

# PALLIATIVE AND END-OF-LIFE CARE FOR LESBIAN, GAY, BISEXUAL, AND TRANSGENDER (LGBT) CANCER PATIENTS AND THEIR CAREGIVERS

KRISTIN G. CLOYES, WILLIAM HULL, AND ANDRA DAVIS

**OBJECTIVE:** *To identify the unique needs of lesbian, gay, bisexual, and transgender (LGBT) cancer patients and caregivers, and review recommendations supporting more effective and inclusive palliative and end-of-life care.*

**DATA SOURCES:** *Published research and clinical guidelines.*

**CONCLUSION:** *Transitions in care raise particular challenges for LGBT patients, including provider communication, perceptions of safety and acceptance, and assessing and respecting patients' definitions of family and spirituality.*

**IMPLICATIONS FOR NURSING PRACTICE:** *LGBT patients and their caregivers need competent nurses to support them, especially during transitions. Implementing LGBT-inclusive education, training, and practice will improve outcomes for LGBT cancer patients and their caregivers – and potentially all patients.*

**KEY WORDS:** *LGBT, palliative care, end-of-life care, hospice.*

Kristin G. Cloyes, PhD, MN, RN: Associate Professor, University of Utah College of Nursing, Salt Lake City, UT. William Hull, BSN, Doctoral Student: University of Utah College of Nursing, Salt Lake City, UT. Andra Davis, PhD, MN, RN: Assistant Professor, Washington State University College of Nursing, Vancouver, WA.

Address correspondence to Kristin G. Cloyes, PhD, MN, RN, 6523 SE 41st Ave., Portland, OR 97202. e-mail: [Kristin.cloyes@nurs.utah.edu](mailto:Kristin.cloyes@nurs.utah.edu)

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Health care providers and scientists have recently begun to pay more attention to the health care experiences of lesbian, gay, bisexual, and transgender (LGBT) patients and caregivers. While this attention is relatively new for providers and researchers who are not themselves members of the LGBT community, there is a growing body of work in oncology concerning the needs of LGBT patients, their caregivers, and families. For example, organizations like LGBT HealthLink and the National LGBT Cancer Network have been making strides in raising awareness and promoting

best-practice recommendations for cancer care in the LGBT community.<sup>1,2</sup> To date, less attention has been paid to palliative and end-of-life care for LGBT patients, but this is changing. In 2017, the practice guide “LGBTQ-Inclusive Hospice and Palliative Care” was the first comprehensive guide aimed at giving professionals practical information for providing competent care to the LGBT community.<sup>3</sup> Despite the advances in oncology, however, there are relatively few research studies – including intervention studies and comparative research on factors that influence outcomes for LGBT and non-LGBT groups – that focus on issues for LGBT cancer patients and their caregivers.

This article focuses on the unique challenges faced by LGBT cancer patients, caregivers, and providers involved in palliative and end-of-life care, and synthesizes the literature most salient to the intersection of sexual orientation, gender identity, cancer, and considerations for care. Both palliative and end-of-life care involve a dynamic continuum of care, and are characterized by a number of significant transitions. This article will focus on how these transitions can pose particular challenges for LGBT cancer patients and their caregivers.

Cancer care transitions raise issues related to inclusive and effective provider communication, disclosure or non-disclosure of orientation or transgender, gender-nonconforming or queer identity as patients encounter new providers and settings, how family is defined by the patient and their providers, and the need to consider the spiritual needs of LGBT patients. Finally, recommendations are offered for education, training, and practice for oncology nurses working with LGBT cancer patients, caregivers, and their networks of family and friends. This information will help oncology nurses and researchers better understand the unique needs of the LGBT community. Nurses can improve patient-centered care and shared decision making, reduce avoidable burdens that stem from provider lack of understanding and experience, facilitate conversations about issues to identify patients’ goals of care and to support patient autonomy, and communicate more respectfully and effectively with LGBT patients.

### MULTI-DIMENSIONAL TRANSITIONS ALONG A CONTINUUM OF CARE

Both palliative and end-of-life care are delivered via a spectrum of services, and are

characterized by a series of transitions that occur on personal, family, and systems levels.<sup>4-6</sup> Care practices, settings, and systems often meet when a patient with chronic or recurrent cancer transitions from treatment with a curative focus, to care that aggressively addresses symptoms and ameliorates suffering while also maximizing quality of life for the time remaining.<sup>7</sup> The transition to death and bereavement and the provision of after-care services by hospice programs represents another opportunity to support partners, spouses, family, and friends as they process their grief and loss and come to terms with this complex life event.<sup>4</sup>

Ideally, the transitions that define the continuum of care – from palliative to hospice to bereavement and after care – serve as critical developmental and existential milestones in the lives of individuals, their caregivers, and families.<sup>8</sup> These transitions raise additional challenges when their significance is unacknowledged, poorly managed, or ill-supported by professional care providers with whom patients and families interact. The shift from palliative to hospice care can be made more difficult for patients and families because of providers’ reported discomfort with broaching the topics of end-of-life planning and goals of care, failure of acute treatment providers to educate patients and caregivers to support informed decision making, poor communication between providers, patients, and caregivers, and patients’ and caregivers’ misunderstandings or negative perceptions about hospice care as “giving up.”<sup>6</sup>

Experts cite how patients’ and caregivers’ perceptions of meaningful support, effective coordination between oncology, palliative, or hospice services, and continuity of care are all imperative elements in optimizing outcomes for cancer patients and families.<sup>9</sup> Each of these elements depends on effective communication, a topic that receives a lot of attention in palliative care training and practice.<sup>10</sup>

### LGBT-SPECIFIC ISSUES RELATED TO TRANSITIONS IN CARE

Negotiating these multiple transitions can be challenging for many patients and caregivers under the best of circumstances because each transition introduces a new risk for disconnection among these elements as patients encounter new settings and providers and different practices.<sup>6</sup> LGBT cancer

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