

Discrimination Fears Deter LGBTQ+ Patients from Advance Care Planning



Holly Vossel, August 09, 2022

Members of LGBTQ+ communities are foregoing advance care planning conversations due to fears of discrimination, recent research has found.

A little more than 57% of roughly 200 sexual and gender minority adults indicated in a survey that a fear of disclosing their sexual orientation or gender identity was a barricade to advance care planning, according to [research](#) in the Journal of the American Medical Association (JAMA).

Among transgender and gender nonconforming respondents in particular, 70% reported encounters with some form of discrimination in their health care experiences. This deterred them from discussing their goals of care and end-of-life wishes with providers, the study found.

Training health care staff to help patients feel safe in these discussions is essential to addressing this problem, according to Arthur Fitting, nurse and LGBTQ+ program manager at VNS Health.

with these patientHealth care providers. The concept of cultural humility should be a key component of that education, he said.

The term “cultural humility” emerged in the late 1990s. It describes an approach to communication that demonstrates understanding and sensitivity around the complex nature of identity.

“These are really difficult conversations to have with anyone, but there’s been so much trauma in the LGBTQ+ community that providers need to have a real understanding about,” Fitting told Hospice News. “It’s important for providers to understand that sexual orientation and gender identity are always relevant to the patient’s lives. You hear cultural competency as a sort of ‘buzz word,’ but it’s really about being able to develop a safe space for LGBTQ+ patients to be taken care of and share their wishes.”

Formerly the Visiting Nurse Service of New York, VNS Health recently [rebranded](#) as it expanded geographic reach across the Empire State. The hospice, home health and palliative care provider serves close to 40,000 patients on any given day. VNS Health collaborates with the advocacy organization SAGE to train staff of all walks in working with LGBTQ+ communities, including those in clinical, back-office and leadership roles.

These patients often report a history of discrimination and bias that has “greatly impacted” their access to health care and their ability to build trust in providers, Fitting added.

Hospices have worked to improve [engagement](#) with underserved LGBTQ+ communities, but have a ways to go in understanding the unique challenges and experiences. This reflects issues that exist throughout the larger health care system, including among providers upstream of hospice that assist patients with advance care planning. A 2018 AARP [study](#) found that 60% of the LGBTQ+ community is concerned about a lack of sensitivity to their needs among health care providers.

Missteps often occur when it comes to incorporating cultural humility into their staff training processes, according to Fitting. One common pitfall is insufficient time focused on cultural competence for working with LGBTQ+ patients, he added.

Most nurses and clinicians receive a mere two hours on average in LGBTQ+ health education during the course of their medical training, said Fitting. This means that those entering the health care field are often unprepared to address the cultural, societal and medical forces at play in the community.

Hospice organizations often find themselves “playing catch up” in offering this kind of training, he stated.

Even the phrase “cultural competence” itself may be an oversimplification, according to Joseph Bleiberg, lead licensed social worker with the hospice care team at VNS Health.

Cultivating understanding of patients’ life experiences and developing effective communication skills can be a life-long learning process, rather than a status one achieves by taking a class or seminar.

“All staff have ongoing training and workshops around cultural awareness and humility,” Bleiberg told Hospice News. “It’s definitely not defined as ‘cultural competence,’ because as soon as we think we know everything, then we’re toast. It’s about life-long learning and constant community outreach. It’s not a one-time thing.”

Survey respondents also identified mistrust of the health care system as a factor in their reticence to engage in end-of-life goal conversations. The experiences of the LGBTQ+ population has generated doubts that providers will support and honor their wishes, the JAMA research found.

For example, one study participant voiced a concern that they wouldn’t receive hormone therapy treatments that supported their gender identity at the end of life.

“The last thing I want to do is get sick for six months and die not looking like the person I lived my life as,” they told JAMA researchers. “I think it’s very, very important for clinicians to be able to say, ‘If it could lengthen your life by eight months, would you want us to withhold your hormone therapy or vice versa?’ I think [clinicians] need to ask really detailed questions like that.”

In another example, some LGBTQ+ respondents in the JAMA research expressed concerns that current advance care planning practices don’t include the full scope of possible surrogate decision-makers beyond the “traditional” definition of a patient’s identified family members.

Familial dynamics and structures can differ for LGBTQ+ patients compared to others, oftentimes due to discrimination or rejection among family members. Patients may have a closer bond with people outside of their biological relatives. Some use the terms “lavender family” or “chosen family” to describe these relationships.

But a “chosen family” status is often not recognized in health care, or related laws and regulations. Consequently, the people most likely to support the patient during their illness are frequently excluded from the decision-making process.

This can hinder goal-concordant care as well as providers’ ability to understand and support these decisions, according to Khannah Wetmore, social worker at the Hospice of the Western Reserve. This also puts the LGBTQ+ community at higher risk for re-traumatization during goals of care conversations, Wetmore [previously told Hospice News](#).

Another common thread JAMA researchers found was a preference among sexual and gender minority groups to discuss end-of-life care decisions and values outside of clinical settings. This was again tied to fears of discrimination resulting from past health care experiences.

One strategy is to have advance care planning conversations in the home rather than in a health care facility. This can be more conducive to fostering trust, according to Bleiberg. But the challenge is not only gaining access to these patients in the home, but also having staff understand how to navigate these conversations carefully, he continued.

Providers should also keep in mind the propensity for fear of discrimination and trauma experiences when bringing up advance care planning conversations, Bleiberg stated.

“Part of the goals of care or advanced care planning conversation is that there are relationships that go beyond these [family] dynamics,” said Bleiberg. “Starting these conversations in the home where the patient is automatically starting from a place where they and their caregivers and partners feel more comfortable talking about what they want at the end of life and what decisions are most important to make.”

Hospice News is an online trade publication based in Chicago, covering the hospice care industry, reaching an audience of over 19,000.