

Pediatric Oncology Survivorship: Beyond the Physical Effects

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1

Disclosures

- None

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2

2

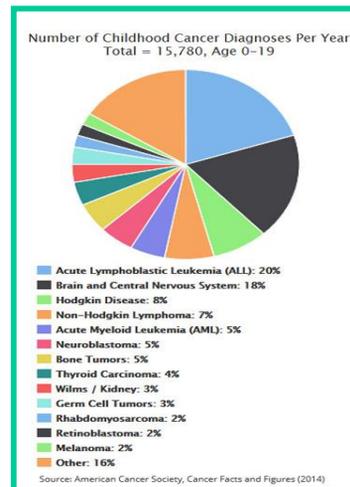
Objectives

- 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

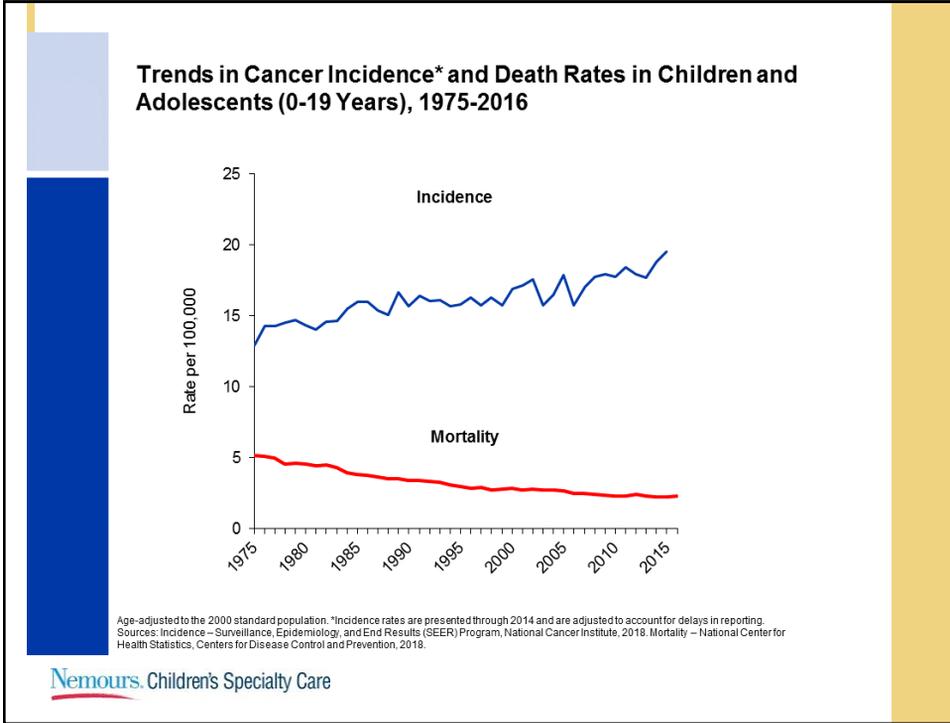
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Pediatric Oncology

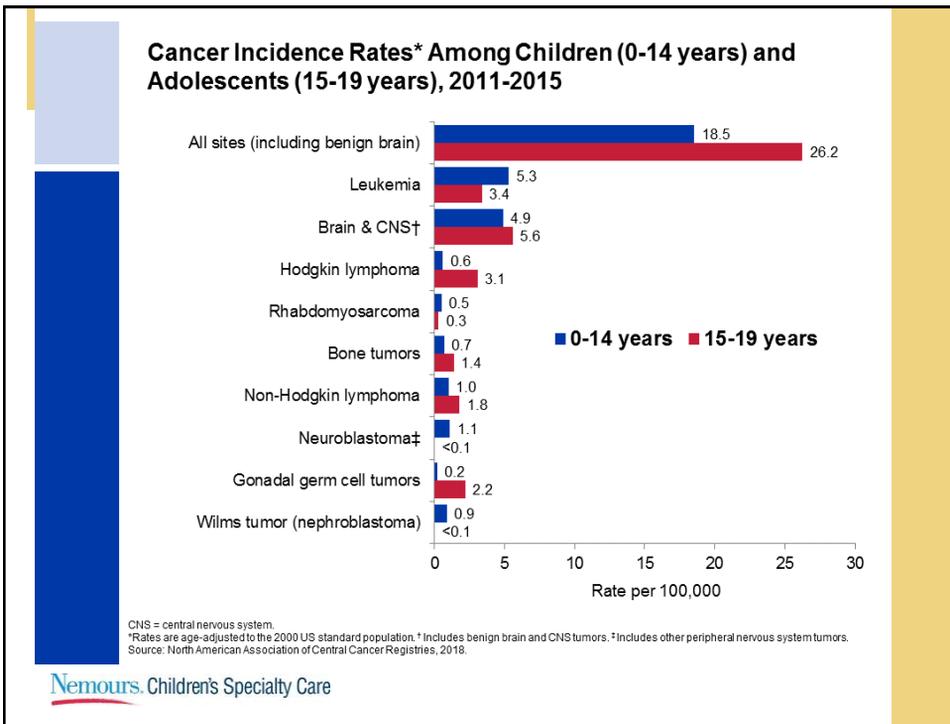
- 2019: estimated 11,060 new cases for patients age 0-14
 - Overall survival 85-90%
- Incidence rates have increased
 - 6%/year
- Remains the #1 cause of death from disease
 - 57% of all children up to 19 years of age



4



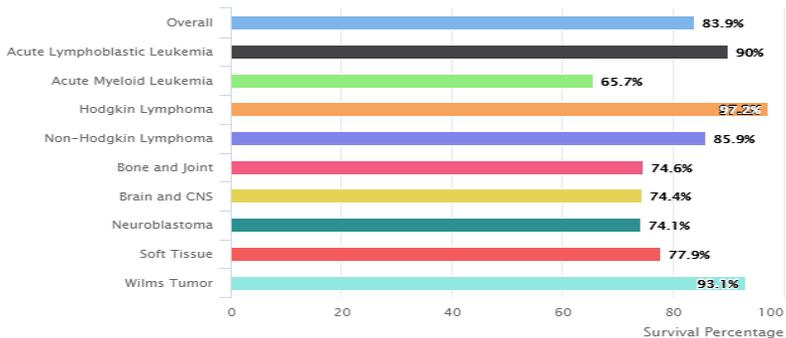
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6

Pediatric Oncology Survival

5-Year Survival Rate, Age 0-19



Source: Surveillance, Epidemiology, and End Results (SEER) Program (seer.cancer.gov)

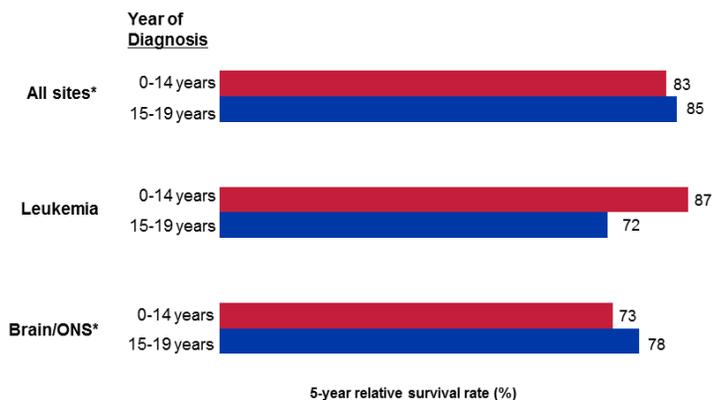
SEER 9 area. Based on follow-up of patients into 2012

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7

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



ONS=other nervous system. Based on follow up of patients through 2015.

*Excludes benign brain tumors.

Source: Surveillance, Epidemiology, and End Results (SEER) Program, National Cancer Institute, 2018.

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8

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

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9

9

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

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10

10

Adverse Psychosocial/Quality of Life Effects

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

11

Risk Factors

Patient	<ul style="list-style-type: none"> • Female sex • Young age at diagnosis • Family history of depression, anxiety, or mental illness 	<ul style="list-style-type: none"> • Lower household income • Lower educational achievement • Failure to graduate high school
Cancer/treatment	<ul style="list-style-type: none"> • Bone tumor • CNS tumor 	<ul style="list-style-type: none"> • CNS-directed therapy • History of hematopoietic cell transplant
Premorbid/comorbid medical conditions	<ul style="list-style-type: none"> • Neurocognitive problems • Depression • Physical limitations • Seizures 	<ul style="list-style-type: none"> • Scarring or disfigurement • Vision loss • Hearing loss • Premorbid learning or emotional difficulties

12

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

13

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

14

Mental Health Disorders

- ❖ Depression
- ❖ Anxiety
- ❖ Posttraumatic stress
- ❖ Suicidal ideation

15

Risk Factors

Patient	<ul style="list-style-type: none"> • Female sex • Family history of depression, anxiety or mental illness • Not in a relationship • Poor social support • Perceived poor physical health 	<ul style="list-style-type: none"> • Lower household income • Lower educational achievement • Failure to graduate high school • Unemployment • No health insurance
Cancer/treatment	<ul style="list-style-type: none"> • CNS tumor 	<ul style="list-style-type: none"> • CNS-directed therapy • History of hematopoietic cell transplant
Premorbid/comorbid medical conditions	<ul style="list-style-type: none"> • Chronic pain • Permanent hair loss 	<ul style="list-style-type: none"> • Scarring or disfigurement • Premorbid learning or emotional difficulties

16

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

17

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

18

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	<ul style="list-style-type: none"> • Adolescent/young adult (at diagnosis or follow-up) • Male sex 	<ul style="list-style-type: none"> • Lower household income • Lower educational achievement • Psychological distress
Cancer/treatment	<ul style="list-style-type: none"> • None 	
Premorbid/comorbid medical conditions	<ul style="list-style-type: none"> • None 	

Signs and Symptoms

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

21

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

22

Fatigue/Sleep Problems

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

23

Risk Factors

Patient	• None	
Cancer/treatment	• CNS tumor	• Pulmonary radiation
Premorbid/comorbid medical conditions	• Depression • Obesity	• History of sleep disturbance

24

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

25

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)

26

Psychosocial Disability Due to Pain

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

27

Risk Factors

Patient	• Female sex	
Cancer/treatment	<ul style="list-style-type: none"> • CNS tumor • Hodgkin lymphoma • Vincristine exposure 	<ul style="list-style-type: none"> • Amputation • Limb-sparing surgery • Radiation to bone/joint
Premorbid/comorbid medical conditions	• History of osteonecrosis	

28

Signs and Symptoms

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

29

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)

30

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

31

Risk Factors

Patient	<ul style="list-style-type: none"> • Unemployment 	<ul style="list-style-type: none"> • Lower household income • Lower educational achievement
Cancer/treatment	<ul style="list-style-type: none"> • Testicular cancer • Higher cumulative alkylators (ex: cyclophosphamide, ifosfamide) • Combinations of alkylators 	<ul style="list-style-type: none"> • Treatment with MOPP • Cyclophosphamide for conditioning for transplant with radiation to abdomen/pelvis, tests, brain • Unilateral orchiectomy
Premorbid/comorbid medical conditions	<ul style="list-style-type: none"> • None 	

32

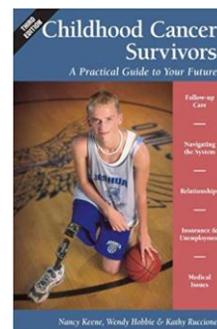
Prevention and Intervention

- 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

33

What Can We Do?

- Discussions need to be ongoing
 - At diagnosis
 - During treatment
 - Long-term follow-up
 - Transition



34

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

35

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
2. American Cancer Society. Cancer.org
3. SEER Data

36

Thank You! QUESTIONS



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37

37

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.

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LYMPHOMA
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38

 **LLS EDUCATION & SUPPORT RESOURCES**




- **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
- **Education Videos**
Free education videos about survivorship, treatment, disease updates and other topics: 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
- **What to Ask**
Questions to ask the treatment team: www.LLS.org/whattoask
- **Other Support Resources**
LLS Community, discussion boards, blogs, support groups, financial assistance and more: www.LLS.org/support

39



THANK YOU

We have one goal: A world without blood cancers



40