

The role of hospice and palliative care in supporting and fostering trust among the LGBTQ+ population

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Introduction

There are multiple transitions along the continuum of care, from a state of health, to the diagnosis and progression of a serious illness, to an eventual transition toward end-of-life care and bereavement. These are pivotal opportunities to provide patients and loved ones with support, mitigate suffering, and optimize quality of life. To accomplish these goals, specialty palliative care is often introduced as an additive support to an individual's medical team; in contrast to general or primary palliative care (which refers to symptom management and support provided by the existing medical team), specialty palliative care involves an interdisciplinary group of specialty-trained clinicians and team members.

However, for people who have experienced repeated discrimination and marginalization by the healthcare system, these transition points in illness—and the introduction of new issues, new complications, and new medical teams—represent particularly vulnerable moments. In the United States, this is true for many individuals of minority sexual orientation and gender identity, wherein sexual orientation is defined as an individual's inherent identity in regards to whom they are attracted to, and gender identity refers to an individual's inherent sense of male, female, or other gender, which may be same or different from their sex assigned at birth.¹

In this article, we highlight challenges commonly faced by lesbian, gay, bisexual, transgender, and queer or questioning (LGBTQ+) individuals as they seek serious illness care in the United States. We call for hospice and palliative care clinicians to mitigate these challenges by recognizing our own biases and limitations and by committing to

the intentional work of practicing inclusivity. We believe these steps are needed to ensure that all individuals receive high-quality care.

Understanding the challenge: a call for accountability

First, hospice and palliative care clinicians are encouraged to understand that LGBTQ+ individuals are not a monolithic group, but rather a diverse population of individuals. Unfortunately, however, many LGBTQ+ individuals share the experience of marginalization and disparity in healthcare (as well as many other domains of American life) as a result of their sexual or gender identity.² They may be at greater risk for mental illness and substance misuse compared to people who identify as heterosexual,^{3,4} and they experience decreased odds of having routine primary care, lower uptake of cancer screening measures, and higher rates of undesirable weight control/perception.^{5,6} These disparities relate to marginalization when accessing care. In one study, LGBTQ+ interviewees described mistreatment, vulnerability, exclusion, and erasure during their interactions with the healthcare system.⁷ Such experiences can generate an aversion to healthcare services, which becomes increasingly problematic in the context of serious illness.

Second, LGBTQ+ individuals face unique challenges as they encounter serious illness and end-of-life issues driven by a healthcare system that historically has not practiced inclusive, sensitive care. For example, social support is crucial to confronting serious illness; however, older LGBTQ+ adults are less likely to have children, more likely to live alone, and more likely to be socially isolated.^{8,9} Older LGBTQ+ individuals

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have described a sense of having to go back *into the closet* and adapt to their social surroundings due to fear of rejection.¹⁰ Meanwhile, *chosen families* (loved ones who may or not be biologically related) face legal uncertainties and lack of recognition. Advance care planning (i.e. designation of health care proxies and completion of living wills or advance directives) is vital for older LGBTQ+ adults, as it may be the only lawfully accepted means to advocate for seriously ill significant others.^{11,12} However, only 49% of LGBTQ+ individuals who want to appoint a same-sex partner as their decision-maker have completed documentation to this effect.¹³ All of these factors place LGBTQ+ individuals and their loved ones at greater risk of marginalization, preventable suffering, and inadequate care when they encounter serious illness.

Third, and perhaps most importantly, hospice and palliative care clinicians are strongly encouraged to examine our own role in perpetuating healthcare disparities, and our own responsibility to foster a culture of inclusive care. For example, in some areas in the United States, options for hospice enrollment may be limited to faith-based organizations, some of which may hold historic (or current) policies and stances that stigmatize LGBTQ+ individuals. These affiliations can generate fear and trauma for some LGBTQ+ patients toward the end of life, even if discriminatory practices are not overt.¹⁴ Meanwhile, in a recent cross-sectional study, the majority of interdisciplinary hospice and palliative care professionals reported either perceiving or directly observing inadequate, disrespectful, or abusive care of LGBTQ+ patients and family members—in hospital and hospice settings across the United States.¹⁵ Unfortunately, this study suggests that discriminatory practices and attitudes remain both culturally normative and geographically widespread in the places where LGBTQ+ patients receive hospice and palliative care.

To begin to address this problem, clinicians should realize that not all biases are intentional or overt, even a well-intentioned provider who believes in inclusivity may hold implicit biases that deteriorate the quality of care.¹⁶ For example, a skilled palliative care consultant may omit a caregiver needs assessment because they missed the opportunity to identify that the *close friend* in the patient's room is actually a same-gendered life partner. In another example, a well-intentioned hospice provider, despite having elicited a

patient's sexual orientation, may not have conducted a thorough spiritual needs assessment, having wrongly (perhaps unintentionally) assumed that their LGBTQ+ patient is less likely to be spiritual or religious.^{14,17} These are only a few examples of the ways that hospice and palliative care clinicians may make unintended but damaging assumptions about LGBTQ+ patients. To counteract these powerful and persistent assumptions, we recommend that clinicians first build awareness of their own implicit biases, followed by intentionally seeking, practicing, and implementing inclusive care strategies.

Inclusive practices in hospice and palliative care

With these challenges in mind, what can hospice and palliative care clinicians do to support LGBTQ+ individuals through serious illness? First, it is essential to acknowledge that sexual orientation and gender identity are an integral part of one's personhood. Supporting LGBTQ+ individuals with serious illness, as with all individuals, means allowing patients and loved ones the space and opportunity to express themselves in whatever way is most comfortable, and providing support that aligns with *their* identity, preferences, and values.¹⁶ We believe that inclusive, sensitive care for LGBTQ+ individuals aligns with the fundamental mission of most hospice and palliative clinicians, who bear witness to some of the most vulnerable moments and serious threats to personhood that one can encounter in the course of providing interdisciplinary, whole-person care.

Next, we recommend that clinicians actively seek and implement care strategies that foster inclusivity and respect, beginning with the initial palliative care consultation or hospice intake. Clinicians can do this by intentionally using inclusive language, identifying what values and preferences are important to an individual, and engaging the interdisciplinary team to ensure the patient's preferences are communicated and respected (Table 1). Exploration of the crucial members of the patient's social circle can be done in a non-judgmental manner, keeping in mind that LGBTQ+ patients may have chosen families which may or may not include biological relatives. It is also important to elicit who the patient does and does not want visiting them or receiving information about their health. Although the later stages of serious illness can be a time

Table 1. Tips for Fostering an Inclusive Care Environment.

Do not assume a person's sexual orientation or gender identity. Instead, create space for patients to disclose this information if they desire. This can be done using inclusive language and options on written forms, as well as in verbal communication.

Use of inclusive language signals a provider's intentional effort to counteract bias and foster a safe and respectful care environment.

Ask the patient to identify others present in the home, clinic, or hospital setting (instead of assuming that a different-sex visitor is a significant other, or that a same-sex visitor is not)

Know that a patient may identify a same-sex partner as a friend due to fear of discrimination, especially before you have built an atmosphere of trust and sensitivity.

Ask "do you have a partner or significant other?" instead of "husband, wife, etc."

Ask "what are your pronouns?" or use gender-neutral terms such as "folks or people."

Ask "who is important in your life?" or "who is important in your care?" instead of "who is your family?"

Be mindful of how you communicate in the medical record. Request consent from the patient before documenting sensitive information.

Ensure that the entire team's communication going forward is aligned with preferences as indicated by the patient.

Become familiar with common terms used by and in reference to the LGBTQ+ community.

Avoid asking unnecessarily personal, probing questions, especially if it becomes clear that the patient is not comfortable sharing further details.

Source: Strategies adapted from K. Acquaviva's *LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice*,¹⁶ and Barrett and Wholihan's "Providing Palliative Care to LGBTQ Patients."¹⁸ LGBTQ: lesbian, gay, bisexual, transgender, and queer.

of reconciliation for some, clinicians should be sensitive to complex family dynamics that may make these experiences difficult or potentially undesirable for the patient.¹⁹

In addition, the end of life can be an especially vulnerable time for LGBTQ+ individuals. For most Americans, the majority of time and services under hospice care is spent in a person's home. Many people find it difficult to invite strangers into their home, and this may be especially salient in the LGBTQ+ community, where one's home is often the only place a person can be their *true selves*. This is a privilege that others may take for granted. The initial hospice intake at home, therefore, is crucial to establishing and demonstrating the care team's commitment to a safe and respectful care environment; the strategies outlined in Table 1, while not exhaustive, can help.

Even after a patient's death, loved ones in the LGBTQ+ community may experience disenfranchised grief. This form of grief occurs when one experiences loss that is not openly accepted, acknowledged, or supported by those around them, including the healthcare community.¹⁹ Surviving same-sex partners have endorsed feeling excluded from medical decisions, communication with the medical team, funeral services, and bereavement groups. In fact, partners with modest support systems or those who have not

shared their relationship status with loved ones may feel compelled to act strong or hide their mourning. These individuals are at higher risk for complicated grief, and thus warrant greater awareness and bereavement support on the part of hospice and palliative care teams.²⁰

It is worth noting that hospice and palliative care teams already possess skills that are indispensable to fostering more inclusive, respectful care for LGBTQ+ patients. Open-ended, non-judgmental exploration of patients' and loved ones' illness experiences is fundamental to the practice of palliative care. These skills (including open-ended questions, attention to emotion, and a willingness to genuinely walk with patients from different backgrounds) can be utilized to better understand LGBTQ+ patients' health-related experiences. In addition, hospice and palliative care teams often position themselves as advocates for whole person-caregiver care by facilitating conversations about serious illness, concretizing patients' goals and values, and collaborating with other healthcare professionals to align the plan of care with those values. Clinicians can use this approach to advocate for LGBTQ+ patients, creating a care dynamic that centers around LGBTQ+ experiences with respect and humility. We believe the responsibility to right the biases and injustices experienced by many LGBTQ+ patients and their loved ones falls on every individual in the

healthcare system, including hospice and palliative care clinicians. This is underscored by very recent data showing that discriminatory care remains prevalent in hospice and hospital palliative care settings.¹⁵ Hospice and palliative care teams can meet the challenge of caring for LGBTQ+ individuals with serious illness by practicing and internalizing the tenets of cultural humility: continuous self-education, non-judgment, flexibility, acknowledgment of one's own implicit biases, and appreciation of people's multidimensionality.²¹

Conclusion

In summary, LGBTQ+ individuals continue to experience differential access, discrimination, and marginalization in healthcare, which places them at risk for worse health outcomes. This may be especially true for older LGBTQ+ individuals, who may experience more mistrust in (and fear of stigmatization by) the healthcare system even as they develop serious medical illnesses. For these reasons, hospice and palliative care teams will play an increasingly important role in supporting LGBTQ+ individuals throughout the illness trajectory. In order for hospice and palliative care clinicians to deliver on the field's mission of whole person/caregiver care, we recommend that clinicians identify and critically examine their own biases and assumptions, that they intentionally seek out and practice inclusive care strategies, and that they collaborate to foster an atmosphere of trust and respect for all patients.

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