



CENTER FOR
DEVELOPMENT
& DISABILITY

Case for Pediatric Palliative Care in New Mexico

Laurel Christensen, MS, MSW Candidate (May 2021)



LEND Competencies

1.1 Demonstrate knowledge of the principles of family-centered care

1.5 Demonstrate an awareness/sensitivity to the impact of disability on family

1.9 Identify family-centered practices in the community and services systems

2.1 Demonstrate knowledge of the principles of interdisciplinary practice

3.4 Describe health disparities within the MCH population and offer strategies to address them

4.6 Apply the model of ethical decision-making in analysis of health-related ethical dilemma

4.7 Demonstrate leadership skills in the facilitation of a seminar or meeting

5.2 Demonstrate skills in access/utilization of electronic information, resources, and databases

5.5 Demonstrate verbal presentation skills including use of Powerpoint

6.3 Demonstrate networking and advocacy skills

6.5 Demonstrate an understanding of health care funding

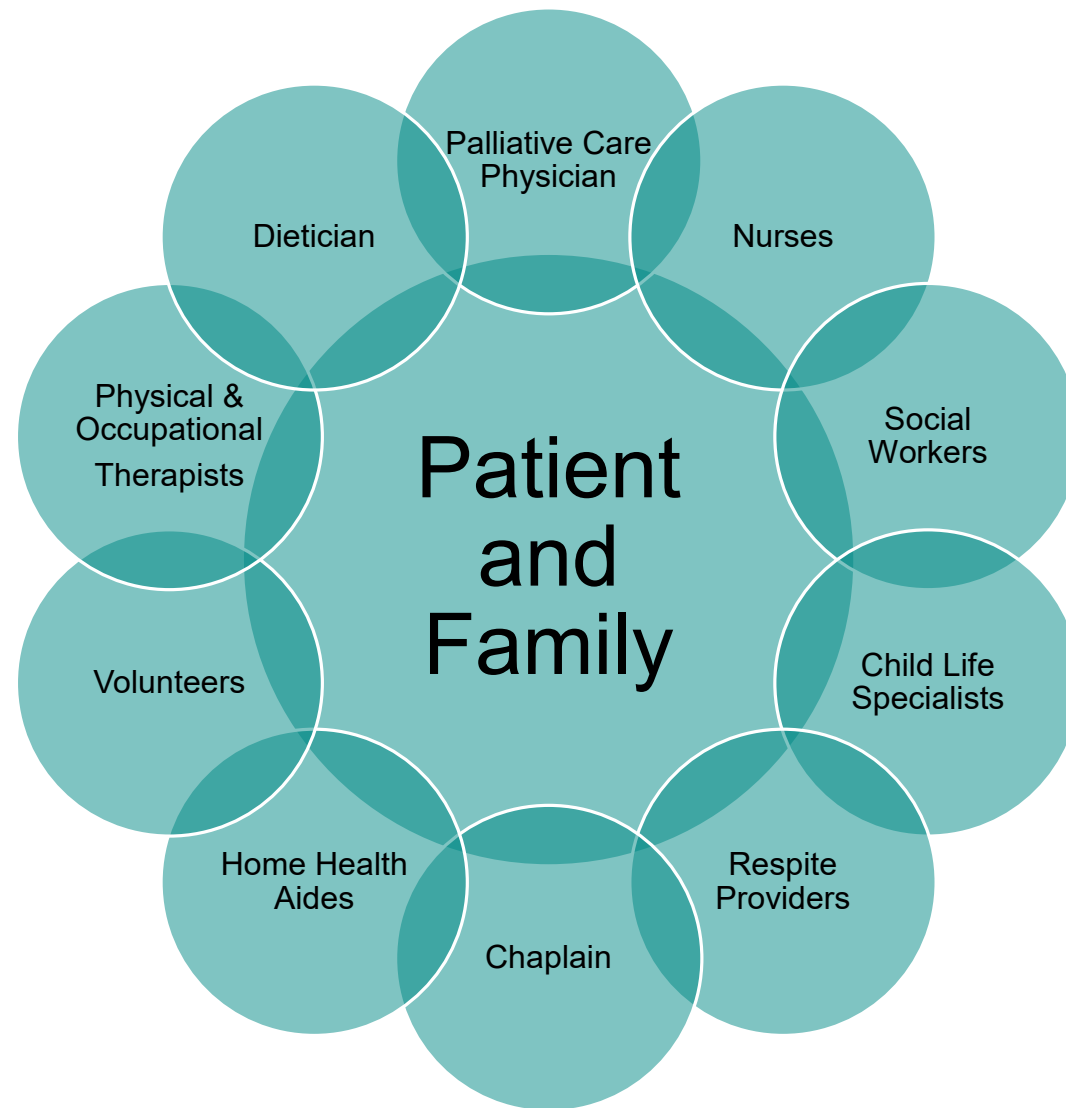
What is palliative care?



“the prevention and relief of suffering of adult and pediatric patients and their families facing the problems associated with life-threatening illness. These problems include the physical, psychological, social and spiritual suffering of patients, and psychological, social and spiritual suffering of family members”

(World Health Organization, 2018, p. 5)

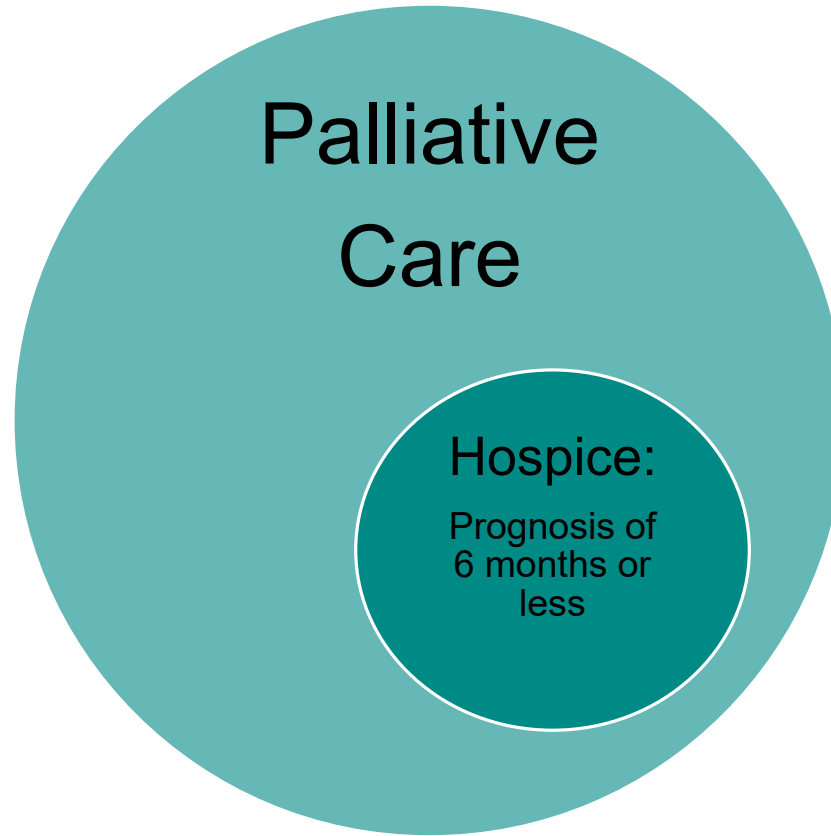
What is palliative care?



What is palliative care?



- Community, clinic, or hospital based
- Palliative versus hospice—important distinction



- Affordable Care Act (ACA, 2010)
 - Concurrent care in palliative and hospice

Problem Framing

Why add pediatric palliative care?

- Additional layer of wrap around care uniquely suited to each family.
- Specialized attention to and training in considering quality of life at each stage of the illness.
- Focus on communication and coordination of care.

Who benefits from adding pediatric palliative care?

- Children with chronic illness or complex medical needs such as cancer, heart or lung conditions, neurologic disorders, and many others.
- Parents and caretakers of these children.
- Siblings, other family members, and friends.

Problem Framing

Gap analysis for New Mexican children

- Difficult to get accurate count of potential palliative referrals.
- ~9.2% of infants in NM have low birthweight; national average is 8.3% NM-IBIS (2018).
- ~380 patients on Medically Fragile Medicaid Waiver Program (V. Woodard, personal communication, January 25, 2021).
- Kids Count reports that ~36 per 100k children aged 0-19 died from all causes in 2019 versus ~25 per 100k for the entire US (Kids Count, 2021).
- CAPC's 2019 report card on palliative care availability in the US places New Mexico in the bottom 5 states with an overall grade of D (CAPC, 2019).

Research—Data and Statistics

Patient Centered Benefits of PPC

- Specialized pain and symptom control including opioids when necessary.
 - Groh et al. (2013) reported significant reduction in symptoms as perceived by caregivers.
- Nearly 50% reduction in inpatient days across a diverse patient population reported by Gans et al. (2016).
- Notable increase in reported quality-of-life scores using standardized assessments for patients and caregivers (Groh et al., 2013).
- Significant decrease in depression and anxiety in parents (Groh et al., 2013).

Research—Data and Statistics

Cost Effectiveness of PPC

- Sickest 10% of the US population accounted for about 65% of health care expenditures (CAPC, 2019).
- PPC programs have proven cost effective for families and insurance payers (Chong, 2018).
- Potential savings of \$1500-\$3000 per patient per month (CAPC, 2019).
- Gans et al. (2016) reported overall savings exceeding \$7 million during 2-year span in California study.

Research— Current Status of PPC in NM



○Mariposa Hospice at UNMH

- Pilot program
- Limited census
- Based in Albuquerque
 - (H. Ghanem, personal communication, November 9, 2020)

○Hero's Path Palliative Care

- Community based
 - Non-profit
- In fundraising stages
 - (J. Bartz, personal communication, November 10, 2020 & March 8, 2021)

Product



Infographic for promoting PPC on next slide

Intended for use by providers in all types of pediatric clinics

Introduce PPC as soon as at initial diagnosis as recommended by AAP (Gans et al., 2016)

Ongoing conversation leading to PPC consult

Pediatric Palliative Care

A young child with blonde hair, wearing a bright yellow raincoat, is holding a silver umbrella. The child is looking directly at the camera with a slight smile. The background is a soft-focus outdoor setting, possibly a park or a street with trees.

Who?

A multidisciplinary team of professionals including a palliative care specialist, nurse, social worker, and child life specialists will be involved in creating a unique care plan for your entire family. You do not have to forego any other treatments or stop visiting any specialists.

Where?

Services can occur in the hospital, in a clinic, or in your home depending on the agency.

Why?

Navigating chronic childhood diagnoses is difficult in biological, social, psychological, and spiritual areas for the entire family. Reducing pain and symptoms, focusing on childhood and quality of life, and providing care management can help you focus on your family.

What?

An additional layer of care with specialists who assist with pain and symptom management, work to coordinate complex medical systems, and continually stay focused on quality of life for your family.

When?

Support can begin at the time of initial diagnosis and continue indefinitely. There is no time limit or qualifying life expectancy.

Dissemination

- Infographic dissemination on hold
- Present to Children's Medical Services social workers
- Present to Medically Fragile Medicaid Waiver program RN case managers
- Continue to raise awareness and educate public and providers
 - Potentially becoming a board member for community organizations
 - Advocate for policy at the state and national levels

Recommendations

Expand inpatient
PPC program at
UNMH

Implement
inpatient PPC
program at
Presbyterian
Hospital

Advocate for
community
based PPC
agencies in
Metro Area

Utilize outreach
clinics with
Children's
Medical Services

Project ECHO
delivery of PPC
to rural areas of
NM

Consider
implementation
of Surprise
Question (Burke
et al., 2018)

Consider
implementation
of Pediatric
Palliative
Screening Scale
(Bergstraesser
et al., 2013)

Do not be daunted by the world's grief.

Do justly, now.

Love mercy, now.

Walk humbly, now.

You are not obligated to complete the work,
but neither are you free to abandon it.

THE TALMUD

Resources

- Bergstarsser, E., Hain, R. D., & Pereira, J. L. (2013). The development of an instrument that can identify children with palliative care needs: The Paediatric Palliative Screening Scale (PaPaS Scale): A qualitative study. *BMC Palliative Care*, 12(1). <https://doi.org/10.1186/1472-684X-12-20>
- Burke, K., Coombes, L. H., Menezes, A., & Anderson, A. (2018). The 'surprise' question in paediatric palliative care: A prospective cohort study. *Palliative Medicine*, 32(2). <https://doi.org/10.1177/0269216317716061>
- Center to Advance Palliative Care [CAPC]. (2019). America's care of serious illness: 2019 state-by-state report card on access to palliative care in our nation's hospitals. <https://reportcard.capc.org/>
- Chong, P. H., De Castro Molina, J. A., Teo, K., & Tan, W. S. (2018). Paediatric palliative care improves patient outcomes and reduces healthcare costs: Evaluation of a home-based program. *BMC Palliative Care*, 17(11). <https://doi.org/10.1186/s12904-017-0267-z>
- Gans, D., Hadler, M. W., Chen, X., Wu, S., Dimand, R., Abramson, J. M., Ferrell, B., Diamant, A. L., Kominski, G. F. (2016). Cost analysis and policy implications of a pediatric palliative care program. *Journal of Hospice and Palliative Medicine*, 52(3). <https://dx.doi.org/10.1016/j.jpainsymman.2016.02.020>
- Groh, G., Borasio, G. D., Nickolay, C., Bender, H., von Luttichau, I., Fuhrer, M. (2013). Specialized pediatric palliative home care: A prospective evaluation. *Journal of Palliative Medicine*, 16(12). <https://doi.org/10.1089/jpm.2013.0129>
- National Coalition for Hospice and Palliative Care. (2019). *National Coalition for Hospice and Palliative Care*. <https://www.nationalcoalitionhpc.org/>
- New Mexico's Indicator-Based Information System. (2018). *Health indicator report of birth outcomes—Low birthweight*. Retrieved on February 12, 2021 from <https://ibis.health.state.nm.us/indicator/view/LowBirthWt.Cnty.html>
- The Annie E. Casey Foundation. (2021). Child and teen death rate in New Mexico. *Kids count data center*. Retrieved on <https://datacenter.kidscount.org/data/tables/7243-child-and-teen-death-rate?loc=33&loct=2#detailed/2/33/true/1729,37,871,870,573,869,36,868,867,133/any/14285,17513>
- The Patient Protection and Affordable Care Act [ACA], Publ. L. No. 111-148, 124 Stat. 119 (2010). <https://www.govinfo.gov/content/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf>
- Thomas, A., Rubenstein, J., Jarrell, J. A. (2021). Principles of pediatric palliative care #405. *Journal of Palliative Medicine*, 24(1). <https://doi.org/10.1089/jpm.2020.0581>
- World Health Organization [WHO]. (2018). *Integrating palliative care and symptom relief into paediatrics: A WHO guide for health care planners, implementers, and managers*. <https://www.who.int/publications/i/item/integrating-palliative-care-and-symptom-relief-into-paediatrics>



Questions?

THANK YOU FOR LISTENING