JOHNS HOPKINS CHILDREN'S CENTER · Children's National · UNIVERSITY of MARYLAND SCHOOL OF MEDICINE

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

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Financial Disclosures

- We have no financial disclosures…

Objectives

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

Outline

Kelly
- Childhood cancer and treatments

Amanda
- Psychosocial considerations

Hallie
- Rehabilitation considerations and recommendations

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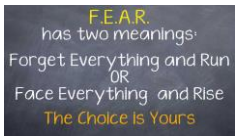
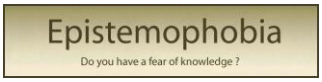
Fear





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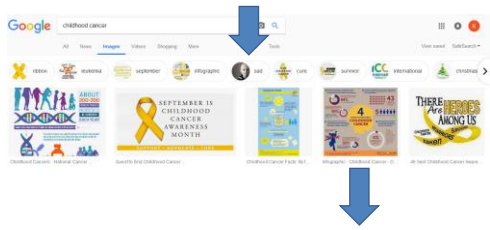
Fear??



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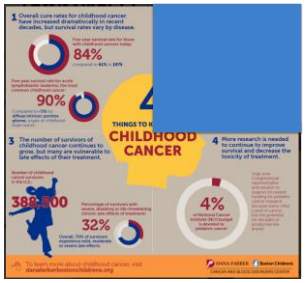

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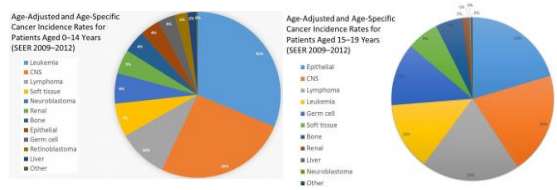
Childhood Cancer

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



https://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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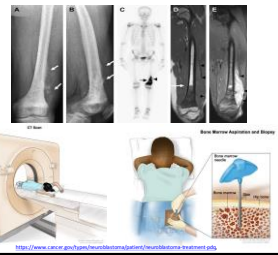
Diagnostics

- History and Physical
- Blood work
- Biopsy

Imaging
- X-rays
- Ultrasound
- CT/CAT scan
- MRI
- PET scan
- Bone scan
- MIBG (Metaiodobenzylguanidine)



Kaste SC, et al. Imaging Pediatric Bone Sarcomas. Radiol Clin North Am. 2011 Jul;49(4):749–65 https://www.cancer.gov/types/neuroblastoma/patient/neuroblastoma-treatment.pdq

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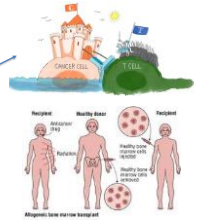
Medical Treatments

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



https://www.indiamart.com/proddetail/bone-marrow-transplant-treatment-7761649730.html, https://www.celgene.com/redirecting-immune-cells-fight-myeloma/

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Points of Entry of Physical Therapy

Pre-diagnosis
- Outpatient evaluation and/or treatment
- Outpatient gait training
- Inpatient general medical or orthopedic floors
- Rheumatology, orthopedic, and/or chronic pain clinics

Diagnosis
- Inpatient admission
- Outpatient oncology clinic

Treatment or late-effects
- 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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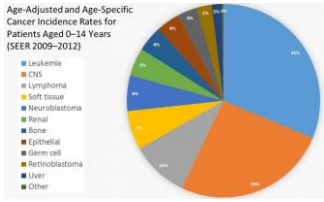
Types of Childhood Cancers

- Leukemia
- Brain Tumors
- Lymphoma
- Sarcoma
  - Bone
  - Soft Tissue
- Neuroblastoma
- Renal (kidney)
  - Wilms Tumor



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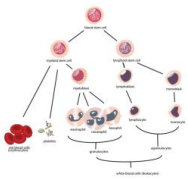
Blood Cells

- Red blood cells (hemoglobin): carry oxygen
- Platelets: help blood to clot

White Blood Cells (WBC)

- 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://lyceum.algonquincollege.com/lts/onlineCourses/anatomy/content/module11-8.htm

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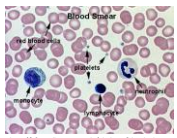
Blood Cell Counts

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



http://lifesci.dls.rutgers.edu/~babiarz/bloodtx.htm

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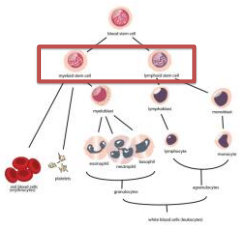
Leukemias

- Epidemiology
  - 4.7 per 100,000 children per year
  - 5-year survival: 83.9%
  - Highest incidences age 1-4 years old
  - Median age of diagnosis: 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
  - Bone pain
  - Fatigue
  - Pallor



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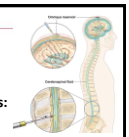
Leukemia

- **Treatment:**
  - 2 to 3 years of steroids and chemotherapy
    - Most common chemotherapy:
      - Vincristine
      - Methotrexate (Intrathecal)
      - Cytarabine (Intrathecal)
      - Busulfan
      - Cyclophosphamide
      - Doxorubicin
      - L-asparaginase
      - 6 MP (Mercaptopurine)
  - 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
  - Delayed processing speed

https://www.cancer.gov/images/cdr/live/CDR493773-750.jpg

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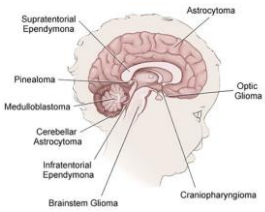
Brain Tumors

- 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



https://www.acco.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
  - Peripheral Neuropathy
  - Spasticity
  - Decreased balance
  - Ataxia (posterior fossa)
  - Participation restrictions
  - Decreased neurocognitive function

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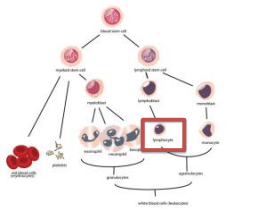
Lymphoma

- Epidemiology
  - 800 new cases per year
  - 5-year survival ~80%
  - >3 years old – adolescence
- Pathophysiology
  - Starts in 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)



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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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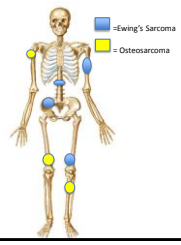
Sarcoma

- 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
  - Peripheral neuropathy
  - Musculoskeletal asymmetries
  - Physical limitations
  - Participation limitations
  - Adverse general health

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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
  - Allograph
  - Distraction Osteogenesis
- Amputation
- Rotationplasty
- Resection of lung metastasis

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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.

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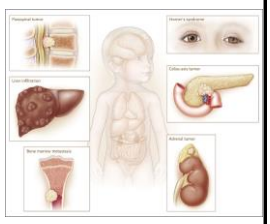
Neuroblastoma

- 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)
  - Opsoclonus myoclonus
    - Irregular, rapid eye movements (swimming)
    - Brief, shock-like muscle spasms (ataxia-like)



https://www.nejm.org/doi/full/10.1056/NEJMra0804377

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Neuroblastoma

- **Treatment:**
  - Most common chemotherapy:
    - Cyclophosphamide
    - Cisplatin or carboplatin
    - Vincristine
    - Doxorubicin
    - Etoposide
  - Observation
  - Surgery
  - Radiation
  - Iodine 131-MIBG therapy
  - Bone Marrow Transplantation
- **Long-term physical effects:**
  - Impaired health-related physical performance
  - Peripheral neuropathy
  - Weakness

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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

https://www.youtube.com/watch?v=GFdyuBn0ywe

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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

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Medical Plans of Care

Induction →	Consolidation/ Intensification →	Maintenance
Surgery →	Radiation →	Chemotherapy
Surgery →	Radiation	
Chemotherapy →	Surgery →	Chemotherapy
Surgery →	Chemotherapy	
Chemotherapy →	Radiation	

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http://www.chemocare.com/

Chemotherapy

- **Busulfan, Myleran** (leukemia, neuroblastoma)
  - Fatigue, tiredness, decreased appetite, hair loss, nausea/vomiting, diarrhea, myelosuppression
- **Cisplatin, Carboplatin** (brain tumors, lymphoma, sarcoma, neuroblastoma)
  - Myelosuppression, nausea/vomiting, 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
- **Cytarabine** (leukemia)
  - Back pain, fever, headache, nausea, neck pain or rigidity, sleepiness, vomiting , weakness, myelosupression
- **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

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http://www.chemocare.com/

Chemotherapy cont.

- **Etoposide** (lymphoma, brain tumors, sarcoma, neuroblastoma, Wilms tumor)
  - Myelosupreesion, 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
- **Thieotepa** (brain tumors, neuroblastoma)
  - Nausea/vomiting, decrease in blood cell counts, diarrhea, hair loss, skin rashes, mouth sores
  - "Thieotepa 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

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Other treatment effects

- **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 asymmetry, 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)

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Treatment-Specific Impairments

Peripheral Nervous System
- Peripheral Neuropathy
  - Clinical assessment and observation
  - ped-mTNS

Musculoskeletal System
- Range of Motion
- Strength
- Osteonecrosis
  - Children's Hospital Oakland Hip Evaluation Scale (CHOHES)
- Radiation Fibrosis

Central Nervous System
- Balance/Processing Speed
  - BOT-2
  - Timed up and go (TUG)

Cardiopulmonary
- Physical Fitness
  - 6-minute walk test
  - 9-minute walk-run test
  - 3-minute step-test
  - Bruce Treadmill Protocol
  - Timed up and down stairs (TUDS)

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PT Assessment: Peripheral Neuropathy

Gilchrist L. & Tanner L. 2016:
- ~6 months into treatment
  - ↓ ankle active and passive dorsiflexion range of motion and strength
  - ↓ BOT-2 balance and strength subscores, 6-minute walk test (6MWT) distance
  - GaitRite - ↓ velocity, step length, and cadence; ↑ base of support
  - Step length: ankle range of motion and balance

Wright et al. 2017:
- mean time off treatment 35.7 months
  - ↓ peak hip extension, knee flexion in loading, dorsiflexion at initial contact, plantarflexion at pre-swing, and dorsiflexion in swing
  - ↓ step length, lower ankle moments and power
  - Co-activation and atypical firing of gastrocnemius and tibialis anterior muscles

Gilchrist et al. 2017:
67 children treated for ALL, lymphoma, or solid tumor
- **ped-mTNS score ≥ 5**
  - On treatment (delayed intensification): 86.5%
  - 6-months off-treatment: 40.3%
    - ALL: 11.2%
    - Lymphoma: 57.7%
    - Solid Tumor: 60.0%

ped-mTNS (0 – 24)
- ROM
- Strength
- Sensation
  - Light touch
  - Pin
  - Vibration
- Deep Tendon Reflexes

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The Stoplight Program: Children's Hospitals and Clinics of Minnesota

Table 2. The Stoplight Program for Children and Adolescents With Acute Lymphoblastic Leukemia.

Functional Performance	Outcome Measurement	Red Level	Red Intervention	Yellow Level	Yellow Intervention	Green Level	Green Intervention
Activity level	Performance scale	≤60	• Strengthening • Activity modification	70-90	• Strengthening • Cycle training	>80	• 60 min/day PA recommendation
Joint ROM	Visual estimation/ goniometer	Abnormal flexibility	• Stretching • Orthotics • Neuromuscular reeducation	Abnormal flexibility	• Stretching • Orthotics • Neuromuscular reeducation	Normal flexibility	• Ankle and hamstring stretching during treatments
Passive ankle ROM	Goniometer	>0°	• Gait training • Strengthening	0-10°	• Gait training • Strengthening	≥10°	• See above
Floor to stand	½ kneel to stand	Unable	• Motor skill training	Needs upper extremity support	• Motor skill training	Independent	• See above
Gait	Observational analysis	Toe drag Toe walking Moderate foot slap Drop foot Lateral lurch	• Gait training • Orthotics • See above	Mild foot slap Short step length Endurance	• Gait training • Consider orthotics • See above	Normal heel-toe gait patterns	• See above
Balance	SLS	Severe impairment for age	• Balance training	Moderate impairment for age	• Balance training	At norm for age	• Balance incorporated in PA
Gross motor skills	PDMS II or BOT-2	≥ 1.5-2 SD below mean	• Motor skill training • See above	1-1.5 SD below mean	• Motor skill training • See above	Within 1 SD of mean	• See above
Typical PT frequency		1/week		1-2/month		Reassessments	

Abbreviations: BOT-2, Bruininks-Oseretsky Test of Motor Proficiency, version II; PA, physical activity; PDMS II, Peabody Developmental Motor Scales version II; ROM, range of motion; SLS, single leg stance.

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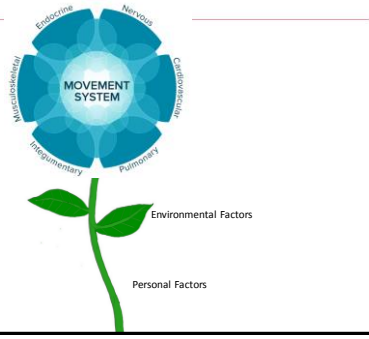

Coping with Childhood Cancer- An Overview

- 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

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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

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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

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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

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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

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Coping Issues for School-Age Children

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

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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

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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

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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)

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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 (1/4-1/3) of children and families experience more significant distress that indicate need for increased care.
  - Abrams et al., 2007; Aldridge & Roesch, 2007; Kazak et al., 2012; Patenaude & Kupst, 2005

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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.*)

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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**

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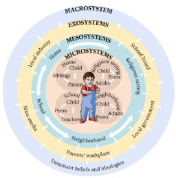
Family Dynamics

- 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



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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

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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).

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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.
  (Compas et al., 2012; Folkman & Moskowitz, *2004*)

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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.**
  - If you are worried about a patient, there are others that can assess and provide treatment for more significant psychological issues that may arise.

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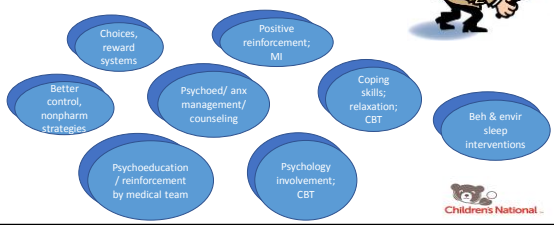
The Nonadherent Patient

Be a detective: What might be contributing to refusal?



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Long term physical effects of childhood cancer

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- Obesity
- Atherogenic dylipidea
- Increased blood pressure
- Insulin-resistance
- Osteoporosis
- Fatigue
  - Amplified by physical inactivity (Naylager, et al. 2016)

Why the late effects?

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

Why exercise after cancer

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

P.J. Piscione [a], E. Bouflet [b], B. Timmons [c], K.S. Courneya [d], D. Tetzlaff [e], J.E. Schneiderman [f], C.B. de Medeiros [f], U. Bartels [h], D.J. Mabbott [g,h]

- 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 exercise after cancer cont.

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- Marchese (2004): after in-person and home exercise PT program, children with ALL improved ankle dorsiflexion range of motion and knee extension strength.
- Tanner (2019): Children with ALL who participated in Stoplight Program (a proactive physical therapy program) demonstrated increased ankle dorsiflexion range of motion, and BOT-2 scores for bilateral coordination, running speed/agility, and strength compared to children who did not participate in program during treatment.

Why is exercise a challenge in this population?

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

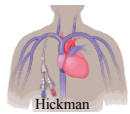
Treatment considerations

- 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

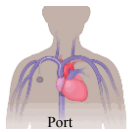
Chemotherapy specific impairments

Treatment	Impairment	Disability
Methotrexate	Cognitive impairment, developmental delay, learning problems, motor/coordination impairments, osteoporosis (increased risk of fractures)	Decreased age-appropriate ADL, 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	Parasthesia, 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 endrance/exercise tolerance, limited participation in sports
Cisplatin/Carboplatin	High-frequency sensorineural hearing loss, tinnitus	Affects communication skills and potentially speech/language
Cyclophosphamide/Ifosfamide	Neurotoxicity (reversible) with somnolence, disorientation, lethargy, hallucinations, AVN	Limit age-appropriate ADLs, may impact ambulation

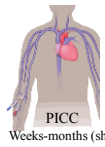
Central line/port considerations



Hickman
- Tunneled
- Needs to be covered before showering
- No swimming



Port
- Can be implanted for years
- Least restrictive
- Avoid impact to chest



PICC
- Weeks-months (short term)
- Avoid repetitive overhead arm movement
- Needs to be covered before showering
- No swimming

American Cancer Society

Blood counts

- 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
  - Typically won't transfuse until <7 unless symptomatic

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

Keeping up with peers: use of outcome measures

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- 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

Treatment strategies

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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

Fun PT is the best PT

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- 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

Questions?

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http://ebrajan.blogspot.com/2012/01/childhood-leukemia.html

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