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- Email customerservice@OccupationalTherapy.com

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Occupational Therapy Considerations for the Pediatric Stem Cell Transplant Patient

Laura Stimler, OTD, OTR/L, BCP, C/NDT
OccupationalTherapy.com

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Learning Outcomes:

- identify common pediatric cancer diagnoses and non-malignant conditions that may warrant stem cell transplantation.
- describe types of pediatric stem cells transplants and potential side effects across the continuum of care.
- select appropriate occupational therapy assessment tools and interventions for pediatric patients following SCT in various practice settings.

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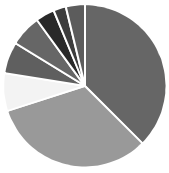
Introduction

3

Pediatric Cancer



- Leukemia (30%)
- Brain and spinal cord tumors (26%)
- Neuroblastoma (6%)
- Wilms Tumor (5%)
- Lymphoma (3-5%)
- Rehabdomyosarcoma (3%)
- Retinoblastoma (2%)
- Bone cancer (osteosarcoma and Ewing) (3%)

(ACS, 2016)

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Commonly used to treat

- Leukemia
- Lymphoma
- Myelodysplastic Syndrome (MDS)
- Myelofibrosis
- Multiple myeloma (cancer of plasma cells)

(www.bethematch.org, 2019)

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Non-malignant Conditions

- Severe aplastic anemia
- Fanconi's anemia
- Paroxysmal Nocturnal Hemoglobinuria (PNH)
- Sickle cell disease
- Thalassemia
- Wiskott-Aldrich Syndrome (WAS)
- Severe Combined Immunodeficiency Syndrome (SCIDS)

(www.bethematch.org, 2019)

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Statistics

- In 2015, approx. 429,000 childhood cancer survivors lived in the US (SEER Cancer Statistics Review 1975-2015; cancer.gov/childhood)
- In 2018, approx. 10,590 new cases were diagnosed among children birth – 14 years (NCI, 2018)
- According to the NCI, approx. 1,180 children were expected to die in 2018
- Survival rates have dramatically improved over last 30 years

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Pediatric Cancer Treatment and Stem Cell Transplantation (SCT)

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Pediatric Cancer Treatment

- Surgery
- Radiation
- Chemotherapy
- Immunotherapy
- Stem cell transplantation (SCT)
- Pediatric oncologist
- Pediatric surgeons
- Radiation oncologists
- Pediatric oncology nurses
- NPs and PAs

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History of Stem Cell Transplantation

1896

Early discussion outlined in the Journal of the American Medical Association

Physicians explored the idea of replacing damaged parts of the body with healthy organs since the earliest days of medicine

1940s

During and after WWII, research on transplantation was a high priority

Increased need to treat victims exposed to high doses of radiation leading to bone marrow failure, and those in need of skin grafts & blood transfusions

Following WWII

Significant amounts of radiation exposure created an opportunity to research treatments related to bone marrow failure and leukemia

Evidence suggesting graft rejection was related to histocompatibility continued to grow

(de la Morena & Gatti, 2011)

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History continued

1950s-1960s	1970s	1980s-1990s
Early transplants were being performed with growing evidence identifying complications related to graft rejection	Increased emphasis on donor selection and prevention of GVHD	Rapid increase in frequency of transplants performed and t-cell depletion techniques introduced
First HLA antigens in humans were described	First successful transplant from unrelated donor performed	National and international registries developed and cord blood was used as a source of stem cells
Research grew highlighting rejection prevention		

(de la Morena & Gatti, 2011; MSKCC, 2019)

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Stem Cell Transplantation Today

- Now considered standard of care for many groups
- Two main types:
  - **Autologous** (patient is “donor”)
  - **Allogeneic** (matched related or unrelated donor)
    - Matched related (sibling, close family member)
    - Unmatched unrelated (national registry)
    - Umbilical cord (“cord blood” taken from placenta)

(ACS, 2016)

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Stem Cell Transplantation Today

- Mini-transplants (non-myeloablative)
  - Reduced-intensity conditioning (RIC)
- **Syngeneic** stem cell transplant: identical sibling
- Half-matched transplant
- Human leukocyte antigens (HLA) and histocompatibility testing

(ACS, 2016)

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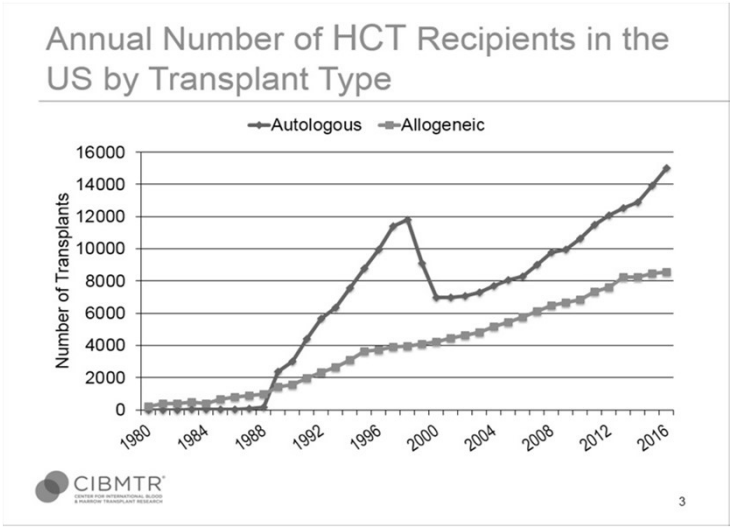

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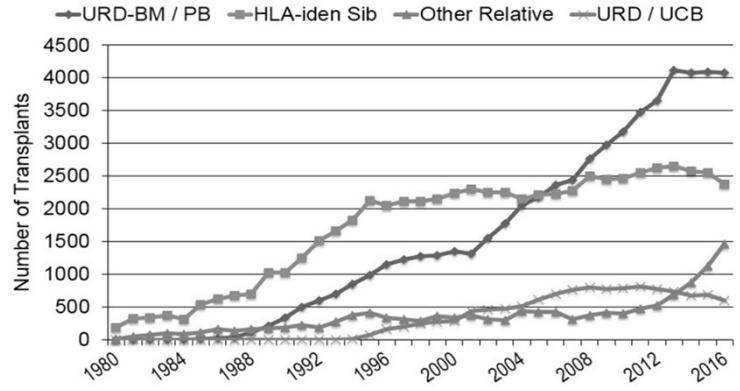
Allogeneic HCT Recipients in the US, by Donor Type



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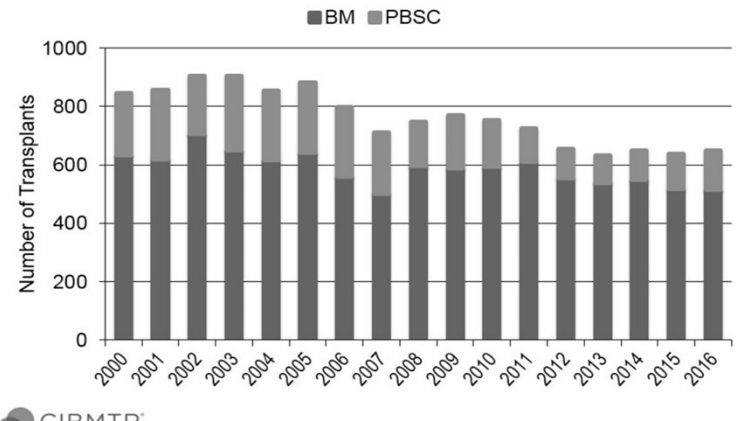
HLA-Matched Sibling Donor Allogeneic HCT in Patients <18 Years



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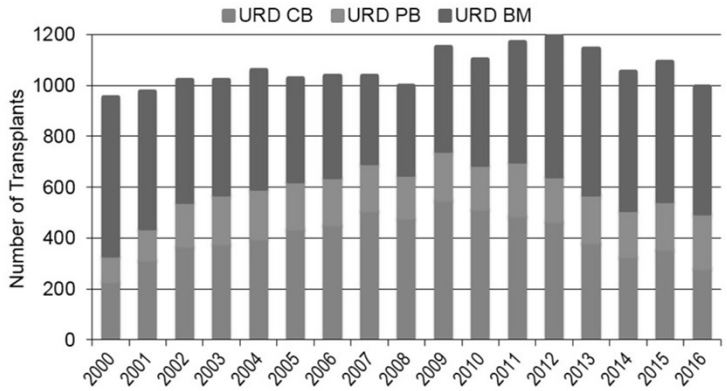
Unrelated Donor Allogeneic HCT in Patients <18 Years



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Process for SCT

- Stem cells come from bone marrow, peripheral blood, or umbilical cord blood (apheresis)
- Preparative or Conditioning Regimen:
  - Begins with RT and/or chemo (approx. 1-2 weeks)
  - Total body irradiation (TBI)
    - kills diseased cells in prep for healthy blood (approx Day-7)
- Medication given through central venous catheter (i.e., Hickman® Broviac®)
- Few days of rest
- Leukapheresis: auto SCT process for removing WBCs from stem cells.

(bmtinfonet.org, 2018; MSKCC.org, 2018; NCI, 2018)

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Day of Transplant: "Day 0"

- Healthy blood cells are infused, similar to that of a blood transfusion
- Receive stem cells through IV catheter (similar to receiving blood transfusion) and takes 1-5 hours

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CONTINUED

Recovery

- Post transplant:
  - positive-numbered days (Day +1, etc.)
  - **Engraftment:** period of time during which healthy blood cells are produced (2-3 weeks, depending on the type of transplant)
- Recovery phase: wait for new blood cells to form
- Discharge from hospital is considered when bodies can produce blood cells efficiently and the patient's appetite improves.
- Can take 1-2 years for immune system to normalize

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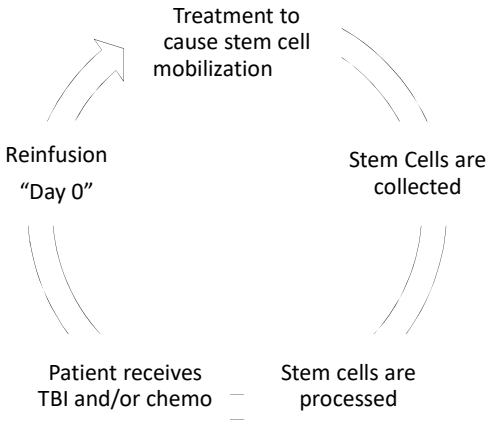
Autologous SCT Process



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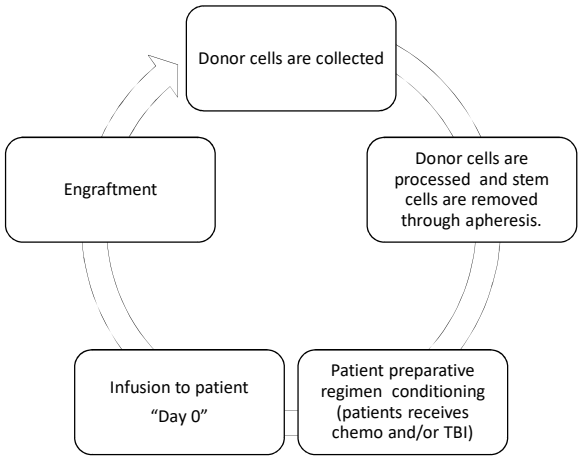
Allogeneic SCT Process



(LLS, 2018)

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Side Effects of SCT

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Physical Side Effects

- Infections
- Nausea, vomiting, diarrhea
- Mucositis
- Hair loss
- Muscle spasms and cramping
- Bladder irritation and liver problems
- Cardiopulmonary complications
- Fatigue
- Hearing loss

(Stark et al., 2016; NCI, 2018)

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Complications

- Veno-occlusive Disease (VOD)
- Pancytopenia/thrombocytopenia
- Graft-Versus-Host Disease (GVHD)
  - Occurs in approx. 30-70% of allogeneic SCT
  - Condition that occurs when recipient's body recognizes donor cells as foreign, and rejects the stem cell transplant
    - Acute (aGVHD)
    - Chronic (cGVHD)

(Evangelist & Smith-Gabai, 2018)

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Graft-Versus-Host Disease

Acute GVHD (aGVHD)

- Develops within 100 days post transplant
- Skin, GI tract, or liver
- Skin integrity changes and rash develops
- GI issues, jaundice

Chronic GVHD (cGVHD)

- Develops after 100 days post transplant
- One of the most frequent complications and causes of death following allo transplants (30-70%) (Tecchio et al., 2013)
- Single or multiple organ involvement

(Evangelist & Smith-Gabai, 2018; Gerber & Molnar, 2009; LLS, 2018)

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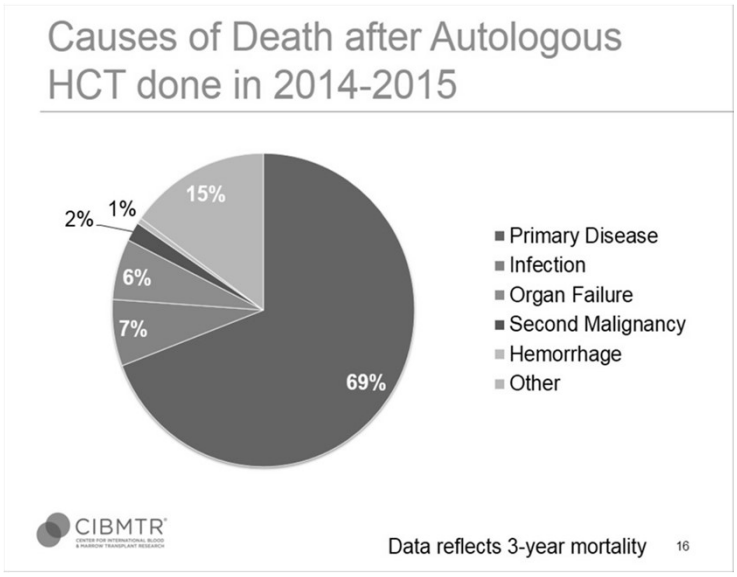

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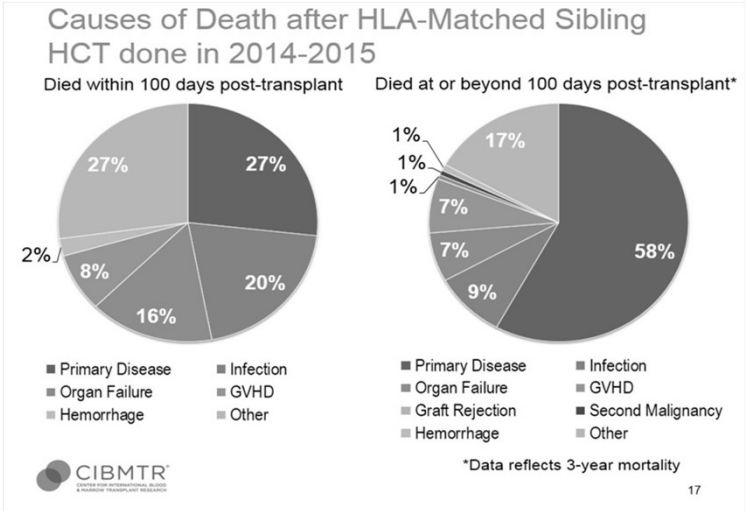

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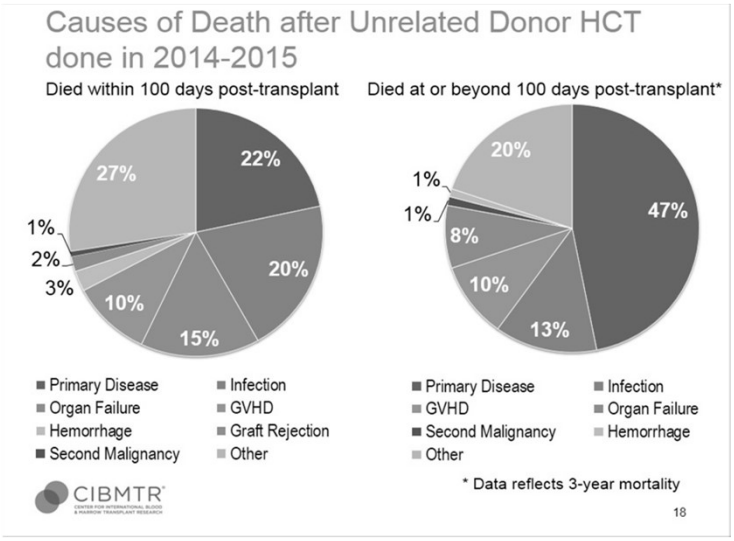

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Chemotherapy-Induced Peripheral Neuropathy (CIPN)

- Sensory and motor components
- Decreased fine motor control reported among children diagnosed with leukemia treated with vincristine
  - (Reinders-Messelink et al., 2001; Sabarre, Rassekh & Zwicker, 2014)

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Psychosocial Side Effects

- Anxiety
- Depression
- Self-image
- PTSD in parents and siblings

(Coban, Adanir, & Ozatalay, 2017)

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Functional Implications

- Decreased strength, fatigue
- Delayed acquisition of motor skills
- Cognitive changes due to disease and severe side effects of treatment
- Social isolation
- Limited opportunity to explore natural environment
- Decreased exposure to sensory experiences

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Evaluation

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Evidenced-based OT Evaluation

Areas for evaluation

- ROM/goniometry
- MMT
- Strength
- Pain scales
- Monofilaments/sensation
- Fatigue
- ADL performance
- Mood and sexual function
- Play
- Psychosocial functioning

Commonly used assessment tools

- COPM
- PedsQL
- MOCA
- BOT-2
- AIMS
- PDMS
- pedsTNS (Total Neuropathy Scale)

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Intervention

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OT Intervention

- Education on activity parameters
  - ROM
  - Cardiopulmonary
  - Infection prevention
    - Good hand hygiene, bedside treatments
    - Wash all items or use only new
- Check vitals and labs daily
  - Treatment may impact HR, BP, cognition, vision/hearing, appetite (Braveman & Hunter, 2017)

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Thrombocytopenia and Therapeutic Activity

- Retrospective review study on pediatric patients admitted for STC in acute care setting
- Analyzed correlation between activity intensity and occurrence of bleeding complications
  - No correlation noted between bleeding events or rehabilitation activity (Ibanez et al., 2018)
- Follow institution-specific guidelines
  - Hgb, INR, platelets, IVIG, ATG

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Evidence supports exercise

- Implement strategies to decrease barriers related to side effects and symptoms (i.e., maintain strength, endurance, functional capacity, decrease pain)
  - Exercise (Blackburn et al., 2016; Bogg et al., 2015)

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ADL performance

- During ADL routine, flossing, contact sports, heavy exercise or sexual intercourse may have limitations during to low platelet levels and bleeding precautions
  - Typically all activities are cleared with platelet levels above 50,000
- Shave with electric razor, gently blow nose, soft-bristled toothbrushes (Evangelist & Smith-Gabai, 2017)
- Prioritize sleep and rest!

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Play

- Play-based therapy to decrease anxiety for children receiving complex medical procedures and treatment
  (Grissom et al., 2016)
- Create accessible play opportunities during inpatient admissions and access to safe items
  - Sticker charts for motivation
  - Use of objects in room (towels, tape, gloves, basins, straws, etc.)
  - Window markers and sensory stimulation

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Education

- Formal Liaison programs to ease the transition back into school settings

  (Hay, Nabors, Sullivan, & Zygmund, 2015)

- Prioritize education participation for families and patients
- CREATE THE CULTURE!!

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OT Follow-up

- Rehab services are frequently recommended in outpatient setting following discharge
- OT focus:
  - Stress management (relaxation techniques, cognitive-behavioral strategies)
  - Self-monitoring
    - Rate of Perceived Exertion (RPE)
    - Exercise
    - Returning to work or school
    - Sexual health
    - Play

(LLS, 2018; Smith-Gabai, 2017)

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Additional support services:

- Physiatry
- PT, Speech
- Child Life
- Psych
- Nutrition
- Music/dance therapy
- Education
- Integrative Medicine

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Survivorship

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Survivorship Considerations

- Risk for organ complications, cardiopulmonary complications, sleep issues, sexual/reproductive development, slowed growth rate, bone loss and osteoporosis, cataracts, depression, anxiety, relapse or secondary cancer
- Improved overall survival (Svenberg et al., 2016)
- Complications are more common following allo SCT (Hierlmeier et al., 2018)

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Summary

- Cancer survivorship is a chronic condition (Baxter et al., 2017)
- Pediatric SCT patients are at risk for delay due to significant side effects of treatment and strict isolation precautions.
- Evidence supports the use of exercise, relaxation/mindfulness, play, and the involvement of OT for both qualitative and quantitative gains in pediatric patients admitted for SCT.

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Resources on SCT

- Children's Oncology Group (COG)
- American Cancer Society
- National Cancer Institute
- Blood & Marrow Transplant Information Network (www.bmtinfonet.org)
- Be the Match® operated by the National Marrow Donor Program® (US) https://bethematch.org/
- American Society for Blood and Marrow Transplantation (ASBMT) www.asbmt.org

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Resources on SCT

- The Center for International Blood & Marrow Transplant Research (CIBMTR) www.cibmtr.org
- National Bone Marrow Transplant Link (nbmtLINK) www.nbmtlink.org
- https://www.nccn.org/ (National Cancer Comprehensive Network [NCCN])

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OT & Cancer Rehab Resources

- AOTA Cancer Rehabilitation Digital Badge Program:
  - Occupational Therapy's Unique Contributions to Cancer Rehabilitation
  - Impact of Psychosocial Aspects of Cancer on Occupational Engagement
  - Lymphedema and Breast Cancer for OT Practitioners
  - Lymphedema Basics
  - The Role of OT with Cancer Related Fatigue
  - Cancer-Associated Cognitive Impairment
- AOTA's Oncology Fact Sheet
- OT Practice Guidelines for Cancer Rehabilitation with Adults (Braveman & Hunter, 2017)
- Cancer Rehabilitation: Principles and Practice (Stubblefield & O'Dell, 2009)

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Q & A:
What are your questions?

Laura Stimler: lstimler@spalding.edu

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CONTINUED

Please refer to additional word document for complete reference list

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