

LGBTQ-Inclusive Hospice and Palliative Care: Transforming Professional Practice

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Kimberly D. Acquaviva. *LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice*. New York, NY: Harrington Park Press, 2017, 250 pp., paperback (\$25.00, ISBN: 9781939594143); hardcover (\$60.00, ISBN: 9781939594150); E-book (\$19.99, ISBN: 9781939594167).

IN THE INTRODUCTION TO HER BOOK, *LGBTQ-Inclusive Hospice and Palliative Care*,¹ author Kimberly Acquaviva, PhD, MSW, CSE, writes about a needed fundamental paradigm shift for health professionals caring for LGBTQ* communities—shifting the focus from providing *special* care for LGBTQ people (author’s emphasis) to inclusive care for *all* people, including those who identify as sexual and gender minorities. Unlike previous writings on hospice, end-of-life, and palliative medicine for LGBTQ populations, which often describe LGBTQ communities as “Special Populations” and relegate them to a chapter in a health text that some readers may skip altogether, Acquaviva argues for a different approach. Being inclusive is an active process and attainable by all health professionals, Acquaviva posits. She writes that one of her goals for this book was to show readers with all beliefs and from all backgrounds, including those who are conservative, that one does not have to change religious or moral beliefs to provide good care to LGBTQ individuals. She adds “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.”¹

It is apt that the book’s first chapter is entitled “Self-Awareness and Communication.” In this chapter, the author encourages readers to recognize and assess attitudes, beliefs, and feelings around sexual orientation, gender identity, gender expression, and gender presentation as well as death and dying. Moreover, Dr. Acquaviva has readers reflect on their own unconscious biases about these topics to mitigate their effects on clinical judgments and behaviors.

The remainder of this 250-page book provides the reader with methods to create a more inclusive clinical experience for LGBTQ people in end-of-life and hospice care through a structured framework of competency-based learning objectives. These objectives are meant to address the needs of physicians, advanced practice nurses, registered nurses, social workers, counselors, and chaplains working in the field of hospice and palliative care. Arranged into 10 chapters,

Dr. Acquaviva guides the reader through ways in which individual health professionals, administrators, and health organization leaders can adopt a structure of self-awareness and change the way they assess, interact with, and support the LGBTQ patients and families with whom they work. Dr. Acquaviva conveys these messages in a way that avoids a moralistic tone, but emphasizes the need to adopt inclusive behaviors such as empathic and facilitating verbal and nonverbal interactions, including self-disclosure, touch, and humor.

The author covers a diverse range of topics such as improving the hospice and palliative care provider’s ability to provide inclusive, nonjudgmental care when planning, engaging in, and reflecting on patient interactions; understanding the various constructs used to describe sexuality and gender; describing barriers to palliative and hospice care particular to sexual and gender minority individuals; taking a comprehensive LGBTQ-inclusive health history; using shared decision-making with LGBTQ patients and families; helping patients and families identify their goals of care; reviewing ethical principles and legal issues affecting LGBTQ patients; teaching patients and families about patient care skills; understanding the developmental tasks of life completion and life closure; and developing institutional inclusion of LGBTQ communities and patients in the clinical setting.

The book’s chapters are carefully structured with listed objectives, key terms, and a summary. Each chapter includes key points to remember and ends with a set of discussion questions as well as a chapter activity in which the reader has an opportunity to reflect on and apply the chapter content. Perspectives or personal stories submitted by patients and providers illustrate the chapters. The book concludes with a comprehensive glossary of terms and bibliographic references.

As a clinician whose expertise is not in end-of-life care or palliative care, I found the book’s content to be illuminating with respect to the care of all patients facing end-of-life concerns and especially those from LGBTQ families and communities. Communication strategies such as the CAMPERS process—clear purpose, attitudes and beliefs, mitigation plan, patient, emotions, reactions, and strategy—provide a framework to work with a variety of patients, including those who are sexual or gender minorities. The patient, provider, and family perspectives add broad social context and help the reader apply fundamental and nuanced communication concepts. Whether the voices heard from the perspectives address a

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*Dr. Acquaviva uses the term “LGBTQ” to be “inclusive of all who self-identify as lesbian, gay, bisexual, transgender, gender nonconforming, queer, and/or questioning.”¹

person's chosen pronouns or relationship status, they do so in an affirming and human manner. Overall, the book is very easy to read and functions as an expertly written and expert-vetted guidebook on developing best communication and care practices for LGBTQ end-of-life care. Although there are other works that address LGBTQ hospice and palliative care issues, such as *Geriatric Palliative Care*² and the *Textbook of Palliative Care Communication*,³ they do not integrate LGBTQ content or present LGBTQ populations within the inclusive framework as described by Dr. Acquaviva.

Dr. Acquaviva's superb book does have a few small gaps. Although she describes a tool that she developed, called the Five-Dimension Assessment Model, to ascertain broad patient history in palliative and hospice care, and reviews several pertinent patient care questions about sexual behavior and sexual function, she does not offer the reader a sense of how to respond after patients answer normalized questions about their sexuality. Additional specific recommendations or resources would be helpful to guide clinicians who learn that their client is experiencing pain with sexual activity but may lack specific sexual health expertise. However, she does differentiate between and provide examples of relevant patient care questions regarding intrusive questions that arise from prurient interest.

Another area that could have been developed further is that of HIV and AIDS. The text does not mention HIV-associated stigma and how this may influence end-of-life and palliative care discussions. HIV is mentioned in Dr. Acquaviva's book, but only in the context of developing an inclusive non-discrimination statement for health organizations. Other critiques of the book are that the text is quite dense and there are few images. There are text boxes, but no figures or diagrams that would have been helpful in conveying knowledge to those who are visual learners. Finally, a readily available set of organization resources was not included as part of the book in print, but the author did provide the URL

where the reader can find additional resources, including downloadable pocket guides.⁴

Overall, Dr. Acquaviva was successful in authoring a book that accomplishes the difficult goal of weaving together the topics of hospice and palliative care, sexual and gender minority health, and ethics and spirituality, using plain language that is easy to comprehend. This book is indispensable for health professionals and health professional students who want to prepare themselves for better understanding and addressing issues that arise at the intersection of end-of-life care and sexual and gender minority health.

Author Disclosure Statement

No competing financial interests exist.

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