



Published in final edited form as:

*Semin Oncol Nurs.* 2018 February ; 34(1): 60–71. doi:10.1016/j.soncn.2017.12.003.

## Palliative and End-of-Life Care for Lesbian, Gay, Bisexual, and Transgender (LGBT) Cancer Patients and Their Caregivers

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### Abstract

**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.

### Keywords

LGBT; palliative care; end-of-life care; hospice

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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 patients and their caregivers navigate these same transition-related risks, while also facing a host of other issues related to a longstanding history of bias, discrimination, and marginalization. This has led members of the community to distrust the medical establishment and health providers, and to engage in self-protective practices like avoiding health care encounters because of past experiences or expectations of mistreatment, or not disclosing sexual orientation or gender identity to providers.<sup>11–13</sup> Therefore, transitions along the cancer care continuum represent a particularly risky juncture for LGBT patients and families, especially around issues related to provider lack of knowledge and poor communication, disclosure or non-disclosure, and perceptions of family and spirituality.

## **Lack of Provider Knowledge and Experience Can Hamper Communication**

There is a growing body of work addressing LGBT-specific concerns regarding cancer prevention and treatment,<sup>14,15</sup> but until recently the fields of palliative care and hospice has been largely silent on best practices regarding the LGBT community.<sup>3,16</sup> More research is needed on LGBT patient–provider communication in palliative and hospice settings, and how competency shapes better and worse patient outcomes.<sup>2,14</sup> It has already been shown that LGBT patients with chronic illnesses and their caregivers report experiencing provider bias across a range of treatment and service settings.<sup>11,13</sup> Poor communication, providers' lack of awareness, education, and competency training, conscious and unconscious biases, and reliance on assumptions rather than knowledge and experience with LGBT patients create additional unnecessary barriers to effective communication and, therefore, care.<sup>16</sup>

As LGBT patients transition across different treatment settings and providers, they may worry about whether they will experience open, safe, and affirming communication with providers, or face awkward or discriminatory interactions. This is a major concern because adequate care depends on meaningful communication among all parties regarding the cancer patient's sense of self, their identity, their hopes, fears, and wishes, and their core values.<sup>4,10,17</sup> For example, to communicate with cancer patients about changes in their prognoses and how these developments influence options and recommendations for treatment, providers must form trusting relationships with patients within which this sensitive

information can be clearly and effectively shared and discussed. Continuity of care also depends on effective communication between providers and teams across settings, which requires assurance that accurate and thorough information regarding patient history, treatment, preferences, and goals of care will be shared.<sup>9</sup>

### **Is it Safe to Tell You Who I Am? To Disclose or Not to Disclose**

Whether to share information about one's sexual orientation or gender identity must be revisited by LGBT patients and caregivers with each transition between providers and setting. Some LGBT patients may feel that this is a core aspect of their identity and therefore important for any provider to know, while others may feel that it is not necessary for the provider to know. All health care providers interacting with patients must consider the best way to sensitively and respectfully invite a patient to share this information.<sup>3,16</sup> People receiving care in diverse settings report a higher level of comfort after disclosing being LGBT to providers and improved patient–caregiver–provider alignment, sense of well-being, and quality of care.<sup>18</sup> This is particularly true when patients are provided reassurance – through clear non-discrimination policies, messaging, signage, and affirming communication and behavior of care providers and support staff—that disclosure will mean more informed, individualized, and authentic response from the provider.<sup>19</sup>

A patient's perception that it is safe to share this information with a provider is especially critical because of the existential and values-based nature of the questions, decisions, and processes encompassed in palliative and end-of-life care. For example, cancer patients with life-limiting illness and providers may discuss goals of care and perceptions of quality of life that touch on intimate and sensitive topics, such as planning for eventual dependence on family members or close friends to help meet daily needs that enable them to remain at home. Patients' and caregivers' discomfort or distrust related to sharing their self-identity impacts the quality of relationship between patients and providers and hampers communication in ways that extend far beyond single patient–provider interactions.<sup>20,21</sup> It can complicate the formation of the kind of relationships that increase the likelihood of providers broaching the subject of palliative or end-of-life care in the first place.<sup>22</sup> Further, it can lead to avoidance on either side, leaving patients or caregivers without the support and resources they need at critical times. If, because of a perception of riskiness and lack of safety, a lesbian caregiver is reluctant to tell a hospice nurse about her partner's sleep disturbances, or a transgender woman avoids asking an oncology nurse for needed help with indwelling catheter care, then these are effectively iatrogenic problems caused by poor communication and/or unacceptable practice.

Moreover, providers who are unaware of cancer patients' and caregivers' LGBT identities are unable to help patients and caregivers identify the knowledge and resources needed to navigate challenges, such as ensuring that necessary documentation and legal provisions (advance directives and Durable Power of Attorney documentation) are in place to protect and ensure their wishes and goals of care are honored and followed.<sup>18</sup>

Perceptions of whether it is safe to disclose one's sexual and gender identity can have especially momentous effects on patients transitioning to home-based services like home

hospice care. For example, Witten reports that transgender older adults often see their own home as a place of safety and sanctuary where they can fully express all aspects of their sense of self.<sup>23</sup> Yet LGBT patients and caregivers have reported feeling anxious or unsafe in their own homes when receiving in-home care services because of a sense that service providers may not approve of their LGBT identity.<sup>11,24</sup> Patients and caregivers also report altering presentation of their home environment to hide items that may suggest their LGBT status to protect the patient, themselves, or other family members from judgement or mistreatment.<sup>25,26</sup>

## Chosen Family, Family of Origin, and Core Principles of Care

Two core principles lay at the heart of both palliative and end-of-life care. First, the patient and their family is the unit of care, because so many of the issues and goals of care require working within the dynamics of a patient's close social network.<sup>17,27,28</sup> Second, each individual patient has the right to define who counts as their family, what family means to them, and who will be involved in their care planning and process.<sup>4,17</sup> These principles align with the concept of "family of choice" or "chosen family," wherein LGBT individuals construct familial and relational ties that may replace or augment kinship ties with biological relatives and/or their family of origin.<sup>3,29</sup> Chosen families are contrasted with "family of origin" or the family the patient was born or adopted into, and often formed when people are rejected by their family of origin because of their sexual orientation or gender identity.<sup>3,29</sup> Chosen families are no less strongly bonded or significant to a patient than more historically traditional forms of family (eg, the heteronormative "nuclear" family) and may include partners, spouses, friends, and biological and adopted children. In short, chosen families are family, and consist of whoever the patient identifies as family.

LGBT patients may indicate that their past or current relationships with people in their family of origin are a source of distress, preventing them from achieving a sense of closure or feeling at peace.<sup>24</sup> Providers should not assume, however, that all LGBT people have negative or problematic relationships with family members or that these ruptures can be healed at this time; this may be increasingly true for younger cohorts within the community because social acceptance toward the LGBT community continues to broaden. Protecting patient autonomy by respecting the right of patients and their appointed others to self-determine family identification and involvement becomes an especially critical mandate for nurses working with vulnerable patients who may be or become unable to advocate for themselves.

Informal caregivers involved with cancer patients may also be LGBT; this may be the case for caregivers who are parents, adult children, siblings, or friends of LGBT cancer patients, as well as for caregivers who present as partners or spouses and LGBT caregivers for heterosexual and cisgender patients. The National Alliance for Caregiving 2015 report estimated that 9% of caregivers identify as LGBT,<sup>30</sup> and a 2006 MetLife survey found that LGBT people are more likely to be caregivers for others, compared with heterosexual and cisgender counterparts (1 in 4 vs 1 in 5).<sup>31</sup> The same issues that complicate LGBT patient-provider communication can make being an LGBT caregiver for a loved one with cancer more complicated.<sup>13,32-35</sup> For their part, LGBT caregivers report feeling underserved by

support groups or services that assume heteronormative family and cultural structures, and in which the majority of participants are not LGBT.<sup>36</sup>

Finally, chosen family members may be at increased risk during the transition from death to bereavement because of disenfranchised grief, defined as a mourning process marked by stigma and a lack of social recognition and validation that the bereaved person has suffered a significant loss, and subsequent lack of support.<sup>37,38</sup> If bereavement support groups are operating with heteronormative assumptions, and the language, resources, or materials they use fail to acknowledge or represent LGBT experiences, they are unlikely to feel safe or welcoming.<sup>36,37</sup>

## Assumptions About Spirituality

Finally, many of the most important transitions that cancer patients with life-limiting illness and their caregivers experience are existential and may invoke hope, despair, questions, and convictions about life's meaning and purpose, acceptance, love, and transcendence.<sup>27,39</sup> Patients nearing end of life face the developmental tasks of closure, completion, and thoughts about legacy.<sup>8</sup> For many people, spirituality and faith are closely tied to these psychosocial and emotional processes, interwoven with their close relationships with partners, spouses, other members of chosen family, and with their histories within their families of origin. As such, patients' conceptions about spirituality have significant impact on their decision making and goals of care and their perceptions of what a life well-lived and a "good death" means for them.<sup>40,41</sup>

It is an unfortunate fact that the history of the LGBT community in the US has been marked by discrimination, marginalization, exclusion, and worse by religious organizations and faith communities that are intolerant of or condemn homosexuality, transgender and non-binary gender identity, and gender non-conformity. Because of this, oncology nurses and others working with LGBT cancer patients may assume – in cases where a patient's LGBT identity is known by providers – that these patients or caregivers do not ascribe to spiritual beliefs and practices.<sup>42</sup> Survey research suggests that many LGBT adults do hold spiritual beliefs, particularly in terms of relationship, interconnectedness, and transcendence, and that these beliefs and practices are significant components of their sense of self, their values, and worldview.<sup>24,42</sup> Personal spiritual beliefs are deeply important to the well-being of many LGBT cancer patients, yet their needs may be at even greater risk of going unacknowledged, unassessed, and unsupported by providers than with non-LGBT patients.<sup>3</sup>

Spiritual assessment and support can be a critical intervention for LGBT patients seeking to work through and heal experiences of stigma and trauma related to religious issues in their family of origin.<sup>3,24</sup> Nurses need to understand that delivery arrangements that are normative to them and other health providers may raise particular concerns for LGBT patients and caregivers that affect their ability to access and utilize services. For example, in some geographic areas hospice and end-of-life care are often delivered through religiously affiliated organizations, including those with public anti-LGBT platforms.<sup>23</sup>



## **Recommendations for Education, Training, and Practice**

The ability to provide effective, high-quality care for LGBT cancer patients and their families depends on the providers' ability to translate insights gained from research and advocacy organizations into evidence-based practices that can be applied and sustained in education and practice. Table 1 presents a list of general resources for oncology nurses and others seeking to provide more LGBT-inclusive and -affirming palliative and end-of-life care.

### **Recommendations for Education and Training**

Education recommendations focus on how clinicians who work with patients engaged in palliative and end-of-life care can educate themselves and others about LGBT-specific issues and needs. Key resources to support LGBT-inclusive education and training are summarized in Table 2.

### **Develop and Implement Inclusive Training and Education Curricula**

Palliative and end-of-life curricula has existed for 20 years targeting the needs of general practicing nurses as well as specialty nurses, including case studies focusing on the needs of diverse populations; however, these curricula do not yet explicitly identify the need for specific training regarding the LGBT community. LGBT patients and caregivers should be represented in all facets of nursing education, including didactic and clinical coursework; this creates a foundation on which formal curricula can build. Learning resources including readings, case studies, multimedia resources, and guest speakers from the LGBT community (patients and providers) should not be limited to single LGBT-focused units, but must be integrated throughout.<sup>11</sup>

### **Address Discomfort and Lack of Experience Directly and with Support**

Discomfort related to not knowing the appropriate terminology and anxiety of saying or doing the wrong thing can cause nurses and other providers to feel ill-at-ease and insecure,<sup>43</sup> and this sense can be amplified by the intensity of the care context.<sup>44</sup> Addressing these knowledge deficits by providing both information and opportunities for mentored interactions with LGBT patients and families can increase the chances that initial experiences with LGBT patients and caregivers are positive.<sup>26,45–47</sup> Integrating both higher frequency of contact with LGBT patients in clinical placements and providing the support needed to ensure more positive experiences are essential steps to address conscious and unconscious biases. "Upstreaming" these opportunities so that they occur before students enter into palliative or end-of-life care settings is important.

### **Learn and Teach About Resources That Support LGBT Patients and Their Caregivers**

Providing supportive and competent care for people with life-limiting illness is a general nursing expectation and competency for all nurses, not reserved for only palliative and hospice nurses.<sup>17</sup> To ensure optimal care, nurses and other providers must learn about resources beyond those available through their own organizations, and how to access these resources. Ideally, providers will be able to direct patients and caregivers toward tangible

sources of support, such as local LGBT-specific aging services and advocacy organizations (eg, local SAGE chapters) or online resources that offer support.<sup>15,26,48</sup>

### **Use Models That Emphasize History and Context**

Nursing, palliative, and end-of-life education should all integrate models and frameworks that emphasize how individual patients' situations result from complex intersections among historical, social, economic, cultural, political, and individual levels. For example, the life course approach addresses how generational cohorts experience historical events and conditions that interact with individual factors to influence care needs and outcomes. Intersectionality theory highlights how sociodemographic factors intersect to position individuals in relation to social, political, economic, and historical structures of oppression (eg, homophobia, transphobia, heteronormativity, lack of legal protection, institutionalized discrimination.) Intersectionality recognizes the diversity of individuals within sociodemographic groups defined by collective categories like "sexual orientation" or "gender identity," highlighting how the LGBT community is composed of diverse groups with both overlapping and divergent needs and concerns.<sup>13</sup> The Health Equity Promotion Model,<sup>49</sup> developed through research with the LGBT community, emphasizes synergy between risk and protective factors resulting from interactions between individual characteristics and socio-historical context, and urges clinicians to consider how individual and community strengths are developed through adversity and may be tapped to promote better outcomes.

### **Emphasize Strength and Resilience**

Education and training should also recognize that resilience has been a longstanding characteristic of the LGBT community.<sup>13</sup> Many LGBT patients and caregivers, particularly older adults, have sought care by navigating health systems in which they were unsure of their acceptance, or even safety.<sup>26,50</sup> LGBT community members have therefore filled gaps and developed ways to protect and care for themselves, their loved ones, and members of the LGBT community in the absence of formal and systematic support. Some have argued that the grassroots mobilization of members of the LGBT community who organized and educated themselves to provide end-of-life care to partners, friends, chosen family, and neighbors during the AIDS crisis of the late 20<sup>th</sup> century was a major factor in the growth and acceptance of hospice in the US.<sup>51</sup> LGBT cancer patients and caregivers are likely to have important insights into and experiences with strategies for outreach, navigation, and support; these should be included in palliative and end-of-life education.

### **Ensure Ongoing Competency Training and Evaluation**

Competency is not an accomplishment but an ongoing process of building knowledge and capacity; as nurses learn more from the increasing amount of research on LGBT-specific needs, continuing education regarding how these insights translate into optimal care is needed.<sup>33,48</sup> Competency training should be ongoing,<sup>26</sup> and should include mentorship and opportunities for providers to consult with more experienced providers and community organizations.<sup>15</sup>



## Recommendations for Practice

Recommendations include the ability to apply enhanced knowledge and training in interactions with LGBT cancer patients and their caregivers. Key resources to support LGBT-inclusive practice are presented in Table 3.

### Learn and Practice-Inclusive Communication Skills

As discussed earlier, effective communication is essential to every aspect of care at every point along the care continuum. Among the most basic and ubiquitous recommendations found in the literature is the need to avoid assumptions when interacting with LGBT patients and caregivers.<sup>19,48,52,53</sup> While quick recognition of patterns is a hallmark of skilled clinical practice, unconscious bias combined with trenchant cultural stereotypes, lack of awareness, and lack of experience can create communication barriers with farther-reaching effects on patient outcomes, such as when these factors lead patients to avoid seeking care. Moreover, relying on assumptions is antithetical to the practice of patient- and family-centered care. Being able to ask what you need to know to provide individualized care, while maintaining an open demeanor, using non-judgmental language, and clearly communicating why requested information is clinically relevant are essential skills.<sup>16</sup>

By asking patients or family caregivers how they would like to be addressed, and to introduce others who may be present, the provider allows the patient to define and use the terms that are relevant to them.<sup>16</sup> Solicit the patient's goals of care, taking cues from the patient and their caregivers about what they value, who they consider to be family (see below), and how or whether they want others to be involved.<sup>12,54</sup> The role of providers in safeguarding a patient's right to define their own goals of care, including who they want to be involved and how, can be especially critical for vulnerable LGBT patients who lack the social support of a partner or chosen family to protect their wishes.<sup>12,50</sup>

Effective communication also requires that providers acknowledge patients' partners, spouses, chosen family, and friends, and their roles as informal caregivers and sources of support.<sup>38,46</sup> The accounts of older LGBT patients suggest that even when partners and spouses are present at appointments, and even in the context of home-based services, they may be ignored by service providers.<sup>11,50,55</sup> Beyond basic social politeness, the inclusion of significant others' in care leads to better treatment and mental health for patients.<sup>21</sup> Providers need to recognize partners and friends as significant sources of information and as partners in care by assessing and involving the social networks of LGBT cancer patients, with patient guidance.<sup>22</sup> Understanding that past experiences of discrimination may influence present interactions with providers, and being ready to offer support directly or via appropriate referral is also critical to delivering quality, compassionate care.<sup>38</sup>

### Create Opportunity and Space for Patients to Disclose

Ideally, intake forms and other medical documents patients and their surrogates complete should provide an opportunity for LGBT patients to self-identify or disclose if they choose by offering a range of inclusive options for gender, sexual orientation, relationship status, household composition, residential arrangements, etc. This simple step alone can signal the

awareness and openness of service providers.<sup>15,33</sup> While most people may feel comfortable being asked directly whether they are LGBT, some – particularly older adults – may be less comfortable with direct inquiries,<sup>56</sup> especially when they have experienced trauma related to discrimination in the past.<sup>56,57</sup> The practice of using inclusive language in each patient encounter, with all patients, from the outset of each encounter signals that providers do not follow heteronormative assumptions, that they recognize a diversity of patients, families, and experiences. Moreover, service providers that are seen as honoring and respecting all forms of diversity may be more likely to be seen as safe or supportive by LGBT patients.<sup>57</sup>

### **Allow the Patient to Define Family and the Role of Family**

A best-practice principle in both palliative and end-of-life care – allowing each patient to define family and who counts as family for themselves – is ideally applied in every health care context, and is fundamentally inclusive.<sup>19</sup> Likewise, the patient should also define the meaning and importance of other close relationships for themselves. Acquaviva<sup>3</sup> suggests an approach to LGBT-inclusive family assessment that includes: 1) informing the patient why knowing more about their family is important to providing quality care; 2) acknowledging family of origin and chosen family as two different kinds of family; 3) asking the patient who they consider to be chosen family and/or family of choice; 4) assessing the patients' perceptions of relationships named (eg, as a source of support or a source of stress); and 5) asking whether the patient wants persons named to be involved in their care planning process. Further, other sources of support should be assessed, including community groups and social connections, because these may be important sources of support. Above all, nurses and other providers should avoid making assumptions about personal and familial relationships without learning directly from the patient or their appointed surrogate who they wish to be included in care planning.

### **Extend Bereavement Support Services to Chosen Family and Close Others**

Ensure that those who are identified as family and significant others by the patient and their appointed surrogates are offered bereavement services as appropriate and desired. When possible or feasible, ask the patient and their caregiver who they would want to be sure is included, and who they see as needing these services. Bereavement and grief support services also need to be accessible and delivered in a manner that is welcoming and affirming. For example, support groups that mix LGBT and non-LGBT participants partners and spouses may not feel as welcoming or useful if LGBT participants feel the need to explain or normalize their situation for others rather than process their own grief.<sup>19</sup> Knowing what will work best requires individualized assessment and options that allow participants to choose what is best for them. Because LGBT cancer patients and caregivers have unique experiences because of their minority status, they are at risk for being underserved by programs that are designed with embedded heteronormative assumptions. Also, when possible, organizations should explore multiple modes of delivery such as in-person or online support groups.<sup>26</sup> Distance-accessible options may be particularly helpful for people who live in rural communities and experience social isolation, and those who may feel more comfortable in this setting.

### **Assess Spiritual Needs and Offer Meaningful Spiritual Support**

Spiritual assessment should be an integral part of ongoing goals of care conversations; these topics should be revisited at multiple points along the care continuum, but are especially critical at times of transition.<sup>39,40</sup> Nurses may feel that spirituality is the purview of a chaplain or other member of the team, but a nurse who is open-minded and patient-focused may actually be better positioned to broach this subject with a patient initially. Again, the use of inclusive language is critically important, as is mindfulness about how the language one uses can signal that some beliefs are expected and acceptable while others are not.<sup>3</sup> As with family, spirituality and what it means to the patient (if anything) is best defined by the patient themselves. Even the best-intended comments or questions, if not conveyed in open and inclusive language, can have a negative impact on patients. Finally, avoid telegraphing or imposing your personal beliefs related to religion and spirituality because this may stifle a patient's ability to express their own sense of spirituality.<sup>3,41</sup>

### **Create and Maintain a Non-Discriminatory and Inclusive Practice Setting**

Beyond individuals' behaviors and knowledge, palliative and hospice service providers must pay attention to environmental and cultural factors that support inclusivity and continuity of care. As noted earlier, intake forms, patient surveys, and assessment instruments should be designed to provide LGBT patients and caregivers opportunities to disclose their sexual orientation and/or gender identity – to be acknowledged as fully and wholly themselves – which often means asking all patients about orientation and gender identity and revising other demographic items to include a wider array of choices (eg, changing “marital status” to “relationship status” and including choices like “partnered” and “civil union”). Organizations that require or encourage providers and staff to receive LGBT-specific education should advertise these efforts as part of their core values statement. The visibility of LGBT-friendly signage and emblems and photographs representing diverse relationships and gender presentations also provide important cues about safety and acceptance.<sup>34</sup> Follow-up assessments like patient care surveys should seek focused feedback from LGBT patients about the inclusivity and quality of services. Asking both LGBT and non-LGBT patients about their perceptions of LGBT-friendliness could provide important insights about how efforts to create an inclusive climate, one that benefits all patients, can be achieved.<sup>33</sup>

To ensure the sustainability and effectiveness of initiatives, organizations should consider broad non-discrimination policies that include a zero-tolerance stance toward discriminatory language and behavior at all levels of service.<sup>33,34</sup> These policies should cover both service consumers and LGBT employees.<sup>26</sup> To be truly effective, this would require implementing systems of accountability within organizations that include measures for additional education and remediation as needed.<sup>11,52</sup> Ultimately, accountability expectations should be linked to external reinforcements such as funding, reimbursement, and accreditation standards, with clear benchmarks for meeting standards of service.<sup>11</sup>

### **Promote Continuity of Care**

Because of the complex and systematic nature of factors that may negatively impact outcomes for LGBT patients and caregivers, a network of support is needed to counteract these factors. Close collaboration between providers with whom patients and caregivers have

already established relationships and the members of the palliative care or hospice teams is needed to mitigate the potentially negative effects of the multiple transitions outlined earlier, as is collaboration with partners, chosen family, and other patient-identified sources of support.<sup>15</sup> To promote the development of these relationships and facilitate communication, organizations should consider forming or joining an LGBT-friendly network of providers and this designation should be published, advertised, and made available through service directories and other accessible resources.<sup>22</sup>

## Implications for Oncology Nursing

The ability to provide effective care for LGBT cancer patients and caregivers depends on two essential insights: 1) LGBT patients and their caregivers have unique needs related to palliative and end-of-life care support; 2) addressing these needs in a meaningful way requires enacting not only LGBT-specific knowledge, but also invokes known best practices for these fields, including essential competencies for relationship-building and effective communication. Many of the recommendations offered here include concepts and practices that would enhance optimal outcomes with patients from all walks of life because they are fundamental to truly patient-centered care. Improving palliative and end-of-life care for LGBT cancer patients, therefore, is likely to have a broader benefit of enhancing effective and supportive care for all oncology patients, effectively “raising all boats.” Oncology nurses are well-positioned to improve care experiences and outcomes for LGBT patients and caregivers. Understanding the unique history and challenges that members of the LGBT community face, as well as the community’s strengths and capacity of resilience, is the key to providing competent and effective care.

## Acknowledgments

William Hull was supported by the National Institute Of Nursing Research of the National Institutes of Health Award under award number T32NR013456.

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TABLE 1

## Resources Supporting Inclusive LGBT Palliative and End-of-Life Care

Resource	Description
Hospice Foundation of America <a href="https://hospicefoundation.org/End-of-Life-Support-and-Resources/Coping-with-Terminal-Illness/How-to-Choose/LGBT-Resources">https://hospicefoundation.org/End-of-Life-Support-and-Resources/Coping-with-Terminal-Illness/How-to-Choose/LGBT-Resources</a>	LGBT educated and affirming services
National Resources Center on LGBT Aging <a href="http://www.lgbtagingcenter.org/resources/resource.cfm?r=4">http://www.lgbtagingcenter.org/resources/resource.cfm?r=4</a>	Tips on finding LGBT-affirming services
Human Rights Campaign <a href="http://www.hrc.org/hei/for-lgbt-patients">http://www.hrc.org/hei/for-lgbt-patients</a>	Information on insurance, human and civil rights, LGBTQ-friendly providers and resources
American College of Surgical Oncology Position Statement: Strategies for Reducing Cancer Health Disparities Among Sexual and Gender Minority Populations <a href="http://ascopubs.org/doi/full/10.1200/JCO.2016.72.0441">http://ascopubs.org/doi/full/10.1200/JCO.2016.72.0441</a>	Recommendations for reducing cancer disparities among sexual and gender minority populations
National Comprehensive Cancer Network <a href="https://www.nccn.org/professionals/physician_gls/pdf/palliative.pdf">https://www.nccn.org/professionals/physician_gls/pdf/palliative.pdf</a>	Professional practice guidelines for cancer palliative care (general)
National Hospice and Palliative Care Organization <a href="https://www.nhpc.org/tools-and-resources">https://www.nhpc.org/tools-and-resources</a>	Tools and resources in palliative care (general)
National LGBT Cancer Network <a href="http://cancer-network.org/">http://cancer-network.org/</a>	Evidence-based recommendations to improve LGBT cancer care, directory of LGBT-welcoming cancer providers, clinician resources, support for survivors
Hospice and Palliative Care Nurses Association <a href="http://hpna.advancingexpertcare.org/">http://hpna.advancingexpertcare.org/</a>	New LGBTQ special interest group of HPNA (professional nurses' association advancing care in chronic and life-limiting illness through education, competence, advocacy, leadership, and research)
Acquaviva K. (2017). LGBT-inclusive hospice and palliative care. New York: Harrington Park Press <sup>3</sup>	A practical guide on tailoring palliative and hospice services for LGBTQ patients; includes both basic information and LGBT-specific guidelines
Barrett N, Wholihan D. (2016). Providing palliative care to LGBTQ patients. In Pace J, Wholihan D (eds.) Palliative and end-of-life care. pp. 501–512. Philadelphia: Elsevier	An introduction and overview for nurses seeking information for improving palliative care practice with LGBTQ patients

**TABLE 2**

## Recommendations for Palliative and End-of-life Education and Training

Recommendations	<ul style="list-style-type: none"> <li>• Develop and implement inclusive curricula</li> <li>• Address provider discomfort and lack of experience with LGBT patients directly, with structured support</li> <li>• Learn and teach about resources that support LGBT patients and their caregivers</li> <li>• Use models that emphasize history and context to teach about LGBT needs</li> <li>• Emphasize strengths and resilience</li> <li>• Ensure ongoing competency training and evaluation</li> </ul>
Resources	<p>Nurses' Health Education About LGBTQ Elders (HEALE) cultural competency curriculum  <a href="http://www.nursesheale.org/">http://www.nursesheale.org/</a>National LGBT Health Education Center  <a href="https://www.lgbthealtheducation.org/">https://www.lgbthealtheducation.org/</a>National LGBT Cancer Network cultural competency trainings for health and social service agencies  <a href="http://cancer-network.org/wp-content/uploads/2017/02/best_practices.pdf">http://cancer-network.org/wp-content/uploads/2017/02/best_practices.pdf</a>Cultural competency toolkit  <a href="http://www.lgbtcultcomp.org/">http://www.lgbtcultcomp.org/</a></p>

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**TABLE 3**

Recommendations for Inclusive Palliative and End-of-life Practice

Recommendations	<ul style="list-style-type: none"> <li>• Learn and practice LGBT-inclusive communication skills</li> <li>• Create opportunity and space for patients to disclose their orientation and/or gender identity</li> <li>• Allow the patient to define who is family and the role of family in care</li> <li>• Extend bereavement and grief support services to chosen family and close others</li> <li>• Create and maintain a non-discriminatory and inclusive practice setting</li> <li>• Promote continuity of care</li> </ul>
Resources	<p>Acquaviva (2017). LGBTQ-inclusive hospice and palliative care: a practical guide for transforming professional practice<sup>3</sup></p> <p>Candrian &amp; Lum (2017) Lesbian, gay, bisexual and transgender communication. In: Textbook of palliative care communication<sup>16</sup></p> <p>National Resource Center on LGBT Aging</p> <p>Age-Friendly Inclusive Services. A Practical Guide to Creating Welcoming LGBT Organizations</p> <p><a href="http://www.lgbtagingcenter.org/resources/pdfs/Sage_AgeToolKit_FINAL_FPO.pdf">http://www.lgbtagingcenter.org/resources/pdfs/Sage_AgeToolKit_FINAL_FPO.pdf</a>(br)Resources supporting culturally competent care</p> <p><a href="http://www.lgbtagingcenter.org/resources/resources.cfm?s=4">http://www.lgbtagingcenter.org/resources/resources.cfm?s=4</a></p>

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