

20
21

Pediatric Palliative Care

WEBINAR SERIES



GREATER ILLINOIS
PEDIATRIC PALLIATIVE
CARE COALITION



pediatric palliative
care coalition



CHILDREN'S HOSPICE
&
PALLIATIVE CARE
COALITION

CSU The California State University

SHILEY INSTITUTE FOR PALLIATIVE CARE

Jacob's Heart[™]
CHILDREN'S CANCER SUPPORT SERVICES

2021 Pediatric Palliative Care Webinar Series



**Certificate in
Clinical Pediatric Palliative Care**
Physicians, NP's, PA's, RN's

**Multidisciplinary Certificate
Pediatric Palliative Care**
SW's, Chaplains, Child Life Spc, others

Specialized Pediatric Palliative Care training in...

- COMMUNICATION
- PAIN & SYMPTOM MANAGEMENT
- EASING SUFFERING
- CARE DELIVERY
- TEAM SUPPORT
- ETHICAL PRINCIPLES & CHALLENGES

Online, Interactive
PEDIATRIC PALLIATIVE CARE EDUCATION
for All Disciplines and Teams

CE * CME
Team Tool-Kits
Practice Resources
Pediatric Expert Instructors/Authors

CSU The California State University

**SHILEY INSTITUTE
FOR PALLIATIVE CARE**

[csupalliativecare.org / pediatrics](http://csupalliativecare.org/pediatrics)

2021 Pediatric Palliative Care Webinar Series



CSU The California State University

**SHILEY INSTITUTE
FOR PALLIATIVE CARE**

1.0 CE Contact Hours. CE's provided through Cal State San Marcos (CSUSM) Extended Learning.

Provider approved by the California Board of Registered Nursing, Provider #CEP 11422 and by the Board of Behavioral Sciences, through the CSUSM WASC Accreditation.



20
21

Pediatric Palliative Care

WEBINAR SERIES

Register Now

Tuesday, August 17 [SEP]

Increasing Sensitivity in Clinical Practice with the Transgender Population with Kat O'Donnell MSW, LCSW [SEP]

Thursday, September 23 [SEP]

Beyond Words: Using Expressive and Integrative Therapies as Communication Tools with Jenny Goldhammer, MM, MT-BC, John Mark, MD and Lily Rich, PsyD

October 19 [SEP]

Bereaved Parents View on End-of-Life Care Emily Johnston, MD, Janelle Molina, Lori Butterworth, M.Ed. [SEP]

November 16 [SEP]

Alternative Payment Strategies to Enhance Access to Pediatric Palliative Care with Conrad Williams, MD

2021 Pediatric Palliative Care Webinar Series

Housekeeping

- This webinar is being recorded.
- Post questions in the chat box at any time.
- Questions will be answered at the end of the presentation if time allows.
- If times runs out, we will send your questions to the speakers.



SHILEY INSTITUTE FOR PALLIATIVE CARE

Jacob's Heart[™]
CHILDREN'S CANCER SUPPORT SERVICES



2021

PEDIATRIC PALLIATIVE CARE
COALITIONS NETWORK WEBINAR

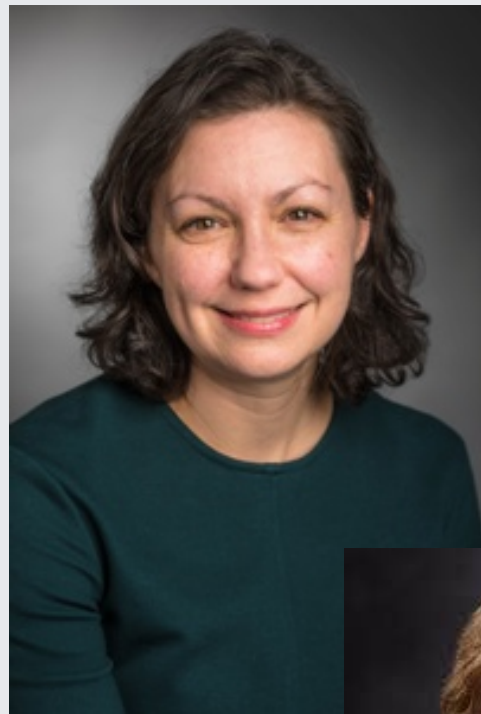
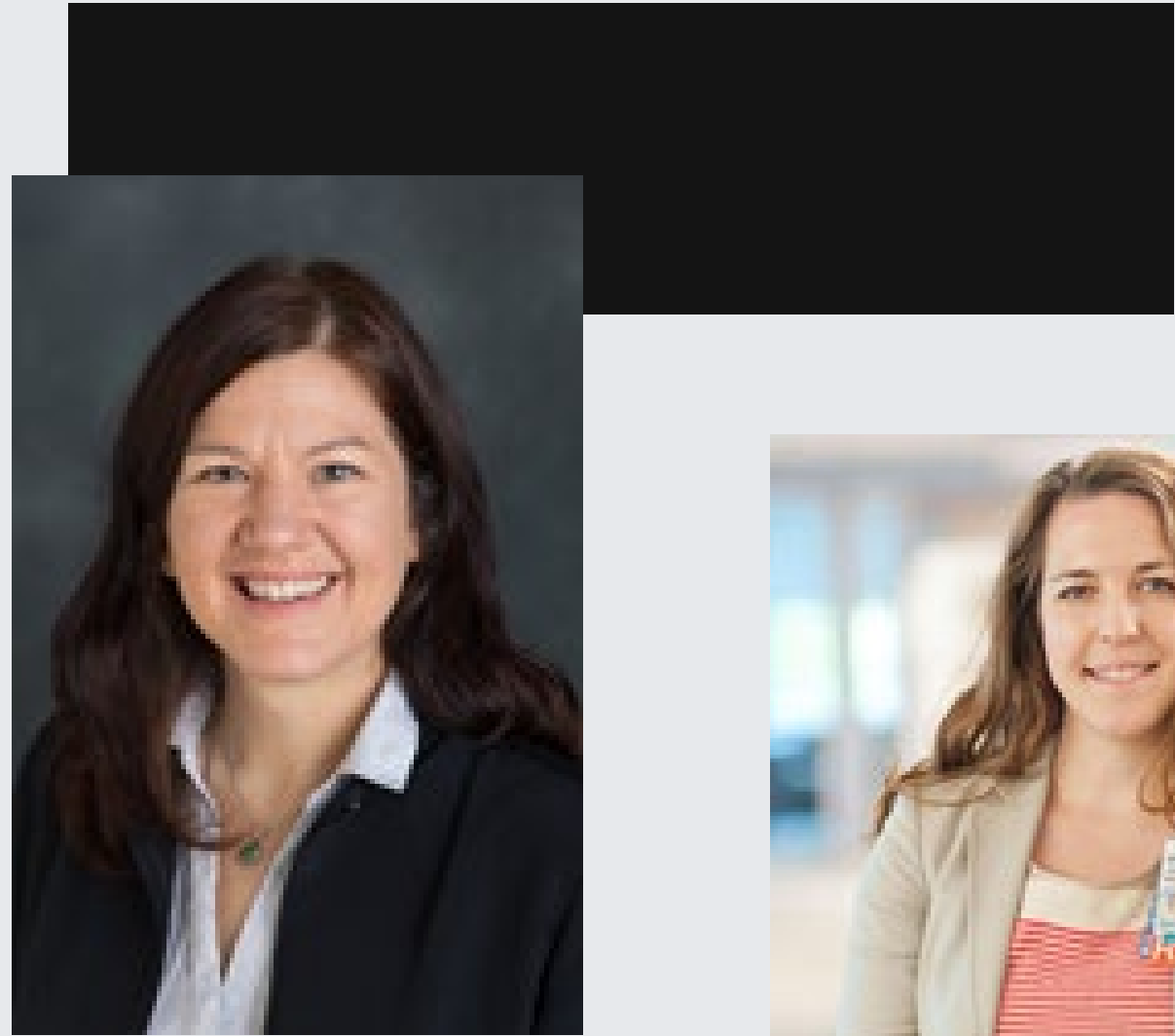
How Effective is Pediatric Concurrent Hospice Care? Research Updates

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



Presentation Outline

- Preliminary findings
- Non -hospice, health care services
- Effective of concurrent care
- Thanks, acknowledgements, questions



The Pediatric
EOL Care
Group

Concurrent Care

Patient Protection and Affordable Care Act 2010, Section 2302

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. (1)

Preliminary Findings

-
- Wide variation in implementation across the states (2)
 - Sparse evidence (3)
 - Methodological work (4,5,6,7,8)

-
- Very medical complex (9)
 - Mental/behavioral health conditions (10)
 - Children with cancer (11)
 - AYAs (12)
-



Research Question # 1

What non -hospice, healthcare services do children use in concurrent hospice care?

Is there a pattern in the care services?

What is the profile of children in the clusters of care?

Pattern of Non-Hospice, Health Care Services ⁽¹³⁾



DESIGN

Non-experimental



SAMPLE

6,243 decedents in concurrent care over 3 years



DATA SOURCES

2011-2013 Medicaid; 2010 US Census; CMS Hospice Provider of Service; CMS Hospice Utilization and Payment



ANALYSIS

Latent Class Analysis

Non -Hospice, Health Care Services

- 1) inpatient hospital,
- 2) durable health equipment,
- 3) home health,
- 4) medications,
- 5) labs & x-rays,
- 6) other services,
- 7) targeted case management,
- 8) physician services,
- 9) outpatient hospital,
- 10) personal care,
- 11) private duty nursing,
- 12) transportation,
- 13) rehabilitation,
- 14) physical therapy/occupational therapy/speech therapy,
- 15) clinic,
- 16) other practitioners,
- 17) psychiatric services,
- 18) dental services,
- 19) residential care, and
- 20) nurse practitioner services

~500,000

Non-hospice, health care services
during concurrent care

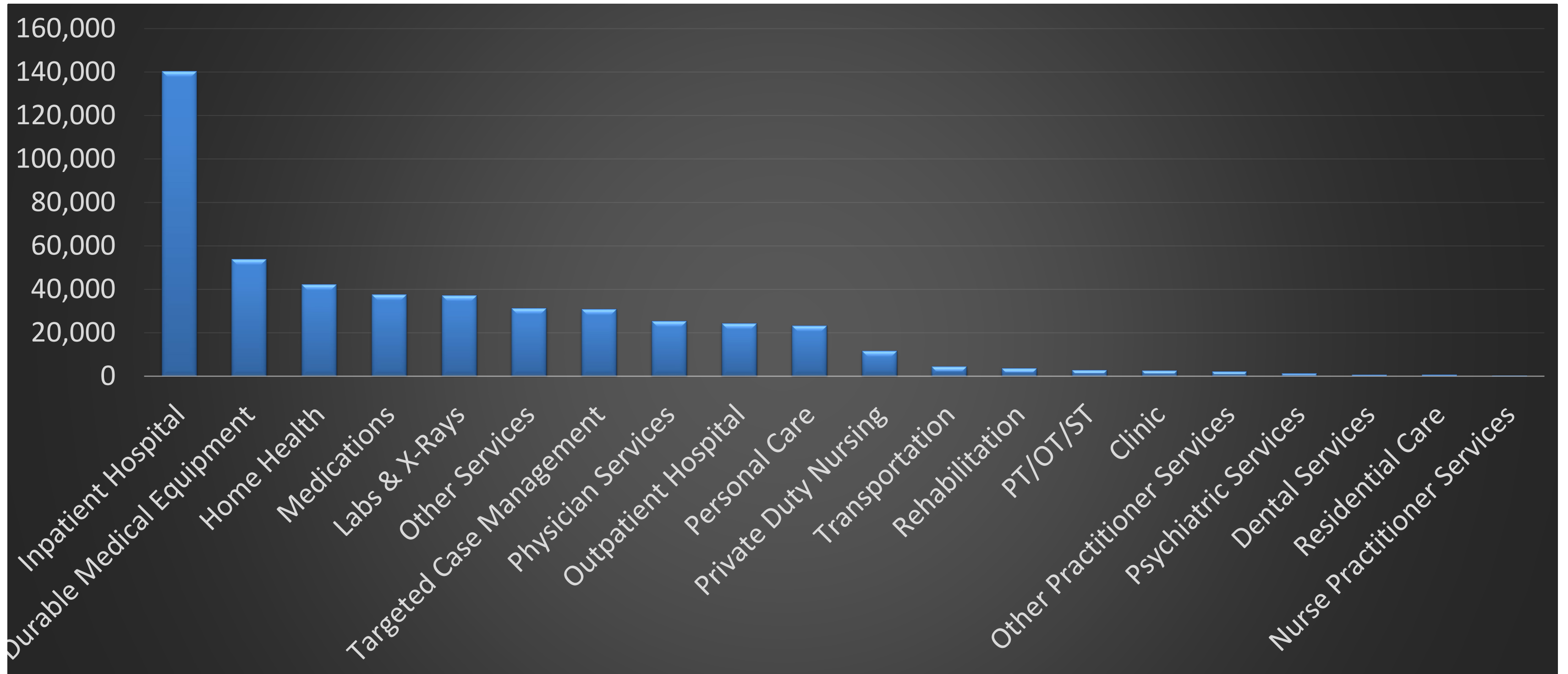
80

Average number of services per child

Top Services

1. Inpatient treatments and therapies
2. DME
3. Home health
4. Medications

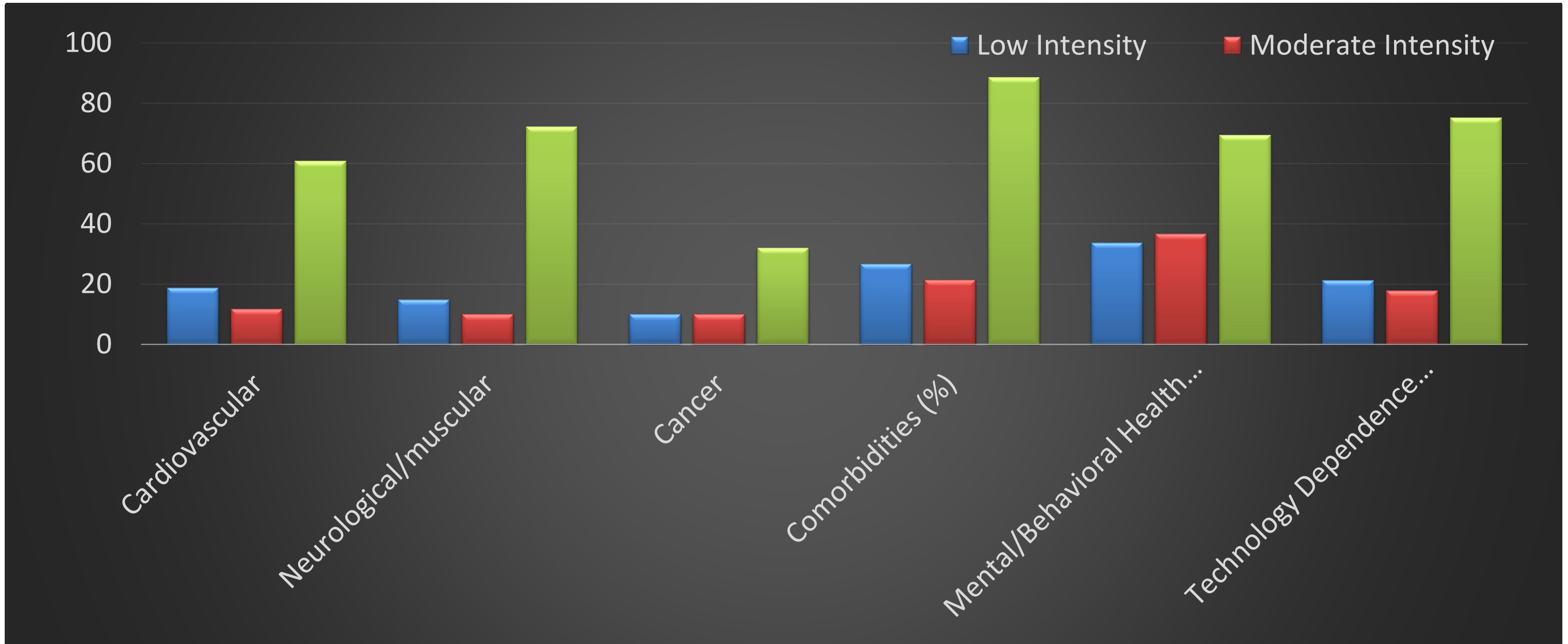
Health Care Services Used during Pediatric Hospice Concurrent Care



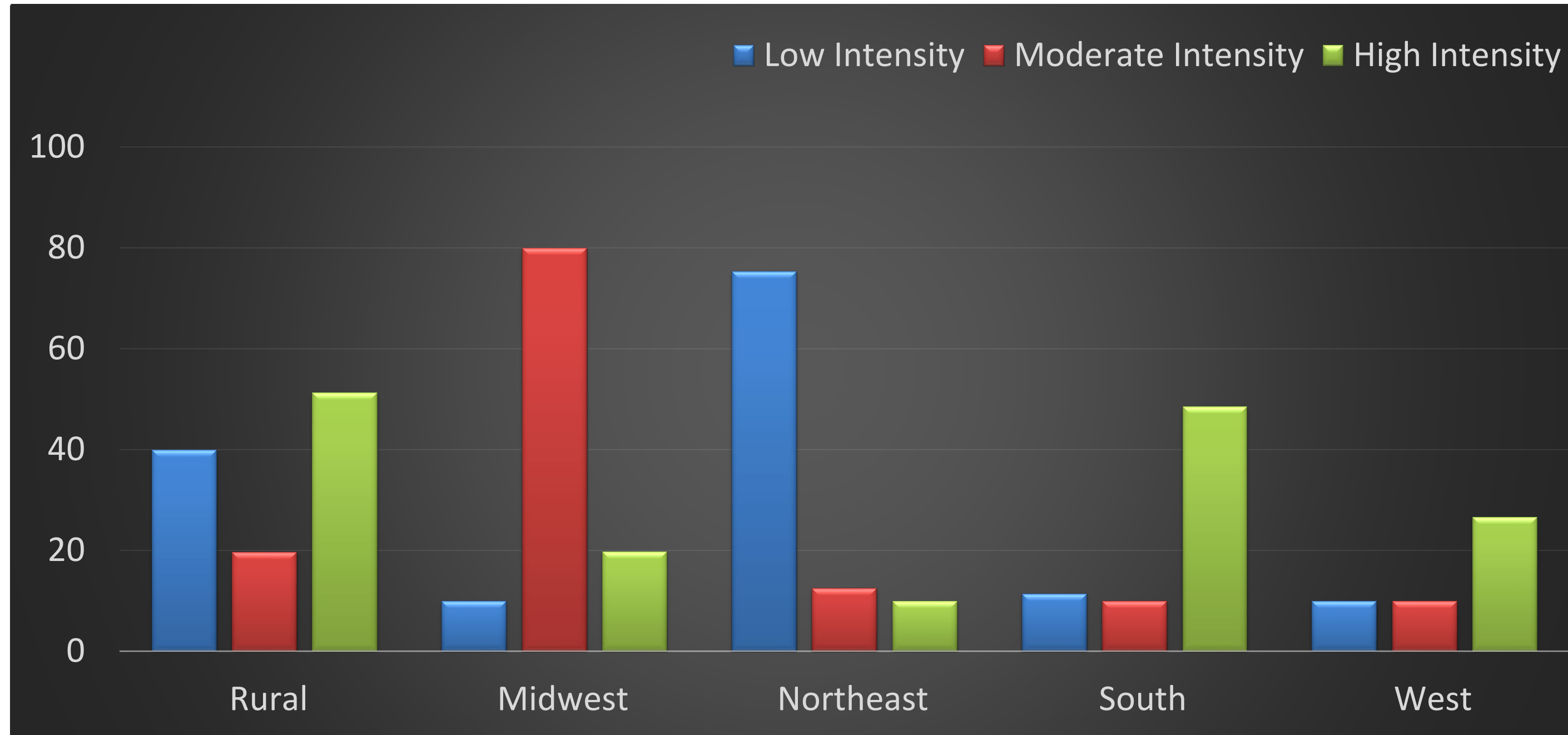
3 Clusters of Services

- Low Intensity (61%)
- Moderate Intensity (18%)
- High Intensity (21%)

Health Profile by Cluster



Socio -Dem ographic Profile by Cluster



CONCLUSION

The findings revealed a significant number and wide variety of health care services among children in the study

The vast number of services used by children in the sample suggests that care coordination in concurrent hospice care might be significant

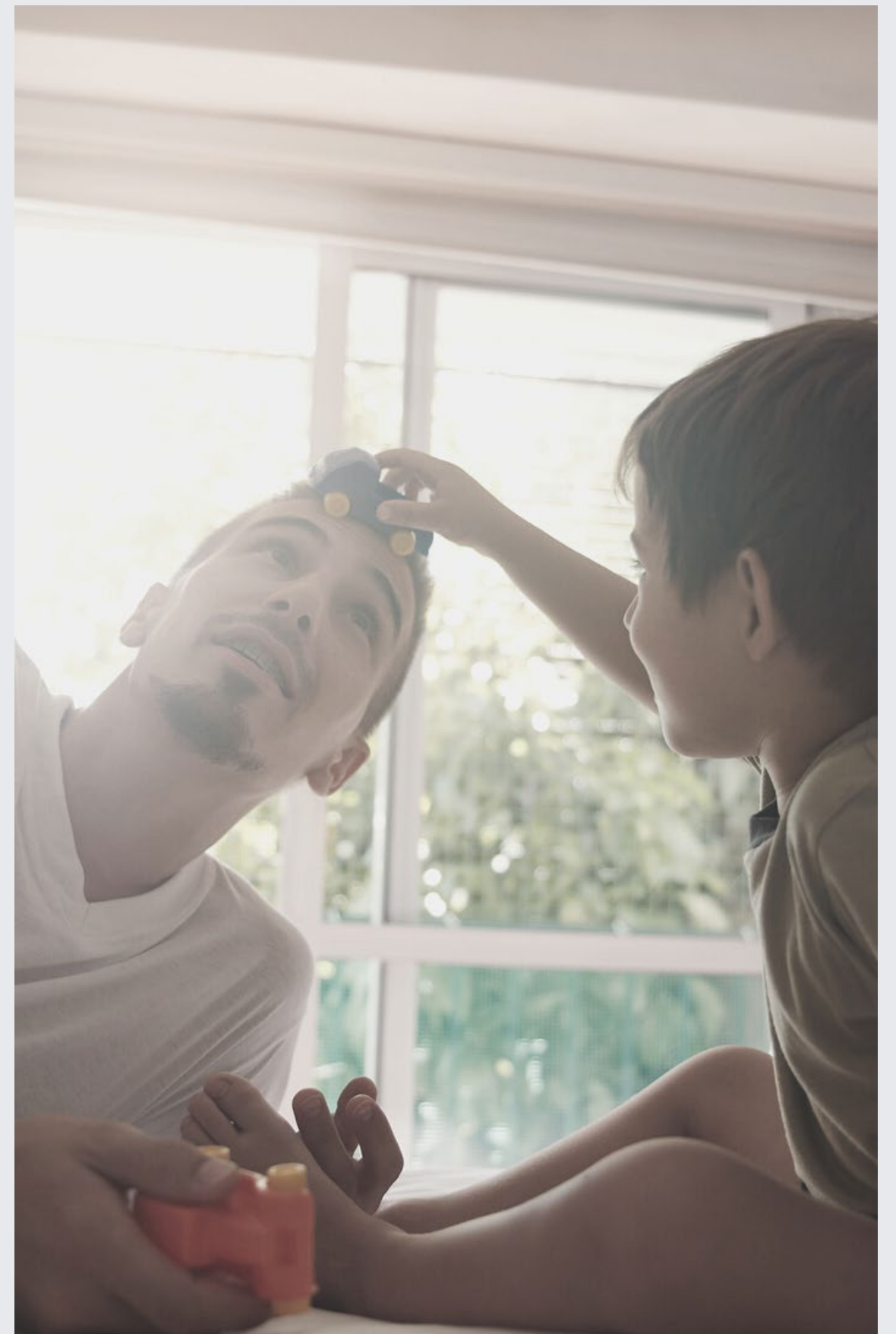
While we anticipated that children in concurrent hospice care would have high intensity of health care use, the low intensity group was unexpected

We identified that low intensity was predominately in the Northeast region, moderate in the Midwest, and high in the South

Children use concurrent hospice care differently

Concurrent hospice care is not a one end-of-life care

-size-fits all approach to



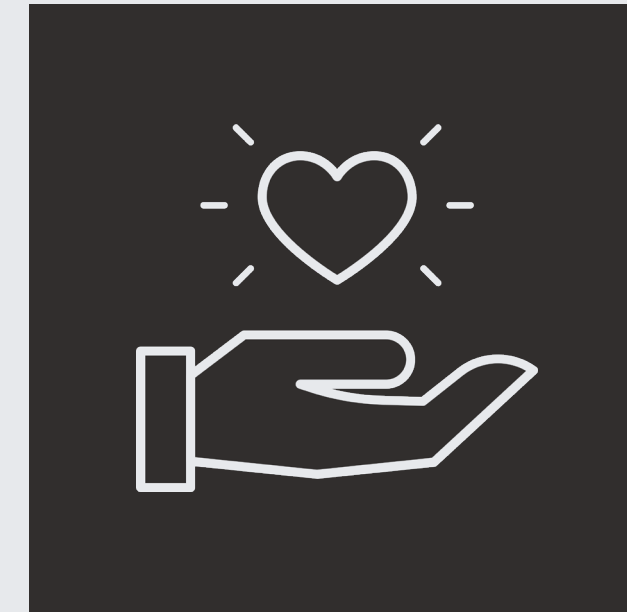
Research Question #2



Hospice Live Discharges



Hospice Length of Stay



Hospice Transitions

How does concurrent care
impact care continuity?

Effectiveness of Concurrent Care



DESIGN

Quasi -experimental



SAMPLE

18,152 decedents in hospice care over 3 years



DATA SOURCES

2011-2013 Medicaid; 2010 US Census; CMS Hospice Provider of Service; CMS Hospice Utilization and Payment



ANALYSIS

Comparative effectiveness analysis – instrumental variable analysis approach



STANDARD HOSPICE CARE



CONCURRENT HOSPICE CARE



Care Continuity Outcomes

- *Hospice live discharge* was the number of times a child disenrolled and re-enrolled in hospice care. In other words, they left hospice care alive and reenrolled into hospice at a later date.
- *Hospice length of stay* was defined as the total number of days a child was enrolled in hospice care during the study timeframe.
- *Hospice transitions - emergency room (ER) transition* was defined as whether the child used the emergency room during hospice care.
- *Hospice transitions - inpatient* was admission to inpatient care during hospice enrollment.

Concurrent Care vs. Standard Care

Hospice Live Discharge

- Total = 20.4
- Concurrent Care = 19.5
- Standard Care = 20.7

Hospice Length of stay

- Total = 57 days
- Concurrent Care = 88.5 days
- Standard Care = 48.8 days

Hospice Transitions - ER

- Total = 16.5%
- Concurrent Care = 19.5%
- Standard Care = 13.4%

Hospice Transitions - Inpatient

- Total = 10.0%
- Concurrent Care = 10.9%
- Standard care = 10.0%

Results



Hospice Live Discharge

Significantly less likely to disenroll and reenroll



Hospice Length of Stay

Significantly higher length of stay in hospice care



Hospice Transitions

Significantly more likely to transition to the ER or admit to inpatient care during hospice

CONCLUSION

Concurrent hospice care was effective at improving care continuity among hospice-specific outcomes, but not as effective among hospital-based outcomes



SUMMARY

Our team is generating new empirical evidence about pediatric concurrent care, something that has been absent from much of the literature.

These findings highlight the uniquely different non-hospice, health care services used during concurrent care and its impact on care continuity.

Acknowledgements & Thanks You

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.



**GREATER ILLINOIS PEDIATRIC
PALLIATIVE CARE COALITION**

References

LIST OF SOURCES USED

1. 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.
2. Laird, J.M., Keim-Malpass, J., Mack, J.W., Cozad, M.J. & Lindley, L.C. (in press). Examining variation in state Medicaid implementation of ACA: The case of Concurrent Care for Children. *Health Affairs*.
3. Lindley, L.C., Keim-Malpass, J., Svyrenko, R., Cozad, M.J., Mack, J.W., & Hinds, P.S. (2020). Pediatric concurrent hospice care: A scoping review and directions for future research. *Journal of Hospice & Palliative Nursing*, 22(3), 238-245.
4. Svyrenko, R., & Lindley, L.C. (in press). Defining rurality in end-of-life research: Evaluation of common measures. *The Journal of Health Care for the Poor and Underserved*.
5. Lindley, L.C. Fortney, C.A., & Cozad, M.J. (2021). Predictive ability of an illness severity measure: Implications for nursing research. *Journal of Nursing Measurement*, 29(2), epub.
6. Cozad, M.J., Lindley, L.C., Eaker, C., Carlosh, K.A., & Profant, T. (2019). Debunking myths about health insurance claims data for public health research and practice. *American Journal of Public Health*, 109(11), 1584-1585.
7. Lindley, L.C., Cozad, M.J., & Fortney, C.A. (2019). Pediatric complex chronic conditions: Evaluating two versions of the classification system. *Western Journal of Nursing Research*, 42(6), 454-461.
8. Lindley, L.C., Svyrenko, R., & Profant, T.L. (2020). Data infrastructure for sensitive data: Nursing's role in the development of a secure research enclave. *Computers, Informatics, Nursing Plus*, 38(9), 427-430.
9. Keim-Malpass, J., Cozad, M.J., Svyrenko, R., Mack, J.W., & Lindley, L.C. (2021). Medical complexity and concurrent hospice care: A national study of Medicaid children from 2011 to 2013. *Journal for Specialists in Pediatric Nursing*. Epub.
10. Lindley, L.C., Svyrenko, R., & Beebe, L. (2021). Mental health and developmental disabilities in US children admitted to hospice care: A comparison of age groups. *International Journal of Palliative Nursing*, 27(3), 124-130.
11. Svyrenko, R., Mack, J.W., & Lindley, L.C. (2021). Differences in characteristics of children with cancer who receive standard versus concurrent hospice care. *Pediatric Blood & Cancer*. Epub.
12. Mooney-Doyle, K., Keim-Malpass, J., Svyrenko, R., & Lindley, L.C. (2021). A comparison of young adults with and without cancer in concurrent hospice care: Implications for transitioning to adult health care. *Journal of Adolescent and Young Adult Oncology*. Epub.
13. Lindley, L.C., Svyrenko, R., Mooney-Doyle, K., Mendola, A., Newmann, W., & Keim-Malpass, J. (2021). Patterns of health care services during pediatric concurrent hospice care: A national study. *American Journal of Hospice & Palliative Medicine*, epub.





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

ASSOCIATE PROFESSOR & NIGHTINGALE ENDOWED
FACULTY FELLOW

University of Tennessee, Knoxville
College of Nursing

email: llindley@utk.edu

project website: <https://pedeolcare.utk.edu/>

