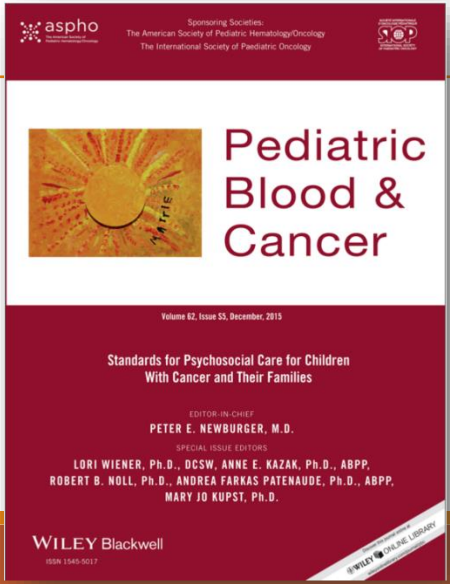
Mattie Miracle
CANCER FOUNDATION
It's not just about the medicine!™

APOS
american psychosocial oncology society
Advancing the science and practice of psychosocial care for people affected by cancer

Pediatric psychosocial standards of care: A review and discussion of in-progress research projects on implementation of the standards



aspho
Sponsoring Societies:
The American Society of Pediatric Hematology/Oncology
The International Society of Paediatric Oncology
SIOP

Pediatric
Blood &
Cancer

Volume 62, Issue S5, December, 2015

Standards for Psychosocial Care for Children
With Cancer and Their Families

EDITOR-IN-CHIEF
PETER E. NEWBURGER, M.D.
SPECIAL ISSUE EDITORS
LORI WIENER, Ph.D., DCSW, ANNE E. KAZAK, Ph.D., ABPP,
ROBERT B. NOLL, Ph.D., ANDREA FARKAS PATENAUDE, Ph.D., ABPP,
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National Cancer Institute

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Mattie Miracle Cancer Foundation
Washington, DC

Agenda

- Why the Standards Were Created
- Review the Research Grant Process
- Dr. Kimberly Canter & Rebecca McIntyre – **Standard #6** (care of parents)
- Dr. Alexandra Psihogios – **Standard #12** (adherence)
- Dr. Kathryn Kirkpatrick – **Standard #11** (school support)
- Dr. Kristin Long – **Standard #10** (supporting siblings)
- Dr. Marie Barnett – **Standard #13** (palliative care)
- Dr. Gillian Regan – **Standard #14** (bereavement)
- Future Directions
- Questions & Answers

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)

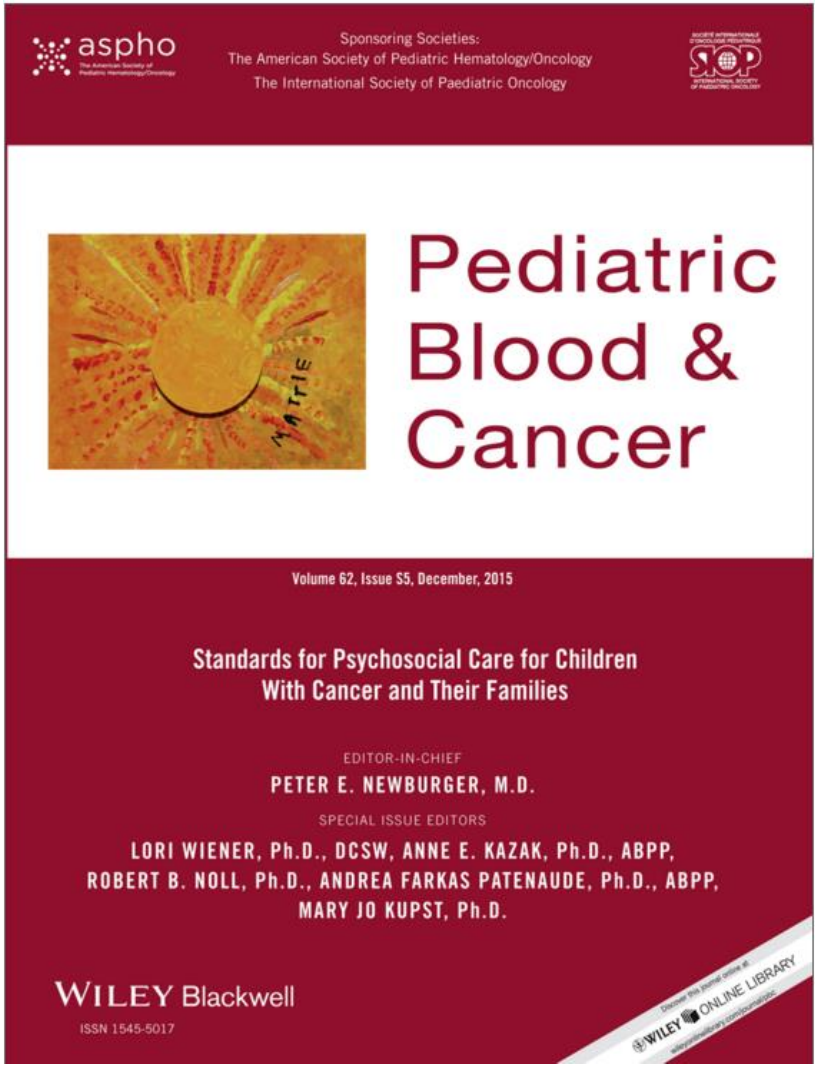
- Mattie Miracle voiced its vision to create Psychosocial Standards of Care.
- Convened key researchers and clinicians in the psychosocial field to brief Congress and present a full day of scientific presentations about cutting edge psychosocial research.
- Over 85 attendees from 12 States.

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.

Standards Published - December 2015



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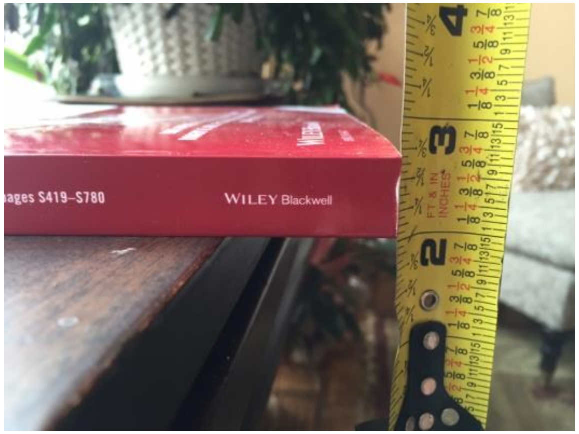
16 papers
66 authors
Total of 1,217 studies



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

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.

A Review of the Research Grant Process

Lori Wiener, Ph.D., DCSW
National Cancer Institute

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

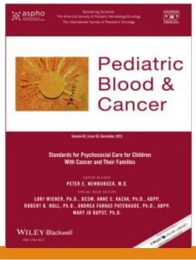
1. Assessment of well-being and emotional functioning
2. Neurocognitive status
3. Psychotherapeutic interventions
4. School functioning
5. Training, communication, and documentation of psychosocial services

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



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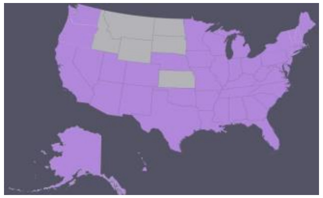
Professional Endorsements

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

Updates



I. **PIPS-CSS Study** (Anne Kazak, PI)

- Scialla … Kazak. Implementing the psychosocial standards in pediatric cancer: **Current staffing and services** available. *Pediatric Blood & Cancer*. 64, e, 2017.
- Scialla … Kazak. **Delivery of care** consistent with the Psychosocial Standards in Pediatric Cancer: Current practices in the United States. *Pediatric Blood & Cancer*, 65(3), e26869, 2018.
- Kazak … Wiener. The multidisciplinary pediatric psycho-oncology workforce: A national report on **supervision for staff and training** opportunities. *Psycho-Oncology (in press)*

II. **Social Work Standards Assessment**

- 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*, 57(4), 2018

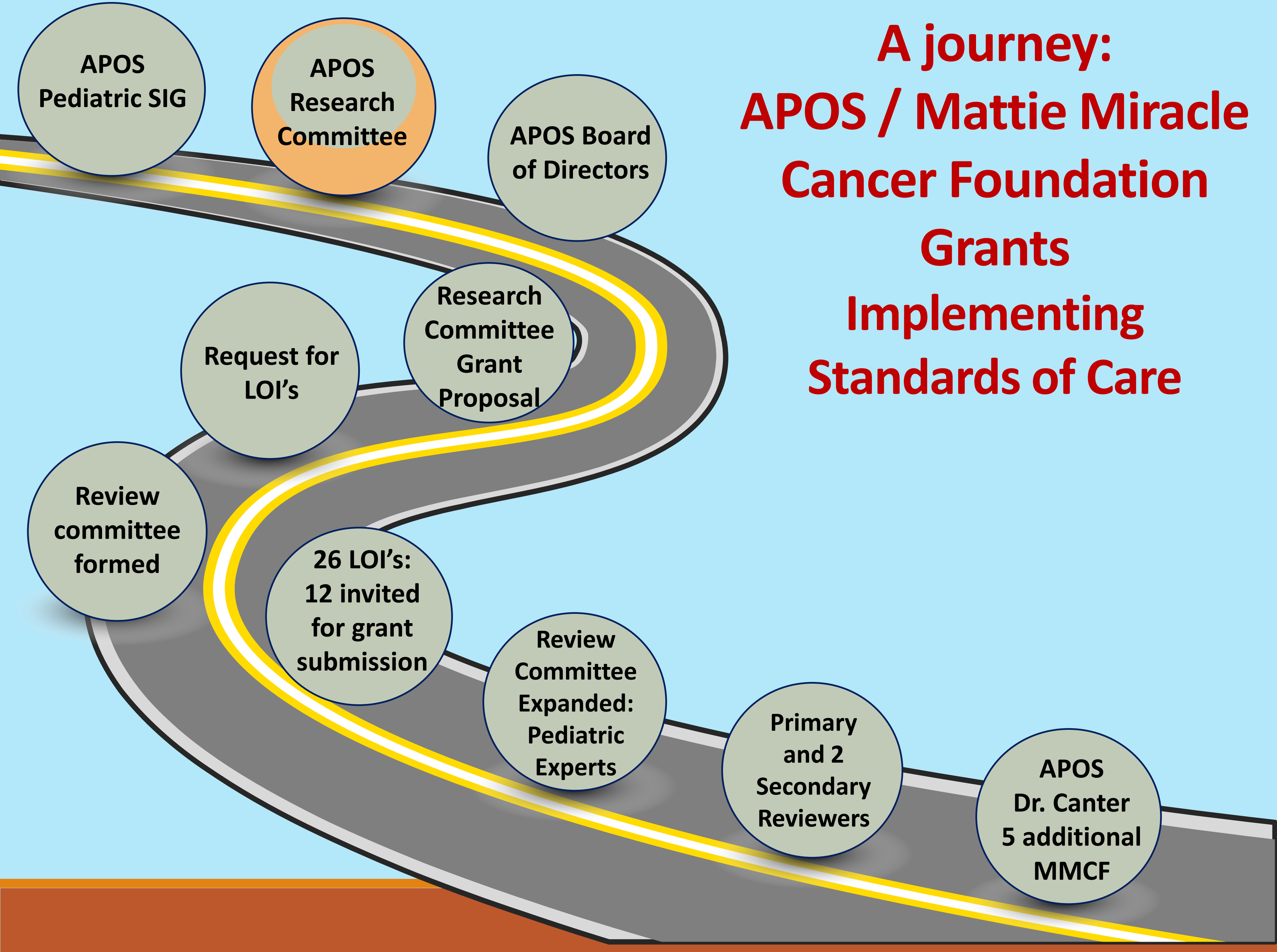
III. **Palliative and Bereavement Standards**

- 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*. 21(4), 452-462, 2018
- Wiener **…** Weaver. Personalized and yet standardized: An informed approach to the **integration of bereavement care in pediatric oncology settings**. *Palliative and Supportive Care*, 16, 706-711, 2019.

IV. **Mattie Miracle Cancer Foundation Research Grant Awards**

V. **Matrix and Guidelines Development** (SIG)

A journey:
APOS / Mattie Miracle Cancer Foundation Grants Implementing Standards of Care



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

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 Psihogios, 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.

Community Implementation of a Psychosocial eHealth Intervention for Parents of Children with Cancer

Kimberly Canter, Ph.D., & Rebecca McIntyre, LCSW

Parents and caregivers of children with cancer should have early and ongoing assessment of their mental health needs. Access to appropriate interventions for parents and caregivers should be facilitated to optimize parent, child, and family well being.

Background

Support for parents is important…and many challenges exist in terms of delivering in-person psychosocial interventions

- Interventions are often well-received (e.g., 95% of SCCIP-ND completes found the program helpful, 100% said topics were important)

Past work from our research group documents challenges related to recruitment and retention:

- Families with higher levels of PTSS and distress were more likely to drop out before completing the intervention.
- Recruitment rates of 45% and 23% in RCTs
- 61% of those declining citing scheduling/time difficulties in one study

Background

eHealth is an emerging and rapidly accelerating area of interest in the field of pediatric psychology

- Over 80% of households in the US have access to a computer, with approximately 90% reporting internet access

Within pediatric oncology, eHealth interventions are not widely studied

Opportunity for eHealth interventions to address some intervention access issues for parents and have a wider reach

Background

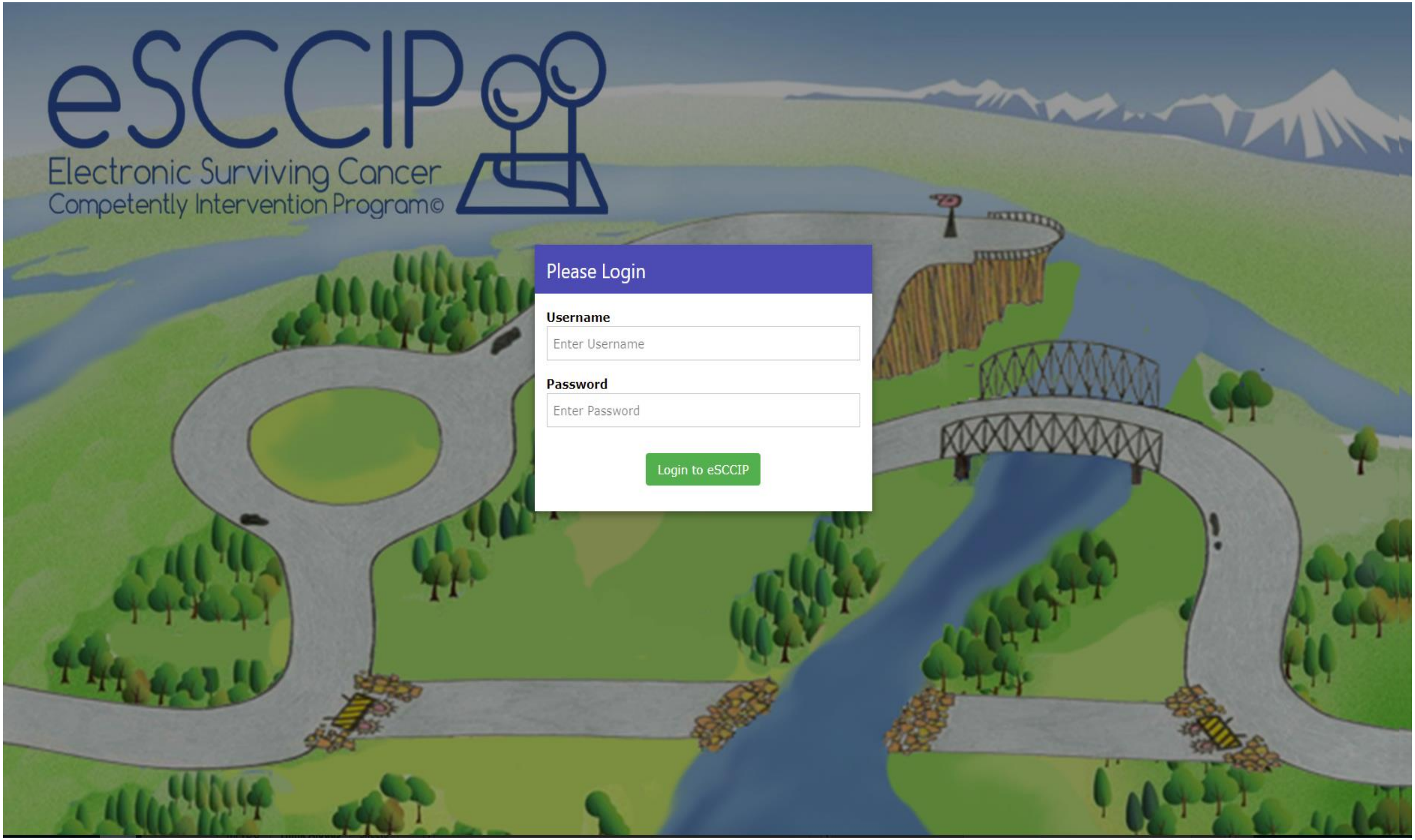
eSCCIP consists of four self-guided online modules, including an introductory module

- Mix of videos, interactive activities, and free-text responses

Videos are a mix of "skills" videos and the multifamily video discussion group

Each "core" session followed by a telehealth follow-up visit with a therapist

Data (free response questions, clicks on pages) is captured securely and viewed by therapist before the telehealth follow-up


eSCCIP
Electronic Surviving Cancer Competently Intervention Program©
Please Login
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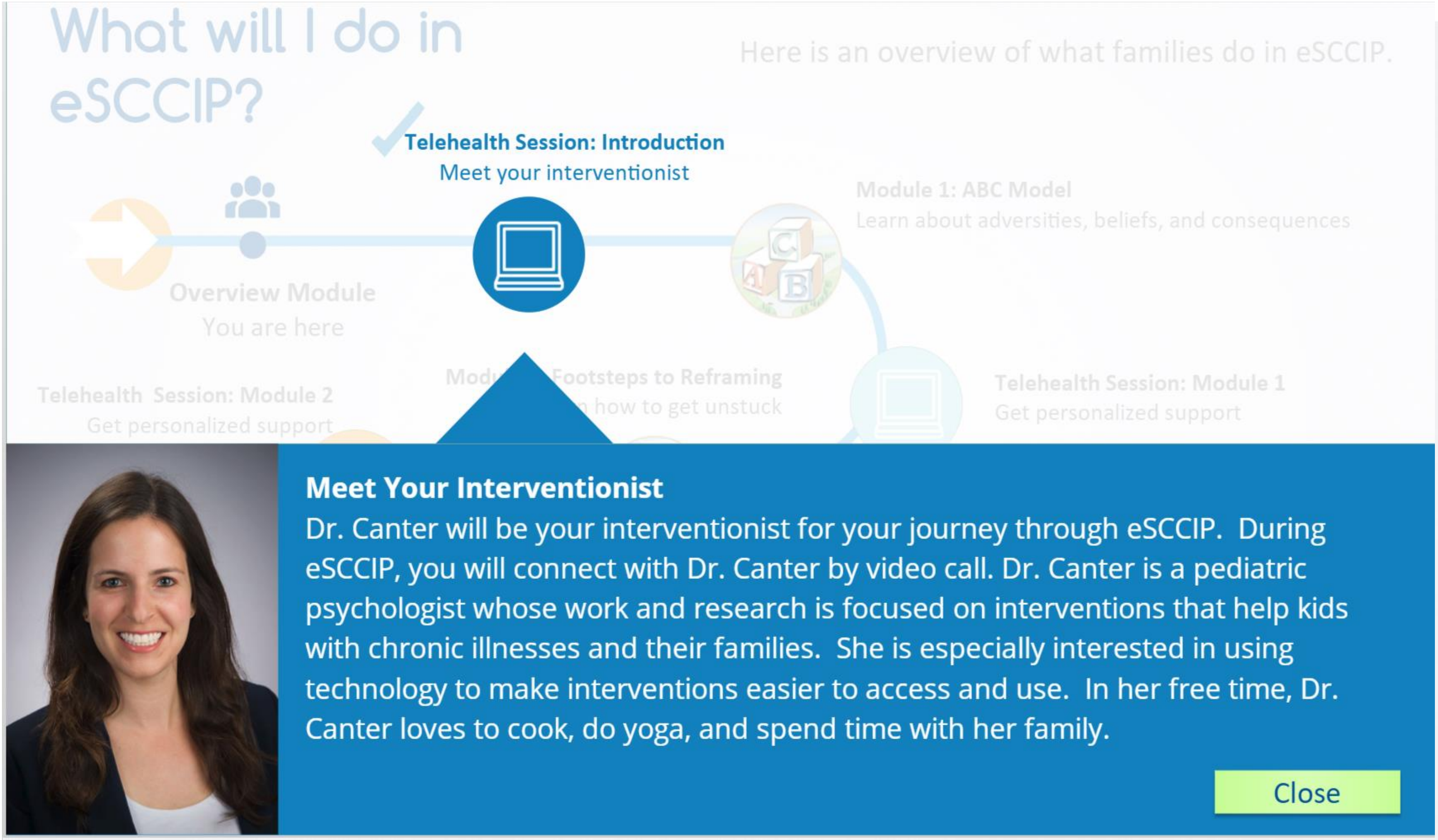
Enter Username
Password
Enter Password
Login to eSCCIP



What will I do in eSCCIP?

Here is an overview of what families do in eSCCIP.

Telehealth Session: Introduction
Meet your interventionist

Overview Module
You are here

Module 1: ABC Model
Learn about adversities, beliefs, and consequences

Telehealth Session: Module 1
Get personalized support

Mod Footsteps to Reframing
n how to get unstuck

Telehealth Session: Module 2
Get personalized support

Meet Your Interventionist

Dr. Canter will be your interventionist for your journey through eSCCIP. During eSCCIP, you will connect with Dr. Canter by video call. Dr. Canter is a pediatric psychologist whose work and research is focused on interventions that help kids with chronic illnesses and their families. She is especially interested in using technology to make interventions easier to access and use. In her free time, Dr. Canter loves to cook, do yoga, and spend time with her family.

The ABC Model: Adversities

Watch the video to learn about the ABC Model and how to identify Adversities.

Click play to start the video

The Footsteps to Reframing: Challenge

Use this activity to practice using the Footsteps. Read each thought, then drag it to the Footstep it best describes. Incorrect items will bounce to the starting position. Correct items will snap into place.

Our family will come through this stronger

I can't know
hether treatment
will b

I have great friends who helped me face other challenges

e

I appreciate little things more than I used to

can't control
ether m
has can

Our family is good at getting through hard times

Control what I say to other members in my family

eSCCIP Family Session: Footsteps to Reframing

Spend time with eSCCIP families by watching these four brief videos. Listen carefully for the ways they have reframed their thinking using the Footsteps.

Step 1
Accept the Uncontrollable

Step 2
Focus on the Controllable

Step 3
Acknowledge Strengths

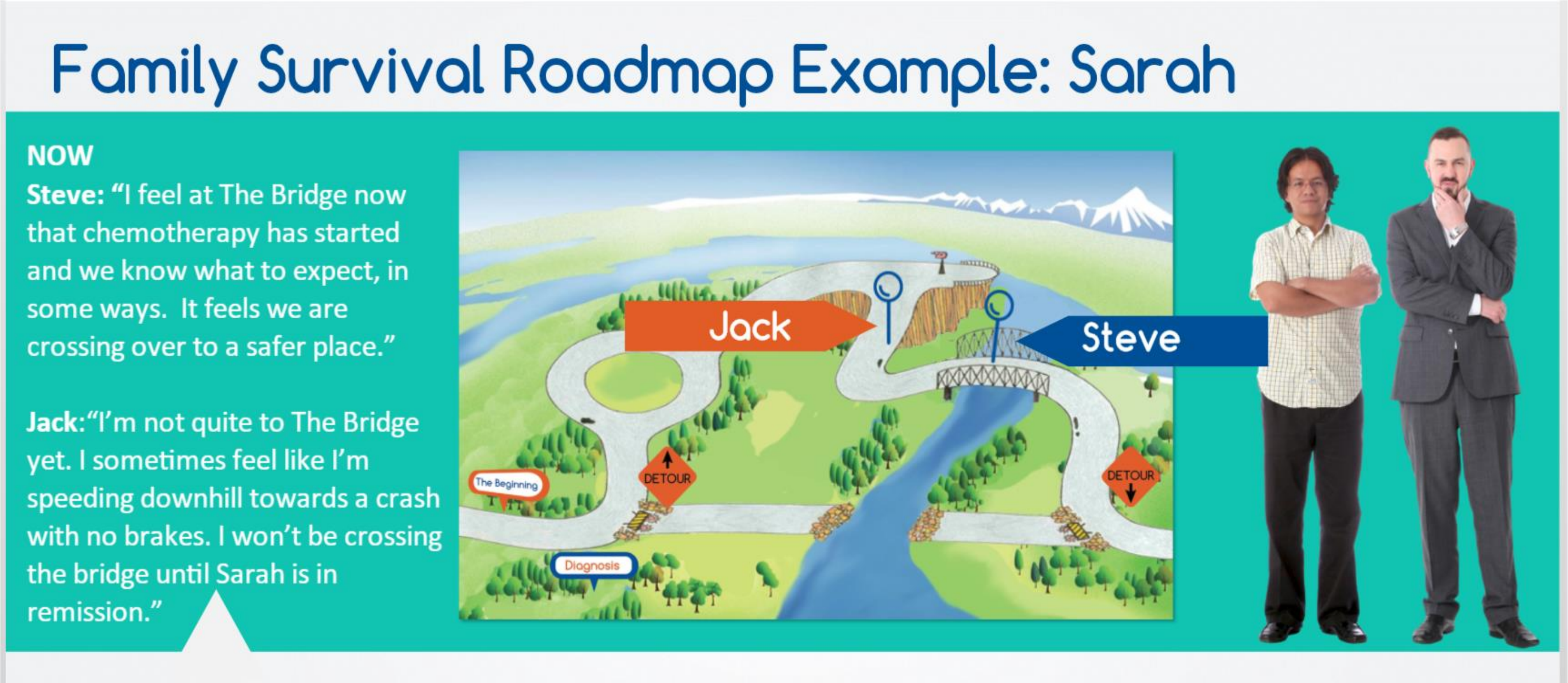
Step 4
Use the Positive

Click Play to start each video

The Footsteps: Examples

Now that we’ve covered the basics, check out some examples of the Footsteps.
Pick at least one example to view, but feel free to view as many as you find helpful.

Click each family to learn more about them
Then choose a family and click Go for the example

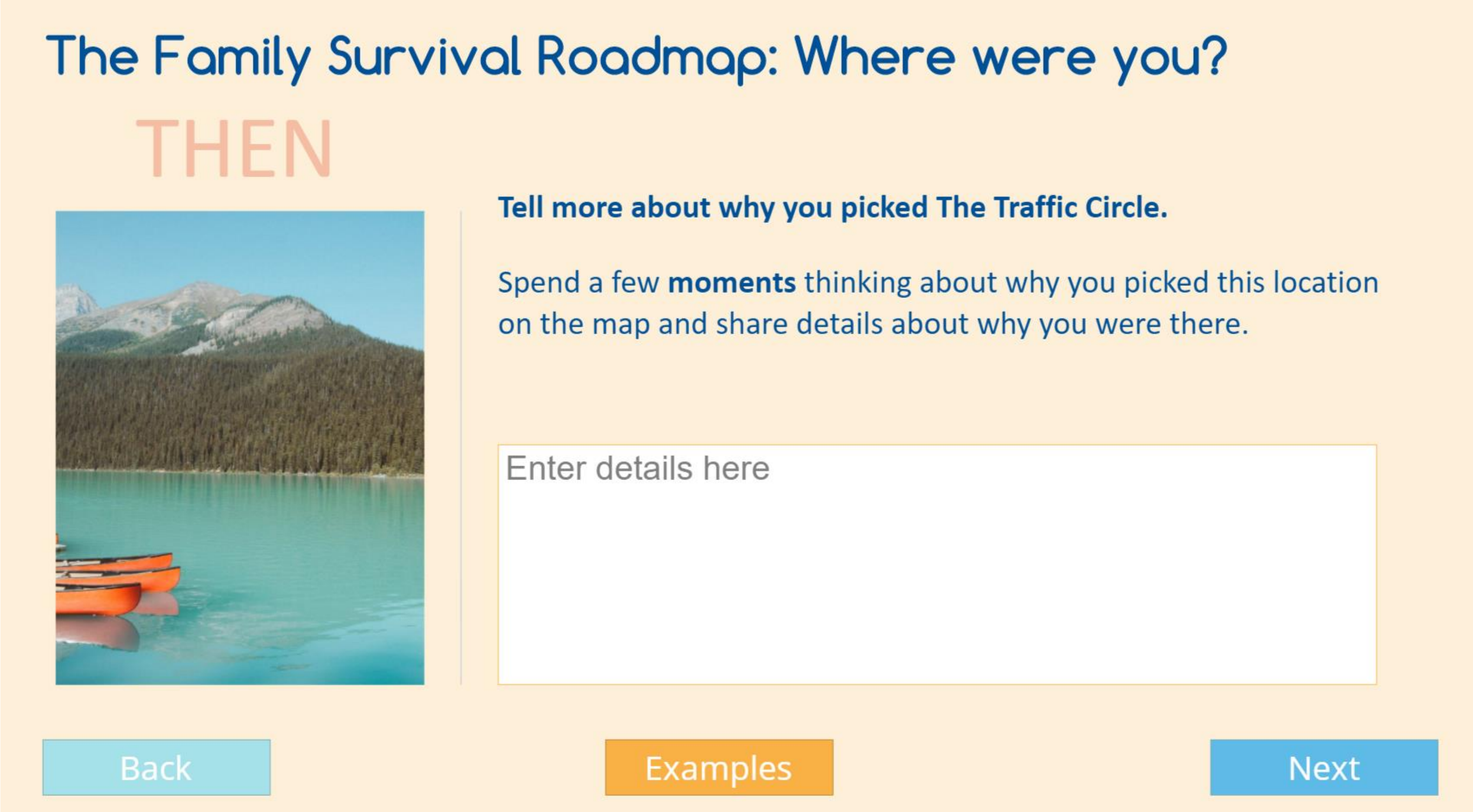


Family Survival Roadmap Example: Sarah

NOW

Steve: "I feel at The Bridge now that chemotherapy has started and we know what to expect, in some ways. It feels we are crossing over to a safer place."

Jack:"I'm not quite to The Bridge yet. I sometimes feel like I'm speeding downhill towards a crash with no brakes. I won't be crossing the bridge until Sarah is in remission."



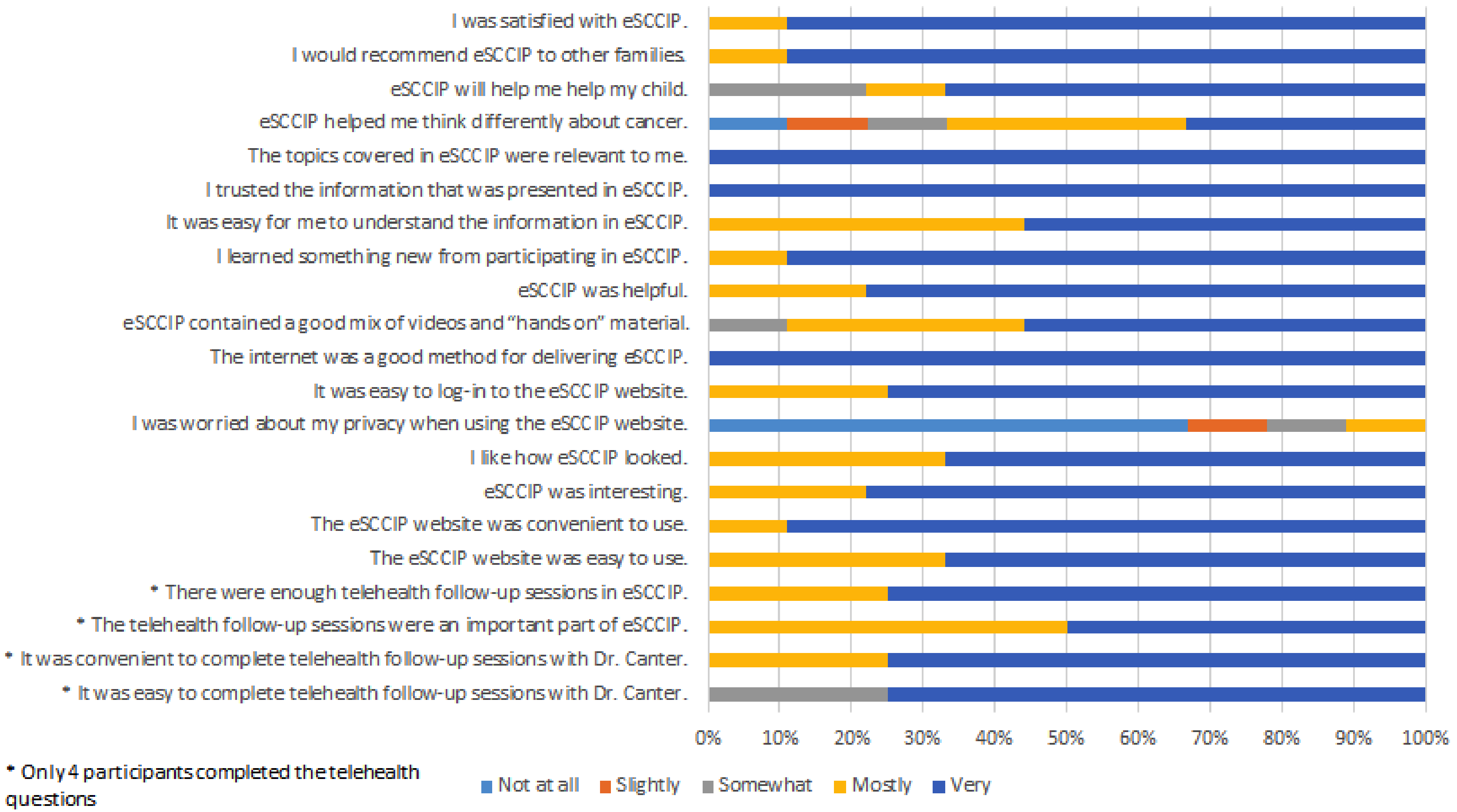
The Family Survival Roadmap: Where were you?

THEN

Tell more about why you picked The Traffic Circle.

Spend a few **moments** thinking about why you picked this location on the map and share details about why you were there.

Initial Acceptability and Feasibility Results



* Only 4 participants completed the telehealth questions

Aims of APOS/MMCF Study

Specific Aim 1: Demonstrate the acceptability and feasibility of eSCCIP through testing with a diverse sample of POCC in a community setting.

- Hypothesis 1: 80% of parents who participate in a community pilot test of eSCCIP will endorse the intervention as acceptable, accessible, and feasible at post-intervention, comparable to data from an initial eSCCIP “beta test”.
- Hypothesis 2: 50% of eligible parents approached for participation will enroll in and complete a pilot test of eSCCIP, exceeding in-person participation rates for SCCIP and SCCIP-ND due to reduced participant burden.

Specific Aim 2: Evaluate preliminary effectiveness of eSCCIP through pilot testing with POCC in a community setting.

- Hypothesis 3: Parents who participate in a pilot test of eSCCIP will report a reduction in symptoms of acute distress, posttraumatic stress, and anxiety from baseline to post-intervention.
- Hypothesis 4: Parents who participate in a pilot test of eSCCIP will report an improvement in family functioning from baseline to post-intervention.

Collaboration with Life with Cancer

Life with Cancer (LWC) is a program of the Inova Schar Cancer Institute

Our pediatric hematology/oncology physicians are credentialed at both Inova Children's Hospital and Children’s National Medical Center in Washington, DC.

LWC oncology therapists are embedded in both inpatient and outpatient facilities in addition to the LWC Family Center.

2014 LWC therapists trained in the original SCCIP-ND by Anne Kazak and team. Intervention has been offered for the last couple of years.

LWC looking to expand our telehealth offerings. Excited to offer the eSCCIP to our families beginning March 2019.

Methods

Nemours study team to provide training to Oncology Therapists at Life with Cancer, in partnership with Life with Cancer Co-Investigators

Nemours study team to manage participant data and provide administrative/methodological oversight

Life with Cancer staff to deliver telehealth follow-up to Life with Cancer clients (POCC)

- Goal of one module and one telehealth session per week (1 month total)

Study team to meet regularly to monitor study progress, including data collection and recruitment targets

Methods

To evaluate hypotheses in Aim 1, caregivers will rate eSCCIP using the eSCCIP Evaluation Questionnaire and the Internet Intervention Adherence Questionnaire (IIAQ)

To evaluate hypotheses in Aim 2, data will be collected at baseline and post-intervention on symptoms of posttraumatic stress, acute distress, anxiety, and family functioning.

- The PTSD Checklist (PCL-5)
- The National Comprehensive Cancer Network Distress Thermometer (DT)
- The SCORE-15
- The Generalized Anxiety Disorder 7-Item Scale
- PAT at baseline

Progress To Date

Identification of study team at both sites, including physician champion/site PI at Inova Healthcare System

Submission of dual IRB proposals and establishment of IRB Reliance Agreement

- Significant investment of time and energy!

Training of LWC interventionists and development of training materials

Pre-recruitment lectures for key stakeholders (medical staff and referring providers)

Identification of strategies to minimize participant burden

- Recruitment at existing education events
- Purchasing of iPads to facilitate in-clinic recruitment and data collection

Next Steps and Future Directions

Projected recruitment start date of March 2019

- Overall recruitment target of 30 participants, to be recruited in "waves" of approximately 10 participants
- Ready to "hit the ground running" when final IRB approval obtained

Second pilot test being run at Nemours with funding from NCI (National Institute of Health, Award Number R03CA235002)

Results from both of these studies will be used to develop large RCT with focus on rapid dissemination of eSCCIP

Standard 12:

Assessing Medication Adherence as a Standard of Care in Pediatric Oncology

Alexandra Psihogios, Ph.D.
Children’s Hospital of Philadelphia

Background:
Assessing Adherence as Standard of Care

"Adherence should be assessed routinely and monitored throughout treatment" (pg. S818)

❑ Implementation of this standard in routine clinical care is hindered by several barriers, including:

1. Lack of time
2. Limited use of validated measures
3. Limited understanding of the real-world determinants of pediatric cancer treatment nonadherence

❑ AYA with acute lymphoblastic leukemia (ALL) are an exemplar group with which to pilot new methods of assessing adherence

❑ Must take a daily oral chemotherapy (6MP) for 2-3 years during maintenance, yet nearly 50% fail to meet the critical level of adherence needed to prevent relapse: <95% adherent → 2.5x greater risk of relapse (Bhatia et al., 2014)

Background:
Ecological Momentary Assessment

- Mobile technology represents a scalable approach for addressing this standards-to-practice gap
- **Ecological momentary assessment (“EMA”)** involves brief, recurring surveys of events or experiences, often via text messaging or mobile apps
  - For ex. Each day asking: *“How much pain are you currently experiencing?”, “Did you take your 6MP today?”*
- EMA provides key opportunities to understand real-time adherence behaviors in context, which increases the likelihood of ecological validity and generalizability of later interventions
- Shown high feasibility across studies of AYA with other chronic health conditions (~75% completion rate), but not yet used to study pediatric cancer treatment adherence

Aims:

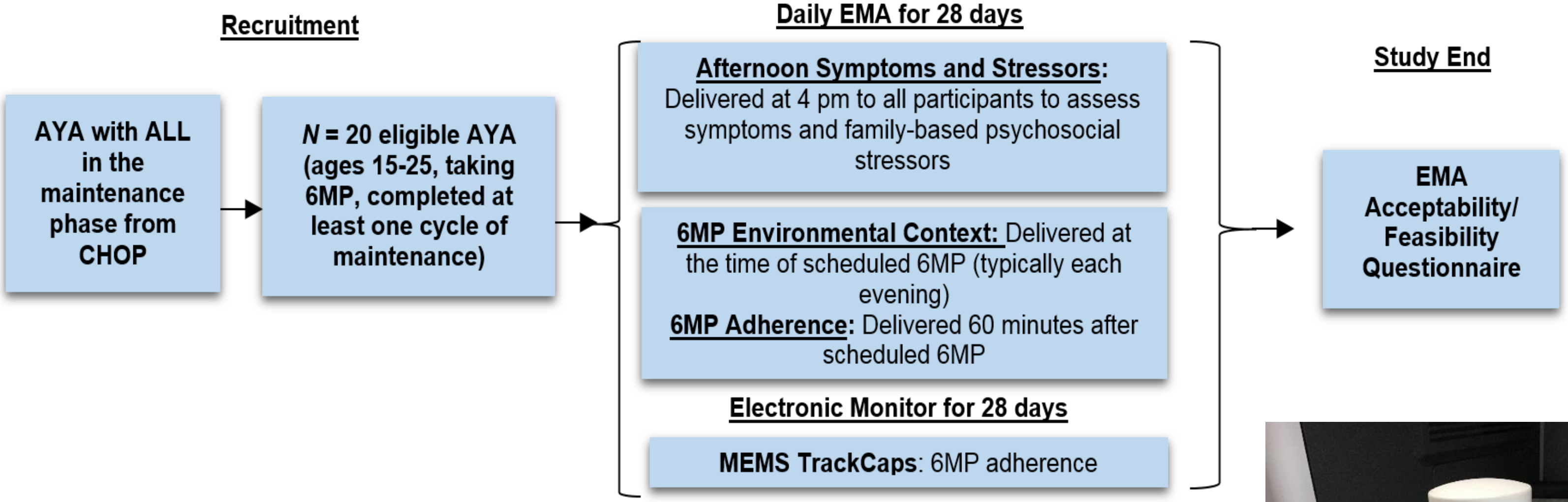
- ☐ Determine the feasibility, acceptability, and initial validity of conducting daily, text message EMA to measure 6MP adherence.
  1. Hyp 1. AYA will agree to participate and complete at least 75% of EMA surveys. They will report EMA as acceptable, feasible, and useful for self-monitoring of 6MP adherence
  2. Hyp 2. EMA of 6MP adherence will significantly relate to a electronically-monitored 6MP adherence via MEMS TrackCaps (gold standard adherence assessment but very costly)

- ☐ Examine daily temporal relationships between symptoms, family stressors, and environmental context with 6MP adherence.
  3. Hyp 3. Worse physical and emotional symptoms, experiencing a family stressor, and being outside of the home with peers during the dose will be associated with missed 6MP in the following 24 hours.

**** Selection of these contextual variables informed by prior research and an evidenced-based social-ecological model of pediatric disease self-management (Modi et al., 2012)*

Methods/Design:

FIGURE 1. Planned Study Design



Recruitment

AYA with ALL in the maintenance phase from CHOP

***N* = 20 eligible AYA (ages 15-25, taking 6MP, completed at least one cycle of maintenance)**

Daily EMA for 28 days

Afternoon Symptoms and Stressors: Delivered at 4 pm to all participants to assess symptoms and family-based psychosocial stressors

6MP Environmental Context: Delivered at the time of scheduled 6MP (typically each evening)
6MP Adherence: Delivered 60 minutes after scheduled 6MP

Electronic Monitor for 28 days

MEMS TrackCaps: 6MP adherence

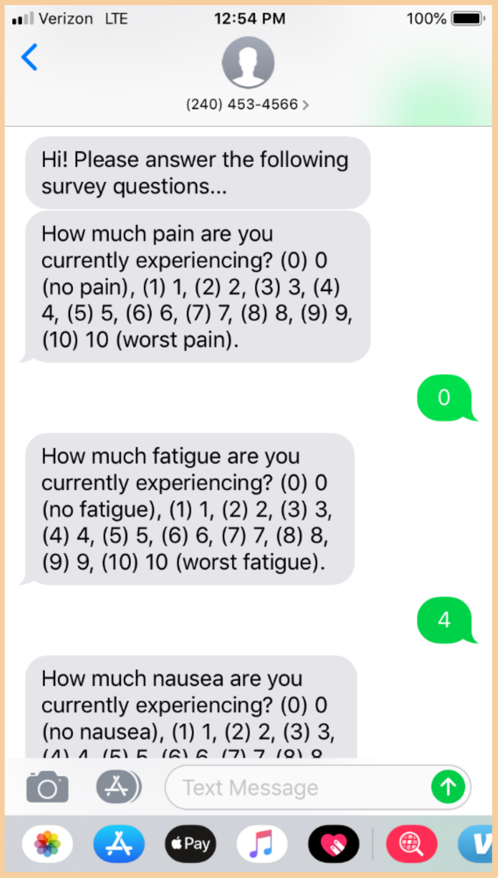
Study End

EMA Acceptability/ Feasibility Questionnaire

- Using **REDCap’s integration with Twilio** as platform for sending text message surveys for affordability and generalizability of methods (each text message costs less than a penny!)

Current Status: Setup Technology & Ready for Recruitment

- ❑ Multi-step process: (1) create surveys in REDCap, designate that surveys will be sent each day, at a set time, (3) integrate REDCap project with Twilio, (4) pilot test with research team prior to initiation of study to address glitches



Hi! Please answer the following survey questions...

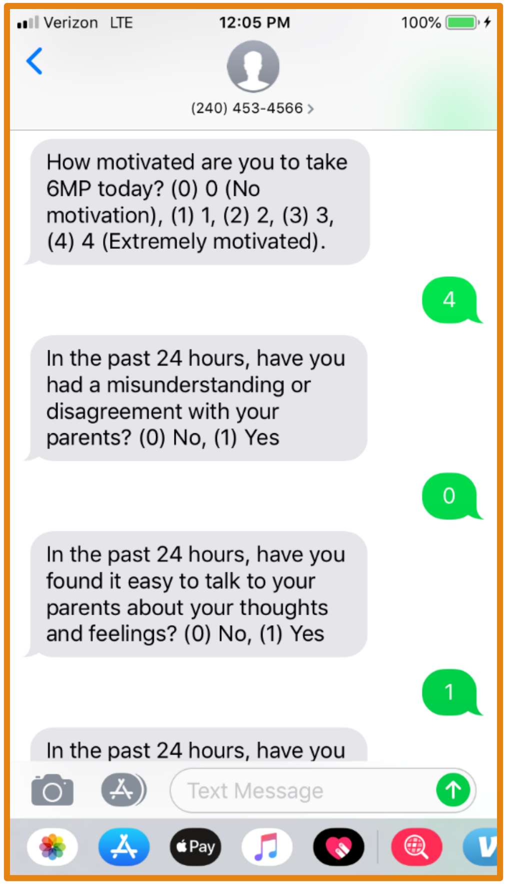
How much pain are you currently experiencing? (0) 0 (no pain), (1) 1, (2) 2, (3) 3, (4) 4, (5) 5, (6) 6, (7) 7, (8) 8, (9) 9, (10) 10 (worst pain).

0

How much fatigue are you currently experiencing? (0) 0 (no fatigue), (1) 1, (2) 2, (3) 3, (4) 4, (5) 5, (6) 6, (7) 7, (8) 8, (9) 9, (10) 10 (worst fatigue).

4

How much nausea are you currently experiencing? (0) 0 (no nausea), (1) 1, (2) 2, (3) 3,



How motivated are you to take 6MP today? (0) 0 (No motivation), (1) 1, (2) 2, (3) 3, (4) 4 (Extremely motivated).

4

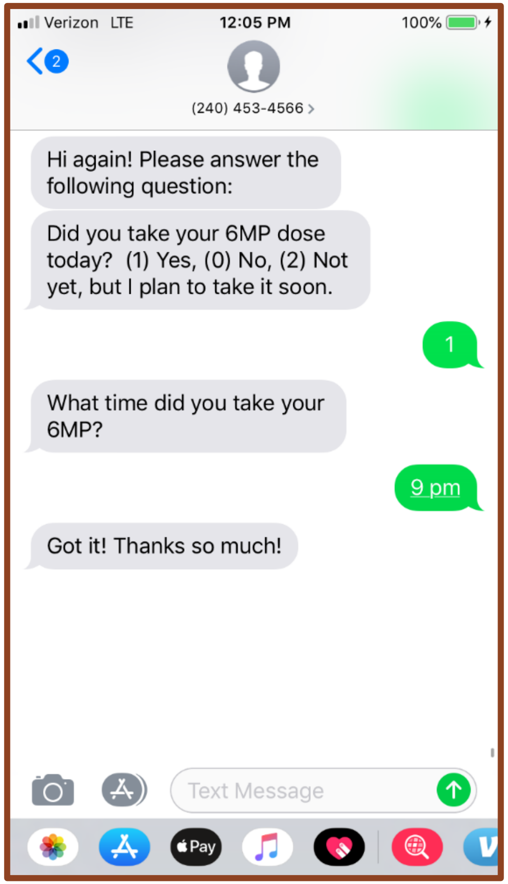
In the past 24 hours, have you had a misunderstanding or disagreement with your parents? (0) No, (1) Yes

0

In the past 24 hours, have you found it easy to talk to your parents about your thoughts and feelings? (0) No, (1) Yes

1

In the past 24 hours, have you



Hi again! Please answer the following question:

Did you take your 6MP dose today? (1) Yes, (0) No, (2) Not yet, but I plan to take it soon.

1

What time did you take your 6MP?

9 pm

Got it! Thanks so much!

Clinical Implications/Future Directions

- Text messaging is cost effective, scalable, the preferred mode of communication for AYA, and **likely one promising method** for improving clinical implementation of the Adherence Standard

- May also be useful for assessing adherence to other medications (e.g., Bactrim) and treatment tasks (e.g., supplemental feeds), across other pediatric cancer groups

- CHOP providers want to see a summary of adherence data in the EHR prior to the clinic visit to facilitate appropriate interventions, and we are working to build such an infrastructure

- Next research steps: designing a just-in-time adaptive text messaging intervention that responds to EMA data to deliver personalized adherence support (NCI K08 proposal under review)

Standard #11:
Academic Continuity and School Reentry Support as a Standard of Care in Pediatric Oncology

Project Title:

Evaluation of a tiered service model to support academic continuity and school re-entry for children with cancer

KATHRYN KIRKPATRICK, PHD, LISW-S
NATIONWIDE CHILDREN’S HOSPITAL

Significance

- School is central to the lives of children and adolescents
- Pediatric cancer diagnosis and treatment can disrupt school attendance
- Treatment comes with a burden of medical and cognitive late effects
- School integration services are essential component of psychosocial care for children with cancer
- Paucity of vigorous research about impact of school services, even though we know anecdotally that the support is essential to patients
- **Expansion of school integration services to all children with cancer will require development of models of care that are *effective, efficient and economically viable, and amenable to dissemination across settings*.**

Aims

Implementation of a tiered services model for school intervention services

- Assess level of school needs using *Brief Inventory of School Needs* (BSNI, Irwin & Elam, 2015)
- Services provided based on intensity of needs

Three primary aims of the study:

1. Assess feasibility and fidelity of tiered service model
2. Evaluate acceptability of tiered service model
3. Monitor resource utilization of the tiered service model and compare with old universal service model

Design

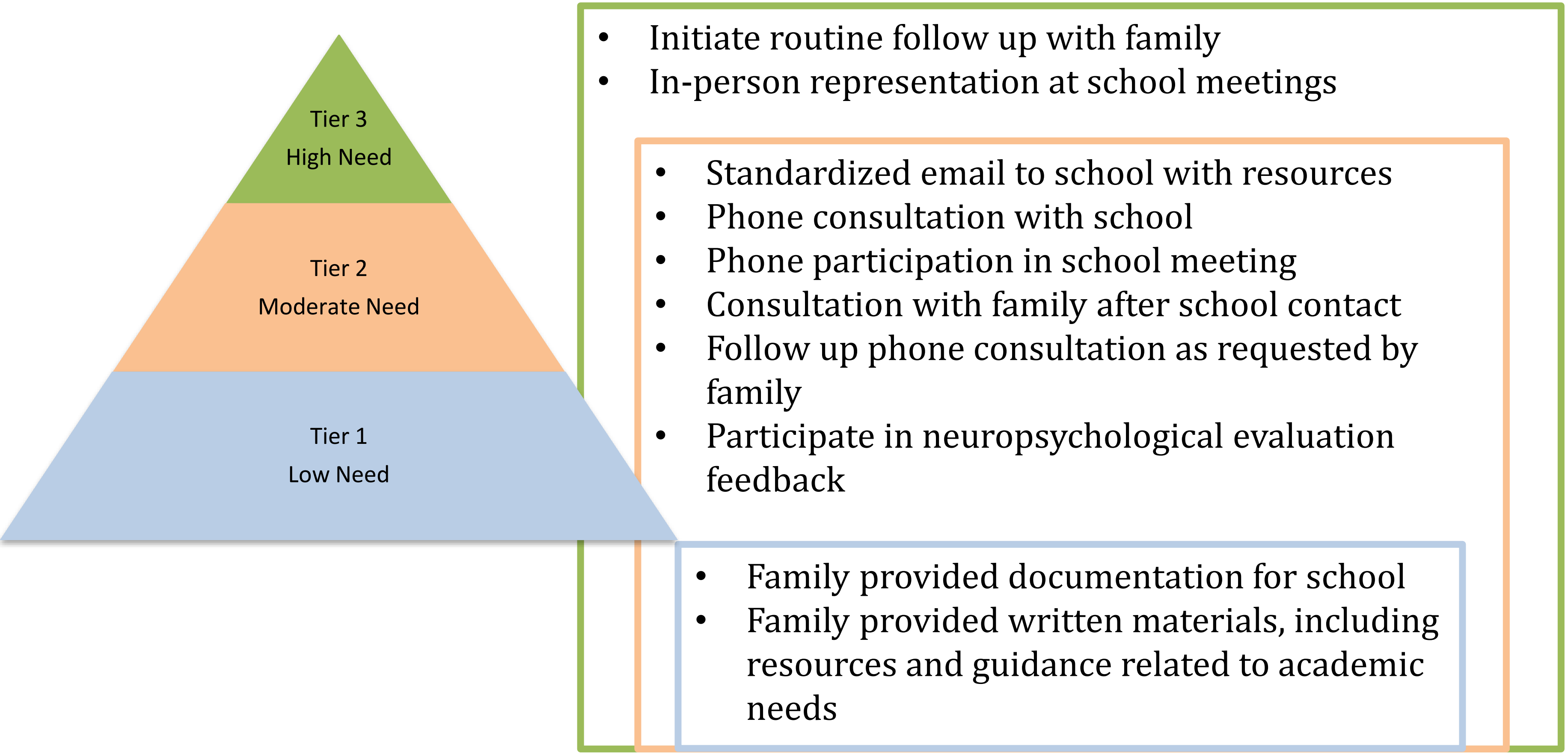
Historical Reference Point:

- Universal services model—all oncology patients were offered the same comprehensive school services
- May 2018—*changed standard of care to tiered model*

Evaluating Tiered Services Model

- Recruitment: All newly diagnosed, school-aged oncology patients and patients entering long term survivor comprehensive care
- Assessment: Standard use of BSNI to assess level of school need
- Tiered Service Delivery: Provide services based on level of need
- Evaluation: Review feasibility, levels of satisfaction, and use of resources

Design



Tier 3
High Need

Tier 2
Moderate Need

Tier 1
Low Need

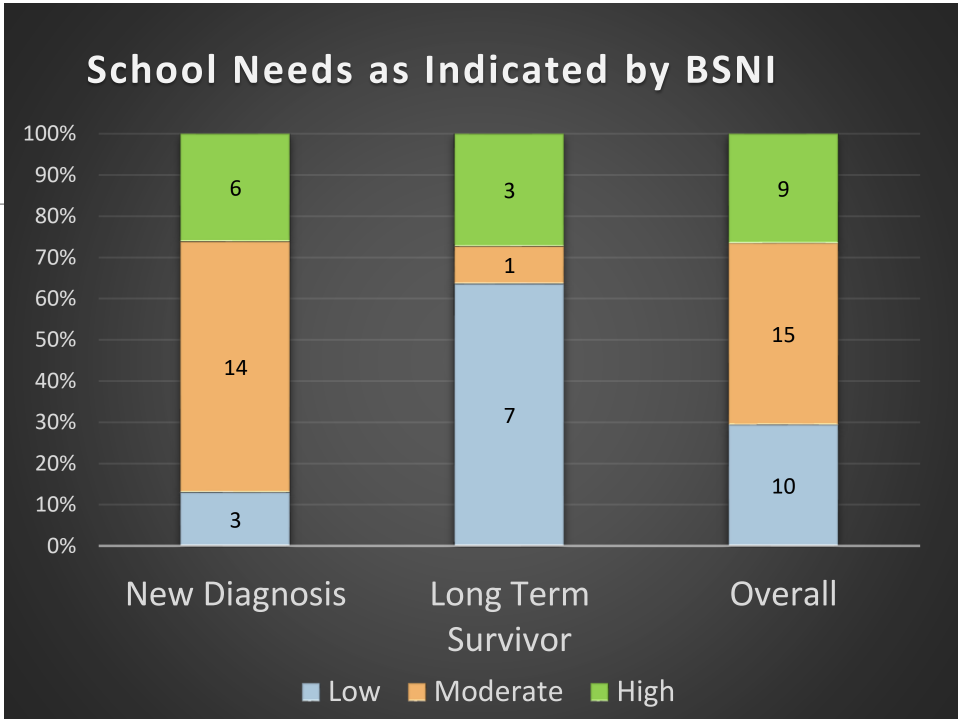
- Initiate routine follow up with family
- In-person representation at school meetings

- Standardized email to school with resources
- Phone consultation with school
- Phone participation in school meeting
- Consultation with family after school contact
- Follow up phone consultation as requested by family
- Participate in neuropsychological evaluation feedback

- Family provided documentation for school
- Family provided written materials, including resources and guidance related to academic needs

Current Status

- Enrollment began in August, 2018 after IRB approval
- Retroactively enrolled all newly diagnosed patients from 07/01/2019; long term survivors enrolled from 09/15/2018
- Very low decline rate
- Some fuzziness with brain tumor eligibility due to institutional structure of referral



- As of 02/15/2019, 34 patients have been enrolled in the study
  - 23 newly diagnosed
  - 11 long term survivors at first comprehensive clinic follow up

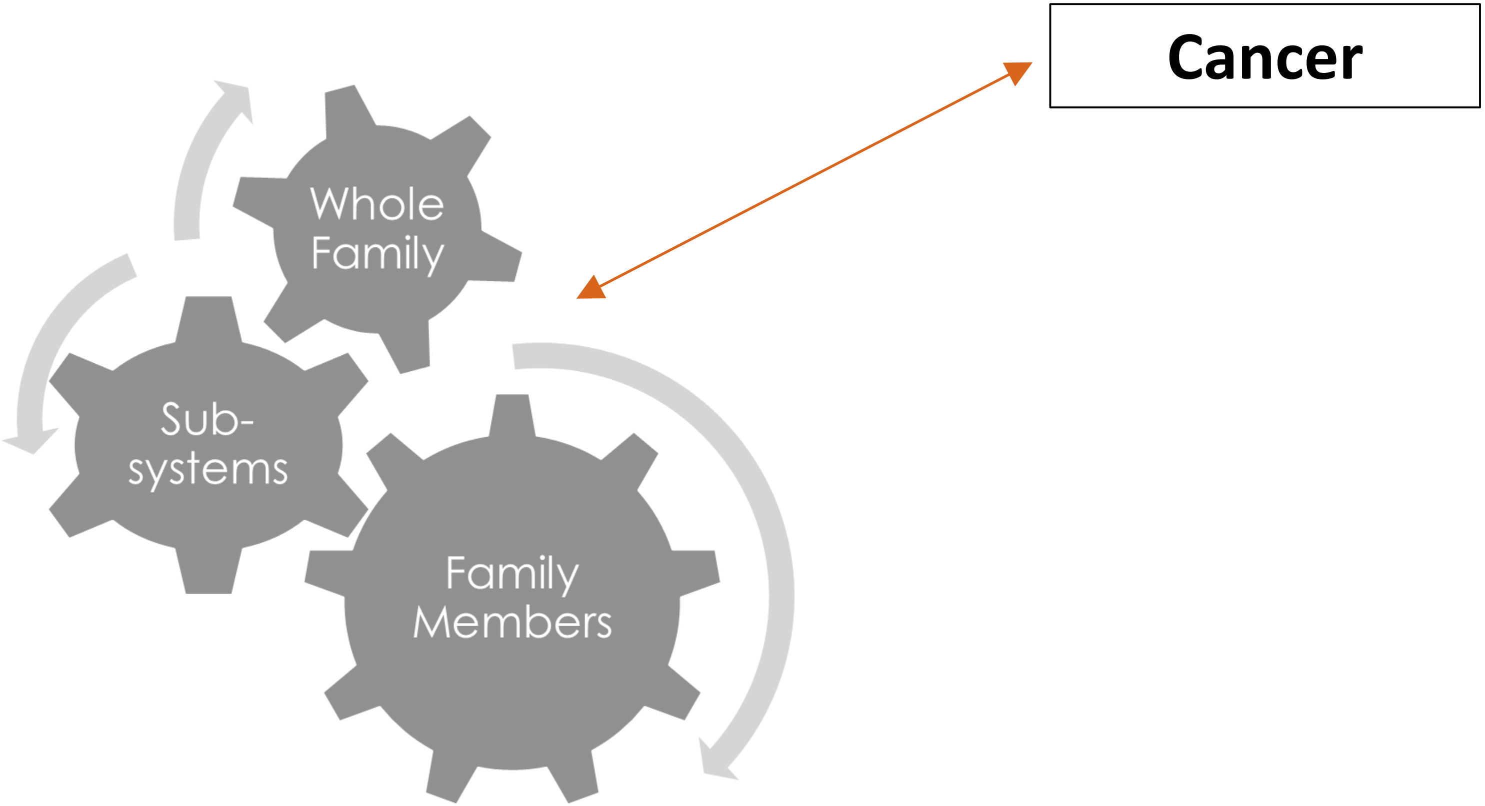
Standard #10: Supporting Siblings

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

Kristin Long, PhD; David Buchbinder, MD; Christina Amaro, M.S.; Maru Barrera, PhD; Lynn Fainsilber Katz, PhD; Cynthia Gerhardt, PhD; Anne Lown, DrPH; Christina Sharkey, M.S.; & Melissa Alderfer, PhD

Why Focus on Siblings?



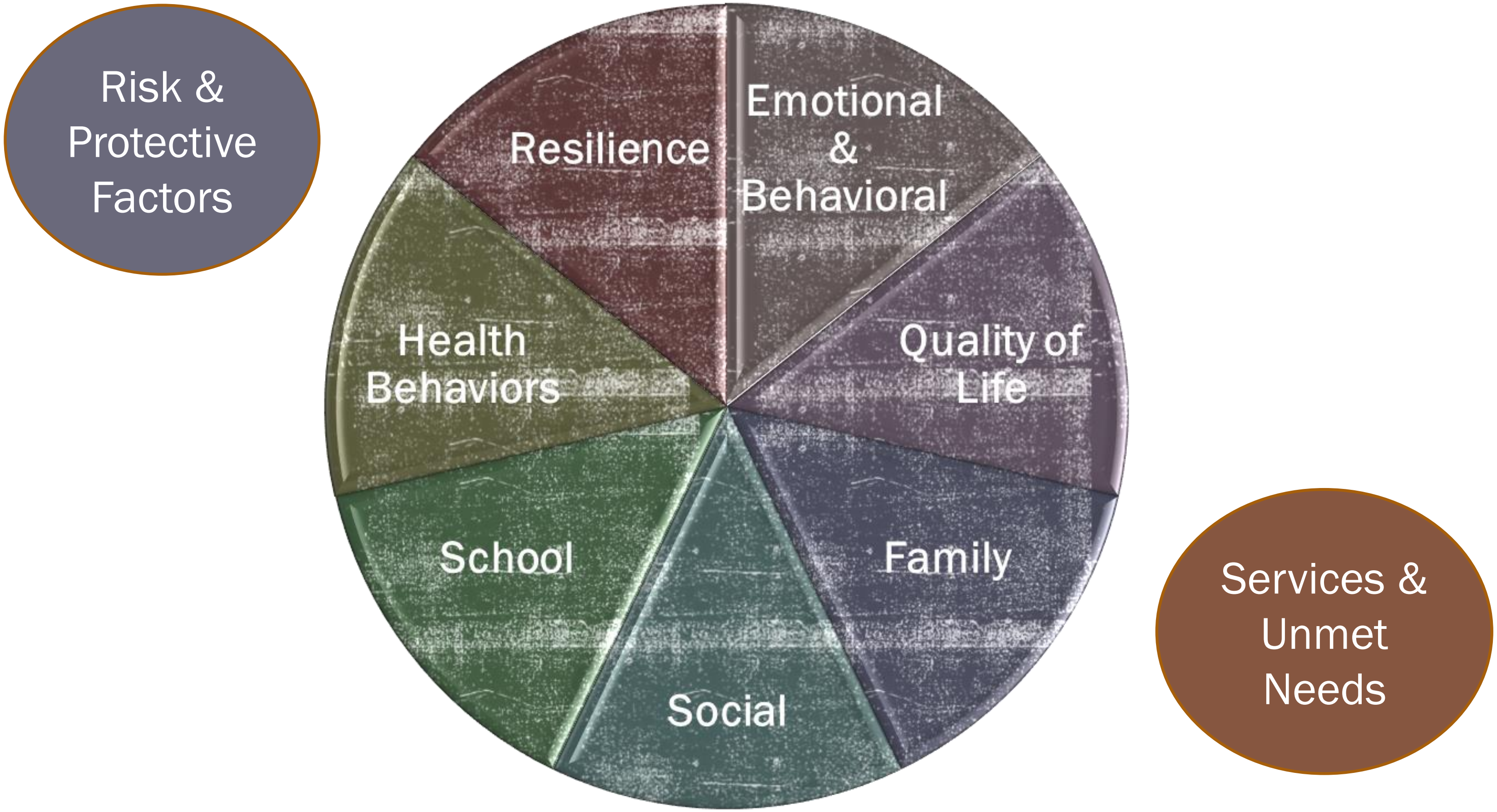
Cancer

Whole Family

Sub-systems

Family Members

Siblings' Psychosocial Functioning



Siblings’ Psychosocial Functioning

Resiliency & psychopathology

- ~25% meet criteria for PTSD
- Pervasive & strong negative emotions

Developmental outcomes

- Unhealthy patterns of family functioning
- More absenteeism, poorer school performance, difficulty concentrating
- Family disruptions & reduced social times

Effects into adulthood

- Distress (bereaved)
- Problematic drinking (early, current, risky, or heavy)
- Increased risk for cardiovascular disease

Long et al., 2018

Implementation of the Sibling Standard

Standard #10:

Routine psychosocial assessment & support for siblings of children with cancer

Gerhardt, Lehmann, Long, & Alderfer 2015

Implementation of the Sibling Standard

- Sibling Standard is among those least likely to be implemented (Scialla et al., 2018)
- Only 1/3 of centers consistently offer psychosocial care to siblings (Jones et al., 2018)

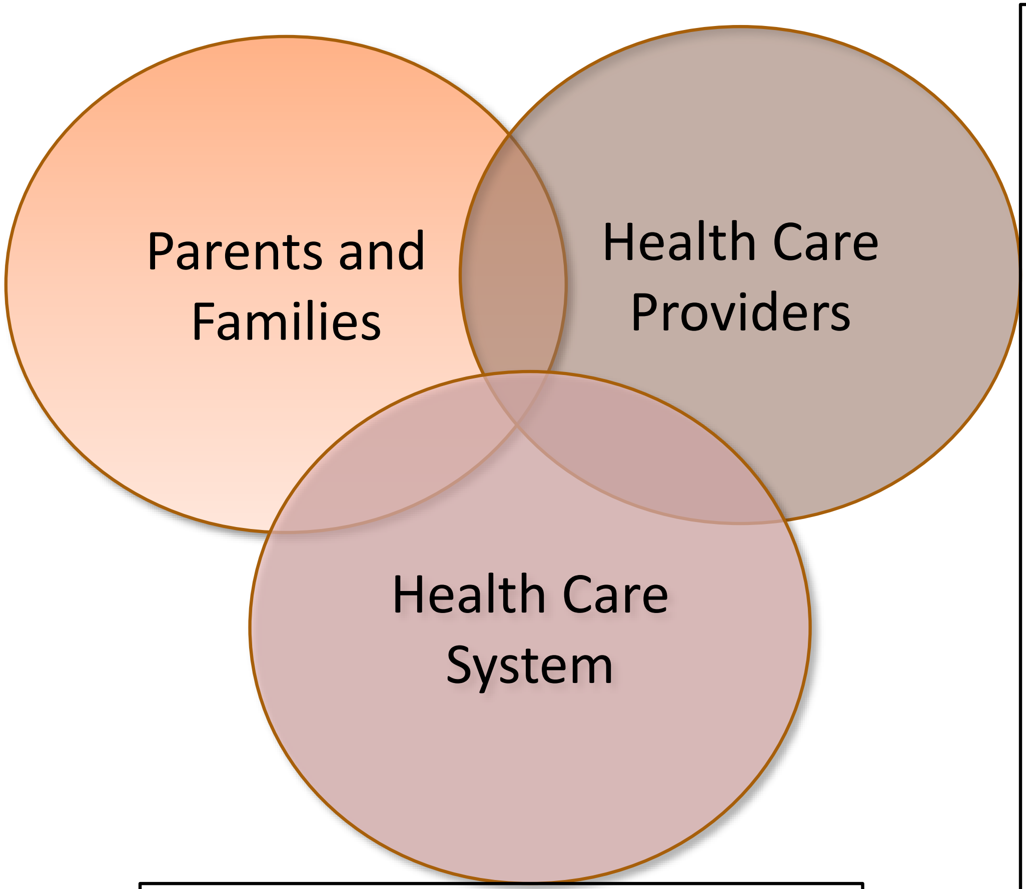
- Still many unknowns…
  - Nature & quality of available sibling services
  - Number of siblings who actually receive services
  - Barriers to / facilitators of offering sibling support

Aims

1. Characterize the range & nature of existing sibling-focused psychosocial assessment & intervention services
2. Describe providers' perceptions of barriers to providing sibling-specific screening and support and identify feasible solutions to sibling support barriers
3. Apply findings to the creation of a blueprint outlining an acceptable, feasible model for delivery of sibling psychosocial care

Potential Obstacles to Sibling Care: A Social Ecological Framework

- Time
- Distance to intervention
- No perceived need for sib support
- Emotional overload
- Fear of stigma



Parents and Families

Health Care Providers

Health Care System

- Lack of psychosocial staff
- Little integration with medical team

- No time to provide care
- Not reimbursed
- Psychosocial care not considered essential
- Lack of evidence-based psychosocial approaches

Sampling & Participants

Parent Study

Preparing to Implement Psychosocial Standards: Current Services and Staffing (PIPS-CSS)

N = 144 programs

Study Population

Programs in which the Sibling Standard of Psychosocial Care was rated by a psychosocial provider (n=132)

Sample

Purposive sampling

8-12 providers ~ optimal (top quartile) integration

8-12 providers ~ suboptimal (bottom quartile) integration

Enroll until saturation occurs

Method

- In-depth, semi-structured interviews
  - (Center characteristics)
  - Current sibling-focused screening or support
  - Extent to which available services are used
    - Unique populations (e.g., bereaved, donors, non-donors, non-English-speaking)
  - Sensitivity to cultural differences/values
  - Barriers to & facilitators of offering sibling services
    - How barriers were overcome
  - Vision: state-of-the-art sibling program
  - Examples of low-cost / easy-to-implement initiatives
  - (Later: review of Blueprint draft)
- Coding (NVivo) & Applied Thematic Analysis

Deliverable: Draft Blueprint for Sibling Care

- Goal = wider implementation of the sibling standard
- Creation of a draft “Blueprint for Sibling Care”
  - Range of services
  - Including low-cost, feasible options

- Next Steps
  - Develop the draft “Blueprint for Sibling Psychosocial Care” (Mattie Miracle Project)
  - Apply findings to a subsequent evaluation of feasibility, acceptability, & implementation thereof

Working Group

- Sibling Partnership for Advocacy, Research, & Care in Childhood Cancer (SPARCCC)
  - Committed community-academic partnership with the goal of focusing the attention of researchers, clinicians, the pediatric oncology community, and the general public on the experiences and needs of siblings of children with cancer (http://sparcccpartnership.wixsite.com/sparccc)
- Interdisciplinary work group
  - Psychology, oncology, social work, community partners
- Integration of trainees
  - Boston University & University of Oklahoma
- Research questions, data collection & interpretation, & application of findings are firmly grounded in community partnership model

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Team-based integration of Palliative Care in Pediatric Oncology Practice:

Implementing the Pediatric Psychosocial Standards of Care

Marie Barnett, Ph.D.
Memorial Sloan Kettering Cancer Center
New York, NY

Memorial Sloan Kettering
Cancer Center
1884

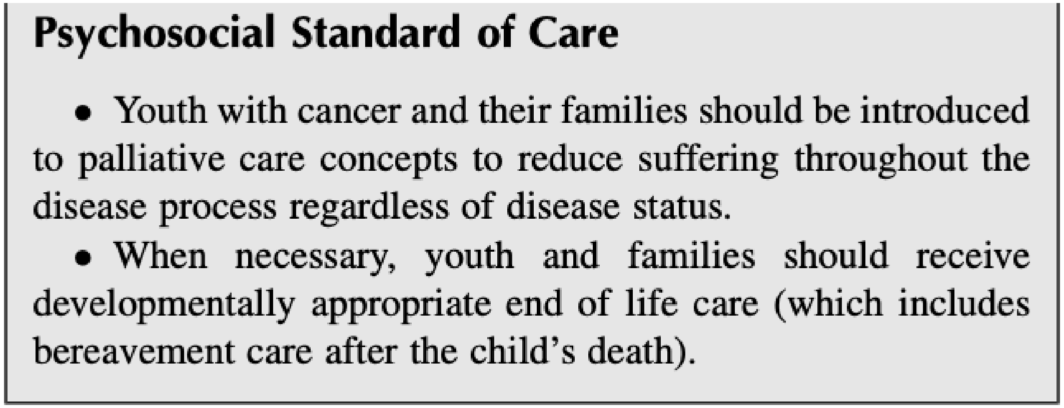
Study Significance

Palliative Care as a Standard of Care in Pediatric Oncology

Meaghann S. Weaver, MD, MPH,[1,2*,†] **Katherine E. Heinze**, BSN, RN,[3,†] **Katherine P. Kelly**, PhD, RN,[4,†]
Lori Wiener, PhD, DCSW,[5,†] **Robert L. Casey**, PhD,[6] **Cynthia J. Bell**, PhD, RN,[7,8,†] **Joanne Wolfe**, MD, MPH,[9]
Amy M. Garee, RN, MS, PNP,[10,†] **Anne Watson**, PhD, MSc, RN,[11,†] **and Pamela S. Hinds**, PhD, RN, FAAN[4,12,†]

The study team conducted a systematic review of pediatric and adolescent palliative cancer care literature from 1995 to 2015 using four databases to inform development of a palliative care psychosocial standard. A total of 209 papers were reviewed with inclusion of 73 papers for final synthesis. Revealed topics of urgent consideration include the following: symptom assessment and intervention, direct patient report, effective communication, and shared decision-making. Standardization of palliative care assessments and interventions in pediatric oncology has the potential to foster improved quality of care across the cancer trajectory for children and adolescents with cancer and their family members. Pediatr Blood Cancer 2015;62:S829–S833.

Key words: communication; family-centered care; palliative care; psychosocial support; quality of life



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).

- ☐ Summary of evidence
  - ☐ Symptom assessment and intervention
  - ☐ Patient and family-centered communication
  - ☐ Compassionate and honest communication
  - ☐ Decisional preferences, developmentally appropriate and informed
  - ☐ Tangible support

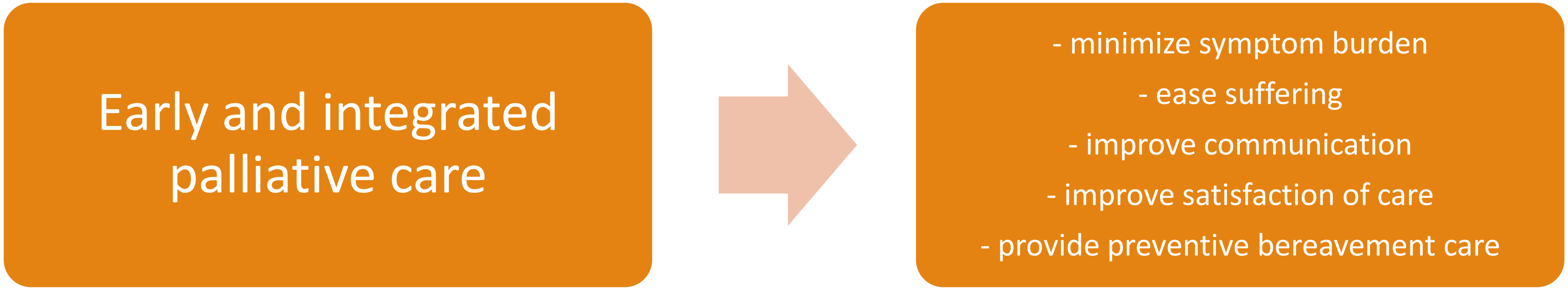
Identified a lack of standardized general and psychosocial palliative care guidelines in childhood cancer.

Where does a patient's primary medical team fit into this?

Weaver et al. (2015); Weaver et al. (2016).

Study Significance

- What is palliative care?
  - Treatment approach to improve quality of life with prevention and relief of suffering
  - Involves **early** identification, assessment, and **integrated** treatment planning in areas of physical, psychological and spiritual functioning
  - Emphasizes holistic care of a child's body, mind, and spirit – AND includes family
  - Pediatric palliative care begins at the time of diagnosis
  - Multidisciplinary treatment approach



Early and integrated palliative care

- minimize symptom burden

- ease suffering

- improve communication

- improve satisfaction of care

- provide preventive bereavement care

In clinical practice, early Pediatric Palliative Care (PPC) can be operationalized with disease-specific, standardized PPC referral criteria, effective communication, and shared decision-making among primary medical teams and providers.

Friedrichsdorf et al., 2015; Wang et al., 2013; Wolfe et al., 2008; Wolfe et al., 2018; World Health Organization (WHO).

Study Significance

- Focuses on the psychosocial standard
  - Youth with cancer and their families should be introduced to palliative care concepts to reduce suffering throughout the disease process regardless of disease status.
- Early, integrated, and family-centered pediatric palliative care (PPC) encapsulates the mission of the Mattie Miracle Cancer Foundation, tenets of palliative care, and the Pediatric Psychosocial Standards of Care

Requires implementing and fostering
close collaboration and commitment
with primary medical teams early in treatment.

Aims

- Aim 1:
  Establish and implement standardized, disease-specific eligibility criteria and clinical care recommendations for early introduction and referrals to Pediatric Palliative Care (PPC).
  - **Objective 1:** Create standardized, disease-specific eligibility criteria and clinical care recommendations for sarcoma, neuroblastoma, leukemia/lymphoma teams.
  - **Objective 2:** Track rates of referrals after implementation of team-specific guidelines.

- Aim 2:
  Demonstrate increased palliative care knowledge, understanding, and comfort among medical providers.

Aim 1

Design

- Modified Delphi process
  - Reach expert consensus on disease-specific eligibility criteria and clinical care recommendations.
  - Consensus reached among identified and willing oncologic providers ("panelists") (sarcoma, neuroblastoma, leukemia/lymphoma teams).
  - Assessing strength of agreement and building increased group consensus across each "round."
  - All rounds completed electronically via REDCap.
  - Results shared among participants and presented in medical team meetings.

Round 1

- Study Investigators establish questions using literature, PPC concepts, PPC utilization, and case examples.

- Panelists respond to open-ended questions and rate the appropriateness of criteria by rating the importance and relevance (Likert scales).

Round 2

- Panelists review and rate the appropriateness of questions and criteria using a Likert-type rating scales.

- Content and criteria is synthesized and revised following the RAND-modified Delphi process.

Round 3

- Panelists review the revised questions and criteria using Likert-type rating scales to achieve greatest consensus and specificity.

- Content and criteria is finalized following the RAND-modified Delphi process.

Aim 1

Design

- ☐ Rates of PPC referrals will be tracked after completion of Delphi analysis and presentation of results at disease specific team meetings.
  - ☐ PPC consults will be obtained from the Electronic Medical Record (EMR) and DataLine queries for PPC referrals.

Aim 2

Design

- Pediatric Palliative Care Survey for medical providers
  - Face-valid questions, developed by Study Investigators
  - Sent to providers across 5 disease groups (neuroblastoma, leukemia/lymphoma, neuro-oncology, sarcoma, bone marrow transplant)
  - Likert-type responses
  - Administered via REDCap
  - Baseline survey (14 questions)
  - Follow-up survey (16 questions)

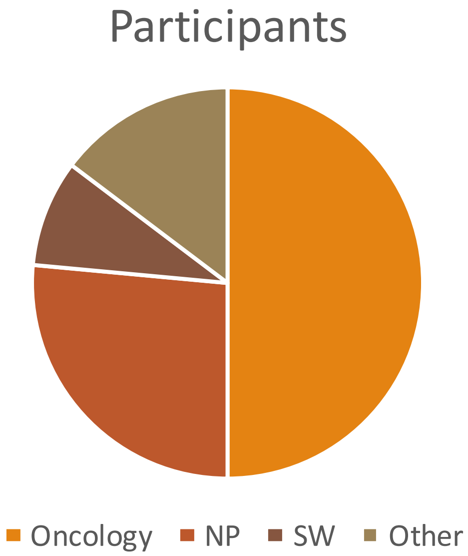
Survey Topics

medical current utilization and understanding of PPC	expectations of PPC utilization
perceived barriers to PPC discussions	perceived barriers to PPC referrals and utilization
motivation to increase palliative care discussions with patients/families	motivation to increase PPC referrals/utilization

Currently, how likely are you to discuss PPC concepts or services during medical appointments?
Currently, how would you describe your understanding of PPC?
Currently, how would you describe your comfort level with introducing PPC with your patients?

Early Findings

- Baseline PPC Survey for medical providers completed (N=34)
- 27 oncology providers invited to participate in the Delphi Process
  - n=26 agreed, n=1 declined
- First Round of the Delphi survey has been sent to providers.



"How satisfied are you with your current level of understanding and communication of palliative care concepts with patients and families?

- 41% unsatisfied or unsure;
- 18% very satisfied

"Currently, how likely are you to discuss PPC concepts or services during medical appointments (when clinically appropriate)?"

- *85% likely or extremely likely*

"How well do you think the PPD program currently meets the expectations of the published standard for Palliative Care in pediatric oncology?

- *29% major improvements needed*
- *47% some improvement needed*

Next Steps

- Complete collection of Round 1 Delphi Surveys and analysis

- Send Round 2 Delphi Survey for completion and analysis

- Send Round 3 Delphi Survey for completion and analysis

- Results presented at Medical team meetings

- Tracking PPC referrals

- Followup PPC Medical Providers survey

Acknowledgments

Pediatric Oncology Providers

- Neuroblastoma, Leukemia/ Lymphoma, Sarcoma providers
- Oncologists, NP's, social workers, fellows

Pediatric Palliative Care Team

- Julia Kearney, MD
- Ben Record, MD
- Rosanna Silber, NP

Psycho-Oncology Team

- Julia Kearney, MD
- Molly MacGregor, MD
- Stephen Sands, PsyD

Patient-Reported Outcomes, Community, Engagement, and Language (PRO-CEL) Team

- Tom Atkinson, PhD
- Katie Lynch, PhD
- Jacqueline Vera

Mentors

- Jennifer Ford, PhD
- Julia Kearney, MD
- Chris Nelson, PhD

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Life After Death:

A Novel Online Support Group for Parents Who Have Lost a Child to Cancer

Gillian Regan, PhD

Atrium Health
Levine Children's

Significance

Psychosocial Standard of Care for Bereavement (Standard 14):

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.

Background

- Bereaved caregivers at-risk for poor psychological and physical health outcomes
- Bereavement support is often distributed inconsistently due to limited resources
- Desire to maintain relationships with the hospital following their losses
- Significant need for bereavement support within pediatric oncology settings

Lichtenthal et al., 2015; Steele et al., 2013

Aims

1. To provide ongoing bereavement support and mitigate the psychosocial effects of losing a child to cancer
2. To fulfill one of the psychosocial standards of care
3. To administer measures that identify clinical characteristics and improve services provided
4. To create a manual to assist with dissemination

Design

- Pre-existing, ongoing monthly online (Facebook) bereavement support group led by psychosocial staff

- Completion of questionnaires at three time points (via REDCap)
    - *Demographics*
    - *Group feedback*
    - *Post-traumatic growth (PTGI)*
    - *Prolonged grief (PG-13)*

- Development of procedural manual

Design

Measure	Baseline	6 Months	12 Months
PG-13	x		x
PTGI	x		x
Demographics	x		x
Group Measure		x	x

Project Status

- Baseline surveys**:** *Complete*
- **March**: Send out group measure; collect data and incorporate changes into group; start brainstorming procedural manual
- **April-July**: Develop and finalize manual
- **August**: Send out final questionnaires; disseminate manual
- **September**: Analyze data and prepare for APOS presentation/publication; disseminate manual

Initial Data Analysis

Variable	*M* or N (%)
Gender (female)	7 (100%)
Relationship to child	
Biological mother	6 (84%)
Other: Biological aunt	1 (14%)
Caregiver race/ethnicity	
Caucasian	6 (84%)
Other: Biracial	1 (14%)
Caregiver age	43.29 years
Child age at death	11.07 years
Time since child's death	41.29 mos.
Child's diagnosis	
Solid tumor	6 (86%)
Leukemia	1 (14%)
Caregiver employment status	
Full-time outside of the home	1 (14%)
Part-time outside of the home	4 (57%)
Working in the home	1 (14%)
Unemployed	1 (14%)
Change in employment status since death of child	
No	2 (29%)
Yes	5 (71%)

Variable	*M* or N (%)
Participated in support group previously?	
No	4 (57%)
Yes	3 (43%)
Was the previous support group online?	
No	2 (67%)
Yes	1 (33%)
Was it pediatric-cancer specific?	
No	2 (67%)
Yes	1 (33%)
Sought mental health treatment?	
No	4 (57%)
Yes	3 (43%)
Reason(s) for joining the group?	
Familiarity with staff	5 (71%)
Peer support	3 (43%)
Knowing I'm not alone	6 (86%)
Emotional support	3 (43%)
What do you hope to get out of the group?	
Ongoing connection with hospital staff	1 (14%)
Peer support	5 (71%)
Feel that I'm not alone	5 (71%)
Resources that are from the hospital where my child was treated	1 (14%)
Emotional support	7 (100%)

Initial Data Analysis

Variable	*M*	Range
Post-traumatic growth (PTGI)	50.14	18-78
	N (%)	
Prolonged grief (PG-13)		
Separation Distress	6 (86%)	
Duration Criterion	4 (57%)	
Cognitive, Emotional, and Behavioral Symptoms	2 (29%)	
Impairment Criterion	4 (57%)	
"*Meets criteria"	1 (14%)	
**Note*: This is not used as a diagnostic tool.*		

Thank You!

For questions or more information, please contact:

Gillian.Regan@AtriumHealth.org

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

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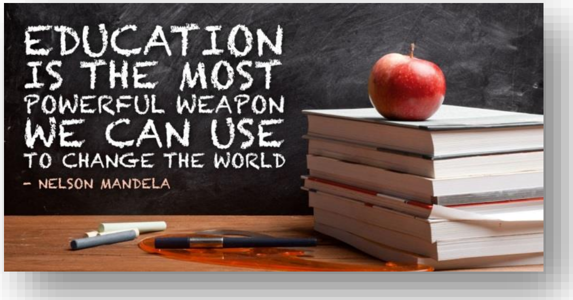
2. Legislation and Regulation

- ☐ 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



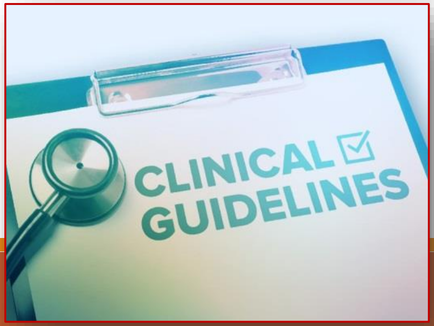
- Build knowledge of Standards universally, and have associations embrace both use and application of standards in accreditation and educational programs
  1. Associations to endorse and to support standards
     - ✓ AACAP, APA, APHON, APOS, APOSW, ASPHO, COG, CAPO, etc.
  2. Incorporate Standards into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