Partnering with Families to Validate Questionnaires Assessing Unmet Needs of Children, Adolescents, and Parents/Caregivers at the End of Cancer Treatment

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BACKGROUND

Ending cancer treatment & transitioning to survivorship:
- What are the needs?
- Are needs being met?
- What measures are available to determine needs?

Coming off Therapy (COT) questionnaire (Nagel et al., 2002)
- Parent survey only
- No reported validity/reliability

PURPOSE

1. Adapt COT to End of Treatment (EOT) Questionnaires
   - Children, AYAs, Parents/Caregivers
2. Validate Questionnaires

METHODS

Family Advisory Board members as experiential experts:

Step 1: Completed online survey
- to establish face validity

Step 2: Participated in focus groups
- to establish content validity

Step 3: Discussed and reworked each item until 100% consensus

RESULTS

COT Questionnaire

<table>
<thead>
<tr>
<th>Topic</th>
<th>Yes</th>
<th>No</th>
<th>I don’t know</th>
<th>I would have liked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review of diagnosis and prognosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Review of treatment (e.g., surgery, radiation, chemotherapy)</td>
<td>yes/no</td>
<td></td>
<td></td>
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<tr>
<td>Review of side effects of treatment (e.g., hair loss, muscle pain, bone pain, low counts)</td>
<td>yes/no</td>
<td></td>
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<tr>
<td>Plan for follow-up care at this center (e.g., scans, bloodwork, timing of follow-up visits)</td>
<td>yes/no</td>
<td></td>
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<tr>
<td>The ongoing role of your family doctor</td>
<td>yes/no</td>
<td></td>
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<td>Provision of ongoing family emotional support/counseling</td>
<td>yes/no</td>
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<td>A discussion of family stress/anxiety coming off therapy</td>
<td>yes/no</td>
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<td>Genetic counseling</td>
<td>yes/no</td>
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<tr>
<td>Hepatitis testing</td>
<td>yes/no</td>
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</tbody>
</table>

EOT Questionnaire – Child Version

What information was included in your talk? (check all that apply):

- Review of your diagnosis
- Review of your treatment
  - (chemotherapy, radiation, surgery, etc.)
- Review of your side effects
  - (weight gain, low counts, feeling tired, etc.)
- Plan for follow up at clinic
  - (scans, blood work, etc.)
- Health topics you need to know
  - (when to get vaccines, exercise do’s and don’ts, etc.)
- School issues
  - (learning, concentrating, making friends, etc.)
- Role of your pediatrician
- How to find support or counseling for you or your family
- Discussion of worries about finishing treatment

DISCUSSION/APPLICATIONS

- Through this process, our questionnaires were validated
- The questionnaires will lend integrity and relevance to future studies
- Plans:
  1. Replicate process to develop EOT Questionnaire for healthcare professionals
  2. Utilize questionnaires to study needs and gaps in services at EOT
  3. Establish reliability of questionnaires through dissemination

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