

## WHAT IS LGBTQ+ INCLUSIVE CARE?

In nursing practice, nurses are expected to provide care with “compassion and respect for the inherent dignity, worth, and unique attributes for every person.”<sup>1</sup> Lesbian, gay, bisexual, transgender, queer, or Questioning (LGBTQ+) culture-specific care is an essential component of the American Nurses Association (ANA) Nursing Code of Ethics as outlined in the 2018 ANA position statement on Nursing Advocacy for the LGBTQ+ Population, which states, “Nurses must deliver culturally congruent care and advocate for lesbian, gay, bisexual, transgender, queer, or questioning (LGBTQ+) populations.”<sup>2</sup>

The National Institutes of Health (NIH) Sexual and Gender Minority (SGM) Research Office defines SGM populations as those that include but are not limited to individuals who identify as lesbian, gay, bisexual, asexual, transgender, two-spirit, queer, and/or intersex. Individuals with same-sex or -gender attractions or behaviors and those with differences in sex development are also included. Those populations also encompass those who do not self-identify with one of those terms but whose sexual orientation, gender identity or expression, or reproductive development is characterized by non-binary constructs of sexual orientation, gender, and/or sex.<sup>3</sup>

## BARRIERS AND CHALLENGES FACED BY THE LGBTQ+ COMMUNITY

In 2011, the Institute of Medicine report *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People* cited a lack of social support and legal protections as significant barriers to access and quality of palliative care.<sup>3</sup> Barriers and challenges faced by the LGBTQ+ community include:<sup>4</sup>

- Social stigma; misunderstanding; and long-standing discrimination, violence, and victimization related to sexual and gender identity
- Barriers within the healthcare setting that include patient-provider interactions
- Physical and mental health concerns disproportionately affecting the SGM patient community
- Unique needs at the end of life
- Nontraditional family structures
- Policy-level approaches to mitigate health disparities
- Lack of self-awareness of clinicians’ conscious and unconscious biases

## SPECIFIC NEEDS OF LGBTQ+ COMMUNITY AT THE END OF LIFE

Factors influencing care of the LGBTQ+ community at the end of life include:

Patients living with chronic illnesses experience higher rates of depression and anxiety and are more likely to have lower rates of satisfaction with healthcare experiences.<sup>5</sup>

There is potential for social isolation and less access to caregivers due to nontraditional family structures. Clinicians have conscious and unconscious internal biases that may act as barriers to providing care that is patient-centered and aligned with the values and beliefs of the patient and family in need of hospice and palliative care.

## INTERVENTIONS

- Provide palliative nursing care that is individualized to meet the needs of each patient and that patient's self-identified support system.
- Provide an environment of care delivery that is welcoming and inclusive.
- Include families of choice in medical decision-making.
- Facilitate completion of both advance care planning documents and legal documents to include surrogate decision-makers, healthcare durable power of attorney documents, advance directives, living wills, and out-of-hospital orders for life-sustaining treatments.
- Acknowledge sexual identity as an important aspect of self-identity at the end of life.

## PATIENT ENGAGEMENT

As people who may identify with multiple minority labels engage with major institutionalized systems, such as health care, there is a risk for increased discrimination and bias.<sup>5,6</sup> The mnemonic CAMPERS can help palliative care clinicians to create safe and nonjudgmental spaces for patient care in seven steps:<sup>7</sup>

- Clear purpose: What is the clinician's clear purpose for the interaction?
- Attitudes: self-awareness of the clinician's inherent assumptions and implicit biases
- Mitigation plan: Reframe patient-alienating language; clarify the role in providing person-centered values and goal-directed care. Use inclusive language to establish trust, maintain respect, and demonstrate inclusivity to support positive outcomes in care. Acknowledge the impact of the patient's history of marginalization within the healthcare system.
- Patient: Know the patient's story in their own words. This includes their preferred name, gender identity, gender pronouns, family of choice, and short- and long-term goals.
- Emotions: Acknowledge one's own emotions and build support resources for self-care.
- Reactions: Be aware of verbal and nonverbal responses to frustrations, anger, availability, accessibility, and responsiveness to patients' needs.
- Strategy: Reflect on experiences and encounters to improve communication and professional development.

Successful interventions in caring for patients identifying as LGBTQ+ benefit from multiple perspectives to anticipate, prevent, and treat physical, psychological, social, and spiritual needs. Consider social work, psychology, counseling, and spiritual care specialists for palliative and hospice support, as well as interventions to address concerns regarding caregiver support, fear, anxiety, guilt, depression, spiritual and cultural rituals, and financial concerns as culturally appropriate.

## DESIRED NURSING OUTCOMES

- Promote informed, shared decision-making in treatment interventions for the LGBTQ+ community.
- Support shared decision-making in a manner that is focused on patient and family choices and goals using principles of substituted judgment and best interest.
- Improve quality of life by exploring patient and family beliefs and expectations related to LGBTQ+ inclusive care.
- Support surrogates with education related to signs and symptoms of psychological and psychiatric distress, as well as techniques to help alleviate distress.
- Validate that decision-makers and the family of choice are aware of the patient's preferences.
- Promote optimal patient comfort.
- Maximize functional status and quality of life for both the patient and the family of choice within the context of the patient's illness progression.
- Promote ongoing discussions about goals of care relating to disease progression, interventions, and management.
- Explore the patient's instrumental, psychosocial, and spiritual needs to identify resources for coping and support.

## REFERENCES

1. American Nurses Association. Code of Ethics (3rd ed.). Silver Spring, MD: American Nurses Association; 2015.
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3. National Institutes of Health Sexual and Gender Minority Research Office. Home page. <https://dpcpsi.nih.gov/sgmro>. Accessed May 27, 2021.
4. Institute of Medicine. The Health of Lesbian, Gay, Bisexual, and Transgender People Building a Foundation for Better Understanding. Washington, DC: National Academy of Sciences; 2011.
5. Dahlin CM, Moreines LT, Root MC (Eds.). Core Curriculum for the Hospice and Palliative APRN (3rd ed.). Pittsburgh, PA: Hospice and Palliative Nurses Association; 2020.
6. Barrett N, Wholihan D. Providing palliative care to LGBTQ patients. *Nursing Clinics of North America*. 2016;51(3):501-511. doi: 10.1016/j.cnur.2016.05.001
7. Acquaviva, KD. *LGBTQ-Inclusive Hospice and Palliative Care: A Practical Guide to Transforming Professional Practice*. New York, NY: Harrington Park Press; 2017.

## SEXUAL ORIENTATION

**GAY:** male-identified individual sexually and/or romantically attracted to male-identified people; may also be used as a broader term for non-heterosexual people

**LESBIAN:** female-identified individual sexually and/or romantically attracted to female-identified individuals

**BISEXUAL:** an individual who is attracted to two or more genders; may also be identified as attraction to genders similar to and different from one's own gender

**ASEXUAL:** an individual who never or seldom experiences sexual attraction

**PANSEXUAL:** an individual who is attracted to individuals irrespective of gender

**QUEER:** a broad term for someone who is not heterosexual or cisgender and not utilized by all LGBTQ+ people

## GENDER IDENTITY

**TRANSGENDER:** an individual whose gender does not align with their sex assigned at birth

**CISGENDER:** a term used to describe someone who is not transgender

**NON-BINARY:** a term used by those who describe their gender as something outside of man or woman

**TWO SPIRIT:** Native American/First Nations individual whose gender is both male and female

**GENDER NON-CONFORMING:** an individual whose gender presentation does not align with typical expectations of their gender

**GENDERQUEER:** an individual whose gender does not fall within the binary, whose gender is fluid or non-conforming

## LGBTQ+ RESOURCES

**ANA Position Statement: Nursing Advocacy for LGBTQ Populations**

**HPNA Podcast Corner Ep. 6: Providing Palliative Care to LGBTQ Patients**

**HPNA Webinar: Palliative Care to Patients with HIV**

**HPNA's LGBTQ+ SIG (Special Interest Group)**

**National Resource Center on LGBT Aging**

**GLMA: Healthcare Professionals Advancing LGBT Equality**

**SAGE: Advocacy & Services for LGBT Elders**

**The GLAAD Foundation: Accelerating LGBTQ acceptance in media**

**The Human Rights Campaign**

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