

How not to be afraid of kids (and parents of kids) with cancer

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- We have no financial disclosures...



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Objectives

- Describe the epidemiology, pathology, physiology, and clinical manifestations of the most common pediatric cancers.
- Recognize common musculoskeletal, cardiopulmonary, neurological impairments in individuals with this disease as they are related to function and participation.
- Identify the medical and physical therapy management and measurements of pain, functional, and quality of life in survivors of childhood cancer.
- Describe psychological and social considerations that may affect physical therapy interventions.
- Establish a working understanding of the role of physical therapist in pediatric oncology patients.

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Outline

- Kelly**
- Childhood cancer and treatments
- Amanda**
- Psychosocial considerations
- Hallie**
- Rehabilitation considerations and recommendations

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Fear



F.E.A.R.
has two meanings:
Forget Everything and Run
OR
Face Everything and Rise
The Choice is Yours

Epistemophobia
Do you have a fear of knowledge?

Fear??



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2 Cancer in children is rare, but it's the leading cause of disease-related death in children in the United States.

43

5

www.ncbi.nlm.nih.gov

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Childhood Cancer

- 16,000 childhood and adolescent cancer new diagnoses every year
- 17.6 per 100,000 children

Age-Adjusted and Age-Specific Cancer Incidence Rates for Patients Aged 0–14 Years (SEER 2009–2012)

Cancer Type	Incidence Rate (%)
Oncocytic	~25%
CNS	~20%
Lymphoma	~15%
Leukemia	~10%
Germ-cell	~5%
Soft tissue	~5%
Bone	~5%
Reticuloma	~2%
Renal	~2%
Liver	~2%
Other	~2%

www.ncbi.nlm.nih.gov

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Childhood Cancer Survivorship

- The founder of National Coalition of Cancer Survivorship (NCCS), Fitzhugh Mullan, first defined **survivor** in a 1985 article published in *The New England Journal of Medicine*.
 - A person was considered a **survivor** from diagnosis to death.
- Overall 5-year survival exceeding 80%
- Currently, >420,000 childhood cancer survivors living in the U.S.
 - 80.5% experience a severe, life-threatening, or disabling chronic condition by age 45
 - ~ 3-fold increased risk for functional impairment and activity limitations

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Diagnostics

- History and Physical
- Blood work
- Biopsy

Imaging

- X-rays
- Ultrasound
- CT/CAT scan
- MRI
- PET scan
- Bone scan
- MIBG

Keller SC, et al. Imaging Pediatric Bone Sarcoma. *Radial Clin North Am*. 2013;33(4):787-805. www.ncbi.nlm.nih.gov

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Medical Treatments

- Chemotherapy
- Steroids
- Surgery
- Radiation
- Immunotherapy
- Bone Marrow Transplant

www.ncbi.nlm.nih.gov/pmc/articles/PMC3704478/

www.cancer.org/reducing-side-effects-of-treatment

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Points of Entry of Physical Therapy

<p>Pre-diagnosis</p> <ul style="list-style-type: none"> — Outpatient evaluation and/or treatment — Outpatient gait training — Inpatient general medical or orthopedic floors — Rheumatology, orthopedic, and/or chronic pain clinics <p>Diagnosis</p> <ul style="list-style-type: none"> — Inpatient admission — Outpatient oncology clinic 	<p>Treatment or late-effects</p> <ul style="list-style-type: none"> — Chemotherapy admissions — Post-operative hospitalizations — Acute rehabilitation stay — Outpatient evaluation and/or treatment — Schools — Long-term follow-up clinics
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Special Considerations

- Age at diagnosis
 - Related to normal development
- Length of treatment
 - Hospitalizations
- Secondary effects from treatments
 - Short-term
 - Long-term
- Family Unit
- School/Academics
- Psychosocial considerations

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Types of Childhood Cancers

Age-Adjusted and Age-Specific Cancer Incidence Rates for Patients Aged 0-14 Years (SEER 2009-2012)

Cancer Type	Age-Adjusted and Age-Specific Cancer Incidence Rate (%)
Leukemia	~45%
CNS	~15%
Lymphoma	~10%
Soft tissue	~8%
Neuroblastoma	~5%
Bone	~5%
Epithelial	~5%
Germ cell	~3%
Retinoblastoma	~2%
Liver	~2%
Other	~10%

<http://seer.cancer.gov/seerstatweb/>

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Blood Cells

- Red blood cells (hemoglobin): carry oxygen
- Platelets: help blood to clot
- Granulocytes: phagocyte
 - Neutrophils: ingest bacteria
 - Eosinophils: allergic reactions and attack parasites
 - Basophils: release histamine
- Lymphocytes: regulate immune system
 - T-cell
 - B-cell
- Monocytes: phagocytic WBC
 - Dendritic: antigen-presenting
 - Macrophages: larger phagocyte, antigen-presenting (histiocyte)

Phagocyte:

<http://www.allgcpathology.com/biology/charles/leukemia/content/module1-6.htm>

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Blood Cell Counts

- Anemia
 - Hemoglobin
- Thrombocytopenia
 - Platelets
- Neutropenia
 - Neutrophils
- Pancytopenia
 - Combination

<http://fslsc.dsi.rutgers.edu/~baburz/bloodx.htm>

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Leukemias

- Epidemiology
 - 4.7 per 100,000 children per year
 - 9-year survival: 83.9%
 - Highest incidence age 1-4 years old
 - Median age: 6 years
- Pathophysiology
 - immature stem cells that proliferate within bone marrow and affect production of all blood cells.
 - Lymphoid or myeloid
 - Acute or chronic
- Clinical manifestations
 - Enlarged lymph nodes
 - Enlarged liver or spleen
 - Fever
 - Easy bleeding or bruising
 - Night sweats
 - Weight loss
 - Fatigue
 - Pallor

<http://www.allgcpathology.com/biology/charles/leukemia/content/module1-8.htm>

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Leukemia

- Treatment:
 - 2 to 3 years of steroids and chemotherapy
 - Most common chemotherapy:
 - Vincristine
 - Methotrexate (Intrathecal)
 - Busulfan
 - Cyclophosphamide
 - Doxorubicin
 - L-asparaginase
 - Bone marrow transplant
- Long-term physical effects:
 - Peripheral neuropathy
 - Decreased bone mineral density
 - Osteonecrosis
 - Impaired:
 - Range of motion
 - Strength
 - Balance
 - Motor proficiency
 - Mobility
 - Gait and jumping biomechanics

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Brain Tumors

- Epidemiology**
 - 3.1 to 5.3 per 100,000 children per year
 - 5-year survival: 74.2%
 - Median age at diagnosis: 8 years
- Pathophysiology**
 - Mass of abnormal tissue growth in the brain
- Clinical manifestations**
 - Headache
 - Vomiting (especially in the morning)
 - Vision, speech, and hearing changes
 - Worsening balance or unsteady gait
 - Unusual sleepiness
 - Weakness
 - Increased head circumference

<http://www.ecog.org/brain-cancer/>

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Brain Tumors

- Treatment:**
 - Most common chemotherapy:
 - Carboplatin, Cisplatin
 - Cyclophosphamide
 - Etoposide
 - Methotrexate
 - Thiotepa
 - Vincristine
 - Surgery
 - Radiation
 - Steroids
- Long-term physical effects:**
 - Poor physical fitness/exercise tolerance
 - Decreased strength
 - Spasticity
 - Decreased balance
 - Ataxia (posterior fossa)
 - Participation restrictions

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Lymphoma

- Epidemiology**
 - 800 new cases per year
 - 5-year survival ~80%
 - >3 years old – adolescence
- Pathophysiology**
 - Stem cell / infection-fighting lymphocytes
 - Non-Hodgkin's lymphoma
 - Burkitt and Burkitt-like lymphoma
 - Large cell lymphomas
 - Lymphoblastic lymphoma
 - Hodgkin's lymphoma
- Clinical manifestations**
 - Painless enlargement of lymph node
 - Night sweats
 - Persistent fatigue
 - Fever and chills
 - Unexplained weight loss
 - Anorexia
 - Pruritus (itchiness)

<http://openmri.org/medbullets.com/ResidentCourses/ResidentCoursesContent/medbullets%20.htm>

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Lymphoma

- Treatment:**
 - Most common chemotherapy:
 - Methotrexate (intrathecal)
 - Cyclophosphamide
 - Vincristine
 - Doxorubicin
 - Steroids
 - Surgery
 - Radiation
 - Bone Marrow Transplant
- Long-term physical effects:**
 - Peripheral Neuropathy
 - Poor physical fitness

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Sarcoma

- Epidemiology**
 - 900 total cases per year
 - 400 new cases a year under the age of 20-years-old in the US
 - 5-year overall survival about 70%
 - Most common in adolescence
- Pathophysiology**
 - Arise from the bone, soft tissue, or mesenchymal cells
 - Osteosarcoma (immature osteoid)
 - Ewing's Sarcoma (small, round, blue cell)
 - Rhabdomyosarcoma
 - Non-rhabdomyosarcoma soft tissue
- Clinical manifestations**
 - Intermittent pain that often worsens at night
 - Swelling
 - Decreased range of motion
 - Altered gait or upper extremity use

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Sarcoma

- Treatment:**
 - Most common chemotherapy:
 - Cyclophosphamide
 - Cisplatin or carboplatin
 - Vincristine
 - Methotrexate
 - Doxorubicin (Adriamycin)
 - Etoposide
 - Surgery
 - Radiation
- Long-term physical effects:**
 - Decreased physical fitness
 - Decreased range of motion
 - Decreased strength
 - Pain from osteosarcoma or treatment
 - Impaired bone mineral density
 - Musculoskeletal asymmetries
 - Physical limitations
 - Participation limitations
 - Adverse general health

Sarcoma Surgery

Surgical Goals:

- Negative margins
- Assessment of chemotherapy effectiveness
 - Biopsy
 - Percent (%) necrosis
 - Optimize function of limb/body part
 - Avoiding compromise of neurovascular bundles
 - No risk of increased mortality

Surgical Options:

- Limb Sparing/Salvage
 - Wedge resection
 - Endoprosthesis
 - Allograft
 - Distraction Osteogenesis
- Amputation
- Rotationplasty
- Resection of lung metastasis

PT Clinical Points Specific to Management of Patients with Bone Tumors:

- **Wound Healing:** Delayed wound healing with chemotherapy. Care must be taken with progressive range of motion opposing incisions.
- **Muscles/structures spared, resected, or re-routed:** Know what you are and are not strengthening or ranging.
- **Secondary effects of chemotherapy on overall cardiopulmonary function:** Incorporate cardiopulmonary training as appropriate.
- **Secondary effects of chemotherapy/surgery on neurological system:** Screen for neuropathies. Educate on proper supportive shoes or devices.
- **Secondary effects of chemotherapy/surgery on bone health:** Care must be taken with progressive range of motion, weight bearing, and shearing/contact activities.
- **Patient/family goals and expectations:** Need to addressed and re-addressed frequently throughout management.
- **Communication is essential for success:** Open communication between oncologists, orthopedic oncologists, social workers, other physical and occupational therapists.
- **Be realistic with goal setting.**
- **When in doubt, do no harm.** Then seek guidance/knowledge.

Neuroblastoma

Epidemiology

- Most commonly < 2 years of age

Pathophysiology

- Neuroendocrine tumors that arise from neuroblasts (immature nerve tissue) and are found throughout the developing sympathetic nervous system

Clinical manifestations

- Lumps under the skin in abdomen or chest
- Bone pain
- Horner's syndrome
- Bruising around eyes
- Weakness
- Changes in bowel habits (loose stools)
- Opisthotonus myoclonus
 - Irritability, rapid eye movements (swimming)
 - Brief, shock-like muscle spasms (atxia-like)

Neuroblastoma

Treatment:

- Most common chemotherapy:
 - Cyclophosphamide
 - Cisplatin or carboplatin
 - Vinristine
 - Doxorubicin
 - Etoposide
- Observation
- Surgery
- Radiation
- Iodine 131-MIBG therapy
- Bone Marrow Transplantation

Long-term physical effects:

- Impaired health-related physical performance
- Peripheral neuropathy
- Weakness

Wilms Tumor

Epidemiology

- 1 in 100,000 children per year
- 5-year survival ~90%
- < 5 years old

Pathophysiology

- Early cells of the kidney do not develop into glomeruli or nephrons, but into clusters of the immature cells

Clinical manifestations

- Abdominal pain
- Lump in abdomen
- Blood in the urine
- High blood pressure
- Loss of appetite
- Fatigue
- Persistent fever

Wilms Tumor

Treatment:

- Most common chemotherapy:
 - Doxorubicin
 - Vincristine
 - Cyclophosphamide
 - Etoposide
 - Dactinomycin
 - Irinotecan
- Surgery
- Radiation

Long-term physical effects:

- Scoliosis
- Peripheral neuropathy
- Impaired health-related physical performance

Chemotherapy

<http://www.chemocare.com/>

- Busulfan, Myleran** (leukemia, neuroblastoma)
 - Fatigue, tiredness, decreased appetite, hair loss, nausea/vomiting, diarrhea, myelosuppression
- Cisplatin, Carboplatin** (brain tumors, lymphoma, sarcoma, neuroblastoma)
 - Myelosuppression, nausea/vomiting that usually, tinnitus and hearing loss, fluctuations in electrolytes, kidney damage
 - Allergic reaction: rash and increased breathing
- Cyclophosphamide** (leukemia, lymphoma, sarcoma, neuroblastoma, Wilms Tumor)
 - Nausea/vomiting, abdominal pain, decreased appetite, sore mouth, taste changes, diarrhea, hair loss, bladder damage
- Dactinomycin** (sarcoma, Wilms tumor)
 - Nausea/vomiting, fatigue, cold sores, diarrhea, skin problems, sensitivity to sunlight, radiation recall
- Doxorubicin, Daunorubicin** (leukemia, lymphoma, sarcoma, Wilms tumor)
 - Nausea/vomiting, hair loss, red-colored urine, myelosuppression, heart failure

Chemotherapy cont.

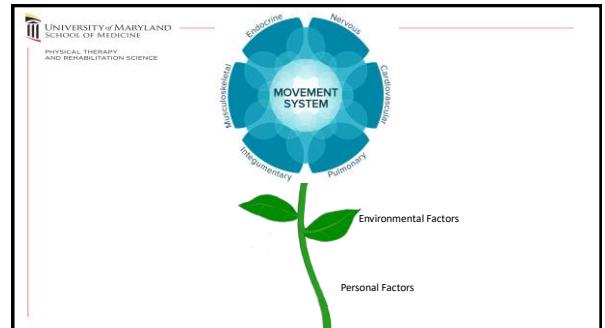
<http://www.chemocare.com/>

- Etoposide** (lymphoma, brain tumors, sarcoma, neuroblastoma, Wilms tumor)
 - Myelosuppression, hair loss, nausea/vomiting, low blood pressure, mouth sores, diarrhea, poor appetite, radiation recall, peripheral neuropathy
- Ifosfamide** (lymphoma, sarcoma)
 - Nausea/vomiting, poor appetite, myelosuppression, hair loss, blood in urine, sleepiness
- L-asparaginase, Elspar** (leukemia, lymphoma)
 - Drowsiness, nausea/vomiting, and cramping
 - Allergic reaction: rash or increased breathing effort
- Methotrexate** (leukemia, brain tumors, sarcoma)
 - Nausea/vomiting, decrease in blood cell counts, diarrhea, skin rashes, mouth sores, dizziness, headache, drowsiness
- Thiotepa** (brain tumors, neuroblastoma)
 - Nausea/vomiting, decrease in blood cell counts, diarrhea, hair loss, skin rashes, mouth sores
 - “Thiotepa baths”
- Vincristine, vinblastine** (leukemia, brain tumors, lymphoma, sarcoma, neuroblastoma, Wilms tumor)
 - Weakness, loss of reflexes, nausea/vomiting, hair loss, diarrhea or constipation, abdominal cramping, myelosuppression, peripheral neuropathy

Other treatment effects

[http://www.chemocare.com/](#)

- Steroids** (leukemia, brain tumors, bone marrow transplant)
 - Osteonecrosis, myopathy (proximal mm.), muscle tremors, burning of hands and feet
- Surgery** (lymphoma, brain tumor, sarcoma, neuroblastoma, Wilms Tumor)
 - Disruption of neurovascular bundle, infection, musculoskeletal symmetry, weakness, delayed healing
- Radiation** (brain tumors, sarcomas, neuroblastoma, Wilms Tumor)
 - Fibrosis, musculoskeletal asymmetry, weakness, decreased wound healing, osteonecrosis, nausea/vomiting, fatigue, encephalopathy (acute or delayed)



Coping with Childhood Cancer- An Overview

As advances in treatment have improved prognosis and survival for a majority of children, more focus has been placed on the social, emotional, and behavioral impact of childhood cancer and how we can mitigate that impact

There is a large body of evidence as to how children, adolescents, and families cope with diagnosis and treatment along the illness trajectory





Impact of Cancer on Children and Families

Diagnosis and Early Treatment

- Information overload; Rapid treatment decisions
- Navigating a new environment and staff; separation from home/community; Disruptions to normal family routines; New financial burden
- Painful or distressing procedures; Side effects

Ongoing Treatment

- Routines established
- Temporary and permanent physical changes (e.g., hair loss, weight gain, amputation)
- Difficulty adhering to treatment regimen
- School and peer issues
 - Absenteeism, fatigue, cognitive impacts
 - Missed opportunities for peer socialization and participation in age-appropriate activities



Impact of Cancer on Children and Families

Ending Treatment

- Excitement that treatment is over
- But - loss of "safety net" & support; fear of recurrence; transition to other providers (C. M. Wakefield et al. 2011)
- Survivorship
 - Continued monitoring of health (more medical treatment beyond cancer)
 - 2 in 3 survivors have at least one late effect from treatment (e.g., physical, neurocognitive, psychological)
 - 25% of those late effects are considered severe or life-threatening (Oeffinger et al 2006)
 - Ongoing impact on cognitive, educational/employment, and social outcomes
 - Particularly for survivors of pediatric brain tumor



Impact of Cancer on Children and Families

Relapse or Recurrence

- More treatment, more uncertainty, threat of death, maintaining hope
- Dying and Death
 - Anticipation and reality of loss
 - Talking with and supporting children
 - Facing life after the child's death
 - Ensuring that the child will be remembered
 - Need for comfort, support during and after this time



Coping Issues for Very Young Children

- Fear of separation from parents
 Painful or frightening procedures
 Restrictions in play, exploration
 Temporary regression in developmental milestones
 Attempts to control- tantrums, clinging, aggression, withdrawal



Coping Issues for School-Age Children

- Disruption of school
 Loss of peer interactions, activities
 Greater understanding of seriousness of condition
 Procedural distress



Coping Issues for Adolescents

- Disruption of school, peer activities
 Dependence vs Independence
 Intense emotional reactions to situations
 Increased need for/use of social support
 More focus on existential/identity issues, image



Patient and Family Distress- What do we know?

- In children, adjustment difficulties are expected
 - Anxiety, sadness, fear, and irritability common
 - Concerns over changes in appearance
 - Behavioral challenges- regression, tantrums, adherence

In general, most children with cancer and survivors are NOT at increased risk for psychopathology (Patenaude & Kupst, 2005)

- Levels of clinical depression, anxiety disorders, behavioral disorders, and PTSD are similar to rates in general population



Patient and Family Distress- What do we know?

Certainly, most families of children with cancer experience significant distress at diagnosis and during treatment.

Distress is greatest closest to the time of diagnosis but tends to normalize over the first year, and in the long term, most families are resilient (Vrijmoet-Wiersma CM et al., 2008; Pai et al., 2007)

- Despite the universal impact of cancer diagnosis and treatment, longitudinal studies indicate that most children and families are able to cope with the disease, treatment, and aftermath (A. N. Abrams, et al., 2007; A. E. Kazak et al., 2012; R. B. Noll & M. J. Kupst, 2007; Vrijmoet-Wiersma et al., 2008; A. M. Wechsler, & I. Sanchez-Iglesias, 2013)



Patient and Family Distress- What do we know?

This does not mean lack of problems!

- Life-changing – but RESILIENCE is the rule rather than the exception and families adapt and become better able to cope

While some degree of distress is to be expected, a subset ($\approx 1/4 - 1/3$) of children and families experience more significant distress that indicate need for increased care.

- Abrams et al., 2007; A. A. Aldridge & S.C. Roesch, 2007. *J Behav Med*, 30: 115-129; Kazak et al., 2012; Patenaude & Kupst, 2005



What Factors Influence QOL/Adaptation?

Early factors tend to be predictive of later outcomes

- Previous functioning, previous experiences with stress, previous ways of coping, coping early in treatment
- Family functioning, resources, social supports, concurrent stresses (M. A. Alderfer, et al., 2010; K. A. Long & A. L. Marsland; 2011; Y. Okado, A. M. Long & S. Phipps, 2014; C.M.J. Vrijmoet-Wiersma et al. 2008)

Family Factors

- Family support, adaptability, cohesion; Parent-child response and coping (A. F. Patenaude & M. J. Kupst, 2005; Bruce, 2006; Vrijmoet-Wiersma et al., 2008; Alderfer et al, 2009; Long & Marsland, 2011; A. F. Klassen, et al., 2011; Kupst et al., 1995; Long & Marsland, 2011; Okado et al., 2014; A. Pai et al., 2006.)



Messaging to Caregivers and Families

Normalization of distress

- Adjustment difficulties are to be expected and here's what we expect
- Developmental view

Behavioral expectations (including consequences!) are important

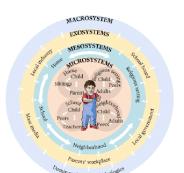
- Role of routine, structure, and choices
- Positive reinforcement for appropriate behavior and consequences for inappropriate behavior
 - Permission to continue having expectations and implementing consequences in the treatment context

Role of family dynamics



Family Dynamics

- Cancer doesn't happen in a vacuum
- The child is part of a number of systems, and the FAMILY system is critical to how the child copes
- Caregivers are often more distressed than patients themselves (and for longer)
 - Children, especially young children, look to their parents for cues



Family Dynamics

Transmission of anxiety from parent to child impacts child coping in both the short and long-term

- Role of psycho-education (i.e., helping parents understand their role in their child's coping)
- Taking time to build rapport with parents
- Enlisting them as partners and coaches for the child



What does this all mean for you?

Consider a collaborative, systems, and strengths-based approach

Take some time to review a child's history and understand if they are one of those patients who is having more typical adjustment issues or more significant distress

Consult with other team members (social workers, psychologists, child life specialists) to understand that child and family. Ask about the child's strengths and factors that contribute to their resilience (so you can capitalize on/harness those).



What does this all mean for you?

Take time to build rapport with parents, as they will be your best partners in working with the child

Pay attention to individual differences – one size does not fit all

Understand that coping is a process. It will change based on a child's developmental stage, their physical and mental state, how they perceive situations as time goes on, how they feel supported, etc.

(B. E. Compas et al., *Annu Rev Clin Psychol.* 8, 455-480, 2012; S. Folkman & J. T. Moskowitz, *Annu Rev Psychol.* 2004, 55, 745-774)



What does this all mean for you?

Pediatric oncology generally involves a number of psychosocial providers. Use them to your advantage. Partner with them. Consult with them. Learn from them. Teach them. You do not have to figure it all out on your own. And if you are worried about a patient, there are others that can assess and provide treatment for more significant psychological issues that may arise.



The Nonadherent Patient

Be a detective: What might be contributing to refusal?



Choices, reward systems
Positive reinforcement; MI
Coping skills; relaxation; CBT
Beh & envir sleep interventions
Psychology involvement; CBT
Psychoeducation / reinforcement by medical team
Better control, nonpharm strategies



Long term physical effects of childhood cancer



- Obesity
- Atherogenic dyslipidemia
- Increased blood pressure
- Insulin-resistance
- Osteoporosis
- Fatigue

Amplified by physical inactivity
(Naylager, et al. 2016)

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Why the late effects?



- More sedentary during/post treatment
- Family/caregivers overly cautious
- Lack of education of expectations after cancer

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Why exercise after cancer

Exercise training improves physical function and fitness in long-term paediatric brain tumour survivors treated with cranial irradiation

P.J. Plicciene¹, E. Bouffet², B. Timmons³, K.S. Courneya⁴, D. Tetzeloff⁴, J.E. Schneiderman⁵, C.B. de Medeiros¹, U. Barid⁶, D.J. Mabbott^{1,6*}

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- Howell et al (2017): moderate-vigorous physical activity increased with web-based intervention
- Schadler et al (2018) exercise during treatment
 - Improves QoL
 - Prevents physical decline
 - Decreases medical complications from treatment

Why is exercise a challenge in this population?

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- Physically
 - Tx side effects
 - Weakness
- Psychological
 - Motivation
 - Energy
 - Learned dependence
- Appointment constraints
- Treatment constraints
 - Neutropenia
- Lack of peers
 - Access versus exposure

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Treatment considerations

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- Where is patient in their treatment? Other considerations
 - During treatment
 - Frequency of treatment and patient specific side effects
 - Type of treatment: radiation, chemotherapy, surgical
 - Level of activity pre and during treatment
 - Post treatment
 - Length of time since treatment
 - Treatment course: chemotherapy, XRT, surgical
 - Complexity of course
 - Multiple inpatient unplanned admissions, ICU stays
- Lines
- Blood counts

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Chemotherapy specific impairments

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Treatment	Impairment	Disability
Methotrexate	Cognitive impairment, developmental delay, learning problems, motor/coordination impairments, osteoporosis (increased risk of fractures)	Decreased age-appropriate ADLs, limited participation in sports, impact self-esteem, mobility deficits
Corticosteroids	Myopathy (proximal muscle weakness), osteoporosis, AVN, growth failure	Decreased mobility, hip pain, gait abnormalities, impacts self-esteem
Vincristine	neuropathy	Paresthesia, distal weakness, foot drop, impaired use of hands
Anthracycline (doxorubicin, daunorubicin)	Cardiomyopathy, arrhythmias, decreased left ventricular function	Diminished capacity to perform age-appropriate ADLs, decreased endurance/exercise tolerance, limited participation in sports
Cisplatin/Carboplatin	High-frequency sensorineural hearing loss, tinnitus	Affects communication skills and potentially speech/language
Cyclophosphamide/Ilosfamide	Neurotoxicity (reversible) with somnolence, disorientation, lethargy, hallucinations, AVN	Limit age-appropriate ADLs, may impact ambulation

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Central line/port considerations

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Hickman	Port	PICC
<ul style="list-style-type: none"> • Tunneled • Needs to be covered before showering • No swimming 	<ul style="list-style-type: none"> • Can be implanted for years • Least restrictive • Avoid impact to chest 	<ul style="list-style-type: none"> • Weeks-months (short term) • Avoid repetitive overhead arm movement • Needs to be covered before showering • No swimming

American Cancer Society
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Blood counts

JOHNS HOPKINS MEDICINE

- Based on APTA Acute care lab value interpretation resource (2017)
- White blood cells: normal 5-10
 - Neutropenic <1.5: symptoms based approach especially with fever
 - Increased risk for infection so wear mask, be mindful of others especially sick
- Platelets: normal 140-400 k/uL
 - Thrombocytopenia <150
 - when less than 20: symptoms based approach, avoid resistance
 - Mindful of activities that may result in falls
 - Transfuse is based on individual goal
- Hemoglobin: normal male: 14-17.4 g/dL, female 12-16 g/dL
 - Anemic if <8 symptoms based approach, monitor SpO₂
 - Do not typically transfuse until <7 unless symptomatic

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Symptom based approach to blood values with PT participation

No serious adverse events during or within 48 hours of 406 sessions
 – 37 adverse events including tachycardia, fever

Hb was normal in <25%
 • Anemic and moderate thrombocytopenia participated in resisted exercise

Is patient typically requiring transfusion?

Safety of Symptom-Based Modification of Physical Therapy Interventions in Pediatric Oncology Patients With and Without Low Blood Counts

Rehabilitation Oncology 2017

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Keeping up with peers: use of outcome measures

- Bruininks-Oseretsky Test of Motor Proficiency, Second Edition (BOT™-2)
 - Normative data: 4.0-21.11 years old
 - Balance, coordination, strength, fine motor subtests
- Six minute walk test:
 - Norms: >5 years old
- 30 second walk test
 - Norms: 5-13 years old
- PROMIS-Fatigue Pediatric
 - Short Form v1.0
- Gait analysis
 - Step length, velocity, cadence norms 1-10 years old

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Treatment strategies

Diagnosis dependent

- Post-op at increased frequency
- Maintain/promote community access and age appropriate level of activity
- Gait changes

Durable medical equipment:

- Orthotics, bioness, wheelchairs



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Fun PT is the best PT

- Walking with flippers
 - anterior tibialis strengthening
- Prone on swing and scooter
 - Trunk extension/glut activation
- Standing on inverted wedge
 - Posterior weight shift
- Balance beam: lateral steps for postural control
- Using toes to pick up cotton balls
 - Sitting/standing
 - Anterior tibialis/balance

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Questions?



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

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References – Kelly

PHYSICAL THERAPY AND REHABILITATION SCIENCE

- Adams ML, Lipitz SR, Cohen SD, Tarbell NJ, Treves ST, Diller L, Greenbaum N, Mauch P, Lipsitz SE. Cardiovascular status in long-term survivors of Hodgkin's disease treated with chest radiotherapy. *J Clin Oncol*. 2004;22(15):3035-3041.
- Balmanoukian AS, Bartsch G, et al. (2005). Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000. National Institutes of Health Pub. No. 06-5767. Bethesda, MD.
- Campbell's Physical Therapy for Children, 5th Edition Editors: Robert J. Palisano, Margo N. Orlin, Joseph Schieber Chapter 16, Pediatric Oncology, Victoria Marchese, Kristin M. T. Tuck, et al.
- DiCaprio M and Friedlander G. Malignant bone tumors: limb sparing versus amputation. *Journal of Academy of Orthopaedic Surgeons*. 2003; 11(1):25-37.
- Geller D and Gorlick R. Osteosarcoma: a review of diagnosis, management, and treatment strategies. *Clinical Advances in Hematology & Oncology*. 2010;8(10):705-718.
- Glicklich L, Tanner L. Gait Patterns in Children with Cancer and Vincristine Neuropathy. *Pediatr Phys Ther*. 2016;28(1):16-22. doi:10.1097/PT.0000000000000008
- Glicklich L, Tanner L, Nester C, et al. Normalized gait and arm recovery of chemotherapy-induced peripheral neuropathy after treatment for pediatric non-CNS cancer. *Pediatr Blood Cancer*. 2017;64(1):180-187.
- Hansen A, Pluim STM, Weijnen M, et al. Health-related fitness in very long-term survivors of childhood cancer: A cross-sectional study. *Pediatr Blood Cancer*. 2018 Apr;65(4). doi: 10.1002/pbc.27022. Epub 2017 Dec 22.
- Hopkins S, San J, Graham C, Thordell J. Functional and upright time following limb salvage, amputation and rotationplasty for pediatric sarcoma of the bone. *Journal of Pediatric Orthopedics*. 2009;29(3):405-408.
- Cancer Clinic - Oncocare. <http://oncocare.com/about/efitlist.aspx>. Accessed December 14, 2018.
- Hudson MM, Mertens AC, Crowley JJ, et al. Health status of adult long term survivors of childhood cancer: a report from the Childhood cancer survivor study. *JAMA*. 2003 Jun 12;289(24):3272-3281.
- Kida CC, et al. Imaging Pediatric Bone Sarcomas. *Radiol Clin North Am*. 2011 Jul;49(4):749-65.
- Lauwens Smith DM, Li L, Chang C, et al. Patterns and severity of vincristine-induced peripheral neuropathy in children with acute lymphoblastic leukemia. *J Peripher Nerv Syst*. 2015;20:37-46.
- Marchese V, Spaulding E, Callahan C, et al. Relationship among range of motion, functional mobility, and quality of life in children and adolescents after limb-sparing surgery for malignant glioma. *Pediatr Phys Ther*. 2006;18(2):238-244.
- Marchese VG, Chiarollo LA, Lange BJ. Strength and functional mobility in children with acute lymphoblastic leukemia. *Medical and Pediatric Oncology*. 2003;40(4):230-232.
- Marchese V, Sanders O, York T, Creath R, Rogers M. Motion analysis of a jumping task in childhood leukemia survivors. *Rehab Oncol*. 2017;35:9-14.
- Moyer-Milner LI, Randall L, Bruggers CJ. Fitness of children with standard-risk acute lymphoblastic leukemia during maintenance therapy: response to home-based exercise and



References – Kelly cont.

- PHYSICAL THERAPY AND REHABILITATION SCIENCE**
- Nagrani J, Kamuzaman A, Ness K, et al. Twenty year follow-up of survivors of childhood osteosarcoma: a report from the childhood cancer survivor study (CCSS). *Cancer*. 2011; 117(8): 6258-6265.
 - Ness KK, Neglia J, Clinton D, and Robison L. Limb salvage and amputation in survivors of pediatric lower-extremity bone tumors: what are the long-term implications? *Journal of Clinical Oncology*. 2002; 20(22):4493-4501.
 - Ness K, Martens A, Hudson M, Wolf M, et al. Limitations on physical performance and daily activities among long-term survivors of childhood cancer. *Annals of Internal Medicine*. 2012; 156(10): 711-718.
 - Ness KK, Hudson MM, Pui CH, et al. Neuromotor impairments in adult survivors of childhood acute lymphoblastic leukemia. *Cancer*. 2012;118:828-834.
 - Ness KK, Kull IE, Jones KD, et al. Physiologic frailty as a sign of accelerated aging among adult survivors of childhood cancer: a report from the St Jude Lifetime cohort study. *J Clin Oncol*. 2013; 31(14): 1782-1788.
 - Ness KK, Hudson MM, Gruber-Bonney JL, et al. Physical performance limitations in the Childhood Cancer Survivor Study cohort. *J Clin Oncol*. 2009 May 10;27(14):1382-1388.
 - Noone AM, Howlader N, Krapcho M, Miller D, Brest A, Yu M, Ruht J, Tatalovich Z, Mariotto A, Lewis DR, Chen HS, Fauer E, Cronin KA (eds). SEER Cancer Statistics Review, 1975-2015, National Cancer Institute, Bethesda, MD. https://seer.cancer.gov/csr/1975_2015/, based on November 2017 SEER data submission, posted to the SEER web site, April 2018. Accessed December 2018.
 - Oeffinger KC, et al. Chronic health conditions in adult survivors of childhood cancer. *New England Journal of Medicine*. 2008; 359 (15): 1572-1582.
 - Ozrem GT, Gitterman H, Liao P, et al. CTRUS statistical report: primary brain and central nervous system tumors diagnosed in the United States in 2007-2011. *Neuro Oncol*. 2014;16(suppl 4):iv2-iv6.
 - Packer RJ, Salwen B, Portney L, Martin H. Functional outcomes following amputation and limb salvage surgery at different levels in the lower extremity. *Physical Therapy*. 2005 Jun; 95(6): 643-652.
 - Robison LL, Hudson MM. Survivors of childhood and adolescent cancer: life-long risks and responsibilities. *Nat Rev Cancer*. 2014;14:61-70.
 - Robison LM, Hudson MM, Howell CR, et al. Peripheral Neuropathy, Sensory Processing, and Balance in Survivors of Acute Lymphoblastic Leukemia. *J Clin Oncol*. 2018 Aug 1;36(22):2315-2322. doi: 10.1200/JCO.2017.76.7871. Epub 2018 May 29.
 - Ward E, DeSantis C, Robbins A, Kohler B, Jemal A. Childhood and adolescent cancer survival in the United States. *Cancer*. 2014;119:17-26.
 - Wilson J, Gaskins V, Barr RD. Impairment and functional status in children with cancer. *Children (Basel)*. 2015;2(1):1-8.
 - Wright MJ, Galvin V, Barr RD. Impairment and functional status of children and youth who have had acute lymphoblastic leukemia. *Phys Ther*. 2009;89:782-790.
 - Wright MJ, Hallon JM, Martin RJ, Barr RD. Long-term gross motor performance following treatment for acute lymphoblastic leukemia. *Mid-Pediatr Oncol*. 1998;31:86-90.
 - Wright MJ, Tworek CM, Gorster JW. Gait characteristics of children and youth with chemotherapy induced peripheral neuropathy following treatment for acute lymphoblastic leukemia. *Gait Posture*. 2017 Oct;63:139-140.

References – Amanda

- Ahrens, A. N., Hazen, E. P., & Penson, R. T. (2007). Psychosocial issues in adolescents with cancer: Cancer treatment reviews, 33(7), 622-630.
- Alderfer, M. A., Nawariva, N., & Kasai, A. E. (2007). Family functioning and posttraumatic stress disorder in adolescent survivors of childhood cancer. *Journal of Family Psychology*, 21(5).
- Alderfer, M. A., Long, K. A., Lown, E. A., Hamill, A. L., Ostrowicki, N. L., Heck, J. M., & Ewing, L. J. (2010). Psychosocial adjustment of siblings of children with cancer: a systematic review. *Psycho-oncology*, 19(8), 839-853.
- Aldridge, A. A., & Rosch, S. C. (2007). Coping and adjustment in children with cancer: A meta-analytic study. *Journal of behavioral medicine*, 30(2), 105-129.
- Bruce, M. (2003). A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents. *Clinical psychology review*, 23(3), 233-256.
- Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual review of clinical psychology*, 8, 355-388.
- Folkman, S., & Moskowitz, J. T. (2000). Coping: Pitfalls and promise. *Annu Rev Psychol*, 51, 745-774.
- Folman, S., & Moskowitz, J. T. (2000). Coping: Pitfalls and promise. *Annu Rev Psychol*, 51, 745-774.
- Klassen, F., Anthony, S. J., Khan, A., Song, L., & Klassen, R. (2012). Identifying determinants of quality of life of children with cancer and childhood cancer survivors: a systematic review. *Cancer Causes Control*, 23(6), 663-672.
- Kripalani, M. J., Natta, M. B., Richardson, C. C., Schleimann, J. L., Lovinger, J. V., & Due, L. (1995). Family coping with pediatric leukemia: Ten years after treatment. *Journal of pediatric psychology*, 20(3), 669-682.
- Kripalani, M. J., & Bringer, K. (2002). Stress and coping in the pediatric cancer experience. *Comprehensive handbook of childhood cancer and sickle cell disease: A biopsychosocial approach*, 2, 101-120.
- Long, K. A., & Alderfer, M. A. (2007). Family adjustment to childhood cancer: A systematic review. *Critical child and family psychology review*, 14(2), 9-28.
- Null, F. B., & Kripalani, M. J. (2007). Commentary: the psychological impact of pediatric cancer hardness: the exception or the rule? *Journal of Pediatric Psychology*, 31(6), 809-819.
- Oeffinger, J. C., Merhige, A. C., Sikka, C. A., Kawakami, T., Hudson, M. M., Meadows, A. T., ... & Schwartz, C. L. (2007). Chronic health conditions in adult survivors of childhood cancer. *New England Journal of Medicine*, 357(5), 570-582.
- Okuda, Y., Long, K. A., & Jaser, S. (2012). Coping between parent and child distress and the moderating effects of life events in families with and without a history of pediatric cancer. *Journal of Psychosocial Oncology*, 30(3), 309-326.
- Pai, A. L., Dotter, D., Zabrocki, K., Moore, M., & Youngstrom, E. (2006). A meta-analysis of the effects of psychological interventions on outcomes of psychological distress and adjustment. *Journal of Pediatric Psychology*, 31(6), 978-986.

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References – Hallie



- Howell CR, et al. Randomized web-based physical activity intervention in adolescent survivors of childhood cancer. *Pediatric Blood & Cancer*. 2018; 65(8): 1-7.
- Piscione PJ, et al. Exercise training improves physical function and fitness in long-term paediatric brain tumour survivors treated with cranial irradiation. *Eur J Cancer*. 2017; 80: 63-72.
- Miriam, et al. Experience of barriers and motivations for physical activities and exercise during treatment of pediatric patients with cancer. *Pediatric Blood Cancer*. 2014; 61: 1632-1637.
- Gilchrist L & Tanner S. Safety of exercise: Indications of physical therapy interventions in pediatric oncology patients with reduced red blood count. *Rehabilitation Oncology*. 2017; 35(1): 3-8.
- Schaefer KL, Kleinerman ES & Chandra J. Diet and exercise interventions for pediatric cancer patients during therapy: tipping the scales for better outcomes. *Pediatric Research*. 2018 (83): 50-56.
- Dusing SC, & Thorpe DE. A normative sample of temporal and spatial gait parameters in children using the GAITRite electronic walkway. *Gait Posture*. 2007 25(1): 136-139.
- Childhood Cancers: Questions and Answers - National Cancer Institute." National Cancer Institute - Comprehensive Cancer Center - Questions and Answers - Childhood Cancers - Childhood-Cancer-Sites-Types/childhood-Central-Venous-Catheters." American Cancer Society - Cancer: Venous Catheters, 11 Feb. 2016, www.cancer.gov/cancertopics/factsheet/Sites-Types/childhood.
- Nayager T, Anderson L, Cranston A, Athale U, Barr RD. Health-related quality of life in long-term survivors of acute lymphoblastic leukemia in childhood and adolescence. *Qual Life Res*. 2016 Nov 24
- Liberstein M, et al. Thirty-second walk test: Expansion of normative data. *Pediatric Physical Therapy*. 2018; 30(1): 18-25.

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