Book Review *LGBTQ-Inclusive Hospice and Palliative Care*

Kimberly D. Acquaviva
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LGBTQ-Inclusive Hospice and Palliative Care is written by Kimberly Acquaviva, who is a professor at George Washington University in the School of Nursing. Acquaviva has a doctorate in human sexuality education with a master's degree in social work from the University of Pennsylvania. Although this book is written for all hospice and palliative care providers, Acquaviva's emphasis on social justice, respect for human diversity, and value of cultural competence clearly applies to social work practice. This book is most valuable for what it reveals about the experiences of LGBTQ patients.

Acquaviva begins by suggesting that practitioners must evaluate one's propensity to facilitate LGBTQ-inclusive care. The author engages the reader in a seven-step self-awareness process designed to help hospice and palliative care providers clarify the purpose for their intervention and know their attitudes and beliefs, mitigation plans, patients, emotions, reactions, and strategies (also referred to as CAMPERS). The author suggests the creation of a mitigation plan rooted in self-awareness is most essential to remain client-centered.

Chapter 2 addresses terminology that may apply in working with LGBTQ patients. The author defines cisgender and transgender as they relate to congruence between gender identity and gender assignment. Gender identity and gender expression are defined relative to internal perception and external expression. Gender discordance is indicated by a lack of congruence between anatomical sex and gender identity, which can lead to gender dysphoria. Gender-neutral pronouns such as *they* and *ze* may be preferred over the gendered pronouns of *he* and *she*.

Chapter 3 describes decades of oppression against sexual minorities along with common myths and misperceptions that may further undermine LGBTQ-inclusive care. Acquaviva links this experience of oppression to perceptual and financial barriers and presents numerous concerns of LGBTQ patients that risk

limiting access to care. For example, transgender patients may erroneously fear that they must discontinue hormone therapy if they enter hospice. Hospice and palliative care programs are encouraged to address the systemic need for inward change (e.g., staff training) and outward change (e.g., website, brochure) to be more inclusive of LGBTQ patients.

In Chapter 4, Acquaviva discusses a Five-Dimension Assessment Model with recommendations for how to ask sensitive questions. Transgender and gender nonconforming patients are at greatest risk for being asked intrusive questions. Hospice and palliative care providers can affirm patients by acknowledging a patient's gender identity and are advised to take cues from LGBTQ patients to determine the extent to which a same-sex partner, extended family members, and friends should be included in the assessment process. Providers can help by conveying receptivity to diverse family forms.

A case scenario is presented in Chapter 5 that describes the experience of emotional and spiritual distress involved in determining the appropriateness of palliative sedation. The author discusses how to complete a genogram to clarify the nature of significant relationships. LGBTQ patients may not be estranged or have complicated relationships with their family members, but advocacy may be required to ensure patient self-determination and autonomy. When there is family conflict, it is especially important to have someone legally authorized to make medical decisions on the patient's behalf.

Chapter 6 addresses goal setting that is patient- and family-centered. This includes an environmental and safety risk assessment. Acquaviva notes that LGBTQ patients are more likely to smoke cigarettes, a safety risk when a patient requires oxygen therapy. Hospice and palliative care providers should educate the patient and family about precautions with the use of oxygen equipment if patients prefer to continue smoking safely. This involves directing the patient to disconnect from their oxygen source for at least 10 minutes before going outside to smoke.

Ethical duties, goals, and the iterative nature of advanced care planning are addressed in Chapter 7. Acquaviva advises LGBTQ patients who are not married and are estranged from family members to seek legal assistance to ensure their wishes will be honored. If an LGBTQ patient has an unmarried life partner, that person needs to be designated as the patient's health-care power of attorney to remain involved in the decision-making process. Otherwise, the patient's legal spouse or next of kin is likely to retain this right. LGBTQ patients also need legal assistance to write a funeral directive and/or to ensure property ownership transfers to an unmarried life partner or friend.

Also, Acquaviva points out in Chapter 7 that information on sexual orientation, sex anatomy, and gender identity is protected under the Health Insurance Portability and Accountability Act. Hospice and palliative care providers should not share this information outside the care team. Information about a patient's sex anatomy should only be shared if it is necessary for quality care and if the patient consents to this disclosure.

Chapter 8 focuses on how to address patient and caregiver knowledge and needs relative to patient-care skills, end-stage disease progression, pain and symptom management, medication management, disposal of supplies, and signs and symptoms of imminent death. This chapter is most inclusive of the universal needs associated with hospice and palliative care. Education helps prepare patients and their families for imminent death.

Psychosocial and spiritual issues are addressed in Chapter 9, which discusses supportive strategies for assessing anticipated developmental landmarks with implications for quality of life. Acquaviva focuses on how to support patients experiencing spiritual/existential distress. The author distinguishes between a spiritual history and spiritual assessment and describes how colleagues can work together to ensure client needs are met. Tables throughout the chapter summarize extensive information about psychosocial and spiritual issues, including examples of how to properly word questions and document responses.

In the final chapter, hospice and palliative care providers are encouraged to evaluate their organizations for signs of LGBTQ inclusion. Institutions can communicate a commitment to inclusive care through their marketing and outreach efforts, nondiscrimination policy, employee training and benefits, and intake paperwork and procedures. An organization's commitment to LGBTQ patients and their families should extend to their LGBTQ employees through, for example, a nondiscrimination policy that protects employees based on sexual orientation, gender identity, gender expression, or gender presentation.

LGBTQ-Inclusive Hospice and Palliative Care is written in a practitioner-friendly style that allows for immediate application. Author reflections and practitioner comments lend insight and presence to the narrative, making it accessible for undergraduate and graduate students if used as a course supplement. Each chapter begins with a chapter objective and summary and ends with key points, discussion questions, and chapter activity for easy reference. This book provides examples and refers to downloadable pocket guides to facilitate inclusive care, which may apply in other settings as well (Acquaviva, 2016).

Acquaviva makes visible what has been invisible, perhaps even to LGBTQ patients. For example, LGBTQ patients may not identify with terms such as

cisgender or *genderqueer*. They may not employ gender-neutral pronouns such as *ze*, *hir*, or *zir*. LGBTQ patients may not view themselves as gender nonconforming or reference a same-sex spouse as husband or wife. The use of unfamiliar terms risks a new form of labeling and objectifying LGBTQ patients. Hence, hospice and palliative care providers need to be sensitive to diversity within the LGBTQ community rather than imposing cultural artifacts of inclusion.

Reference

Acquaviva, K. D. (2016). Free resources for LGBTQ-inclusive care: Downloadable pocket guides. Available at https://www.lgbtq-inclusive.com/resources-and-checklists