

# Introduction

I survived two powerful tornadoes in my lifetime. When I was 11 years old, a violent tornado devastated my hometown of Salina, Kansas. Ironically, our family lived in “tornado alley” in a small brick house without a basement or storm cellar.<sup>1</sup> When public sirens announced imminent danger of a tornado, we had to run through the storm, cross the main street in front of our house, and pound furiously on the front door of the elderly couple who offered us shelter in their basement. On that fateful night in 1973, our pajama-clad family ran out of our home into the greenish darkness of the severe storm, wind and rain spiraling around us, toward hoped-for safety on the other side. My palms still sweat when I recall the panic I felt as I banged my fists frantically on our neighbors’ front door to wake them while my youngest brother screamed, “Don’t let me die! Don’t let me die!” Thankfully, we survived the storm and our home was spared damage, but the traumatic effects of this experience left me trembling for years at the mere prediction of rain within miles of where I lived.

The second tornado in my life appeared suddenly and incomprehensibly from clear blue skies when I first noticed piercing pain in my shoulder joints. But as the warning winds

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1 “Tornado alley” refers to a geographic zone in the United States where tornados are common.

of this disease increased in velocity, damage began to appear: fingers so swollen I could not grip a toothbrush, feet that felt like the bones had been crushed with a sledgehammer, and pain that ricocheted from shoulder to knee to elbow as if my body was a pinball machine. After months of tests, treatments, and anxiety, the tempest was diagnosed as rheumatoid arthritis (RA), an incurable autoimmune disease characterized by systemic fatigue, chronic joint pain, and inflammation. Although the funnel cloud that heralded the diagnostic stage has long since passed, I continue to live with the after-effects of this life-altering tornado. What made the storm of RA, the *disease*, more challenging for me was the lack of psycho-spiritual support for my *illness* experience.<sup>2</sup> My intention in writing this book is to raise awareness of the psycho-spiritual dimensions of chronic illness so all types of spiritual caregivers can ease suffering and promote well-being for people living with long-term health conditions.

The Centers for Disease Control and Prevention (2019) tell us that “six in ten Americans live with at least one chronic disease.” Numbers may be even higher in other parts of the world (e.g., Di Benedetto *et al.* 2014). Worldwide, billions of people live with incurable health conditions. Given these staggering numbers, it’s critical for *all* care providers to understand how chronic health conditions affect body, mind, and spirit.

Many people describe chronic illness as “a spiritual event” (Balboni and Balboni 2018) because diagnosis with an incurable condition often generates spiritual struggles, beginning with the quintessential question of *Why?* Spiritual distress threatens our ability to cope with pain, to be resilient in the face of ongoing losses and uncertain prognoses, and to maintain a sense of well-being (Abu-Raiya, Pargament, and Exline 2015a). Spirituality comes to the forefront for most people during times of serious illness, and patients want to address spirituality as a part of their

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2 I define illness, disease, and other key terms in Chapter 1. You can also find **bold** words and phrases in the Glossary.

health care (Kelly, May, and Maurer 2016; MacLean *et al.* 2003; Piderman *et al.* 2008).

Even though the healthcare community around the world recognizes the need for greater attention to patients' spirituality (e.g., Dyer 2011; Gijssberts *et al.* 2019b; Kruizinga *et al.* 2018; National Consensus Project for Quality Palliative Care 2018), numerous studies document the fact that the spiritual dimension of illness (and the chaplains who provide spiritual care) often remains marginalized or neglected in healthcare settings worldwide (Appleby, Wilson, and Swinton 2018b; Arora 2013; Balboni and Balboni 2018; Cheng *et al.* 2018; Franzen 2018; Hutch 2013; Timmins *et al.* 2018; VanderWeele, Balboni, and Koh 2017). Even faith-based healthcare institutions that profess a core value of providing spiritually integrated care may neglect patients' spirituality (Taylor *et al.* 2018). Most biomedical clinicians don't feel equipped or comfortable addressing spirituality (e.g., Appleby *et al.* 2018a; Badaracco 2007; Damen *et al.* 2018). Also problematic are spiritual caregivers<sup>3</sup> outside the healthcare arena (e.g., clergy, spiritual directors) who remain largely unaware of often-invisible chronic health conditions affecting people around them. This spiritual caregiver describes the status quo:

We are prone to think of illness as a single acute crisis experience in which we are called to provide spiritual support, counsel, and encouragement. Like most other crises, we usually perceive illness as having a beginning, a turning point, and a conclusion. People either get better or they die, and for the most part we can handle that within our pastoral and theological grab-bag.

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3 I use *spiritual care/caregivers* to reflect the broad definition of **spirituality** described in this book (see the Glossary and Chapter 1). *Pastoral theology* and *pastoral care* are most often associated with Christian theologies. These terms appear in some quotes and, in the context of this book, should be read as a placeholder for *spiritual care/caregivers*. Schuhmann and Damen (2018) and Anderson (2001) describe the way pastoral/spiritual caregivers continue to grapple with self-identity as the spiritual/religious landscape changes around them.

Chronic illness, however, has the power to alter all our predictable patterns of care and counsel. (Vander Zee 2002, p.181)

This book is for professional spiritual care providers, social workers, therapists, and healthcare professionals who care for people affected by incurable diseases. That said, **life-affirming** spiritual care comes from many sources. In fact, spiritual care is more often provided by the patient's family and friends than professional caregivers, and patient satisfaction with spiritual care does not necessarily depend on *who* provides care, but on addressing their spiritual needs (Hanson *et al.* 2008). With this in mind, I also hope this book will equip patients and their informal family caregivers to live well with chronic illness.

## Methodology

Peer-reviewed research makes up the sacred canon of the Western healthcare system. Professional organizations that credential chaplains in the United States (e.g., the Association of Professional Chaplains and the Spiritual Care Association) recognize that chaplains need to be research literate in order for their profession to thrive in healthcare contexts (Fitchett *et al.* 2014; HealthCare Chaplaincy Network 2018). In the evidence-based and socially just approach to spiritual care presented in this book, I include studies about diverse illness experiences and spiritualities from around the world. Because evidence-based practice can privilege the voices of researchers over the voices of patients/participants, I also cite studies in support of my experiences, observations, and claims to bear witness to the patients'/participants' stories, "amplifying voices that would otherwise be silent, and connecting in solidarity voices that are otherwise isolated" (Frank 2017, p.6).

I use a critical correlation method (Graham, Walton, and Ward 2005) that brings the fields of spirituality, psychology, and medicine into dialogue about long-term illness experiences. I strive to honor "the distinctive norms and values of each

‘conversation partner’” (Ramsay 2004, p.5).<sup>4</sup> I am mindful that the critical correlation method has been critiqued for its focus on the individual (e.g., Graham *et al.* 2005; Ramsay 2004). The use of my own story as a case study is also an individual experience of chronic illness. I address this concern by using an **intercultural spiritual care** approach (Doehring 2015, first published 2006) that considers how experiences are shaped by the familial, social, and cultural communities and systems that make up a person’s **web of life** (Miller-McLemore 2008).<sup>5</sup>

The field of pastoral/spiritual theology and care has also been critiqued for privileging the Christian tradition (e.g., Mercadante 2012; Schneiders 2005). My personal spiritual history includes active membership in Lutheran, United Methodist, Episcopal, and Roman Catholic traditions. I am aware of and honor Christian values that remain embedded in my spiritual orienting system. However, today my *lived* spirituality aligns with Buddhist, Hindu, and core shamanic beliefs and practices.<sup>6</sup> Researchers might categorize me as a “none,” “unaffiliated,” or “a religious resistor” (Pew Research Center 2012, 2018). More generously, I might be

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4 I am aware that tension between the biomedical goal of curing and the spiritual care goal to facilitate healing can complicate illness and death for patients and providers. Biopolitics is beyond the scope of this book. Coble (2017) provides a helpful exploration. I write with the assumption that biomedical professionals and spiritual caregivers share goals of well-being, quality of life, and a “good death,” as defined by the patient.

5 Park (2014) notes that Miller-McLemore’s shift from “living human web” to “living web” provides “more room to include different aspects of our lives such as the Internet and other technological developments as well as various non-human contexts such as the global environment and climate change” (p.3.2).

6 For years, I considered myself a Buddhist Christian. See Knitter (2009) for another example of this hybrid identity. In 1991, I married into a Hindu family and embraced aspects of Hindu spirituality. Goldberg (2010) would describe me as a practical Vedantist because I “view spirituality as a developmental process in which each person’s spiritual path must be constantly adjusted to suit his or her temperament, circumstances, and ever-evolving needs” (p.23). Since 2013, I have been immersed in intensive education, training, and practice in core shamanism, which I describe in my illness narrative in this book.

described as “**spiritual but not religious**” (Mercadante 2012). For the purposes of this book, I will identify as **spiritually fluid**, a term coined by Bidwell (2018) to describe people who are:

drawn to multiple traditions at different points in their lives, lured by Mystery itself (which some people, particularly those from a monotheistic stance, call G-d, or the ultimate, or the numinous, or the transcendent). These people are restless until they rest in a combination of spiritual thought and practice—a combination that speaks to and engages their entire being... their spirits adapt to or incorporate multiple experiences, communities, spiritual catalysts, and other circumstances that nourish and mold who they are at a given moment. (p.16)

Use of my personal narrative in this book is one limited way to share “stories seldom heard” from marginalized persons (Moschella 2018, p.20). As a “native informant” (Park 2014, p.3.11), I study, as well as report from, the lived experiences of these marginalized communities:

- Women, whose voices are heard in greater number today, but who remain socially disadvantaged and disempowered around the world (e.g., Gray 2018).
- People living with chronic diseases, whose invisibility is multiplied when their health condition is itself invisible to others. Women are even more disadvantaged as the primary group living with often-invisible chronic conditions (Hirsch 2018; Thorne, McCormick, and Carty 1997).
- People who are spiritually fluid, a group that remains “almost invisible outside academic conversations. They exist at the edges of spiritual and religious communities, erased from public view and rarely heard in public conversations about religion” (Bidwell 2018, p.19). More specifically, I represent people whose spiritual practices

include direct engagement with the spiritual dimension (i.e., people who practice core shamanism), experiences that are often underreported for fear of stigma (Laird, Curtis, and Morgan 2017; Yaden *et al.* 2016).

## Narrative framework

People make sense of their lives through narratives or stories (e.g., Grant, Sallaz, and Cain 2016). **Narrative approaches to spiritual care** view people as **living human documents**, explicitly and implicitly telling the stories of their lives (e.g., Cooper-White 2004; Gerkin 1984). People seek to reinforce the plots of their life stories *and* they are also able to create more life-affirming narratives when existing stories do not contribute to their well-being (e.g., Arora 2013; Carr, McCaffery, and Ortiz 2017; Neuger 2001; Risk 2013; White and Epston 1990). Narrative approaches view storytelling as a healing practice for both individuals and communities (Frank 2017). Narrative methods contribute “thick descriptions” (Geertz 1973) that help spiritual caregivers better understand the diversity of experiences, backgrounds, and contexts that affect the people in their care (Arora and McCulliss 2015; Moschella 2018).

The relatively new field of narrative medicine focuses on **illness narratives** to help healthcare providers “enter the worlds of their patients, if only imaginatively, and to see and interpret these worlds from the patients’ point of view” (Charon 2006, p.9; see also Stanley and Hurst 2011). One healing professional said that “narrative medicine is to the management of suffering as biomedicine is to the management of disease” (Egnew 2018, p.163). Illness narratives are created by patients and the people in their **web of life** to make sense of illness and suffering from that person’s particular vantage point. Illness narratives help people answer questions like *Why is this illness happening?* and *How will I cope with this illness and suffering that results from it?* Narratives around a particular illness experience influence each other and

the ways in which people within the patient's web of life interact (Kalitzkus and Matthiessen 2009).

Many illness narratives are structured as restitution, chaos, or quest narratives (Frank 2013, first published 1995). In a restitution narrative, the person is healthy, becomes sick, and regains health. This story's happy ending is typically associated with acute illness experiences, and it's the most common type of illness narrative. Chronic illness is often told as a chaos narrative in which the person never gets better. In quest narratives, the person actively embraces the illness experience, often in the form of a journey, and gains from the illness experience.

The narrative framework in this book is provided by the story of Dorothy Gale, the protagonist in the beloved literary and film classic *The Wizard of Oz* (Baum 1899; Fleming and Vidor 1939). The original literary rendition of *The Wizard of Oz* has been read as a metaphor for topics such as political-historical commentary in the late 19th century (e.g., Liebhold 2016) and the spiritual journey in contemporary times (e.g., Houston 2012). Years ago, I discovered that *The Wizard of Oz* also rings true as a quest metaphor for the chronic illness journey. I expanded on Fetters' (2006) use of the story to teach medical students and have since used *The Wizard of Oz* to teach hundreds of spiritual caregivers, healthcare providers, undergraduate and graduate students, and adults learners<sup>o</sup> about chronic illness experiences.

The cinematic version of *The Wizard of Oz* is oft-cited as one of the favorite films of all time (e.g., Shoard 2010). The story is familiar to millions of people across generations who have seen it broadcast regularly on television since 1956 (Library of Congress 2018). The film stands the test of time because Dorothy's tale is a **hero's journey**, an archetypal story in which people readily see themselves (Campbell 2008; see an example of using the hero's journey to understand work-life balance with multiple sclerosis in Vijayasingham 2018). Although *The Wizard of Oz* is not explicitly a story of chronic illness, this hero's journey aptly illustrates the liminal space inhabited by people with

chronic health conditions who vacillate between **illness-in-the-foreground** (Dorothy in the Land of Oz) and **wellness-in-the-foreground** (Dorothy in Kansas).

I will use my personal quest narrative as a case study to help flesh out the archetypal experiences revealed in Dorothy's narrative. I write this book and share my story from the intersection of four distinct, yet overlapping, worlds:

- I am Co-Director and Assistant Clinical Professor of Spiritual Care for the Interdisciplinary Graduate Certificate and Master of Science in Palliative Care<sup>7</sup> degree programs at the University of Colorado Anschutz Medical Campus in Denver, Colorado. I teach spiritual care practices to palliative care providers around the world, including biomedical clinicians (physicians, nurses, physician assistants, pharmacists), social workers, psychologists, spiritual caregivers, and other allied health professionals.
- As the John Wesley Iliff Senior Adjunct Lecturer in Spiritual Care at the Iliff School of Theology in Denver, Colorado, I teach spiritual care to graduate and doctoral students who will support and help diverse people in varied contexts, with a special emphasis on people who are underserved or marginalized.
- As a spiritual director/companion for over two decades and as a healer using core shamanic practices,<sup>8</sup> I have provided spiritual care to many people who live with chronic health conditions.
- I am a person living with a chronic health condition. Over 20 years ago, I was diagnosed with rheumatoid arthritis, a chronic, invisible, incurable disease. I use my

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7 **Palliative care** is specialized health care that eases physical, psychological, social, and spiritual suffering and improves quality of life for people and families living with serious and life-limiting illnesses.

8 I describe spiritual direction and core shamanic practices in Chapter 4.

story to provide contemporary and concrete examples of the spiritual dimensions of chronic illness. My story also offers glimpses into the potential for wholistic healing and well-being made possible by core shamanic practices that honor interconnections among mind, body, and spirit at energetic and spiritual levels.

## Looking ahead

The chapters in this book follow Dorothy's journey from Kansas to Oz and back. Dorothy's tale has much to teach us about the journey of chronic illness. Following the tornadic experience of illness onset and diagnosis, our hero reluctantly begins to explore an unknown land where illness is in the foreground. As Dorothy and her companions follow the Yellow Brick Road in search of healing, we'll consider how their experiences can inform our practice of spiritual care for people with long-term health conditions.

Our hero/patient eventually returns to Kansas, the land of wellness-in-the-foreground. Because of her experiences in Oz, she can claim citizenship within both worlds of wellness and illness, highlighting the way many people with chronic illnesses must navigate shifts between these experiences. I use my own story to further illuminate practices of spiritual care that can ease suffering on the chronic illness journey. In each chapter, I offer guidelines and practical tools to help you integrate what you learn from this book into your own lives and practices of spiritual care.

Chapter 1 describes the unsettling threat and onset of a life-altering disease: the unwanted call to the hero's journey of chronic illness. This chapter also introduces important terms and concepts. In Chapter 2, I describe common ways people make meaning about the cause of illness. We focus on how people make meaning of chronic illness early in their experience, typically around diagnosis, illustrated by Dorothy in her conversation with Glinda, the Good Witch.

As our hero begins her journey on the Yellow Brick Road, the reality of long-term illness threatens Dorothy's well-being. Chapter 3 describes common psycho-spiritual concerns associated with chronic illness experiences. We consider losses, disenfranchised grief, anxiety, depression, demoralization, and the desire for hastened death. We also reflect on the burden family caregivers bear as part of their illness experience.

In Chapter 4, Dorothy and her companions cope with the stress of illness in the chronic phase of their journeys. I identify common spiritual struggles associated with chronic illness, describe how people draw on spirituality to cope with stress, and recommend spiritual coping strategies that facilitate healing and well-being. Chapter 5 takes a closer look at the therapeutic relationship between patient and healer. We explore aspects of healing relationships and the importance of hope, using Professor Marvel and the Wizard of Oz as our case studies. In Chapter 6, the film ends as Dorothy shifts into a recovery phase and returns to wellness-in-the-foreground in Kansas. We return to the type of meaning making that typically occurs later in the chronic illness trajectory. We consider potential benefits and opportunities for post-traumatic growth from chronic health conditions. Finally, we consider how people ultimately negotiate a balance within and between the worlds of wellness-in-the-foreground and illness-in-the-foreground.

Although I write directly to spiritual caregivers, this book is for everyone affected by chronic health conditions. Perhaps you seek a better understanding of the spiritual dimensions of your own illness or wish to support someone you care for in some capacity. My hope is that immersion in Dorothy's story and my personal experiences will enhance your ability to care for people you know who live with chronic health conditions. Always keep in mind that illness experiences are unique for each person, and spiritual care must be specific to the person to help alleviate suffering. May these stories encourage you as you offer compassionate, authentic, and potentially transformative care

for people with chronic health conditions. Whatever brings you to the Land of Oz, I invite you to join me now as we follow the Yellow Brick Road.