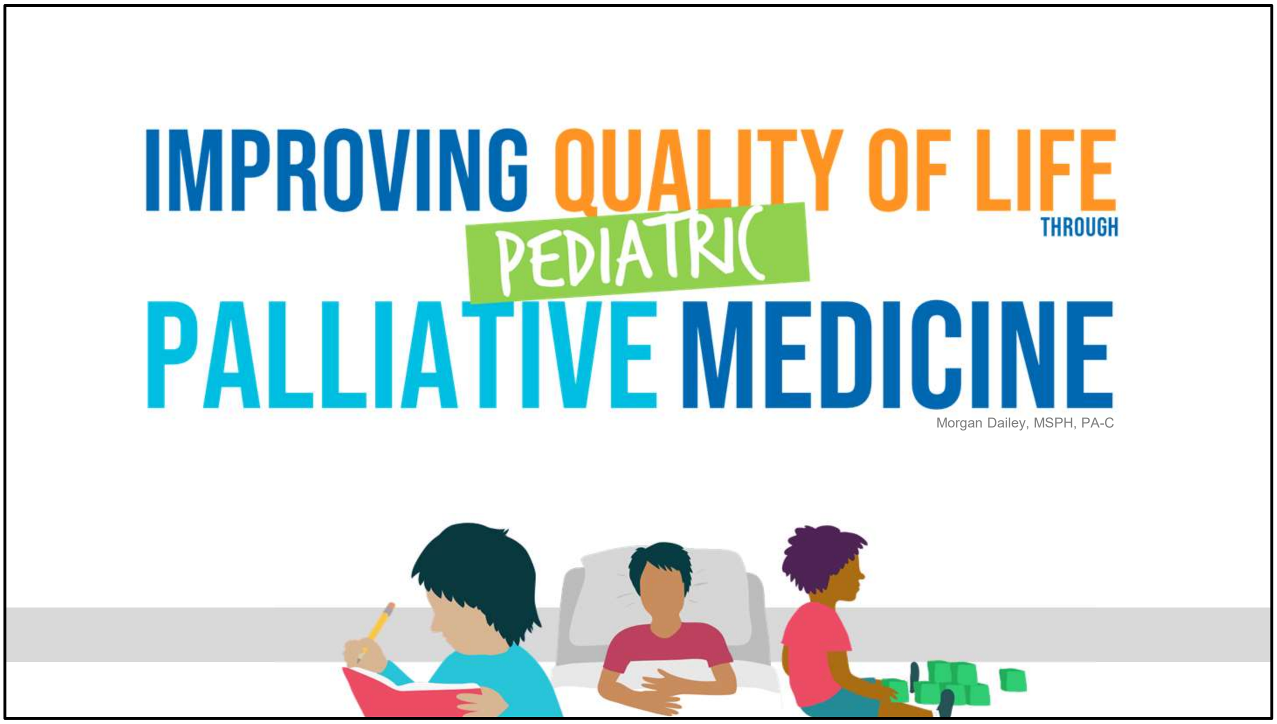


IMPROVING QUALITY OF LIFE THROUGH PEDIATRIC PALLIATIVE MEDICINE

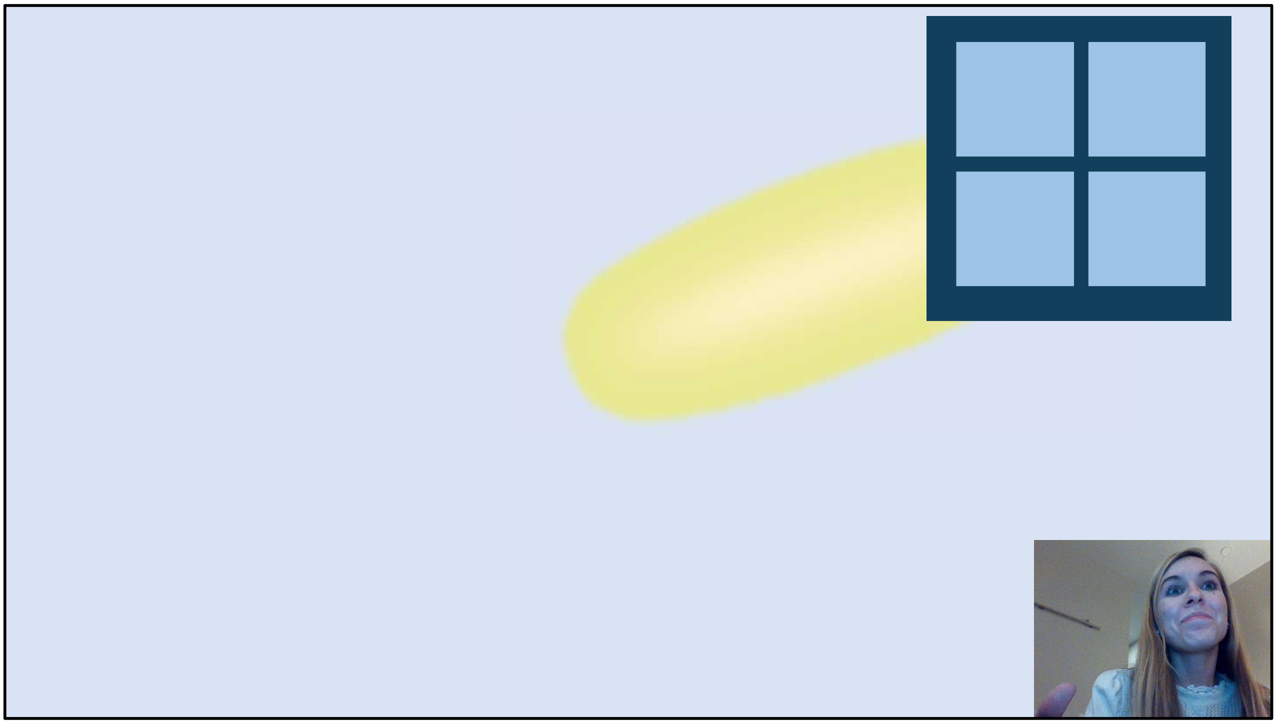
Morgan Dailey, MSPH, PA-C

1. Discuss the background of hospice and palliative medicine, including: terminology, describing its history, and explaining its structure

2. Evaluate research on quality of life outcomes for pediatric patients enrolled in a palliative care program

3. Recognize the role of a PA in pediatric hospice and palliative medicine

OBJECTIVES



HOSPICE

Patient has been deemed by health care provider to have 6 months or less to live. Cannot pursue other medical treatments.*

PALLIATIVE MEDICINE

Improving a patient’s quality of life by managing pain and other distressing symptoms of a serious illness. Can be provided along with other medical treatments.

INTERDISCIPLINARY TEAM

BACKGROUND

DEFINITION

BACKGROUND

TIMELINE

1960s

1967: Cicely Saunders, London

1969: *On Death and Dying*, by Elisabeth Kubler-Ross

Close chest CPR, shock, iron lung, bird ventilators

Adapted from Dr. Joe Rotella's presentation: History of Hospice and Palliative Medicine

BACKGROUND

TIMELINE

1960s

1967: Cicely Saunders, London

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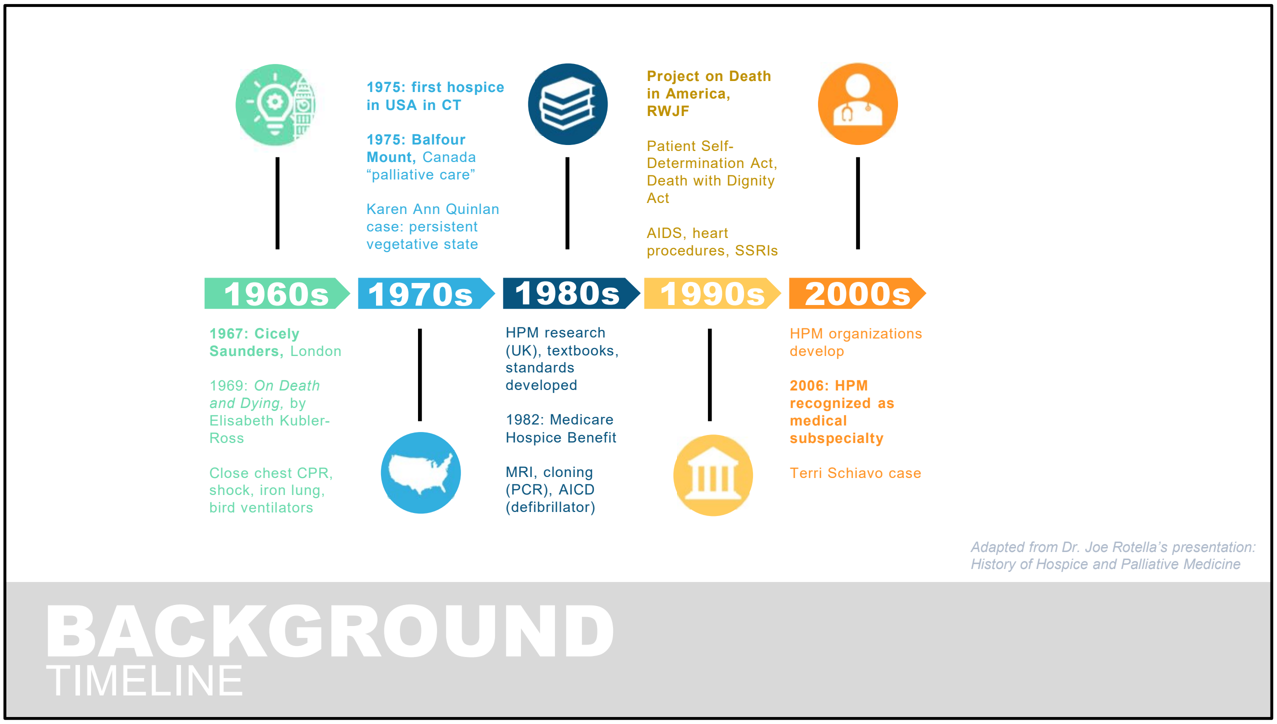
1970s

1975: first hospice in USA in CT

1975: Balfour Mount, Canada "palliative care"

Karen Ann Quinlan case: persistent vegetative state

Adapted from Dr. Joe Rotella's presentation: History of Hospice and Palliative Medicine



BACKGROUND

TIMELINE

1960s

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Close chest CPR, shock, iron lung, bird ventilators

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1975: first hospice in USA in CT

1975: Balfour Mount, Canada "palliative care"

Karen Ann Quinlan case: persistent vegetative state

1980s

HPM research (UK), textbooks, standards developed

1982: Medicare Hospice Benefit

MRI, cloning (PCR), AICD (defibrillator)

1990s

Project on Death in America, RWJF

Patient Self-Determination Act, Death with Dignity Act

AIDS, heart procedures, SSRIs

2000s

HPM organizations develop

2006: HPM recognized as medical subspecialty

Terri Schiavo case

Adapted from Dr. Joe Rotella's presentation: History of Hospice and Palliative Medicine

BACKGROUND

TIMELINE

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AIDS, heart procedures, SSRIs

2000s

HPM organizations develop

2006: HPM recognized as medical subspecialty

Terri Schiavo case

2010s

CMMI, MCCM

More research, Reports (IOM, etc) *Being Mortal* by Atul Gawande

ACA, Triple Aim, Quadruple Aim, Ebola, EHR

Adapted from Dr. Joe Rotella’s presentation: History of Hospice and Palliative Medicine

FAMILY-CENTERED

SOCIAL WORK

HPM

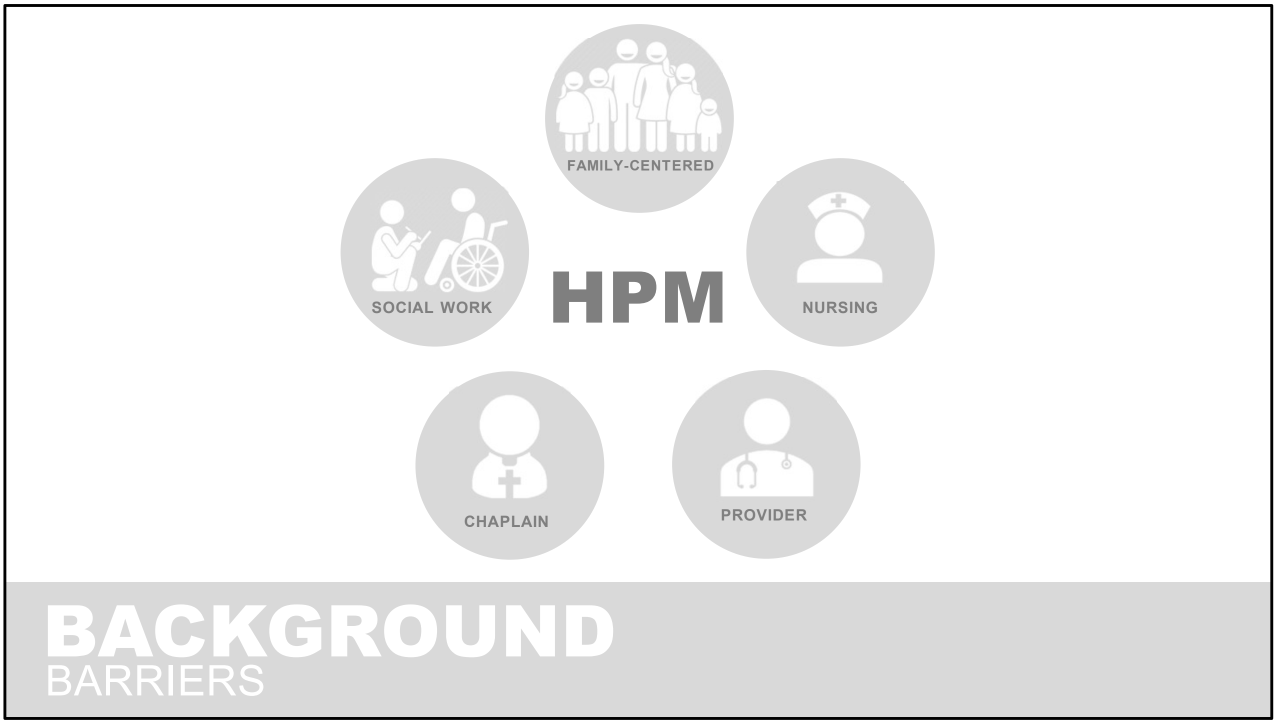
NURSING

CHAPLAIN

PROVIDER

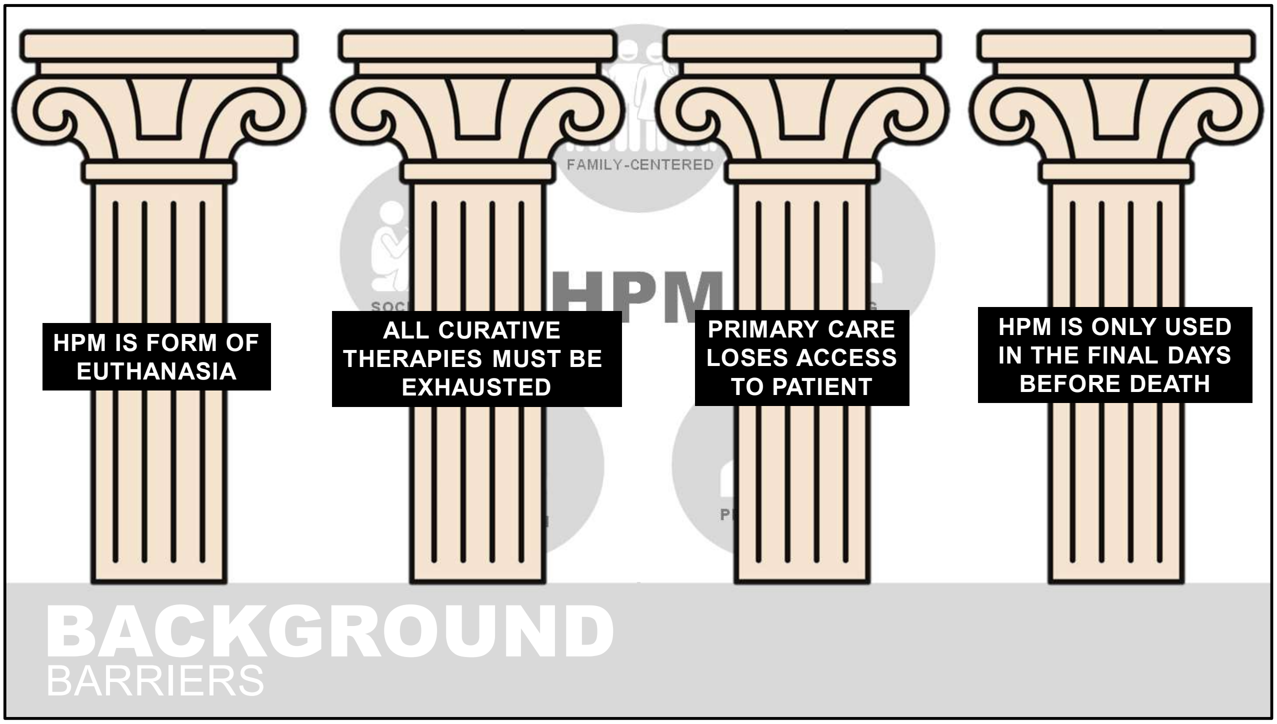
BACKGROUND

BARRIERS



BACKGROUND

BARRIERS



HPM IS FORM OF EUTHANASIA

ALL CURATIVE THERAPIES MUST BE EXHAUSTED

PRIMARY CARE LOSES ACCESS TO PATIENT

HPM IS ONLY USED IN THE FINAL DAYS BEFORE DEATH

BACKGROUND

BARRIERS

BACKGROUND

DEFINITION

> *“HPM is an extra layer of support for patients and families going through difficult medical situations.”*
> *– Dr. Dustin Dillon, Pediatric HPM Physician*

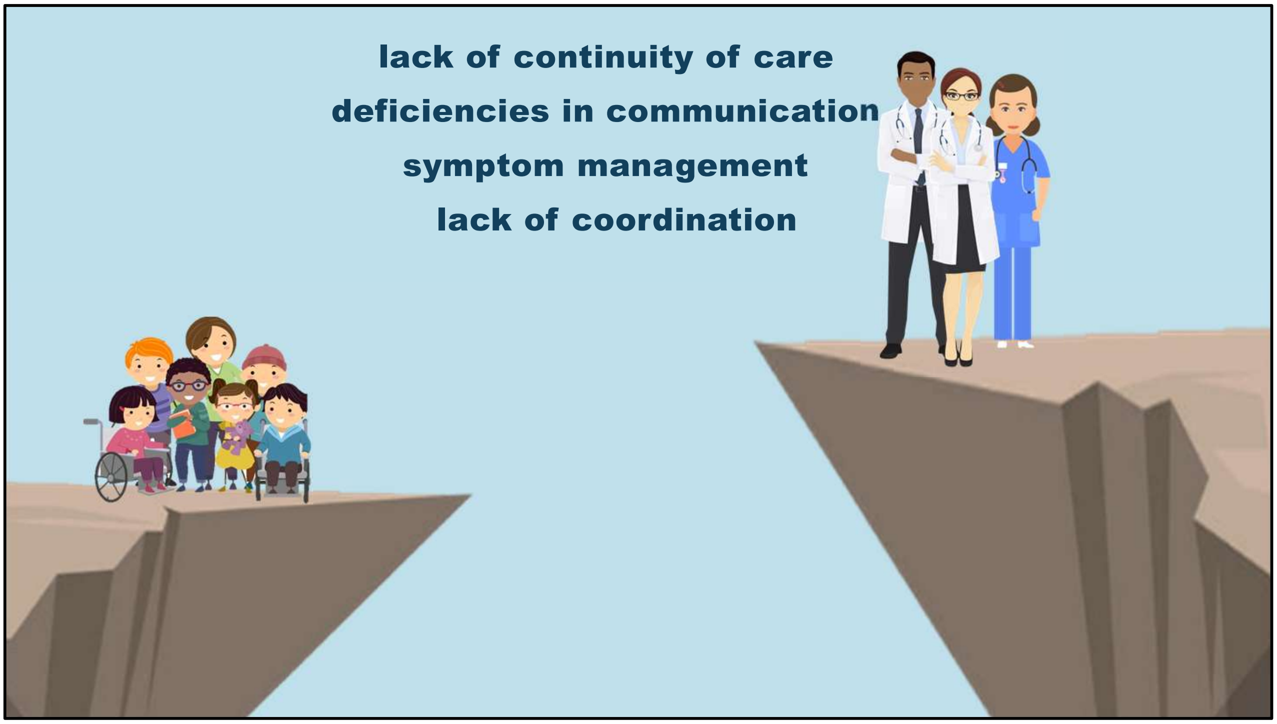
- Provide expert **pain and symptom management**
- Practice evidenced-based **prognostication**
- **Address suffering** in whole person context
- **Interdisciplinary approach,** including pastoral care
- Crucial conversations, **shared decision making**
- Ensure care is **based on patient and family wishes**

BACKGROUND

DEFINITION

BACKGROUND

DEFINITION

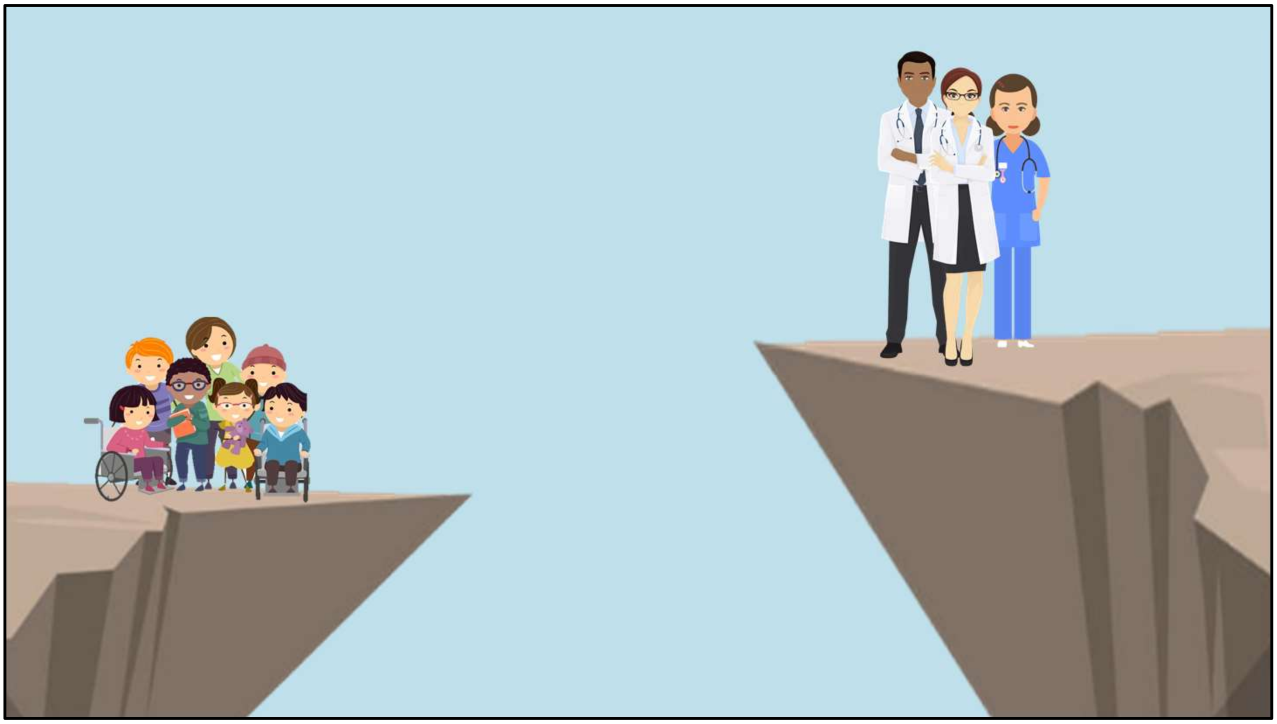


lack of continuity of care

deficiencies in communication

symptom management

lack of coordination



Does integration of pediatric palliative medicine improve quality of life for pediatric patients facing life-threatening and life-limiting conditions?

CLINICAL QUESTION

treatment toxicities

disease progression

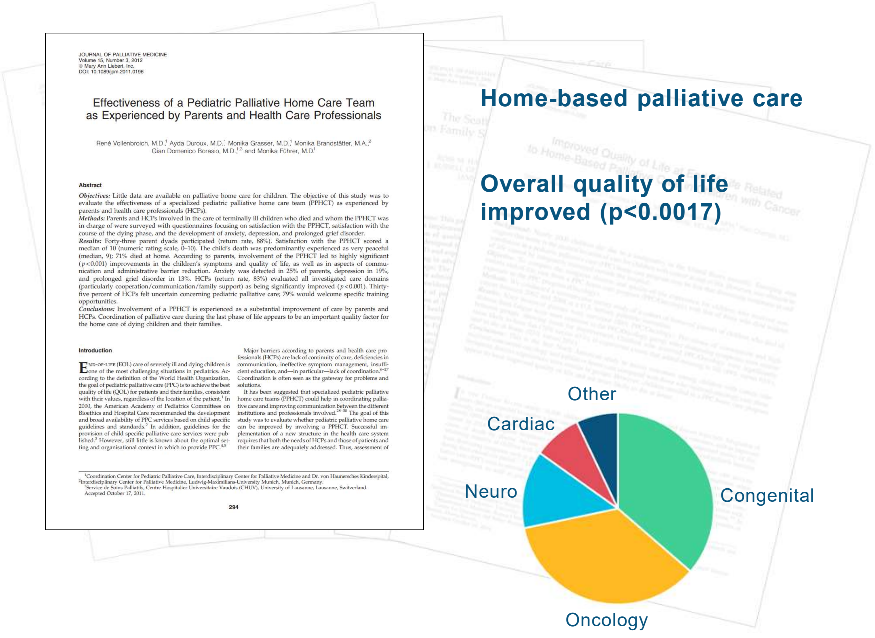
Improved Quality of Life at End of Life Related to Home-Based Palliative Care in Children with Cancer

Improve QoL?

Time to improve?

Emotional QoL?

Physical QoL?



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Effectiveness of a Pediatric Palliative Home Care Team as Experienced by Parents and Health Care Professionals

René Vollenbroich, M.D.,[1] Ayda Duroux, M.D.,[1] Monika Grasser, M.D.,[1] Monika Brandstätter, M.A.,[2]
Gian Domenico Borasio, M.D.,[1,3] and Monika Führer, M.D.[1]

Abstract

Objectives: Little data are available on palliative home care for children. The objective of this study was to evaluate the effectiveness of a specialized pediatric palliative home care team (PPHCT) as experienced by parents and health care professionals (HCPs).
Methods: Parents and HCPs involved in the care of terminally ill children who died and whom the PPHCT was in charge of were surveyed with questionnaires focusing on satisfaction with the PPHCT, satisfaction with the course of the dying phase, and the development of anxiety, depression, and prolonged grief disorder.
Results: Forty-three parent dyads participated (return rate, 88%). Satisfaction with the PPHCT scored a median of 10 (numeric rating scale, 0–10). The child's death was predominantly experienced as very peaceful (median, 9); 71% died at home. According to parents, involvement of the PPHCT led to highly significant ($p<0.001$) improvements in the children's symptoms and quality of life, as well as in aspects of communication and administrative barrier reduction. Anxiety was detected in 25% of parents, depression in 19%, and prolonged grief disorder in 13%. HCPs (return rate, 83%) evaluated all investigated care domains (particularly cooperation/communication/family support) as being significantly improved ($p<0.001$). Thirty-five percent of HCPs felt uncertain concerning pediatric palliative care; 79% would welcome specific training opportunities.
Conclusions: Involvement of a PPHCT is experienced as a substantial improvement of care by parents and HCPs. Coordination of palliative care during the last phase of life appears to be an important quality factor for the home care of dying children and their families.

Introduction

End-of-life (EOL) care of severely ill and dying children is one of the most challenging situations in pediatrics. According to the definition of the World Health Organization, the goal of pediatric palliative care (PPC) is to achieve the best quality of life (QOL) for patients and their families, consistent with their values, regardless of the location of the patient.[1] In 2000, the American Academy of Pediatrics Committees on Bioethics and Hospital Care recommended the development and broad availability of PPC services based on child specific guidelines and standards.[2] In addition, guidelines for the provision of child specific palliative care services were published.[3] However, still little is known about the optimal setting and organisational context in which to provide PPC.[4,5]

Major barriers according to parents and health care professionals (HCPs) are lack of continuity of care, deficiencies in communication, ineffective symptom management, insufficient education, and—in particular—lack of coordination.[6–27] Coordination is often seen as the gateway for problems and solutions.

It has been suggested that specialized pediatric palliative home care teams (PPHCT) could help in coordinating palliative care and improving communication between the different institutions and professionals involved.[28–30] The goal of this study was to evaluate whether pediatric palliative home care can be improved by involving a PPHCT. Successful implementation of a new structure in the health care system requires that both the needs of HCPs and those of patients and their families are adequately addressed. Thus, assessment of

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[3]Service de Soins Palliatifs, Centre Hospitalier Universitaire Vaudois (CHUV), University of Lausanne, Lausanne, Switzerland.
Accepted October 17, 2011.

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Home-based palliative care

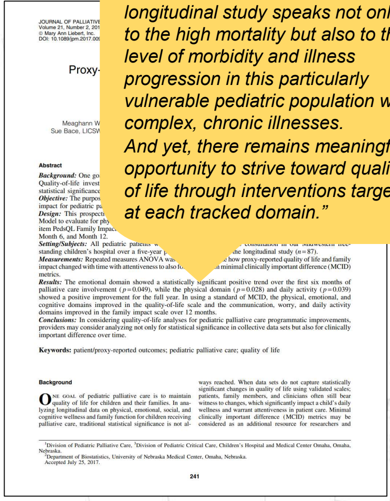
Overall quality of life improved (p<0.0017)

Improve QoL?

Time to improve?

Emotional QoL?

Physical QoL?


JOURNAL OF PALLIATIVE
Volume 21, Number 2, 201
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2017.00

Proxy-

Meaghann W
Sue Bace, LICSW

Abstract

Background: One go
Quality-of-life invest
statistical significance
Objective: The purpos
impact for pediatric pa
Design: This prospecti
Model to evaluate for phy
item PedsQL Family Impac
Month 6, and Month 12.
Setting/Subjects: All pediatric patients w … consultation in our Midwestern free-standing children's hospital over a five-year p … the longitudinal study ($n = 87$).
Measurements: Repeated measures ANOVA was … how proxy-reported quality of life and family impact changed with time with attentiveness to also fo … minimal clinically important difference (MCID) metrics.
Results: The emotional domain showed a statistically significant positive trend over the first six months of palliative care involvement ($p = 0.049$), while the physical domain ($p = 0.028$) and daily activity ($p = 0.039$) showed a positive improvement for the full year. In using a standard of MCID, the physical, emotional, and cognitive domains improved in the quality-of-life scale and the communication, worry, and daily activity domains improved in the family impact scale over 12 months.
Conclusions: In considering quality-of-life analyses for pediatric palliative care programmatic improvements, providers may consider analyzing not only for statistical significance in collective data sets but also for clinically important difference over time.

Keywords: patient/proxy-reported outcomes; pediatric palliative care; quality of life

Background

One goal of pediatric palliative care is to maintain quality of life for children and their families. In analyzing longitudinal data on physical, emotional, social, and cognitive wellness and family function for children receiving palliative care, traditional statistical significance is not always reached. When data sets do not capture statistically significant changes in quality of life using validated scales; patients, family members, and clinicians often still bear witness to changes, which significantly impact a child's daily wellness and warrant attentiveness in patient care. Minimal clinically important difference (MCID) metrics may be considered as an additional resource for researchers and

---

[1]Division of Pediatric Palliative Care, [3]Division of Pediatric Critical Care, Children's Hospital and Medical Center Omaha, Omaha, Nebraska.
[2]Department of Biostatistics, University of Nebraska Medical Center, Omaha, Nebraska.
Accepted July 25, 2017.

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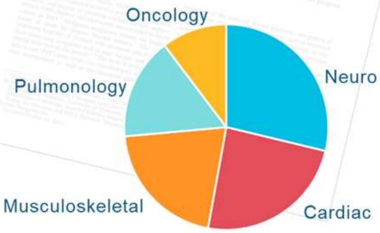
> *"The reality that one-third of the study population died during time of longitudinal study speaks not only to the high mortality but also to the level of morbidity and illness progression in this particularly vulnerable pediatric population with complex, chronic illnesses.*
> *And yet, there remains meaningful opportunity to strive toward quality of life through interventions targeted at each tracked domain."*

Hospital-based palliative care (rural Nebraska)

Emotional QoL improved within first 6mo of enrollment ($p=0.0495$)

Physical QoL improved within first 12mo of enrollment ($p=0.03$)

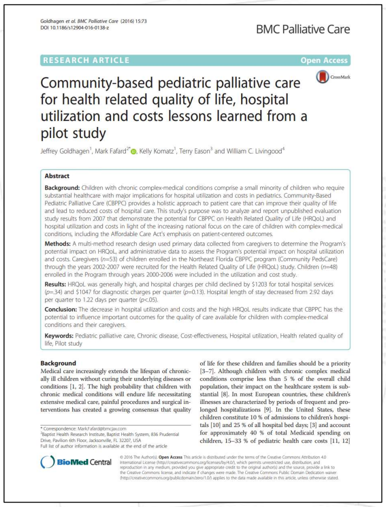


Improve QoL?

Time to improve?

Emotional QoL?

Physical QoL?



Goldhagen *et al. BMC Palliative Care* (2016) 15:73
DOI 10.1186/s12904-016-0138-z

BMC Palliative Care

RESEARCH ARTICLE Open Access

Community-based pediatric palliative care for health related quality of life, hospital utilization and costs lessons learned from a pilot study

Jeffrey Goldhagen[1], Mark Fafard[2*], Kelly Komatz[1], Terry Eason[3] and William C. Livingood[4]

Abstract

Background: Children with chronic complex-medical conditions comprise a small minority of children who require substantial healthcare with major implications for hospital utilization and costs in pediatrics. Community-Based Pediatric Palliative Care (CBPPC) provides a holistic approach to patient care that can improve their quality of life and lead to reduced costs of hospital care. This study's purpose was to analyze and report unpublished evaluation study results from 2007 that demonstrate the potential for CBPPC on Health Related Quality of Life (HRQoL) and hospital utilization and costs in light of the increasing national focus on the care of children with complex-medical conditions, including the Affordable Care Act's emphasis on patient-centered outcomes.

Methods: A multi-method research design used primary data collected from caregivers to determine the Program's potential impact on HRQoL, and administrative data to assess the Program's potential impact on hospital utilization and costs. Caregivers (*n*=53) of children enrolled in the Northeast Florida CBPPC program (Community PedsCare) through the years 2002-2007 were recruited for the Health Related Quality of Life (HRQoL) study. Children (*n*=48) enrolled in the Program through years 2000-2006 were included in the utilization and cost study.

Results: HRQoL was generally high, and hospital charges per child declined by $1203 for total hospital services (p=.34) and $1047 for diagnostic charges per quarter (p=0.13). Hospital length of stay decreased from 2.92 days per quarter to 1.22 days per quarter (p<.05).

Conclusion: The decrease in hospital utilization and costs and the high HRQoL results indicate that CBPPC has the potential to influence important outcomes for the quality of care available for children with complex-medical conditions and their caregivers.

Keywords: Pediatric palliative care, Chronic disease, Cost-effectiveness, Hospital utilization, Health related quality of life, Pilot study

Background

Medical care increasingly extends the lifespan of chronically ill children without curing their underlying diseases or conditions [1, 2]. The high probability that children with chronic medical conditions will endure life necessitating extensive medical care, painful procedures and surgical interventions has created a growing consensus that quality of life for these children and families should be a priority [3–7]. Although children with chronic complex medical conditions comprise less than 5 % of the overall child population, their impact on the healthcare system is substantial [8]. In most European countries, these children's illnesses are characterized by periods of frequent and prolonged hospitalizations [9]. In the United States, these children constitute 10 % of admissions to children's hospitals [10] and 25 % of all hospital bed days; [3] and account for approximately 40 % of total Medicaid spending on children, 15–33 % of pediatric health care costs [11, 12]

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[2]Baptist Health Research Institute, Baptist Health System, 836 Prudential Drive, Pavilion 6th Floor, Jacksonville, FL 32207, USA
Full list of author information is available at the end of the article

BioMed Central

Home-based study (Florida)

↓Days impaired (p=0.01)

↓Activity limitation due to fear (p=0.01)

Improve QoL?

Time to improve?

Emotional QoL?

Physical QoL?

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The Seattle Pediatric Palliative Care Project: Effects on Family Satisfaction and Health-Related Quality of Life

ROSS M. HAYS, M.D.,[1] JEANETTE VALENTINE, Ph.D.,[2] GERRI HAYNES, R.N.,[2]
J. RUSSELL GEYER, M.D.,[1] NANCI VILLAREALE, R.N., M.S.N.,[2] BETH MCKINSTRY,[1]
JAMES W. VARNI, Ph.D.,[3] and SHERVIN S. CHURCHILL, M.P.H.[2]

ABSTRACT

Purpose: This paper presents the components of a pediatric palliative care demonstration program implemented in Seattle during the period 1999–2001. It reports findings from the evaluation of quality of life and family satisfaction among enrolled participants. The program was designed to enhance patient–provider communication using the Decision-making Tool (DMT) and experimented with comanagement by clinicians and insurers to support decision-making in advanced serious pediatric illness.

Design: The project design consisted of ethical decision-making, provider education, and flexible administration of health benefits through co-case management between insurers and care providers. The evaluation study design is a nonexperimental pretest, posttest design comparison of pediatric quality of life and family satisfaction at program entry with repeated measures at 3 months postprogram entry. Quality of life was measured with parent proxy reports of health-related quality of life using the PedsQL™ Version 4.0, and family satisfaction was measured with a 31-item self-administered questionnaire designed by project staff.

Results: Forty-one patients ranging in age from infancy to 22 years old were enrolled in the program over a 2-year period. Parents consented to participate in the evaluation study. Thirty-one specific diagnoses were represented in the patient population; 34% were some form of cancer. Improvements in health-related quality of life over baseline were observed for 21 matched pairs available for analysis in each domain of health-related quality of life; positive changes in reports of emotional well-being were statistically significant. Improvements over baseline in 14 of 31 family satisfaction items were statistically significant.

Conclusions: Pediatric palliative care services that focus on effective communication, decision support, and co-case management with insurers can improve aspects of quality of life and family satisfaction.

INTRODUCTION

PALLIATIVE CARE INVOLVES a complex set of clinical and psychosocial tasks in the care of patients who may be simultaneously pursuing curative therapeutic goals and comfort measures more typical of end-of-life care.[1] The Institute of Medicine's recent study, which investigated care for children who die and their families, draws an important distinction between palliative care and

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[3]Department of Landscape Architecture and Urban Planning, College of Architecture, Department of Pediatrics, College of Medicine, Texas A&M University, College Station, Texas.

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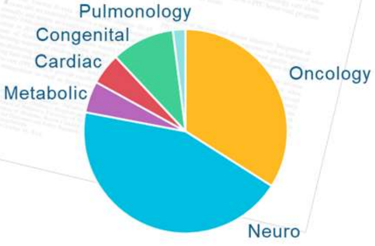
Hospital-based study (Seattle, Washington)

Emotional QoL improved (p<0.005)

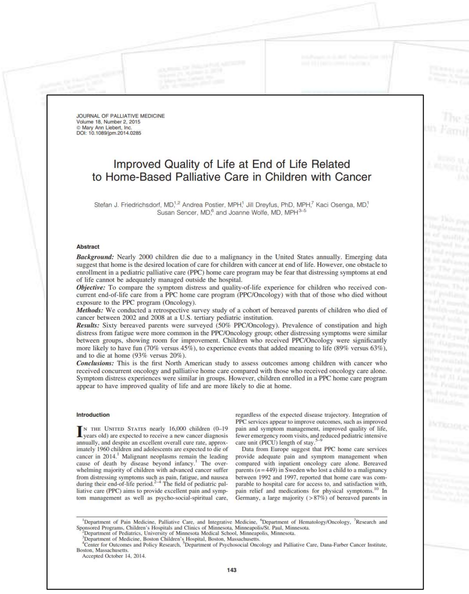


Improve QoL?

Time to improve?

Emotional QoL?

Physical QoL?



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Improved Quality of Life at End of Life Related to Home-Based Palliative Care in Children with Cancer

Stefan J. Friedrichsdorf, MD,[1,2] Andrea Postier, MPH,[1] Jill Dreyfus, PhD, MPH,[7] Kaci Osenga, MD,[1]
Susan Sencer, MD,[6] and Joanne Wolfe, MD, MPH[3–5]

Abstract

Background: Nearly 2000 children die due to a malignancy in the United States annually. Emerging data suggest that home is the desired location of care for children with cancer at end of life. However, one obstacle to enrollment in a pediatric palliative care (PPC) home care program may be fear that distressing symptoms at end of life cannot be adequately managed outside the hospital.
Objective: To compare the symptom distress and quality-of-life experience for children who received concurrent end-of-life care from a PPC home care program (PPC/Oncology) with that of those who died without exposure to the PPC program (Oncology).
Methods: We conducted a retrospective survey study of a cohort of bereaved parents of children who died of cancer between 2002 and 2008 at a U.S. tertiary pediatric institution.
Results: Sixty bereaved parents were surveyed (50% PPC/Oncology). Prevalence of constipation and high distress from fatigue were more common in the PPC/Oncology group; other distressing symptoms were similar between groups, showing room for improvement. Children who received PPC/Oncology were significantly more likely to have fun (70% versus 45%), to experience events that added meaning to life (89% versus 63%), and to die at home (93% versus 20%).
Conclusions: This is the first North American study to assess outcomes among children with cancer who received concurrent oncology and palliative home care compared with those who received oncology care alone. Symptom distress experiences were similar in groups. However, children enrolled in a PPC home care program appear to have improved quality of life and are more likely to die at home.

Introduction

In the United States nearly 16,000 children (0–19 years old) are expected to receive a new cancer diagnosis annually, and despite an excellent overall cure rate, approximately 1960 children and adolescents are expected to die of cancer in 2014.[1] Malignant neoplasms remain the leading cause of death by disease beyond infancy.[1] The overwhelming majority of children with advanced cancer suffer from distressing symptoms such as pain, fatigue, and nausea during their end-of-life period.[2–4] The field of pediatric palliative care (PPC) aims to provide excellent pain and symptom management as well as psycho-social-spiritual care, regardless of the expected disease trajectory. Integration of PPC services appear to improve outcomes, such as improved pain and symptom management, improved quality of life, fewer emergency room visits, and reduced pediatric intensive care unit (PICU) length of stay.[5–9]

Data from Europe suggest that PPC home care services provide adequate pain and symptom management when compared with inpatient oncology care alone. Bereaved parents ($n = 449$) in Sweden who lost a child to a malignancy between 1992 and 1997, reported that home care was comparable to hospital care for access to, and satisfaction with, pain relief and medications for physical symptoms.[10] In Germany, a large majority (>87%) of bereaved parents in

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[1]Department of Pain Medicine, Palliative Care, and Integrative Medicine, [6]Department of Hematology/Oncology, [7]Research and Sponsored Programs, Children's Hospitals and Clinics of Minnesota, Minneapolis/St. Paul, Minnesota.
[2]Department of Pediatrics, University of Minnesota Medical School, Minneapolis, Minnesota.
[3]Department of Medicine, Boston Children's Hospital, Boston, Massachusetts.
[4]Center for Outcomes and Policy Research, [5]Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, Massachusetts.
Accepted October 14, 2014.

Home-based study (Minnesota)

Increased fun (p=0.03)

Increased participation in meaningful event (p=0.02)

No significant difference in symptom burden, pain management.

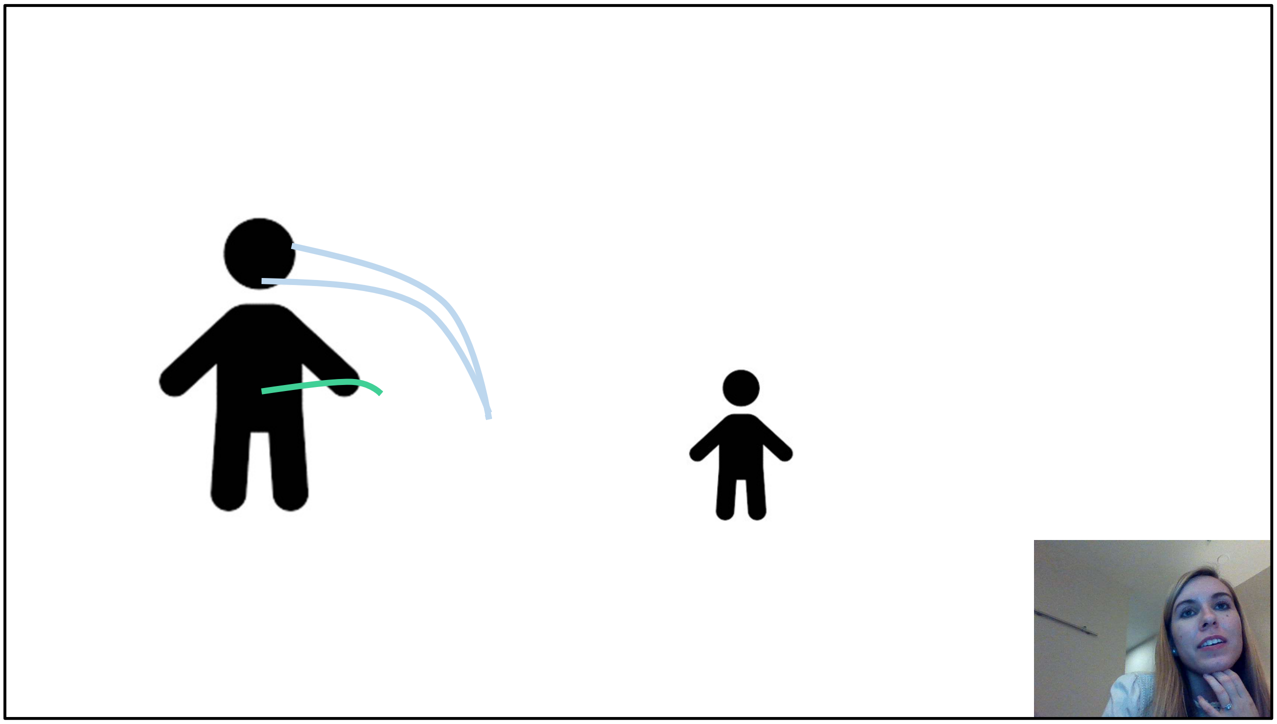
Higher degree of fatigue
***not prevalence (p=0.007)**

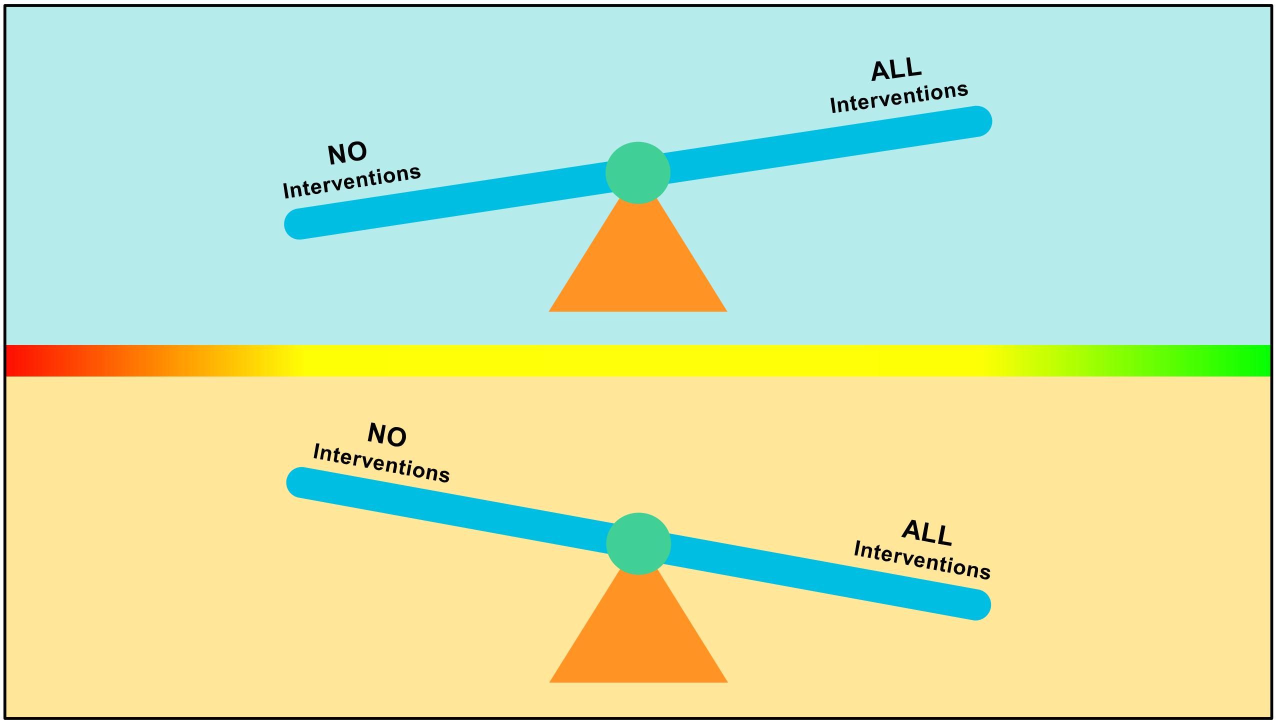
Improve QoL?

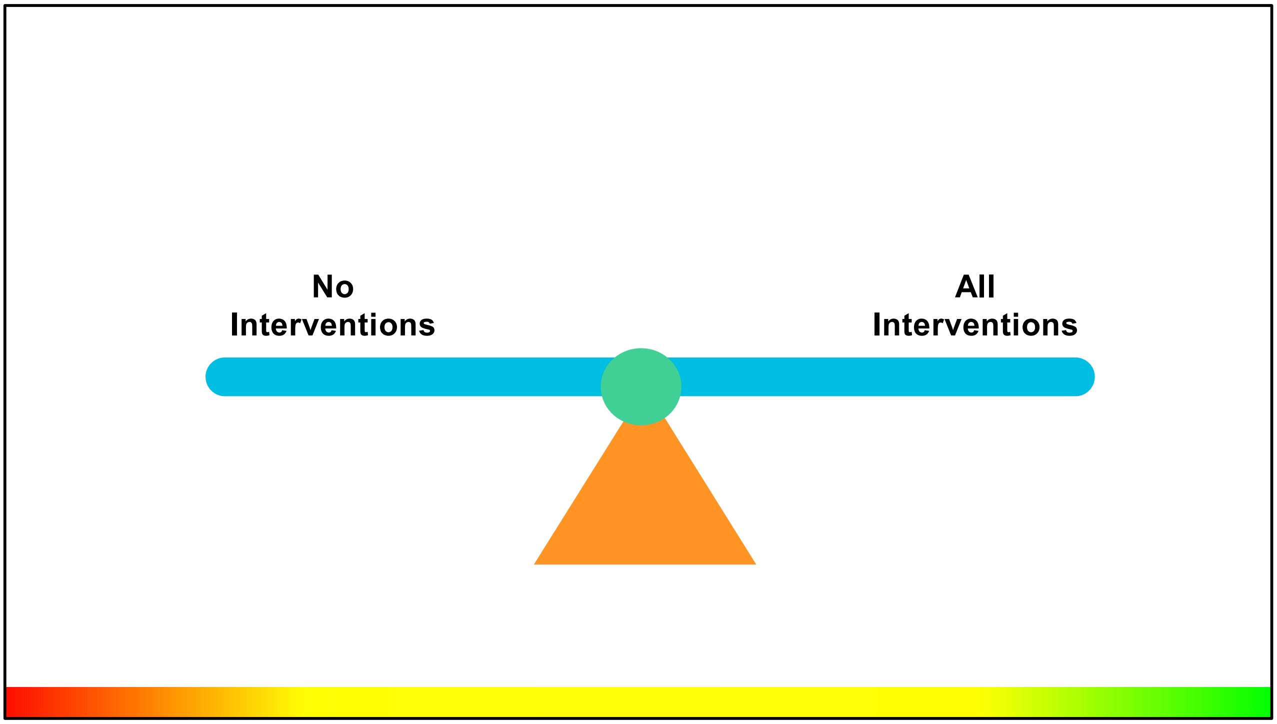
Time to improve?

Emotional QoL?

Physical QoL?




ALL
Interventions
NO
Interventions
NO
Interventions
ALL
Interventions



No Interventions

All Interventions

LIMITATIONS

- Parent perceptions
- Recall bias
- Small sample sizes
- Non-validated surveys
- Single center or few centers
- Native language only

STRENGTHS

- Results are consistent across multiple states, multiple countries
- QoL can be used as an indicator for quality of EOL care
- Good survey response rates
- Longitudinal study: following patients over longer period of time (Weaver et al.)

QoL: Quality of Life
EOL: End of Life

> *“When data sets do not capture statistically significant changes in quality of life using validated scales; patients, family members, and clinicians often still bear witness to changes, which significantly impact a child’s daily wellness and warrant attentiveness in patient care.”*

Weaver, et. Al “Proxy-Reported Quality of Life and Family Impact for Children Followed Longitudinally by a Pediatric Palliative Care Team”

DATA
CONSIDERATIONS

ROLE OF A PA

PEDIATRIC HOSPICE AND PALLIATIVE CARE

- Settings
  - Inpatient
  - Outpatient
  - Home

- Refer patients to hospice

- Attending hospice provider

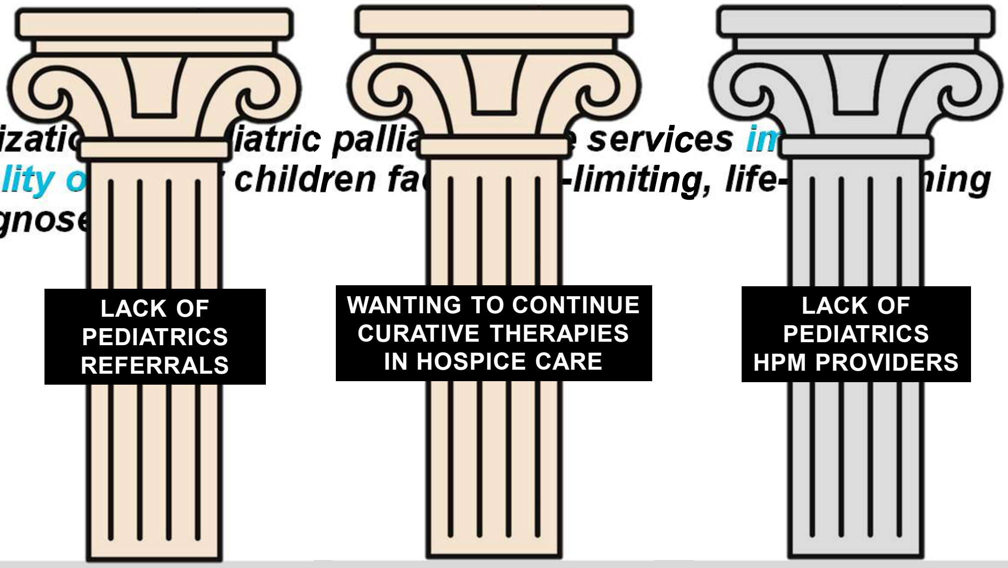
- Role
  - Provide care individually and as a team
    - Symptom management
    - Pain management
    - Counseling and education
    - Develop goals of care
    - Care coordination
  - Submit orders
  - Bill for services and reimbursement

- Limitation: cannot certify terminal illness, cannot recertify

**Medicare Patient Access to Hospice Act:
Effective January 1, 2019**

ROLE OF A PA
PEDIATRIC HOSPICE AND PALLIATIVE CARE

Utilizatio iatric pallia e services im
quality o children fa -limiting, life- ning
diagnose



LACK OF PEDIATRICS REFERRALS

WANTING TO CONTINUE CURATIVE THERAPIES IN HOSPICE CARE

LACK OF PEDIATRICS HPM PROVIDERS

DISCUSSION, CONCLUSION

- Lack of referrals may be due to:
  - Misconceptions about pediatrics palliative care
  - Lack of financial coverage

- Availability of providers

FUTURE DIRECTIONS

REFERENCES

1. Williams A, M., Wheeler S, M. Palliative care: What is it? *Home Healthc Nurse*. 2001;19(9):550-556. doi: 10.1097/00004045-200109000-00013.
2. Rotella, J. Hospice and Palliative Medicine History. Presentation. AAHPM. October 2019.
3. Open Society Foundation. Project on Death in America Report of Activities: July 1194- December 1997 . Presentation. 1998.
4. Lindley C, L. Healthcare reform and concurrent curative care for terminally ill children: A policy analysis. *Journal of Hospice & Palliative Nursing*. 2011;13(2):81-88. doi: 10.1097/NJH.0b013e318202e308.
5. Kaye EC, Rubenstein J, Levine D, Baker JN, Dabbs D, Friebert SE. Pediatric palliative care in the community. *CA: A Cancer Journal for Clinicians*. 2015;65(4):315-333. doi: 10.3322/caac.21280.
6. Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life related to home-based palliative care in children with cancer. *J Palliat Med*. 2015;18(2):143-150. doi: 10.1089/jpm.2014.0285.
7. Hays RM, Valentine J, Haynes G, et al. The seattle pediatric palliative care project: Effects on family satisfaction and health-related quality of life. *J Palliat Med*. 2006;9(3):716-728. doi: 10.1089/jpm.2006.9.716.
8. Goldhagen J, Fafard M, Komatz K, Eason T, Livingood WC. The impact of community-based palliative care on health related quality of care, hospital utilization and costs: Lessons learned from a pilot study. *BMC Palliative Care*. 2016;15(1). doi: 10.1186/s12904-016-0138-z.
9. Weaver M, Wichman C, Darnall C, Bace S, Vail C, Macfadyen A. Proxy-reported quality of life and family impact for children followed longitudinally by a pediatric palliative care team. *J Palliat Med*. 2018;21(2):241-244. doi: 10.1089/jpm.2017.0092.
10. Vollenbroich R, Duroux A, Grasser M, Brandstätter M, Borasio GD, Führer M. Effectiveness of a pediatric palliative home care team as experienced by parents and health care professionals. *J Palliat Med*. 2012;15(3):294-300. doi: 10.1089/jpm.2011.0196.
11. Varela AMS, Deal AM, Hanson LC, Blatt J, Gold S, Dellon EP. Barriers to hospice for children as perceived by hospice organizations in North Carolina. *American Journal of Hospice and Palliative Medicine*. 2012;29(3):171-176. doi: 10.1177/1049909111412580.
12. AAPA Reimbursement Department. PAs Can Be Reimbursed for Medicare Hospice Services in January 2019. Website. AAPA. 2018.
13. Osenga K, Postier A, Dreyfus J, Foster L, Teeple W, Friedrichsdorf SJ. A comparison of circumstances at the end of life in a hospital setting for children with palliative care involvement versus those without. *J Pain Symptom Manage*. 2016;52(5):673-680. doi: 10.1016/j.jpainsymman.2016.05.024.
14. Thrane SE, Maurer SH, Cohen SM, May C, Sereika SM. Pediatric palliative care: A five-year retrospective chart review study. *J Palliat Med*. 2017;20(10):114-1111. doi: 10.1089/jpm.2017.0038.

REFERENCES

15. Keim-Malpass J, Hart TG, Miller JR. Coverage of palliative and hospice care for pediatric patients with a life-limiting illness: A policy brief. *Journal of Pediatric Health Care*. 2013;27(6). doi: 10.1016/j.pedhc.2013.07.011.
16. Kaye EC, Gushue CA, Demarsh S, et al. Illness and end-of-life experiences of children with cancer who receive palliative care. *Pediatric Blood & Cancer*. 2018;65(4):n/a. doi: 10.1002/pbc.26895.
17. Huang I, Shenkman E, Madden V, Vadaparampil S, Quinn G, Knapp C. Measuring quality of life in pediatric palliative care: Challenges and potential solutions. *Palliat Med*. 2010;24(2):175-82. doi: 10.1177/0269216309352418.
18. Samsel C, B EL. End-of-life care in a regional level IV neonatal intensive care unit after implementation of a palliative care initiative. *Journal of Perinatology*. 2015;35(3). doi: 10.1038/jp.2014.189.
19. Knapp C, Madden V, Revicki D, et al. Health status and health-related quality of life in a pediatric palliative care program. *J Palliat Med*. 2012;15(7):79-797. doi: 10.1089/jpm.2011.0504.
20. Groh G, Borasio GD, Nickolay C, Bender H, Von Lüttichau I, Führer M. Specialized pediatric palliative home care: A prospective evaluation. *J Palliat Med*. 2013;16(12):1588-1594. doi: 10.1089/jpm.2013.0129.
21. Keele L, Keenan H, Sheetz J, Bratton S. Differences in characteristics of dying children who receive and do not receive palliative care. *Pediatrics*. 2013;132(1):72. doi: 10.1542/peds.2013-0470.
22. Thienprayoon R, San JM, Grossoehme D. Provider-prioritized domains of quality in pediatric home-based hospice and palliative care: A study of the Ohio pediatric palliative care and end-of-life network. *J Palliat Med*. 2018;21(3):29-296. doi: 10.1089/jpm.2017.0333.
23. Widger K, Medeiros C, Trenholm M, Zuniga-Villanueva G, Streuli J. Indicators used to assess the impact of specialized pediatric palliative care: A scoping review. *J Palliat Med*. 2019;22(2):199-219. doi: 10.1089/jpm.2018.0420.
24. Feudtner C, Womer J, Augustin R, et al. Pediatric palliative care programs in children's hospitals: A cross-sectional national survey. *Pediatrics*. 2013;132(6):1063. doi: 10.1542/peds.2013-1286.
25. Hilden J. It is time to let in pediatric palliative care. *Pediatric Blood & Cancer*. 2016;63(4):583-584. doi: 10.1002/pbc.25877.
26. Carroll JM, Torkildson C, Winsness JS. Issues related to providing quality pediatric palliative care in the community. *The Pediatric Clinics of North America*. 2007;54(5):813-827. doi: 10.1016/j.pcl.2007.06.002.
27. Lindley LC, Mark BA, Daniel Lee S, Domino M, Song M, Jacobson Vann J. Factors associated with the provision of hospice care for children. *J Pain Symptom Manage*. 2013;45(4):701-711. doi: 10.1016/j.jpainsymman.2012.03.010.
28. Niswander LM, Cromwell P, Chirico J, Gupton A, Korones DN. End-of-life care for children enrolled in a community-based pediatric palliative care program. *J Palliat Med*. 2014;17(5):589-591. doi: 10.1089/jpm.2013.0576.

THANK YOU