NHPCO Project ECHO 2023

Equity Where It Matters

Topic: Cultural Humility in Pediatric Care

Date: March 2, 2023

NHPCO Project ECHO Team

Program Director

Aparna Gupta – Vice President, Quality

Program Lead

Sarah Simmons – Director, Quality

Program Coordinator

Karuna Tamrakar – Program Specialist, Quality

IT Support

Tej Chana – Data Analyst, Quality

Content Expert

India Harris-Jones – Manager, Health Equity and Diversity

Content Expert

Rory Farrand – Vice President, Palliative & Advanced Care

Curriculum Advisor

Nicole McCann-Davis – Communications Expert and Health Equity Advocate, External Consultant

DEI Intern

Aiyah Adam – University of Richmond, Senior

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.

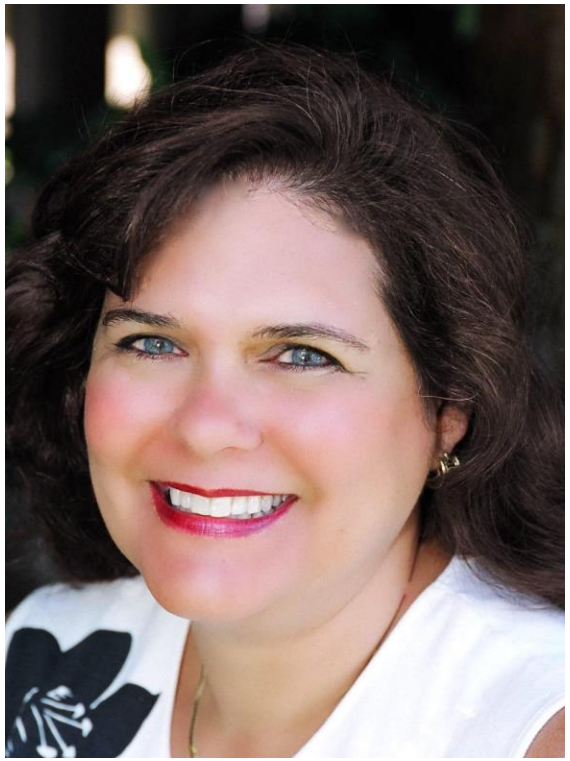
Ground Rules and Video Teleconferencing Etiquette

- 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)**

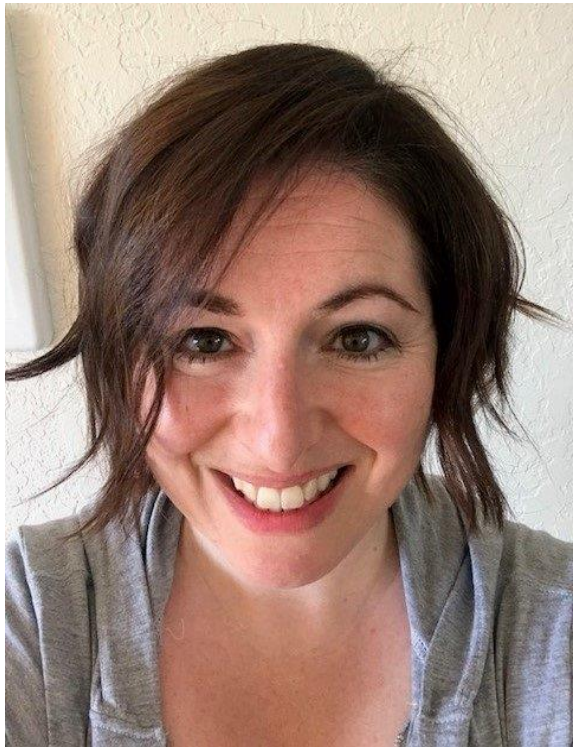
Today's Agenda

- 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



Christy Torkildson, PhD, RN, PHN, FPCN, HEC-C
Associate Professor, Program Lead, MSN-Public Health, Grand Canyon University
Director Children's Hospice and Palliative Care Coalition of California, CA



Yelena Zatulovsky, MA, LCAT, MT-BC, CCLS, HPMT, PhD(c)
Doctoral Candidate, Clinical Bioethics, Loyola University Chicago
Vice President of Patient Experience, AccentCare, IL

Poll Question

When thinking about pediatric palliative and hospice care, what comes to mind?

www.menti.com CODE: 6265 2992

Didactic Presentation:

Cultural Humility in Pediatric Care

Common Misconceptions About Minors

- **Myth**: **Infants and children do not experience pain.**
  - **Fact**: Children have a unique coping mechanism and are able to distract themselves in a way that adults typically cannot. However, this does not negate their experience of pain and there is research to support this.
  - **Fact**: There are disparities in pain and symptom management as a result of this belief!

- **Myth**: **Minors do not have the capacity to understand illness and death. Minors should be protected from the knowledge that they are dying**.
  - **Fact**: Evidence shows that children over the age of 3-4 years old have the intuitive knowledge that they want the truth and be permitted to express their emotions/thoughts. Object permanence is required to understand the concept of death, and developmentally that occurs around this age.

- **Myth**: **Parents have the power to decide.**
  - **Fact**: Minors, in some states as young as 10 years old, have the rights to consent for mental health counseling, addiction counseling, reproductive health, and/or medical records.

Common Misconceptions About Minors

- **Myth**: **Minors do not want to talk about their own death.**
  - **Fact**: Minors show great concern for their parents/guardians and families and don't participate in these conversations as a result. Their silence should be a cautionary sign; and can have a detrimental impact on their physical and emotional well-being. Learning developmentally-appropriate ways to engage in these dialogues can open the lines of communication.
- **Myth**: **Children should never attend funerals/memorials.**
  - **Fact**: Other minors within the family system should be encouraged to participate in care, including decisions related to being home when their sibling/family member dies and whether they want to attend funerals/memorials. The developmental need (yes, even for adults) to say goodbye is imperative irrespective of age.

Decision-Making & Respecting the Pediatric Patient's Voice

- **Assent vs. consent**
  - Locus of Control - a minor's belief that they have the ability to master their environment
    - External Locus of Control
    - Internal Locus of Control
- **Mature minor statutes**
  - Medical Care
  - Mental Health Counseling
  - Addiction Counseling
  - Reproductive Health
- **Right to an open future**
- **Medical records**
- **Informed consent**
  - DNROs & school board/district
  - Death at home & criminal investigation of expected home death/county-specific

Poll Question

What are topics that feel uncomfortable and scary for us?

www.menti.com CODE: 6265 2992

Hot Topics With/For Minor Patients

- **Approach with humility**
  - Emotions
  - Choice in language
  - Legal: Abuse/Neglect
- **Gender and gender identity**
- **Sexual identity, sexuality, and body image**
- **Social injustice**
- **Social pain**

A Cultural Humility Outline

Possible Communication Norms	• How do you prefer to be addressed? • What is the primary language spoken in your home? • What is the best way to partner with you and your family-of-choice?
Tradition and Health Beliefs (Historical Narratives/Healthcare Disparities That May Impact Care, if any)	• How is illness, death, and after death/afterlife discussed in your family-of-choice, if at all? • Are there any experiences with health providers in the past that weigh upon you? Positively? Negatively?

Considerations for Pain and Symptom Management	• How do you view the experience of pain? Are you comfortable identifying/rating it? Are you comfortable verbalizing it?
	  • Are there any differences between your views and those of your family-of-choice/community?
	• How do you view medication? Are there medications that you are concerned about?
	  • Are there any differences between your views and those of your family-of-choice/community?

Considerations for Advanced Directives	• How are conversations related to final wishes, DNR, etc. best initiated with you (and your family-of-choice)? • (Threshold Question) Is there something that is key to your quality of life (ex. like when someone has to perform personal care for you or when you aren't able to knit anymore), that when no longer possible would indicate a time to focus on discussing your final wishes? • How do you define "suffering"?
Considerations for Imminent Dying and At Death	• Is there a word that you and your family-of-choice use when one is close to death? Or after a death has occurred? • Are there any rituals and important traditions that we can honor when you are close to death? • Are there any rituals and important traditions that we can honor when you have died? • Are there any rituals and important traditions that we can honor following your death?
Family Structure and Dynamics	• In your family-of-choice, who makes decisions about important plans, needs, etc.? • Who would you like to be involved in discussions and decision-making? • Are there any members of your community (like clergy) that should be involved in meetings to support you and your family-of-choice's needs?

accentCare.

REMINDER: Persons of the same backgrounds do not always identify in similar ways or carry the same beliefs. When initiating dialogues about an individual's identity, ALWAYS lead with questions to demonstrate compassion, sensitivity, humility, and genuine interest.

Case Study Presentation:

Let's give Lewis* a voice!

*** Lewis is a fictional patient made up of a multitude of different pediatric patient stories. We have chosen to use a name because it has a direct impact to the cultural identity of our case.**

Situation

- Intact family with two children, 15 y/o daughter and 11 y/o son
- Family immigrated to US when daughter was an infant from Asia,
  - Parents understand some English but are not comfortable in the language
  - Although living in the United States for 14 years, parents rely on and follow traditions from their family of origin
  - Daughter is an *All-American* teenager, honor roll student, involved in dance, piano and other school activities including sports. Currently refuses to speak anything other than English
- Son diagnosed with Duchenne's Muscular Dystrophy at age 2
  - Duchenne's Muscular Dystrophy (DMD) is a genetic disorder characterized by progressive muscle degeneration and weakness due to the alterations of a protein called dystrophin that helps keep muscle cells intact. There is no cure and most patients die in adolescents/young adulthood from respiratory/cardiac compromise although with technology some patients are living into adulthood. (MDA.org)
  - DMD is an x-linked recessive trait, Mothers are carriers but 30% of cases are new mutations. (Rare Diseases Info)
  - Incidence is 1 in 3,600 male live births; most common myopathy.

The Patient's Parents

- In the next 2 minutes, **use the chat box** to list everything that is coming to your mind with regards to the parents/family.
- At the end of this time, we will refocus our discussion on the patient

Background & Assessment

- Patient is cognitively intact, reads well beyond developmental level; wants to please everyone.
- His primary source of socialization is gaming online
- Home schooled with district provided educators
- Patient is exploring his gender identity – uses they/them pronouns
- Patient is losing milestones
- Can no longer walk, needs support to transfer,
  - Needs a special wheelchair to stay upright
  - Just started having to use the SmartVest every two hours/24 hours per day
  - Has been hospitalized twice for pneumonia in the past three months
  - Cardiac function decreasing
  - Oxygen dependent
  - GT dependent
- Teams involved with patient include
  - Tertiary Children's Hospital – Medical Treatment Facility
  - Hospital and Community-Based Palliative Care
- Referral to Hospice recommended

Discussion and Recommendations

Discussion and Recommendations: Empowering the Pediatric Voice

- How do you do that?
- Why is it important/why does it matter?
- What do we need to learn?
- Who do we need to learn it from?
- Where do we create space for the minor's voice?
- When do we create space for the minor's voice?
- When do we create space for the other voices?
  - Who are the other voices?
- What does cultural humility mean when serving a pediatric population?

Key Takeaways

- Elements of Cultural Humility in Pediatric Care:
  - Reducing disparities including pain and symptom management, access to care, and consent
  - Developing comfort with hard conversations
  - Do not stereotype! When you recognize one patient, you know one patient!

- **Listen to the voice of the minor patient!**

- Actionable Steps:
  - Ask questions
  - Identity is driven by the individual, not the group
  - Use of cultural humility tool to understand the unique needs of this pediatric patient
  - Honor the interdisciplinary team; work together, not in silos
  - Help to amend your EMR to be more culturally appropriate for this population

- Next Steps:
  - Identify your own biases (implicit and explicit):
  - Become an advocate for the minor patient: practice approaches with parents/guardians
  - For the activists among us (a starting place): participate in lobbying for CMS to change their SOGI identifiers

Definitions

Minor

- NHPCO's PAC published pediatric standards in 2022, they define minors from prenatal to young adult (up to 21st birthday)
- Presenters are using *minor* because pediatric has a connotation most often associated with the term *children*

Disparities

- Lack of similarity or inequality
- Healthcare disparity typically refers to differences in groups in relation to health insurance coverage, access to, use of care, and quality of care

Demographics

- Refers to gender, race, faith, etc. and other identifying factors

SDOH

- Social Determinants of Health

Bias

- Preconceived notions that are applied to others, typically those with differences from ourselves; these may create generalizations, stereotypes, and discriminate groups
- Explicit
- Implicit

Cultural Competence

- Competence implies that we can know/understand something 100%
- A Cautionary Tale

Humility

- "...is a process of self-reflection to understand personal and systemic biases and privilege that may contribute to health disparities"
- Is person-centered where the patient is the expert
- A willingness to learn so that self-reflection is critical

References/Resources

- Harvard's *Project Implicit*: https://implicit.harvard.edu/implicit/takeatest.html
- UCLA's *Implicit Bias Series*: https://equity.ucla.edu/know/implicit-bias/
- Stanford's *Innovation Lab*: https://womensleadership.stanford.edu/resources/tools
- Muscular Dystrophy Association: https://www.mda.org/
- Rare Diseases Info: https://rarediseases.info.nih.gov/diseases/6291/duchenne-muscular-dystrophy/
- *Hospice Through the DEI Lens: A Research Study Identifying Barriers to Hospice Care in Underserved Communities,* National Hospice and Palliative Care Organization. (Inclusion Access Toolkit)
- *LGBTQ+ Resource Guide.* National Hospice and Palliative Care Organization
- *Finding the Right Words: Cohesion and Divergence in Inclusive Language Guidelines, Online Journal of Issues in Nursing, October, 2022; 27(3).*
- *Transgender Myths: Dispelling Common Misconceptions, My American Nurse, August, 2022.*
- *Cultural Humility, Nurse Educator, 2022; 47(5).*
- *Cultural Humility: A Concept Analysis, Journal of Transcultural Nursing, 2016; 27(3).*
- *Cultural Competence or Cultural Humility? Moving Forward Beyond the Debate, Health Promotion Practice, 2020; 21(1).*
- *Increasing Sensitivity in Clinical Practice with the Transgender Population, Kaitlyn O'Donnell, MSW, LCSW, 2021 https://www.linkedin.com/in/kaitlynkodonnell/*

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 18 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: March 16, 2023

Topic: Exploring lived experiences to address social determinants of health in end-of-life care

Date: April 6, 2023

Topic: Caring Through Interpersonal Conflict

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-trz4oGtQeKFw41UElYNwjSli8QCBF

For more information:

innovation@nhpco.org