

Introduction to the REACH Pediatric Palliative Care and Hospice ECHO[®] Program: Supporting Hospice Nurses in Caring for Children

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Initial Disclosures

Project ECHO® and REACH collect registration, participation, chat comments. This data can be used for reports, maps, communications, surveys, quality assurance, evaluation, and to inform new initiatives.

Your individual data will be kept confidential.

For educational purposes, we will record this session and it will be available on our website to all participants.

By participating in this session, you are consenting to be recorded. We appreciate and value your participation!

If you have questions or concerns, please email REACH@stjude.org

Nursing Continuing Professional Development Activity

St. Jude Children's Research Hospital is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation.

1. Arrive no more than 5 minutes after start of session and stay until the end
2. Participate in case discussion
3. Complete evaluations
4. Keep track of how many sessions you attend

Zoom Etiquette

- **Mute microphone** when not speaking
- Remember to **unmute before speaking**
- Speak close to microphone
- Please keep your **camera ON**, if possible
- **IT Issues?** Chat or email REACH@stjude.org

Zoom Etiquette

- Ensure correct naming on your screen
 - Click on the three dots on your small screen in Zoom or find yourself by clicking “Participants”
 - Choose “rename”
 - Type your **first name, last name, and hospice organization**
- To communicate during sessions:
 - **Raise your hand** if you would like to speak
 - **Use chat** for comments and questions

Ground Rules

- Safe space...everyone's questions, thoughts, and concerns are valid and valuable
- Take space and make space
- What's said here, stays here (Vegas!)
 - To protect the privacy of all participants, please keep everything discussed during the session confidential
 - When sharing real life examples from your work during discussions, only share de-identified information

Objectives

- Welcome to the REACH initiative and introductions
- Review Project ECHO®
- Introduce the REACH Pediatric Palliative Care and Hospice ECHO® Program
- Recognize ways that pediatric hospice care is uniquely different from adult care
- Learn about the Concurrent Care Act and how it applies to delivery of pediatric hospice care
- Model case discussion
- Wrap Up
- Mindfulness activity



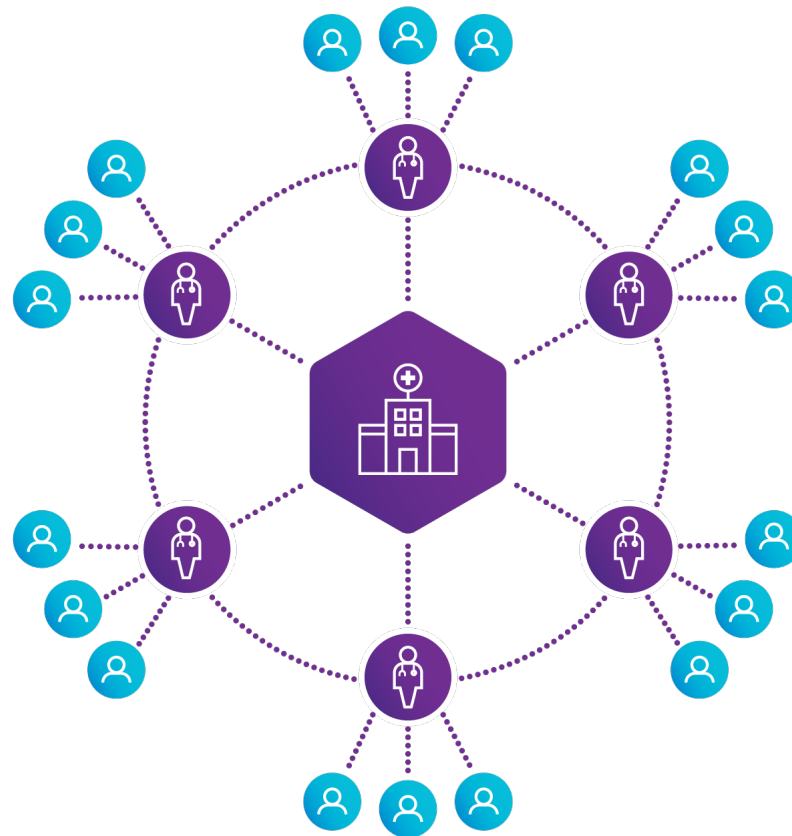
REACH

Regional Pediatric Education and Assistance
Collaborative for Hospice Nurses

REACH Initiative

Vision: Hospice nurses in the state of Tennessee will have access to expert pediatric-specific training and support to empower them in provision of high quality, compassionate care to children and their families.

Mission: Through our partnership with Project ECHO, we will provide evidence-based knowledge, resources, peer support, and community for hospice nurses across our state.



Pediatric hospice and palliative medicine experts

Hospice nurses practicing in the community

Pediatric patients and families





Extension for Community Healthcare Outcomes

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Outcomes of Treatment for Hepatitis C Virus Infection by Primary Care Providers

Sanjeev Arora, M.D., Karla Thornton, M.D., Glen Murata, M.D.,
Paulina Deming, Pharm.D., Summers Kalishman, Ph.D., Denise Dion, Ph.D.,
Brooke Parish, M.D., Thomas Burke, B.S., Wesley Pak, M.B.A.,
Jeffrey Dunkelberg, M.D., Martin Kistin, M.D., John Brown, M.A.,
Steven Jenkusky, M.D., Miriam Komaromy, M.D., and Clifford Qualls, Ph.D.

This article (10.1056/NEJMoa1009370) was
published on June 1, 2011, at NEJM.org.

N Engl J Med 2011;364:2199-207.

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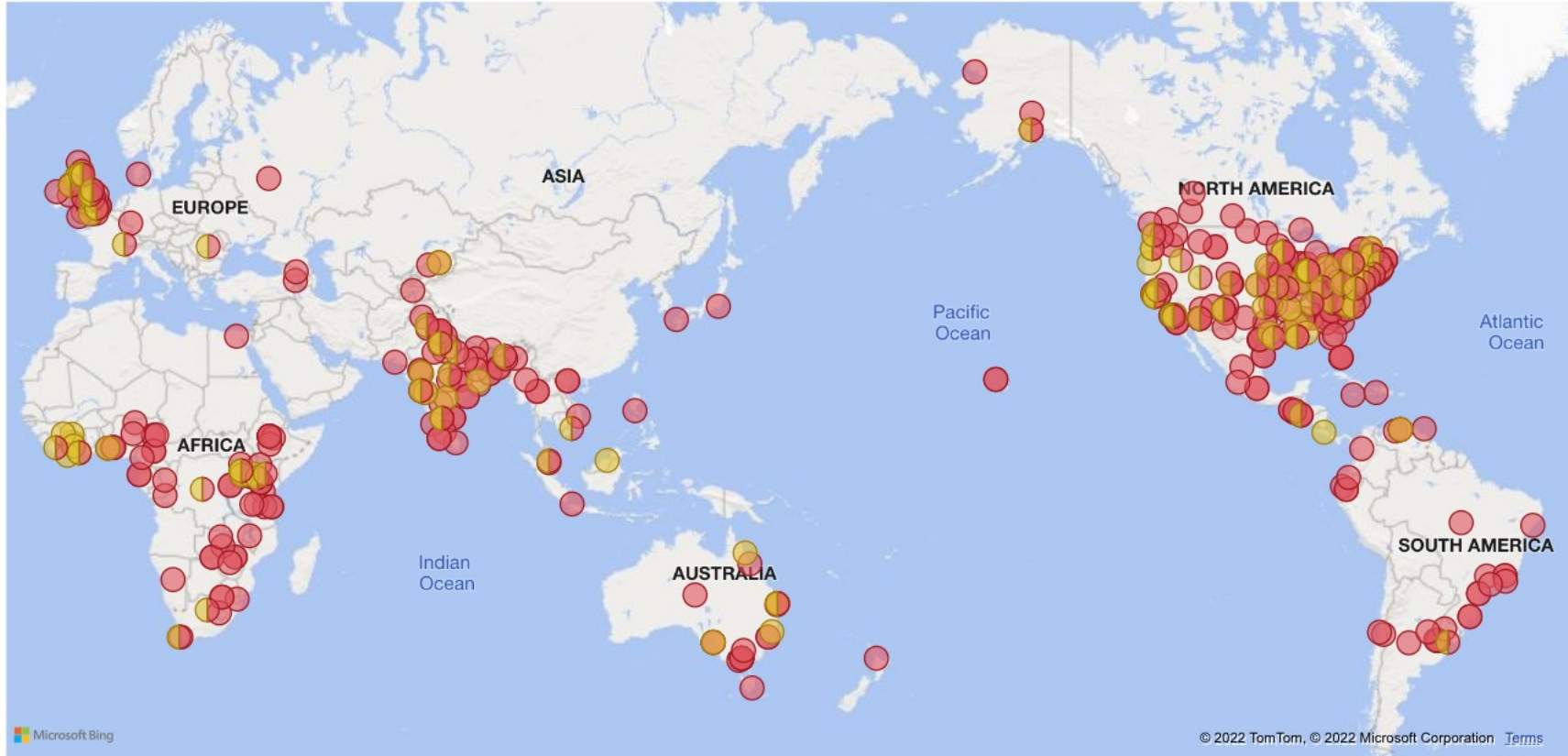


ECHO Programs

Programs
1773

Countries
69

Status: ● Active ● Planned



REACH Pediatric Palliative Care and Hospice ECHO®

- Convenient and easily accessible virtual environment that connects experts with community hospice nurses
- Share evidence-based pediatric specific education and support to empower nurses in delivering high quality, compassionate care to children and their families
- We are committed to providing these sessions for hospice nurses in the community and also welcome other interdisciplinary participants

REACH Pediatric Palliative Care and Hospice ECHO®

- Virtual sessions will occur monthly on the 3rd Thursday of the month from 1-2:30P CST
 - Welcome, announcements, and introductions
 - Didactic presentation
 - Case-based discussion
 - Mindfulness activity
- If you are unable to join a session in real time, you can find the recordings on our website to view whenever is convenient for you



REACH Pediatric Palliative Care and Hospice ECHO®

- Please visit stjude.org/reach for more information including:
 - Curriculum overview
 - Registration form
 - Case discussion form
 - Session recordings
 - Additional resources
- Please email REACH@stjude.org with any questions, comments, or suggestions

Pediatric vs. Adult Hospice

Providing palliative and hospice care to pediatric patients and their families is uniquely challenging and requires pediatric-specific training

Pediatric vs. Adult Hospice

- Pediatric patients range in age from infants to young adult
- Developmental needs vary widely



Pediatric vs. Adult Hospice

- Large variety of hospice-qualifying diagnoses, including many rare disorders
 - Cancer
 - Congenital malformations
 - Heart disease
 - Chronic lung disease
 - Neurologic conditions
 - Genetic conditions
- *You don't have to be an expert in all these conditions...it's okay to ask questions and look things up (we do all the time!)

Pediatric vs. Adult Hospice

- Pediatric patients can continue to receive disease-directed therapies while receiving hospice services

Section 2302 of the Affordable Care Act, titled Concurrent Care for Children[†]

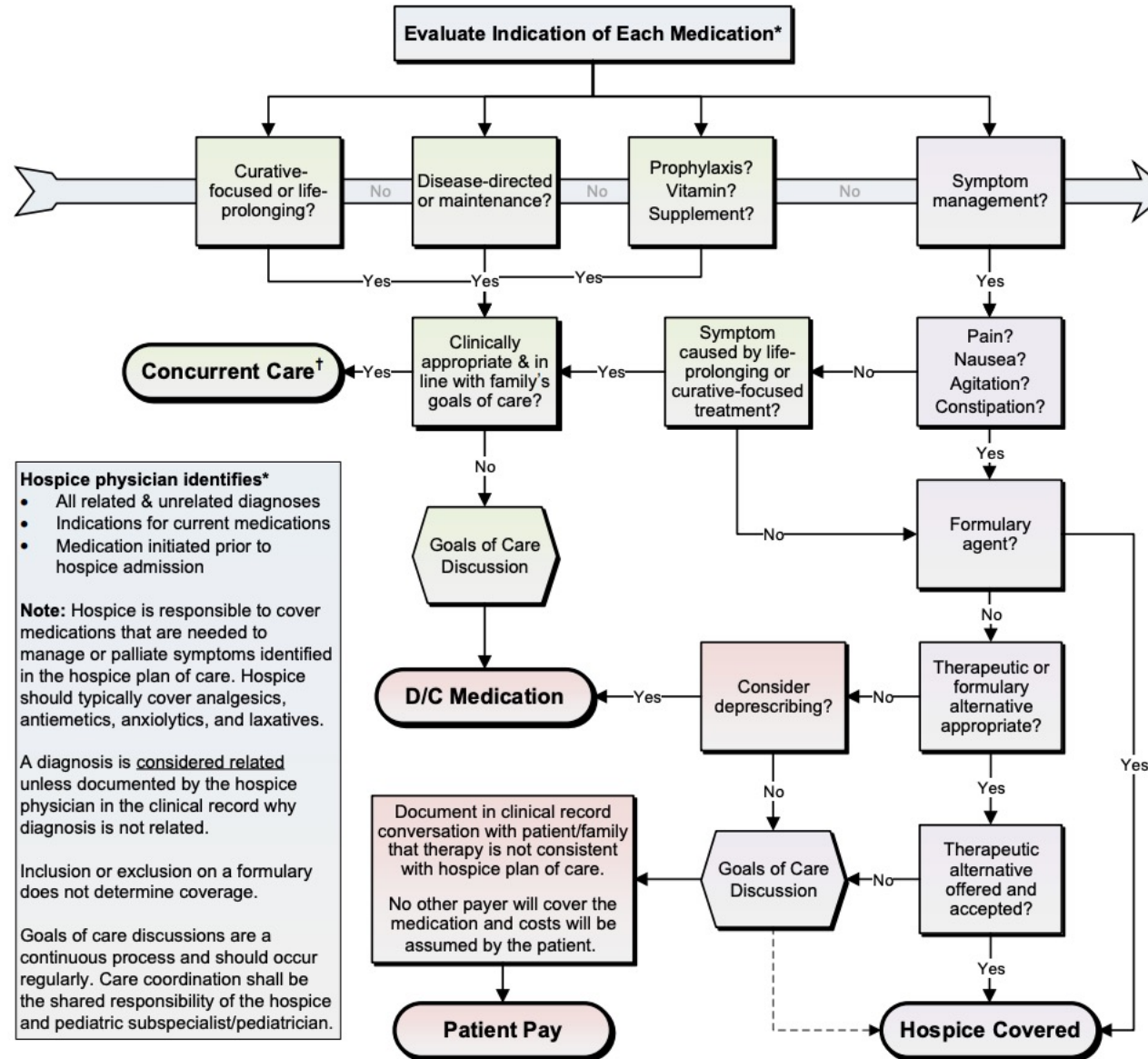
Seriously ill children who are <21 years of age and have a 6-month prognosis are entitled to receive hospice benefit in addition to all necessary disease-directed therapies with the goal of providing access to comprehensive care to live as long and as well as possible. Medicaid shall continue to be responsible to pay for disease-directed therapies in addition to the hospice benefit providing comfort-directed therapies.

Medicaid shall reimburse appropriate Medicaid-enrolled providers directly through the usual and customary Medicaid billing procedures. A hospice provider shall not be responsible for life-prolonging treatment, medications prescribed by non-hospice providers/subspecialists, or any aspect of the patient's medical care plan that is focused on treating, modifying, or curing a medical condition (even if that medical condition is also the hospice-qualifying diagnosis). Life-prolonging services and hospice services shall be billed and reimbursed separately, meaning the child can receive services concurrently.

Concurrent Care

- Limited guidance from the Centers for Medicare and Medicaid Services
- State-level Medicaid implementation of concurrent care has varied significantly
- States have options to provide more expansive services and eligibility

Use in conjunction with details in NHPCO's Concurrent Care for Children Implementation Toolkit.
Always take into consideration patient-specific factors when making these decisions.



Hospice physician identifies*

- All related & unrelated diagnoses
- Indications for current medications
- Medication initiated prior to hospice admission

Note: Hospice is responsible to cover medications that are needed to manage or palliate symptoms identified in the hospice plan of care. Hospice should typically cover analgesics, antiemetics, anxiolytics, and laxatives.

A diagnosis is considered related unless documented by the hospice physician in the clinical record why diagnosis is not related.

Inclusion or exclusion on a formulary does not determine coverage.

Goals of care discussions are a continuous process and should occur regularly. Care coordination shall be the shared responsibility of the hospice and pediatric subspecialist/pediatrician.

Tennessee Pediatric Palliative and Hospice Care Collaborative

- Newly formed statewide coalition working to improve care for children with serious illness
- Actively involved in advocacy with state Medicaid program to ensure effective implementation of the legislation

Pediatric vs. Adult Hospice

- Pediatric patients often have multiple:
 - Medications
 - Devices and equipment
 - Providers
- *You don't have to be an expert with all these medications and devices...it's okay to ask questions!
- Learn who “owns” what for troubleshooting

Pediatric vs. Adult Hospice

- Pediatric patients often won't have DNR orders
- Navigating these conversations requires building trust over time
- Typically, we do not initiate this discussion at time of hospice enrollment

Pediatric vs. Adult Hospice

- Pediatric patients exist in the context of a family
 - Parents
 - Grandparents
 - Siblings
- Provide family centered care



Model Case Discussion

Model Case Discussion

Submit cases via online form on our website

www.stjude.org/reach

Model Case Discussion

- 7-year-old boy with hospice diagnosis of metastatic bone cancer
- Worsening pain to right lower extremity, impacting ability to play and spend time with his family and friends
- Initial pain regimen:
 - Oxycodone 5 mg Q4 scheduled
 - Oxycodone 5 mg Q2 PRN breakthrough pain
- Current pain regimen:
 - Morphine 7.5 mg Q4 scheduled
 - Morphine 7.5 mg Q2 PRN breakthrough pain
- Question for experts: How can we optimize pain management?

Model Case Discussion

- Additional questions from the group?
- Additional questions from experts?
- Discussion with experts
- Recommendations from experts

Resources

NHPCO Pediatric Concurrent Care

<https://www.nhpcoco.org/palliativecare/pediatrics/pediatric-concurrent-care/>

Thank You!

- Please visit stjude.org/reach for more information including:
 - Curriculum overview
 - Registration form
 - Case discussion form
 - Session recordings
 - Additional resources
- Please complete your surveys to claim CEU credit
- Email REACH@stjude.org with any questions, comments, or suggestions
- Next session: October 20, 2022



Mindfulness and Music

- Body scan
- Diaphragmatic breathing
- Resources
 - Music Ideas: Spotify playlist (updated periodically)
[Playlist](#)
 - Mindfulness: Body scan script and audio
ggia.berkeley.edu/practice/body_scan_meditation