NURSING GRAND ROUNDS: PEDIATRIC PALLIATIVE CARE

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Disclosure Statement

• I do not have any conflict of interest, nor will I be discussing any off-label product use.

• This class has no commercial support or sponsorship, nor is it co-sponsored.
Hopes for today...

- Explain principles of palliative care as it relates to the pediatric patient population

- List resources for hospice and palliative care in the Pacific Northwest region for pediatric patients

- Develop strategies to partner with the hospice and palliative care multidisciplinary team and the community
Dame Cecily Saunders

You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.
Palliative care is specialized health care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

Provided by a specially-trained team, palliative care specialists work together with a patient’s other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient’s prognosis. It is appropriate at any age and at point in a serious illness and can be delivered with curative treatment. (1)
Growth of Palliative Care

• The field of palliative care has shown **stunning growth** over the last 15 years. Today, more than 1,700 hospitals with 50+ beds have a palliative care team, and palliative care is spreading beyond the hospital into **community settings** where people with serious illnesses actually live and need care. 

(1)
Palliative Care at Seattle Children’s

Ross Hays, M.D., Medical Director
Jeff Beck, M.D., Attending
Jori Bogetz, M.D., Attending
Eileen Rhee, M.D., Attending
Abby Rosenberg, M.D., Attending
Kim Sawyer, M.D., Attending
Amy Trowbridge, M.D. Attending
Alisa Van Cleave, M.D., Attending
Macallagh McEvoy, ARNP, Nurse Practitioner
Arika Patneaud, LICSW, Social Work, Manager
Daphne Lindsey, LICSW, Social Work, Consultant
Lauren Schmidt, LICSW, Social Work, Consultant
Maya Scott, MSW, Social Work, Consultant
Anne Anderson, BSN, Nurse Care Coordinator
Dawn Marie Pares, Program Coordinator
Pediatric Palliative Care (PPC)

PPC helps to provide the best possible quality of life for patients and their families.
PPC helps patients and families manage the pain, symptoms and stress of serious illness.
PPC is a partnership of patient, family and all of the medical specialists.
PPC provides an extra layer of support for families and patients with serious illness.
PPC is appropriate at any age and at any stage of serious illness and can be provided along with curative treatment. (1)
Why is there a need for Pediatric Palliative Care?

Children with medical complexity are increasing in prevalence because of....

Increased survival rates of infants born prematurely, with congenital anomalies and/or with chronic conditions

Improved treatments for acute illness in fields such as intensive care and oncology (1)
What are the numbers?

Estimates on the prevalence of US children currently living with life-threatening or chronic, complex conditions such as congenital and chromosomal abnormalities, diseases of the nervous system or cancer, range from 400,000 and up, and more than 40,000 infants and children die annually. As many as 17 million adults are serving as caregivers to a seriously ill child. (1)
Any child with a potentially life limiting or life threatening condition including...

- Those born without an expectation to survive until adulthood
- Those who acquire an illness, such as cancer
- Those who suffer trauma
Palliative care provided by the primary team with focus around quality of life, symptom management and support around decision making and goals of care
Pediatric Hospice

“Would you be surprised if this child died in the next 6 months?”
Hospice is support in the home for the whole family.

Hospice focuses on hope for the best quality of life and symptom control. This means often kids go to school, and live their lives pretty well until the end.

Hospice is paid on a per diem basis, meaning that the hospice provides medications, equipment, supplies and a multidisciplinary team (nurse, social worker, spiritual care, bath aid, volunteers, etc)
Hospice Concurrent Care

• On March 23, 2010, President Obama signed the Patient Protection and Affordable Care Act (PPACA) into law enacting a new provision, Section 2302, termed the “Concurrent Care for Children” Requirement (CCCR). (2)
• Hospice Concurrent Care: Includes all of the benefits of hospice, plus continued life prolonging or curative therapies for patients with Medicaid.
Hospice Care with private insurance

Hospice Concurrent Care with Medicaid and some insurances.

Pediatric Palliative Care: Hospices can provide support with the WA State Medicaid Pediatric Palliative Care benefit: up to 6 visits per month for RN and MSW. Some private insurances also have a palliative care benefit.

Hospital based programs at Seattle Children’s, Mary Bridge in Tacoma and Sacred Heart in Spokane.
How do we do this work or collaborate?

HINTS FOR SUCCESS.....
Be respectful of family culture
Be prepared to sit on the floor and play!
Go in pairs to visit with family
Stay in touch by phone with the primary team with questions or updates
Attend to siblings
Be comfortable with the “grey”
Be patient with family, move slowly, don’t ask about POLST or funeral planning at first visit
Communication Hints....

SIT DOWN, LISTEN, SILENCE

Listen carefully, are they asking a question, or is it an emotion cue? “It sounds like you’re really worried”

With kids’ questions, remember less is more. “Is that something you’re worrying about?” “What do you think?”
Communicating with Hope

• “I know you are hoping your disease will be cured. Are there other things you are hoping for?” or “If things don’t go as we hope, is there anything I need to know?”

• Denial vs Extreme Hope

• Hope changes, “regoaling” hope shifts away from cure or long life to comfort or peace.
Questions?

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Resources

1. https://www.capc.org/about/palliative-care/
3. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3805677/
Resources

- courageousparentsnetwork.org
- partnershipforparents.net
- Pediatric Pain and Symptom management Guidelines from Dana Farber http://pinkbook.dfci.org/assets/docs/bl_ueBook.pdf
- Vital Tips app