

NHPCO Project ECHO *Equity Where It Matters*

Key Takeaways: Cultural Humility in Pediatric Care

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Key points:

- **Common misperceptions:** There are common misconceptions about minors that can diminish their voice, such as their perceived inability to experience pain, do not want to talk about their own death, and should not attend funerals. Ultimately, this can further alienate minor patients from taking part in the decision-making process in medical cases.
- **Decision making:** Respecting a minor patient's voice can relate to understanding their respective decision-making process, with the locus of control, both internal and external, playing a role. Mature minor statutes allow mature adolescents the ability to give consent for medical care, and granting patients that option proves important.
- **Intentionality:** Topics to approach with humility include emotions which range by age group, language choices, and legal abuse/neglect. Additionally, gender identity, social injustices, and social pain all are topics to be intentionally approached. It is important for health providers to develop comfort with hard conversations, and through this there could result in an increase in access to care and consent. Active listening and intentional language are of most importance when interacting with minor patients.

Actionable Steps:

- Recognize that each minor patient is unique and ask questions to further guide your understanding
- Utilize the "Cultural Humility" tool found in the "Cultural Humility in Pediatric Care" presentation slides to outline potential leading questions for minor patients
- Emphasize collaboration in your organization to honor the strength interdisciplinary teams can create when making decisions
- Help your organization in amending your Electronic Medical Records system to implement cultural humility
- Become an advocate for the minor patient: practice approaches with parents/guardians
- Participate in lobbying for Centers for Medicare and Medicaid Services (CMS) to change their sexual orientation and gender identity (SOGI) identifiers

Conversation Starters:

- How can I identify my own biases, both explicit and implicit, to better guide my approach to interacting with minor patients?
- What systematic changes can my organization participate in to uplift a minor's role in their patient decision making process?
- How can my organization implement the "Cultural Humility tool" to be a resource that is consistently used by health providers?
- Does your organization have an Ethics Committee, or access to an Ethics Committee, to address ethical concerns that may arise in providing care to pediatric patients?



Participant Perspectives:

- While balancing patient and parent perspectives, we may risk the parents' rejection of care if we don't proceed cautiously and with respect. Ensure that team is not *excluding* the parents in place of the minor – must include the entire family unit in decision-making.
- It's important to ensure that minor patients understand their diagnosis and choices before asking them to make choices. Some patients who have experienced the long-term effects of a life-limiting illness may have a good understanding of their prognosis, while others may not.
- "While parents and caregivers may have more life experiences that help with decision-making, the patient is the only one who truly understands how the disease is impacting them physically, emotionally, and spiritually."
- "The healthcare professional needs to be able to use a variety of strategies to meet the needs of the family unit as well as the dignity and respect of the patient regardless of age."
- "What I've found useful is discussing issues in a group setting with the child and the parents and playing 'devil's advocate' for both sides."
- "Finding supervision that helps clinicians reflect on the moral distress is really important."
- "The need for appropriate language interpretation, providing resources in various manners, cultural need to ask family what they want, ask about traditional meds."

References:

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- Muscular Dystrophy Association: <https://www.mda.org/>
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- *Finding the Right Words: Cohesion and Divergence in Inclusive Language Guidelines*, *Online Journal of Issues in Nursing*, October, 2022; 27(3).
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- *Cultural Competence or Cultural Humility? Moving Forward Beyond the Debate*, *Health Promotion Practice*, 2020; 21(1).
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- NHPCO Diversity Tools and Resources <https://www.nhpco.org/education/tools-and-resources/diversity>
- Culturally and Linguistically Appropriate Services (CLAS) <https://thinkculturalhealth.hhs.gov/clas>
- Leave No One Behind: Equity and Access in Palliative Care <https://wfrtds.org/report-on-access-to-palliative-care/>
- CMS Framework for Health Equity <https://www.cms.gov/about-cms/agency-information/omh/health-equity-programs/cms-framework-for-health-equity>

