

# **NHPCO Project ECHO**

## **Ethical Dilemmas Across Health Equity: 2024**

### **Equitable Ethics in Pediatric Care: A Palliative and Hospice Care Lens**

**August 6, 2024**

# Disclosures

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## **Disclosure**

The faculty and planners for this educational event have no relevant financial relationship(s) with ineligible companies to disclose.

## **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**

Please complete program evaluation materials following each session.

# Ground Rules and Video Teleconferencing Etiquette

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- 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

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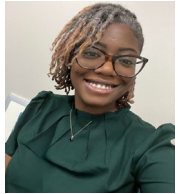
- Introduction of Faculty – NHPCO Team
- Didactic Presentation – Faculty
- Case Study Presentation – Faculty
- Discussion – Session Participants, Faculty, and NHPCO Team
- Key Takeaways – Faculty and NHPCO Team
- Closing Remarks – NHPCO Team

# Project ECHO Team



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# Faculty Members

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# Didactic Presentation

# Objectives

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- **Identify challenges in access to pediatric palliative/hospice care**
- **Differentiate between facilitators and barriers to the provision of services**
- **Discuss potential solutions to increase access to pediatric palliative/hospice care**



# Introduction

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## **Definition of Equitable Ethics:**

Ensuring fair treatment and opportunities for all patients, regardless of background or circumstance.

## **Focus:**

Application of these principles in pediatric palliative and hospice care.

## **Why is there a need?**

# Palliative vs. Hospice Care

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## **Palliative Care:**

Aimed at providing relief from symptoms and stress of a serious illness. Can be given alongside curative treatment.

## **Hospice Care:**

- Focuses on the comfort and quality of life for patients with a terminal illness, typically with a prognosis of six months or less.\*
- For most children hospice is provided with concurrent care, this became a benefit for pediatrics in 2010.

# Importance of Equitable Ethics

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## **Moral Obligation:**

Ethical duty to treat all patients with fairness and compassion.

## **Legal Requirements:**

Adherence to laws and guidelines ensuring non-discriminatory practices.

## **Healthcare Outcomes:**

Improved patient satisfaction and health outcomes through equitable care.

# Key Principles of Equitable Ethics

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## **Justice:**

Fair distribution of healthcare resources.

## **Non-Maleficence:**

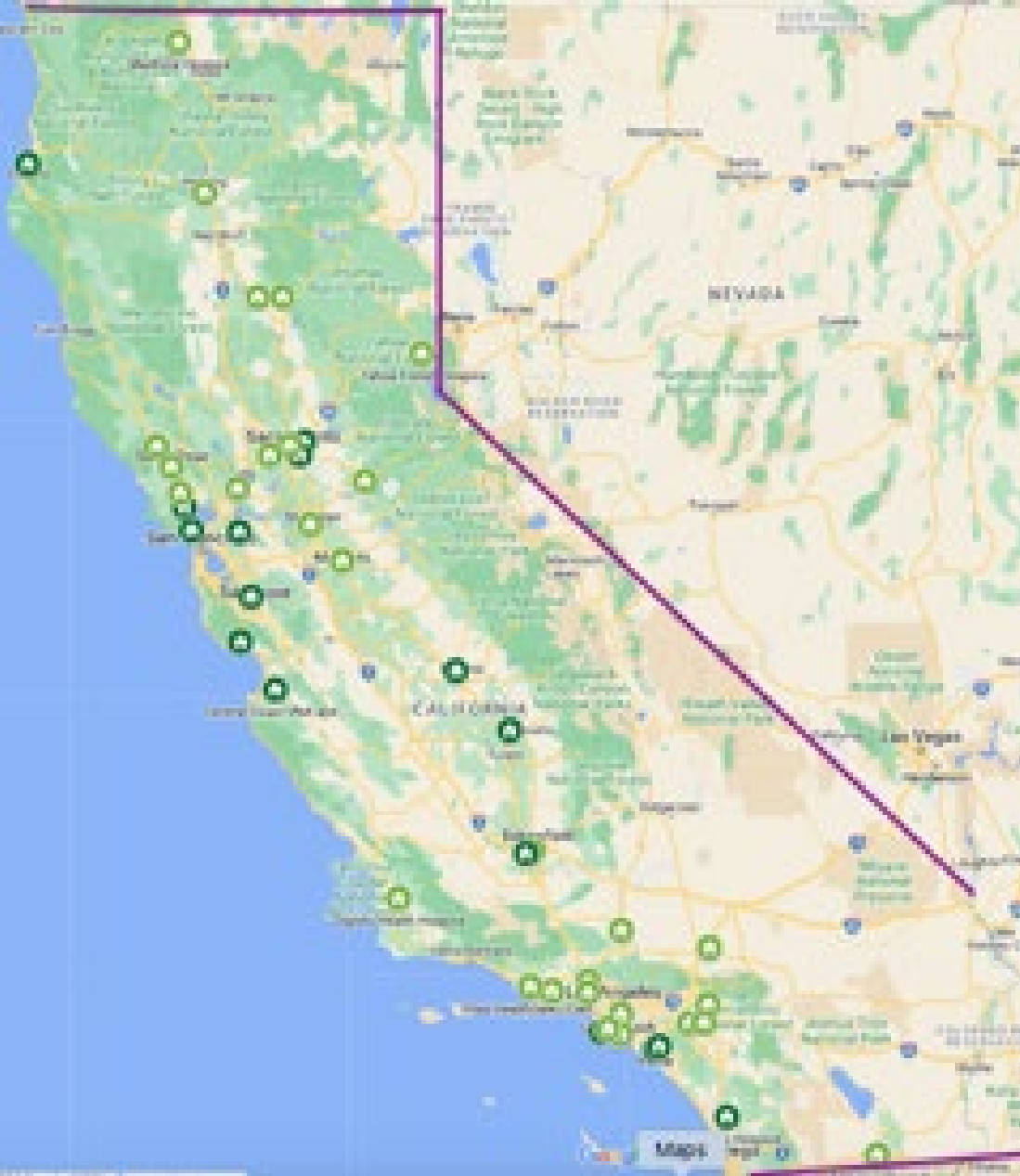
Avoidance of harm.

## **Beneficence:**

Act in the best interest of the patient.

## **Autonomy:**

Respect for patient and family choices.



- California is the most populated state in the US and is arguably home to the largest population of children with medical complexity.
- Research by Dr. Lindley and her team found that “...hospice is increasingly providing essential pediatric services to children and their families. Children are increasingly utilizing hospice services – and concurrent care for those are eligible. **30% more children are seeking hospice care over the past decade**, but the percentage of hospices with pediatric experience & special pediatric programs **has steadily declined over the past decade, especially in California.**”

# What the data shows:

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- Due to the shortage of pediatric hospices, many adult hospice programs care for pediatric patients.
- In California, Dr Lindley and her team found, the number of adult hospices that will care for a pediatric patient has been consistently decreasing. **During the time period of 2018-2021 adult hospices that would take a pediatric patient decreased by 32%**

## NHPCO Pediatric Facts & Figures, 2023 edition

### Key findings include

- The #1 Facilitator to taking pediatric patients was trained staff in pediatrics
- The most common barrier was lack of pediatric trained personnel.
- However, one of the most concerning findings was the number of free-standing children's hospitals in the United States who reported access to community-based hospice services for their patients.
- Between 2016-2019, the percentages of hospitals that reported access averaged 40%. However, in 2020 that number dropped to 26%. This is consistent with the finding in the state of California.

# Barriers to Equitable Pediatric Care

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## **Socioeconomic Status:**

Financial constraints affecting access to care.  
Lack of knowledge of services

## **Cultural Differences:**

Language barriers and differing beliefs about healthcare.

## **Geographic Location:**

Limited access to specialized care in rural or underserved areas.

## **Healthcare Disparities:**

Inequalities in the availability and quality of care.

# Strategies for Equitable Palliative and Hospice Care

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## **Interdisciplinary Teams:**

- Collaboration among healthcare professionals to address the holistic needs of the patient and family.
- Creating partnerships to increase access and education to enable the provision of care

## **Cultural Humility Training:**

Equip healthcare providers with the skills to understand and respect diverse backgrounds enabling to learn from their patients and families.

## **Community Outreach Programs:**

Increase awareness and accessibility of palliative and hospice care services

## **Family-Centered Care:**

Involve family members in care planning and decision-making processes.



# Ethical Decision-Making Framework

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## **Identify Ethical Dilemma:**

Recognize the ethical issues involved.

## **Gather Information:**

Collect relevant data and perspectives.

## **Evaluate Options:**

Consider possible courses of action.

## **Make a Decision:**

Choose the most ethical and equitable option.

## **Implement and Reflect:**

Act on the decision and evaluate the outcomes.

# Didactic Presentation Q&A

# Case Study Presentation

# Case Study

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- **Overcoming cultural barriers in immigrant populations.**
- **Providing equitable care in rural areas with limited resources.**

# Situation

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- 3-year-old, male drowning victim with significant hypoxic ischemic encephalopathy.
- Tracheostomy, Oxygen and Tube feeding dependent; total care
- Increasing respiratory requirements; repeated hospitalizations pneumonias, seizures
- Parents have decided against a ventilator
- Want him home to die
- Family lives in a rural area

# Background

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- Family are migrant farm workers; primary language is Spanish and Mixteca
- No other family; however, have been working at the same farm for several years.
- Family are legal residents
- There are 3 other siblings (ages 12-18)
- Patient drowned while playing with his older siblings, who left him unsupervised for a brief period near a creek.
- Patient has been in the children's tertiary hospital 3 months; team trying to get home health & hospice to send the patient home; hospital is 2 hours from home
- Patient actively declining

# Assessment

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- Two hospice who service the area, none with a pediatric program
- Both hospices have experience working with the migrant community
- No Mixteca interpreters; however, there are Spanish interpreters and the interpreter phone service
- Neither hospice is willing to take a child

# Recommendations

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## What can we do to get equitable access to end-of-life care for this child and family?

- Will one of the child's providers partner with hospice to be resource, facilitate pain/symptom management.
- Can the tertiary palliative care team provide education and training for the hospices to help them care for pediatric patients
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# Discussion and Recommendations

# Key Takeaways

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- **Willingness to try different models of care i.e., partnering with pediatric experts**
- **The importance of equity in pediatric palliative and hospice care to improve access to services.**
- **Commitment to ongoing education, policy advocacy, and commitment to equitable care practices**
- **If we do not keep talking about the need for services for our most vulnerable children and their families, this downward trend will continue. The challenges are significant but if we use our voices, partner with our state coalitions and national organizations we can make a difference.**

# References

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- U. S. Department of Health and Human Services, (2023). NIH style guide: Age. [https://www.nih.gov/nih-style-guide/age#:~:text=Adolescents%20\(13%20years%20through%2017,adults%20\(65%20and%20older\)\\*](https://www.nih.gov/nih-style-guide/age#:~:text=Adolescents%20(13%20years%20through%2017,adults%20(65%20and%20older)*)
- Weaver, M.S., Chana, T., Fisher, D. Fost, H., Hawley, B., James, K., Lindley, LC., Samson, K., Smith, S.M., Ware, A., and Torkildson, C. (2023). State of the service: Pediatric palliative and hospice community-based service coverage in the United States. *Journal of Palliative Medicine*, 26(11), 1521-1528; <http://doi.org/10.1089/jpm.2023.0204>

# Resources

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- Children’s Hospice and Palliative Care Coalition of California: [www.chpcc.org](http://www.chpcc.org)
- Pediatric Palliative Care Coalition of Pennsylvania: <https://www.ppcc-pa.org/>
- Pediatric End-of-Life Care Research: <https://pedeolcare.utk.edu>
- National Hospice and Palliative Care Organization: [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics)
- Hospice Action Network Policymaking 101:  
[https://hospiceactionnetwork.org/wp-content/uploads/HAN-Policy-Making-101\\_Final.pdf](https://hospiceactionnetwork.org/wp-content/uploads/HAN-Policy-Making-101_Final.pdf)

# Session Evaluation and Certificate of Completion

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- Your feedback is valuable as we plan upcoming sessions! Please complete the Project ECHO: [Ethical Dilemmas Across Health Equity Session Post-Session Evaluation](#)
- Project ECHO sessions are not accredited for continuing education, but we are able to offer a confirmation of completion for participants who attend at least four live sessions and complete all session evaluations as well as a final miniseries evaluation.

# Upcoming Sessions

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**Date: August 13**

Topic: Appointed Guardianship and Balancing Legal, Ethical, and Equitable Responsibilities

**Date: August 20**

Topic: Confronting Ethical Dilemmas: Real-Life Challenges and Insights

**Date: August 27**

Topic: Summary Wrap-Up: Conducting an Ethics Review

# Additional Information

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NHPCO Project ECHO webpage:

<https://www.nhpc.org/regulatory-and-quality/quality/projectecho/>

For more information:

[projectecho@nhpc.org](mailto:projectecho@nhpc.org)