Ethical Dilemma's in Caring for the Pediatric Oncology Patient

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Objectives

- Pediatric cancer overview
- Recognize the appropriate application of DNR and DNI in Pediatric Oncology
- Recognize the ethical dilemma associated with end of life issues in Pediatric Oncology
- Understand the concept of Consent and Assent in Pediatric Oncology
- Understand the role of the Courts in the management of ethical dilemmas that arise in Pediatric Oncology patients
- Understand the complications of childhood cancer therapy
- Understand the role of the primary care provider in the management of childhood cancer survivors

Overview of Pediatric Oncology

- Every day, 43 children are diagnosed with cancer
  - Approximately 15,600 children/year
- Childhood cancer affects all ethnic, gender and socio-economic groups
- The average age of children diagnosed is six years
- More than 40,000 children undergo treatment for cancer each year

Overview of Pediatric Oncology

- Etiology is largely unknown
- Associated conditions
  - Cancer predisposition syndrome: Li Fraumeni
  - Chromosomal abnormalities: Down’s syndrome
  - Genetic syndromes : NF1
  - Immunodeficiencies: CVID, AIDS
  - Ionizing radiation exposures
  - Environmental carcinogens
  - Bone marrow failure syndromes

Most Common Pediatric Cancers

Age 0 -14

- Leukemia 30%
- CNS 21%
- Lymphoma 9%
- Neuroblastoma 7%
- Rhabdo/STS 7%
- Wilms 5%
- Osteo/Ewing 4%
- Germ cell 3.5%
- Retinoblastoma 3%
- Hepatoblastoma 1%

Age 15-19

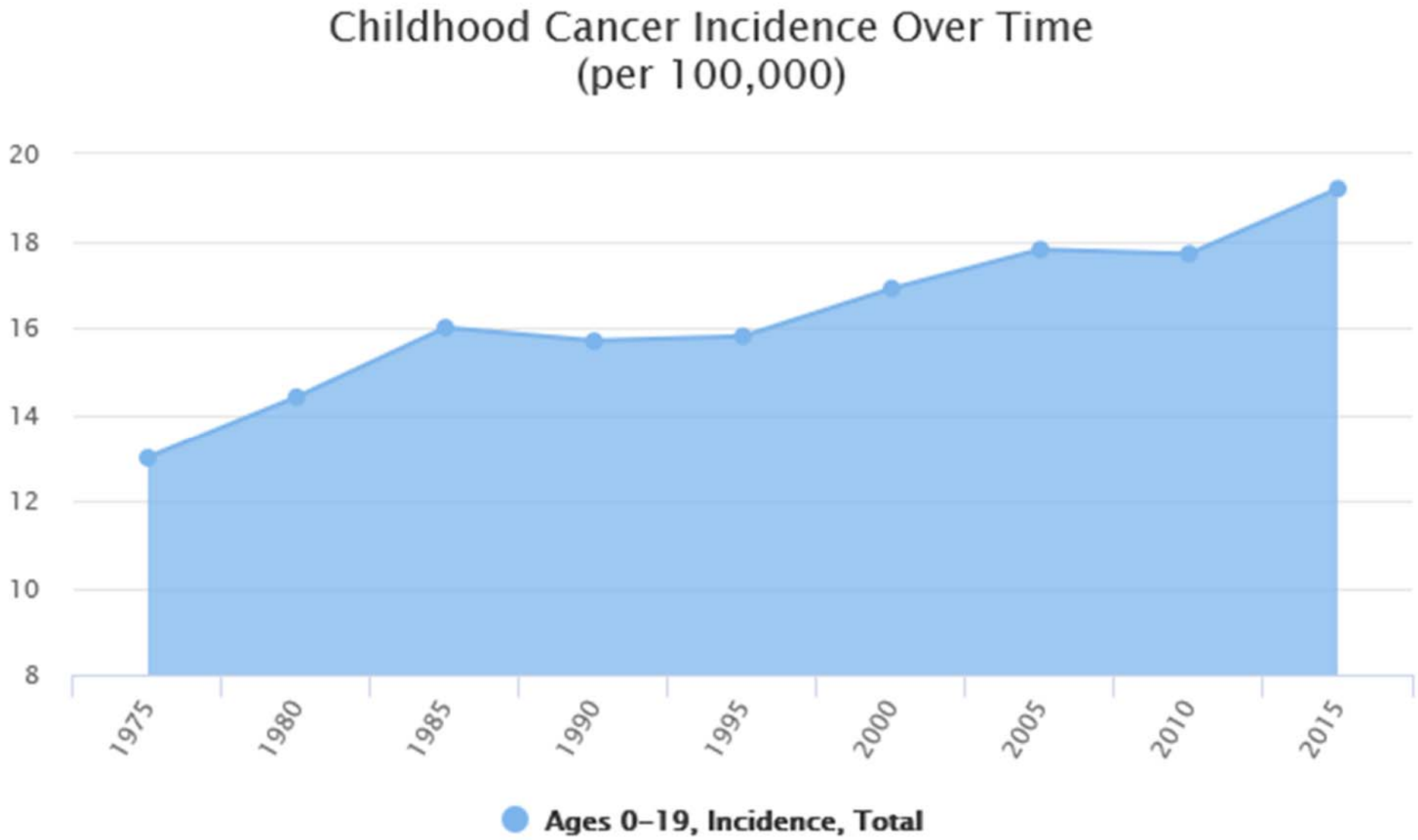
- Lymphoma 24%
- Germ cell 14%
- Leukemia 12%
- CNS 10%
- Rhabdo/STS 9%
- Thyroid 9%
- Melanoma 7%
- Osteo/Ewing 6%

Outcomes

- Nearly 85% of children diagnosed with cancer will survive for 5 years
  - 75% by 10 years
- From an overall survival rate of 10% just fifty years ago
  - Through cooperative groups : COG
  - Treatment protocols that are uniform
- 380,000 childhood cancer survivors in the US population
  - 1 in 530 adults ages 20-39
  - Projected increase to 0.5 million childhood survivors by 2020
- 60% of children who survive cancer suffer late-effects, such as infertility, heart failure and secondary cancers

Cancer Incidence Over Time

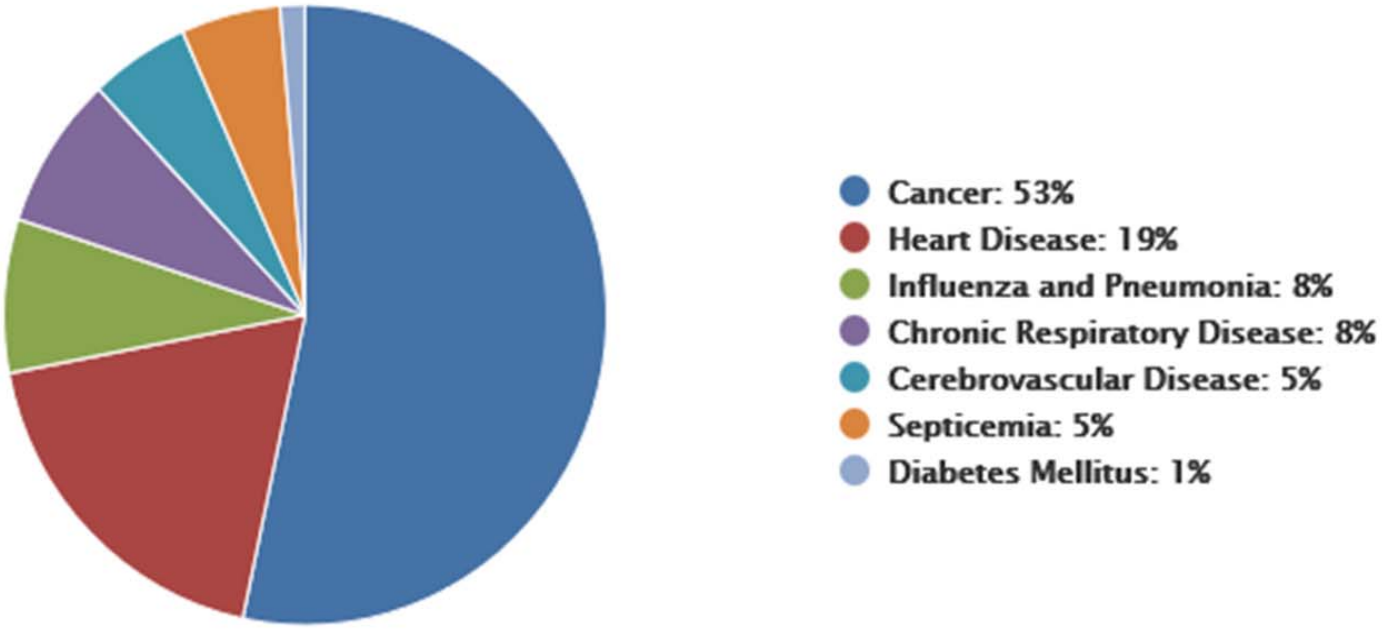
- Even as the cure rate continues to improve:
  - Incidence of childhood cancer has been steadily increasing over the last few decades
  - About 13 children per 100,000 in 1975 to about 19 children per 100,000 in 2015


Childhood Cancer Incidence Over Time
(per 100,000)
20
18
16
14
12
10
8
1975
1980
1985
1990
1995
2000
2005
2010
2015
Ages 0–19, Incidence, Total

Childhood Cancer Mortality

- Childhood cancer remains the leading cause of death by disease among children in the United States
- More than 12% of children diagnosed with cancer do not survive

Number of Childhood Deaths by Disease Per Year
Ages 1–19
Total = 4,446



CASE PRESENTATIONS

Case Study #1: A 17-year-old female has been diagnosed with widely metastatic Ewing sarcoma. The family and patient want every therapy available. The 5-year overall survival for widely metastatic Ewing sarcoma is 22%. The patient is admitted to the hospital where the primary admitting team wants to discuss with her and her family the option for a DNI/DNR. Conversely, the [oncology] consulting team believes the DNI/DNR discussion is too premature given that the patient's organ function is normal and she is not at imminent risk of death at this time.

Case Study #2: A 12-year-old boy is diagnosed with Li-Fraumeni syndrome and AML. He has a medical history of neuroblastoma successfully treated at 4 years of age. Due to genetic mutation in his AML, it could not be cured with chemotherapy alone so she had to go to transplant. Transplant course was rocky and 2 months after transplant she relapsed again. She was still extremely pancytopenic with no evidence of bone marrow recovery and treatment team in both hospitals were of the opinion that there was nothing more that could be done for her. Mom wants her to try experimental phase 1 therapy whereas patient has no interest on further therapy and wants to die peacefully.

Case Study #3: 11-year-old male with newly diagnosed leukemia. His uncle recently died from lung cancer. Parents want to proceed with treatment for patient, but do not want the patient to be informed about his diagnosis or treatments. Parents have requested that all discussions about the diagnosis and consents for treatment be done outside the presence of the patient.

Case Study #4: A 3-year-old patient whose parents are Jehovah's Witnesses has a new diagnosis of leukemia and a hemoglobin of 3.8. Parents adamantly refused to transfuse him even after they were told that he would die without a transfusion. Several doctors, including patient's primary care provider, met with the parents to let them know that this is a treatable disease if the patient receives a blood transfusion immediately. Parents still refused.

Case Study #5: A 17-year-old female with metastatic Ewings Sarcoma and severe bone pain. Patient is receiving Dinatuximab. She has failed all pain medications by primary Oncologist including Narcotics. She has intractable pain and wants to stop therapy even though she knows that she will die without therapy, as she has communicated that her pain is worse that death.

Role of the Primary Care Provider in the Management of Childhood Cancer Survivors

Cancer for children is a lifelong diagnosis.

First they have to survive cancer treatments, then they have to survive a lifetime of late-effects these treatments gave them.

Cures come with a cost.

Children's Cancer Research Fund®

ChildrensCancer.org

Complications of Cancer Therapy

- Endocrine
  - Reproductive Issues
  - Growth Hormone (GH) Deficiency
  - Hyperprolactinemia
  - Hypopituitarism
  - Central Adrenal Insufficiency
  - Early Puberty
  - Hypothyroidism

Complications of Cancer Therapy

- Organ damage
  - Heart Problems
  - Kidney Health
  - Lung (Pulmonary) Health
  - Liver Health
  - Spleen
  - Bladder Health
  - Bone health
  - Nerve damage
  - Eyes and Ear damage

Complications of Cancer Therapy

- Secondary Cancer
  - Breast Cancer
  - Leukemia
  - Glioblastoma Multiforme
  - Meningioma
  - Sarcoma

Complications of Cancer Therapy

- Psychosocial
  - Diet and Physical Activity
  - Educational Issues
  - Emotional Health
  - Finding Healthcare
  - Bankruptcy
  - Divorce

Follow Up After Therapy

- The Childhood Cancer Survivor Study of 10,397 survivors found that
  - 62.3% had at least one chronic medical condition
  - 25.7% had a severe or life-threatening condition

Follow Up After Therapy

- Post therapy patients are followed closely by the oncologist
  - Follow up is gradually spaced out as the patient continues to do well
- By the time the patient is off therapy for 5 year they are considered long term survivors
  - 2 years in some institutions with a survivorship program
- Long-term survivors need follow-up visits once a year for life
  - This may vary considerably depending on individual circumstances
- Follow up of long term survivors can be done by:
  - Dedicated survivorship program
  - Oncologist
  - **Primary care provider**

Primary Care Provider Perspectives

- PCPs are concerned about their own readiness to assume responsibility for follow-up care of survivors of childhood cancer
- PCPs reported inadequate access to treatment histories (36%)
- PCPs comfortable conducting follow-up surveillance for cancer recurrence (52%)
  - Same number described themselves as unprepared to evaluate or manage late effects
- Majority
  - Expressed enthusiasm for survivor-care plans or similar products;
  - Welcomed practice guidelines in print or online
  - Wanted descriptions of survivors' diagnoses and treatment summaries
  - Desired individualized recommendations for late-effect management of cancer survivors

Caring for Cancer Survivors
A Survey of Primary Care Physicians*
Sharon L. Bober, PhD1 ; Christopher J. Recklitis et al

Primary Care Provider Perspectives

- With regard to the care of survivors of childhood cancer
  - 72% of general internists reported never receiving a treatment summary
    - Although over half reported caring for at least one cancer survivor
- Internists reported feeling ‘somewhat uncomfortable’ in caring for survivors of HOD, ALL, and osteosarcoma
- ‘Somewhat unfamiliar’ with the available surveillance guidelines
  - in a case vignette, most did not recommend appropriate surveillance for late adverse events or cancer recurrence.
- The most-useful resources in caring for childhood cancer survivors
  - Treatment summaries
  - Access to surveillance guidelines

General Internists’ Preferences and Knowledge About the Care of Adult Survivors of Childhood Cancer
A Cross-sectional Survey
Eugene Suh, MD, Christopher K. Daugherty

Follow Up After Therapy

- The Institute of Medicine and National Research Council recommend that a patient completing primary treatment for cancer be
  - Given a summary of treatment
  - Comprehensive plan for follow-up
- In addition, it is suggested that this survivorship care plan be provided to the patient's primary care provider.
- Such a plan would inform the patient (and health care provider) of
  - the long-term effects of cancer and its treatment,
  - identify psychosocial support resources in the community,
  - provide guidance on follow-up care,
  - prevention, and health maintenance

SUMMARY OF CANCER TREATMENT
Date of preparation: February 2011

Name: John Doe		Date of Birth: 1/1/86	
Cancer Diagnosis: Acute Myelocytic Leukemia (AML)			
Treatment centers: Children's Cancer Hospital, University of California Irvine Medical Center, Children's Hospital of Orange County Date of diagnosis: 1/1/2005; age at diagnosis; 19 years old Relapse: 7/1/2005 CNS disease, 5/7/2006 bone marrow Date of completion of therapy: 7/19/2006			
Radiation Therapy			
Date start	Date Stop	Field	Dose (cGy)
7/11/2006	7/18/2006	Total body irradiation (TBI)	1,200
		Whole brain, retro-orbital and brainstem	600
Chemotherapy			
Drug Name		Dose (units or mg/m²)	
Cytarabine (IT/IV)			
L-asparaginase			
Mitoxantrone		48 mg/m2 (equivalent to 192 mg/m² doxorubicin)	
Etoposide			
Daunorubicin		300 mg/m2 (equivalent to 250 mg/m² doxorubicin)	
Fludarabine			
Idarubicin		48 gm/m2 (equivalent to 240 mg/m² doxorubicin)	
Methotrexate (IT)			
DepoCyt (IT)			
Cumulative anthracycline dose		682 gm/m²	
Immunotherapy			
Gemtuzumab (AAML03P1)			
Alemtuzumab (BMT preconditioning)			
Rituximab (GVHD treatment)			
Allogenic, unrelated, 10/10 matched on 7/19/2006			
Preconditioning: Campath, Cyclophosphamide (120 mg/kg) and 1,200 cGy TBI. Chronic GVHD of skin and GI tract: treated with Rituximab, Prednisone and Cyclosporine.			
Potential Late Effects		**Screening Recommendations****	
• Cardiovascular problems • Lung problems • Osteoporosis • Thyroid problems • Fertility problems • Bladder problems • Dental problems • Cataracts • Psychosocial problems including anxiety and depression • Second cancers (rare)		• Annual labs to include: CBC, comp profile, TSH, urinalysis, lipid profile, insulin, CRP, 25-OH vitamin D level, testosterone • Echocardiogram/EKG every year • Pulmonary function test every 1-2 years • Bone density study every 2 years • Dental exam yearly, cleaning every 6 months • Eye exam every year • Counseling and treatment as indicated • Dermatology exam every year	

Figure 1. Example of the summary of cancer treatment and follow-up care plan. BMT, bone marrow transplantation; CBC, complete blood

Limitations of Treatment Summary

- Same for all patients with the same disease
  - Not Individualized
- Follow up guidelines continually change
  - Not always updated
- Does not have screening questions

Passport For Care (PFC)

- The hypothesis behind the development of the PFC is that
- Access to guidelines that are customized to a patient's medical history will enhance:
  - Physician behavior in the care of long-term survivors
  - The quality of the care provided
  - Health outcomes of these patients
- Premise that use of the PFC:
  - Alters health care provider behavior to increase compliance with COG guidelines
  - Improve survivor knowledge of and adherence to self- and provider screening recommendations
  - Healthy behavior

Passport For Care

- The PFC is a web-based clinical-support tool for clinical care providers and the survivors of childhood and young-adult cancer
  - Based on the survivor's clinical characteristics and
  - Treatment history
- PFC is based on the COG guidelines on late effects to generate individualized recommendations for
  - Follow-up screening
  - Select educational materials relevant to the specific survivor

Passport For Care (PFC)

- The healthcare provider is provided with all of the information necessary to evaluate the survivor
  - Including the appropriate questions to ask when taking the history,
  - Specific findings to search for in physical examination
  - Appropriate laboratory and diagnostic tests to order.
- These outputs are individualized for each survivor on the basis of his or her unique treatment history
- It also gives the provider a Treatment Summary

Survivor Healthcare Passport

Recommended Follow-Up

UCSF Survivors of Childhood Cancer Program

SWIM ACROSS AMERICA

Physician: Oncologist, MD **Phone:** (415) 123-4567 **Updated:** 09/2012

History, Physical Exam, and Psychosocial Assessment Yearly; Dental Exam Every 6 Months

Specific Therapy-Related Risks

System	Exam	Time Frame
Auditory	Hx of hearing difficulties/tinnitus/vertigo, otoscopic exam	Yearly
Cardiovascular	Detailed cardiovascular history and exam; ECHO/MUGA Fasting Lipid Profile	Yearly As needed
Reproductive	Pubertal/menstrual/sexual function/med/pregnancy hx	Yearly
GI/Hepatic	Hx of pain/emesis/distention/constipation, abdominal exam	Yearly
Musculoskeletal	Height/Weight/Sitting Height; Spine exam for scoliosis/kyphosis	Yearly; until mature
Second Cancer	Hx of fatigue/bleeding/easy bruising, dermatologic exam, CBCD Hx of lesions/moles/bone pain, derm/bone exam in trunk region	Yearly until 2016 Yearly
Urinary	BP, UA, Detailed voiding hx	Yearly

Please refer to www.survivorshipguidelines.org for detailed Long-Term Follow-Up Guidelines from COG

Treatment History

UCSF Benioff Children's Hospital

CureSearch Children's Oncology Group

Patient: Jane Doe **DOB:** 1/2/2003
Diagnosis: Wilms Tumor, Right Kidney, Stage II Favorable **Diagnosis Date:** 8/5/2005
Protocol: CCG-4941, Not On Study **End Therapy:** 2/10/2006

Chemotherapy	Date Start	Date End	Cumulative Dose	Total Dose
Actinomycin, IV	8/9/2005	2/10/2006	4.47 mg/m²	2.04 mg
Carboplatin, IV	8/29/2005	1/23/2006	1744 mg/m²	794 mg
Etoposide (VP-16), IV	8/29/2005	1/25/2006	854 mg/m²	389 mg
Vincristine, IV	8/10/2005	2/10/2006	17.7 mg/m²	8 mg

Significant Surgery	Site	Date
Right Nephrectomy, Lymph Node Biopsy	Right Kidney, Periaortic Lymph Node	8/5/2005
Central Line Placement/Removal	Left External Jugular Vein	8/5/2005 // 10/16/2005
Central Line Placement/Removal	Right Internal Jugular Vein	10/29/2005 // 3/14/2006

Radiation Therapy	Date Start	Date End	Involved Field	Dose
External Beam	8/10/2005	8/17/2005	Abdomen	1080cGy

Passport For Care

- The PFC enables users to store the survivor treatment summaries
- Automatically generate survivor care plans using the latest guidelines when needed for reference
- Modification of the treatment summary and survivor care plan should the survivor experience a relapse or subsequent malignancy
- Alerts to clinicians are provided if more-immediate attention is required for particular survivors
- PFC application is managed centrally,
  - Changes to the guidelines or other resources (such as survivor education materials) can be made in one location
  - survivor care plans updated automatically for relevant survivors

Summary

- Ethical dilemma’s in care of Oncology patients is varied
- Applying a team approach to the management of these patient can help with these issues
- Awareness of resources available in the Hospital/Community is critical
- Greater than 80% of pediatric patients with cancer treated with modern therapy survive for 5 years or more.
- Although cancer remains the leading disease-related cause of death in children in the USA and other developed nations
- Survival rates continue to improve

Summary

- The role of the PCP in caring for Oncology patients is increasing
- Current recommendations to help the PCP adequately care for childhood cancer survivors include:
- Detailed treatment summaries:
  - Diagnosis
  - Therapy
- Follow up guidelines
  - Individualized
  - Questions to ask at visits
  - Evaluations such as blood work and imaging
- If you follow a childhood cancer survivor, make sure you have the right tools!


...because kids can't
fight cancer alone.

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