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

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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

Sad things happen. They do. But we don't need to live sad forever.

— Mattie Stepanek —
Case Study

- 45-year old male with metastatic Stage IV lung cancer, multiple cancer treatments have failed. He was recently discharged from the 3\textsuperscript{th} 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
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.

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

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