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
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
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

Keim-Malpass et al. (2012)
Background - Key Stakeholders

Concurrent care involves a very wide range of stakeholders

[Logos of various organizations related to healthcare and Medicaid]
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

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).
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/
Challenges - Financing

Uncertainty

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

Miller et al. (2012)
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

Lindley et al. (under review)
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

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

<table>
<thead>
<tr>
<th>Age</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 to 5</td>
<td>43%</td>
</tr>
<tr>
<td>6 to 14</td>
<td>37%</td>
</tr>
<tr>
<td>15 to 20</td>
<td>20%</td>
</tr>
</tbody>
</table>

- Male: 53%
- Non-Caucasian: 69%
- Hispanic: 15%

<table>
<thead>
<tr>
<th>Coverage</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coinsurance</td>
<td>18%</td>
</tr>
<tr>
<td>CCC</td>
<td>75%</td>
</tr>
<tr>
<td>CCC+2</td>
<td>64%</td>
</tr>
<tr>
<td>Region-South</td>
<td>76%</td>
</tr>
<tr>
<td>Rural</td>
<td>41%</td>
</tr>
</tbody>
</table>

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

Laird & Lindley (2019)
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 ….

- Education
- Research & Quality Improvement
- Practice
- Advocacy
Implications - Education

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

- Continuing education opportunities
- Curriculum development
- Training modules
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

Hargadon et al. (2017)
Implications - Advocacy

Get involved – Stay involved

☑ State-level engagement
  • Pediatric coalition
  • Hospice association
  • State Medicaid Office

☑ Federal-level engagement
  • CMS
  • Tricare

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
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


