

# Benefits & Challenges of Pediatric Concurrent Care Evidence from 10 years

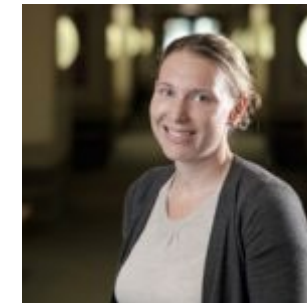
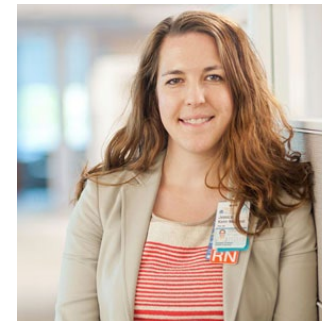
TPPCC 6<sup>th</sup> Annual Midwinter Conference  
Lisa C. Lindley, PhD, RN, FPCN, FAAN  
February 21, 2020



THE UNIVERSITY OF  
**TENNESSEE**  
KNOXVILLE

# Introductions

- Team Members
  - Pam Hinds, PhD, RN FAAN
  - Jenny Mack, MD, MP
  - Jess Keim-Malpass, PhD, RN
  - Melanie Cozad, PhD
  - Theresa Profant
  - Rodion Svyrenko, PhD
  - Jessica Laird



Background

Challenges

# HAPPY ANNIVERSARY

Benefits

March 23, 2020

Implications

# Objectives

- **Review background of concurrent care**
- **Identify challenges of concurrent care**
- **Highlight benefits of concurrent care**
- **Explore implications of concurrent care**

# Background

- **Definition**
- **History**
- **Key Stakeholders**
- **Financing**

# Background - Definition

A voluntary election to have payment made for hospice care for a child (as defined by the State) shall not constitute a waiver of any rights of the child to be provided with, or to have payment made under this title for, services that are related to the care of the child's condition for which a diagnosis of terminal illness has been made (ACA, section 2302).

# Background - History

The history of concurrent care predates ACA 2302 by about a decade

- Demonstration projects
- Champions
- State legislation
- Federal legislation

# Background - Key Stakeholders

Concurrent care involves a very wide range of stakeholders





# Background - Financing

Initial payment for concurrent care was Medicaid

- Medicaid payment for services
- Payment for services – date overlap
- State Medicaid billing procedures

# Challenges

## Predicted 2010

- Survival of Medicaid hospice benefit
- Fragmented care
- Care coordination
- 6 month prognosis
- No private insurance
- Limited state-level resources

## Actual 2020

- Definition
- History
- Key Stakeholders
- Practice
- Financing
- Evidence

# Challenges - Definition

A voluntary election to have payment made for hospice care for a child (as defined by the State) shall not constitute a waiver of any rights of the child to be provided with, or to have payment made under this title for, services that are related to the care of the child's condition for which a *diagnosis of terminal illness* has been made (ACA, section 2302).

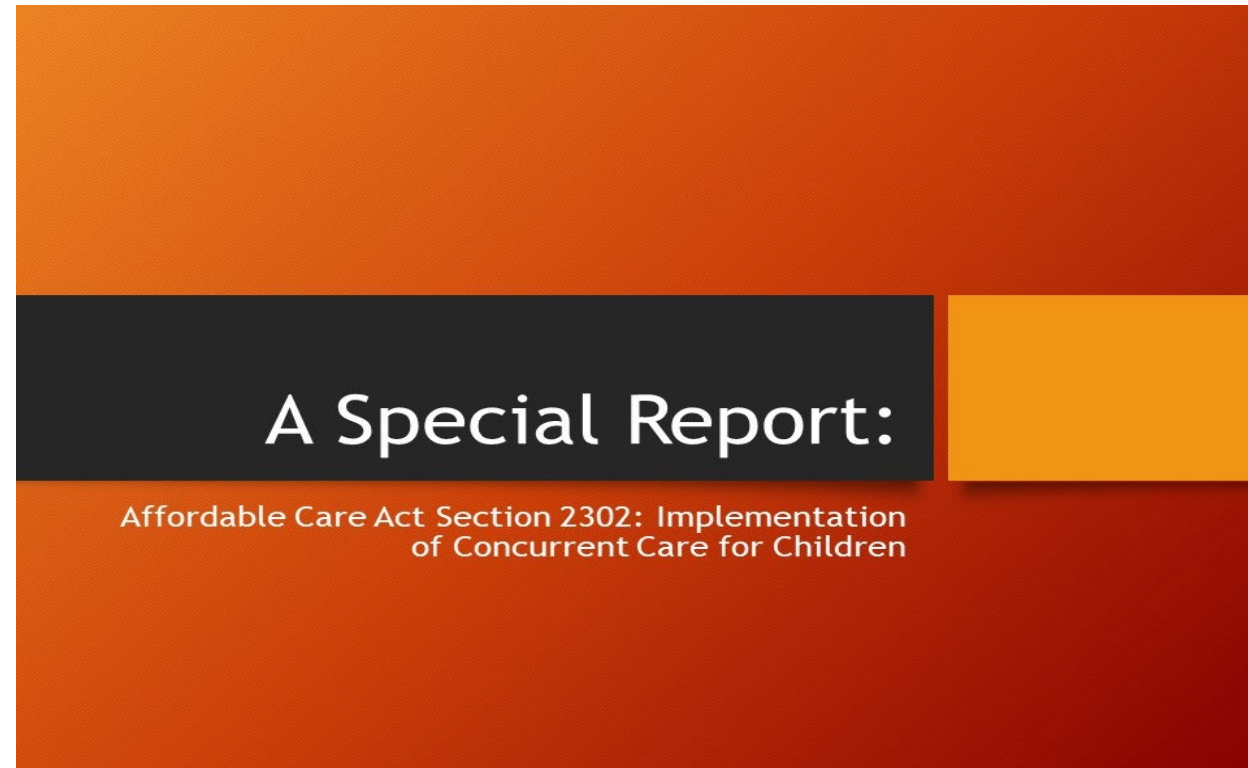
# Challenges - History

## A decade of change

- Demonstration projects – ACA 2302 different
- Champions – gone
- State legislation - different
- Federal legislation – limited communication/implementation variation

# Implementation – blog series

[pedeolcare.utk.edu/special-report-6-part-series/](http://pedeolcare.utk.edu/special-report-6-part-series/)



# Challenges - Financing

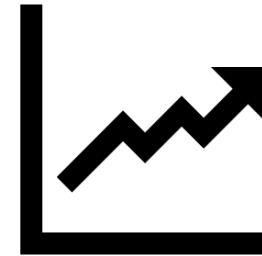
## Uncertainty



- Hospice vs. treatment payment
- Care coordination
- Coordination of insurances
- Cost shifting (DME, Medications)

# Challenges - Practice

## Shifting care environment



- Non-pediatric provider
- Extended LOS in hospice (144 vs 76 days)
- Durable medical equipment (DME) high (5 times higher)

# Challenges - Evidence

## Lack of evidence

- Conducted scoping review
- Identified 14 articles (9 pediatric)
- Narrative (7), case studies (3), quantitative (3), and qualitative (1)
- No baseline information
- No information on facilitators or barriers
- Limited outcomes data
- No evaluation of effectiveness



LOOK  
AT THE  
BRIGHT  
SIDE

# Benefits

## Predicted 2010

- No more “terrible” Choice
- Reduce out-of-pocket expenses for families
- Evidence-based practices = curative
- Continuity of care
- States with experience

## Actual 2020

- State uptake complete
- Increasing utilization by children and families and decreasing costs
- Codifying guidelines
- Generating evidence

# Benefits - State Uptake

Implementation complete

- ➔ By 2017, almost all states and DC have implemented
- ➔ Rhode Island ?

Written, publicly available information that states have implemented

# Benefits - Utilization & Costs

## Increasing utilization

- Over 70% kids enrolled
- Private insurance more common than Medicaid (63% vs. 37%)
- Tricare now offers

## Improving financial performance

- Financial loss reduced - \$96/day vs. \$13/day
- Avg. cost of personnel visits reduced - \$79/day vs. \$67/day
- Inpatient costs reduced - \$76/day vs. \$0.14/day

# Profile of Concurrent Care Children Preliminary (n=249)

- Age
  - 0 to 5 43%
  - 6 to 14 37%
  - 15 to 20 20%
- Male 53%
- Non-Caucasian 69%
- Hispanic 15%
- Coinsurance 18%
- CCC 75%
- CCC+2 64%
- Region-South 76%
- Rural 41%

Data: 2011 to 2013 Medicaid  
Sample: Concurrent care only children  
Analysis: Descriptive statistics

# Profile of Concurrent Care Children Texas Preliminary (n=141)



- Age
  - 0 to 5 45%
  - 6 to 14 36%
  - 15 to 20 18%
- Male 51%
- Non-Caucasian 82%
- Hispanic 25%
- Coinsurance 21%
- CCC 69%
- CCC+2 60%
- Rural 33%

Data: 2011 to 2013 Medicaid  
Sample: Concurrent care only  
children  
Analysis: Descriptive statistics

# Benefits - Guidelines

Key stakeholders within states developing guidelines

- 15 states crafted their own concurrent care guidelines
  - Texas
  - Louisiana

# Guidelines (cont.)

## Recommending guidelines with core elements

- Definitions
- Payment information
- Staffing plan
- Care coordination approach
- Eligibility documentation
- Clinical practices – evolving plan of care



# Benefits - Research

- Emerging area of scholarship
  - Effectiveness
  - Life prolonging care
  - Rural
  - AYA
  - Cost structure
- Technical assistance & expert opinion

# Implications

What we still need ....





# Implications - Education


Integrate concurrent care content into education for providers, students, & families


- Continuing education opportunities
- Curriculum development
- Training modules

State of the Science:  
**PEDIATRIC  
END-OF-LIFE  
SIMULATION**

  
**Symptom Management**  
Pain, nausea, and constipation are common symptoms at the end-of-life. Existing simulations acknowledge this. In doing so, students are able to practice clinical skills such as starting intravenous lines, administering pain medication, and using non-pharmacologic techniques to relieve nausea.

  
**Communication**  
Children, caregivers and siblings have big questions when it comes to final moments. Are they in pain? What are all these tubes for? What can we expect? Simulation provides students with an opportunity to address difficult questions in a calm, safe environment where it's okay to say the wrong thing.


  
**Family-Centered Care**  
Families are complicated. Family composition, socioeconomic status, and support systems must be taken into consideration to provide competent family-centered care where families feel comfortable making decisions and participating in care.

  
**Limitations**  
We commend those who have developed pediatric end-of-life care simulations, but we also recognize there is much more work to do. From our search, we have found no simulations focusing on pediatric inpatient hospice care. Concurrent care has not been incorporated into simulation, meaning students may not understand the nurse's role in providing palliative care to a child who is also receiving curative care. Finally, to our knowledge no APRN simulations have been developed.

  
**Why it matters**  
Simulation offers an opportunity for students to develop clinical skills and communication techniques in a setting that is realistic, nonthreatening, and allows students to reflect on their performance. High-fidelity mannequins which may blink, speak, create breath sounds, heart rates and blood pressures complement the patient backstories they accompany. Students immersed in simulation can more deeply connect with patient stories, feel increasingly confident in communicating with families and develop a sense of competency in better serving pediatric patients who suffer from life-threatening illnesses.

To learn more visit <https://pedeolcare.utk.edu>

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# Implications - Research & QI

Terrific source of projects

A few ideas:

- Care coordination
- Staff education
- Non-pediatric providers
- Families



# Implications - Practice

## Concepts to integrate into clinical practice

- Evolving plan of care
- Care coordination
- Roles and responsibilities
- Community of practice
  - Resources
  - Podcasts
  - Blogs
  - Twitter
  - Facebook



# Implications - Advocacy

Get involved – Stay involved

- ✓ State-level engagement
  - Pediatric coalition
  - Hospice association
  - State Medicaid Office
- ✓ Federal-level engagement
  - CMS
  - Tricare

GUIDELINES

# Summary

- Important care delivery option for children
- Issues and challenges with implementation
- With minimal guidance and support, our community is making it work
- Still much work to be done

# Acknowledgements

thank  
you!



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