

**NHPCO Project ECHO *Equity Where It Matters* Key Takeaways:  
Supporting LGBTQ Patients at the End of Life  
June 1, 2023**

**Key points:**

- **What is Gender?** the characteristics of women, men, girls and boys that are socially constructed. This includes norms, behaviors, and roles associated with being a woman, man, girl, or boy, as well as relationships with each other. As a social construct, gender varies from society to society and can change over time.
- **What is gender identity?** One's innermost concept of self as male, female, a blend of both or neither – how individuals perceive themselves and what they call themselves. One's gender identity can be the same or different from their sex assigned at birth.
- **What is gender expression?** External appearance of one's gender identity, usually expressed through behavior, clothing, body characteristics or voice, and which may or may not conform to socially defined behaviors and characteristics typically associated with being either masculine or feminine.
- **Impact of Stigma in EOL Care for LGBTQIA2S+ patients and families:** Stigma in EOL Care can have a negative impact on patients, providers, and in policy through unfair treatment, pay inequities, and fewer educational opportunities, just to name a few. Stigma can also negatively affect the emotional, mental, and physical health of stigmatized groups and the communities they live in.
- **LGBTQIA2S+ patients and families have the same medical and quality of life needs as** cisgendered, heterosexual patients and families: Your training as a hospice and palliative care professional will support LGBTQIA2S+ patients medically, but your implicit (and not-so-implicit) bias can get in the way.
- **The patient defines family:** 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. This is true for all patients, not just LGBTQIA2S+ patients.

**Actionable Steps:**

- Normalize asking about/sharing pronouns
- Change all “he/she” instances in written documents to “they”
- Get in the habit of talking with LGBTQIA2S+ patients about who they consider family and if they are concerned about members of their biological family interfering or complicating their care.
- Ask about and normalize chosen family structures and dynamics
- Support smooth care team transitions by sharing information important to families and patients with the members of the bereavement team and others (with permission)
- Update intake forms and other documentation with welcoming and inclusive language
- Agencies looking for resources may be well-served to find local advocates to discuss the importance of equitable LGBTQIA2S+ care

**Conversation Starters:**

- How can you support LGBTQIA2S+ patients and families to feel seen and safe?
- What are your assumptions about “family?”
- How are the policies and language of your organization supportive of a binary gender framework and heteronormative standards? How could you change them to be welcoming to LGBTQIA2S+ patients and families?



### Participant Perspectives:

- “You don’t always get a say in this person’s journey, this person gets to decide who is on the journey with her.”
- “It’s about seeing the person who is the patient and showing up for them.”
- “The question of self-regulation *should* be coming up across the board as we work with people who make diverse personal choices.”
- “I would ask the parents to talk outside. if they're enflamed, it's likely distressing to the patient and caregiver.”
- “D should be able to make decisions and L would be the secondary decision make as the spouse. The nurse should be advocating for the patient. I agree with having the parents step out of the room.”
- “It can also be worthwhile to involve the social worker to help D fill out Advanced Directives.”
- “We can both be uncomfortable together.”
- “This is about seeing the person who is the patient and showing up for them.”
- “For those of you outside of the LGBTQ+ community, hopefully this case is helping you see that there is a further dynamic then what you normally see; there is familiarity in this case, however there is an additional element of personhood, in a time when someone is incredibly vulnerable and needing to be affirmed and cared for in that way.”
- “Nothing impacts administrators like local people. Finding people in the community to advocate [on behalf of SAGE LGBTQ certification] really makes a big difference. “
- “There are family issues that we may not be able to deal with. We need to recognize that D has her issues that she is working through being terminally ill, their wife that is having to deal with issues with a terminal spouse, they are both young, which also has context that needs to be acknowledged and the parental feelings. This is not something that could be effectively done in one visit. The parents, while insensitive, are dealing with the loss of a child, which is unnatural. These parents are losing a child again (because of the separation that their beliefs caused). They would need resources beyond what hospice can do. I would definitely reach out to outside resources for the family and for the staff.”
- “This is not only an added element, but is a *critical* element when people are feeling vulnerable.”
- “Advance care planning is critical in these situations.”

### References:

- APA Dictionary of Psychology; *Stigma Definition*: <https://dictionary.apa.org/stigma>
- *The health stigma and discrimination framework: A global, crosscutting framework to inform research, Intervention Development, and policy on health-related stigmas - February 2019*: <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-019-1271-3>
- *Stigma & Bias in Healthcare: The Obstacles, Consequences and Changes Needed, BioMed Central August 2020*: <https://www.qualityhealth.org/wpsc/2020/08/17/stigma-bias-in-healthcare-the-obstacles-consequences-andchanges-needed/>
- *When Health Care Isn’t Caring: Lambda Legal’s Survey of Discrimination Against LGBT People and People with HIV*. New York: Lambda Legal, 2010.
- Cloyes KG, Hull W, Davis A. Palliative and End-of-Life Care for Lesbian, Gay, Bisexual, and Transgender (LGBT) Cancer Patients and Their Caregivers. *Semin Oncol Nurs*. 2018;34(1):60-71.

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- Healthcare Equality Index Resource Guide, 2023.
- <https://transstudent.org/graphics/> (accessed, May 10, 2023.)
- Institute of Medicine(US). Committee on Lesbian, Gay, Bisexual, and Transgender Health Issues and Research Gaps and Opportunities. The Health of Lesbian, Gay, Bisexual and Transgender (LGBT) People: Building a Foundation for Better Understanding. Washington, DC: Institute of Medicine; 2011.
- Candrian C, Lum H. Lesbian, gay, bisexual, and transgender communication. In: Wittenberg E, Ferrell BR, Goldsmith J, Smith T, Glajchen M, Handzo GF, editors. Textbook of Palliative Care Communication. New York: Oxford University Press; 2016. pp. 229–237.
- Kamen CS, Smith-Stoner M, Heckler CE, Flannery M, Margolies L. Social support, self-rated health, and lesbian, gay, bisexual, and transgender identity disclosure to cancer care providers. Oncol Nurs Forum. 2015;42:44–51.

**Other Reading, Listening, and Viewing Resources:**

- Gen Silent, documentary (2010)  
<https://www.imdb.com/title/tt1605721/>
- Disclosure, documentary (2020)  
<https://www.disclosurethemovie.com/about>
- Trans Dudes with Lady Cancer, documentary (2019)  
<http://www.transdudeswithladycancer.org/>

- Lingua Franca, movie (2019)
- The Man Enough Podcast: The Urgent Need for Compassion with Alok  
<https://www.youtube.com/watch?v=Tq3C9R8HNUQ>
- We Can Do Hard Things podcast: What makes us beautiful? What makes us free? with Alok  
[https://podcasts.apple.com/us/podcast/alok-what-makes-us-beautiful-what-makes-us-free/id156453072\\_2?i=1000552537690](https://podcasts.apple.com/us/podcast/alok-what-makes-us-beautiful-what-makes-us-free/id156453072_2?i=1000552537690)
- The Remedy: Queer and Trans Voices on Healthcare, edited by Zena Sharman (2016)
- SageCare  
<https://sageusa.care/>
- Healthcare Equality Index Resource Guide  
<https://www.thehrcfoundation.org/professional-resources/hei-resource-guide>

