Psychosocial assessment tools and the Pediatric Psychosocial Preventative Health Model

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Goals

• Provide an overview of the background/rationale for family psychosocial risk screening
• Present the Pediatric Psychosocial Preventative Health Model (PPPHM)
• Discuss screening approaches and introduce the Psychosocial Assessment Tool (PAT)
• Discuss gaps in our knowledge and next steps
Family Psychosocial Risk

- Children live in families, and families within broader social contexts - pediatric cancer is inherently family-centered

- The majority of families are resilient, but many have psychosocial concerns that can and should be addressed with evidence based treatments

- In COG institutions, only 9% of families were offered empirically supported evaluations, about half were offered psychosocial care in month 1 after diagnosis but < 11% used empirically based treatments (Selove et al., 2012)

- Need to better identify, in an inclusive and effective manner, specific family risks, in order to deliver comprehensive evidence based care matched to risk

Family psychosocial adjustment – themes from the literature

- Children have expected emotional reactions (anxiety, depression, behavior problems)
- Mothers and fathers (caregivers) have a range of reactions, including traumatic stress responses
- Siblings are impacted by cancer (positive/negative)
- There is a trajectory of improved functioning
- Pre-illness functioning predicts longer-term outcomes
- Social isolation is a predictor of worse outcomes
- Cancers that impact the central nervous system are associated with neurocognitive & psychosocial difficulties

Screening approaches...
A range of approaches and outcomes

- Batteries of measures
- Very Brief Screeners
- Clinical interviews
- Short Standardized Instruments
- Others?

Pediatric Psychosocial Preventive Health Model

CLINICAL/TREATMENT
- Consult behavioral health specialist.
- Intensify psychosocial services.
- Address impact on medical treatment.

TARGETED
- Monitor child/family distress and risk factors.
- Provide interventions specific to symptoms or adherence needs.

UNIVERSAL
- Provide psychoeducation and family-centered support.
- Screen for indicators of higher risk.

Severe, escalating, or persistent distress.
Acute or elevated distress. Other risk factors present.
Children and families are distressed but resilient.
Brief parent-report screener of psychosocial risk*
All literacy English and Spanish versions (4th grade reading level)
Current research in US, Canada, Australia, the Netherlands, Greece, Israel, Brazil, Italy, Singapore
Available in English, Spanish (US, S. American), Dutch, Portuguese, Hebrew, Greek, Polish, Italian, Japanese, Chinese/Mandarin, Korean, Swahili, Hindi
Adapted for use in the United Kingdom, Singapore, Canada and Australia, New Zealand
Used at 52 U.S. sites/27 states since 2007 (approximately 4400 administrations) and 30 international

* Most use in oncology. Adaptations include sickle cell disease, organ transplantation, cardiology, burns, IBD, weight management, BMT, diabetes, liver disease, DSD, fetal myelomeningocele, aplastic anemia, international adoption, chronic pain and migraines. Also versions specific to NICU, PICU, PACU.
**Domains**
- Demographic
- Diagnosis
- Family structure
- Family resources
- Social Support
- Child knowledge of disease
- School enrollment
- School placement
- Child problems
- Sibling problems
- Family problems
- Family beliefs
- Stress responses
  - Infants/young children
  - Traumatic stress responses
  - Suicidality

**Subscales**
- Structure/Resources
- Family Problems
- Social support
- Stress reactions
- Child problems
- Sibling Problems
- Family beliefs

**Scoring/Interpretation**
Items are scored “positive” based on research literature and clinical expertise.

- Total score = sum of scales
- Maps on to PPPHM
- Scores <1 Universal, ≥1 < 2 are Targeted, ≥ 2 Clinical

Clinically relevant but unscored items are highlighted.
PAT Formats

Available in English and Spanish. Immediate risk scoring and family-centered reports to support decision making and communication.
Psychosocial Assessment Tool (Wednesday)

Please answer the following questions and click the Continue button.

* Indicates a required field.

* What is Wednesday’s current daycare/schooling?
Hold down the Control (Ctrl) key to select multiple items from the list

Select all that apply:
- In Daycare
- Hard Start
- Preschool/Pre-K
- K-12
- Home schooled
- Homebound
- Gifted
- Special education
- Dropped out of school
- Finished High school

School History:

* Has Wednesday ever repeated a grade?
  - Yes
  - No

* Has Wednesday ever been suspended or expelled?
  - Yes
  - No

* Has Wednesday ever been teased or bullied at school?
  - Yes
  - No
  - Don’t know
Psychometric summary

• Internal consistency
  – alpha = .81

• Two week test-retest reliability
  – r = .78 - .87, p < .001

• Criterion Validity (total score)
  – Significantly correlated for mothers and fathers
    ASDS, STAI, BASC-2, FES

• Content Validity (subscales)
  – Stress reactions and ASDS/STAI (p < .001)
  – Child problems and BASC-2 (p < .001)

• Receiver Operator Curves (ROCs) indicate excellent sensitivity and specificity (p < .001)


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Cross cultural screening for psychosocial risk in pediatric cancer

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Wei-Ting Hwang, Ph.D.
Perelman School of Medicine of the University of Pennsylvania
Support for the PPPHM

Percent of families at each risk level (as measured by the Psychosocial Assessment Tool)

<table>
<thead>
<tr>
<th></th>
<th>CHOP</th>
<th>CHOP</th>
<th>CHOP</th>
<th>CHOP</th>
<th>RCH</th>
<th>CHOA</th>
<th>HSC</th>
<th>NL</th>
<th>UMMC</th>
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</thead>
<tbody>
<tr>
<td>Clinical</td>
<td>7</td>
<td>13</td>
<td>4</td>
<td>7</td>
<td>12</td>
<td>15</td>
<td>5</td>
<td>4</td>
<td>18</td>
</tr>
<tr>
<td>Targeted</td>
<td>34</td>
<td>32</td>
<td>24</td>
<td>29</td>
<td>27</td>
<td>34</td>
<td>36</td>
<td>28</td>
<td>32</td>
</tr>
<tr>
<td>Universal</td>
<td>59</td>
<td>55</td>
<td>72</td>
<td>75</td>
<td>62</td>
<td>51</td>
<td>59</td>
<td>68</td>
<td>50</td>
</tr>
</tbody>
</table>

**US PAT users**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical</td>
<td>11</td>
</tr>
<tr>
<td>Targeted</td>
<td>34</td>
</tr>
<tr>
<td>Universal</td>
<td>55</td>
</tr>
<tr>
<td>N = 4329</td>
<td></td>
</tr>
</tbody>
</table>

**Current PAT study (ACS)**

<table>
<thead>
<tr>
<th></th>
<th>All (N=211)</th>
<th>En (N=174)</th>
<th>Sp (N = 37)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical</td>
<td>10</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>Targeted</td>
<td>31</td>
<td>31</td>
<td>32</td>
</tr>
<tr>
<td>Universal</td>
<td>59</td>
<td>61</td>
<td>51</td>
</tr>
</tbody>
</table>

* Nemours (AIDHC, NCH), CHOP, M.D. Anderson

# Sample Interventions by Risk Level

<table>
<thead>
<tr>
<th>Severe, escalating problems</th>
<th>Crisis intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychology, psychiatry, C-L</td>
<td>Medication</td>
</tr>
<tr>
<td>Buddy system</td>
<td>1:1</td>
</tr>
<tr>
<td>Security, Legal</td>
<td>Child welfare</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supportive counseling – intensive</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical play for problems</td>
<td>Adherence to treatment</td>
</tr>
<tr>
<td>Adaptation to illness</td>
<td>Pain, distress</td>
</tr>
<tr>
<td>Severe or escalating problems</td>
<td>Patient care conferences</td>
</tr>
<tr>
<td>Custody/divorce/guardianship issues</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Psychosocial Education</th>
<th>Medical play – normative or group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pastoral counseling</td>
<td>School contact – letters or visit</td>
</tr>
<tr>
<td>Case management</td>
<td>Supportive Counseling – General</td>
</tr>
<tr>
<td>Trauma informed care</td>
<td><a href="http://www.healthcaretoolbox.org">www.healthcaretoolbox.org</a></td>
</tr>
</tbody>
</table>
Basics of Trauma-Informed Care

Reduce Distress
- Ask about fears and worries.

Emotional Support
- Who and what does the patient need now?

Remember the Family
- Gauge family stressors and resources.

How Providers Make a Difference

Healthcare providers are experts in treating illness and saving lives. After attending to the basics of physical health (A-B-C: Airway, Breathing, Circulation), you can promote psychosocial recovery by paying attention to the D-E-F (Distress, Emotional Support, Family).

What is Trauma-Informed Pediatric Care?
Trauma-informed pediatric care means incorporating an awareness of the impact of traumatic stress on ill or injured children and families as a part of treating the child.
## Challenges to screening

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Strategies to overcome</th>
</tr>
</thead>
</table>
| Stigma                        | Assure acceptability of screening  
Make screening standard for all  
Provide education on comprehensive care  
Document pt/family satisfaction with screening                                    |
| Unrecognized need             | Show how screening aids management of care  
Discuss how screening can improve care/outcomes  
Address discipline specific concerns                                              |
| Time                          | Determine actual time necessary to screen  
Integrate screening into routine clinical processes  
Schedule appointments to accommodate time                                         |
| Concern re: response to identified needs | Create algorithms that match high risk items with existing resources  
Use aggregate data to argue for more psychosocial personnel                      |
| Impact on workflow            | Determine format and who screens  
Create alerts for high risk responses (immediate attention)  
Identify who reviews and who coordinates response  
Integrate results in HER                                                           |
| Sustaining screening          | Continue to train providers to implement  
Monitor pathways of care  
Generate and show data for results and refinement  
Billing codes for screening time                                                   |

Gaps and next steps

• Psychosocial personnel across and within centers are inconsistent and often minimal (*no good data on this*)
• Need evidence based standards - The Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) – and their adoption
• Must assure that the unique multifaceted needs of children and families are maintained in the “rush to screen”
• Consider the child (adolescent/young adult) input in screening
• Identify what happens after screening?

  *Screen, Assess, Treat, Test, Track*

• When to screen?
• Identify outcomes of screening..does screening lead to treatments that are...
  More appropriate to needs?
  More effective in promoting adjustment?
  Delivered earlier or more efficiently?
For more information:

Psychosocialassessmenttool@nemours.org

www.healthcaretoolbox.org