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

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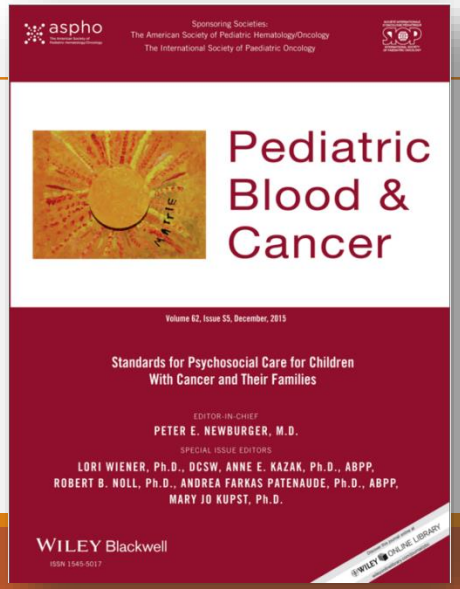
Washington, DC



Agenda

- Why the Standards Were Created (VB 2-16)
- History & Implementation Research (LW 17-23; WP 24-27; LW 28-43)
- Matrix and Guidelines Development (LW 44-52)
- Innovative Roadmap Underway (SM 53-76)
- Evaluating Usefulness of Roadmap (WP 77-80)
- Future Directions (PB 81-90)

Mattie Brown's Life Inspired the Standards

Victoria Sardi-Brown, Ph.D., LPC
Co-Founder & President

Mattie Miracle
CANCER FOUNDATION
It's not just about the medicine!™

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

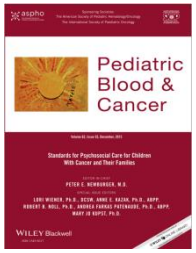
1. Assessment of well-being and emotional functioning
2. Neurocognitive status
3. Psychotherapeutic interventions
4. School functioning
5. Training, communication, and documentation of psychosocial services

2013-2014
Monthly teleconferences

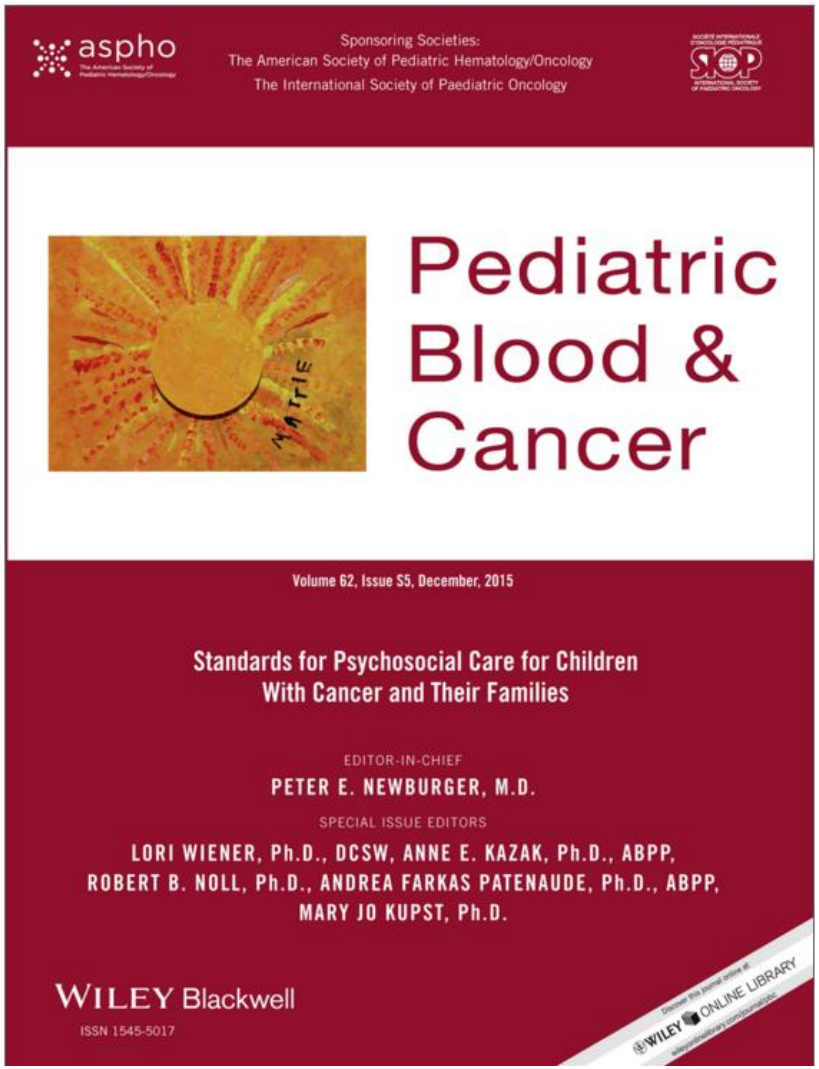
2014
2nd Think Tank consolidated data info **15** consensus Standards

2014-2015
Systematic reviews for evidence-based Standards

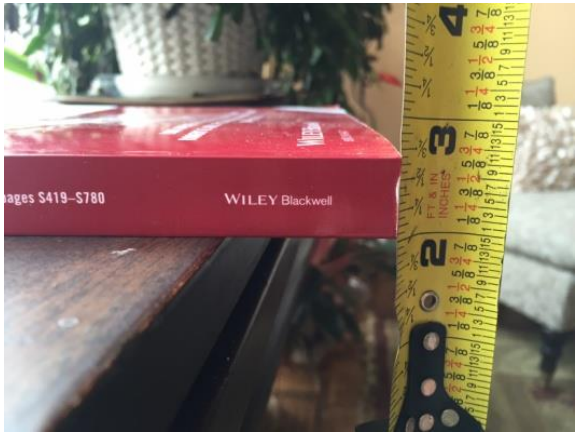
16 Papers
66 Authors
1,217 studies
Pub: Dec. 2015



Standards Published - December 2015



16 papers
66 authors
Total of 1,217 studies

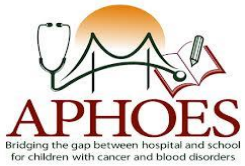


15 Psychosocial Standards of Care

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



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

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

RESEARCH CONDUCTED SINCE STANDARDS WERE PUBLISHED

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.

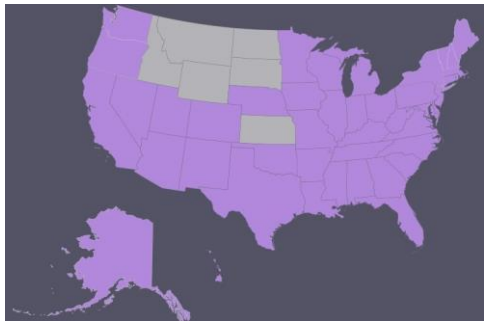
Six sections

- 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
Psychologist	57
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 is important – 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. This has workforce implications
- 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, and 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?

 Yes

 No

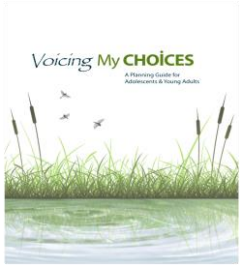
THE PATIENT PERSPECTIVE

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 advanced 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 an… …nning decreas… …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

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- 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

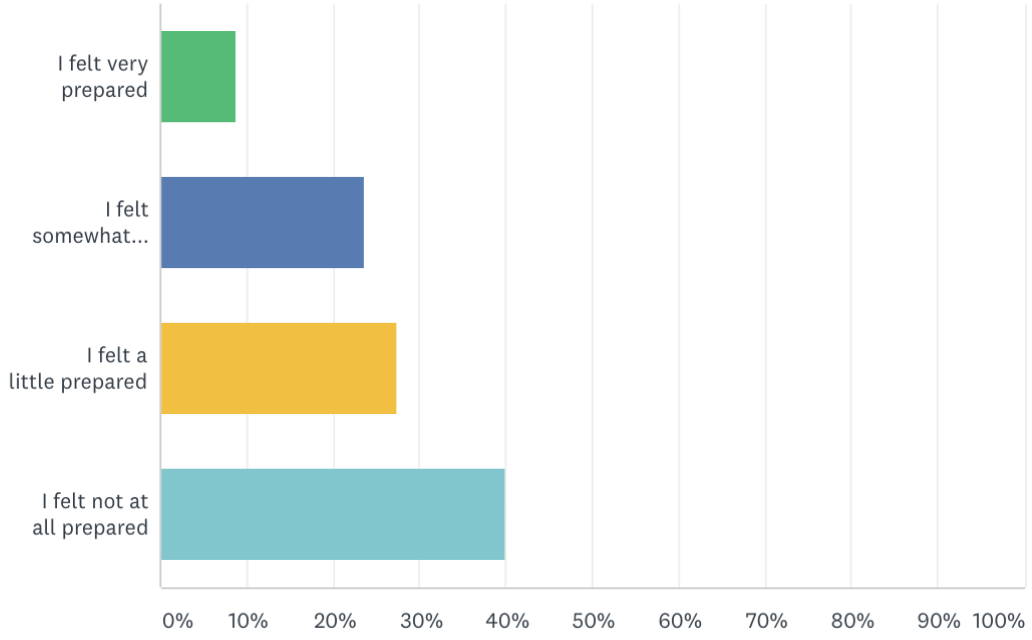
Bereaved Parents of Children who Died of Cancer

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, and 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.
- Estimated completion time was 20 minutes.
- Personal identifiers were not collected. Remained open for 3 months.

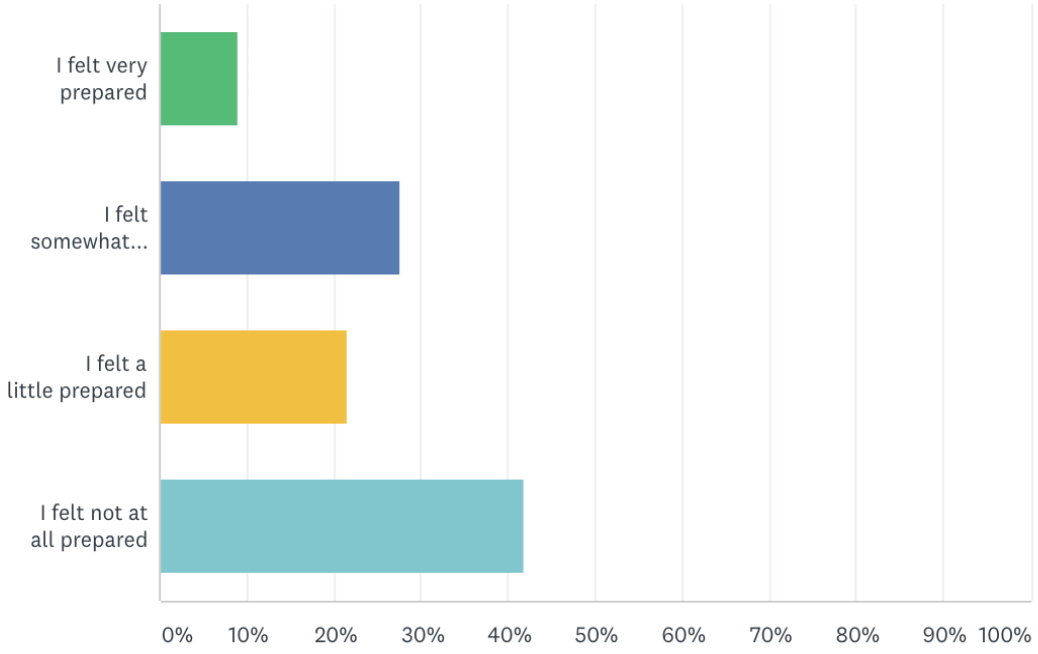
MEDICAL PROBLEMS

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



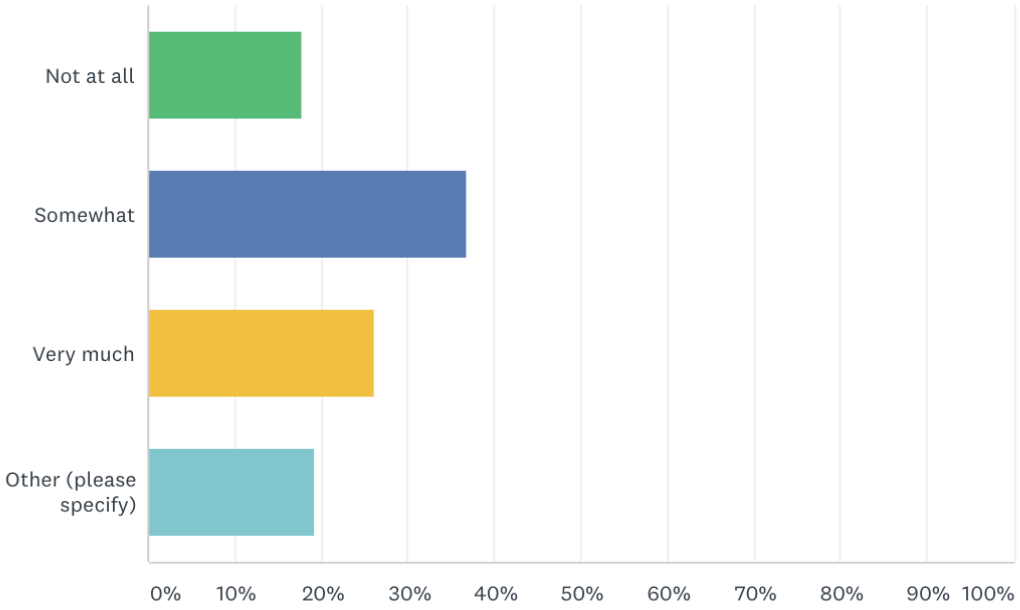
EMOTIONAL NEEDS

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



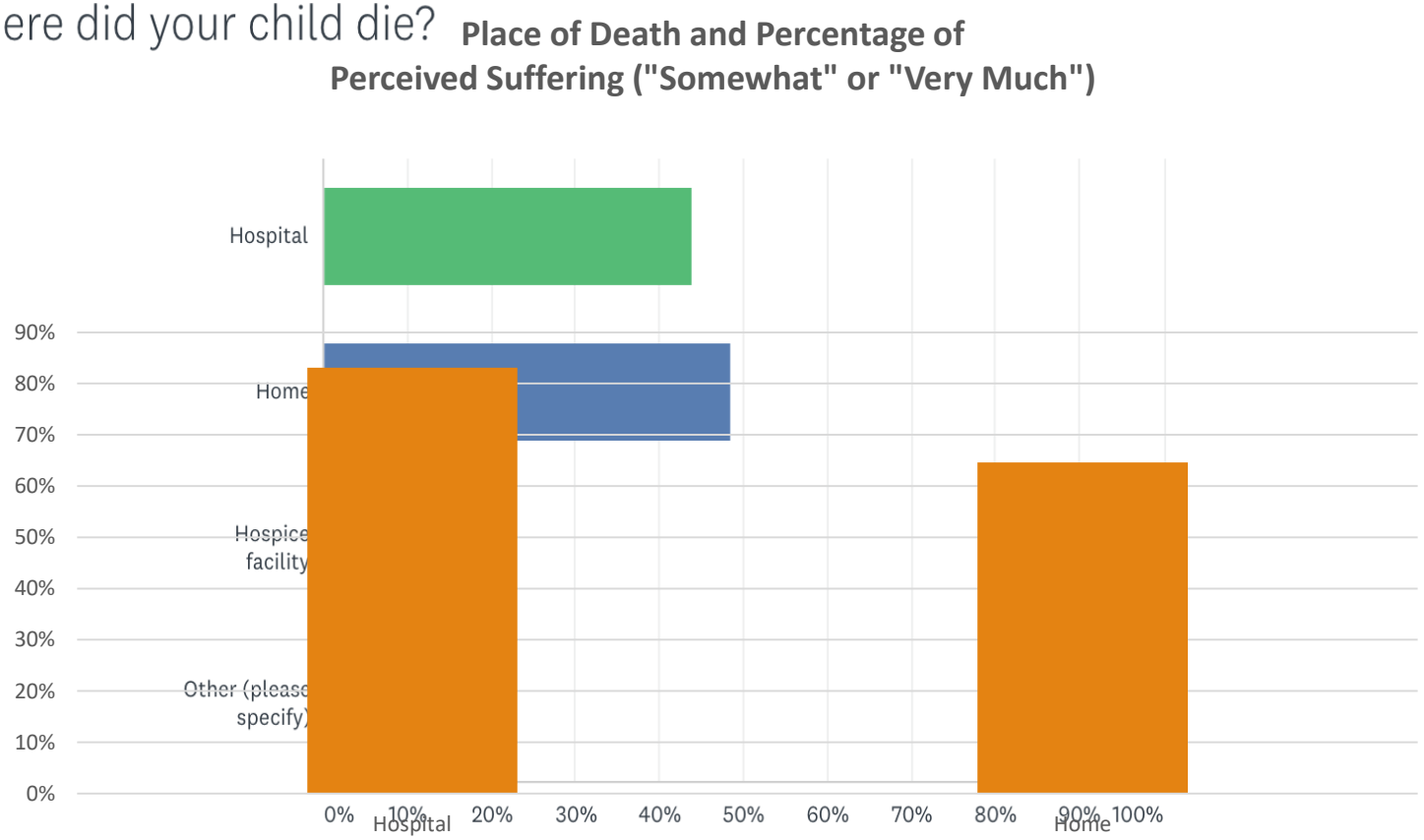
SUFFERING

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



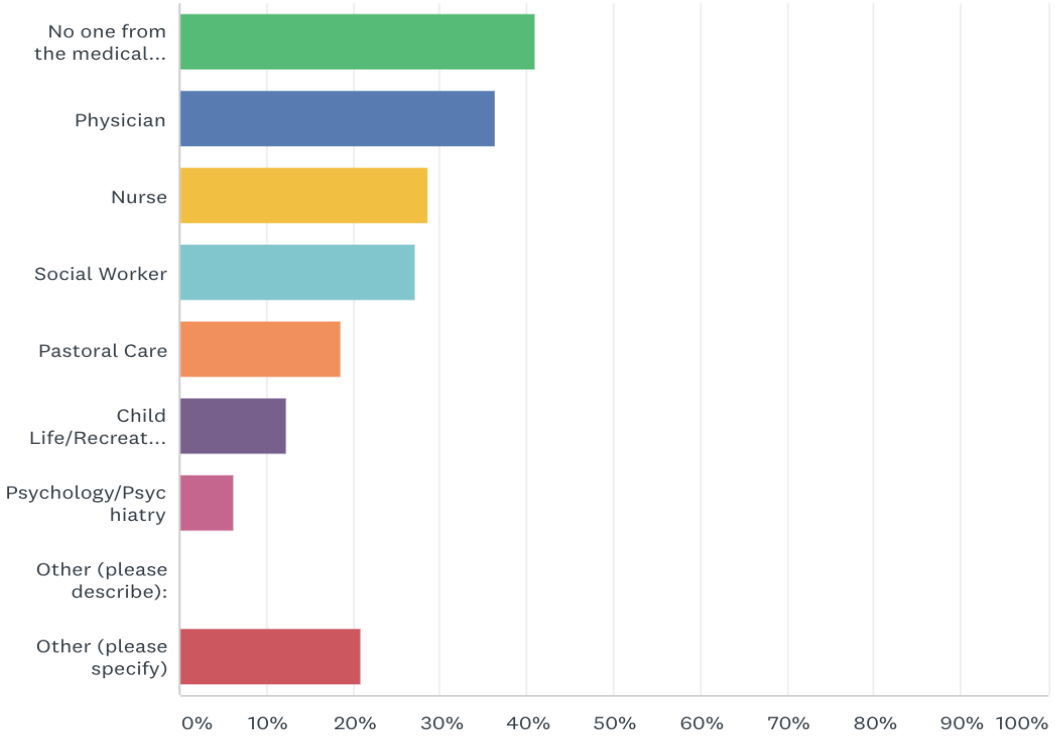
PLACE OF DEATH

Where did your child die?



BEREAVEMENT

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



Are the Palliative and Bereavement Standards being Implemented?

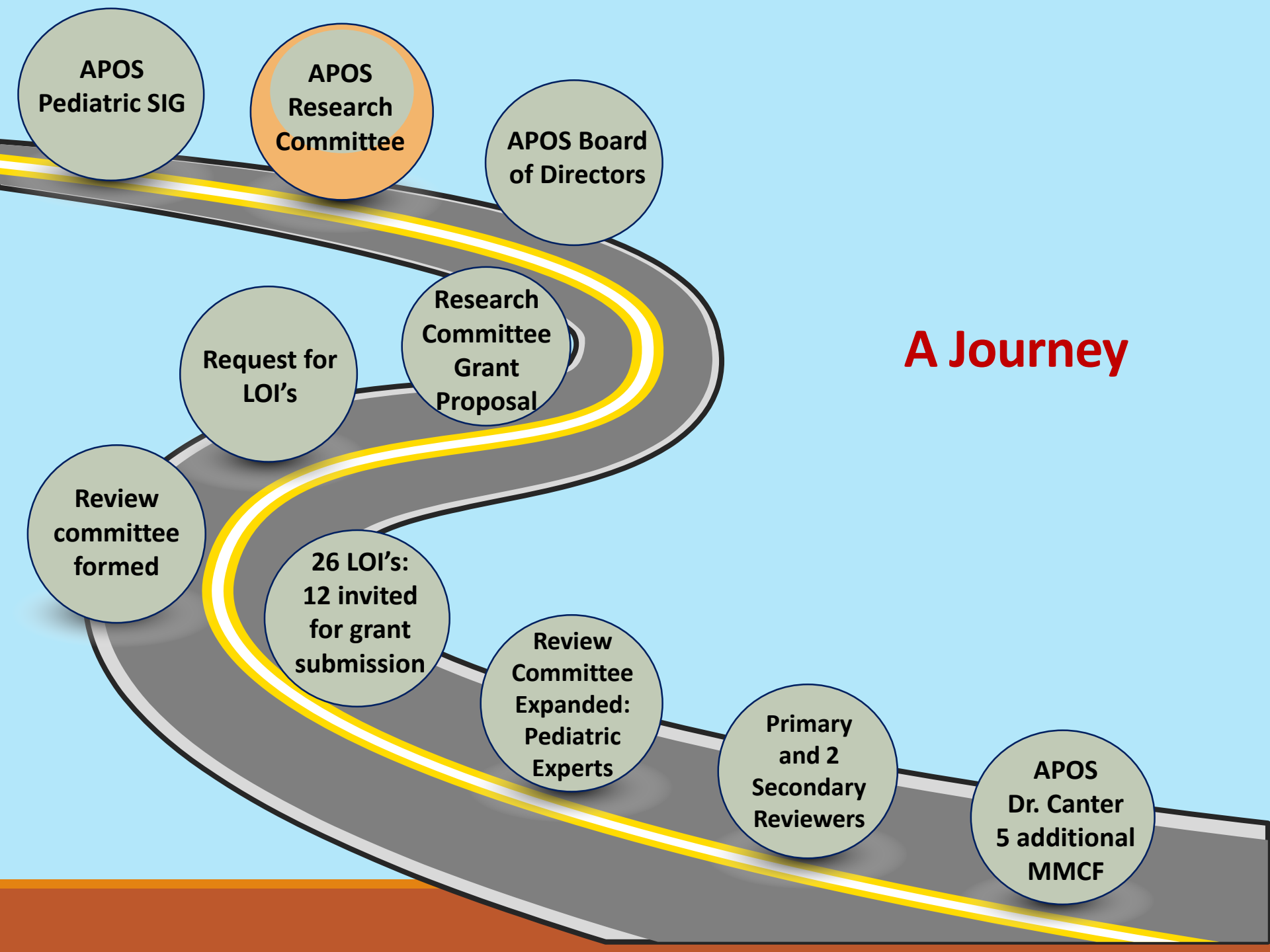
 Yes

 No

NEXT STEPS

Mattie Miracle Cancer Foundation Research Grant Awards

IMPLEMENTATION OF THE STANDARDS!


APOS Pediatric SIG
APOS Research Committee
APOS Board of Directors
Research Committee Grant Proposal
Request for LOI's
Review committee formed
26 LOI's: 12 invited for grant submission
Review Committee Expanded: Pediatric Experts
Primary and 2 Secondary Reviewers
APOS Dr. Canter 5 additional MMCF
A Journey

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.

Matrix and Guidelines Development

Matrix & Guidelines

- 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
- Multidisciplinary external reviews needed
- Focus groups at APOSW!
- 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
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	• General intelligence • Attention, memory, language, executive functions • Neurosensory functions • Perceptual processing • Processing speed • School performance • Behavior/Psychosocial adaptation Periodicity: Baseline, post-treatment, 2-3 years post-treatment	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
Monitor/Assessment of children with brain tumors and/or those who receive CNS directed therapies for neuropsychological deficits.	☐ Train pediatric cancer team in screening procedures that can identify children with risk factors or acute mental status changes. ☐ Prioritize timing of neuropsychological monitoring/assessment as an essential part of acute and late effects care (e.g. during treatment). ☐ 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. ☐ 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). ☐ Reimbursement for neuropsychological monitoring and assessment services vary	Monitoring tools may include parent/school/child report, standardized check-lists or questionnaires, and/or brief mental status or cognitive screening. Suggested domains when monitoring results in need for neuropsychological assessment: ☐ General intelligence ☐ Attention, memory, language, executive functions ☐ Neurosensory functions ☐ Perceptual processing ☐ Processing speed ☐ School/Academic performance ☐ Behavior/Psychosocial adaptation 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 Domains identified above should be included as clinically indicated.

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains	Levels				
		1	2	3	4	5
5a. Assessment of risk for financial hardship is incorporated at time of diagnosis for all pediatric oncology families	• 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	No formal process exists to assess financial hardships at initial screening Financial screening or referral is available upon request only	*	Families receive a financial screening at time of diagnosis Targeted referral for financial counseling and supportive resources (including both governmental and charitable supports) is offered based on results of family assessment Staff educated on impact of financial hardship	*	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 Targeted referral for financial counseling and supportive resources (including both governmental and charitable supports) is offered based on results of family assessment Staff educated on impact of financial hardship

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
5a Assessment of risk for financial hardship should be completed at the time of their child's diagnosis for all pediatric oncology families. **5b Longitudinal reassessment and intervention of financial risk occurs throughout the cancer treatment trajectory and into survivorship and bereavement.**	☐ Obtain comprehensive screening information on the financial needs of parents/caregivers throughout the cancer trajectory including survivorship and bereavement. ☐ 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. ☐ 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.	☐ 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. ☐ American Academy of Family Physicians Social Needs Screening Tool https://sirenetwork.ucsf.edu/tools-resources/screening-tools. ☐ Dana Farber/Boston Children's Cancer & Blood Disorders Center. HMH (Household Material Hardship) Clinical Screen (Dr. Kira Bona) ☐ Targeted referral for financial counselling (to social work or other appropriate discipline) ☐ Referral to applicable governmental supports (local/national organizations) ☐ Referral to applicable charitable supports (local/national organizations)

Pediatric Psychosocial Standard Institutional Assessment

Standard	Domains	Levels				
		1	2	3	4	5
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	• **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)	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	*	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	*	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.

*"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)	☐ Identify team members who will be providing/can provide education and guidance related to disease and treatment, hospitalization and procesures, 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). ☐ 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. ☐ 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. ☐ 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.	Written, visual, and tactile psychoeducational tools including, e.g., ☐ 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). ☐ 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 ☐ https://www.imaginaryfriendsociety.com/ (A series of short informational videos for children in both English and Spanish about disease, treatment, procedures, and common emotions). ☐ Developmentally appropriate teaching tools for explaining disease, treatment, and procedures to children, e.g., - Cellie Coping Kit https://www.chop.edu/health-resources/cellie-cancer-coping-kit - Medikin Doll

Online Rating Tool

Standard Reviewed _____ **Your Name**_____

Matrix

1. The **Matrix** provides enough information for a center to score/grade how they are implementing the standard.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments.

2. The score (1, 3 and 5) with ability to score better or worse (2 & 4) provides enough flexibility for a center to score how they are implementing the standard.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments.

Guidelines

1. The **standard** is clearly described.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments.

2. The items in the **Actions column** are clear/easy to comprehend.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments.

3. The items in the **Strategies column** are appropriate for most pediatric cancer programs.

1 Strongly Disagree	2	3	4	5	6	7 Strongly Agree

Comments.

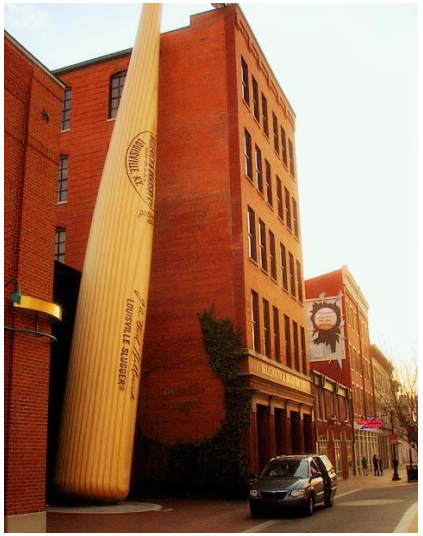
The Empowering Impact of the Pediatric Oncology Psychosocial Standards of Care

Spencer Moorman, MSSW, CSW
University of Louisville School of Medicine

- Background & Job Responsibilities
- Psychosocial Care Before the Standards
- The Arrival of the Standards
- PDSA (Plan-Study-Do-Act)
- Standards Conceptualization, Utilization & Tracking
- Results
- Barriers and Facilitators/Takeaways
- Future Goals for Improved Implementation

Background:

UNIVERSITY OF LOUISVILLE



Job Landscape & Responsibilities

First Full Time Outpatient Social Worker

UNIVERSITY OF LOUISVILLE SCHOOL OF MEDICINE

@ 100 new diagnoses per year (ALL, AML, Solid Tumor, Brain Tumor)

@38 of those brain tumor patients (seen in outpatient setting)

@ 250 Long term follow up patients (many presenting with deep issues affiliated with years of little or no psychosocial support/therapy

@ 200 hemophilia, von willebrand's and storage pool disorder pts

@150 patients with sickle cell disease

The Inpatient Landscape Treatment Center Overview… Norton Children's Cancer Institute

- **25-40 beds**
- **2 social workers -Case management focus**
- **(job share the weekdays-Monday & Tuesday; Wednesday-Friday) Case management focus**
- **Music Therapist (Part-time)**
- **Art Therapist**
- **Child Life Specialist**
- **Referral Resources (Few Tried and True)**
- **Psychiatrist**
- **Chaplain**
- **Part-time Psychologist**
- **Volunteers**
- **Foundation Resources**

Multidisciplinary pediatric brain tumor program

Stem cell transplant program specifically for children

Pediatric Pediatric apheresis and photopheresis programs

Ocular oncology programs

An immunotherapy and cancer vaccine program

One of the country's largest sickle cell anemia treatment programs

Adolescent and Young Adult Program and transition clinic

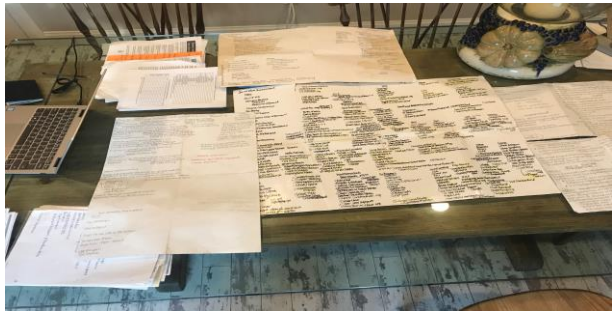
Life after cancer survivorship program

Pediatric bleeding and clotting program (hemostasis and thrombosis)

Yellow= Social Work Involvement

Job Responsibilities Continued…

Yearly Data Reporting: Sickle Cell Disease & Hemophilia
In Sickle Cell Disease:
PCORI grant,ST3P Up, Transition Coordinator
HRSA Embrace ECHO grant: Site Collaborator
And Project Reports & Communication
Committees & Other Roles:
NHF National SWWG, Region IV North Advisory Committee,
Hemophilia Advisory Committee-KY Commission
KY Pediatric Cancer Research Foundation Secretary
Norton Clinical Care Committee



Last but not least…

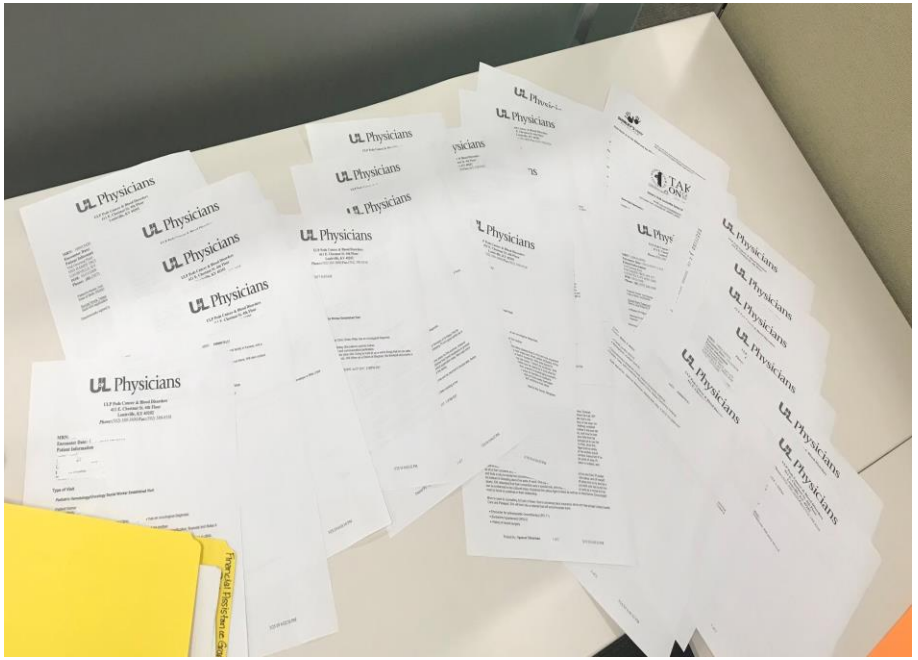
raiseRED

Student-Patient-Family Relations Coordinator

- Uof L's Largest Student Run Philanthropic Organization
- Creator & Coordinator of Patient Pal Program
- Yearly Reports on Progress

Reality sets in…

Before the Standards…



Before the Standards…

Varied Access to Care & Service Delivery

Reactive Service Delivery *if* and when services *are* delivered

No Systematic Process

Where does this belong?

Lists -Post Its –Research Everywhere (trying to sort it out)

Operated in a Silo-Little Continuity of Care

No Clear Goals or Expectations

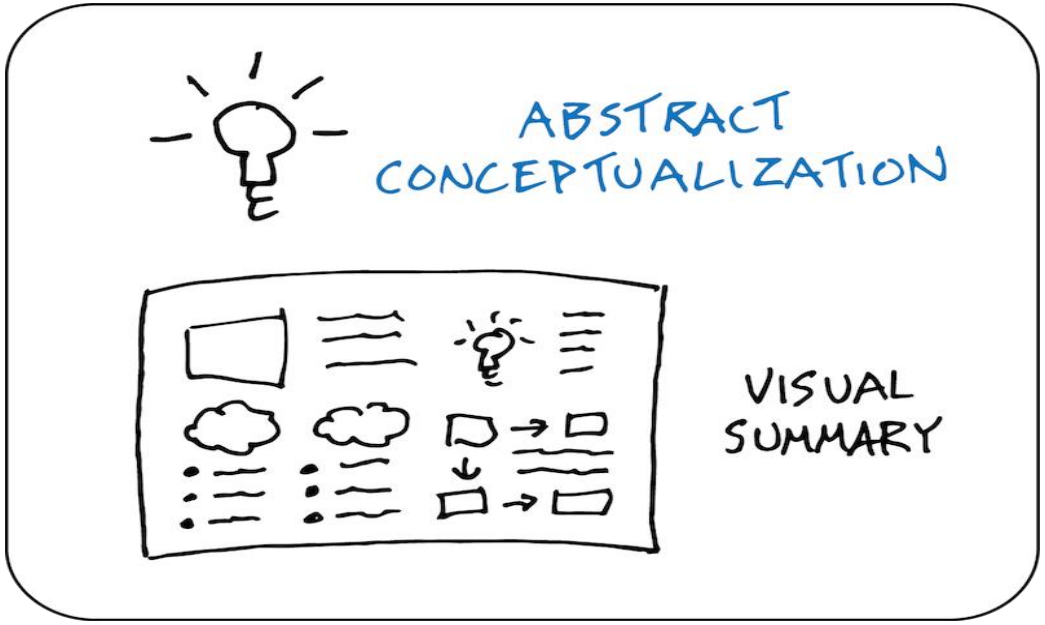
Are they getting all that they should be?

Exhausted-Running on Fumes

And then…
The Birth of the Standards!!!!

THANK GOD

Armed with Knowledge and Defined Guidelines… Now What?

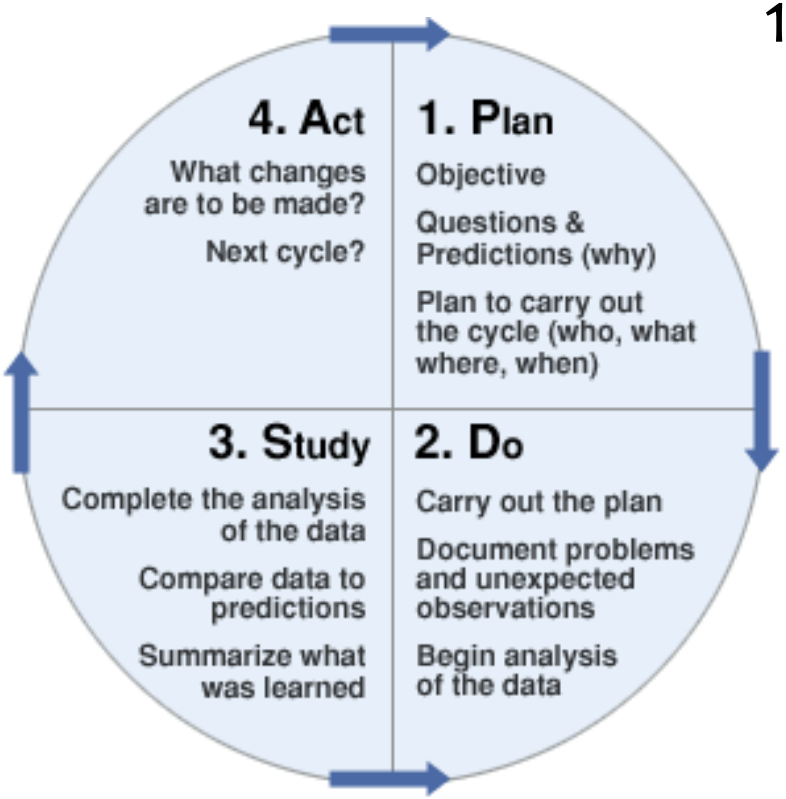


Implement processes which will systematically guarantee **standards of care delivery** to **every patient and family, every time**

AIM: Develop a **systematic process** for service delivery via a psychosocial roadmap tool, a **means of measuring standards of care execution,** for improved implementation and tracking of the newly established guidelines

Desired Outcome: Improved access to care, proactive service delivery, **reduced variation in care delivery,** reduced stress

THE PDSA CYCLE



1. PLAN

A) Psychosocial Roadmap Assessment
   Questions for each standard
   Standard Checklists (1.1, 2.1, etc.)

B) Chemo Roadmap Counterpart
   Breakdown of each standard-
   who, what, where, when, why

C) Create Standards Encounters Tracker
   Visual tool to track "touches"

D) Submit data into RedCAP database

A) Psychosocial Roadmap Assessment

Standard Specific Questions

Example for Standard 4 (The What Part)

Patient Name

Patient Age at Diagnosis (Dx)

Diagnosis

Diagnosis Date

Treatment Plan/Duration

Parent (P)/Guardian (G)/Caretaker (C)

Employment/School Status/Grade

Parent (P)/Guardian (G)/Caretaker (C)

Employment/School Status

Coping Skills Used Before Dx

Pets

Family Support System Description

Travel Accessibility/Distance to Treatment

Previous History of Counseling

Family Dynamic/Married/Divorced/Single

Insurance Status

Communication Modes/Family Contact Info

Trauma History

Resources Already Utilized

Family Beliefs

Socioeconomic Status

Language

Friends

Substance Abuse

Community Organizations Utilized

Perspective about Dx

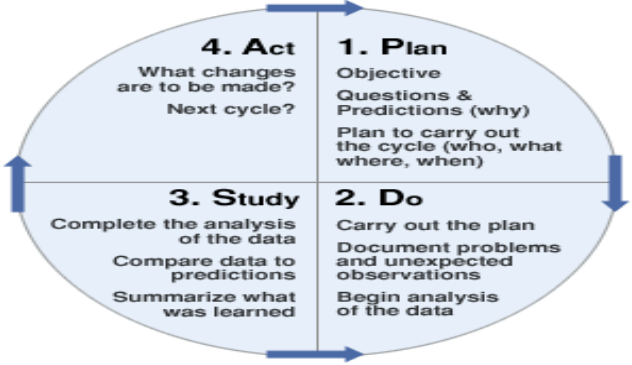
Siblings/Age/Grade/Interests

Screening Results

1. PLAN

Psychosocial Roadmap Assessment Standard Checklists (1.1, 2.1, etc.)

Checklist Example-Standard 4



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

Thought vs Fact

Gilda's Support

Caregiver Support

Literature-Books

Organizational Support

Meditation

PLAN
Psychosocial Roadmap Assessment Standard Operational Checklists

Examples from Standards 1 & 3

Months (M)/Year (Y)
PAT
FIBI
PHQ-9
SCARED
Beck's Depression Inventory
SCREEM
HRQL
Distress Thermometer
Social Work Assessment
Other
Other

Months/Year (Y)
What to Expect When Treatment Ends
IEP-504 -College-Vocational School
Follow Up Summary
Survivorship Book
Scholarships
Social Events & Retreats
Psychological Counseling/Referrals
Fertility
Transition Checklist
Distress Screening
QOL Screening
Perma-V Screening
Other

1. PLAN B) Chemo Roadmap Counterpart

Make Psychosocial Counterpart to Medical Roadmap

Chemo Roadmap Template Example

4.21.1 Maintenance – VHR B-ALL Patients (All Arms) Patient name on

Maintenance begins on Day 57 of IM II or when peripheral counts recover to ANC ≥ 750/μL and platelets ≥ 75 000/μL (whichever occurs later) for Cycle 1. For subsequent cycles, follow dose modifications for low counts and platelets. See Section 4.21 and 5.10 for details. This Therapy Delivery Map is on one (1) page.

DRUG	ROUTE	DOSAGE	DAYS	IMPORTANT NOTES	OBSERVATIONS
VinCRIStine (VCR)	IV push over 1 min*	1.5 mg/m²/dose	Days 1, 29 & 57	+ Or infusion via minibag as per institutional policy **Maximum dose: 2 mg**	a. Hx, PE, Wt., Ht. b. CBC/diff/platelets c. CSF cell count, cytospin[1] d. Bilirubin, ALT & Creatinine e. Osteonecrosis study (optional) f. Neurocognitive study (optional) [1] Obtain with each IT administration **OBTAIN OTHER STUDIES AS REQUIRED FOR GOOD PATIENT CARE**
PrednISONE (PRED)	PO (may be given IV)	20 mg/m²/dose BID	Days 1-5, 29-33 & 57-61	Total daily dose: 40 mg/m²/day, divided BID See Section 4.21 for admin guidelines Note: IV methylprednisolone may be substituted for prednisone at 80% of the oral dose	
Mercaptopurine (MP)	PO	75 mg/m²/dose/day*	Days 1-84	See Section 4.21 & Appendix I for administration guidelines *See Section 5.10 for suggested starting dose based on TPMT status	
Methotrexate (MTX)	PO	20 mg/m²/dose/week	Days 8, 15, 22, 29, 36, 43, 50, 57, 64, 71 & 78	**Omit on days when IT MTX is given.**	
Intrathecal Methotrexate (IT MTX)	IT	Age (yrs) Dose 1-1.99 8 mg 2-2.99 10 mg 3-8.99 12 mg ≥ 9 15 mg	Day 1 **Also Day 29 of Cycles 1 & 2 for patients who did NOT receive CNS radiation.**	See Section 4.21 for administration guidelines Note age-based dosing	

For patients with CNS3 disease cranial XRT (See Section 4.21 & 14.0) should begin during the first 4 weeks of Maintenance therapy and should be completed by Day 29.

Enter Cycle # Ht (h): cm Wt (h): kg BSA: m²

B) Chemo Roadmap Counterpart

Breakdown of each standard- who, what, where, when, why

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	• 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

Fill in Information Pertinent to Your Circumstances

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
Financial Risk Assessment, Targeted Financial Counseling and Supportive Resource Access, Longitudinal Reassessment and Intervention *	Pediatric Oncology Families	Clinic In Patient Rehab Neuro Oncology Clinic Telephone Online Websites Community Based and National Organizations _____ Social Work, Psychology, Child Life Specialists, Psychiatrists, Clinical Educators, Patient/Nurse Navigators, Financial Counselors, Insurance Navigators	See Section 5 for Admin options (*) and checklist	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 _____ As Needed for Appropriate Monitoring and Follow Up	• Pediatric Oncology families are at high risk for financial burden during treatment with associated negative implications for quality of life and negative health

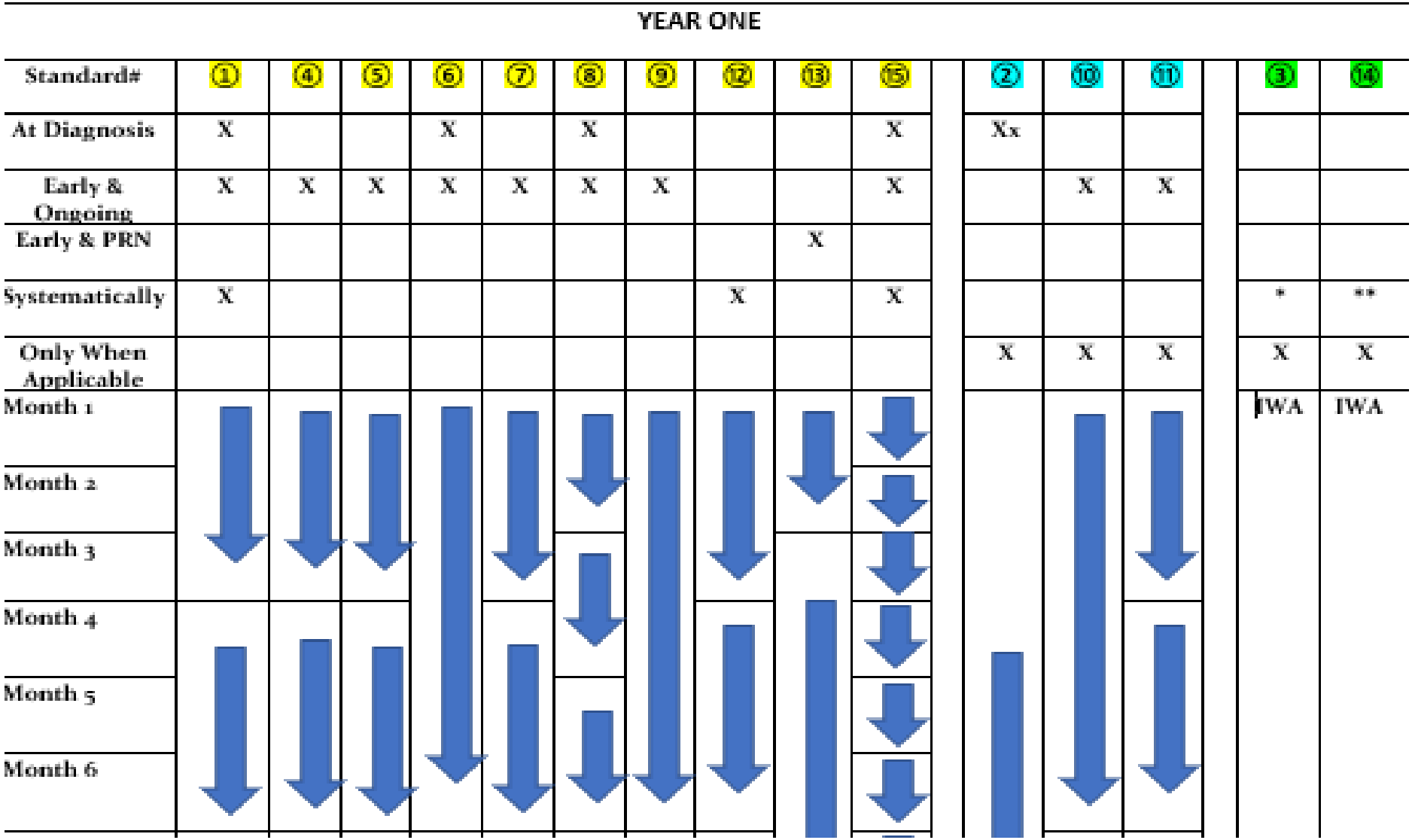
Yellow=Checklists for your practice (What)

Green= Touch/Encounter Goal for your practice (When)

Red= Staff & Other Resources Needed to Better Implement Standard (How)

C) Tweakable Visual Tool for Big Picture Illustration of Care

Education Tool for Those Who Don't Get It



C) Standards Encounter Tracker
Visual Tool to Track and Plan Touches

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

1. PLAN Conceptualization of the Standards

Predictions: These tools will help improve implementation of the standards by providing expectations for proactive service delivery and executed encounters

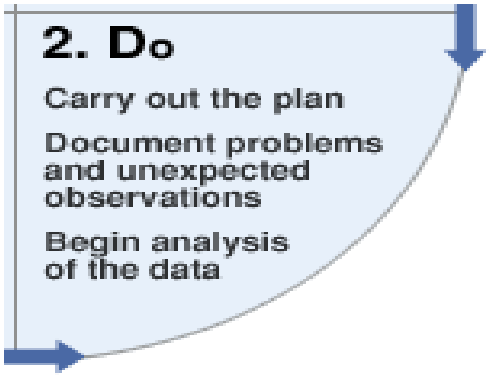
A) Psychosocial Roadmap Assessment
   Questions for each standard
   Standard Checklists (1.1, 2.1, etc.)

B) Chemo Roadmap Counterpart
   Breakdown of each standard-
   who, what, where, when, why

C) Create Standards Encounters Tracker
   Visual tool to track "touches"

D) Submit data into RedCAP database

2. DO- Used tools in practice with a few patients of each dx



Observations:

Tools drove my practice

Reactive to proactive

Aroused competitive spirit to fill in the map as much as possible

Frazzled to focused

More aware of opportunities to enhance standard with partnerships and programs

Advocacy Bandit Birthed

"Psychosocial Standards of Care

"Well, ya know, the standards say..."

Patients loved the correlation between maps

Mattie Miracle
CANCER FOUNDATION

Defining Essential Psychosocial Care *Creating Standards for Psychosocial Care for Children with Cancer and their Families*

THE GIFT of the Standards:

For Social Work:	For Patients:
Direction	Clear Expectations
Clarification	Access to Improved/Focused Care
Realization	Understanding of Big Picture and Importance of each Screening, Intervention, Discussion, School Talk, Camp Opportunity, Palliative Care Introduction and so forth
Motivation	
Relief	

The Standards and Advocacy Referencing the Standards at Every Turn

- Weaponry
- Staff Meetings
- Huddles
- Grand Rounds (showed my posters)
- Opportunities to Educate
- Show Your Knowledge
- Ideal Tool for Helping our Patients
- Fuel for Grant Submission Opportunities

Some more Observations…

BARRIERS

Limited Time in Implementing the Data Entry (regarding my goals)

Keeping up with patient care while doing bigger picture projects

Lack of Troops on the Ground

Those who just don't get it

Funding

FACILITATORS

The control to impact and design change w these standards

Other means of access and delivery in service design

An increased chance of appreciation and respect for the work of pediatric oncology social workers through the legitimization of each topic

The standards speak for themselves

As a Result…

Evaluation for each standard is completed

Hiring has been approved for **two additional full time clinical social workers**

Received funding to help support a **school liaison and additional neuropsych testing**

Made job descriptions for each position needed

Asked to present a big picture vision for a future Psychosocial Program and Team to administration with Norton Healthcare and ULP

Have program ideas and website packages ready for any interested donors

Evaluation of each Standard and Progress Made Example

• 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

Progress Made…

Progress	Wish List
• Social Work (SW) is now notified of new dx from hand off meeting notes • Consent Conference is now part of SW checklist • Drs check in w SW when meeting w new pts in clinic as extra reminder • Psychosocial Roadmap Assessment given • Proactive Individualized plans created and systematic scheduled • Checklist for standard created	• Full Time Psychologist • Outpatient Child Life Specialist • Additional Clinical Social Worker
• Grant submitted to supply additional testing resource at the Novak Center • Standard now explained, addressed and/or introduced during roadmap assessment • Proactive planning taking place to ensure timely testing for services • All possible referrals for additional testing options gathered	• Additional referral options to help with long waiting lists and prompt implementation of needed services in school and otherwise • Medicaid providers in KY and IN • School Interventionalist to ensure proper services are received

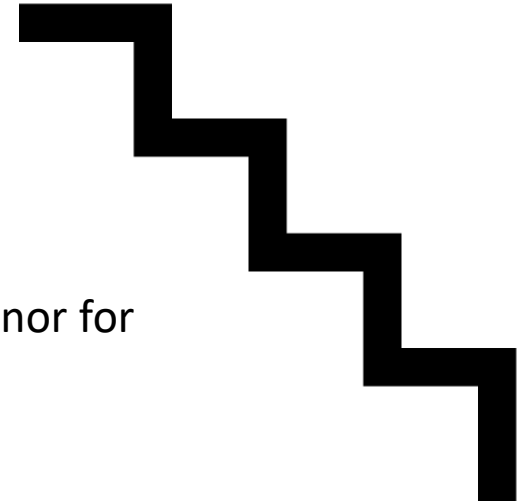
Next Steps…

3. STUDY

Retrospective comparison of old standard patient charting with new standard of care tools
Measure number of touches and number of standards executed
AND then also…

4. ACT

- Make Changes to Process
- Simplification of tools
- Solidify new partnerships for standard delivery and find donor for web-based support idea=a website model of care with individualized delivery of information



Overwhelmed to Empowered
Take Control of what you Can
Keep it Simple
Track it! You're doing it anyway!
New Appreciation for Standard 5
And Others
The Matrix/Guidelines are gifts

Implementation of Standards

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

Mattie Miracle
CANCER FOUNDATION
Spreading hope through psychosocial support™

APOS
american psychosocial oncology society

2. Legislation and Regulation

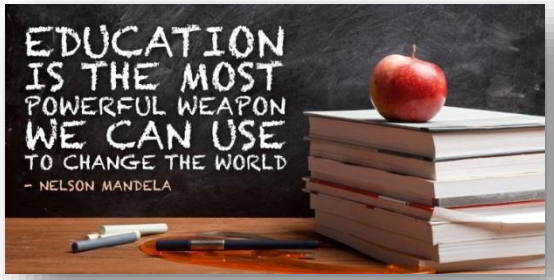
- Establish the Standards formally as essential care, and use regulatory and legislative actions to mandate their use
  1. Legislate Standards as essential care
  2. Get Medicaid to declare Standards as an essential component of comprehensive cancer care, and support reimbursement of services
  3. Mandate/Regulate 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



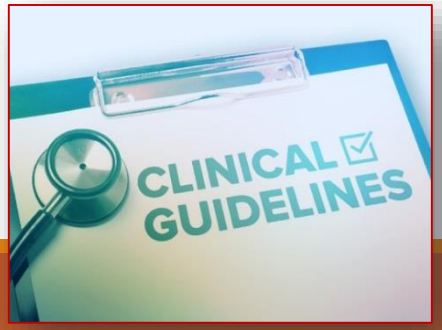
- Build knowledge of Standards universally, and have associations embrace both use and application of standards in accreditation and educational programs
  1. Associations to endorse and to support standards
     - ✓ AACAP, APA, APHON, APOS, APOSW, ASPHO, COG, CAPO, etc.
  2. Incorporate Standards into 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