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Psychosocial Considerations for Pediatric Patients Undergoing Treatment for Cancer

LAURA STIMLER, OTD, OTR/L, BCP, C/NDT

Objectives

1) Identify psychosocial concerns and conditions among pediatric oncology patients.

2) Recognize relevant and evidence-based psychosocial assessment tools for occupational therapy practitioners.

3) Identify appropriate and evidence-based psychosocial occupational therapy intervention techniques.
Pediatric Oncology Overview

Pediatric Cancer Statistics

- Leading cause of death by disease between infancy through 14 years
- Second leading cause of death in children
- Estimated 10,380 new cases in the US are expected to occur in 2016 (between ages 0-15 years)

(American Cancer Society, 2016)
Common Cancers Among Children

- Leukemia 31%
- CNS 25%
- Neuroblastoma 6%
- Wilm's Tumor 5%
- Non-Hodgkin Lymphoma 4%
- Hodgkin Lymphoma 4%
- Rhabdomyosarcoma 3%
- Osteosarcoma 3%
- Retinoblastoma 2%
- Ewing Sarcoma 1%

(American Cancer Society, 2016)

Pediatric Survival Rates

Survival rates have dramatically improved!!
- 5 year survival rate is currently over 83%

<table>
<thead>
<tr>
<th></th>
<th>Survival Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Today</td>
<td>83%</td>
</tr>
<tr>
<td>1970's</td>
<td>58%</td>
</tr>
</tbody>
</table>

(American Cancer Society, 2016)
Pediatric Psychosocial Development

Infant
- Sensorimotor/attachment

Preschool age
- Egocentric/associated logic
- Family is primary domain of social support

School age
- “Mastery of skills”/Logical thinking
- Proud to participate in care

Pediatric Specific Burdens

- **Family issues**
  - Feel need to protect child from everything
  - Financial stress
  - Difficulty dealing with siblings
  - Unable to a break from burden of care

- **Patient issues**
  - Limited understanding of life and death depending on developmental process
  - May lack verbal skills to describe feelings, pain
  - May protect others at own expense
  - Not legally competent

(www.chionline.org)
Adolescent Psychosocial Development

• Develop independence from family
• Establish interpersonal relationships
• Development of individual sense of identity
• Pursue education and employment goals

Adolescent Specific Burdens

• Now dependent on families again for self care and emotional support
• Altered body image and low self esteem
• Education and career plans are disrupted
Psychosocial Implications

Zachary: Age 4
http://www.humansofnewyork.com/

Social Interaction

[Graph showing WeeFIM® item rating pattern comparison at admission]
History

• During the last 40 years, a subspecialty devoted to cancer related psychosocial care has been established

• Late development is result of 2 things:
  ◦ Only then (1970’s) had the stigma attached to cancer diminished to the extent that most patients were told their diagnosis
  ◦ Negative stigma attached to mental illness and psychological problems

(Jacobsen, Holland, & Steensma, 2012)

Recent Developments

• Formulation of standards of cancer care by Institute of Medicine and other organizations

• Development of clinical practice guidelines by the National Comprehensive Cancer Network (NCCN) and other organizations to include specific recommendations for the psychosocial care

• Formulation and implementation of measurable indicators of the quality of psychosocial care in oncology settings including those used as part of the American Society of Clinical Oncology’s Quality Oncology Practice Initiative.

(Jacobsen et al., 2012)
Standards Specific to Pediatrics

• Youth diagnosed with cancer, including family members, should be assessed routinely for psychosocial needs throughout trajectory of care
• Pediatric patients diagnosed with brain tumors and other high risk conditions should be tested throughout treatment for neuropsychological deficits
• Long term survivors of childhood and adolescent cancers should be screened annually for depression, distress, and anxiety
• Siblings of pediatric patients are considered to be an at-risk population and should be screened

(Weiner, et al. 2015)

Issues Addressed in Standards

Distress
Depression
Delirium/neuropsychological function
Anxiety

(Jacobsen et al., 2012)
Periods of Increased Vulnerability

- Treatment failure
- Recurrence
- Progression of disease
- Transition to survivorship

(Sheldon, Harris, & Arcieri, 2012)

National Comprehensive Cancer Network (NCCN)

Developed and revised guidelines for distress management in cancer patients

(Sheldon et al., 2012)

Tool for measuring distress:
- Distress Thermometer (DT)

(NCCN, 2013)
Pediatric Evidence-Based Considerations

Studied 91 pediatric patients between ages 2-34 (majority between 5-18 years)

- Distress Rating Scale (DRS)
- Children’s Depression Inventory (CDI)
- Pediatric Quality of Life Generic Core Scales Cancer Modules (PedsQL)
- Brief Symptom Inventory = 18 items (BSI – 18)
- Intensity of Treatment Rating Scale 2nd Edition (ITR-2)
- Cumulative tri-level Distress Classification

(Patel et al., 2011)
Results

Distress Ratings over time for patients and caregivers 0-10

- Patient Self-Rating (5-18)
- Patient Self-Rating (>18)
- Parent Rating of Patients
- Psychosocial Team Rating of Patients
- Medical Team Rating of Patients
- Caregiver Self-Rating
- Psychosocial Team Rating of Caregivers
- Medical Team Rating of Caregivers

(Patel et al., 2011)

Multidisciplinary Approach

- Psychiatry
- Psychologist
- Nursing
- Social Work
- Child Life Specialist
- Integrative Medicine
- Family and caregiver
- Spiritual Care
OT Evaluation

• Pediatric Quality of Life Inventory (PedsQL)
  o Physical Health Summary, Psychosocial Health Summary, & Total Health Related Quality of Life Score
  o Parent report
  o Child Report [Palmer, Meeske, Katz, Burwinkle, & Varni, 2007]
### PedsQL Physical Health Summary

#### About My Health and Activities

<table>
<thead>
<tr>
<th>Problem</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. It is hard for me to walk more than one block</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. It is hard for me to run</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. It is hard for me to do sports activity or exercise</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. It is hard for me to lift something heavy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. It is hard for me to take a bath or shower by myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

*Palmer et al., 2007*

### PedsQL Psychosocial Health Summary

#### How I Get Along With Others

<table>
<thead>
<tr>
<th>Problem</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have trouble getting along with other kids</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Other kids do not want to be my friend</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I cannot do things that other kids my age can do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

*Palmer et al., 2007*
OT Evaluation

Canadian Occupational Performance Measure

Short Child Occupational Performance Evaluation (SCOPE)
- Occupation-focused assessment
- Determines how a child’s volition, habituation, skills, and the environment facilitate or restrict participation

(Boyer et al., 2008)

OT Intervention
Occupational Therapy Intervention

• Encourage participation in ADLs, leisure activities, and age appropriate occupations.
• Modify environment to promote play and familiar routines.
• Incorporate relaxation techniques and coping strategies.
• Provide family training.

Occupational Therapy Intervention

• Decrease burdens of cancer treatment including fatigue, pain, and decreased cognition through education/HEP
• Encourage communication with siblings and peers
• Request appropriate referrals for additional support services.
• DME training and discharge recommendations for necessary services and community resources
Relaxation Program

• Descriptive study on clients’ experience of participating in an occupational therapy-led relaxation program
  ◦ Retrospective, hermeneutic phenomenology approach
  ◦ 4 themes identified
  (Cooper, 2014)

Play

• Randomized Clinical Trial:

Effectiveness of unstructured play facilitated by occupational therapist on stress in hospitalized pediatric clients
  ◦ Results: significant difference when considering age and gender (p<0.001) in intervention group
    ◦ Boys ages 7-11 years decreased 36%
    ◦ Girls ages 7-11 years decreased 47%
  (Potasz, Vilela de Varela, Coin de Carvalho, Fernandes do Prado, & Fernandes do Prado, 2012)
Summary

- Pediatric cancer patients are at risk for psychosocial challenges including distress, anxiety, and depression.
- Standards have been established by accrediting bodies and organizations to improve the delivery of psychosocial services to the pediatric cancer population.
- Occupational therapists play a critical role in addressing the psychosocial needs of this population through assessment and intervention.
- Evidence on the role of occupational therapy and pediatric cancer patients is limited.

What are your questions?

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