PSYCHOSOCIAL STANDARDS OF CARE FOR CHILDREN WITH CANCER AND THEIR FAMILIES

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How to Insure Children & Families Receive Optimal Care

- Need to determine essential elements that all pediatric oncology programs must (standards) and should (guidelines) have (www.livestrong.org/essential elements)

- There have been many standards and guidelines published – but not implemented (L. Wiener et al., 2013, Psycho-Oncology, 24, 204-211)

- Must be evidence-based and have strong support from stakeholders and influential groups
Steps in the Process
Psychosocial Symposium on Capitol Hill

Symposium was held at the Capitol Hill Visitor Center to address the question.... **What is needed for comprehensive psychosocial care?** This full day event included a congressional briefing, 12 different professional sessions, and a parent panel.

- There were 85 attendees, representing 12 different States. Attendees included nurses, social workers, professional counselors, child life specialists, art therapists, occupational therapists, psychologists, medical doctors, and patient advocates.

- Representatives Chris Van Hollen (D-MD), Mike McCaul (R-TX), and Jackie Speier (D-CA) were in attendance, along with Senator Jack Reed (D-RI).

- The congressional briefing and presentations were conducted by:

  1. Dr. Anne Kazak (Nemours) – Scientific Chair of the Symposium
  2. Dr. Bob Noll (University of Pittsburgh)
  3. Dr. Andrea Patenaude (Dana Farber)
  4. Dr. Ken Tercyak (Georgetown University Hospital)
  5. Dr. Lori Wiener (NCI/NIH)

   Featuring Dr. Jimmie Holland (Memorial Sloan Kettering)

Where is the evidence?
The Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) was Born

Goal: Develop evidence-based standards for the psychosocial care of children and adolescents with cancer and their families.
Where to start? Preparation

1. Reviewed published guidelines, recommendations, standards

2. Asked psychosocial experts:
   - What are the 5 most important things we should know about families in order to provide optimal care?
   - List challenges to developing and implementing psychosocial standards/guidelines. Be specific.
   - What are some of the most innovative / effective ways to implement or provide psychosocial care?

3. Brought experts together from professionals who provide psychosocial care to children with cancer and their family members
Systematic review

- 27 articles: 5 standards; 19 guidelines, 3 consensus based reports relating to childhood cancer or where pediatric cancer was not excluded

- Several excellent examples (e.g., IOM, CAPO, SIOP, SIOPE, COG, Livestrong)

- Issues: limited to one population; one disease, not comprehensive, too general, not evidence-based

- Implementation not addressed

Next Steps

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Psychosocial Think Tank #1

- Multi-disciplinary: Twenty psycho-oncology leaders from the U.S. and other international institutions. Fields represented: social work, psychology, psychiatry, nursing, and parent advocates.
- Morning didactic - Existing standards, lessons from adult oncology

Livestrong Essential Elements

**ESSENTIAL Element** of psychosocial care:

- An element that has a positive impact on the quality of life for all cancer patients and their family members,

- Can be implemented across a wide variety of settings,

- Is supported by an evidence base which exists in behavioral science or when an evidence base does not exist, it embodies one of the following:
  
  - Addresses expressed needs of children with cancer or their family members
  
  - Has been agreed upon through consensus of the provider community and can be tested through future research

(Livestrong, 2011)
Afternoon Think Tank Work

- Small groups (assessment, interventions, school/staff) reviewed themes from literature, survey, clinical experience
  - **What is truly “essential”**
- Consensus session – 25 Essential Elements emerged

Five working groups established:

1. **Neurocognitive/Neuropsychological**
   - Leader: Dr. Robert Annett (University of Mississippi)
2. **School Issues**
   - Leader: Dr. Robert B. Noll (University of Pittsburgh)
3. **Child and Family Psychotherapeutic Interventions**
   - Leader: Dr. Lori Wiener (NCI/NIH)
4. **Screening and Assessment**
   - Leaders: Dr. Anne Kazak (Nemours) and Dr. Mary Jo Kupst (Medical College of Wisconsin)
5. **Staff and Documentation**
   - Leader: Dr. Andrea Patenaude (Dana Farber)
In the year between the two think tank, working groups were charged with investigating and critiquing the related professional literature to determine whether there was sufficient and compelling evidence to support each of the essential recommendations generated during the think tank.
AGREE II/Purpose

**APPRAISAL OF GUIDELINES FOR RESEARCH & EVALUATION II** purpose:

- Assess the quality of guidelines;
- Methodological strategy for guideline development;
- What information and how information should be reported in guidelines

http://www.agreetrust.org/
Methodology: The Standard Development Process

Clear process for drafting the guidelines/standards

- Evidence is provided for each recommendation, either from existing literature or, where there is no published evidence, from a rigorous process of defining clinical consensus.
- The source of support is also described in tables that outline the research available.
- Reviews (ratings) sent to pediatric psycho-oncology experts and pediatric oncologists.
Rating Scale: 25 Standards

- Literature search strategy is adequate
- Strength and limitations of the body of evidence clearly described
- Explicit link between the recommendations and the supporting evidence
- Potential organizational and logistic barriers that could prevent successful implementation have been addressed
- Recommendations provides advice and/or tools on how it can be put into practice.
- Potential resource implications of applying the recommendations have been considered
Think Tank #2
Re-gathering of Experts

February, 2014: 2nd Childhood Cancer Psychosocial Think Tank at APOS conference in Tampa, FL.

- Same and some different members attended
- Small working groups reviewed work they were not part of writing (evidence, rating forms)
  - Decided whether there is sufficient evidence
  - Recommendation: Tier
    - Tier 1 (Standard/Must), Tier 2 (Should), Tier 3 (Strive)
- Full Group: Consensus of Evidence and Tiers
Consensus Results

- Overlap identified
- Quality of the evidence needs review and strength of the recommendations graded
- Additional reviews (stakeholders) important
- Implementation plan needed
Standards Consolidated: Authors Identified:
April 2014

- Leaders re-convened
- Consolidated standards (15)
- Plan for literature appraisal and evaluation of study/evidence rigor decided
- Primary authors identified
- Inclusion criteria and search terms identified
- Monthly phone calls
Records identified through database searching
(K = 4,006)

Additional records identified through other sources

Record titles reviewed after duplicates removed
(k = 2,692)

Abstracts screened
(k = 336)

Abstracts excluded
(k = 169)

Full-text articles excluded
(k = 73)
Descriptive Study (k = 23)
Commentary (k = 6)
Biomedical (k = 0)
Non-cancer (k = 13)
Not pediatric or AYA (k = 8)
Active treatment or survivorship (k = 5)
End-of-life/palliative care (k = 8)
Not parent-focused (k = 6)
Not intervention or outcome focused (k = 3)

Studies selected for inclusion (k = 94)
Grading of Recommendations Assessment, Development and Evaluation (GRADE)
Quality of Evidence

High Quality
- Further research is very unlikely to change our confidence in the estimate of effect

Moderate Quality
- Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate

Low Quality
- Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate

Very Low Quality
- Any estimate of effect is very uncertain
Strength of Recommendation
(Benefits: Risks & Burdens)

Strong Recommendation
- The literature indicates the desirable effects of adherence to a recommendation outweigh the undesirable effects (e.g. improvement in QoL, reduction in burden of treatment, reduced resource expenditures).

Weak Recommendation
- Weak recommendation indicates the desirable effects of adherence to a recommendation probably outweigh the undesirable effects (e.g. deleterious impact on QoL, morbidity, increased use of resources).
Summary: Standards Development

- Critical issue and questions identified
- Multidisciplinary guideline development group
- Consumer involvement
- Systematic searches – Inclusion/exclusion relevant literature
- Clear process for drafting the standards (AGREE II)
- Consultation throughout the drafting of the document was conducted by sending rating forms for individual elements to experts not involved in the writing of the document
- Peer Review
Pediatric Cancer Psychosocial Standards

<table>
<thead>
<tr>
<th>Standard</th>
<th>Quality of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Routine and systematic assessment of the psychosocial needs of youth and families is essential.</td>
<td>High 149 Studies</td>
</tr>
<tr>
<td>2. Monitoring of neuropsychological deficits during and after treatment is essential for those at high risk.</td>
<td>High 129 Studies</td>
</tr>
<tr>
<td>3. Annual screening of the psychosocial functioning of long-term survivors is essential.</td>
<td>Moderate/High 101 Studies</td>
</tr>
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### Pediatric Cancer Psychosocial Standards

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<td>4. Access to <strong>psychosocial support and interventions</strong> throughout the cancer trajectory is essential.</td>
<td>High 173 Studies</td>
</tr>
<tr>
<td>5. Assessment of risk of <strong>financial hardship</strong> with referrals for support as needed is essential.</td>
<td>Moderate 24 Studies</td>
</tr>
<tr>
<td>6. Early and ongoing assessment of <strong>behavioral needs of parents</strong> and access to appropriate interventions are essential.</td>
<td>Moderate 159 Studies</td>
</tr>
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# Pediatric Cancer Psychosocial Standards

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<td>7. <em>Education and anticipatory guidance</em> about disease, treatment, short and long term effects are essential.</td>
<td>Moderate 23 Studies</td>
</tr>
<tr>
<td>8. Developmentally appropriate <em>preparatory information</em> about <em>invasive procedures</em>, and interventions as needed, are essential.</td>
<td>Low-Education High-Interventions 65 Studies</td>
</tr>
<tr>
<td>9. Opportunities for <em>social interaction</em> during treatment and into survivorship is essential.</td>
<td>Moderate 59 Studies</td>
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# Pediatric Cancer Psychosocial Standards

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<td>10. Appropriate supportive services for <em>siblings</em> is essential.</td>
<td>Moderate 117 Studies</td>
</tr>
<tr>
<td>11. <em>School re-entry support</em> – educating school about cancer, treatment, implications for school experience is essential.</td>
<td>Low 17 Studies</td>
</tr>
<tr>
<td>12. Routine assessment of <em>adherence</em>, with monitoring throughout treatment is essential.</td>
<td>Moderate 14 Studies</td>
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## Pediatric Cancer Psychosocial Standards

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<tr>
<td>13. Introduction of <strong>palliative care</strong> concepts, with <strong>end of life care</strong> provided where necessary, is essential.</td>
<td>Moderate 73 Studies</td>
</tr>
<tr>
<td>14. Contact with the family after a child’s death to assess needs, continue care, and provide resources for <strong>bereavement care</strong> is essential.</td>
<td>Moderate 95 Studies</td>
</tr>
<tr>
<td>15. Open, respectful <strong>communication</strong> among providers and families, appropriate <strong>documentation</strong>, and <strong>trained</strong> psychosocial providers are essential.</td>
<td>Moderate/Low 35 Studies</td>
</tr>
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Example: Summary of Evidence – Neuropsychological Assessment

<table>
<thead>
<tr>
<th>Standard</th>
<th>Evidence Summary</th>
<th>Methodology</th>
<th>Quality of Evidence</th>
<th>Strength of Recommendation</th>
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<tr>
<td>Children with brain tumors and others at high risk for neuropsychological deficits as a result of cancer treatment should be monitored for neuropsychological deficits during and after treatment</td>
<td>Empirical research for brain tumors indicates significant impairments associated with tumor and treatment</td>
<td>Cross-sectional; longitudinal studies; Significant replication of findings. Large scale follow-up studies; clinical trials group consensus</td>
<td>High Quality Given consistent findings from numerous well-designed studies</td>
<td>Strong Given the impact of disease and treatment factors on later neuropsychological functioning</td>
</tr>
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**Example: Summary of Evidence – Bereavement Care**

<table>
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<tr>
<th>Standard</th>
<th>Evidence Summary</th>
<th>Methodology</th>
<th>Quality of Evidence</th>
<th>Strength of Recommendation</th>
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<tr>
<td>A member of the health care team should contact the family after a child’s death to assess needs, continue care, and provide resources for bereavement care is essential.</td>
<td>Many bereaved parents and family members experience long-lasting negative outcomes. Parents want and appreciate follow-up. Professional support can assist with grief.</td>
<td>Quantitative, qualitative studies, and literature reviews. Majority cross-sectional surveys and in depth interviews. Limited RCTs. Some replication of findings</td>
<td>Moderate</td>
<td>Strong</td>
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<tr>
<td></td>
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<td></td>
<td>Given risk-benefit ratio including significant impact on bereaved family members and positive outcomes with contact made after the death of a child</td>
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Standards for Psychosocial Care for Children with Cancer and their Families

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16 Papers
66 Authors
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Total of 1,217 studies
Professional Endorsements: Phase 2

- The following professional organizations have officially endorsed the standards
  - Association of Pediatric Hematology/Oncology Nurses (APHON)
  - Association of Pediatric Hematology/Oncology Educational Specialists (APHOES)
  - Society of Pediatric Psychology (SPP)
  - Association of Pediatric Oncology Social Workers (APOSW)
  - American Academy of Child and Adolescent Psychiatry (AACAP)
  - American Psychosocial Oncology Society (APOS)
  - The National Children’s Cancer Society

- We will continue to seek endorsements and other collaborations to insure implementation.
Overall Vision

- Phase 1 – Define, Create & Publish The Standards
  - Develop and document evidence-based standards of care spanning last two decades of research
  - Publish in a Tier 1 Medical Journal (Pediatric Blood & Cancer)
  - Completed!

- Phase 2 – Get The Standards Endorsed by Professional Organizations and Other Entities

- Phase 3 – Implementation & Evaluation
  - Four-part approach
    1. Research and Development
    2. Legislation and Regulation
    3. Education and Accreditation
    4. Implementation and Delivery

- Development of a Center of Excellence
References

- Wiener, L. et al. (2013), *Psycho-Oncology*, 24, 204-211