Pediatric Oncology Survivorship: Beyond the Physical Effects

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Disclosures

- None
Objectives

- Understand the current growing population of pediatric oncology survivors
- Understand the common long-term effects for all pediatric oncology patients, regardless of their treatment plan or course
- Understand potential risk factors for common long-term medical side effects
- Understand resources available for patients with medical long-term effects and when referral should be considered

Pediatric Oncology

- 2019: estimated 11,060 new cases for patients age 0-14
  - Overall survival 85-90%
- Incidence rates have increased
  - 6%/year
- Remains the #1 cause of death from disease
  - 57% of all children up to 19 years of age
Trends in Cancer Incidence* and Death Rates in Children and Adolescents (0-19 Years), 1975-2016

Cancer Incidence Rates* Among Children (0-14 years) and Adolescents (15-19 years), 2011-2015

*Rates are age-adjusted to the 2000 U.S. standard population.
†Includes benign brain and CNS tumors.
‡Includes other peripheral nervous system tumors.

Pediatric Oncology Survival

5-Year Survival Rate, Age 0-19

Source: Surveillance, Epidemiology, and End Results (SEER) Program (seer.cancer.gov)
SEER 9 area. Based on follow-up of patients into 2012.

5-year Relative Survival Rates (%) in Children and Adolescents by Age, 2008-2014

All sites*: 0-14 years 15-19 years
0-14 years 83 85
15-19 years

Leukemia 0-14 years 15-19 years
0-14 years 72 87
15-19 years

Brain/ONS*: 0-14 years 15-19 years
0-14 years 73 78
15-19 years

Child and other nervous system. Based on follow-up of patients through 2015.
*Excludes nerve sheath tumors.
Source: Surveillance, Epidemiology, and End Results (SEER) Program, National Cancer Institute; 2018.
Pediatric Oncology Survival

- Significant increase in pediatric and adult survivors
- Estimated 429,000 adult survivors (2015)
  - 1/530 age 20-39
- 60% children **will** have late medical effects
- 25% will have a **severe** late medical effect
- Children’s Oncology Group Guidelines
  - 20+ members make up panel of experts with hundreds comprising the task force

Late Effects: All Oncology Diagnoses

- Adverse psychosocial/quality of life effects
- Mental health disorders
- Risky behaviors
- Psychosocial disability due to pain
- Fatigue, sleep problems
- Limitations in health care and insurance access
Adverse Psychosocial/Quality of Life Effects

❖ Social withdrawal
❖ Educational problems
❖ Relationship problems
❖ Underemployment/unemployment
❖ Dependent living

Risk Factors

<table>
<thead>
<tr>
<th>Patient</th>
<th>Cancer/treatment</th>
<th>Premorbid/comorbid medical conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female sex</td>
<td>Bone tumor</td>
<td>Neurocognitive problems</td>
</tr>
<tr>
<td>Young age at diagnosis</td>
<td>CNS tumor</td>
<td>Depression</td>
</tr>
<tr>
<td>Family history of depression, anxiety, or mental illness</td>
<td>CNS-directed therapy</td>
<td>Physical limitations</td>
</tr>
<tr>
<td>Lower household income</td>
<td></td>
<td>Seizures</td>
</tr>
<tr>
<td>Lower educational achievement</td>
<td></td>
<td>Scarring or disfigurement</td>
</tr>
<tr>
<td>Failure to graduate high school</td>
<td></td>
<td>Vision loss</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hearing loss</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Premorbid learning or emotional difficulties</td>
</tr>
</tbody>
</table>
**Signs and Symptoms**

- Disengagement from activities previously interested in
- Poor motivation
- Decline in school performance
  - Poor attention
  - Difficulty with organization ("executive function")
  - Poor memory
  - Worsening grades
- Disinterest in pursuit on “next steps”
  - Relationships
  - Employment
  - Dependent living

**Prevention and Intervention**

- Ensure good psychosocial assessment by pediatrician or survivorship oncologist
- Referral to psychology
- School liaison or counselor at school
  - Education and vocational resources
- Neuropsychological evaluation (potential 504/IEP needs)
  - School
  - Psychologist
- Involvement in local cancer support systems
  - Adolescent and young adult groups
- Online resources
  - Ex: Americans With Disabilities Act
  - Cancer and Careers
# Mental Health Disorders

- Depression
- Anxiety
- Posttraumatic stress
- Suicidal ideation

## Risk Factors

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</table>
| • Female sex  
  • Family history of depression, anxiety or mental illness  
  • Not in a relationship  
  • Poor social support  
  • Perceived poor physical health | • Lower household income  
  • Lower educational achievement  
  • Failure to graduate high school  
  • Unemployment  
  • No health insurance | • CNS tumor  
  • History of hematopoietic cell transplant |
| • Lower household income  
  • Lower educational achievement  
  • Failure to graduate high school  
  • Unemployment  
  • No health insurance | • CNS-directed therapy  
  • History of hematopoietic cell transplant | • Chronic pain  
  • Permanent hair loss |
| • CNS-directed therapy  
  • History of hematopoietic cell transplant | • Scarring or disfigurement  
  • Premorbid learning or emotional difficulties | • Scarring or disfigurement  
  • Premorbid learning or emotional difficulties |
Signs and Symptoms

- Increased emotional lability
  - Tearful
  - Angry
  - Short-tempered
- Disinterest in previously enjoyed activities
- Social isolation
- Nausea
- Heart palpitations
- Poor sleep (more or less)/fatigue
- Increased or decreased appetite
- Change in weight
- Nightmares of previous cancer experience

Prevention and Intervention

- Ensure good psychosocial assessment by pediatrician or survivorship oncologist
- Referral to psychology/psychiatry
  - Psychiatrist necessary if psychotropic medications required
- School liaison or counselor at school
- Evaluate parent for posttraumatic stress
- Involvement in local cancer support systems
  - Adolescent and young adult groups
Risky Behaviors

▪ “Behaviors known to increase the likelihood of subsequent illness or injury”

EXAMPLES
❖ Smoking
❖ Alcohol
❖ Drug use
❖ Driving without a seatbelt or recklessly

Risk Factors

| Patient | • Adolescent/young adult (at diagnosis or follow-up)  
|        | • Male sex  
|        | • Lower household income  
|        | • Lower educational achievement  
|        | • Psychological distress  

| Cancer/treatment | • None  

| Premorbid/comorbid medical conditions | • None  

Signs and Symptoms

- Increased signs of anxiety or depression (outlined previously)
- Withdrawal from previous activities
- Increased car accidents
- Declining school attendance

Prevention and Intervention

- Ensure good psychosocial assessment by pediatrician or survivorship oncologist
- Appropriate anticipatory guidance about increased risk
- School liaison or counselor at school
- Refer to resources for smoking cessation and/or drug and alcohol use
  - Smokefree.gov
  - Alcoholics Anonymous
Fatigue/Sleep Problems

- Generalized fatigue
- Easily fatigued
- Increased sleep
- Decreased sleep
- Disturbed sleep

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</thead>
<tbody>
<tr>
<td>Patient</td>
<td>None</td>
<td></td>
<td></td>
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<tr>
<td>Cancer/treatment</td>
<td>CNS tumor</td>
<td>Pulmonary radiation</td>
<td></td>
</tr>
<tr>
<td>Premorbid/comorbid medical conditions</td>
<td>Depression</td>
<td>Obesity</td>
<td>History of sleep disturbance</td>
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Signs and Symptoms

- Inability to participate in previous activities
- Falling asleep during the day
- Difficulty falling asleep
- Difficulty falling back asleep
- Increased number of awakening during sleep

Prevention and Intervention

- Ensure no other underlying physical source of fatigue
  - Anemia
  - Endocrinopathies (ex: thyroid)
  - Nutritional deficiencies
  - Cardiac disease
  - Pulmonary disease
- Referral to specialists if medical effect is contributing
- Referral to psychology or counselor if mental health is contributing
- Good sleep hygiene (no screen, consistent time)
Psychosocial Disability Due to Pain

❖ Common complaint DURING treatment
❖ Acute and/or chronic pain
❖ Multifactorial

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<tr>
<td>Cancer/treatment</td>
<td>CNS tumor</td>
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<tr>
<td></td>
<td>Hodgkin lymphoma</td>
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<td>Vincristine exposure</td>
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<td>Amputation</td>
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<td></td>
<td>Limb-sparing surgery</td>
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<td></td>
<td>Radiation to bone/joint</td>
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<tr>
<td>Premorbid/comorbid medical conditions</td>
<td>History of osteonecrosis</td>
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</table>
Signs and Symptoms

- Pain symptoms are limiting patients’ ability to participate in their typical activities

Prevention and Intervention

- Ensure good psychosocial assessment, including impact of physical symptoms on emotional outcome, by pediatrician or survivorship oncologist
- Psychological consultation if chronic pain is present
- Psychiatry consultation if psychotropic medications needed
- Pain rehabilitation clinic
  - Focus on tackling pain symptoms from all aspects (physical, mental, and emotional)
Limitations in Health Care and Insurance Access

- Finding a physician that is comfortable managing a more complicated young patient
- Ongoing copays
- Multiple visits/tests
  - With escalating costs when patients’ income is little to small
- Transition of insurance at certain age/life point
  - Already established condition → potential increased cost

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</thead>
<tbody>
<tr>
<td>• Unemployment</td>
<td>• Testicular cancer</td>
<td>• None</td>
</tr>
<tr>
<td>• Lower household income</td>
<td>• Higher cumulative alkylators (ex: cyclophosphamide, ifosfamide)</td>
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</tr>
<tr>
<td>• Lower educational achievement</td>
<td>• Combinations of alkylators</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Treatment with MOPP</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Cyclophosphamide for conditioning for transplant with radiation to abdomen/pelvis, tests, brain</td>
<td></td>
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<tr>
<td></td>
<td>• Unilateral orchiectomy</td>
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</table>
Prevention and Intervention

▪ Early discussion by Survivorship Oncologist
▪ Active involvement by patient in their care EARLY on
▪ Online resources
  – Centers for Medicare and Medicaid Services (CMS)
  – Patient Advocate Foundation
  – Healthcare.gov
  – Cancer Legal Resource Center

What Can We Do?

▪ Discussions need to be ongoing
  – At diagnosis
  – During treatment
  – Long-term follow-up
  – Transition
What Can We Do?

- Resources
  - Use ALL of your team
  - Online resources are plentiful
  - Local resources, as well as local chapters of national groups
    - Ex: Leukemia & Lymphoma Society
  - Examples
    - *Childhood Cancer Survivors* by Nancy Keene, Wendy Hobbie, and Kathy Ruccione
    - *Educating the Child with Cancer* by Nancy Keene (ed.)
    - www.cancer.gov; Facing Forward: Life After Cancer
    - Many examples in the COG Survivorship Guidelines

References

1. Children’s Oncology Group: Long-Term Follow-up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancer. Version 5.0. October 2019
3. SEER Data
Thank You!
QUESTIONS

LLS EDUCATION & SUPPORT RESOURCES

• Information Specialists
  – EMAIL: infocenter@LLS.org
  – TOLL-FREE PHONE: 1-800-955-4572

• Free Nutrition Consults: www.LLS.org/nutrition

• Caregiver Support: www.LLS.org/caregiver

• Free Education Booklets: www.LLS.org/booklets

• Free Telephone/Web Programs: www.LLS.org/programs

• Live, weekly Online Chats: www.LLS.org/chat

• LLS Community: www.LLS.org/community

BEATING CANCER IS IN OUR BLOOD.
• **LLS Podcast, The Bloodline with LLS**
  Listen in as experts and patients guide listeners in understanding diagnosis, treatment, and resources available to blood cancer patients: [www.thebloodline.org](http://www.thebloodline.org)

• **Education Videos**
  Free education videos about survivorship, treatment, disease updates and other topics: [www.LLS.org/educationvideos](http://www.LLS.org/educationvideos)

• **Patti Robinson Kaufmann First Connection Program**
  Peer-to-peer program that matches newly diagnosed patients and their families: [www.LLS.org/firstconnection](http://www.LLS.org/firstconnection)

• **What to Ask**
  Questions to ask the treatment team: [www.LLS.org/whattoask](http://www.LLS.org/whattoask)

• **Other Support Resources**
  LLS Community, discussion boards, blogs, support groups, financial assistance and more: [www.LLS.org/support](http://www.LLS.org/support)

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**THANK YOU**

We have one goal: A world without blood cancers