NHPCO Project ECHO 2023

Equity Where It Matters

Topic: Supporting LGBTQ+ Patients at End-of-life

Date: Thursday June 1, 2023

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NHPCO Project ECHO Team

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Disclosures

Disclosure

The planners and faculty disclose that they have no financial relationships with any commercial interest.

Data Collection

In order to support the growth of the ECHO® movement, Project ECHO® collects participation data for each ECHO® program. Data allows Project ECHO® to measure, analyze, and report on the movement's reach. Data is used in reports, on maps and visualizations, for research, for communications and surveys, for data quality assurance activities, and for decision-making related to new initiatives.

Evaluation

You will be receiving an email with a link to complete a short survey about this session. Please complete the survey within 48 hours. We ask all participants to take the survey as it will help us to improve future sessions.

Ground Rules and Video Teleconferencing Etiquette

- This is an all share-all learn format; judging is not appropriate
- Respect one another – it is ok to disagree but please do so respectfully
- Participants – introduce yourself prior to speaking
- One person speaks at a time
- Disregard rank/status
- Remain on mute unless speaking and eliminate or reduce environmental distractions to improve sound/video quality
- Use video whenever possible; make eye contact with the camera when you are speaking
- **Do not disclose protected health information (PHI) or personally identifiable information (PII)**

Today’s Agenda

- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

Session Faculty

Cal Cates, LMT (Licensed Massage Therapist)

Founder and Executive Director, Healwell, VA

Rev. Dr. Donnie Anderson

Minister of Pilgrim United Church of Christ, MA

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Didactic Presentation

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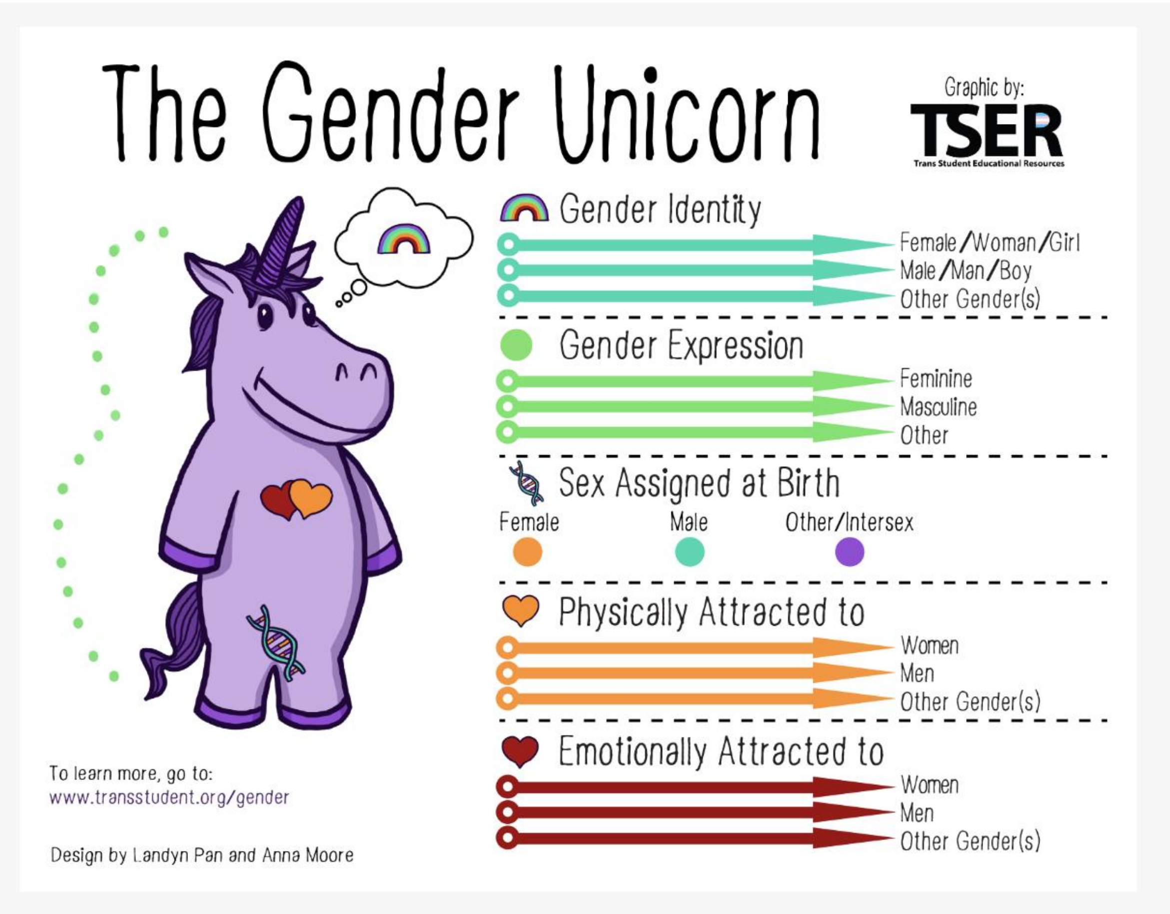
Humans Are Complex. All Humans.



Everyone—transgender or not—has a gender identity.

Sexual orientation and gender are not predictive of one another.

Being LGBTQIA2S+ means different things to different people. Like a lot of other aspects of who people are (like race or religion), there's no one way to be LGBTQIA+, and no one way for LGBTQIA+ people to look or feel about themselves.

LGBTQIA2S+ people have proportionately less education, are less likely to have health insurance, and are more likely to be low-income and have unmet medical needs because of the cost of care than their cisgendered and heterosexual counterparts.

The LGBTQIA2S+ Experience

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Discrimination Prevents Positive Outcomes

According to the Human Rights Campaign's Healthcare Equality Index, 70% of transgender and gender non-conforming respondents and 56% of lesbian, gay, or bisexual respondents reported that they had experienced at least one of the following types of discrimination from healthcare providers:

- refusing to provide needed care
- refusing to touch them or using excessive precautions
- using harsh or abusive language
- blaming them for their health status
- being physically rough or abusive

Overlooked Disparities

LGBTQIA2S+ patients and families…

- report feeling underserved, unsafe and/or unwelcome by support groups or services that assume heteronormative family and cultural structures, and in which most or all participants are not LGBTQIA2S+
- are at increased risk of mental health issues during the transition from death to bereavement as a result of disenfranchised grief
- Typically engage hospice and palliative services later than their cisgendered and heterosexual counterparts (who are already waiting until the last minute)
- are more likely to be caregivers for others, compared with heterosexual and cisgender counterparts (1 in 4 *vs* 1 in 5)

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Caregivers Who Can Be Curious and Aware Are a Gift

Ways that past trauma and internalized homophobia and transphobia can show up:

- Lesbian partner is afraid to tell a provider about her partner's sleep disturbances.
- Trans woman is uncomfortable asking her nurse for help with an indwelling catheter.
- Patient is afraid to invite their "obviously" transgender/queer/gay loved one to visit when members of the care team are present.
- Patient/family hides photos, banners, flags or other items that clearly demonstrate that they identify as LGBTQIA2S+ to avoid possible discrimination.

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Presentation Q&A

What do you wonder?

https://letsqueerthingsup.com/2015/02/20/7-ways-to-lovingly-support-your-gender-non-binary-partner/

Case Study Presentation

Who gets to be family?

Situation

- A 24-year-old non-binary person D has been living with ovarian cancer for the past 6 months. Despite oophorectomy and chemotherapy, the cancer has spread to the patient’s pelvis and abdomen. They enrolled in home hospice after a recommendation from their oncologist given the rapid progression of their cancer.

- D has been largely ambulatory in recent weeks despite bouts of fatigue and nausea. They have been able to take themselves to the bathroom and to attend to basic hygiene tasks, but the stairs to their bedroom on the second floor of the home they share with their wife, L (also 24 years old), have become too difficult to climb.

- When D enrolled in hospice, L’s first request was that they have a hospital bed on the main floor of the house so D could rest and sleep without having to navigate the stairs.

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Background

- Last year, D and L (who is a cisgendered woman who identifies as lesbian) got married. They did not invite D’s parents or family to the wedding because D’s family had not previously been accepting of their relationship.

- With D’s permission, L informed D’s family of their admission to hospice, about the progression of their cancer, and about D’s prognosis.

- D’s mom and dad have just arrived (though they were not expressly invited) while a care visit is taking place in the home. They are furious that D is in a hospital bed. They shout at the nurse who is present, saying, “Clearly, this *girl* (motioning to L) doesn’t know how to take care of our daughter. She’s not that sick!” They demand to see D’s medical paperwork, suggesting that, as D’s parents, they have the right to be involved in the decisions being made.

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Assessment

- As you think about the people in this family dynamic, what questions do you have about them that might impede your ability to see them as “people in need of competent, kind, end of life care?”
- What are some ways this nurse could respond to the patient’s parents in this situation?
- Pretend you’re this nurse. What identities do you hold that could make it difficult to remain clear about how best to moderate this situation? Are you a parent? Do you struggle with your adult child’s life choices or partner choices? Are you a member of the LGBTQIA2S+ community?
- What rights do D’s parent’s have in this situation?
- What is the nurse’s job in this situation?

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Discussion and Recommendations

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Discussion and Recommendations

- Discussion questions
  - What are some ways you could signal that you are prepared to create a safe space for the patient and their loved ones?
  - Where did communication possibly break down in ways that led to this tense situation? How could that breakdown have been prevented? Is it possible to have prevented it?

- Recommendations
  - Get curious about family dynamics and your own assumptions about who “qualifies” as family.
  - Remember that comprehension is not necessary for compassion.
  - Remember that correct use of pronouns and chosen names can be incredibly valuable in building a sense of safety and rapport. Consider including your own pronouns when you introduce yourself. You can always use 'they/them' until you know someone's pronouns. For example, "They're feeling tired today", "I'll wait for them here.”

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Key Takeaways

- **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.
- **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.

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.

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References

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Session Evaluation and Certificate of Completion

- Your feedback is valuable as we plan upcoming sessions!
  - Please complete the Project ECHO Session Evaluation

- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for each session. To receive confirmation of completion, please complete the following within 10 days of each session using the links found on the Project ECHO webpage.
  - *Project ECHO Session Evaluation*
  - *Project ECHO Post-Session Knowledge Check*

NHPCO Health Equity Certificate

- Would you like to demonstrate your commitment to delivering culturally competent care across the continuum of serious illness in an equitable, inclusive, and person-centered manner?
  - NHPCO is pleased to offer a Health Equity Certificate for individuals who participate in at least 17 sessions in the *Equity Where It Matters* series

- To receive participate in the Health Equity Certificate, please complete the following within 10 days of each session using the links found on the Project ECHO webpage.
  - *Project ECHO Session Evaluation*
  - *Project ECHO Post-Session Knowledge Check*

Upcoming Sessions

Date: June 15

Topic: Breaking Down Language Barriers to Build Connection with Our Patients

Date: July 6

Topic: Improving Patient Satisfaction Through Dignity, Respect, and Genuine Engagement

Additional Information

NHPCO Project ECHO webpage:

https://www.nhpco.org/regulatory-and-quality/quality/projectecho/

NHPCO Project ECHO session recordings and Key Takeaways:

https://www.nhpco.org/regulatory-and-quality/quality/projectecho/2023-project-echo-session-recordings/

NHPCO Project ECHO Registration Link:

https://nhpco.zoom.us/meeting/register/tZEsfu-trz4oGtQeKFw41UElYNwjSIi8QCBF

For more information:

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