OBJECTIVES

1. Understand the implications of a cancer diagnosis on the child and family.
2. Identify common challenges faced by children with cancer and their siblings.
3. Identify ways in which nurses can support patients and families experiencing cancer.

ALTHOUGH THE WORLD IS FULL OF SUFFERING, IT IS FULL ALSO OF THE OVERCOMING OF IT.

Helen Keller
THE FAMILY'S JOURNEY

- While children and family tend to adapt and develop healthy coping mechanisms shortly after diagnosis, the cancer journey is often a bumpy ride.
- Finding new normal.
- Transitions stressful.
- No definitive end to the "traumatic" situation.
- Encourage family to maintain as many daily routines as possible.
- Maintain expectations of child.
- House rules should be minimally changed.
- Encourage independence and autonomy.
Psychosocial Functioning Risk Factors

Personal factors
- Age
- Cognitive and academic functioning
- Prior psychosocial functioning
- Personality/temperament
- Treatment intensity
- Visibility of disease or treatment effects
- Duration of disease/time since diagnosis
- Degree of CNS involvement

Family/Environmental factors
- Family resources
- Support system
- Family adaptability, communication and cohesiveness
- Individual members coping
- Concurrent stressors

PSYCHOSOCIAL IMPACT OF CANCER

Impact on the child
- Fear/worries
- Loss of control
- Losses (e.g., school, friends, activities)
- Concern regarding physical changes

Impact on parents
- Guilt
- Fear/worries
- Overprotection
- Financial stressors
- Decision making
- Isolation/loneliness
- Sadness/anger

Impact on siblings
- Jealousy
- Isolation/loneliness
- Stress/anger

STAGES OF THE CANCER JOURNEY

1. Diagnosis
2. Initiation of Treatment / On Treatment
3. End of Treatment
4. Survivorship
5. End of Life / Death
THE SCHOOL’S ROLE: DIAGNOSIS

• Parents and child learn of diagnosis
  • Natural Reactions to Diagnosis
    • Overwhelm / Shock
    • Anxiety
    • Emotional distress – Why me? Am I going to die?
    • Guilt/Blame
    • Difficulty coping to change/loss
  • A roadmap for treatment can help the family focus on what needs to be done.
  • Families also benefit from knowing their experience is “normal.”

• School learns of diagnosis
  • Reassure parents that school supports are available.
  • Don’t feel pressured to establish plan in that moment.
  • Notify teachers of child’s diagnosis.
  • Plan to regroup once parents have more detailed treatment plan.

STANDARDS OF CARE – SCHOOL REENTRY

• Psychosocial Standards of Care for Children with Cancer and Their Families published in December 2015 in PBC.
• 15 standards outlined
  • Academic Continuity and School Reentry Support as a Standard of Care in Pediatric Oncology (Thompson et al.)
• Recommendations:
  1. In collaboration with parents, school-aged youth diagnosed with cancer should receive school reentry support that focuses on providing information to school personnel about the patient’s diagnosis, treatment, and implications for the school environment and provides recommendations to support the child’s school experience.
  2. Pediatric oncology programs should identify a team member with the requisite knowledge and skills who will coordinate communication between the patient/family, school, and the health care team.

SCHOOL REENTRY

• Goals
  • Communication is key!
  • Keep the communication lines open with parents.
  • Communicate with the health care team – Lori Phillips, RN is Blank Children’s School Liaison.
  • School attendance is encouraged as soon as it is medically safe.
  • Quality of life important! (Maybe more important than academic!)”
  • Parents are not always on the same page as providers.
  • Balance academic challenge with comfort.
SCHOOL REENTRY

• Establish a plan
  • Outline a 504 Plan or Health Plan.
  • Establish appropriate accommodations.
  • In some cases, homebound will be appropriate.
• Risk factors to consider:
  • A child with previously identified academic or psychosocial concerns.
  • Diagnosis or treatment that impacts the CNS.
• School reentry visit with child life specialist.
  • Reduces anxiety about return to school while addressing peers’ questions.
• Kathy O’Connor covers the state of Iowa for many chronic illnesses.
  • Kathy.oconnor@unitypoint.org
• APHOES (www.aphoes.org)

COMMON SCHOOL ISSUES THAT ARISE

• School avoidance
• Somatic concerns
  • Fatigue
  • Pain
  • Nausea
• Peer difficulties
• Academic difficulties

SCHOOL INTERVENTIONS

• Contingency/Nursing Plan
  • Motivation for attending school, staying in the classroom
  • Personalized reinforcement
  • A scheduled routine (e.g., half days)
  • Appropriate supports (e.g., scheduled breaks)
• Peer support
  • School reentry visit
  • 1-to-1 or small group time
SCHOOL INTERVENTIONS - MINDFULNESS

Definition: A mental state achieved by focusing one’s awareness on the present moment, while calmly acknowledging and accepting one’s feelings, thoughts, and bodily sensations.

Benefits:
- Good for our minds (reduces depression, anxiety)
- Changes our brains
- Improve focus
- Foster compassion and altruism
- Improve relationships
- Helpful in schools
- Fights obesity

DON’T FORGET THE SIBLINGS!

- Normal Reactions
  - Loneliness / isolation
  - Jealous of patient’s attention
  - Acting out/negative-attention seeking
  - Responsibility for disease
  - Sadness & anger
  - Wish to be sick

- Assessment of their needs equally important!
  - Distress greater around time of diagnosis.
SURVIVORSHIP

- 5-year survival rate has increased dramatically over the past 30 years, from 58% in the mid-1970's to 83% in 2012.
- In 2006, it was estimated that there are 270,000 survivors of childhood cancer – equates to one in 640 young adults between 20 and 39 years old are a survivor.

SURVIVORSHIP

- Long-term consequences of disease treatment realized.
- Shifting viewpoint to chronic illness.
- Limited knowledge of medical history.

Natural Reactions:
- Concerns of relapse/secondary cancer.
- Difficulty identifying/connecting with peers.
- Future health concerns/choices.
- Risky behaviors.
THE PRICE OF SURVIVORSHIP

LATE EFFECTS DOMAINS
- Growth and development.
- Organ function.
- Reproductive capacity and health of offspring.
- Secondary carcinogenesis.
- Psychosocial sequelae.

LATE EFFECTS RISK FACTORS
- Tumor-related factors
  - Tumor biology
  - Direct toxic effects
  - Tumor-induced organ dysfunction
  - Mechanical effects
- Treatment-related factors
  - Radiation therapy (dose, volume)
  - Chemotherapy (agent, intensity)
  - Surgery
  - HSCT
- Host factors
  - Quality of treatment
  - Infection
  - Tobacco use
  - Premorbid conditions
  - SES
NEUROCOGNITIVE LATE EFFECTS

- One of most common late effects.
- Acute vs. long-term effects.
- Range of number & severity.
- Unpredictable.

RISK FACTORS FOR NEUROCOGNITIVE LATE EFFECTS

- CNS Directed Therapies
  - Cranial radiation therapy (CRT).
  - Systemic chemo with high dose methotrexate or cytarabine.
  - Intrathecal chemotherapy.
  - Higher CRT dose (dose-response).
  - TX with both CRT and chemotherapy.
- Brain tumors and Acute Lymphoblastic Leukemia (ALL)
- Female gender.
- Child's age (young children at greater risk).
- Tumor location.
- Lower SES.

MOST COMMON COGNITIVE LATE EFFECTS

- Decline in intellectual functioning.
- Memory problems (short-term).
- Attention/concentration difficulties.
- Slower processing speed.
- Visual-spatial/motor problems.
- Arithmetic & other learning problems.
- Problems in executive functioning.
PSYCHOSOCIAL IMPACT

- Most children and families are resilient to cancer diagnosis and treatment.
- Coping is a process.
- Wide variety of coping strategies.
- Studies have reported no differences from controls on the following measures:
  - Self-esteem.
  - Hopefulness.
  - Depression, anxiety, or loneliness.
- Small subset develop psychological difficulties.

COMMON PSYCHOSOCIAL LATE EFFECTS

- Posttraumatic stress symptoms (PTSS)
- Somatic Symptoms
- Low self-esteem
- Social problems
- Social anxiety
  - Poor peer acceptance
  - Lower rates of marriage (but lower divorce rates)

PSYCHOSOCIAL OUTCOMES OF AYA

- In a survey of 4,054 AYA cancer survivors compared to 345,592 healthy respondents, AYA cancer survivors were more likely to:
  - Smoke (26% vs. 18%)
  - Be obese (31% vs. 27%)
  - Have cardiovascular disease (14% vs. 7%)
  - Have hypertension (35% vs. 9%)
  - Have asthma (15% vs. 8%)
  - Have a disability (36% vs. 18%)
  - Have poor mental health (20% vs. 10%)
  - Not seek medical care due to cost (24% vs. 15%)
POSTTRAUMATIC GROWTH

- Benefit finding has been identified for survivors and parents.
- Develop a positive view of the impact of cancer on their lives.
- Reflect a positive change in the sense of self, relationships and/or future.

END OF LIFE ISSUES

END OF LIFE IN SCHOOLS

- ALL students impacted
  - Dying child
  - Siblings
  - Peers
  - School personnel impact
CHILDREN AND DEATH

- Ability to understand irreversibility and finality of death occurs between ages 5-7.
- Follow child’s lead in determining amount of information to share.
- Provide honest, developmentally appropriate answers.
- Common worries:
  - Will they be left alone or forgotten?
  - Will they be in pain?
  - Afterlife?

WHEN A CHILD HAS DIED

- Beneficial to have a faculty meeting with liaison from the healthcare team (with parental permission).
- Primary objective is to facilitate an honest understanding of the events that occurred around the child’s death.
- Liaison explores ways in which this information can be disseminated to peers.
- Can also support staff members experiencing grief.
- Telling the students.
  - Consider students age and cognitive development.
  - Include school guidance counselor, social worker to help support students.
  - Children may have a variety of responses, and the grief course is not a linear process.
  - Academic performance may be impacted.
- Consideration of a memorial
  - A ritual event or monument to honor to student
  - A place for children to express their feelings. Also benefit from permission that it’s okay to “move on.”
  - Ensure that it is in line with the family’s wishes.

END OF LIFE RESOURCES

- Child Life
  - Memory making and school visits
- Hamilton’s Funeral and After Life Services
  - Crisis response
  - Grief groups in schools
- Printable resources
- Counseling services
  - School counseling
  - Community psychologists/mental health professionals
THANK YOU!

CONTACT INFORMATION

Heather Christiansen, PsyD
Wendy Wood-Swafford, MD, MPH
Samantha Mallory, MD
Christopher Rokes, MD
Nick Fusilino, MD

BLANK CHILDREN’S HOSPITAL
CANCER AND BLOOD DISORDERS CENTER
1215 Pleasant St., Suite 514
Des Moines, IA 50309
Phone: 515-241-8912
Fax: 515-241-8988
Heather.christiansen@unitypoint.org