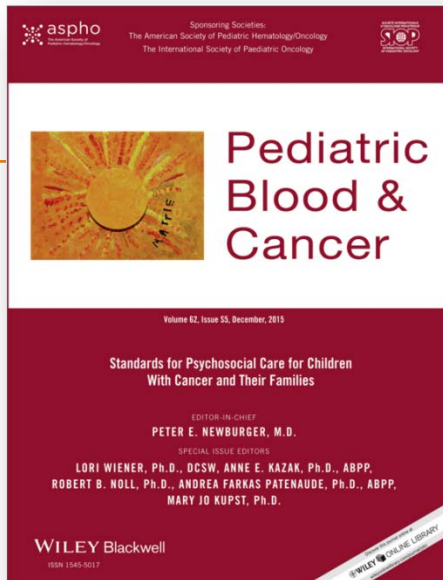


Implementation of the Pediatric Psychosocial Standards of Care: Past, Present and Future



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Bethesda, MD

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Mattie Miracle Cancer Foundation
Washington, DC

During this session.....

- ❑ Why the Standards Were Created
- ❑ Implementation Research
- ❑ Matrix and Guidelines Development
- ❑ Innovative Roadmap Underway
- ❑ Implementation Strategies
- ❑ Moving Forward: Overall Vision



MATTIE BROWN'S LIFE INSPIRED THE STANDARDS

Victoria Sardi-Brown, Ph.D., LPC
CO-FOUNDER & PRESIDENT



Who was Mattie Brown

- ❑ Mattie was our son and only child.
- ❑ He was a healthy, active, bright, and curious child until July 23, 2008.
- ❑ Mattie was diagnosed at age 6 with Osteosarcoma, Bone Cancer.
- ❑ He had four bone tumor sites: 1) right arm (humerus), 2) left arm (humerus), 3) right leg (femur), and 4) left wrist (radius).
- ❑ Mattie had two limb salvaging surgeries, a sternotomy, 10 months of high dosage chemotherapy (Doxorubicin, Cisplatin, Methotrexate, Ifosfamide, and Etoposide), and radiation.
- ❑ The medical treatment had physical and psychological impacts on Mattie and his parents.
- ❑ Mattie was diagnosed with clinical depression, anxiety, and medical traumatic stress.



The Reality of Childhood Cancer



Exhaustion



Depression



Pain



Sadness

- ❑ Cancer treatments produce overwhelming side effects like neuropsychological impairment, behavioral/ psychological difficulties, elevated activity levels, mood swings, irritability, decreased reflexes and decreased fine motor coordination and speed.
- ❑ Psychosocial well-being influences physical functioning and treatment outcomes among children with cancer.



Isolation

Importance of Psychosocial Support



- ❑ Psychosocial care has been shown to yield better management of common disease-related symptoms and adverse effects of treatment such as pain and fatigue (Jacobsen, Holland, & Steensma, 2012).
- ❑ Depression and other psychosocial concerns can affect adherence to treatment regimens by impairing cognition, weakening motivation, and decreasing coping abilities (Institute of Medicine, 2008).
- ❑ Optimal cancer care includes the provision of psychosocial care services (Institute of Medicine, 2008).



Foundation Information

WHO IS MATTIE MIRACLE

The MATTIE MIRACLE CANCER FOUNDATION is a 501(c)(3) tax-exempt public charity. The organization was founded by Victoria Sardi-Brown and Peter Brown, in loving memory of their seven year old son, Mattie.

OUR TAG LINE

It's Not Just About The Medicine™

OUR PROGRAMS

- ❑ We enhance psychosocial **awareness**: through our Annual Walk, presentations at universities and schools, and other community service learning projects.
- ❑ We promote **advocacy** of childhood cancer issues and needs through our annual candy and toiletry drives, lobbying on Capitol Hill, and outreach to families with childhood cancer.
- ❑ We provide access to **psychosocial support**: through funding a child life specialist at MedStar Georgetown University Hospital (Washington, DC) and Children's Hospital at Sinai (Baltimore, MD) and by providing free snack carts to inpatient families caring for children.
- ❑ We fund **research** that advances the goal of implementing the Psychosocial Standards of Care at treatment sites.

Getting Started on Capitol Hill

- ❑ In 2010, we began lobbying on Capitol Hill. **At that time, psychosocial care was not part of the congressional dialogue.**
- ❑ Given our cancer experience, we realized that psychosocial support had to become part of the legislative dialogue for childhood cancer.
- ❑ As we continued to lobby on Capitol Hill, the #1 question posed to us was..... **Where is the evidence to support the importance of psychosocial care?**
- ❑ We concluded that there weren't Standards and therefore we made it our mission to get evidence based Standards established.



Psychosocial Symposium on Capitol Hill (2012)

- ❑ Mattie Miracle voiced its vision to create Psychosocial Standards of Care.
- ❑ Convened key researchers and clinicians in the psychosocial field to brief Congress and present a full day of scientific presentations about cutting edge psychosocial research.
- ❑ Over 85 attendees from 12 States.



The Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) was Born

Goal: Develop evidence-based standards for the psychosocial care of children with cancer and their families.

Standards that address the entire continuum of care..... diagnosis, throughout treatment, survivorship, or end of life, and bereavement care.



Pathway to development of evidence-based Psychosocial Standards



2012
Congressional
Symposium



2013
Online survey of
psychosocial experts



2013-2014
Systemic review of psychosocial guidelines,
Standards, and consensus reports



2013
1st Think Tank developed five
working groups and **25 Standards**

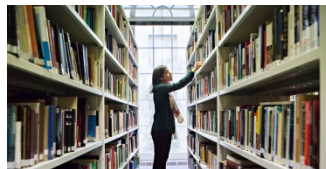
1. Assessment of well-being and emotional functioning
2. Neurocognitive status
3. Psychotherapeutic interventions
4. School functioning
5. Training, communication, and documentation of psychosocial services



2013-2014
Monthly
teleconferences



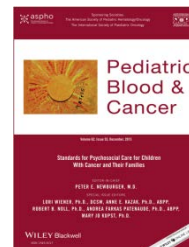
2014
2nd Think Tank consolidated
data into **15 consensus
Standards**



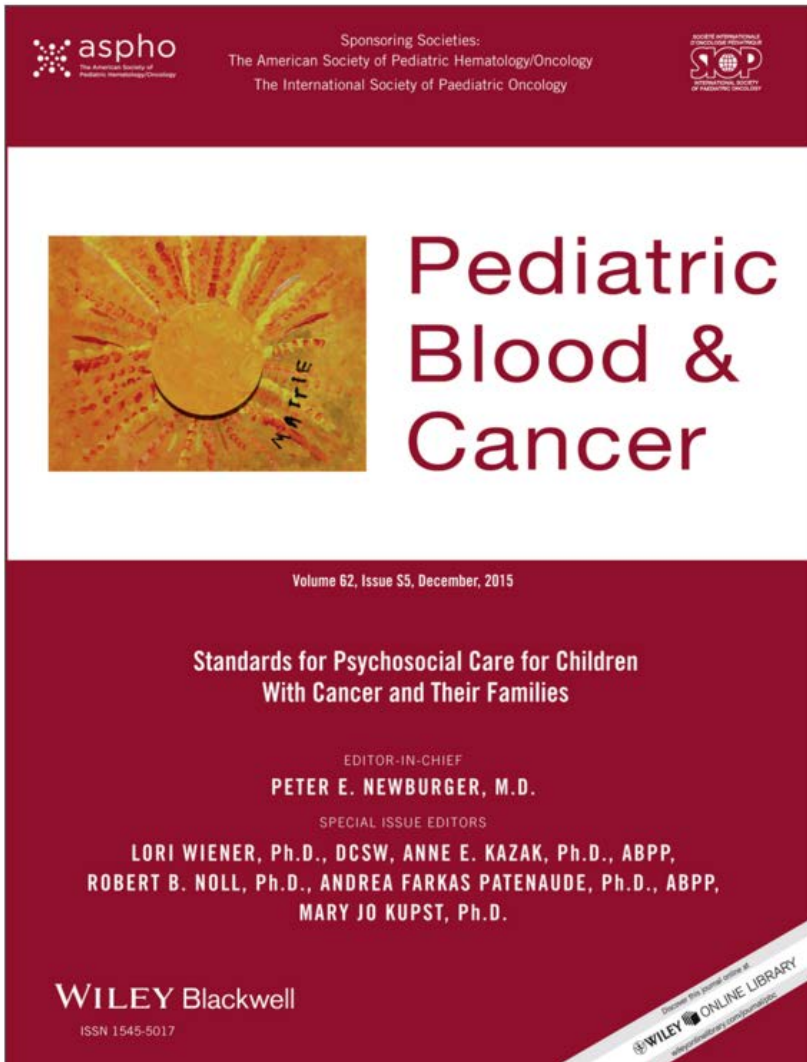
2014-2015
Systematic reviews
for evidence-based
Standards



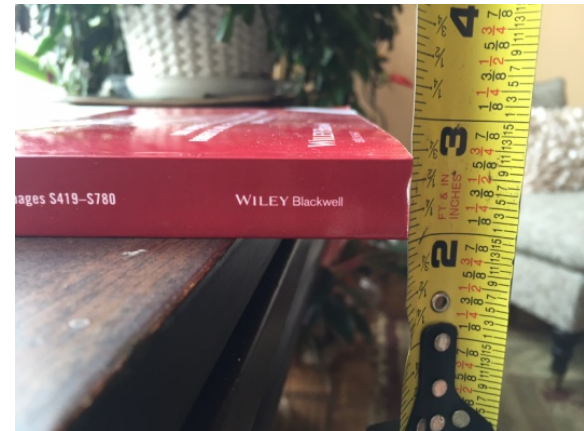
16 Papers
66 Authors
1,217 studies
Pub: Dec. 2015



Standards Published - December 2015



16 papers
66 authors
Total of 1,217 studies

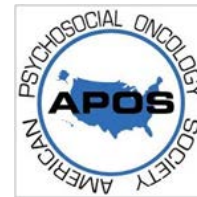


15 Psychosocial Standards of Care

1. Psychosocial Assessment
2. Monitoring and Assessment of Neuropsychological Outcomes
3. Psychosocial Follow-Up in Survivorship
4. Psychosocial Interventions and Therapeutic Support
5. Assessment of Financial Burden
6. Standards of Psychosocial Care for Parents of Children With Cancer
7. Anticipatory Guidance and Psychoeducation
8. Procedural Preparation and Support
9. Providing Children and Adolescents Opportunities for Social Interaction
10. Supporting Siblings
11. Academic Continuity and School Reentry Support
12. Assessing Medication Adherence
13. Palliative Care
14. Bereavement Follow-Up After the Death of a Child
15. Communication, Documentation, and Training Standards in Pediatric Psychosocial Oncology

Professional Endorsements

- 1) American Academy of Child and Adolescent Psychiatry (AACAP)
- 2) American Childhood Cancer Organization (ACCO)
- 3) American Psychological Association's Society of Pediatric Psychology (SPP - Division 54)
- 4) American Psychosocial Oncology Society (APOS)
- 5) Association of Pediatric Hematology/Oncology Educational Specialists (APHOES)
- 6) Association of Pediatric Hematology/Oncology Nurses (APHON)
- 7) **Association of Pediatric Oncology Social Workers (APOSW)**
- 8) American Society of Pediatric Hematology/Oncology (ASPHO)
- 9) B+ Foundation
- 10) Canadian Association of Psychosocial Oncology (CAPO)
- 11) Cancer Support Community (CSC)
- 12) Children's Cause for Cancer Advocacy (CCCA)
- 13) Children's Oncology Group (COG)
- 14) CURE Childhood Cancer
- 15) National Children's Cancer Society (NCCS)
- 16) St. Baldrick's Foundation



Association of Pediatric
Oncology Social Workers



aspho
The American Society of
Pediatric Hematology/Oncology



Canadian Association
of Psychosocial Oncology



Core Psychosocial Standards Team

Dr. Pam Hinds

(Children's National Health Systems)

Dr. Katherine Kelly

(Children's National Health Systems)

Dr. Anne Kazak*

(Nemours Children's Health System)

Dr. Mary Jo Kupst*

(Medical College of Wisconsin)

Dr. Nina Muriel

(Dana-Farber Cancer Institute)

Dr. Bob Noll*

(University of Pittsburgh)

Dr. Andrea Patenaude*, Legacy Member

(Dana-Farber Cancer Institute)

Dr. Lori Wiener*

(National Cancer Institute)



Mattie Miracle's Commitment to Implementation

The Development of Evidence Based Practice Grants:

- ❑ Mattie Miracle is partnering with the American Psychosocial Oncology Society (**APOS**)
 - Fund a \$10,000 Early Investigator Research Grant. Research must focus on the implementation of the Standards.
 - Fund Mattie Miracle Implementation Grants (5 awarded in 2018, ranging from \$2,500-\$5,000)

- ❑ Mattie Miracle is partnering with the Association of Pediatric Hematology/Oncology Nurses (**APHON**)
 - Fund 3 (\$2,500) Evidence Based Practice Grants. Research must focus on the implementation of the Standards.

**IMPLEMENTATION RESEARCH:
STUDIES CONDUCTED SINCE STANDARDS
WERE PUBLISHED**

Lori Wiener, Ph.D., DCSW
National Institutes of Health

Delivery of Care Consistent with the Psychosocial Standards in Pediatric Cancer (PIPS-CSS Study (Anne Kazak, PI)

GOALS

- ❑ Describe the readiness of pediatric oncology programs to implement the Standards in terms of the size and composition of psychosocial teams
- ❑ Discuss how centers are delivering care consistent with the Standards

Scialla, M., Canter, K., Chen, F.F., Kolb, E.A., Sandler, E., Wiener, L., & Kazak, A. (2017). Implementing the psychosocial standards in pediatric cancer: Current staffing and services available. *Pediatric Blood and Cancer*, 64, e26634.

Scialla, M., Canter, K., Chen, F.F., Kolb, E.A., Sandler, E., Wiener, L., & Kazak, A. (2018). Delivery of care consistent with the Psychosocial Standards in Pediatric Cancer: Current practices in the United States. *Pediatric Blood and Cancer*, 65, e26869.

Kazak, A., Scialla, M., Patenaude, A., Canter, K., Muriel, A., Kupst, M.J., Chen, F.F., & Wiener, L. (in press). The multidisciplinary pediatric psycho-oncology workforce: A national report on supervision for staff and training opportunities. *Psycho-Oncology*.

Methods

Survey developed by Dr. Kazak's team, revised with input from Standards leadership team, Nemours oncologists, survey research experts, and psychosocial and administrative representatives from other institutions.

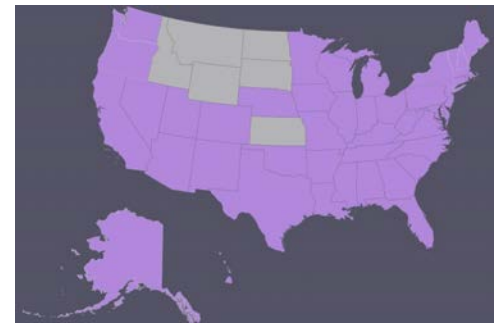
Six sections

- ❖ About You
- ❖ Information About Your Pediatric Cancer Program
- ❖ Psychosocial Staff
- ❖ Psychosocial Service Delivery
- ❖ Specific Types of Psychosocial Care
- ❖ Challenges and Barriers

Likert type scale, forced choice, open ended text

- ❖ Identified all sites in the US that treat pediatric malignancies (n = 200)
- ❖ Sought 3 participants at each site – pediatric oncologist, psychosocial leader, administrator
- ❖ Ascertained names/emails for each participant; Emailed personalized link

Participants



- ❑ 554 surveys sent to specific identified clinical leaders – oncologists, psychosocial staff members – and administrators at 200 programs
- ❑ 290 (52.3%) of all surveys returned
- ❑ 144 programs represented with at least one participant (72%)
- ❑ 60 programs submitted data for all three roles

Oncologist	99 (34.1%)
Psychosocial Leader	133 (45.9%)
Social Worker	64 (48%)
Psychologist	57 (43%)
Child Life Specialist	4
Psychiatrist	3
Other	5
Administrator	58 (20.0%)

Results

- ❑ There is considerable variability in pediatric cancer programs in terms of size and types of care provided
- ❑ Social workers are central to care with access to psychologists often available and psychiatrists less so
- ❑ Child life is usually available; assists in the delivery of much child-centric care
- ❑ Care provided “when there is a problem,” not in a systematic/preventative manner
- ❑ Although the spirit of the Standards are recognized and “met,” the care provided falls short of the evidence based care that could be provided (quality)
- ❑ Some of the more basic care (e.g. aspects of family centered care) may be provided but access to specialized care that can prevent or treat psychosocial problems is less likely
- ❑ Consistency of responses from oncologists and psychosocial providers – this care is perceived as important
- ❑ Integrated care (as opposed to “refer out”) was associated with more positive perceptions of care provided
- ❑ The Standards can be used to guide the design and delivery of care!

Licensing, timing and nature of care initiation, consultation w/the medical team, staff training and supervision

- ❑ Most psychosocial staff are appropriately licensed/credentialed although this does not address whether they have specific training for pediatric cancer
- ❑ Limited supervision, even for emergencies
- ❑ Training is available but not in all centers
- ❑ Funding challenges are considerable. Funding is diversified but not adequate to support programs consistently
- ❑ Can frustrate psychosocial staff, lead to burnout

Social Work Standards Assessment

- ❑ Following the presentation of the Standards at the 2016 APOSW conference 269 APOSW members were invited to participate in a 25-item online survey regarding their experiences in delivering psychosocial care to children and families.
- ❑ 107 social workers from 81 cancer institutions participated.
- ❑ The survey focused on institutional staffing levels, staff credentials and training, utilization of standardized assessment tools, targeted questions based on the 15 Standards
- ❑ Features of programs, program strengths and barriers to provision of care were explored.

Jones, Currin-Mcculloch, Pelletier, Sardi-Brown, Brown, Wiener. Psychosocial standards of care for children with cancer and their families: A **national survey** of pediatric oncology social workers. *Social Work in Health Care*, 2018

Social Work Standards Assessment

- ❑ Participants reported that P/S (psychosocial support) included social workers, child life specialists, psychologists, and psychiatrists.
- ❑ Service provided to children, siblings, and parents across the cancer treatment trajectory and into survivorship or bereavement.
- ❑ 41 (50.6%) of participants reported treating more than 90 new patients each year.
- ❑ Numbers of social workers per institution:
 - one (n=29, 35.8%)
 - two (n=23, 28.4%)
 - three (n=11, 13.6%)
 - four (n=8, 9.9%)
 - five or more (n=10, 12.3%)
- ❑ Majority had either no or one psychologist, and only one or no neuropsychology. Access to psychiatry very limited.

Social Work Standards Assessment

Consistent Remarks

- No formal programs for implementing many of the standards
- High caseload so no time to work the way we know is best
- Those families who present with problems get intervention but those who “seem ok and do not voice needs” do not get as much support.
- No systematic/planned screenings across many of the standards
- Due to patient volume, standardized follow-up is not always feasible
- There are no guidelines to help implement the standards or measure our work

Conclusions: Social Work Survey

- ❑ Many standards were not being systematically implemented.
- ❑ Barriers to implementation included inadequate staffing (similar findings to other studies).
- ❑ Areas for improvement include:
 - ❖ funding for p/s support staff and programs
 - ❖ incorporation of standardized assessment measures
 - ❖ assessment for financial burden throughout treatment and beyond
 - ❖ consistent access to psychology and psychiatry
 - ❖ integrated care for parents and siblings
 - ❖ more inclusion of palliative care services from time of diagnosis
- ❑ Social workers are well positioned to assist in the development of guidelines to measure the impact of implementation.

Are the Palliative and Bereavement Standards being Implemented?

Psychosocial Standard of Care

- Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status.
- When necessary, youth and families should receive developmentally appropriate end of life care (which includes bereavement care after the child's death).

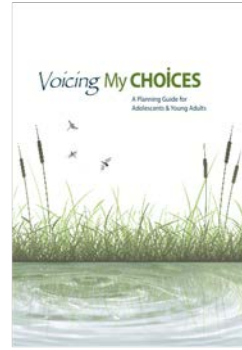
THE PATIENT PERSPECTIVE

THE PROVIDER PERSPECTIVE

THE PARENT PERSPECTIVE

The Patient Perspective

Voicing My CHOICES™ as a Tool for ACP in YA with Cancer/Chronic Illness



Primary Objectives

To determine whether engaging in advance care planning using VMC is associated with **reduced anxiety**, and/or **improved communication about ACP** with family, friends, and/or health care providers.

Preliminary Results (N=90 participants reviewed & completed VMC)

55% had not previously discussed their wishes/preferences with their family at baseline

Of those, 50% shared what they wrote in VMC at follow-up

15% spoke to their HCP re: wishes/preferences at baseline

Of those, 9% shared what they wrote in VMC at follow-up

Both general anxiety and anxiety about planning decreased (p < .01) between baseline and follow up.

...doctors always seem too busy. They come in and out so quickly. They never seem to want to talk about anything but what is needed for me to do that day.

If they raised it with me, I would be happy to share what I want and what I wrote.

Collaborative Sites: Children's National Medical Center, CHOC Children's Hospital, Cook Children's Medical Center, Dana Farber Cancer Institute, Moffitt Cancer Center, University of North Carolina, Montefiore

The Provider Perspective

To better understand successes and gaps in implementing Palliative Care as a Standard of Care

- Cross-sectional online survey (2017): N=142 (39 states, 18 countries)

Bottom line? Children and adolescents with cancer do not yet receive concurrent palliative care in an integrated, inclusive way.

- ❖ **Barrier #1:** “Pediatric oncologists believe they provide adequate palliative care.”
- ❖ **Barrier #2:** “Patient’s disease is too advanced to benefit significantly from referral.”
- ❖ **Barrier #3:** “Pediatric oncologists are unaware of the potential benefits and scope of PPC.”

Weaver ... Wiener. A Summary of Pediatric **Palliative Care Team Structure and Services** as Reported by Centers Caring for Children with Cancer. *Journal of Palliative Medicine*, 2018

Wiener ... Weaver. Personalized and yet standardized: An informed approach to the **integration of bereavement care in pediatric oncology settings**. *Palliative and Supportive Care*, 2019.

THE PARENT PERSPECTIVE

The Parent Perspective

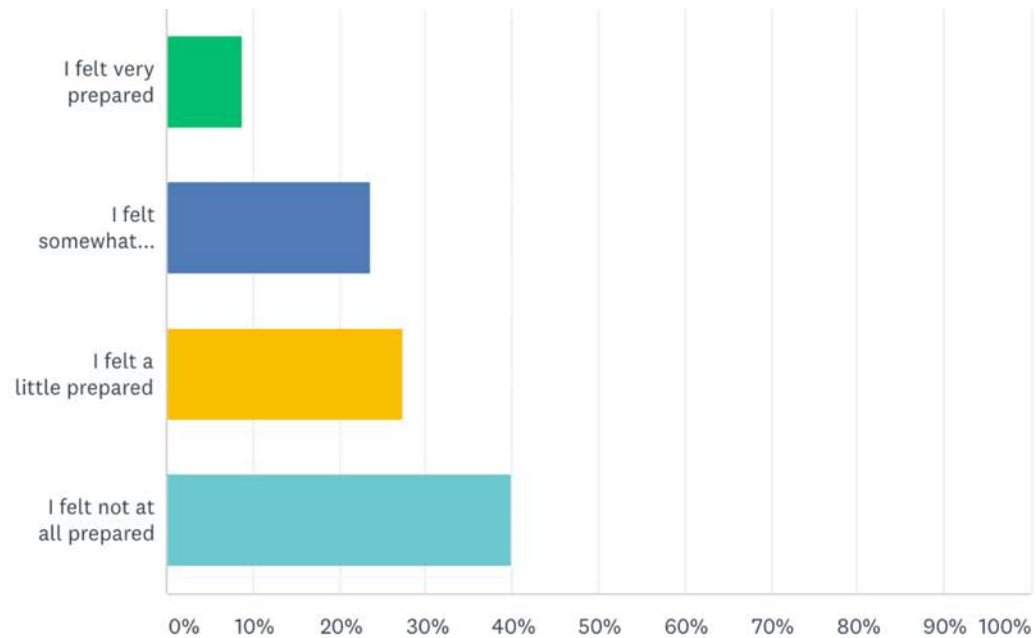
Bereaved Parents of Children who Died of Cancer

April-June, 2018

- ❑ A 46 item survey, developed by pediatric psychosocial professionals with input from bereaved parent advocates
 - ❖ Assessments of support services provided throughout the child's EoL care
 - ❖ Perceived psychosocial needs of the child and family before, during, and after death
- ❑ Introduced by a group member of a well-established closed FB group, *Parents who lost children to cancer* through Survey Monkey with branching logic directing participants to answer questions relevant to their respective experiences.
- ❑ Completion time was 20 minutes.
- ❑ Personal identifiers were not collected. Remained open for 3 months. (N = 167)

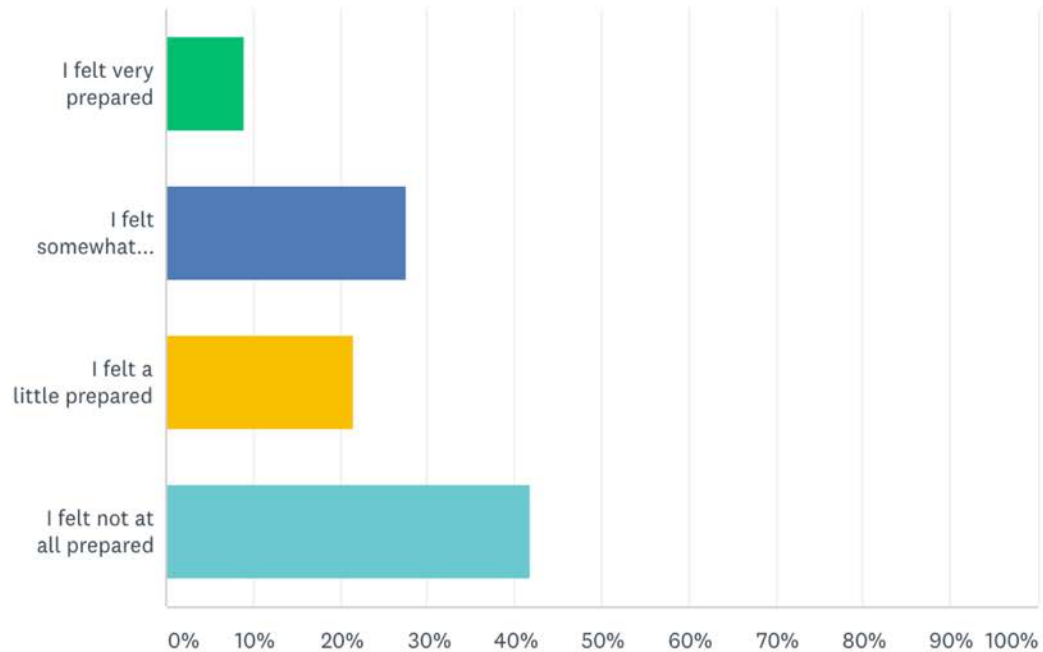
MEDICAL PROBLEMS

Did you feel prepared for the medical problems your child experienced during the end-of-life period?



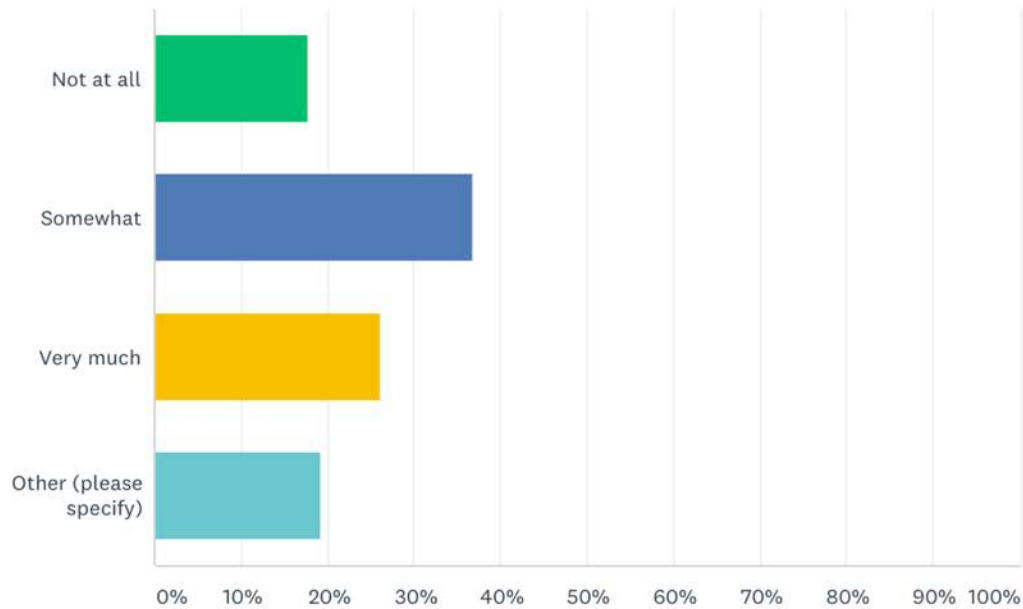
EMOTIONAL NEEDS

Did you feel prepared to address your child's emotional needs during the end-of-life period?



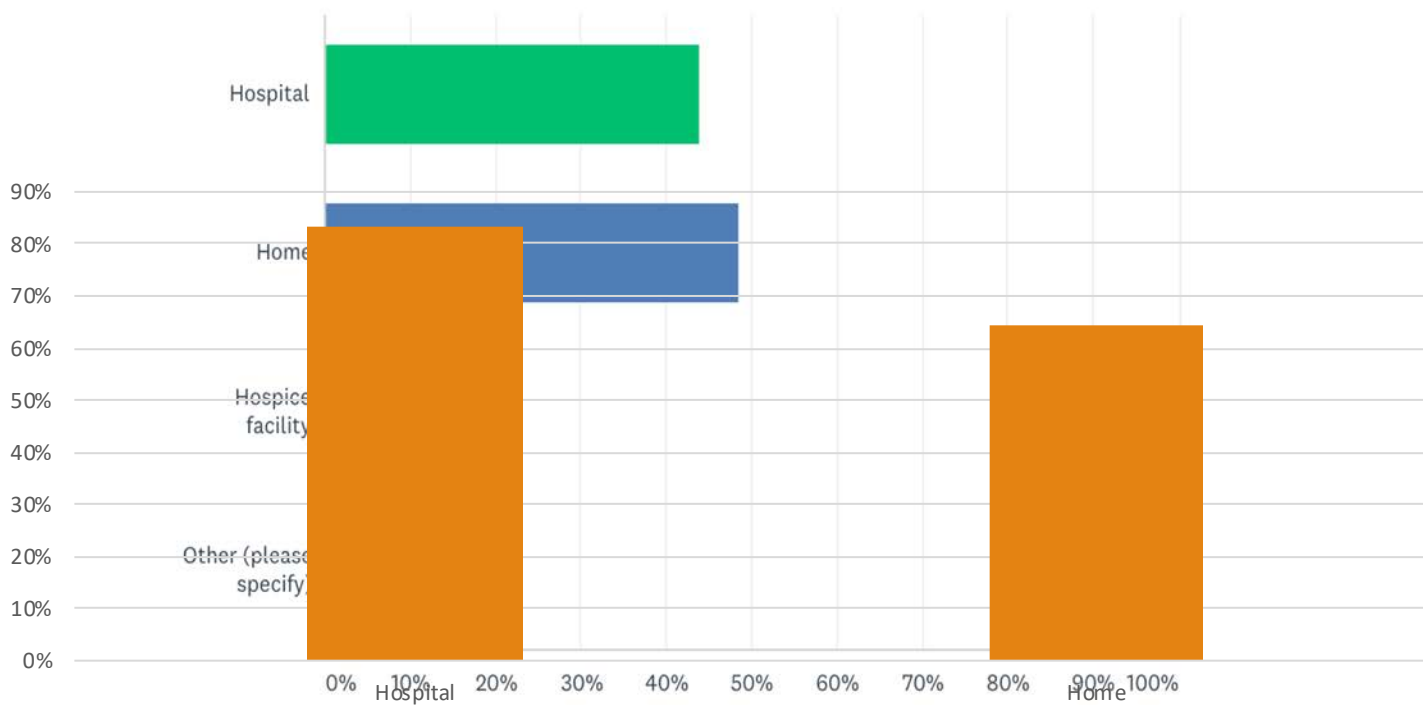
SUFFERING

Do you feel like your child suffered (i.e., pain, shortness of breath, anxiety) at the time of his/her death?



PLACE OF DEATH

Where did your child die? Place of Death and Percentage of Perceived Suffering ("Somewhat" or "Very Much")

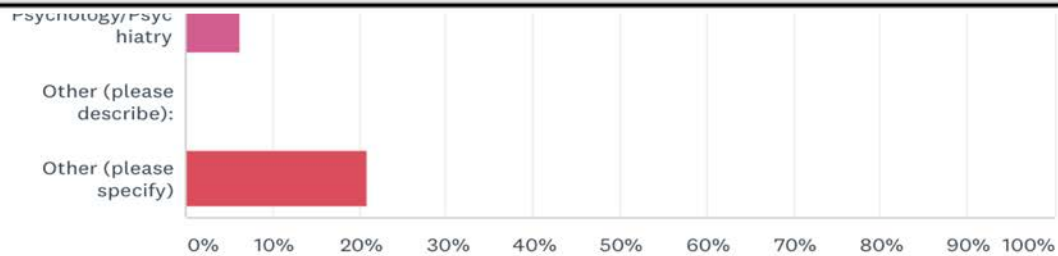


BEREAVEMENT

After your child's death, who from the health care team called your family?
(check all that apply)

Psychosocial Standard of Care

A member of the healthcare team should contact the family after a child's death to assess family needs, to identify those at risk for negative psychosocial sequelae, to continue care, and to provide resources for bereavement support.



Are the Palliative and Bereavement Standards being Implemented?



Yes

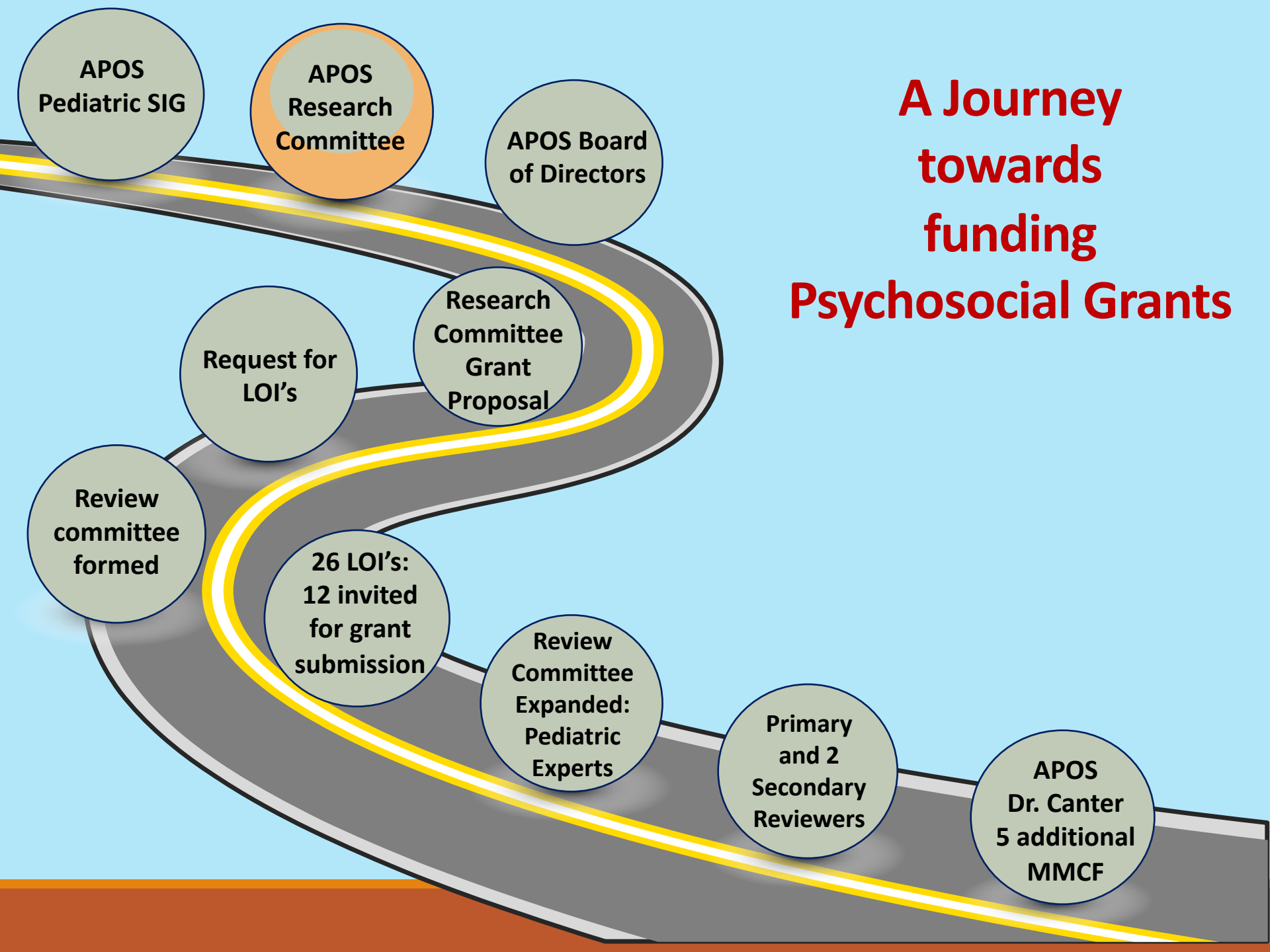


No

**IMPLEMENTATION STRATEGIES AND
INTERVENTIONS ARE NEEDED!**

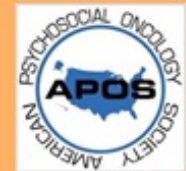
**Mattie Miracle Cancer Foundation Research
Grant Awards**

A Journey towards funding Psychosocial Grants



EARLY INVESTIGATOR RESEARCH GRANT RECIPIENT

Kimberly Canter, Ph.D.



MATTIE MIRACLE IMPLEMENTATION GRANT RECIPIENTS



Marie Barnett, Ph.D.



Kathryn Kirkpatrick, Ph.D.



Kristin Long, Ph.D.



Alexandra Psihogios, Ph.D.



Gillian Regan, Ph.D.

Mattie Miracle Early Investigator Research (APOS)

- ❑ Kimberly Canter, Ph.D. (Nemours Center for Healthcare Delivery Science, Delaware); Addressing **Standard #6** (care of parents). Grant title: Community Implementation of a Psychosocial eHealth Intervention for Parents of Children with cancer.
- ❑ Alexandra Psihogious, Ph.D. (Children's Hospital of Philadelphia, Pennsylvania); Addressing **Standard #12** (adherence). Grant title: Real-time Medication Adherence Assessments among Adolescents and Young Adults with Leukemia.
- ❑ Kathryn Kirkpatrick, Ph.D. (Nationwide Children's Hospital, Ohio); Addressing **Standard #11** (school support). Grant title: Evaluation of a tiered service model to support academic continuity and school re-entry for children with cancer.
- ❑ Kristin Long, Ph.D. (Boston University, Massachusetts); Addressing **Standard #10** (supporting siblings). Grant title: On the Outside Looking In: A Nationwide Examination of Barriers to and Facilitators of Implementing the Standard of Psychosocial Care for Siblings of Children with Cancer.
- ❑ Marie Barnett, Ph.D. (Memorial Sloan Kettering Cancer Center, New York); Addressing **Standard #13** (palliative care). Grant title: Team-based Integration of Palliative Care in Pediatric Oncology Practice: Implementing the Pediatric Psychosocial Standards of Care.
- ❑ Gillian Regan, Ph.D. (Levine Children's Hospital, North Carolina); Addressing **Standard #14** (bereavement). Grant title: Life after death: A novel online support group for parents who have lost a child to cancer.

**Interventions are Great
but.....**

Implementation Strategies Needed

- Pediatric oncology centers have asked for tools to assist with implementing the standards
- Matrix** developed as an *Institutional Assessment Tool* (scoring system) to assess current implementation of each standard
- Guidelines** developed to help improve score/implementation of each standard
- Focus groups at APOSW!
- Multidisciplinary external reviews needed
- Once updated, will be made available

Pediatric Psychosocial Standard Institutional Assessment (Matrix)

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains	Levels				
		1	2	3	4	5
<p>2. Patients with brain tumors and others at high risk for neuropsychological deficits as a result of their cancer treatment are monitored for neuropsychological deficits during and after treatment</p>	<ul style="list-style-type: none"> • General intelligence • Attention, memory, language, executive functions • Neurosensory functions • Perceptual processing • Processing speed • School performance • Behavior/Psychosocial adaptation <p>Periodicity: Baseline, post-treatment, 2-3 years post-treatment</p>	No neuropsychological monitoring provided	*	Patients receive assessment of neuropsychological functioning as clinically indicated (either internal or external referral)	*	Repeat assessment of neuropsychological functioning provided at recommended time points as clinically indicated

Guidelines

Standard 2:

Patients with brain tumors and others at high risk for neuropsychological deficits as a result of their cancer treatment are monitored for neuropsychological functioning during and after treatment.



Actions	Strategies	Resources/Tools
<p>Monitor/Assessment of children with brain tumors and/or those who receive CNS directed therapies for neuropsychological deficits.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Train pediatric cancer team in screening procedures that can identify children with risk factors or acute mental status changes. <input type="checkbox"/> Prioritize timing of neuropsychological monitoring/assessment as an essential part of acute and late effects care (e.g. during treatment). <input type="checkbox"/> If a full neuropsychological assessment is indicated, and a neuropsychologist is not available, create a partnership with existing pediatric neuropsychological providers from other clinical services (e.g. pediatric neurology) or maintain a database of local neuropsychologists outside of the hospital system. <input type="checkbox"/> Parents/caregivers should meet with the neuropsychologist to learn about the outcome from the assessment. When appropriate, interventions should be provided (including recommendations for both home and school). <input type="checkbox"/> Reimbursement for neuropsychological monitoring and assessment services vary 	<p>Monitoring tools may include parent/school/child report, standardized check-lists or questionnaires, and/or brief mental status or cognitive screening.</p> <p>Suggested domains when monitoring results in need for neuropsychological assessment:</p> <ul style="list-style-type: none"> <input type="checkbox"/> General intelligence <input type="checkbox"/> Attention, memory, language, executive functions <input type="checkbox"/> Neurosensory functions <input type="checkbox"/> Perceptual processing <input type="checkbox"/> Processing speed <input type="checkbox"/> School/Academic performance <input type="checkbox"/> Behavior/Psychosocial adaptation <p>If monitoring during treatment led to assessment, repeat assessment after treatment if/when clinically indicated. Otherwise, repeat assessment if clinically indicated during survivorship, monitoring at 2/3 years after treatment</p> <p>Domains identified above should be included as clinically indicated.</p>

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains	Levels				
		1	2	3	4	5
<p>5a. Assessment of risk for financial hardship is incorporated at time of diagnosis for all pediatric oncology families</p>	<ul style="list-style-type: none"> • Pre-existing low-income or financial hardship (ability to cover basic needs, e.g. food, rent) • Single parent status • Transportation to and distance from treating center • Anticipated long/intense treatment protocol • Parental employment status • Family legal status 	<p>No formal process exists to assess financial hardships at initial screening</p> <p>Financial screening or referral is available upon request only</p>	<p>*</p>	<p>Families receive a financial screening at time of diagnosis</p> <p>Targeted referral for financial counseling and supportive resources (including both governmental and charitable supports) is offered based on results of family assessment</p> <p>Staff educated on impact of financial hardship</p>	<p>*</p>	<p>Families receive systematic review with a uniform approach and / or use of a standardized assessment of financial resources at initial screening at time of diagnosis</p> <p>Targeted referral for financial counseling and supportive resources (including both governmental and charitable supports) is offered based on results of family assessment</p> <p>Staff educated on impact of financial hardship</p>

Standard 5:

Assessment of risk for financial hardship should be incorporated at time of diagnosis for all pediatric oncology families. Longitudinal reassessment and intervention should occur throughout the cancer treatment trajectory and into survivorship or bereavement.

Actions	Strategies	Resources/Tools
<p>5a Assessment of risk for financial hardship should be completed at the time of their child’s diagnosis for all pediatric oncology families.</p> <p>5b Longitudinal reassessment and intervention of financial risk occurs throughout the cancer treatment trajectory and into survivorship and bereavement.</p>	<ul style="list-style-type: none"><input type="checkbox"/> Obtain comprehensive screening information on the financial needs of parents/caregivers throughout the cancer trajectory including survivorship and bereavement.<input type="checkbox"/> Domains to be considered in the assessment include: pre-existing low income or financial hardship, housing, utility, and food stability, single parent status, transportation needs and distance from treating center, anticipated long/intense treatment protocol, younger children, children with poorer prognoses, and parental employment status.<input type="checkbox"/> Direct treatment-related costs should be considered: hospital/physician fees, medications, equipment, aid devices such as prostheses and wheelchairs, travel and parking expenses for clinic visits and hospital admissions, food, accommodation, childcare for siblings, communication-related costs, comfort items for their child during hospital/clinic visits.	<ul style="list-style-type: none"><input type="checkbox"/> Use of a financial assessment tool at the time of diagnosis and at intervals throughout the cancer treatment trajectory into survivorship. Basic assessment tool must include domains: housing/transportation/utilities/food.<input type="checkbox"/> American Academy of Family Physicians Social Needs Screening Tool https://sirenetwork.ucsf.edu/tools-resources/screening-tools.<input type="checkbox"/> Dana Farber/Boston Children’s Cancer & Blood Disorders Center. HMH (Household Material Hardship) Clinical Screen (Dr. Kira Bona)<input type="checkbox"/> Targeted referral for financial counselling (to social work or other appropriate discipline)<input type="checkbox"/> Referral to applicable governmental supports (local/national organizations)<input type="checkbox"/> Referral to applicable charitable supports (local/national organizations)

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains	Levels				
		1	2	3	4	5
<p>7a. Youth with cancer and their family members are provided with psychoeducation and information related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation</p>	<ul style="list-style-type: none"> ● Disease education: Diagnosis and treatment, anticipated side effects ● Behavioral and emotional responses ● Availability of developmentally appropriate interventions for coping, distress reduction, and/or behavior management; preparation for medical procedures; and legacy and meaning making, when appropriate ● Informed consent and medical decision making, including advance care planning when appropriate ● Getting to know the hospital system (e.g., unit, team, policies, resources) and preparing for hospitalization ● Healthy lifestyle behaviors and self-care ● Transitions of care (e.g., within hospital, off treatment, to hospice) 	<p>Distribution only of written psychoeducational information related to treatment and side-effects and/or psychosocial adaptation to youth and their families with no or limited guidance at time of diagnosis</p>	<p>*</p>	<p>Youth and their families receive psychoeducational information with discussion of content at time of diagnosis and some, but not all, key points along the cancer trajectory</p>	<p>*</p>	<p>All youth and their families receive regularly scheduled psychoeducation information and discussion or guidance to aid in psychosocial adaptation to treatment at all key points along illness trajectory including (but not limited to): diagnosis, end of therapy, during the transition to long term survivorship, at relapse/recurrence, and/or end-of-life.</p>

*"Youth" refers to children and adolescents with cancer. AYA refers to adolescent and young adults.

Standard 7:

Youth with cancer and their family members should be provided with psychoeducation, information, and anticipatory guidance related to disease, treatment, acute and long-term effects, hospitalization, procedures, and psychosocial adaptation, and be provided throughout the trajectory of cancer care.

Actions	Strategies	Resources/Tools
7a Provide psychoeducation and anticipatory guidance to children and families, as appropriate for stage of treatment (i.e., initial diagnosis, ongoing treatment, end of therapy, relapse, survivorship, end-of-life, bereavement)	<ul style="list-style-type: none"><input type="checkbox"/> Identify team members who will be providing/can provide education and guidance related to disease and treatment, hospitalization and procedures, and psychosocial adaptation. (Psychoeducation and anticipatory guidance can be and likely will be provided by multiple disciplines; in fact, a team approach is recommended if staffing allows).<input type="checkbox"/> Patients and parents/caregivers should meet with psychosocial providers regularly for education and guidance. Scheduled meetings at transition points are important, as well as the ability to contact providers as needed for follow-up.<input type="checkbox"/> Centers should have access to appropriate educational resources and multimedia materials for both caregivers and patients, including, but not limited to books, handouts, videos, medical play toys and dolls, and games.<input type="checkbox"/> Books and videos that explain and normalize the cancer experience and feelings associated with different stages of illness should be available and provided, as indicated.	<p>Written, visual, and tactile psychoeducational tools including, e.g.,</p> <ul style="list-style-type: none"><input type="checkbox"/> Children’s Oncology Website, Patient and Family Section https://www.childrensoncologygroup.org/index.php/patients-and-families (Reliable medical information disease and treatment written in lay terms, as well as sections on coping, school, grief, informed consent, and more).<input type="checkbox"/> COG Healthlinks (Patient education handouts for survivors re: specific late effects and ways to enhance and protect health, e.g., Diet and Physical Activity, Dental Health, Heart Health), available in English and Spanish<input type="checkbox"/> https://www.imaginaryfriendsociety.com/ (A series of short informational videos for children in both English and Spanish about disease, treatment, procedures, and common emotions).<input type="checkbox"/> Developmentally appropriate teaching tools for explaining disease, treatment, and procedures to children, e.g.,<ul style="list-style-type: none">- Cellie Coping Kit https://www.chop.edu/health-resources/cellie-cancer-coping-kit- Medikin Doll

**How can I take this back to my
program?**

The Gift of the Standards

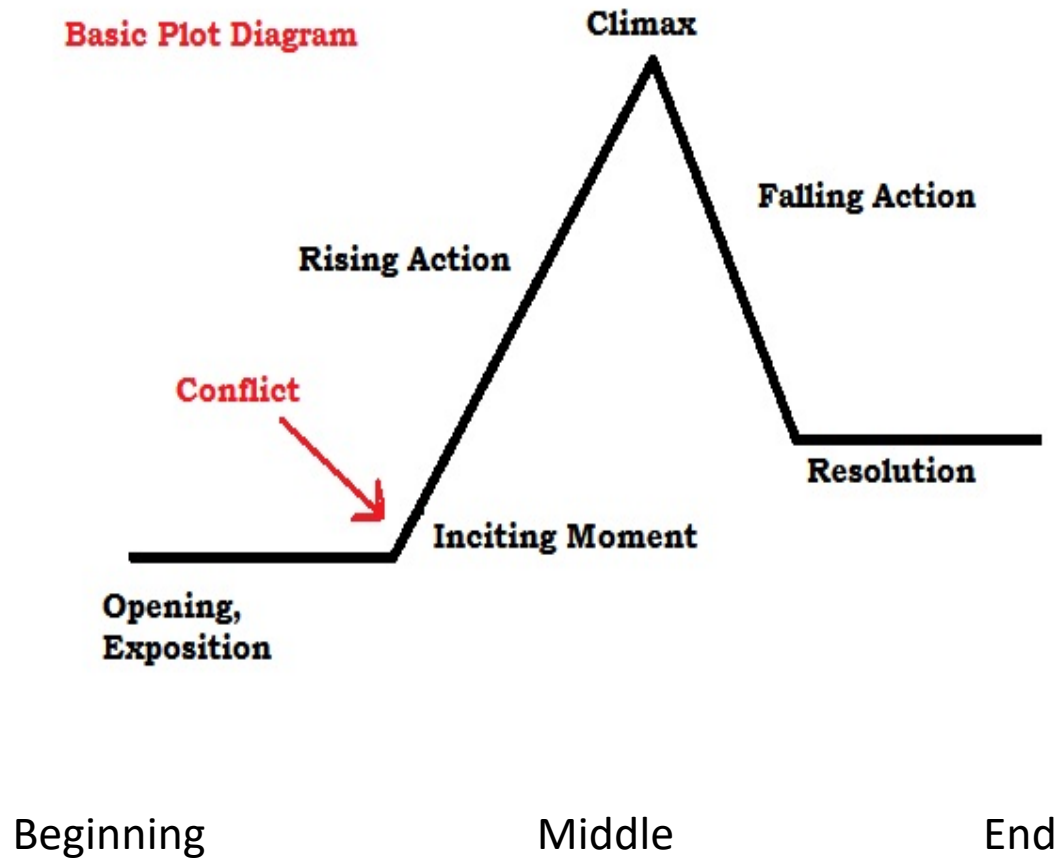
(And Now their Guidelines & Matrixes, too!!!)

*A Story of One Social Worker's Path to
Appreciation*

Spencer Moorman, MSSW, CSW

University of Louisville School of Medicine

The Elements of a Story



A Tale of Two Cities... and Pathways

THE EXPERTS

A NOVICE



The Beginning/ Setting:

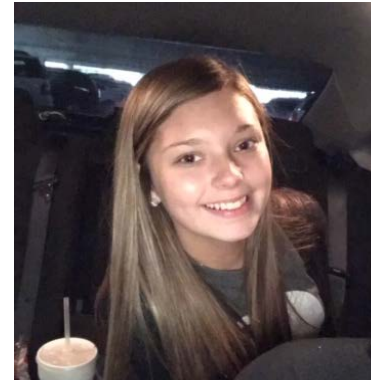


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Setting & Characters:

Job Landscape, Responsibilities & Description



The Conflict: Reality sets in...



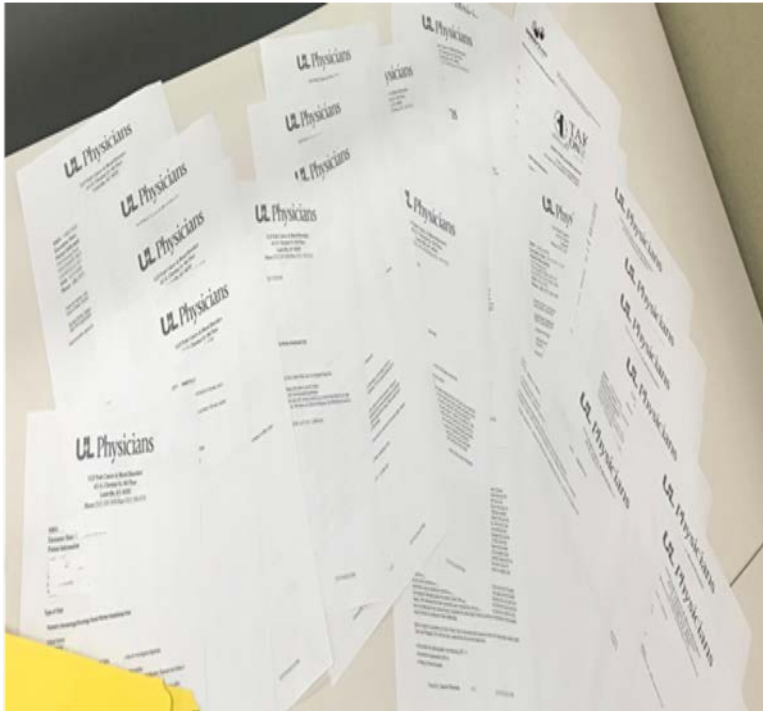
The Conflict: Realizations

Consistent Remarks of the Social Work Standards Assessment

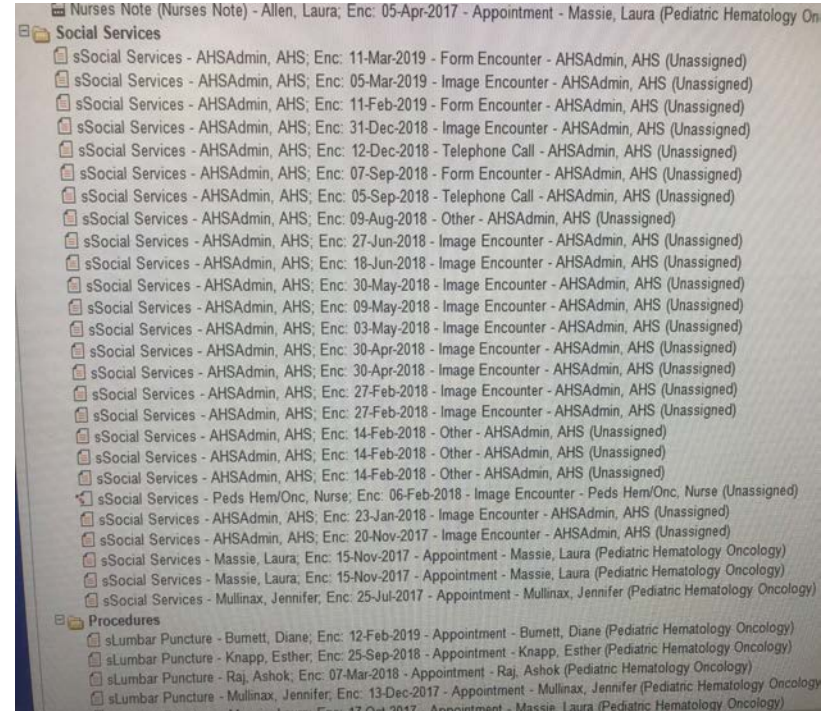
- Care provided “when there is a problem,” not in a systematic/preventative manner
- Although the spirit of the Standards are recognized and “met,” the care provided falls short of the evidence based care that could be provided (quality)
- High caseload so no time to work the way we know is best
- Funding challenges are considerable. Funding is diversified but not adequate to support programs consistently
- Those families who present with problems get intervention but those who “seem ok and do not voice needs” do not get as much support.
- No systematic/planned screenings across many of the standards

Charts-Charts-Charts

NO CHECKLISTS



NO PROACTIVE PLAN OR MAP



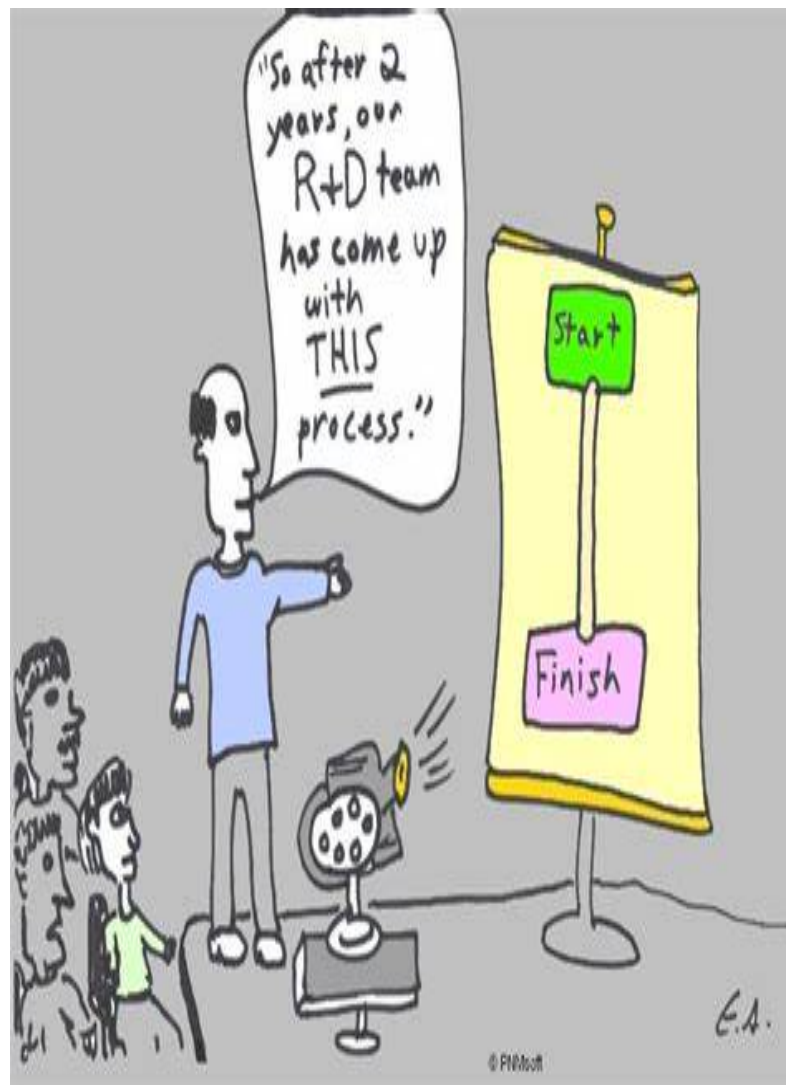
The Conflict - Frustrations Continued:

“There are no guidelines to help implement the standards or measure our work”

- Varied Access to Care and Service Delivery
- Reactive Service Delivery
- No measurement or process in place to gauge baseline treatment

“How do I possibly organize, process, and operationalize care for all deserving patients and families?”

Confused-Exhausted-Frazzled-Overwhelmed



The Inciting Moment



A Clinic Encounter Still Remembered

Finding the Standards!!!



“The Standards can be used to guide the design and delivery of care!”

HOPE-RELIEF-CLARITY-FOCUS-DETERMINATION-RELIEF-RELIEF-RELIEF

Empowered

Empower the Child
- der Online-Kongress -



empower
yourself



“I ^{DESERVE}
to be
supported.”

everydayaffirmations.org



USING the STANDARDS to DESIGN & DELIVER CARE:

A) Psychosocial Roadmap Information

- 1) Information needed to execute each standard
- 2) Standard Checklists -Topics, Resources, Referrals, Interventions, Talking Points for each Standard

B) Chemo Roadmap Counterpart

- 1) Visual Psychosocial Counterpart to Medical Roadmap
Breakdown of each standard (Standard Checklist attachments)
Who, What, Where, When, Why

C) Create Standards Encounters Tracker

- 1) Visual tool to track “touches”
- 2) Visual tool for overall picture of expected encounters

D) Submit data into RedCAP database



Get to Work!

THE MORE I WANT TO
GET SOMETHING
DONE, THE LESS I CALL
IT WORK.

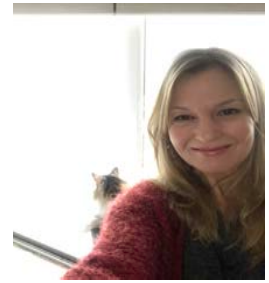
Hard work Quotes

The difference between the ordinary
and the extraordinary is the little
extra

Jimmy Johnson



Meanwhile, unbeknownst to



The Experts



are working on the development of guidelines and matrixes for each standard ...

Created Personal Tools for Utilization in Practice

A Psychosocial Version of the Medical Roadmap

Psychosocial-Standard (Medication/Drug) *Applicable to All Patients	Who (Recipient)	Where/How (Route) Red=More Staff Needed for Baseline Standard Execution	What (Dosage)	When (Days) Months/Year	Why (Important Notes/Observations) Action Steps for Administrators
Systematic Assessments of Psychosocial Health Care Needs *	Patient & Family Members	Clinic In Patient Tele Phone Medicine Online Website ----- Via: Social Worker, Psychology, Child Life Specialists, Psychiatrists, Clinical Educators, Patient/Nurse Navigators, and Spiritual Leaders	See Section 1 for Admin options (*) and checklists	1-3 4-6 Year 1 7-9 10-12 ----- 13-18 19-24 Year 2 ----- 25-30 31-36 Year 3 ----- 37-48 Year 4	<ul style="list-style-type: none"> • The Commission on Cancer guidelines require screening, particularly at diagnosis, family meeting with oncologist to discuss treatment, transitions off treatment • Repeated screening and assessment • Strong and highly consistent research evidence that children and parents experience increased distress, poorer quality of life, and difficulties in psychosocial functioning immediately and in the months after diagnosis of cancer. • Coordination of assessment schedule and execution for patient and family members

Completed Tedious Tool Examples Completed and Utilized (Yes, dizzy making!) Visual tools to track “touches” and see overall plan for expected encounters

YEAR ONE															
Standard#	1	4	5	6	7	8	9	12	13	15	2	10	11	3	14
At Diagnosis	X			X		X				X	Xx				
Early & Ongoing	X	X	X	X	X	X	X			X		X	X		
Early & PRN										X					
Systematically	X							X		X				*	**
Only When Applicable											X	X	X	X	X
Month 1	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	IWA	IWA
Month 2	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓		
Month 3	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓		
Month 4	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓		
Month 5	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓		
Month 6	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓	↓		

M=Month	Dx	M1	M2	M3	M4	M5	M6	M7	M8	M9	M10	M11	M12	
Insert Months	Mar 5th	Mar	Apr	May	Jun	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	
1 Assessments	X		→		→			→				→		
Dates Delivered Insert Dates	03/07 P;M 1		04/8 2		06/5 3			X	X	X			01/20 4	
4 Interventions & Psychiatry Access			→		→			→				→		
Dates Delivered Insert Dates		03/25 P;M 1			06/05 2				10/10 3			X	X	X

Completed Personal Practice Checklists for each Standard

Example of Checklist for Standard 4

Topics, Resources, Referrals, Interventions, & Talking Points

Intervention

CBT Crisis

Family Therapy

PSST

SCCIP-ND

Education

Games

Books

Handouts

Psychiatry Referral

Psychology Referral

Grounding Techniques

Yoga Therapy

Reiki Therapy

Pet Therapy

Art Therapy

Music Therapy

Sexual Health Issues

Health Literacy

Coping Mechanisms

Marital Therapy

Shop Talk

Distorted Thoughts

Problem Solving Therapy

Advocacy Opportunities

Pain Management

Journaling

Mindfulness

Gratitude

Nature Oriented

Dance

Boat Metaphor

Ted Talks

Podcasts

Me

Thought vs Fact

Gilda's Support

Caregiver Support

Literature-Books

Organizational Support

Meditation

Podcasts

Thought vs Fact

Gilda's Support

Caregiver Support

Literature-Books

Organizational Support

Meditation

Meanwhile, the Expert Guidelines were in Development and will soon be available to you...as seen on the next slide

So while Unaware of guidelines and matrix development ...

A) Psychosocial Roadmap Information

Information needed to execute each standard

Standard Checklists -Topics, Resources, Referrals, Interventions,
Talking Points for each Standard



B) Chemo Roadmap Counterpart

Visual Psychosocial Counterpart to Medical Roadmap

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C) Create Standards Encounters Tracker

Visual tool to track “touches”



D) Submit data into RedCAP database

The Phone Call Fall 2018



Matrix and Guidelines Development ?!!!!

The Resolution

“The Standards can be used to guide the design and delivery of care!” **yes**

“Social workers are central to care.” **yes**

“You have the weaponry (standards, guidelines, matrixes, SMGs) to drive your practice.” **yes**

“They (SMGs) are invaluable GIFTS providing measurement, strategies, tools, and actions for progress.” **yes**

Progress Report Drafted for each Standard – Standard 3 & Wishlist

- Yearly psychosocial screening has been implemented in long term clinic
- Appropriate steps have been taken to assist AYA pts with their educational and/or vocational progress, social and relationship difficulties, distress, anxiety, and depression; and risky health behaviors
- SW is now notified via weekly meetings, by physicians and nurses regarding anticipatory guidance about treatment's end and what to expect after curative care is over emotionally & psychologically
- Follow up monitoring protocols are explained and the Importance of follow up care is highlighted
- Insurance navigators will be joining clinic afternoons to assist with AYA coverage
- Retreat opportunities have been realized through Dream Street, Lighthouse Retreat, Camp Mak A Dream, Camp Quality (pals), and Indian Summer for AYA patients in survivorship
- Life After Treatment Seminar is now held yearly to inform pts and families of the issues which accompany survivorship
- A mass email list is being compiled to make this pt population aware of all events, news and opportunities related to them
- Scholarship lists are distributed each week to alert pts of available funding for college and graduate school
- Local social events made available through Norton's YAP program have been advertised
- Patient Pal opportunities for speaking and engagement have been introduced
- Advocacy avenues in KY's state capitol have also been made available and encouraged
- An AYA transition clinic was established to appropriately treat the unique needs of these young people
- A transition process was outlined for more seamless transfer of care
- Checklist was established for this standard (programs, service delivery, resources)

- Full Time Psychologist
- Insurance Navigator
- Additional Clinical Social Worker
- Focused support groups

The Gifts of the Standards

Legitimizes
importance of all
standards –
Outlines path

Illustrates how
much social
workers
accomplish

Powerless to
Powerful

Inconsistent to
Operationalized

Reactive to
Proactive Service
Delivery

Lessons Learned

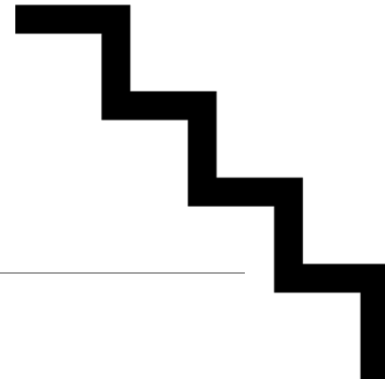


A Sincere Appreciation for the Standards & Gifts Realized through the Process:

- I was armed with weaponry for advocacy opportunities
- This work enabled me to submit for grant funding opportunities in targeting specific needs and gaps in care.
- Earned respect the social work field
 - Invited to present a big picture vision to healthcare administrators for a Pediatric Psychosocial Oncology Program and Team
- Advocacy efforts were successful in obtaining TWO new full time clinical social worker hires
- Many partnership opportunities are being sought as a result of this work and knowledge
- Submitted funding to help support a school liaison/ additional neuropsych testing



Future Steps:



- Presenting individualized web program idea, armed with new guidelines, to Development Office for pairing with possible Donor
- Meeting further with Patients/Families regarding a fun and engaging standards map for them to utilize-in brainstorming phase
- Developing individual standard oriented programs for funding requests and grant submissions
- Drafting job descriptions for each possible position needed
- Highlight areas for support where other resources can be utilized for staffing
- Use new guidelines and matrixes to simplify personal professional tools in practice, and...

Spread the news about the new Guidelines and Matrixe ...



Bringing it all together

Implementation Considerations

Wendy Pelletier, MSW, RSW
Alberta Children's Hospital
Calgary, Canada

How can I implement the Standards in my own Center?

- ❖ Following the review by stakeholders and receipt of a final version of the matrix and guidelines, the work can begin at an individual institutional level.
- ❖ Gather together the psychosocial care team within your institution to take stock of how your program delivers psychosocial care. What would the families say if you asked them if they were being offered psychosocial services that are effective and impactful in improving the cancer experience for them?
- ❖ Have a thorough grasp of the 15 standards
- ❖ Familiarize yourselves with the matrix and the guidelines. How do you measure up? The matrix offers a very substantial and practical tool for assessing where you are in the continuum.

How can I implement the Standards in my own Center

- ❑ Commit to a timeline wherein you review each standard thoroughly and apply the matrix.
 - ❖ Where are the gaps?
 - ❖ What are the barriers to implementation in your individual institution?
- ❑ Is there a way to move the needle...for example, you may be at a score of 1 on the matrix for a standard but, can you see ways to move to a 3, 4, or 5?
- ❑ How can you involve your wider team (nursing/medicine/other allied health) to problem-solve around how to deliver more effective and deliberate psychosocial care.
 - ❖ Is it possible that some of the other team players could adopt a function that frees the social worker's time? For example, does it need to be the social worker who administers an assessment tool (such as the PAT)?
 - ❖ Could someone in your clinic waiting room take on that role and provide you with the results?

How can I implement the Standards in my own Center

- ❑ Educate your wider team and administration about the endorsement of the standards by many major oncology stakeholders and organizations.
 - ❖ Make them aware of your plan for implementation.
- ❑ Familiarize yourself with the ongoing and developing legislation related to the standards.
 - ❖ What will it mean for your individual institution and accreditation down the road if you are not meeting these standards?
- ❑ Have a vision for the kind of care you want to deliver. Social Workers can take the lead! Even in centers where you may be a solo practitioner, or have a very small team, you have an impact.
 - ❖ Studies identify social workers (and child life) as delivering 90% of psychosocial care to children and families in oncology settings (Scialla, 2017).

Implementing Psychosocial Standards of Care

Overall Vision

Peter J. Brown, MBA, FAHM

Mattie Miracle Cancer Foundation



Snapshot

- ❑ Phase 1 – Develop The Standards – **Completed!**
 - ✓ Develop and document evidence-based standards of care spanning last two decades of research
 - ✓ Publish in a Tier 1 Medical Journal (*Pediatric Blood & Cancer*)
- ❑ Phase 2 – Endorsements of Standards – **On-Going**
- ❑ Phase 3 – Standards Implementation – **Delivery Stage**
 - ✓ Four-part approach
 1. Research and Development
 2. Legislation and Regulation
 3. Education and Accreditation
 4. Implementation and Delivery

1. Research and Development

- ❑ Conduct research to address shortfalls and gaps in existing body of evidence
 1. Further explore and develop existing interventions and tools
 - ✓ Doing more of what we already know works, and be more effective in delivering it
 2. Initiate research into areas with weak or no existing evidence
 - ✓ Target underserved and unserved areas that need basic research and evidence to help standards be more complete and rigorous



Implementation Grants

- ❑ In 2018, Mattie Miracle partnered with the American Psychosocial Oncology Society (APOS) to create an Early Investigator Grant and Mattie Miracle Implementation Grants.
- ❑ The purpose of the grants is to produce clinical tools and models that will enable the implementation of the Psychosocial Standards of Care at treatment centers around the country.
 - 26 grant proposals were reviewed by 3 experts in the area of the proposal. The following areas were scored:
 - Significance to psychosocial oncology and the implementation of the Psychosocial Standards, Scientific Merit, Innovation, Appropriateness of Methods and Qualifications of the investigator to conduct the study



2. Legislation and Regulation



- ❑ Establish the Standards formally as essential care, and use regulatory and legislative actions to mandate their use
 1. Legislate Standards as essential care
 2. Get Medicaid to declare Standards as an essential component of comprehensive cancer care, and support reimbursement of services
 3. Mandate/Regulate coverage by insurers to support reimbursement of essential services delivered by health practitioners
 - ✓ Hematology/Oncology, Nursing, Social work, Psychiatry, Psychology, Child Life

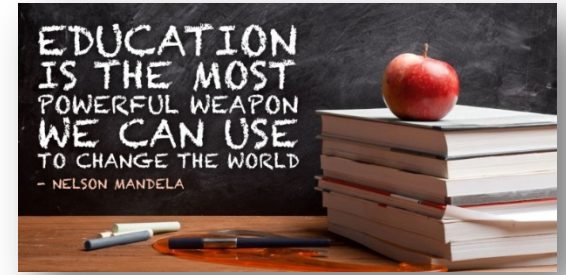
The STAR Act

- ❑ In June of 2018, the STAR Act (**S**urvivorship, **T**reatment, **A**ccess, and **R**esearch) was signed into law.
- ❑ The STAR Act has three main areas of focus:
 - Maximizing childhood cancer survivors' quality of life
 - Moving childhood cancer research forward
 - Helping kids get access to life-saving treatments



- ❑ Dept. of Health and Human Services (HHS) required to review and report on HHS activities related to: **workforce development** for healthcare providers specializing in the treatment of pediatric cancer patients and survivors. Review must assess the effectiveness of psychosocial care services for these individuals and must yield recommendations for improving the provision of such care.
- ❑ Authorizes the NIH to continue funding or supporting research on childhood cancer survivorship to examine aspects like treatment outcomes; barriers to care; the impacts of familial, socioeconomic, and environmental factors; and late effects of cancer treatment and the development of targeted interventions to limit those effects.

3. Education and Accreditation



- ❑ Build knowledge of Standards universally, and have associations embrace both use and application of standards in accreditation and educational programs
 1. Associations to endorse and to support standards
 - ✓ AACAP, APA, APHON, APOS, APOSW, ASPHO, COG, CAPO, etc.
 2. Incorporate Standards into accreditation and licensure programs
 - ✓ Requiring sites and professionals to demonstrate use and application of standards
 3. Embed Standards into educational curriculums and training programs for professionals

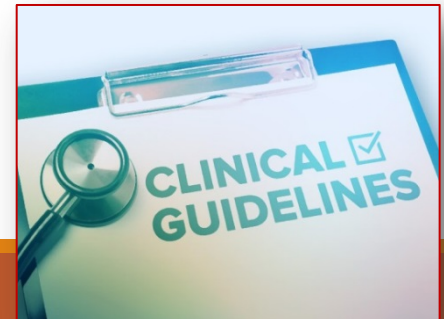
4. Implementation and Delivery

- Define delivery models based on resourcing and develop implementation toolkits for site use
 1. Assess and understand delivery requirements for sites offering services
 2. Identify and develop practical applications of Standards with guidelines for delivery
 3. Define optimal mix of resources to support delivery of standards



Standards Matrix & Guidelines

- ❑ The Psychosocial Standards Core research team and the authors of each of the 15 Standards are in the process of creating a Matrix and Guidelines.
- ❑ The **Matrix** is being developed as an Institutional Assessment Tool (scoring system) to assess current implementation of each Standard.
- ❑ The **Guidelines** are being developed to help improve the treatment centers' score/implementation of each Standard.
 - For example, on the Matrix if a center self scores as a 1 or 2 on the sibling Standard, they could turn to the Guidelines for ways to improve/move to a 3 or even to a 4 or 5 on the Matrix's Likert scale.



Questions & Answers

