Welcome to Today's Faculty

Cheryl Ann Thaxton, DNP, RN, CPNP, FNP-BC, CHPPN, ACHPN, FPCN

Cheryl Ann has enjoyed over 28 years of experience in nursing. She is both an ELNEC Core and ELNEC Pediatric Palliative Care trainer, and she also helped to develop portions of the ELNEC-APRN Pediatric and ELNEC APRN Pediatric Oncology curriculum.

She is currently working as an Advanced Practice Nurse for the Adult/Pediatric Palliative Care Team at Medical City in Texas. Dr. Thaxton worked several years as the Program Coordinator for the Pediatric Quality-of-Life Program at Duke Children's Hospital and Health Center in Durham, North Carolina. She had several years of experience working in the cardiac intensive care setting, primary care, and with neonatal intensive care patients.

She has co-authored several publications related to palliative care and the needs of patients with life-limiting illnesses. Her desire to promote the implementation of culturally sensitive initiatives has helped to develop strategic models of care through education and curriculum development.

In 2014, Dr. Thaxton received an award for being one of the Great 100 Nurses of North Carolina. In 2019, she received the D Magazine Excellence in Nursing Award and she was also designated as a Fellow in Palliative Care Nursing at the Annual Assembly meeting for AAHPM/HPNA in Orlando, Florida. Email contact: thaxca@aol.com

ELNEC
END-OF-LIFE NURSING EDUCATION CONSORTIUM
Advancing Palliative Care

Assisting Children Whose Family Member is Dying of Cancer: Opportunities for Primary Palliative Nurses

Cheryl Thaxton, DNP, CPNP, FNP-BC, CHPPN, ACHPN, FPCN

Christine Knefley, MS, CCLS

Objectives

- Discuss the role of the Palliative Care APRN in caring for children of dying patients
- Discuss the developmental stages of children and communication strategies to utilize to promote best outcomes
- Identify a variety of legacy building activities appropriate for different developmental stages

A Lifetime of Memories

Case Study

- 45-year old male with metastatic Stage IV lung cancer, multiple cancer treatments have failed. He was recently discharged from the 3th hospitalization within a 4 week period for sepsis and malignant pleural effusions. During the follow-up clinic visit, his wife revealed that their children did not know about his cancer diagnosis and the patient is now considering hospice support. The children, ages 14 and 6 years old were outside in the waiting room with their grandparents.

- *Where does the Primary Palliative Care Provider begin?*

Key Questions to Consider

- What is the meaning of illness to the family?
- What is the child's prior experience with sickness/death? (family member, pet(s), friend?)
- What is the child's developmental stage?
- What type of support does the family already have in place (home, church, school)?
- How does the family typically communicate difficult news?

What Children of Dying Family Members May Ask: The 3 C's

- "Can I catch it?"
- "Did I cause it?"
- "Who's going to take care of me?"

(Librach et al, 2011)

Role of the Primary Palliative Nurse

- Assess
- Educate
- Advocate
- Delegate
- Plan
- Follow-up

Infants

- Understanding of death
  - No formal understanding of death
  - Fear of separation
  - Responsive to emotions, the environment, anxiety level of others
- Reactions to death
  - More irritable
  - Cry more
  - More clingy
- Strategies to maximize coping
  - Keep routine as consistent as possible
  - Positive touch
  - Prioritize child over chores, ask for help

Toddlers and Preschoolers

- Understanding of death
  - Not permanent
  - Seen as punishment
  - Egocentric- caused by or related to self
  - Magical thinking
  - Fear of dying
- Reactions to death
  - May show little concern
  - Regression
  - Fear of separation
  - Repeatedly discuss death, may play out death scenes
- Strategies to maximize coping
  - Prepare them for what to expect
  - Be consistent in wording used, use concrete language
  - Address need for security
  - Address misconceptions
  - Allow them to play, including playing out death themes

School-aged Children

- Understanding of death
  - Progression of understanding from possible for others to possible for themselves
  - Irreversibility
  - More interest in biological aspects of death
- Reactions to death
  - Increased crying, anxiety
  - Headaches, stomach aches
  - Denial, hostility
  - Guilt, blame
  - Inattention, withdrawn
- Strategies to maximize coping
  - Explore possible reactions with child
  - Give permission to show (or not show) emotions
  - Honest explanations for death
  - Provide legacy opportunities
  - Listen, validate

Adolescents

- Understanding of death
  - Many have achieved a mature understanding of death
  - Able to think more abstractly
  - Better understands the implications of death
  - Can acknowledge that life is fragile
  - Still some invincibility
- Reactions to death
  - Assume more adult role
  - Preoccupation with death
  - Regression
  - Practice denial by risk-taking
  - More critical of parents
- Strategies to maximize coping
  - Explore possible reactions with child
  - Give permission to show (or not show) emotions
  - Honest explanations for death
  - Provide legacy opportunities
  - Listen, validate
  - Physical touch
  - Emotional contact- “I love you”

Preparing the Words

- Be concrete
  - Dead, died
  - Body stopped working
  - Heart stopped beating
  - Lungs stopped breathing
  - He/she does not feel pain
  - Not able to talk, eat, walk
- Avoid confusing terms and clichés
- Allow for silence
- Prepare answers for questions- both existential and concrete

Where and When

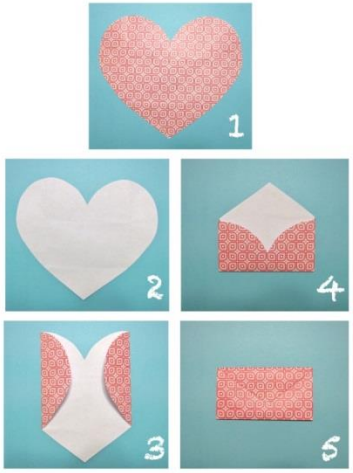
- Identify the safest place
- A private space is preferable
- Talk at the child's developmental level
- Encourage positive touch when appropriate
- Identify the best person to provide the disclosure
  - May or may not be the parent
- Allow enough time
- Remember, it's okay to show emotions

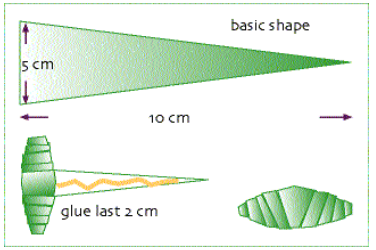
After the Disclosure

- Communicate language used for consistency
- Allow for play opportunities
- Identify ongoing support person/ people
- Offer legacy building opportunities

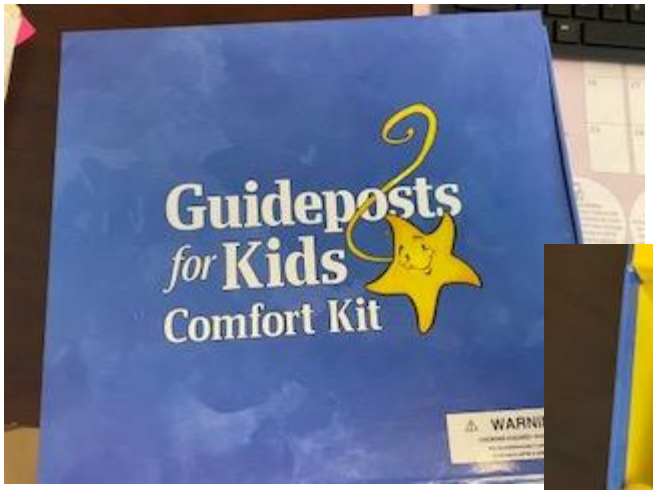
Legacy Activities

- Farewell Messages
  - Opportunity to say good-bye
  - Opportunity to share feelings
  - Can be shared or private





Other Legacy Activities



Conclusion

- The APRN must utilize a developmental approach when caring for children whose family member is dying of cancer.

- The APRN must implement must assess, educate, advocate, delegate, plan, and follow-up while providing support to children in the primary palliative care setting.

- The APRN must seek to partner with Child Life Specialists and Clinical Social Workers.

References

Librach, S. L. & O'Brien, H. (2011). Supporting children's grief within an adult and pediatric palliative care program. *Journal of Supportive Oncology,* 9(4),136-140.

https://www.nebraskamed.com/patients/child-life/resources

- Kids Worry, Too- addresses hospitalization of a loved one
- What Will I Tell the Children- developmental information on death

Questions & Answers

Cheryl Thaxton, DNP, CPNP, FNP-BC, CHPPN, ACHPN, FPCN
University Of Texas Southwestern Medical Center
Dallas, Texas
Cheryl.Thaxton@utsouthwestern.edu

Christine Knefley, MS, CCLS
Children's Medical Center
Dallas, Texas
christine.knefley@childrens.com