

INTRODUCTION

FROM "SPECIAL POPULATION" TO INCLUSION — A PARADIGM SHIFT

When I began work on this book, I set out to write a resource for **hospice** and **palliative care** professionals that would be equally relevant and engaging to palliative care and hospice professionals from multiple disciplines; would change the way readers approach their work with *all* patients, not just with those who are lesbian, gay, bisexual, transgender, queer, and/or questioning (LGBTQ); and would show readers that having conservative religious or moral beliefs and providing high-quality, inclusive care to LGBTQ people and their families are not mutually exclusive. While the majority of the book is dedicated to achieving the first two goals, the third goal is equally important.

In the twelve years that I've been speaking to audiences about caring for LGBTQ individuals with chronic or life-limiting illnesses, one thing has remained fairly constant: health care providers with more conservative religious beliefs come to my presentations with significant discomfort at the outset—if they come at all. Changing the way LGBTQ individuals with chronic or life-limiting illnesses are cared for requires a paradigm shift in the way we (collectively, as health care professionals) approach the conversation about what it means to be inclusive in our compassion. You don't need to change your religious or moral beliefs to provide good care to LGBTQ individuals. So if you are unsure about buying or

reading a book about LGBTQ people, don't be. At its core, this is simply a book about *people*.

LGBTQ-inclusive practice begins with an active choice—a choice to change our practice so that all are welcome and treated with dignity and compassion. I have never met a hospice or palliative care provider who consciously excludes LGBTQ individuals and their families. I do not believe that care professionals make a conscious choice to give poor care to LGBTQ individuals and their families. However, unless palliative care and hospice providers make a conscious choice to engage in LGBTQ-inclusive practice, they are, by default, unintentionally choosing to exclude LGBTQ people from receiving the high-quality care that all people deserve.

WHY THIS BOOK?

There is no shortage of well-researched publications for palliative care and hospice professionals. Several seminal works come to mind immediately:

- *Advanced Practice Palliative Nursing* (Dahlin, Coyne, and Ferrell 2016)
- *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life* (Institute of Medicine 2015)
- *Geriatric Palliative Care* (Chai et al. 2014)
- *Oxford American Handbook of Hospice and Palliative Medicine and Supportive Care* (Yennurajalingam and Bruera 2016)
- *Oxford Textbook of Palliative Medicine* (Cherny et al. 2015)
- *Oxford Textbook of Palliative Nursing* (Ferrell, Coyle, and Paice 2015a)
- *Oxford Textbook of Palliative Social Work* (Altilio and Otis-Green 2011)
- *Pediatric Palliative Care* (Ferrell 2015)
- *Textbook of Palliative Care Communication* (Wittenberg et al. 2015)

In most of the texts listed, LGBTQ populations are either relegated to a stand-alone chapter, as is the case in the *Textbook of Palliative Care Communication* and the *Oxford Textbook of Palliative Social Work*, or they are mentioned briefly within the context of chapters on sexuality, “special populations,” “cultural considerations,” or HIV/AIDS, as in the *Oxford Textbook of Palliative Nursing*, the *Oxford Textbook of Palliative Medicine*, and *Geriatric Palliative Care*. There is no discussion at all of LGBTQ populations in *Pediatric Palliative Care*, with the exception of a brief mention in a chapter about **grief** and **bereavement** where the authors note that “single parents or same-sex parents may not have as many options for support as married parents in a heterosexual relationship” (Limbo and Davies 2015). *Advanced Practice Palliative Nursing* contains a brief acknowledgment that “the APRN will encounter a wide diversity of patients, such as military veterans; individuals with developmental disabilities; individuals with mental illness and personality disorders; prison inmates; the lesbian, gay, bisexual, transgender, and intersex community; individuals with substance use disorders; individuals who are homeless; and individuals of a low socioeconomic status” (Gibson 2016), but no content regarding how to provide LGBTQ-inclusive care. The most glaring absence of LGBTQ persons with serious or life-limiting illnesses, however, is in the 639-page *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, in which the words and phrases *gay*, *lesbian*, *bisexual*, *transgender*, *sexual orientation*, *sexuality*, and *LGBTQ* are never used, not even once.

There is a critical need to move beyond ignoring the existence of LGBTQ people, thinking of LGBTQ people as a “special population,” or conceptualizing LGBTQ people as a group that merits mention only within the context of discussions about disease and dysfunction. When LGBTQ people are relegated to a single chapter in a book, the clinicians most in need of the information may skip reading it entirely. Even more concerning, this approach to the presentation of content

reinforces the idea that LGBTQ people are “other.” (In *Advanced Practice Palliative Nursing*, the single mention of LGBTQ people is included in a list of other “special populations,” sandwiched between “prison inmates” and “individuals with substance use disorders” [Gibson 2016]).

MAKING THE SHIFT TO LGBTQ-INCLUSIVE CARE

This book turns the traditional approach to addressing LGBTQ patients in palliative care and hospice upside down, in order to help clinicians make the shift from providing *special* care to LGBTQ people to instead providing *inclusive* care to *all* people, including those who are LGBTQ.

In writing *LGBTQ-Inclusive Hospice and Palliative Care*, I made a conscious decision to use a conversational tone rather than an academic one. Unlike discipline-specific books that cover dense, foundational content like the pathophysiology of pain, pharmacology, or pain and symptom management, this book seeks to provide both new and experienced hospice and palliative care professionals with the knowledge they need to shift from providing high-quality care to *high-quality LGBTQ-inclusive care*. You may be reading this and thinking that you already provide LGBTQ-inclusive care. You treat every person the same — why would your treatment of LGBTQ people and their families be any different? These are great questions, and ones I hear a lot. Providing LGBTQ-inclusive care requires a shift in the way you think about hospice and palliative care. Being inclusive is not the same as treating everyone the same. In fact, treating everyone the same is an approach that rarely benefits patients, regardless of whether they are LGBTQ, because patients aren't all the same. This book will give you clear, actionable strategies to use in transforming your care of patients so that it is truly LGBTQ-inclusive. The ultimate goal is for LGBTQ-inclusive care to be what you provide to *all* patients — not a “specialized” form of care provided to LGBTQ patients.

USING THIS BOOK TO MAKE THE SHIFT

Providing LGBTQ-inclusive hospice and palliative care involves making subtle changes in the way you approach almost every aspect of care. At first glance, the titles of chapters in this book may appear to reflect topics with which you are already quite familiar. While experienced hospice and palliative care professionals are likely to have a solid background in many of these broad topic areas, the chapters are designed to build on that knowledge rather than duplicate it. To get the maximum benefit out of this book, it is important to read all of the chapters. That being said, I have written this for readers in four distinct disciplines, medicine, nursing, chaplaincy, and social work/counseling, and your own discipline's **scope of practice** will determine whether and how you integrate the content into your professional practice. For example, although everyone should read the chapter on conducting a physical exam, if you are a chaplain, social worker, or counselor, you will not conduct physical exams yourself because they are outside your discipline's scope of practice.

Of course, you don't have to be a physician, registered nurse, advanced practice registered nurse, chaplain, social worker, or counselor to benefit from reading this book. Clinical psychologists, pharmacists, home health aides, licensed practical nurses, licensed massage therapists, registered dietitians, music therapists, speech-language pathologists, physical/rehabilitation therapists, volunteer coordinators, administrators, and educators, will find that this book can help change the way they work with patients, families, staff, students, and volunteers. And if you are a student, it will help you get off on the right foot in terms of LGBTQ-inclusive practice as you begin your work with patients and their families.

COMPETENCY-BASED SCAFFOLDING

LGBTQ-Inclusive Hospice and Palliative Care is built on a scaffolding of learning objectives designed to address the needs of physicians, advanced practice registered nurses

(APRNs), registered nurses (RNs), social workers, counselors, and chaplains working in the field of hospice and palliative care. I developed these learning objectives using discipline-specific competencies, curricular guidelines, and professional standards. Since there are no existing competencies focused on LGBTQ-inclusive hospice and palliative care, I set out to find and compile hospice and palliative care competencies first, and then LGBTQ-specific health care competencies. After gathering competencies in these two broad areas for the four target disciplines, I planned to create a crosswalk between the areas and develop working competencies for LGBTQ-inclusive hospice and palliative care for each discipline. At least, that was the original plan. I had mistakenly assumed it would be relatively easy to find hospice and palliative care competencies and LGBTQ-specific competencies for each of the disciplines, and that the challenge would be in converting them into LGBTQ-inclusive hospice and palliative care competencies.

Unfortunately, of the four health care disciplines this book addresses, only medicine has established detailed competencies for both the care of LGBTQ persons and the care of persons with chronic or life-limiting illnesses (see Association of American Medical Colleges [AAMC] 2014, American Academy of Hospice and Palliative Medicine [AAHPM] 2009, American Academy of Family Physicians [AAFP] n.d., Joint Commission 2011). The social work discipline has indicators for cultural **competence** and general standards for social work practice in palliative and hospice care but no set of competencies specific to working with LGBTQ individuals (National Association of Social Workers [NASW] 2007, NASW 2004, Hay and Johnson 2001). Similarly, the chaplaincy discipline has general competencies for hospice and palliative care chaplains but no competencies specific to working with LGBTQ people and their families (California State University Institute for Palliative Care and Healthcare Chaplaincy Network 2015).

In gathering palliative care and hospice competencies, I looked to the certification requirements outlined by the cre-

credentialing bodies in the four disciplines. The American Board of Medical Specialties administers the Hospice and Palliative Medicine (HPM) subspecialty for physicians, and the American Osteopathic Association's Bureau of Osteopathic Specialists administers the Certificate of Added Qualification (CAQ) in hospice and palliative medicine for osteopathic physicians. Certification requires completion of a fellowship as well as passage of a daylong examination (AAHPM n.d.).

The Hospice and Palliative Credentialing Center (HPCC) administers the Certified Hospice and Palliative Nurse credential as well as the Advanced Certified Hospice and Palliative Nurse credential. Certification requires completion of 500 hours of practice in the previous year (or 1,000 hours in the previous two years) as well as passage of a lengthy examination (HPCC 2016a, 2016b).

The Hospice Medical Director Certification Board (HMDCB) administers the Hospice Medical Director Certification, which requires "400 hours of broad hospice-related activities" and either "two years of work experience in a hospice setting during the previous 5 years," "current, valid board certification in hospice and palliative medicine through the American Board of Hospice and Palliative Medicine (ABHPM), the American Board of Medical Specialties (ABMS), or the American Osteopathic Association (AOA)," or "successful completion of a 12-month clinical hospice and palliative medicine training program accredited by the Accreditation Council for Graduate Medical Education (ACGME) or AOA" (HMDCB 2013).

The National Association of Social Workers Specialty Certification Program administers the Certified Hospice and Palliative Social Worker credential and the Advanced Certified Hospice and Palliative Social Worker credential. Certification requires several years of supervised practice as a hospice and palliative care social worker, but there is no examination.

The Board of Chaplaincy Certification administers the Certified Hospice and Palliative Care Chaplain credential.

Requirements for certification are substantial (including a ten-page essay, three years of experience in hospice and palliative care, and three recommendation letters), but no examination is required.

Because the medicine and nursing competencies were so detailed, I was able to compile a spreadsheet of the competencies from each of the disciplines and then develop working competencies appropriate to each discipline to fill in the gaps. This is not the best way to develop competencies, but it gave me a draft set around which to develop the content of the book. Perhaps *LGBTQ-Inclusive Hospice and Palliative Care* will stimulate leaders from the four disciplines to come together to develop competencies in LGBTQ-inclusive hospice and palliative care.

HOW THE BOOK IS ORGANIZED

Providing LGBTQ-inclusive hospice and palliative care requires changes at two levels: the individual and the institutional. At the individual level, hospice and palliative care professionals can shift toward providing more LGBTQ-inclusive care by adopting a structure of self-awareness and changing the way they assess, interact with, and support the patients and families they work with. At the institutional level, organizations can strengthen their inclusion of LGBTQ individuals and their families by (1) updating language on the forms they use, (2) developing LGBTQ-inclusive messages and outreach strategies, (3) hiring more LGBTQ staff, (4) offering equitable benefits to employees in same-gender relationships and transgender employees, and (5) providing training to employees and volunteers. The chapters in this book build on one another, starting from the individual level in Chapter 1 and working up to the institutional level in Chapter 10. The following is a brief overview.

Chapter 1 describes a seven-step process that hospice and palliative care professionals can use to improve their ability

to provide inclusive, nonjudgmental care when planning, engaging in, and reflecting on a patient interaction. In addition, the chapter describes communication techniques as well as verbal and nonverbal approaches to facilitating LGBTQ-inclusive care.

Chapter 2 explains the relationships among sex, gender, gender identity, gender expression or gender presentation, gender discordance, gender nonconformity, gender dysphoria, sexual orientation, sexual behavior, sexuality, and sexual health and discusses their relevance in the palliative care and hospice setting. In addition, the chapter describes a two-step process for asking patients about their assigned birth sex and true gender and explains the use of gender-neutral pronouns.

Chapter 3 explains why, given the historical and contemporary contexts within which LGBTQ people live, it's not surprising that some LGBTQ patients and families may be reluctant to seek care. The chapter describes three kinds of barriers to palliative care and hospice care—perceptual, financial, and institutional—and offers a two-pronged approach to addressing such barriers for LGBTQ patients.

Chapter 4 describes a new LGBTQ-inclusive approach to taking a comprehensive history that places the primary emphasis on the patient as person.

Chapter 5 explains how to coordinate and facilitate a family meeting focused on shared decision making, how to use shared decision making for issues surrounding palliative sedation, and how family dynamics may play a role in the shared decision-making process.

Chapter 6 explains how to help patients and families identify their own unique goals for care, how to use a set of key questions to refocus interdisciplinary/interprofessional team meet-

PROVIDER PERSPECTIVE

Though I consider myself a conservative Christian, my eyes have been opened regarding the differences in moral and civil beliefs. Several years ago I cared for a patient who was a lesbian. As I made my visits and came to know her and the partner she had shared over twenty years of her life with, I realized that this couple was like any loving, committed couple that I had witnessed hundreds of times before. There were family photos throughout the home, children and grandchildren on both sides were involved, along with any number of relationship quirks that go along with a couple that has been together long-term. What grieved me the most about this experience was the fact that her partner . . . was unable to take Family and Medical Leave Act [FMLA] time because they weren't considered to be married. So as the patient continued to decline, her partner, with whom she had shared almost half of her life, continued to have to work six days a week, almost twelve hours a day, because she was unable to take time off.

Now, my own Christian beliefs still dictate to me that a marriage is solely between a man and a woman. However, I have come to the conclusion that any committed couple, who have been together a number of years, should have the same civil rights of those couples who are of opposite sex. The fact that my patient was a lesbian wasn't the eye-opener for me—it was the fact that as she lay dying, the love of her life was literally two blocks away, working, because she wasn't able to take FMLA time. This seemed very wrong to me. I hope you can use my experience. I have come to believe that though my Christian beliefs can be black-and-white, the bottom line for my faith is still "love," and those [who] love should be able to be by the side of those they love, no matter the gender of their partner.

—JENNIFER HAWKINS, RN, CHPN

ings on patient- and family-centered outcomes of care, and how to conduct an environmental and safety risk assessment.

Chapter 7 provides an overview of the ethical principles that guide practice, the elements of advance care planning, and the legal issues that may have an impact on LGBTQ individuals, in particular, as they navigate serious and life-threatening illness and seek to remain the authors of their own lives.

Chapter 8 provides specific, actionable strategies for teaching patients and families about patient-care skills, end-stage disease progression, pain and symptom management, medication management, disposal of supplies, and signs and symptoms of imminent death.

Chapter 9 explains the developmental tasks of life completion and life closure as well as the roles that despair, hope, and meaning play in the context of advanced illness. The chapter describes LGBTQ-inclusive assessment skills and supportive techniques for addressing psychosocial and spiritual issues, and explains how a spiritual/existential history and a spiritual/existential assessment differ. Finally, this chapter examines the ways in which the members of the interdisciplinary/interprofessional team work in collaboration with one another to support the patient and family in achieving their goals for care in the psychosocial and spiritual/existential domains.

Chapter 10 explains how to assess the structural integrity of an institution's or program's bridge to LGBTQ individuals and their families, and how to construct that bridge in order to reach, welcome, and serve LGBTQ individuals and families. After you have finished reading Chapter 10, consider ways you can encourage your organization to implement the types of changes described.

Each chapter contains the following elements:

- **Chapter Objectives:** Actions or behaviors (e.g., list, describe, explain, recognize, discuss) you should be able to perform after reading the chapter.
- **Key Terms:** Words or phrases covered within the chapter and also defined in the Glossary at the back of the book.
- **Chapter Summary:** A brief overview of the chapter.
- **Perspectives:** Text boxes containing personal stories submitted by palliative care and hospice providers, patients, and families.
- **Key Points to Remember:** A list of the chapter's main ideas or takeaway points.
- **Discussion Questions:** Questions you can use for self-assessment or to guide team-based or classroom-based discussions about the chapter.
- **Chapter Activity:** An activity that provides an opportunity for applying or reflecting on the chapter's content.

At the back of the book, you will find a glossary of important terms, a list of the references cited, and brief biographies of the experts who reviewed and validated the content. Additional resources, such as downloadable pocket guides, can be found on the website for *LGBTQ-Inclusive Hospice and Palliative Care*, <http://www.lgbtq-inclusive.com>.