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Occupational Therapy Considerations for the Pediatric Stem Cell Transplant Patient
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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.
Introduction

Pediatric Cancer

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

(ACS, 2016)
Commonly used to treat

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

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)
Statistics

- 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

Pediatric Cancer Treatment and Stem Cell Transplantation (SCT)
Pediatric Cancer Treatment

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

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)
History continued

1950s-1960s
- Early transplants were being performed with growing evidence identifying complications related to graft rejection
- First HLA antigens in humans were described
- Research grew highlighting rejection prevention

1970s
- Increased emphasis on donor selection and prevention of GVHD
- First successful transplant from unrelated donor performed

1980s-1990s
- Rapid increase in frequency of transplants performed and t-cell depletion techniques introduced
- National and international registries developed and cord blood was used as a source of stem cells

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

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)
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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Annual Number of HCT Recipients in the US by Transplant Type

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)
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

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
Autologous SCT Process

- Treatment to cause stem cell mobilization
- Reinfusion “Day 0”

- Stem Cells are collected
- Stem cells are processed

- Patient receives TBI and/or chemo

Allogeneic SCT Process

- Donor cells are collected
- Donor cells are processed and stem cells are removed through apheresis.

- Engraftment
- Infusion to patient “Day 0”

- Patient preparative regimen conditioning (patients receive chemo and/or TBI)

(LLS, 2018)
Side Effects of SCT

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)
## 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)

## 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)
Causes of Death after Autologous HCT done in 2014-2015

Data reflects 3-year mortality

Causes of Death after HLA-Matched Sibling HCT done in 2014-2015

Died within 100 days post-transplant
Died at or beyond 100 days post-transplant*

Data reflects 3-year mortality
Chemotherapy-Induced Peripheral Neuropathy (CIPN)

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

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

(Coban, Adanir, & Ozatalay, 2017)

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
Evaluation

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)
Intervention

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)
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

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)
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!

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
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!!

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)
Additional support services:

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

Survivorship
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 (Hiermeyer et al., 2018)

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.
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])
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)

Q & A:
What are your questions?
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Please refer to additional word document for complete reference list