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

TPPCC 6th Annual Midwinter Conference

Lisa C. Lindley, PhD, RN, FPCN, FAAN

February 21, 2020

# Introductions

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

March 23, 2020



BIG ORANGE BIG IDEAS

# 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



BIG ORANGE BIG IDEAS

# 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).

Lindley (2011)



BIG ORANGE BIG IDEAS

# Background - History

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

- Demonstration projects
- Champions
- State legislation
- Federal legislation

Keim-Malpass et al. (2012)



BIG ORANGE BIG IDEAS

# Background - Key Stakeholders

Concurrent care involves a very wide range of stakeholders

NHPCO
National Hospice and Palliative Care Organization

# Background - Financing

Initial payment for concurrent care was Medicaid

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



BIG ORANGE BIG IDEAS

# 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

Lindley (2011)

# 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).



BIG ORANGE BIG IDEAS

# 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/

BIG ORANGE BIG IDEAS

# Challenges - Financing

Uncertainty

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

Miller et al. (2012)



BIG ORANGE BIG IDEAS

# Challenges - Practice

Shifting care environment

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

Richar et al. (2019). Steinhorn et al. (2020).



BIG ORANGE BIG IDEAS

# 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

Lindley et al. (under review)



BIG ORANGE BIG IDEAS

BIG ORANGE
BIG IDEAS

# 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

Lindley (2011)

# Benefits - State Uptake

Implementation complete

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

Written, publicly available information that states have implemented

Laird & Lindley (2019)

# 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

Richar et al. (2019) Steinhorn et al. (2020) Wilson Smith et al. (2019)



BIG ORANGE BIG IDEAS

# 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


BIG ORANGE BIG IDEAS

# 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

Laird & Lindley (2019)



BIG ORANGE BIG IDEAS

# Guidelines (cont.)

Recommending guidelines with core elements

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

Laird & Lindley (2019)



BIG ORANGE BIG IDEAS

# Benefits - Research

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



BIG ORANGE BIG IDEAS

# Implications

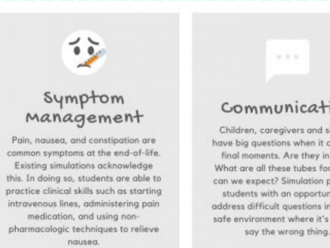
What we still need ….

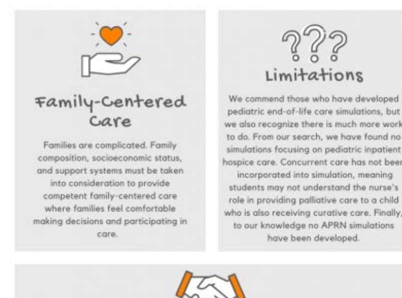
BIG ORANGE BIG IDEAS

# Implications - Education

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

- Continuing education opportunities
- Curriculum development
- Training modules



BIG ORANGE BIG IDEAS

# Implications - Research & QI

Terrific source of projects

A few ideas:

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

BIG ORANGE BIG IDEAS

# 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

Hargadon et al. (2017)



BIG ORANGE BIG IDEAS

# Implications - Advocacy

Get involved – Stay involved

✓ State-level engagement

- Pediatric coalition
- Hospice association
- State Medicaid Office

✓ Federal-level engagement

- CMS
- Tricare

GUIDELINES

Laird & Lindley (2019)

# 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



BIG ORANGE BIG IDEAS

# Acknowledgements

Research reported in this presentation was supported by the National Institute Of Nursing Research of the National Institutes of Health under Award Number R01-NR017848. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Visit our website at www.pedeolcare.utk.edu

# References


Hargadon A, Tran, Q, Stephen K, Homler H. A trial of concurrent care: Shedding light on the gray zone. *J Palliativ Med.* 2017: 20(2):207-10.

Keim-Malpass J, Hart TG, Miller JR. Coverage of palliative and hospice care for pediatric patients with a life-limiting illness: A policy brief. *J Ped Health Care.* 2013;27:511-6.

Laird, J. M., & Lindley, L. C. (October, 2019). Pediatric concurrent hospice care: How did states implement? *Policy Brief #19-001*, University of Tennessee, Knoxville, College of Nursing.

Lindley, L. C. (2011). Health care reform and concurrent curative care for terminally ill children: A policy analysis. *Journal of Hospice and Palliative Nursing, 13*(2)*,* 81–88.

Lindley, L. C., Keim-Malpass, J., Svynarenko, R., Cozad, M. J., Mack, J.W ., & Hinds, P .S. (under review). Pediatric concurrent hospice care: A scoping review and directions for future research. *Journal of Hospice & Palliative Nursing.*

Lotstein, D., & Lindley, L. C. (2019). Improving home hospice and palliative care policies. *Pediatrics*, 144(2), e20183287.

Miller EG, Laragione G, Kang TI, Feudtner C. Concurrent care for the medically complex child: lessons of implementation. *J Palliat Med,* 2012: 15: 1281-3.

Steinhorn, D.M., Lindley, L.C., Richar, C.S., Daley, ME., Vilt, F., & Kestenbaum, M.G. (March, 2020). Cost analysis of pediatric concurrent care: Commercial vs. Medicaid payer. At the 2020 AAHPM/HPNA Annual Assembly, San Diego, CA.

Richar, C.S., Lindley, L.C., Vilt, F., Hoit, T., Kestenbaum, M.G., Steinhorn, D.M. (November, 2019). Creating a financing analysis model for pediatric concurrent care: A pilot study. At the CAPC National Seminar 2019, Atlanta, GA. SPECIAL RECOGNITION.

Wilson Smith, M. G., LaFond, D. A., Keim-Malpass, J., Lindley, L. C., & Matzo, M. (2019). A new era in pediatric hospice care for military families. *American Journal of Nursing, 119*(8), 66-69.