





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

- Reviewed published guidelines, recommendations, standards
- 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, <u>not evidence-based</u>
- Implementation not addressed

Wiener, Viola, Koretski, Perper, Patenaude, *Psycho-Oncology*, 2015





Next Steps

- Reviewed published guidelines, recommendations, standards
- 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.
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Psychosocial Think Tank #1

- □ Held at the 10th annual American Psychosocial Oncology Society (APOS) Conference, February 14, 2013.
- 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



THINK TANK PARTICIPANTS: Vicki and Peter Brown, David Elkin, Martha Grootenhuis, Jimmie Holland, Paul Jacobsen, Barbara Jones, Anne Kazak, Katherine Kelly, Mary Jo Kupst, Anne Lown, Nina Muriel, Robert Noll, Maryland Pao, Sunita Patel, Andrea Farkas Patenaude, Wendy Pelletier, Sean Phipps, Lori Wiener, Denise Tordella, Jaehee Yi, and Sima Zadeh.



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

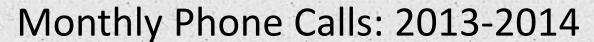
Leader: Dr. Lori Wiener (NCI/NIH)

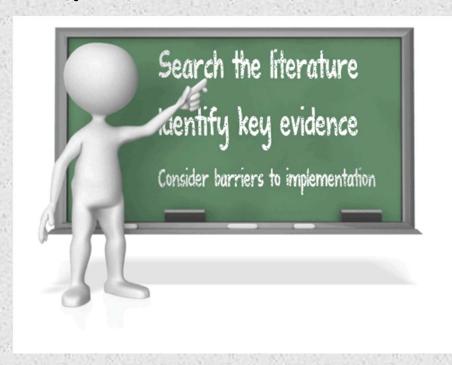
4. Screening and Assessment

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.



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

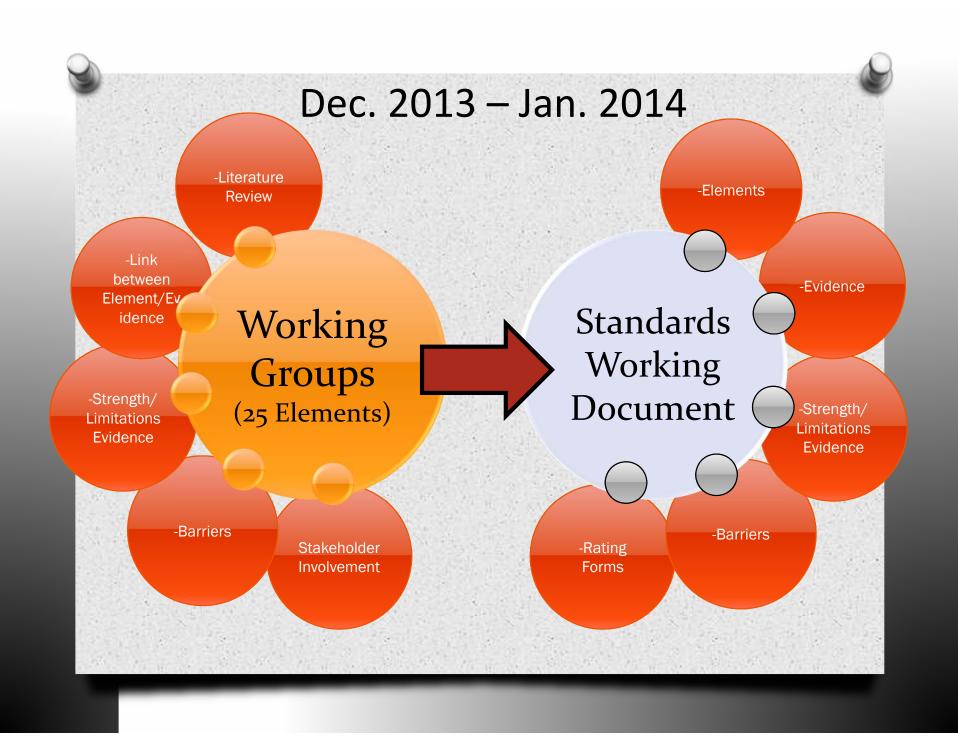
- Evidence is provided for each recommendation, either from existing literature or, where there is no published evidence, from a rigorous process of defining clinical consensus.
- ☐ The source of support is also described in tables that outline the research available
- Reviews (ratings) sent to pediatric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

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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





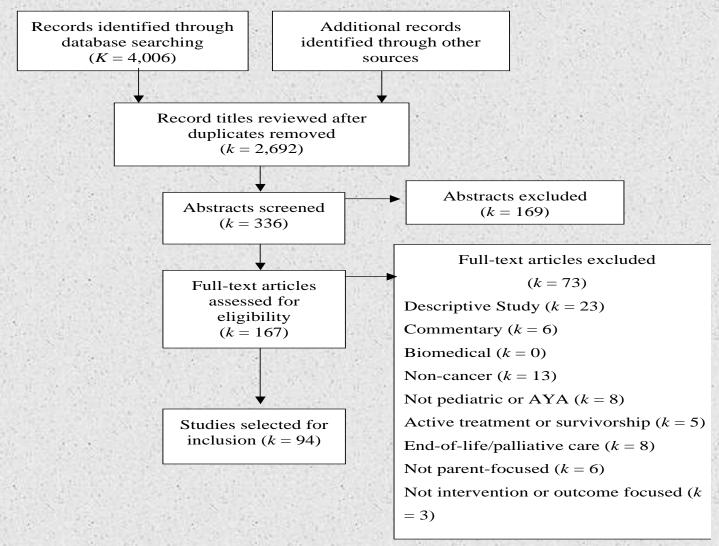
Consensus Results

- Overlap identified
- Quality of the evidence needs review and strength of the recommendations graded
- Additional reviews (stakeholders) important
- Implementation plan needed



- 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





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



(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





Standard	Quality of Evidence
1. Routine and systematic assessment of the psychosocial needs of youth and families is essential.	High 149 Studies
2. Monitoring of neuropsychological deficits during and after treatment is essential for those at high risk.	High 129 Studies
3. Annual screening of the psychosocial functioning of long-term survivors is essential.	Moderate/High 101 Studies





Standard	Quality of Evidence
4. Access to psychosocial support and interventions throughout the cancer trajectory is essential.	High 173 Studies
5. Assessment of risk of financial hardship with referrals for support as needed is essential.	Moderate 24 Studies
6. Early and ongoing assessment of behavioral needs of parents and access to appropriate interventions are essential.	Moderate 159 Studies





Standard	Quality of Evidence
7. Education and anticipatory guidance about disease, treatment, short and long term effects are essential.	Moderate 23 Studies
8. Developmentally appropriate preparatory information about invasive procedures, and interventions as needed, are essential.	Low-Education High- Interventions 65 Studies
9. Opportunities for social interaction during treatment and into survivorship is essential.	Moderate 59 Studies





Standard	Quality of Evidence
10. Appropriate supportive services for siblings is essential.	Moderate 117 Studies
11. School re-entry support – educating school about cancer, treatment, implications for school experience is essential.	Low 17 Studies
12. Routine assessment of adherence, with monitoring throughout treatment is essential.	Moderate 14 Studies





Standard	Quality of Evidence
13. Introduction of palliative care concepts, with end of life care provided where necessary, is essential.	Moderate 73 Studies
14. Contact with the family after a child's death to assess needs, continue care, and provide resources for bereavement care is essential.	Moderate 95 Studies
15. Open, respectful communication among providers and families, appropriate documentation, and trained psychosocial providers are essential.	Moderate/Low 35 Studies



Example: Summary of Evidence – Neuropsychological Assessment

Standard	Evidence Summary	Methodology	Quality of Evidence	Strength of Recommendation
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	Empirical research for brain tumors indicates significant impairments associated with tumor and treatment Gaps: Prospective research in other malignancies	Cross- sectional; longitudinal studies; Significant replication of findings. Large scale follow-up studies; clinical trials group consensus	High Quality Given consistent findings from numerous well- designed studies	Given the impact of disease and treatment factors on later neuropsychological functioning



Example: Summary of Evidence – Bereavement Care

Standard	Evidence Summary	Methodology	Quality of Evidence	Strength of Recommendation
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.	Many bereaved parents and family members experience long-lasting negative outcomes. Parents want and appreciate follow-up. Professional support can assist with grief.	Quantitative, qualitative studies, and literature reviews. Majority cross-sectional surveys and in depth interviews. Limited RCTs. Some replication of findings	Findings from lower level evidence studies were consistent	Given risk-benefit ratio including significant impact on bereaved family members and positive outcomes with contact made after the death of a child







Sponsoring Societies:

The American Society of Pediatric Hematology/Oncology

The International Society of Paediatric Oncology





Pediatric Blood & Cancer

Standards for Psychosocial Care for Children with Cancer and their Families

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Total of 1,217 studies

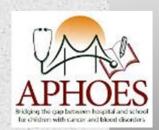




Professional Endorsements: Phase 2

- ☐ 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

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