowing down/inward focus. Out of necessity, one begins to spend much time alone in dealing with this bewildering physical ordeal, or, if one is not physically alone, one begins to focus one's attention more inwardly on the body rather than on one's usual activities and interests. One begins to stop constant mental activity and slow down, in a sense giving in and paying attention to the body despite one's wishes, experiencing these difficult physical sensations from moment to moment and observing one's body much more closely. One becomes aware that one's body is different now, and the pace of one's life seems to slow down. The physical becomes the forefront of one's consciousness in a way that it never has before. At times one feels that one is marshaling all of one's strength and will to simply survive, and one finds one's self doing things and going through physical challenges that one had never before

imagined. One feels outside of one's normal life, including activities and roles, and even outside of one's normal sense of time.

Isolation /no self. Although one may have received ample support and attention from loved ones during the initial emergency period, now that one has begun the everyday experience of living with chronic illness, it may be awkward for others to ascertain how to help and one may find it difficult to ask for help for things that one had previously done independently. One's illness experience brings one's attention inward, and the physical experience may become so absorbing that one may find it difficult to break through this loneliness and to connect with others. With this profound physical change, one now experiences a change in the way one experiences the body, one's daily routines, one's sense of time, and the way that one relates to others. One may find that one does not have the mental framework and language to understand and express this experience even to one's self. One feels a kind of *no self*, or the letting go of a previous self while living in a *no time*.

Mourning losses. One becomes conscious of the sense of loss one feels in losing vital aspects of one's health (for example, the loss of having more energy and being pain-free), physical (and perhaps mental) capacities, and perhaps aspects of one's sexuality and/or appearance and any social roles or status that involved these. One feels that one has lost a simpler, more care-free existence, as now one's life is now filled with self-care tasks and worries about one's health. One feels sadness at these losses of important aspects of one's life, and, now that one lives this forced inward attention to the body, one feels that one is without the everyday distractions to shield one from these sometimes overwhelming feelings. One feels a deep sadness or emptiness at these losses, and depression may set in. One may feel anger at these losses but have confusion about the direction of this anger. One eventually realizes that one can deal with

these losses only by allowing one's self to feel the pain and to grieve over these, rather than trying to avoid them.

Fear and helplessness. One may be seemingly waiting for something to happen or change, but the illness remains, albeit with cycles of improvements and relapses. Despite one's efforts, one becomes conscious that, to some degree, one is helpless and cannot control what is happening in one's body. One recognizes one's fears about what is happening in the body and about what may occur in the future, and this sense of helplessness may be difficult to grapple with. One may begin to pray, or attempt to connect with or call upon a higher power, to help one through this difficult time. One may begin to reconnect to key things from one's childhood or previous experiences that gave one a sense of comfort, connection, or support, including interests or hobbies, spiritual and/or family traditions, or connections with nature.

Confronting the shadow. In spending time alone, one becomes aware of one's own unhealthy emotional responses, lifelong inner conflicts, and habits that are making it more difficult for one to live with illness and to feel well emotionally, spiritually, and mentally. One realizes that one cannot afford these unhealthy ways of being, because they now have more dramatic effects on one's well-being. One may even feel a sense of self-blame or regret in realizing that one's own actions, emotional responses, or lifestyle may have contributed in some way to one's illness onset. Although one wishes to heal one's body and continues to follow the best available treatments for doing so, one also begins to set the intention of healing one's inner wounds and feeling more whole or at peace, even if one cannot heal one's physical symptoms. In feeling a sense of emptiness or loss, one feels a kind of home sickness, or a call to a deeper sense of connection with the self and of feeling more at home in the world. One begins to sit with or confront the unresolved darker aspects of one's self that one had previously avoided through

one's busy daily roles and activities. One may do this in a variety of ways, both alone and with others, and may seek support from classes, therapists, spiritual guides, books, contact with nature, or another meaningful practice. Change involves understanding the skeleton of one's ego structure or personality and the core wounds that this arose from and making a conscious effort to proactively change mindset, habits, and lifestyle.

Moment 3: New Sense of Health and Lifestyle

Creating a new lifestyle. Although one continues to mourn losses and be conscious of one's pain around this, one begins to accept that one must alter aspects of one's habits and lifestyle in order to survive and to assure one's future well-being. One often reacts with resistance and may be slow to make these changes, especially as they relate to the way one eats, enjoys life, spends time with others, works, and lives one's daily routine, but one begins to focus more on what one *can* and *must* do in living with illness in the present and begins to build one's lifestyle around this. One finds that one must detach from one's previous lifestyle in order to feel more at peace. Healthcare professionals may play a vital role in helping one to make these lifestyle changes and one may frequently seek further advice and treatments. One may find that discerning the most appropriate health advice and treatments is a complex and difficult ongoing process. It may be necessary to communicate with other people in one's life about these changes and to express emotions, expectations, and needs for support.

Expanded sense of self. In establishing this new lifestyle, one begins to focus attention on aspects of life that one had previously paid little attention to, including the body, nutrition, new activities or areas of attention, and one's own faculties and abilities that are more rooted in patience and observation. One discovers greater capacity for stillness and may develop greater appreciation for music, nature, reading, or other contemplative or expressive activities. Rather

than focusing on what one had previously done or who one was, one begins to slowly create a new life based on one's physical condition, becoming more open to new practices, habits, lifestyle, roles, areas of interest, and the surrounding world. One reassesses one's values, feeling more motivated to live one's life to the fullest from a place of love, making the most of one's time and energy. One organizes resources to solve practical problems and asks for support when necessary. One sets aside self-judgment, comparisons with others, and fears of losing one's identity and acts with less of an emotional response. One's sense of self expands as one becomes more aware that who one is expands beyond both the physical body and one's previous identity, roles, and image.

Self-observation, self-compassion, and connection with the world. One becomes more observant of one's self and of the world around one, especially of the natural world, and feels resonance and greater peace within it. By being in the natural world, one comes to feel greater tranquility, observing one's self, as all other beings in the world, with greater non-attachment and acceptance. One begins to identify more with being a being in the world and less with the ego identity one had constructed; one's identity transcends and encompasses it. One can observe one's own ego functions more transparently, with greater distance or non-attachment, and to begin to make decisions from a wider perspective rather than from the same familiar ego point of reference. One begins to more clearly see the trajectory of how one has led one's life up until this point and how one's illness onset has been part of this life process. One even begins to appreciate how pain or symptoms can sometimes be clues to allow one to move toward greater balance or integration. One becomes more open to and appreciative of one's dreams in guiding one to unconscious material, insights, and healing. One confronts any obsessions or addictions that have been limiting one. Any sense of self-blame or blame of others for one's illness condition slowly

evolves into acceptance, forgiveness, and appreciation. The trauma around becoming ill has now been calmed. One begins to live with greater self-observation, self-compassion, and a sense of comfort and connection with the world.

Self-worth. One comes to value one's self beyond one's physical abilities, appearance, roles, and, in general, one's ego capacities. One begins to let go of one's own stigmas and feelings of anger, guilt, or worthlessness due to one's illness and simply let it go and accept it as part of life. One values one's self for qualities and abilities that one had previously overlooked or underestimated, and does this simply and unconditionally, for the sole reason that one is a being. One begins to take the necessary time for rest and self-care and also for embracing things that allow one to feel greater joy and happiness, including hobbies, interests, activities, relationships, and one's sexuality. One creates a greater sense of balance in one's life with greater self-compassion and more reasonable self-expectations.

Unique spiritual practice. As one begins to develop a greater awareness of the body, one begins to feel that simply maintaining presence and caring for one's body and general well-being is in itself a form of spiritual practice. One develops a greater interest in and openness to spirituality in general, as one feels a deeper spiritual desire. One develops a greater sense of gratitude, awe, humbleness, and love, and holds intentions of goodness for the world. One begins to bring forth thought patterns and simple daily practices that cultivate and express these qualities. One may have developed these practices, even moments of non-doing, organically or from existing traditions, therapies, or physical practices. One's spiritual practice has now evolved beyond an externally directed practice from a specific tradition, as perhaps one may have practiced in previous moments, as one adopts a more unique, self-directed practice involving one's embodied experience. Mindful daily living itself becomes an important part of

one's spiritual practice. Spiritual practice involves nondoing, listening, openness, gratitude, and embodiment. One becomes aware that one's physical symptoms occasionally bring one into a nonordinary state of consciousness and, although these moments may be unintentional, one appreciates this shift in perspective and incorporates this learning into one's consciousness.

Becoming one's own proactive healer. While, at the beginning of one's illness experience, one relied on the authority of doctors or healing professionals for direction and treatment, with the embracing of this new condition as a new way of life, one becomes more proactive, responsible, and self-directed in regard to one's health. One seeks the resources, knowledge, people, and technology to contribute to one's well-being and does this in a more intuitive way. One is more in touch with one's deeper, integral healing needs and can make adjustments toward greater balance. One has become much more knowledgeable about one's body, one's illness, one's treatment, and healing in general. One considers healing to be limitless and open-ended and looks upon this mystery with interest, humility, and reverence. One becomes conscious of the importance of bringing forth positive intentions and cultivating self-love. One is more appreciative of and open to the wide variety of healing modalities and remains open to sources of healing in one's everyday life. Seeking healing information is an ongoing, never-ending process, and one goes through the sometimes complicated process of discerning the appropriate treatment for one's needs at a given time, sometimes together with health professionals. One is conscious that, in the healing process, one must be both active and passively open and that the process involves profound changes in one's way of being.

Healing wounds and relationships. One deals with one's key life-long emotional issues or wounds, and one feels a sense of healing in moving beyond a point of fixation or trauma. One begins to feel a greater sense of internal freedom and a capacity for a wider range of emotional

reactions to one's circumstances rather than one's habitual one-sided ego reactions. One takes the initiative to contribute to healthier relationships with an approach of love, acceptance, and communication.

Greater physical self-awareness and capacity for dealing with everyday difficulties.

Although daily life with recurring symptoms may sometimes be very difficult, one becomes more aware of one's physical cycles and the many everyday factors that can affect one's health and learns to take these into account, avoid them when possible, and more realistically set limitations and pick and choose one's activities. One can work with the emotions that tend to aggravate one's symptoms and one feels more capable of adapting to and dealing with the ups and downs of physical relapses. One is conscious that one has less freedom or leeway than do others in dealing with constant symptoms and creates a kind of personal strategy plan to deal with one's everyday activities. One becomes more realistic and accepting of what one can and cannot do and reacts to this more pragmatically with less emotional response or judgment. One often feels a conflict or tension between trying to proactively take actions to improve one's health and accepting the loss and grieving. One eventually becomes more comfortable with asking for and receiving support from others and creates a kind of support network, calling upon it especially in dealing with moments of acute symptoms. One has become more aware of one's inner strength in dealing with difficulties beyond illness.

Moment 4: Return arc/integration

Integration of opposites. Rather than identifying with one's previous ego construction or fixed way of being, one becomes more open to a wider range of one's own thoughts, emotions, desires, and interests and interprets these (and one's physical symptoms) as emerging aspects or parts of one's self that can help one to move toward greater wholeness or integration. One

develops the capacity to hold in one's consciousness seemingly contradictory ideas or forces, accepting these aspects as part of the self. One allows the underdeveloped or previously unacknowledged aspects of the self to emerge, such as the masculine/feminine, third or fourth Jungian (1928b/1983) functions (sensorial/intuitive, feeling/thinking), one's introverted/extroverted sides, and so forth, in moving beyond limited aspects of one's ego personality. In general, many of one's cognitive dichotomies, such as the concepts of healthy/sick, mind/body, I/my illness/my body, the illness/my body, I/others, past/present/future, life/death, and I/God, seem to disappear or break down.

Reconnection with the world. Although a chronically ill person must always focus a significant part of one's attention on self-care, one returns back into the world in a new way after a period of relative isolation or inwardness. This cycle continually repeats throughout one's illness experience. Although one is perhaps not doing the same previous activities or is not as visibly or outwardly active as before becoming ill, one returns to make connections with people and the surrounding world in the way that is appropriate for one, taking into account this physical condition. One finds a way to make unique contributions to the world *through* one's illness condition and not *in spite of* it, with an increased awareness of one's gifts, experience, talents, and interests. One has developed greater calmness and attention to areas such as music, art, or other creative interests and has embraced new possibilities of being. One finds a way to share with the world, even in very small, simple ways, one's growth from this illness experience. One's new way of being and lifestyle in many ways is not only beyond one's previous roles, but beyond cultural transcripts, and one is accepting of this. In continually surviving this ordeal, one becomes more aware of one's own inner strength and develops a kind of quiet pride in witnessing one's own personal growth. One feels more at ease with one's lifestyle and the ideas

of solitude versus being out in the world have now become less of a dichotomy and more of a dance along a fluid continuum.

Greater serenity and balance between acceptance and will. One lives with greater serenity or internal calmness in living with limitations and the uncertainty of relapses. When difficulties emerge, one has a greater capacity for finding tranquility, no matter how painful the physical sensations, while at the same time asserting one's will in taking care of one's self. Although one often wishes that these limitations did not exist and occasionally becomes saddened by them, one becomes more content to live within one's circumstances, and one witnesses one's wishes with greater detachment, letting go of one's obsession with being cured of illness. When one feels the need, one continually pulls back into solitary moments of self-care. One becomes conscious that living in a physical body always involves a degree of limitation and discomfort. One decides that it is healthier for one to focus on what *is* and what one can do within this condition rather than on possible scenarios.

Revisiting previously unresolved issues. Even as one becomes more at peace and more accepting of losses and one's current condition, one may find one's self focusing on unresolved personal issues or conflicts, unlived experiences, or unmastered skills that one has not satisfactorily lived in previous stages, perhaps because of one's illness condition. One may feel a sad sense of longing or as if something is incomplete or may even suddenly stumble over these issues and find one's self revisiting these aspects. One may become aware that, because of one's illness condition, one may have been forced to deal with losses, limitations, or worries in an accelerated way as compared with the time span usual for other people of one's age group and one may need to unexpectedly or continually confront these issues. One may become aware of one's own traumas or uneven aspects of development.

Living the ride with embodied attention and joy. On a physical level, one's life may not become easier, as illness sometimes goes into cycles of remission and flare-ups. Losses are constant, new fears emerge, and one may never feel satisfied with the way one's body feels as long as one lives with illness, but one tries to accept, do what one can, and enjoy what is, trying to let go of what one wishes might be or continually questioning *why*. One becomes more patient and develops a greater appreciation for stillness, especially while close to nature. Humor often plays a key role in living with and accepting one's daily circumstance and one finds greater joy in one's embodied experience. One consciously decides, on a continual basis, to be present to one's body rather than trying to escape from these sensations. One accepts that one's choices are more limited and one feels grateful and more resigned to this uncertainty within which we all live. One holds hopeful intentions but, at the same time, detaches from them, knowing that one's body could break down further at any moment. One is painfully aware that living with a chronic illness is like being on a ride that one cannot get off of but, to a certain degree, is a fact of the nature of the embodied experience. Part of one's daily attention is focused on the body and self-care, and, although one may occasionally find this frustrating, one accepts it as a fact of one's life and part of the human condition. Adjustment is a permanent part of one's life.

Compassion and service for others. With greater self-awareness, attention to physical suffering, and sensitivity to the surrounding world, one becomes more compassionate regarding the suffering of other beings. One becomes more appreciative of other beings and more conscious of the profundity of each being's own unique experience and process. One becomes more in awe, appreciative, and more loving, knowing that each being is living his or her own challenges that one cannot pretend to know. One feels greater empathy and connection with other beings and may find one's self focusing on positive intentions for others and/or taking

actions toward the well-being of others as a kind of sacramental participation in the world, albeit in subtle ways. One sees one's contribution to the world in more spiritual, intangible ways that extend beyond one's lifetime.

Connection with others. Although one may feel a need for a certain amount of isolation in taking care of one's self, one cherishes relationships with family, friends, community, and, perhaps, a partner. One is more conscious of one's own motives and emotions and can engage in relationships from acceptance and loving communication rather than from dependence and an expectation that others will fill one's own unresolved needs. One approaches relationships more authentically, regarding others with greater respect and love. Erotic love can be very valuable in contributing to one's sense of joy, embodied connectedness, support, self-esteem, and restorative healing.

Consciousness of an ongoing process of development. One is conscious that one cannot go back to feeling normal or how one once was and that who one *is* reaches beyond this limited notion of the body and the ego self. One is conscious of the multiple, open-ended aspects of health and human development and that one is, in many ways, healthier than ever. One is conscious that one is on a never-ending path of growth or integration and that all daily decisions, mindsets, and intentions can make important contributions to this process. One's illness experience is an integral part of one's sense of self and, for all of its difficulties, one can see how it has given one gifts, insights, and new possibilities. Although at times one wanted others to be aware of one's pain and loss and the unfairness of one's condition, one's anger, outrage, and envy have eventually subsided in favor of a quiet, humble acceptance and personal pride at this invisible sense of growth that one knew one was experiencing, even if others will never

understand it. One is grateful for one's entire life journey, knowing that it all has meaning and purpose and that somehow things are all right.

Acceptance of embodiment and impermanence. One becomes more conscious of one's own embodiment and coexistence with other beings in the world. While becoming more open and attentive to one's physical changes, one also becomes more accepting of the finite nature of one's body and one's eventual death. One finds meaning and purpose in living with life's everyday challenges and gifts rather than measuring one's life by egoic achievements that one had previously focused upon. One finds joy and meaning in simply being alive in the present and being part of the world. One has stronger belief that life is beyond the death of the physical body, and one experiences a greater sense of trust and peace.

Living in the moment with gratitude. One lives more attentively in the present moment, feels more at home in one's body, and values one's life and all that is around one. One lets go of an attachment to the past and anguish about future possibilities and plans and becomes more thankful for what is happening in the moment. By deciding to live more in the present, one experiences a sense of freedom. One feels a profound sense of gratitude or grace, despite continued health difficulties, and feels more connected with the world around one, including the nonhuman world, and can see one's life within a greater context of the past, present, and future beings of the planet.

Comparison between Cycle 2 and Cycle 4 Lenses

I wrote a completely new set of Cycle 4 lenses, even though some of these themes were mentioned in my Cycle 2 lenses. I wrote new lenses because I felt that the original structure or *lack* of structure of the Cycle 2 lenses was limiting my intuitive process of expressing my new ideas. Now I will attempt to compare these two sets of lenses, illuminating the Cycle 2 lenses

that have grown or were eliminated and the new ideas that have emerged. To do this I will use categories created by Esbjörn (2003) in her intuitive inquiry on the role of the body in the psychospiritual development of contemporary women mystics. She introduced the following three categories for presenting the shifts in her Cycle 4 lenses: (a) new, (b) change, and (c) seed lenses. New lenses represent ideas or ways of approaching the topic that were not present in my original lenses. Change lenses will represent lenses that were modified, stretched, or transformed. Seed lenses are ideas that were minimally present in the Cycle 2 lenses but were more nuanced and developed during the intuitive inquiry process. I added a fourth category of (d) eliminated lenses that are ideas present in my Cycle 2 lenses but that are now largely absent from my present conceptualization of the process of psychospiritual transformation through chronic illness. I altered the order of these four types of shifts in lenses, opting to conclude with the new lenses. Presenting the resulting lenses in this way makes for a clearer analysis, so that the reader does not have to compare the new list with the lenses presented in Cycle 2 (Anderson, 2006; 2011).

My Cycle 2 lenses consisted of 30 numbered ideas, indicating the relative placement of this moment within the process. In many cases I made no clear attempt to assign a title to each lens that illustrates its central idea. In the Cycle 4 lenses I present the process of psychospiritual transformation through chronic illness as a series of moments divided into four major phases or groupings. Each moment has a short title. I elected not to number these moments because the process does not reflect a rigid sequence.

Eliminated lenses. These Cycle 2 lenses were eliminated from the original list:

- Lens 1: The first part of this lens is less relevant to the research question because it is more a theoretical attempt at explaining illness rather than a moment within the process of transformation.
- Lens 7: The stability of one's physical condition is not necessarily a part of one's subjective experience of transformation.

Seed lenses. The following Cycle 2 lenses were developed further in the corresponding Cycle 4 lenses.

- Lens 1: The last two sentences are reflected in the first moment of the Cycle 4 lenses.
- Lens 2: Expanded and separated into the moments of *diagnosis* and *isolation/no self*.
- Lens 3: Further developed in *initial emergency period, slowing down/inward focus*, and *expanded sense of self*.
- Lens 4: Expanded in *initial emergency period*.
- Lens 5: Further developed in *isolation/no self* and *losses/disintegration*.
- Lens 6: Further developed in *attempted return*.
- Lens 7: Alluded to in *new lifestyle*.
- Lens 9: The process is described in greater detail and in a more embodied way in *losses/disintegration, mourning losses, confronting the shadow, expanded sense of self, self-worth, and integration of opposites*.
- Lens 10: Expanded upon in *slowing down/focusing inward, mourning losses, new sense of self*, and *revisiting previously unresolved issues*.
- Lens 11: Expanded upon in *greater physical self-awareness and capacity for dealing with everyday difficulties* and *becoming one's own proactive healer*.

- Lens 12: Expanded upon in *living the ride with attention and acceptance of embodiment and impermanence.*
- Lens 13: Expanded upon in *greater serenity and balance between acceptance and will.*
- Lens 14: Expanded upon in *living in the moment with gratitude.*
- Lens 15: Expanded upon in *becoming one's own proactive healer and confronting the shadow.*
- Lens 16: Expanded upon in *becoming one's own proactive healer.*
- Lens 17: Expanded upon in *greater physical self-awareness and capacity for dealing with everyday difficulties and living the ride with embodied attention and joy.*
- Lens 18: Expanded upon in *becoming one's own proactive healer.*
- Lens 19: Expanded upon in *self-observation, self-compassion, and connection with the world.*
- Lens 20: Expanded upon in *unique spiritual practice.*
- Lens 21: Expanded upon in *living in the moment with gratitude.*
- Lens 22: Expanded upon in *return arc/integration.*
- Lens 23: Expanded upon in *return arc/integration.*
- Lens 24: Expanded upon in *confronting the shadow.*
- Lens 25: Expanded upon in *greater serenity and balance between acceptance and will.*
- Lens 26: Expanded upon in *return arc/integration.*
- Lens 27: Expanded upon in *self-worth, integration of opposites, and compassion and service for others.*
- Lens 28: Referred to in *revisiting previously unresolved issues.*
- Lens 29: Expanded upon in *acceptance of embodiment and impermanence.*

- Lens 30: Expanded upon in *consciousness of an on-going process of development*”.

Change lenses. Many of the Cycle 2 lenses are present in the Cycle 4 lenses, but in a much more expanded form. Although the contents of each of the individual Cycle 2 lenses are not necessarily contradictory of the Cycle 4 lenses, the Cycle 2 lenses have developed into more distinct moments with a clearer sequence of the process of psychospiritual transformation through chronic illness.

For example, in Lens 8, resistances are greatly expanded upon in *mourning losses*, *confronting the shadow*, and *creating a new lifestyle*. Denial and resistance occur cyclically from the beginning of one’s illness experience.

New lenses. Nearly all of the Cycle 4 lenses contain new, more in-depth ideas not found in the Cycle 2 lenses. The following Cycle 4 lenses especially consist of departures from the original lenses:

- *Initial emergency period*
- *Attempted return*
- *Losses/disintegration*
- *Slowing down/inward focus*
- *Isolation/no self*
- *Fear and helplessness*
- *Confronting the shadow*
- *Creating a new lifestyle*
- *Expanded sense of self*
- *Self-observation, self-compassion, and connection with the world*
- *Unique spiritual practice*

- *Greater physical self-awareness and capacity for dealing with everyday difficulties*
- *Integration of opposites*
- *Revisiting previously unresolved issues*
- *Living the ride with embodied attention and joy*
- *Acceptance of embodiment and impermanence*
- *Living in the moment with gratitude*

My Own Transformation during Research

I felt a sense of empathetic camaraderie with the group of authors because it was the first time that I had ever read autobiographies of people with similar illness experiences to my own. This helped me to feel more validated and accompanied in my own experience in order for me to be able to more fully enter this topic and explore it intellectually, emotionally, physically, and spiritually without feeling so overwhelmed with pain, sadness, and solitude. By reading these stories I was able to more fully appreciate my own process of survival and transformation, and this helped me to take better care of myself without self-judgment, to find meaning in this experience, and to trust in the universe. I feel a stronger sense of acceptance and gratitude for my illness experience in contributing to my own growth. I now more strongly believe that I can live through this illness experience and live a meaningful, joyful life and that this illness and this research process are allowing me to become more conscious of my own present and future contributions to the world.

This research process also stimulated my own growth in terms of bringing to consciousness my four Jungian (1928b/1983) functions in a more balanced way. My personality is based on *introversion, intuition, feeling, and perceiving*, or INFP in the Myers-Briggs personality system (Briggs Myers, 1995). In addition to the two attitudes and four functions,

Jung also referred to a fourth pair of opposites of the personality called *perceiving* and *judging*, which are functions of the ego and determine whether we are more open and receptive to our surroundings or tend to shape and judge (Grant, Thompson, & Clarke, 1983). My dominant function is the feeling function (as opposed to thinking), which I habitually use in an introverted way. Thus, my most habitual area of focus has been on my own emotions. My second function is intuition, regarding which, as do all people, I tend to use combined with my nonhabitual attitude, which, for me, is extraversion (Grant et al., 1983). I believe that I have been habitually using my intuitive function to make sense of the world around me since my teens. My third function is sensation, or taking in information through body consciousness, which for me is a nonhabitual or nondominant function, but which I have gradually begun to use, due to my illness experience, especially in the past 10 years. With this research I have embraced my own embodiment, and I have tried to express and theorize more from this function. My fourth and least developed function is thinking, and, for me, an even greater challenge is to use this in an extroverted way. This dissertation has been a great exercise for me in moving beyond my own feelings about my experience toward researching from my own embodied experience, using my intuition to gather insights, and taking this to an even further level by using my thinking function to theorize about a phenomenon in and around me. Using analysis and rational thinking to explore and compare my own theory with the existing literature has been an especially great stretch for my thinking function.

I have been experiencing much of the process of psychospiritual transformation through chronic illness, as I have expressed in my Cycle 4 lenses. To a certain degree, I believe that it is not possible to write about an experience until one has lived it. At the beginning of my research, I had not lived this experience of transformation as fully as I do now in the present. At the same

time, I do not pretend to completely embody or experience all of the aspects of the Cycle 4 lenses at all times. I have moved into these or brushed up against these stages or experiences at different times. I know that growth is fleeting and cyclical and that much lies ahead in my own development.

Chapter 8: Cycle 5

Rosemarie Anderson (2011), the creator of intuitive inquiry, described the final cycle of this research method:

Based on working the hermeneutic process of Cycles 1 through 4, in Cycle 5, the intuitive inquirer presents authoritative theoretical speculations and theory related to the topic of study. As in all research reports, at the end of the study, the researcher returns to the literature review done prior to data collection and reevaluates that theoretical and empirical literature in light of her findings. In other words, the researcher must determine what is valuable about the study and what is not—sorting through the assets and liabilities of the interpretive cycles—and determine what can now be said about the research topic, including what she feels is still undisclosed. . . . Intuitive inquiry also requires telling the entire truth about the course of the research project—including (a) mistakes made, (b) procedures and plans that did not work, (c) the researcher's apprehensions and puzzlements about the study and findings, (d) the style of intuitive interpretation used, and (e) what remains unresolved or problematic about the topic or the method. A successful intuitive inquiry invites the reader of the research report to understand the researcher's style of intuitive process and the manner in which intuitions manifested in the course of the interpretive cycles—including the twists, slow-downs, dead ends, and flow of the unconscious journey. (p. 53)

Introduction

This research has been about the process of psychospiritual transformation that a person may experience when living with a chronic illness over a period of more than 7 years. It is about the issues that one faces on this journey and the ways in which one changes; psychospiritual transformation through chronic illness is both a process and a result of growth (Coburn, 2006; Hart, 2000; Imber, 1994).

The limitations and challenges of chronic illness can provide unique opportunities for growth and transformation (Bouvard, 2007, 2008; Butterfield, 2011; Delgado Gaitan, 2009; Ironson et al., 2002; Kramer, 2003; Loffer, 2000; Metzger, 2004; Mindell, 1985; Ruhl, 1995; Simmons, 2000; Skloot, 1996; Williams, 2008). One may live more consciously in the body and become more present, self-aware, and patient (Ambrosio, 2010; Bouvard, 2007, 2008; Delgado Gaitan, 2009; Ironson et al., 2002; Kramer, 2003; Loffer, 2000; Manguso, 2008; Metzger, 2004;

Ruhl, 1995; Simmons, 2000; Skloot, 1996). One calls upon one's individual will and ego strength in surviving this confusing ordeal while surrendering to and trusting in forces beyond the self (Bouvard, 2007, 2008; Butterfield, 2011; Delgado Gaitan, 2009; Kramer, 2003; Loffer, 2000; Metzger, 2004; Ruhl, 1995; Simmons, 2000; Skloot, 1996). Chronic illness can also encourage one to dis-identify with one's own habitual (and sometimes destructive) ego habits and body and embrace new ways of being, partly because one's body will not allow one to continue the same lifestyle, while one also opts to make changes to improve one's future health possibilities in the face of uncertainty (Ambrosio, 2010; Bouvard, 2007, 2008; Butterfield, 2011; Delgado Gaitan, 2009; Fennell, 2001; Goodheart & Lansing, 1997; Kramer, 2003; LeMaistre, 1995; Loffer, 2000; Metzger, 2004; Ruhl, 1995; Simmons, 2000; Skloot, 1996). One begins to live from one's own unique rhythms and needs (Ambrosio, 2010; Bouvard, 2007, 2008; Fennell, 2001; LeMaistre, 1995; Simmons, 2000; Skloot, 1996). By witnessing the changing nature of one's impermanent body and facing continual losses, one becomes conscious of a deeper, more transcendent nature of the self (Butterfield, 2011; Ruhl, 1995; Simmons, 2000; Skloot, 1996; Williams, 2008). One becomes conscious of one's own mortality and elects to make the most of one's time and energy, embracing joy in the present and pursuing meaningful contributions to the world (Bouvard, 2007, 2008; Delgado Gaitan, 2009; Kramer, 2003; Manguso, 2008; Simmons, 2000; Skloot, 1996; Williams, 2008).

The model I have outlined in Cycle 4 contributes a detailed understanding of the process of transpersonal psychospiritual transformation through chronic illness, touching upon a fuller range of human experience and development not present in previous studies and theories on this topic. This study builds upon and contributes to theories of psychospiritual lifespan development (Anderson, 2004b; Hall, 2000; Hillman, 1996; Jung, 1928a/1983, 1939/1983; Kegan & Laskow

Lahey, 2009; Ruumet, 1997, 2006; Washburn, 1995; Wilber, 1999), transpersonal concepts of transformation and healing (Achterberg, 1987; Braud et al., 2000; Hart, 2000; Metzner, 1986, 1987; Maslow, 1999; Mehl-Madrona, 2003; Metzger, 2004), empirical findings on embodied aspects of spiritual growth (Carpeneto, 1997; Esbjörn, 2003), empirical findings on psychospiritual transformation (Coburn, 2006; Gaynor, 1999; Imber, 1994; Smith, 2006), theories and findings on connectedness to nature and an increased sense of wellness (Comeau, 2012; Hansen-Ketchum, 2010; Hinds & Sparks, 2009; Kaplan & Kaplan, 1989; Marsh, 2008; Ryan et al., 2010; van den Berg et al., 2003), empirical findings on psychospiritual transformation through illness (Cole & Hopkins, 2006; Ironson et al., 2002; Loffer, 2000; Taylor, 2003; Spencer-Benson, 2003; Williams, 1995), and the theories that attempt to illustrate the stages of experience and change among people who live with chronic illness (Butterfield, 2011; Fennell, 2001; Goodheart & Lansing, 1997; LeMaistre, 1995; Ruhl, 1995). Although many people who do not live with chronic illness may find themselves facing, to some degree, several of the issues outlined in this theory, it represents a specific developmental experience of people who have lived with chronic physical illness during a period of at least 7 years.

Reflections on the Findings in Light of Theories of Psychospiritual Development and Transformation

My model of psychospiritual transformation through chronic illness is a description of a detailed experience of Jung's (1939/1983) theory of individuation as one begins to confront and embrace both conscious and unconscious aspects of the self toward greater wholeness. One begins to become more aware of one's dreams, the construction of one's own persona, the shadow, the anima/animus, and more integral aspects of the self that were previously unrecognized. In my model, one's (sometimes forced) attention to one's physical sensations can

serve a key role in drawing one away from one's limited ego consciousness, questioning one's own cognitive and emotional patterns, and embracing broader aspects of the self and eventually integrating these into one's consciousness. My model of psychospiritual transformation through chronic illness also entails bringing to consciousness all four Jungian (1928b/1983) functions (*intuition, sensation, feeling, and thinking*), from our dominant function to our fourth, underused function, and integrating both introverted and extroverted aspects of the self. By depriving us of the use of habitual physical and mental capacities, life with chronic illness can often stimulate or accelerate the process of using previously ignored functions.

My theory also contributes an understanding of the growth of people with chronic illness through Kegan and Lahey's (2009) stages of mental development in adulthood. People who begin to experience illness in early adulthood may be firmly identified with their ego identity within the context of social roles and expectations of the *socialized mind* stage. Facing a chronic illness may be especially difficult during the first phase of my model, *an unwilling beginning of the journey* (specifically *attempted return, search for an escape, and losses/disintegration*) because one is facing a reality that directly *contradicts* one's idealized individual identity adopted during the *socialized mind* stage. As one begins to sit with the illness experience, during the moments of my second major stage (specifically, *slowing down/inward focus* and *isolation/no self*), one steps back from one's previous social role and begins to embrace one's own individual sensations, rhythms, needs, beliefs, and truths rather than defining one's self through others or institutions. This marks a shift into Kegan and Lahey's *self-authoring mind*. In the later moments of my third and fourth stages one begins to transcend one's own constructed identity, integrating inner opposites, and to embrace the interconnectedness

between beings, a transcendence that lends fullness and meaning to life. This marks a shift to the *self-transforming mind*.

My model of psychospiritual transformation through chronic illness illustrates an in-depth experience of development through Ruumet's (1997, 2006) stage model, especially in the movement from her Centers Three to Four, as one becomes aware of the limits of one's ego power and shifts from a base of power (mastery and success) to love (compassion, valuing the divine essence in others, and a yearning for meaning) in focusing one's capacities in service of the heart. My model parallels development in Ruumet's Center Four as one begins to more clearly witness one's own ego behavior and inner process, to decondition negative patterns, to tap into one's own spiritual yearning, to become more aware of the mind-body connection, to better understand one's own process of development, and to experience a renewed interest in spiritual traditions and community. The experience of psychospiritual transformation through chronic illness mirrors Ruumet's fifth center as one finds one's voice through unconventional, noncompetitive creativity; expresses an intense yearning for divine connection while previous spiritual practices seem limited; solidifies one's capacity for nonjudgmental self-witnessing; reframes one's life history; consciously participates in the world through the body; becomes more present and nonattached; and develops a sense of mystery and paradox in appreciating the uniqueness of all moments and beings. The latter moments of my model are also similar to Ruumet's Center Six, as one's dualities seem to dissolve and one maintains greater equanimity, joy, presence, trust, and connectedness.

My model also illustrates Campbell's (1949) idea of the Hero's Journey, as I conceive the process of psychospiritual transformation through chronic illness as a *journey* (Jung, 1939/1983; Metzner, 1986) in which one leaves one's comfortable, healthy life and undertakes an unwilling

individual journey through very challenging obstacles. One grieves one's losses, learns new skills, is accompanied by new allies, confronts dark forces, and begins to trust amidst the uncertainty. One returns home with greater self-knowledge, new gifts and skills, greater motivation to share and connect with others, an integration of one's own inner dual forces, and a greater consciousness of one's interconnection with others. In general, the aforementioned theories have informed the underlying framework of my model, giving me a clearer understanding of the process of psychospiritual transformation through chronic illness, so that I may express it in this sequence.

I characterize psychospiritual transformation through chronic illness as: (a) ongoing and touching upon all dimensions or aspects of life (Braud et al., 2000; Coburn, 2006; Hart, 2000; Imber, 1994); (b) a cyclical movement in which one returns to similar issues in new ways throughout the process (Metzner, 1987); (c) developing ego strength rather than ego fixation, and, thus, aligning ego with newly emerging unconscious aspects of the self as the deaths of old ways become new ground for creativity (Hart, 2000; Imber, 1994; Jung, 1939/1983; Ruumet, 1997, 2006; Taylor, 2003); (d) discovering and integrating shadow aspects of the self (Coburn, 2006; Hart, 2000; Jung, 1939/1983; Metzner, 1987), including the resolution or healing of key early wounds or conflicts that have contributed to one's ego patterns and identity (Imber, 1994); (e) a dialectic between focusing one's positive intentions and will and surrendering to forces beyond the self (Hart, 2000); (f) reconciling inner dialectical opposites or conflicts with the capacity to accept and hold in one's consciousness seemingly opposing ideas or aspects of the self and integrate these into one's new way of being (Metzner, 1987; Jung, 1939/1983); (g) greater identification with spiritual aspects of life and the self and less with ego while adopting a contemplative practice (Imber, 1994; Taylor, 2003); (h) greater openness, presence, appreciation

of life, and sense of joy and inner freedom (Hart, 2000; Imber, 1994); (i) moving beyond a limited or one-sided way of being toward greater balance and changes in patterns, structures, and functions of the psyche (Cole & Hopkins, 2006; Metzner, 1986; Smith, 2006) as one's consciousness contains and expands upon one's mindset in previous moments (Coburn, 2006; Ruumet, 1997, 2006; Kegan & Laskow Lahey, 2009); (j) a greater consciousness of how one's symptoms are an integral part of one's process of psychospiritual development, including ways in which they have revealed unresolved needs or have served as opportunities for making life changes toward greater wholeness (Mindell, 1985; Dennehy, 1987; Hillman, 1996; Ruhl, 1995; Strachan, 1992; Walsh, 1990) ; (k) a cyclical dialectical process of dis-identification and reidentification with the body while experiencing a more tangibly felt spirituality in the body (Carpeneto, 1997; Esbjörn, 2003; Esbjörn-Hargens, 2004); (l) a fluid self-reference not fixed in the body (Esbjörn, 2003; Esbjörn-Hargens, 2004); (m) a greater sense of self-acceptance and self-love (Loffer, 2000; Spencer-Benson, 2003); (n) a sense of reconnection or coming home to the self in which one discovers and appreciates one's own strengths, experience, passions, and gifts to the world (Coburn, 2006; Jung, 1939/1983; Metzner, 1987); (o) a greater sense of connection to the world on multiple levels (with diminished boundaries between self, world, and others) and an openness to transcendent powers within and outside the self (Carpeneto, 1997; Coburn, 2006; Gaynor, 1999; Hart, 2000; Imber, 1994; Maslow, 1999); (p) a greater sense of connection with the natural world, experiencing a greater sense of inner peace, community, unspoken dialogue, meaning, and hope (Comeau, 2012; Hansen-Ketchum, 2010; Hinds & Sparks, 2009; Kaplan & Kaplan, 1989; Marsh, 2008; Ryan et al., 2010; van den Berg et al., 2003); (q) a more intuitive sense of one's integral needs rather than a tendency to draw exclusively from external perspectives (Krycka, 2000; Ruhl, 1995); (r) a changed sense of time

(Carpeneto, 1997) with an expanded capacity for witnessing the self and the world with greater nonattachment; (s) an inner commitment to life and a greater sense of trust (Loffer, 2000; Mehl-Madrona, 2003; Smith, 2006); (t) a more paradoxical understanding of dualistic polarities, such as spirit/matter, being/doing, and so forth (Carpeneto, 1997; Esbjörn, 2003; Esbjörn-Hargens, 2004); and (u) greater empathy, openness, and compassion for others (Cole & Hopkins, 2006; Taylor, 2003) as one engages in creative service to the world through one's strengths and experience, inspired by a sense of love and moves beyond cultural scripts in making life changes (Coburn, 2006; Imber, 1994; Loffer, 2000).

Reflections on Theories and Findings of Psychospiritual Transformation Through Chronic Illness

My model of the process of psychospiritual transformation through chronic illness builds upon and contributes to previous theories and empirical findings related to the experience of living with chronic illness (Butterfield, 2011; Fennell, 2001; Goodheart & Lansing, 1997; LeMaistre, 1999; Register, 1999; and Ruhl, 1995) while contemplating deeper and more complete aspects of transpersonal psychospiritual development beyond an acceptance of and adaptation to illness. While I do not necessarily *disagree* with these prior models, I find them limited in describing a fuller range of experience with chronic illness over time. These theories are often more prescriptive than descriptive and focus more on shifts in the person's approach to illness rather than dealing with broader issues of transformation of one's sense of self and the way that one lives in the world. I am attempting to describe the way in which an experience with illness can inspire one to broader, more pervasive aspects of human development.

My model is generally consistent with Goodheart and Lansing's (1997) stage model of people's response to chronic illness, as they both describe an acknowledgement of illness

chronicity, losses and a subsequent psychological disorganization, depression and isolation, and an intensified wish for a cure. I agree with the authors that a turning point in psychospiritual transformation through chronic illness is an acknowledgment of the limits of ego power and one's relative helplessness before one's health situation. This recognition is key to an eventual acceptance of illness and a subsequent adaptation. However, this model does not contemplate a confrontation with previously unrecognized aspects of the self, an expanded identity, body consciousness, a felt sense of spirituality, or changes in one's attitude and sense of connection with the world. The developmental process that I describe in my third and fourth stages is largely absent from this theory.

LeMaistre's (1995) theory is similar to my own in that, after an initial crisis period, the chronic illness sufferer turns his or her attention inward in dealing with physical survival, uncertainty, self-blame, losses, and anger. I agree with the author's idea that, when one faces anger and a sense of helplessness at the loss of control of the body, one tends to eventually shift one's attention to changing one's emotional response to the situation; sometimes one's response is all that one can control. I resonate with LeMaistre's emphasis on recurring depression and yearning to return to a preillness self, reconstruction of the self, and renewal. However, my model contemplates a broader and deeper sense of reconstruction beyond learning new competencies and creating a positive self-image. It entails an integration of previously unrecognized aspects of the self, an exploration of new ways of being in the world, an interconnection with others, and a greater sense of presence and joy. While LeMaistre focused on the creation of new options from the acceptance of a new situation in the renewal stage, I characterize a more complete experience of transpersonal psychospiritual growth beyond the establishment of coping capacities.

I resonate strongly with Fennell's (2001) prescriptive four-stage model of finding meaning in living with chronic illness. In her third stage, *resolution*, she mentioned several of the same issues that I described in my second and third stages, including increased body awareness, an awareness that one cannot return to one's previous life, grieving one's losses, an identity crisis, fear, and a search for a new authentic self and meaning in suffering. Fennell's *integration phase* is also similar to my own final phase, in which one integrates an old and new self and organizes one's life based on one's new identity and realistic conditions toward a more complete life beyond illness. My model contemplates broader aspects of human growth, including an acceptance and integration of multiple aspects of the self (unconscious and transpersonal, not only the old and new ego self), embracing and integrating nonordinary experiences of consciousness, a sense of identification and dis-identification with the body, a sense of connectedness with the world on multiple levels, and a greater consciousness of one's own developmental process and gifts to the world.

Ruhl's (1995) theory of the four psychological responses to illness was helpful to me in understanding the qualitative changes in one's response to illness over time. My model expresses each of Ruhl's four illness responses at different moments, and the authors of the illness narratives that I read in Cycle 3 also moved through these.

Ruhl's (1995) *regression* response appears at the beginning of my model, when one becomes passive, dependent, compliant, and alienated from the body as one is cared for by health professionals and follows their instructions. The *maintenance* response is reflected in my first stage, as one conceives illness as *separate* from the self and seeks mastery over it in attempting to maintain a preillness self-organization. At this moment, one denies aspects of the illness and the corresponding emotions that threaten the idea of the self, as one represses wounded parts and

segregates them from one's sense of self. One attempts to return to one's previous life and overcome a personal sense of weakness while defending one's own will as "potent and effective" (Ruhl, 1995, p. 186) in determining one's fate, a characteristic similar to Butterfield's (2011) chaos state, Goodheart and Lansing's (1997) fourth stage, and Ruumet's (1997, 2006) third center.

I agree with Ruhl (1995) that the *maintenance* response is not the best response for a person with chronic illness. A shift out of this maintenance response is key to the process of psychospiritual transformation through chronic illness, and one begins this shift through self-observation and self-acceptance. This change entails moving away from an identification with an egoic idealized vision of the self (informed by social expectations) and accepting one's self as one *is* in the moment. One then begins the process of remaking one's life based on one's condition, needs, and capabilities or limitations. This body consciousness is important in avoiding what Krycka (2000) referred to as *the splitting of experience*, in which people feel a split between their own understanding of their body and their illness and the doctor's perspective. I agree that this split can lead to a disintegration of experiences and a distance from "the wisdom of the body-mind unity" (Krycka, 2000, p. 71).

Ruhl's (1995) *transformation* response is reflected mainly in my second and third stages, as one experiences a death of the pre-illness self, self-forgiveness, an integration of illness into one's life, an honest appraisal of what one has lost, and an expanded sense of self. I also contemplate for this stage a reassessment of values, finding new meaning or a central purpose, and a process of constant grief, frustration, fury, despair, and adjustment.

My model reflects Ruhl's (1995) *transcendence* response, as one's identity shifts beyond body and ego and one experiences a deeper understanding of one's self and one's illness process.

One also stops trying to wrestle with illness and just to *be*, while experiencing a sense of joy, interconnectedness, mystery, and surrender to a force greater than one's individual will.

Contributions of This Study and Further Questions

I believe that the main contribution of this study is in describing the cycle of psychospiritual transformation through chronic illness and its potential contribution toward transpersonal human development. I believe I have given greater detail and depth to this experience, shedding light on understanding the way that this process of change occurs over time, beginning in early to middle adulthood. Much of my description of this process, especially the elements of transpersonal human growth, was largely absent from the current literature on chronic illness experiences. For example, the importance of spending time in nature as a vital part of one's experience of psychospiritual transformation through chronic illness was an innovative contribution. While my perceptive and expressive skills may be limited and I do not pretend to have outlined the *definitive* experience of psychospiritual transformation through chronic illness, I believe that I have generated some significant brushstrokes in depicting a fuller picture of this experience.

I believe that the model I presented in my Cycle 4 lenses is valuable because I am expressing the detailed nuances of an inner journey that draws upon my own experiences and the experiences of others in our embodied processes of psychospiritual transformation through chronic illness. These ideas were not drawn from abstract ideas or theories but from first-hand experiences. These everyday experiences are often so close to us that it becomes nearly impossible to express them as a sequential narrative over time that would require a high level of self-observation, abstraction, and articulation. This study would not have been possible without the effort by the 8 authors who articulated their detailed personal journeys with illness. These

written narratives were my entry points for understanding the experience of psychospiritual transformation through chronic illness (during a period of at least 7 years), as I believe that this process can neither be adequately accessed nor conveyed through short interviews.

The experience of living with a chronic illness during a substantial period of one's life can serve as an opportunity for cultivating vital aspects of transpersonal human development beyond managing one's illness. While a chronic illness can deteriorate one's body, it can also stimulate one's individuation process or movement toward wholeness. Although the experience can be marked by physical pain, losses, and uncertainty, it can exercise certain spiritual, physical, emotional, and cognitive muscles or areas of growth that can allow us to become more human. Living with a chronic illness is certainly not the *only* kind of experience that can contribute to transpersonal psychospiritual transformation and development, but it certainly does so in unique ways.

A chronic illness experience can contribute to transpersonal psychospiritual transformation and development through the following characteristic experiences that result from the application of my model, many of which are largely absent from the existing models as applied to the chronic illness experience: (a) stimulation of a greater capacity for mindful solitude; (b) cultivation of body consciousness and a felt sense of spirituality by being alive in the present; (c) development of an increased practice of listening to the self and one's needs in a deeper, more integral way, as one gathers input about one's own needs from a wider variety of sources rather than simply from ego functioning, cognitive functions, or external sources; (d) cultivation of stillness, patience, and surrender; (e) strengthening of one's will to survive and to defend one's self, especially during moments of crisis; (f) sharpening of one's cognitive skills in exploring new information, making decisions, and reorganizing one's life in favor of one's

health needs; (g) opportunity to more consciously witness the damaging effects of one's lifestyle, habits, thought patterns, and emotions on one's self (especially on the body) and to change the trajectory of one's life; (h) motivation for one to learn new information about one's body, illness, nutrition, healing modalities, and the surrounding world; (i) cultivation of one's sense of self-worth as one makes the constant, daily commitment of taking care of one's self in unique ways that often go against the context of one's surroundings; (j) the openness to previously unrecognized aspects of the self and the surrounding world that is cultivated by facing sudden physical (and/or cognitive) limitations and new treatment guidelines; (k) the process generated that makes one disposed to undertake new experiences and uncharted paths; (l) the experience of losing essential aspects of one's health and life that can cultivate a sense of nonattachment and impermanence; (m) the opportunity to learn how to engage in active grief in facing losses and so cultivate a greater capacity for facing future losses and one's own physical death; (n) development of a trust or conviction that one's true essence can never be lost, despite the deterioration of the body—that, regardless of losses, somehow all is well; (o) experiences of nonordinary states of consciousness or transcendental experiences that are derived directly from one's illness and that expand one's sense of self and the universe; (p) the development, in living with continual pain, discomfort, and losses, of a sense of gratitude for the positive aspects of one's life while taking little for granted; (q) the opportunity to live with a greater sense of urgency in the moment, redefining one's values and sense of what is important, as due to the recognition of one's uncertain future; (r) a feeling of greater compassion for others and the motivation to find ways to be of service to the world from one's experiences, gifts, and passions that is prompted by the experience of one's own suffering ; and (s) the challenge one faces of

embracing everyday aspects of life that allow one to find joy and meaning, despite one's difficulties.

The target audience for this study consists of people who live with chronic illness. I was hoping to convey to my audience an experience of psychospiritual transformation not as a *prescriptive* model but as a *starting* point for generating sympathetic resonance so that people may reflect more deeply about their own personal processes and find a sense of commonality in this seemingly isolated individual experience. I wanted to put into words the issues that many people with chronic illness face on our never-ending, daily journey of development.

I especially wanted to describe the experiences of people who have lived with a chronic illness since early adulthood because it is an age when one is normally establishing one's ego power and social roles as an independent young adult (Ruumet, 1997, 2006). Illness forces one to confront one's own vulnerability at a time when other members of one's age group are generally not facing their own limitations. Many young adults quietly live this invisible inner phenomenon while facing emotional and spiritual issues more common to people in middle to later stages of life. I believe that living with a chronic illness since early adulthood is qualitatively different from an experience that begins with either childhood onset or onset in midlife. I wanted to focus on the experience that I knew, and I did not want to attempt to generalize to other populations. At the same time, I thought that, if I could describe the process of psychospiritual transformation through chronic illness among people who began their illness onset in early adulthood, the findings could also be helpful to people who faced an illness later in life.

Although I value this study's contributions, I am still left with many doubts, apprehensions, and curiosities about the topic. If this theory represents the process of transformation, then what can be done to help people to more effectively work with each of these

issues toward greater growth? Beyond describing what happens on the path of transformation, *how* can people engage in a more meaningful transformation? This is related to my next personal and professional step in searching for ways to contribute to other people's psychospiritual transformation. It is a complex question, and the answer would vary with each person and each particular issue.

This realization reminds me of one of my secondary research questions: *What contributed to people's transformation process?* Many factors played a role in this process, and these were implicit in many of the narratives. Rather than asking about the kinds of external forces that contributed to the process of psychospiritual transformation through chronic illness, I think it is more relevant to ask about the kinds of *decisions* or *shifts* in attitude that people made that contributed to their transformation process. How exactly did people make these changes, and how might others do this? It is becoming increasingly important to me to think about the kinds of activities, reflections, practices, or assistance that I can attempt to design to help people to more fully or deeply experience psychospiritual transformation through chronic illness. Perhaps this can be the subject of a future book or workshop. At the same time, on the other end of this duality, to some degree, a person simply goes through one's process of growth, and no other person can do it *for* him or her.

Do *all* people who live with chronic illness experience psychospiritual transformation in this way or to this degree? Are some aspects of this model more characteristic of some kinds of illnesses or populations? Is it possible for people to *not* experience transformation? This query may be similar to asking whether all people experience development or growth as they age.

What is the relationship between psychospiritual transformation and the healing of physical symptoms? While it seems that emotional, mental, and spiritual growth may have a

positive effect on one's physical health, this may not always be the case. I can also imagine how extreme situations of physical pain and discomfort may limit possibilities of psychospiritual development.

Methodological Reflections

I did this research during a period of my life in which my body was changing and my experience with illness was becoming more difficult than it had ever been. I attempted to more fully lean into this experience and to understand it from my own perspective and that of other people's understandings. Intuitive inquiry was a powerful and valuable method for allowing me to engage in this dialectical process of dialogue with myself and others on this all-encompassing topic of psychospiritual transformation through chronic illness. Intuitive inquiry offered me a process or structure for (a) attempting to understand and express my own experience with the topic, (b) reviewing other author's ideas about the topic and articulating my own ideas about it, (c) listening to other people's autobiographical narratives about the topic and synthesizing this data, (d) attempting to theorize about what occurs on one's journey of psychospiritual transformation through chronic illness, and (e) reflecting on the significance of this research experience.

This period of living with acute chronic illness and researching about this experience has been exhausting, transformative, confusing, frustrating, and eye-opening. Living with chronic illness often seems lonely and all-encompassing, and spending the past years focusing on this topic has, in some ways, felt like going into a deep, dark cave. Researching it has required focus, discipline, perception, and clarity. At times the research gave me important insights and perspective shifts on my daily experience. At other times I felt lost and swallowed up by the experience. I also felt the need for distractions, in order to back away from this experience and

reconnect with other aspects of life outside the illness experience. I am now more conscious that my topic of psychospiritual transformation is extremely extensive. It is an all-encompassing experience (including all aspects of life) that occurs over a great period of time. It is inseparable from my growth process, and it has been very difficult for me to hold the entirety of this experience or process in my being well enough to be able to express ideas about it. It has been a great challenge for me to consider the specific moments and aspects of this process without losing the whole. The topic itself has often felt elusive to me.

Because of the nature of this ambitious topic, each of the five cycles of research required a significant amount of time and energy. For example, in Cycle 1, simply expressing my experience with and relationship to the topic, became an extensive task. Since the topic was so vast, it was difficult for me to feel satisfied with my work on each cycle, because I felt that I was barely scratching the surface. My progress was also worsened by my own self-doubt, anxiety, and perfectionism in wanting to express everything and leave no stone unturned for fear of being off the mark or not expressing my deeper ideas. I know now that this was an expression of my own ego indulgence. In hindsight, I see now that I spent too much time in trying to express Cycle 1. This was exacerbated by my cycle of escapist distractions from what I began to perceive as an insurmountable task and my own self-punishing tendencies in response to my not advancing at the rate that I wished. At the same time, I can see that during this time I was going through a traumatic change in my body, with deteriorating mental and physical capacities, and I was struggling to understand my condition and how to adapt to it. When I began to express my story of living with chronic illness, I realized that I was tapping into a tremendous level of unexpressed pain and sadness from my previous 15 years with illness. I generated a significant

amount of material for Cycle 1, but I then found myself without the mental and physical capabilities to adequately synthesize these ideas.

Similarly, during Cycle 2, I faced the challenge of synthesizing my wide range of experiences and ideas into a cohesive theory or process. I was in a physical crisis, at first responding with denial and ineffective attempts to calm the pain and discomfort in my body. Years had passed, and I was still searching for an accurate diagnosis and an effective treatment. I began to doubt my own chances of survival, and it was difficult for me to foresee completing this cycle and the rest of the research. I felt that I was drowning in my own illusive ideas, but, after I completed Cycle 2, I was able to work steadily, albeit with physical challenges. In hindsight, I think Cycle 2 would have flowed in a more concentrated way if I had focused my dialogue on a more select group of texts. I believe that I would have been able to concretize my ideas more easily.

Throughout this process, it has been very difficult for me to sit for extended periods, and I have often felt frustrated at losing the continuity of ideas. With my physical changes, my intuitive style changed. At the beginning of this process I often felt intuitive insights by walking, sitting down to meditate in a dark room, or spending time in nature. With the constant pain and discomfort in my muscles and bones I could no longer do these activities. I could not sit quietly or walk, and I needed to engage in constant stretching. I adapted to my body. I meditated on a given topic by carrying it within me as I went about my daily self-care activities. I incubated ideas within, much like seeds growing in soil. Somehow, eventually, ideas would come to fruition.

In the end, I feel that this research truly emerged from an embodied experience. I tried my best to write down the ideas as they came, and it was challenging for me to bring these together

to form a cohesive research process, but I believe that I have expressed what needed to be expressed. Although my Cycle 4 lenses are based on my own experience and the experience of 8 other highly reflective individuals, along with the reactions of 3 resonance panel members who have lived with chronic illness, I cannot gauge the degree to which these lenses are generalizable to other people's experience with chronic illness. I would like the chance to socialize these ideas with my audience through appropriately accessible publications.

Part of me wants to bring the Cycle 4 lenses to a shorter synthesis, but another part of me feels that some important descriptions are still missing. I will let it speak for itself as it is. It is difficult for me to step back and discern how much of this theory is based on a faithful representation of the authors' stories, how much is based on my own experiences and ideas, and how much is from other written sources. Sometimes I uncomfortably felt that I was making this up, but perhaps that sense is more properly attributed to my inner critic with the regard to the intuitive creative process. Perhaps this blurring is part of the magic of intuitive inquiry. These are the ideas that have been reflected through me right now, and I feel that I am too close to them to accurately and fully appraise their merits. I cannot hold all of this information within me at once. I still feel that there is much about the topic that I have not expressed, but, rather than give in to judgment and frustration, I prefer to simply present these ideas as they have emerged.

In the end, I trust that the time and effort that I devoted to this research has been valuable to own transformation, to my contribution to the field of transpersonal psychology, and to my future readers.

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Appendix A: Resonance Panel Questions

Patrick Baltazar

Dissertation research of “Psychospiritual Transformation Through Chronic Illness:

An Intuitive Inquiry”

Sofia University

I am doing doctoral research on the experience of psychospiritual transformation through chronic illness and I am soliciting your brief, but valuable feedback in indicating to me to what degree the results of my study resonate with your personal experience.

I am inviting you to give your feedback because of your experience in living with chronic illness. You will NOT be required to share any personal information with me and your name will not be included in this study.

I simply ask that you read the data results of my intuitive inquiry, which is written as a composite story of a woman’s journey of psychospiritual transformation through chronic illness (based on 8 narratives of people who have lived with chronic illness for at least 7 years), and indicate to me to what degree this story resonates with your own personal experience. I will invite you to highlight specific portions of the text that strongly resonate with or contradict your experience and to share any thoughts, opinions, or feelings that you may have about the results. I hope that your participation will be meaningful to you in your own ongoing transformation experience.

The goal of my research is to understand the subjective experience of psychospiritual transformation through chronic illness. I am doing this by analyzing 8 autobiographies of people who have lived with illness and by reflecting on my own experience. I hope that this study will be meaningful to other people who live with chronic illness and to the family members and practitioners who accompany them. This kind of subjective qualitative research can be validated by comparing the results to other people’s experience of the same phenomenon. You will be part of a “resonance panel” because I wish to determine how much the data results resonate with your experience.

I am seeking resonance panel members who generally meet the following criteria (similar to the 8 authors of the autobiographies):

- (a) Persons who have been living with a chronic physical illness for at least the previous 7 years, an illness which they consider has strongly impacted several aspects of their lives.

- (b) Persons who believe that they have been significantly transformed through their illness experience. By “transformation” I mean a significant shift in the way they consider themselves and the world around them. It could include physical, spiritual, social, familial or other aspects.

If you believe that you generally meet the above criteria please answer the following questions (You can include your answers on this page and return it to me):

1. Does this story resonate with your own experience of transformation through chronic illness?

Please select:

- a) Strongly resonates
- b) Moderately resonates
- c) Somewhat resonates
- d) Resonates very little

Why or why not? Feel free to comment.

2. Highlight any aspects of the text that

- a) strongly resonate with your experience (in yellow) or
- b) contradict your own experience (in blue)

Feel free to comment on any general or specific aspects of the story. You may also wish to indicate to me any important aspects of your experience that were not mentioned in the story.

3. What was it like for you to read this story? Please feel free to add your comments on your own shifts or emotional responses to the text.

I would appreciate it if you could return your feedback to me within a week’s time.

Would you like to receive an e-mail copy of the completed dissertation?

Thank you very much for your participation in the resonance panel and best wishes to you on your journey.

Patrick Baltazar xxxx@xxxx.com