Patient and Parent Experiences of Cancer Symptoms as Assessed by the Memorial Symptom Assessment Scale for Children

Melody Hellsten, DNP, APRN, PPCNP-BC, CHPPN
Symptoms in Childhood Cancer

• Children and adolescents with cancer experience multiple symptoms over the course of treatment

• Symptoms have been shown to cluster together creating challenges in symptom assessment and management

• Symptom burden has been linked to poorer quality of life

Aim

Explore the symptom experience of patients age 7-18 and their primary caregivers based on the symptoms they endorse on a symptom assessment tool

Target Population

English-speaking children ages 7-12 and 13-18 with cancer receiving chemotherapy and their caregivers

Consented 17 patient/caregiver dyads
Memorial Symptom Assessment Scale

• Scales based on Adult MSAS for two age groups
  • 10-18 (Collins, 2000)
    • 30 symptom related questions
    • Individual symptom and total MSAS score
    • 3 subscale scores – Psych, Phys, Global Distress
    • Chronbach α for Psych (0.83), Phys (0.87), GDI (0.85)
  • 7-12 (Collins, 2002)
    • 8 symptom questions
    • Individual symptom and total MSAS score
    • Frequency, Severity, Distress Overall α 0.67

• Provides multidimensional assessment of symptoms

• Most widely used scale in pediatric oncology symptom research
# Demographics

<table>
<thead>
<tr>
<th>Age in years</th>
<th>Overall (n=17)</th>
<th>MSAS 7-12y (n=10)</th>
<th>MSAS 13-18y (n=7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>11.6</td>
<td>9</td>
<td>15.3</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male/Female</td>
<td>12/5 (70.6/29.4)</td>
<td>7/3 (70/30)</td>
<td>5/2 (71.4/28.6)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Overall (n=17)</th>
<th>MSAS 7-12y (n=10)</th>
<th>MSAS 13-18y (n=7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Leukemia No. (%)</td>
<td>11 (64.7)</td>
<td>7 (70)</td>
<td>4 (57.1)</td>
</tr>
<tr>
<td>Lymphoma No. (%)</td>
<td>1 (5.9)</td>
<td>0 (0)</td>
<td>1 (14.3)</td>
</tr>
<tr>
<td>Osteosarcoma No. (%)</td>
<td>3 (17.6)</td>
<td>2 (20)</td>
<td>1 (14.3)</td>
</tr>
<tr>
<td>Ewing's Sarcoma No. (%)</td>
<td>1 (5.9)</td>
<td>0 (0)</td>
<td>1 (14.3)</td>
</tr>
<tr>
<td>LCH No. (%)</td>
<td>1 (5.9)</td>
<td>1 (10)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

* 2 females (1 adolescent and 1 child) completed the MSAS, but not the interview portion of the study
Mixed Methods Approach

- Validated Symptom Assessment Tool

Semi-structured Interview

Data Analysis

MSAS Scores

Themes
MSAS Scoring

• Symptom Score
  • Equals the average scores for severity, distress, frequency
    • 7-12 likert scale 0-3, max score = 9
    • 13-18 likert scale 0-4, max score = 12

• MSAS Total Score
  • 7-12 – avg of all 8 symptom scores
  • 13-18 – avg of all 30 symptom scores

• Subscale Scores – 13-18 only
  • Psych – avg of 6 psychological symptom scores
  • Phys – avg of 11 physical symptoms
  • Global Distress Index – avg of 10 highly prevalent symptoms
Results

Age 7-12, 8 symptom questions

Age 13-18, 30 symptom questions

<table>
<thead>
<tr>
<th>Metric</th>
<th>Age 7-12</th>
<th>Age 13-18</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avg. # of symptoms</td>
<td>3.8</td>
<td>16.0</td>
</tr>
<tr>
<td>Avg. Frequency</td>
<td>1.7</td>
<td>2.3</td>
</tr>
<tr>
<td>Avg. Severity</td>
<td>2.0</td>
<td>2.1</td>
</tr>
<tr>
<td>Avg. Distress</td>
<td>1.6</td>
<td>2.1</td>
</tr>
</tbody>
</table>

MSAS 7-12y

MSAS 13-18y
Symptom Prevalence

Prevalence

- Sleep: 0.50
- Pain: 0.60
- Tired: 0.50
- Feel like vomiting: 0.50
- Worried: 0.40
- Sad: 0.40
- Itchy: 0.30
- Eating: 0.70
Symptom Prevalence

MSAS 13-18

- Concentration
- Lack of Energy
- Nausea
- Drowsy
- Hair Loss
- Dry mouth
- Sleeping
- Shortness of Breath
- Appetite
- Don’t look same
- Pain
- Weight Loss
- Change in Taste
- Irritable
- Vomiting
- Pins Needles
MSAS 13-18 Subscales

MSAS 13-18

A001 A002 A003 A004 A005 A006 A007 A008

MSAS Score GDI PHYS PSYCH
Severity vs Distress

Persistent discussion in literature about relationship of severity to distress

MSAS 13-18 most prevalent symptoms varying by severity to distress

- **HAIR LOSS**
- **CONCENTRATION**
- **DRY MOUTH**
- **WEIGHT LOSS**
- **NAUSEA**
- **SHORTNESS OF BREATH**
- **APPETITE**
- **MOUTH SORES**

Distress < Severity

Distress > Severity
<table>
<thead>
<tr>
<th>Severity</th>
<th>Description</th>
<th>Distress</th>
<th>Discrpcion</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Lack of Energy Frequency Description</td>
<td>2</td>
<td>&quot;it's annoying being tired, which I consider distressing&quot;</td>
</tr>
<tr>
<td>4</td>
<td>Pretty Constant</td>
<td>3</td>
<td>&quot;summer was spent rollerblading, playing soccer&quot;</td>
</tr>
<tr>
<td>1</td>
<td>almost everytime I do something like walk up stairs</td>
<td>2</td>
<td>pretty sluggish today</td>
</tr>
<tr>
<td>3</td>
<td>if I were to try doing something I get really tired. I guess just I lack energy during that time but I get tired really fast doing whatever. I run out of breath.</td>
<td>3</td>
<td>yeah pretty much. Even like when I play guitar, my fingers don't feel the same. They seem to get so tired. I feel like I can't do much really.</td>
</tr>
<tr>
<td>3</td>
<td>just depends what I am doing. So like...I get tired just walking pretty much sometimes. Not through here. I just like, keep walking. I get tired I. Pretty tired I guess.</td>
<td>3</td>
<td>Does it keep you from doing most of the things you like to do? P: Uh huh</td>
</tr>
<tr>
<td>2</td>
<td>when I get off the chemo, it really knocks me out.</td>
<td>3</td>
<td>Feel so tired, so worn out. Sometimes I feel like my body dying, like my cells dying...</td>
</tr>
<tr>
<td>1</td>
<td>It doesn't bother me as much as I thought it would</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Patient-Parent Experience

<table>
<thead>
<tr>
<th>Concentration</th>
<th>Frequency</th>
<th>Description</th>
<th>Severity</th>
<th>Description</th>
<th>Distress</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>3 P: 'throughout treatment'; M: 'most of the time'</td>
<td>2</td>
<td></td>
<td>1 P: 'can't focus, read books' M: 'times can't do anything, just lays there'</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 P: &quot;guess I would change it to a little bit more, I'm worried I might get held back</td>
<td>3 P: 'Just sit and stare'</td>
<td>2 P: &quot;how long it takes me to do my work - won't get it done on time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 P: &quot;usually after chemo...by the weekend it goes away&quot;</td>
<td>3 P: &quot;I don’t know it was really hard to focus on everything...just like being at home I couldn’t focus watching TV or anything&quot;</td>
<td>3 P: &quot;it made me slack off sometimes...in school</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 P: every day</td>
<td>2 P: &quot;I totally forgot what you even asked...I can’t - not a big deal&quot;</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 when doing homework, things that need attention</td>
<td>2 Not that bad, sometimes I just need to focus. Can't focus, a lot is going on in my head</td>
<td>4 I'm not a normal kid anymore. Stresses me out, ...I get frustrated with myself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Expectation
“[I expected] to feel like I was sick all of the time.”
"Even when I play guitar my fingers don't feel the same. They get so tired. I feel like I can't do much really."
"Yeah because when my friends come over I am a little tired and I can't really do much and I would like for it to be easier to get around but it is kind of hard with a lack of energy."
Emotions

“I want to go out because I feel ok, but my body isn’t ok. I don’t quite understand that. It is frustrating and I get mad. I am used to being outside all of the time.”
Family Life

“I think the distressing part is I don't want to be irritable...Normally I am not irritable. They run around the house screaming and I just ignore them. Now, I am like, 'Get them out!'"
"I say it is just something you got to get through if you want to live."
An Emerging Story...
Conclusions

• Experiential symptom assessment enhances a numerically-based tool
  Symptoms thought of across disease trajectory vs episodic in nature
  Symptoms cluster together, are not always independent of one another

• Understanding symptom experience may facilitate improved management, anticipatory guidance and coping

• More work is needed to understand clinical relevance of MSAS scores in directing and evaluating symptom management interventions
Research Team

- Melody Hellsten, DNP, RN, PPCNP-BC
  - Texas Children's Hospital/ Baylor College of Medicine
- Hayden Leeds, MS 3
  - Oregon Health Science Center
- Stacey Berg, MD
  - Texas Children's Hospital/ Baylor College of Medicine
- Patty Baxter, MD
  - Texas Children's Hospital/ Baylor College of Medicine
- Julie Brackett, MD
  - Texas Children's Hospital/ Baylor College of Medicine
- Geri Wood, PhD, RN
  - University of Texas Health Science Center at Houston School of Nursing