Family psychosocial risk screening In pediatric healthcare

Anne E. Kazak, Ph.D., ABPP Enterprise Director, Nemours Center for Healthcare Delivery Science Co-Director, Center for Pediatric Traumatic Stress Nemours MPI, PEDSNet Professor, Sidney Kimmel Medical School of Thomas Jefferson University

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Thanks to the many multidisciplinary team members who have contributed to this work over the past 30+ years. Special appreciation to the children and families who have generously participated in our studies and programs.

Some research presented today is supported by a grant from the American Cancer Society (RSG-19-122) *Psychosocial Risk Screening for Pediatric Health Equity.* A prior ACS grant, *Cross-Cultural Psychosocial Risk Screening in Pediatric Cancer* (RSG-13-015), validated the Psychosocial Assessment Tool (PAT) in English and Spanish and provided essential data to support the current implementation trial. Additional support specific to the implementation of the PAT was also provided by a CureSearch Community Impact Award, *Implementing family psychosocial risk screening in English and Spanish*

Other and previous support for this research has been provided by the Center for Pediatric Traumatic Stress (SM080048), the Nemours Center for Healthcare Delivery Science, the Nemours Center for Cancer and Blood Disorders and the Department of Pediatrics at the Children's Hospital of Philadelphia.

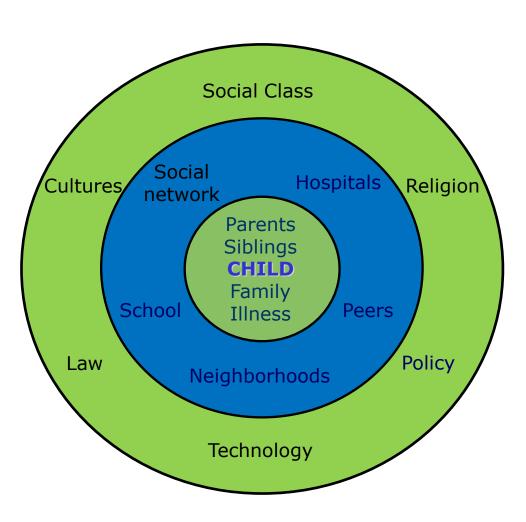
The background research described in this presentation has been supported by the National Cancer Institute (NCI; R21CA98039), St Baldrick's Foundation, American Cancer Society (RSG-13-015), the Substance Abuse and Mental Health Services Administration (SAMHSA; SM058139 SM54325; SM61255), Alex's Lemonade Stand Foundation.

I have no disclosures to report.

Goals of today's presentation

- 1. Present background and rationale for universal, systematic family psychosocial risk screening
- Introduce the Psychosocial Assessment Tool (PAT), an evidence-based screener of family psychosocial risk and resources
- 3. Identify ways in which the PAT (or other screeners) can be integrated into clinical workflows, with attention to barriers and facilitators of implementation

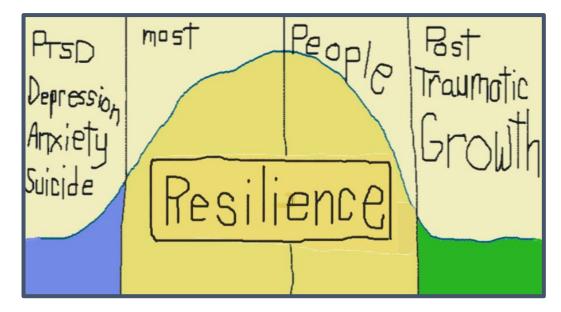
Background



- Integrating psychosocial care into pediatrics is an important goal of comprehensive care
- Psychosocial care is patient and family oriented—child adjustment is inextricably linked to parent/family adjustment
- Addressing a broad array of factors across the patient's and family's *social ecology* is necessary
 - Research provides consistent evidence for multiple aspects of psychosocial risk for families of children with cancer and other conditions that impact initial response to diagnosis, ability to manage the demands of treatment, and long-term outcomes
- Assuring that *all* patients and families receive care matched to their needs is a key element of achieving health equity

Family psychosocial risk and resilience

Majority of children and families are resilient, but many have psychosocial concerns that can impact the course of treatment and medical and psychosocial outcomes



Goal is to identify those at greatest risk as early as possible to prevent escalation of distress and provide evidence based treatments to promote adjustment and positive outcomes Youth with cancer and their families should routinely receive systematic assessments of their psychosocial health care needs ¹

- Screening for psychosocial risks and resources is a first step in the delivery of personalized care plans tailored to family needs and strengths
- Screening can change the course of psychosocial and medical outcomes, is preventative, provides the right intervention at the right time and promotes health equity--assuring that <u>all</u> get care matched to their needs
- Screening is the first standard in the National Pediatric Psychosocial Standards of Care^{1,2}
- Key professional societies recommend psychosocial screening and intervention
- Recently psychosocial screening has been termed the "eighth vital sign"³

¹ <u>http://onlinelibrary.wiley.com/doi/10.1002/pbc.v62.S5/issuetoc</u>

² Kazak et al., Pediatric Blood Cancer 2015; 62: S426-S459

³ Jellinek & Murphy, JAMA Pediatrics, 7/20/20.

Assessing psychosocial risk in <u>all</u> families is critical to address health equity in the delivery of integrated care in pediatrics

- A growing literature documents disparities in cancer systematic differences in survival and relapse in pediatric cancer based on race and ethnicity (Aristizabal et al., 2021; Bhatia, 2011; Delavar et al., 2020; Unger et al, 2021)
- Psychosocial factors including social determinants of health (e.g., household material hardship, SES, child development and behavior, parental distress, cultural values and beliefs) may contribute to inequities by creating barriers that limit consistent engagement in care and adherence to treatment
- Key community members reinforce the importance of screening 100% of children and their families to achieve the goals of universal screening for equity of care and reduction of disparities (Deatrick, et al., 2022)
- Universal and systematic screening controls for bias in assessment and facilitate delivery of care based on actual needs

Standard psychosocial screening using a screening tool reduces disparities in care

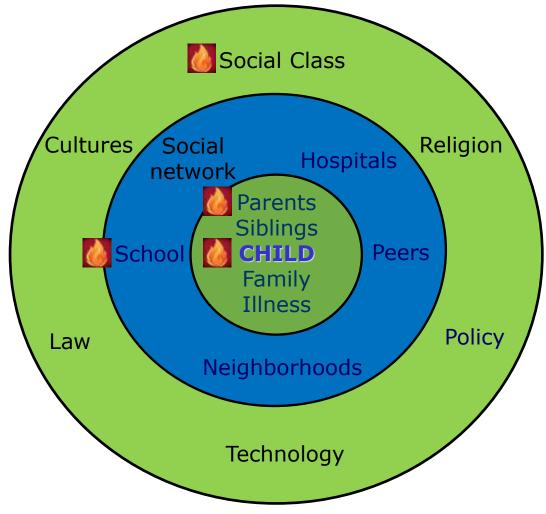
Everyone is starting in the same place. We're asking questions about kind of their financial history or kind of preexisting experiences that they may have had or beliefs, we are not projecting any of our own assumptions or biases or opinions on to families. By asking these questions kind of right at the beginning, it gives families an opportunity to kind of just tell us where they're at and let us know where they're coming from, and in a way that's a little bit more open-ended than it would typically be if all of this information is kind of something that we gather slowly or gather over time... I think the fact that it's universal, makes it a little bit more of an approachable topic for families knowing that all people get asked these questions and that all people are being asked questions that the team really does want the answer to in order to best support them. Particularly since we're administering this one, someone is first diagnosed. That's like an important time point to just say like, these are things that we care about, and these are things we're gonna continue to care about over your treatment course and after it.

Laura Moynihan, LICSW, OSW-C Pediatric Oncology Clinical Social Worker Hasbro Children's Hospital

A social ecological approach to child health: screening is a first step

Screening is intended to identify areas of risk, or hot spots, in the child's *social ecology* that then require further assessment through follow up with child and family considering:

- Pediatric healthcare is family oriented
- Children live in families, and families within broader social contexts
 - Child and family adjustment are linked
 - Children are in situations they cannot be expected to change on their own
- Children may not be able to recognize, understand, and communicate their distress



Benefits of systematic screening for all families as standard care

Benefit to patients, families, and organizations:

- Change the course of psychosocial and medical outcomes
- Integrate as crisis management to reduce/prevent later problems
- Provide the right intervention at the right time
- Promote health equity--assuring that all get care matched to their needs

Benefit to healthcare providers:

- Align with the psychosocial standards
- Help join and build relationships with families
- Facilitate more effective care through early identification of risks and prevention of problems
- Increase the efficiency of workflow by targeting attention and resources to those most in need



- Brief caregiver-report screener of family psychosocial risk, based on the social ecological approach and a public health population-based framework (Pediatric Psychosocial Preventative Health Model; PPPHM)
 - Completed using an online portal (with paper/pencil as backup)
 - All literacy (4th grade reading level) English and Spanish (US/South American) versions
 - Can be completed in ~10 minutes
- Originated and used most widely in pediatric cancer but also validated and used in ~ 20 other patient groups and 20+ languages
 - The PAT has been very well received, and since 2007, it has been used at 150 U.S. sites in 36 states (approx. 16,000 administrations) and 60 international sites in 30 countries

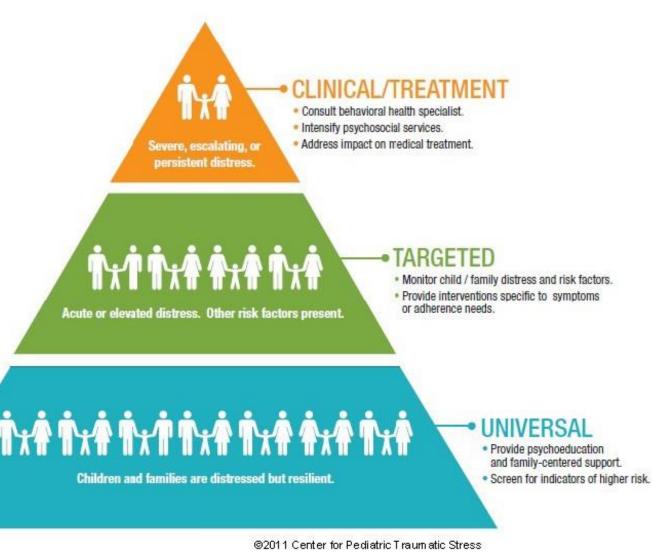
Received the 2023 R. *Bob Smith, III, Ph.D. Excellence in Psychological Assessment Award* Society of Clinical Child and Adolescent Psychology, Division 53 American Psychological Association

Pediatric Psychosocial Preventive Health Model

- The PPPHM is based on the premise that all families should be screened, and, when they are, family psychosocial risk can be understood to fall into <u>three</u> tiers.
- Each tier has implications for psychosocial care.

Kazak, A. (2006). Pediatric Psychosocial Preventative Health Model (PPPHM): Research, practice and collaboration in pediatric family systems medicine. *Families, Systems and Health, 24,* 381-395.

Kazak, A., Scialla, M., Deatrick, J., & Barakat, L. (in press). Pediatric Psychosocial Preventative Health Model (PPPHM): Achieving equitable psychosocial care for children and families. *Families, Systems & Health*.



Development of the PAT

Early versions and research

Dissemination through Center for Pediatric Traumatic Stress (2002) Grants from the NCI (R21) and St. Baldrick's Foundation

Expansion and preparing to implement

Web-based PAT (2014) Implementation pilot *Curesearch* Validation for stem cell transplantation (ALSF) Validation for Sickle Cell Disease (NIH)



PAT domains and subscales

Domains

Demographic Diagnosis Family structure Family resources Social Support School enrollment School placement Stress responses Child knowledge

Child problems Sibling problems Family problems Family beliefs Infants/young children Traumatic stress responses Suicidality

Subscales

Structure/Resources Family Problems Social support Stress reactions Child problems Sibling Problems Family beliefs



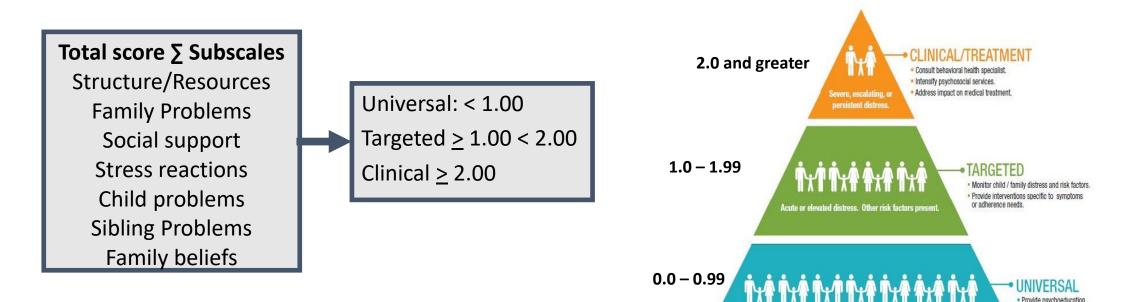
PAT scoring and interpretation

Items are scored "positive" based on research literature and clinical expertise

Pediatric Psychosocial Preventive Health Model

Children and families are distressed but resilient

@2011 Center for Pediatric Traumatic Stress



All clinically relevant items, including "red flags", are included in reports and family-centered support

Screen for indicators of higher risk

Validation for PAT3.0

PAT Scale	Loadings	English	Spanish	Construct(s) or measure	
Family Structure	.6083	0.61	0.52	SES	
Social Support	.6893	0.59	0.69	Medical Outcomes Social Support	All
Child Problems	.5988	0.80	0.78	Strengths & Difficulties	associations were
Sibling Problems	.5793	0.85	0.77	Strengths & Difficulties	statistically
Family Problems	.3680	0.64	0.72	Family Assessment Device	significant and in the
Stress Reactions	.9197	0.84	0.55	PSTD Checklist	expected
Family Beliefs	.4195	0.59	0.42	Self efficacy	direction
Total Score		0.81	0.76	Distress thermometer	

Kazak, A., Hwang, W.T., Chen, F.F., Askins, M., Carlson, O., Argueta-Ortiz, F., & Barakat, L. (2018). Screening for family psychosocial risk in pediatric cancer: Validation of the Psychosocial Assessment Tool (PAT) Version 3. *Journal of Pediatric Psychology*, 43, 737-748.

Kazak, A., Hwang, W.T., Chen, F.F., Askins, M., Carlson, O., Argueta-Ortiz, F., Vega, G., & Barakat, L. (2018). Validation of the Spanish version of the Psychosocial Assessment Tool (PAT) in pediatric cancer. *Journal of Pediatric Psychology*, *43*, 1104-1113.



Other primary research findings

Describe risk over time

There is consistency in PAT scores over time Scores at diagnosis & 4-6 months later r \sim .63 (p < .001)

Identify clinical "cases"

<u>PPPHM levels</u> 64% stay at same level 32% decreased risk 4% increased risk More stable at Universal than Targeted or Clinical

PAT can correctly identify people with high scores (sensitivity) and not identify those who don't (specificity)

Receiver Operating Characteristic (ROC) curves, the Area Under the Curve (AUC) was strong for both the English and Spanish versions of the PAT

PAT total score (English/Spanish) discriminates clinical levels on measures of acute stress [PCL-6] and child behavior [SDQ-C] (AUC = .773/.831 and .839/749 [p's < .001])

Impact clinical care

We alternated and compared assessment with the PAT with Psychosocial Assessment as usual (PAU). When screening with the PAT there were more psychosocial risks in the medical record and in social work notes (7.2 v 2.7, p = .00) and families screened by PAT received more services than PAU (7 v 4) at 8 weeks. Controlling for days in the hospital and amount of Universal services, families at higher levels of risk received 1.6 more intensive services (medical record) and 4.9 more by social work report by 8 weeks.

Alderfer, M., Mougianis, I., Barakat, L., Beele, D., DiTaranto, S., Hwang, W.T., Reilly, A. T., & Kazak, A. (2009). Family psychosocial risk, distress and service utilization in pediatric cancer: Predictive validity of the Psychosocial Assessment Tool (PAT). *Cancer, 115*, 4339-4349.

Kazak, A., Chen, F.F., Hwang, W.T., Askins, M., Vega, G., Kolb, A., Reilly, A., & Barakat, L. (2019). Stability and change in family psychosocial risk over six months and its association with medical and psychosocial healthcare utilization. Pediatric Blood and Cancer, 67: e28051.

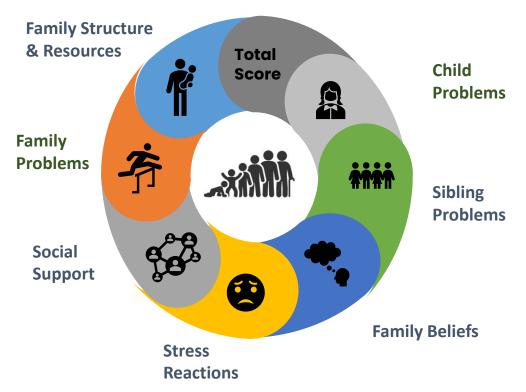
Schepers, S., Sint Nicolass, S., Maurice-Stam, J., Haverman, L., Verhaak, C. & Grootenhuis, M. (in press). Parental distress six month ager a pediatric cancer diagnosis in relation to family psychosocial risk at diagnosis. Cancer.

Kazak, A., Barakat, L., Hwang, W.T., Ditaranto, S., Biros, D., Beele, D., Kersun, L., Hocking, M., & Reilly, A. T. (2011). Association of psychosocial risk screening in pediatric cancer with psychosocial services provided. *Psychooncology*. 20: 715–723.

Social Determinants of Health (SDOH)



Psychosocial Assessment Tool (PAT)



Social determinants of health (SDOH) are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. https://health.gov/healthypeople/priority-areas/social-determinants-health

SDOH are broad and may be measured in various ways. While the PAT was not designed to assess SDOH, items on the PAT, across several subscales, assess many SDOH, with the family as the focus. The total score on the PAT provides a summation of risk (SDOH) identifying a calculation of overall risk level on the Pediatric Preventative Psychosocial Health Model (PPPHM).

SDOH Domain		Corresponding PAT subscales and items (abbreviated)			
Economic Stability	\$	ř	Money problems (food, rent, transportation) Housing stability		
Education			Child's educational status Days absent Caregiver education		
Healthcare			Insurance Support for treatment decision Information		
Neighborhood			Ability to get to appointments Crime/abuse/violence		
Social/Community			Social support Family problems Connect with medical team		

Adaptations and applications of the PAT

(published papers)

Adaptations

Craniofacial Disorders Chronic Pain (headache) Differences of sex development (DSD) Hematopoietic Stem Cell Transplantation Sickle Cell Disease Autism Spectrum Disorders NICU/CICU

Using the "generic" PAT

Asthma Behavioral Health Cardiology Chronic pain (headache) Cystic fibrosis Epilepsy

Inflammatory Bowel Disease
Medical Complexity
PICU
Solid organ transplantation
Weight Management/Obesity

Translations and language adaptations of the PAT

Translations:

Spanish (USA) Spanish (S. American) Spanish (European) **Brazilian Portuguese** Bahasa (Indonesia) Chichewa (Malawi) Chinese/Mandarin Dutch Estonian Farsi

Finnish French (Canadian) Greek Hebrew Italian Japanese Polish Portuguese Setswana (Botswana) Turkish

<u>English Adaptations</u>: Australia Canada New Zealand Singapore

United Kingdom

<u>In Progress</u> Arabic Latvian Romanian Swedish

The PAT is used around the world



Communicating Results to Team

Communication of Results to Staff

The family of ______ completed the PAT on ______ The items the family endorsed on the PAT are consistent with the following level of psychosocial risk and resource availability.

Overall Psychosocial Risk Level:

- Low Risk: The family reports many supportive resources and relatively low psychosocial risk (in number or severity). Any at-risk items are listed below.
 Recommendation: Universal interventions are recommended, including education about psychosocial impact of diagnosis /treatment, focusing on positive coping strategies and support-seeking among family members when needed.
- □ Moderate Risk: The family reports some supportive resources but also some psychosocial risk factors, which may impact illness adjustment or treatment adherence. Specific at-risk items are listed below. Recommendation: Further evaluation or close monitoring may be necessary. Targeted interventions are recommended, focusing on specific family problems, parent / child stress reactions, or parent beliefs that can negatively impact adjustment or adherence.
- □ **High Risk:** The family reports few supportive resources and multiple areas of difficulty that may impede illness adjustment or treatment adherence. Specific areas of difficulty are listed below. Recommendation: Clinical interventions, including mental health evaluation and more intensive family-based psychosocial services may be necessary. A team-based approach may be needed to ensure treatment adherence.

Specific areas of risk endorsed by the family:

Other Notes:



Communicating Results to Family

Communication of Results to Families



Transportation

We know that having a child with cancer is hard. Many families may feel upset and need some help. We are here to help your child and family. We partner with you - working together to best meet your needs

Thank you for completing the Psychosocial Assessment Tool (PAT). Your answers help us learn about you. We learn about the strengths your family brings. And, we learn about your needs for apport. The PAT looks at family strengths, emotional and social support, financial needs, reactions, and other concerns during the cancer journey, and then groups families into one of three levels of resource and support needs.



Sibling Concerns With your input, our goal is to help you help your child through this process - by talking about your needs, your strengths, and how we can help.

Caregiver Beliefs









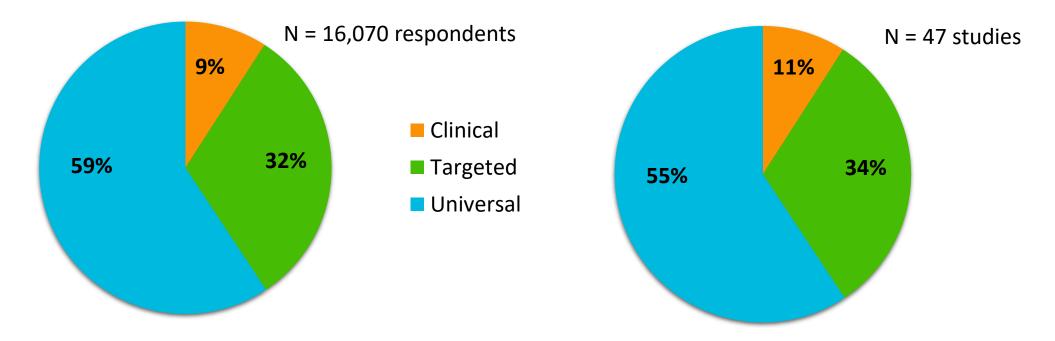


Support for the PPPHM is highly consistent

Percent of families at each risk level (as measured by the Psychosocial Assessment Tool)

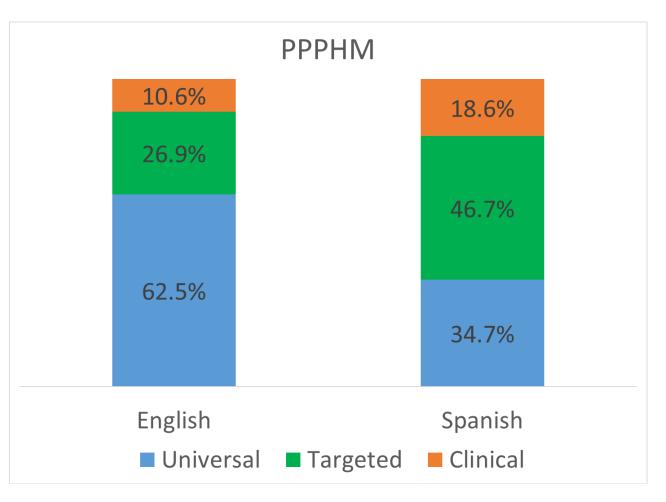
All US PAT Users

Data from scoping review (in press)



Kazak, A., Scialla, M., Deatrick, J., & Barakat, L. (in press). Pediatric Psychosocial Preventative Health Model (PPPHM): Achieving equitable psychosocial care for children and families. *Families, Systems, & Health*.

Evidence for the importance of <u>universal</u> screening



Kazak, A., Hwang, W.T., Chen, F.F., Askins, M., Carlson, O., Argueta-Ortiz, F., & Barakat, L. (2018). Screening for family psychosocial risk in pediatric cancer: Validation of the Psychosocial Assessment Tool (PAT) Version 3. Journal of Pediatric Psychology, 43, 737-748.

Kazak, A., Hwang, W.T., Chen, F.F., Askins, M., Carlson, O., Argueta-Ortiz, F., Vega, G., & Barakat, L. (2018). Validation of the Spanish version of the Psychosocial Assessment Tool (PAT) in pediatric cancer. *Journal of Pediatric Psychology*, *43*, 1104-1113.

When a family scores at the <u>Universal</u> level...the family reports many supportive resources and relatively low psychosocial risk

Recommendations:

Universal interventions including medical and psychosocial education, providing opportunities for connections with their community and with other cancer families, school re-entry, and focusing on positive coping strategies



When a family scores at the <u>Targeted</u> level...the family reports some supportive resources but also some risk factors, which may influence illness adjustment or treatment adherence

Recommendations:

Targeted interventions, focusing on specific family problems material resources, academic challenges, parent/child stress reactions (e.g., procedural distress), or parent beliefs that can negatively impact adjustment and adherence



When a family scores at the <u>Clinical</u> level...The family reports few supportive resources and multiple areas of difficulty that may impede illness adjustment or treatment adherence

Recommendations:

Clinical interventions, including mental health evaluation, more intensive familybased psychosocial services, and a team-based approach may be needed to ensure treatment adherence and minimize prolonged traumatic stress responses

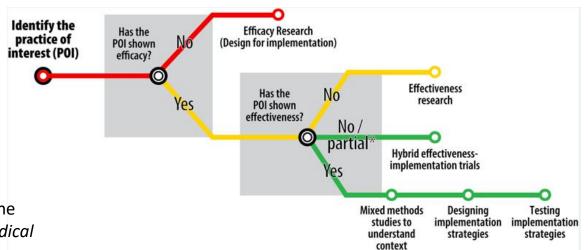


Implementation Science and the gap between what we know and what we do

- Implementation Science is the scientific study of methods to promote the systematic uptake of research findings and evidence-based practices (EBPs) into routine practice to improve the quality and effectiveness of health services
- Shared characteristics with quality improvement and dissemination methods
- Typically employ mixed quantitative-qualitative designs, identifying factors that impact uptake across multiple levels, including patient, provider, clinic, organization, and often the broader community and policy environment
- Implementation science requires a solid grounding in theory and the involvement of trans-disciplinary research teams

Key steps in implementation science

- 1. Understand the relevant research to practice gap
- 2. Establish evidence around facilitators and barriers to implementation
- 3. Develop implementation strategies
- 4. Evaluate implementation outcomes



Lane-Fall, M., Curran, G., & Beidas, R. (2019). Scoping implementation science for the beginner: locating yourself on the "subway line" of translational research. *BMC Medical Research Methodology*, 19: 133.

Price, J., Beidas, R., Wolk, C., Genuario, K. & Kazak, A. (2019). Implementation science in pediatric psychology: The example of type 1 diabetes. <u>Journal of Pediatric</u> <u>Psychology</u>, <u>44</u>, 1068-1073.

1. Defining the gaps in psychosocial care:

Preparing to Implement the Psychosocial Standards of Care – Current Staffing and Services (PIPS-CSS)

- Survey of interdisciplinary staff at U.S. pediatric cancer programs (72% of centers participated)
- Describe the readiness of programs to implement the Standards in terms of the size and composition of psychosocial teams
- Determine how psychosocial staff practice and extent to which centers deliver care consistent with the Standards
- Assess facilitators and barriers to psychosocial care

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 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. (2018). The multidisciplinary pediatric psycho-oncology workforce: A national report on supervision for staff and training opportunities. Psycho-Oncology, 27, 2802-2808.

Psychosocial staffing

Discipline	In our program	Median and range (FTE)
Social workers (MSW)	95.9%	Median = 2.0 0.0 - 24.0
Psychologists	60.3%	Median = 1.0 0.0 - 9.0
Neuropsychologists	30.6%	Median = 0.0 0.0 - 4.0
Psychiatrists	19.0%	Median = 0.0 0.0 - 3.0
Child life specialists	93.4%	Median = 2.0 0.0 - 20.0

Discipline	< 50	51-100	101-250	250+	р
Social workers (MSW)	1.2	2.0	3.0	7.9	0.000
Psychologists	0.6	0.7	1.5 4.0		0.000
Neuropsychologists	0.1	0.3	0.7	1.5	0.000
Psychiatrists	0.2	0.2	0.2	0.5	0.052
Child life specialists	1.3	1.5	2.5	6.9	0.000

62% indicated having <u>other psychosocial staff</u> members, including: Chaplain; Creative Arts Therapists; Educational liaisons; Hospital teachers; Integrative Medicine; Nutrition and Wellness Coordinators; Palliative Care Coordinators; Parent Support Coordinators/Navigators <u>Speak Spanish</u>: social workers (27.8%), psychologists (9%), psychiatrists (6.7%), CLS (15%)

Systematic, universal psychosocial screening is seldom achieved in children's cancer programs

<u>Standard 1</u>	How is care provided (%)	When is care delivered (%)		
Youth with cancer and their family members should routinely receive systematic assessments of their psychosocial health care needs	Informal Discussion	mal Discussion 81.3 When a problem is identified		93.2
	Structured Interview	uctured Interview 66.1 Diagnosis		71.2
	Psychosocial Assessment Tool (PAT)		First week after diagnosis	62.7
	Distress Thermometer		First month after diagnosis	54.2
	Also mentioned were institution specific		Every inpatient admission	57.6
	tools used by social workers and standardized measures of child and	-	Every clinic visit	24.6
			End of treatment	42.4
	family functioning, not specific to cancer		Survivorship visits	54.2

PIPS-CSS Study

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 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.

2. Barriers and facilitators of screening: Examples

Barriers

- Comfort with using a screener and sharing results with families
- Finding a staff member to conduct the screening
- Language and cultural barriers
- Integrating PAT into workflow
- Addressing identified needs

Facilitators

- Facilitates communication with staff and families
- Provides comprehensive assessment of families
- Facilitates clinical care
- Standardizes how sensitive issues are raised
- Reduces health disparities

Implementation pilot

- Goal was to implement the PAT in Southeastern U.S.
- Conducted one day in person training [May 2017]
- Monthly group consultations calls [July Oct 2017]
- Pre and Post evaluations of implementation benefits and challenges
- 9 of 12 centers (75%) implemented successfully
- Most indicated that the PAT was very or extremely helpful in their clinical work (78%)
- Feedback was generally provided to families (67%) and usually within 24 hours (33%) or one week (50%)

Kazak, A., Christofferson, J., Richards, H., Rivero-Conil, S., & Sandler, E. (2019). Implementing screening with the Psychosocial Assessment Tool (PAT) in clinical oncology practice. *Clinical Practice in Pediatric Psychology, 7, 140-150*.



3. Implementation Strategies

- Methods or techniques to enhance the adoption, implementation, and sustainability of a clinical program or practice
- Strategies may be discrete or multifaceted
- There are many implementation strategies, linked to identified facilitators and barriers

iPAT Study Team

Anne Kazak, Ph.D., ABPP (Nemours) Lamia Barakat, Ph.D. (CHOP) *MPIs*

Michele Scialla, MSN (Nemours) Shannon Hammer, M.S. (CHOP) Nithya Ramaswamy, B.S. (CHOP) *Research Coordinators*

Eric Sandler, M.D. (Nemours) *Pediatric Oncologist*

Janet Deatrick, Ph.D., FAAN (PENN) Consultant









Implementing family psychosocial risk screening for pediatric health equity (RSG-19-122)

Kazak et al. Implementation Science (2020) 15:60 https://doi.org/10.1186/s13012-020-01023-w

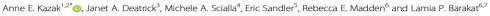
Implementation Science

Open Access

Check for updates

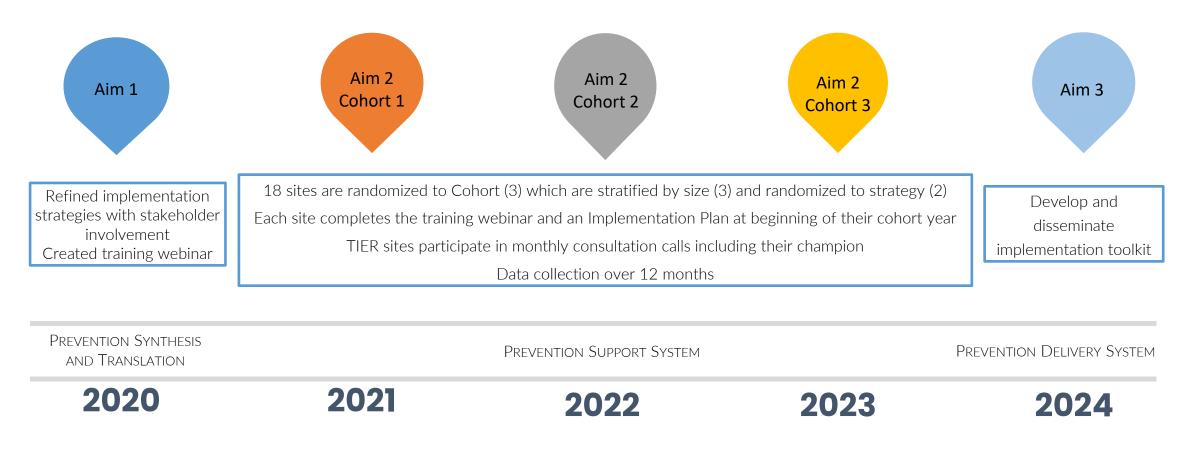
STUDY PROTOCO

Implementation of family psychosocial risk assessment in pediatric cancer with the Psychosocial Assessment Tool (PAT): study protocol for a cluster-randomized comparative effectiveness trial



- 1. Refine strategies for implementation of the PAT in English and Spanish using semi-structured interviews with stakeholders
- Conduct a cluster-randomized trial at 18 sites in the United States
 Strategy I Webinar training and completion of Implementation Plan
 Strategy II Training + Implementation Expanded Resources (TIER; peer consultation calls plus a champion)
- 3. Develop and disseminate a web-based PAT Implementation Toolkit

PAT Implementation Research Timeline



Implementation model: Wandersman, A., Duffy, J., Flaspohler, P., Noonan, R., Lubell, K., Stillman, L., et al. (2008). Bridging the gap between prevention research and practice: The interactive systems framework for dissemination and implementation. *American Journal of Community Psychology*, 41(3-4), 171-181.



Aim 1: Refine implementation strategies with input from diverse stakeholders

- Participants selected for interviews with purposive criterion-based sampling to represent different levels of the social ecology (n = 19)
 - Parent advocates
 - Multidisciplinary health care providers
 - Pediatric oncology organization leadership
 - Healthcare policy leaders
- Consolidated criteria for Reporting Qualitative Research Guidelines (COREQ) guided approach
- Asked to provide in-depth feedback on the two proposed implementation strategies:
 - How to tailor for programs with different types of resources
 - Resources needed to implement the PAT
 - How to increase family engagement
 - Barriers and facilitators

(2021) 2:62

Implementation Science Communications

RESEARCH



Open Access

Using qualitative and participatory methods to refine implementation strategies: universal family psychosocial screening in pediatric cancer

Janet A. Deatrick¹, Anne E. Kazak^{2,3*}, Rebecca E. Madden⁴, Glynnis A. McDonnell², Katherine Okonak², Michele A. Scialla², and Lamia P. Barakat^{4,5}

"That's always the key to the clinical team – is providing the highest quality care – especially if you can do it more efficiently and I just – I think that's gotta be part of the messaging to ensure uptake and sustainable uptake." - Clinician

- Major themes to improve the implementation strategies
 - <u>Theme 1</u>: Engage providers by framing psychosocial screening as an opportunity for more efficient and effective practice
 - <u>Theme 2</u>: Set clear expectations about the importance of screening 100% of children and their families to achieve the goal of achieving universal screening, equity of care, and reduction of disparities
 - <u>Theme 3</u>: Adapt successful strategies for systematic implementation of screening to ensure optimal engagement with children and their families throughout their care
- Strategies were refined for the webinar with emphasis on health equity

Secondary analysis to identify themes related to health equity

Directed content analysis was used to derive codes related to health equity and guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ)

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Advancing health equity in pediatric cancer through implementation of universal family psychosocial risk screening

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Janet A Deatrick <sup>1</sup>, Anne E Kazak <sup>2</sup> <sup>3</sup>, Michele A Scialla <sup>2</sup>, Rebecca E Madden <sup>4</sup>, Glynnis A McDonnell <sup>2</sup>, Katherine Okonak <sup>2</sup>, Lamia P Barakat <sup>4</sup> <sup>5</sup>
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"I think the commitment of a site to screen 100% of patients is key. I think if a site in the initial questions says that their goal is to screen 50%, you're likely to filter out the highest-risk patients inadvertently." - Clinician

- <u>Theme 1</u>: Personal (child, family) and systemic barriers to healthcare contribute to health disparities and can be identified by universal family psychosocial risk screening
- <u>Theme 2</u>: Universal family psychosocial risk screening creates the opportunity for health equity though personalized psychosocial care
- <u>Theme 3</u>: Recognition of health inequities and guidance from the Psychosocial Standards suggests that clinicians and healthcare systems are ethically obligated to screen, provide resources, and advocate for services to meet identified needs

Aim 2: Cluster randomized

implementation trial

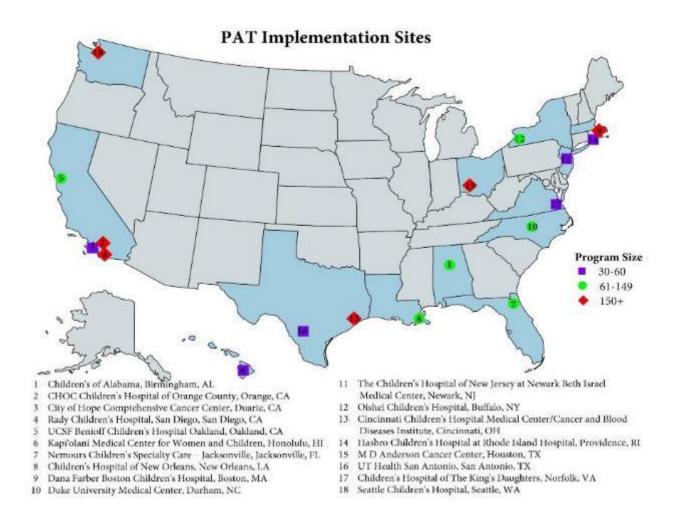


- Implementation strategies selected from Expert **Recommendations for Implementing Change** (ERIC) review¹
- Strategies refined by the stakeholder interviews in Aim 1
- Sites selected based on capacity (PIPS-CSS study), location, and population demographics
- 18 centers stratified by size (3) and year in the study/cohort (3) and condition (2)
- All sites participate in a professionally prepared training webinar
- All sites complete an implementation plan
- Strategy II sites identified a Champion and have monthly consultation calls

¹ Powell, B., Waltz, T., Chinman, M., Damschroder, L., Smith, J., Matthieu, M., Proctor, E. & Kirchner, J. (2015). A refined compilation of implementation strategies: Results from the Expert Recommendations for Implementing Change (ERIC) project. Implementation Science, 10:21. DOI 10.1186/s13012-015-0209-1.

Implementation Strategies and Outcomes We use multi-level approaches to implement PAT and measure outcomes

- Selected sites based on resource-level (readiness to implement) and those with larger Spanish speaking populations
- Address access to care and delivery of care in peer consultation calls and role of champions (Strategy II)
- Added exit interviews to expand upon key barriers and facilitators associated with universal screening
- Consider and document adaptations to protocol including implementation strategies and engage consultants in maintaining study integrity



All sites complete iPAT training

- Three-hour professionally prepared webinar
- Attendees: Site Principal Investigator, Screeners, Champion(s) (TIER)
- Webinar covers:
 - Background on screening and importance of universal screening
 - Overview of the iPAT study and Aim 2
 - Scientific evidence for the PAT
 - Review of the PAT and details for how to use the PAT
 - Review of the role champion and expectations related to consultation calls (TIER)
 - Completion of the PAT Implementation Plan
- The webinar includes video clips of parents, oncologists, psychologists, and social workers





All sites complete a PAT Implementation Plan

- The Implementation Plan serves as a "contract"
- It is the basis on which we will evaluate the success of screening implementation in meeting aims of universal screening that informs care
- Site team completes the Plan together as the last part of the iPAT training
- Major sections of the PAT Implementation Plan:
 - Who screens?
 - Who will be screened?
 - How will PAT scores be used in clinical care?
 - Institutional considerations
 - Responsibilities of the champion (TIER)
 - Data collection procedures



What is a Champion? (TIER only)

- Advocates for the implementation of universal screening with the PAT for newly diagnosed families with cancer
 - Motivates screeners to conduct universal psychosocial risk screening
 - Discusses study with clinicians outside the screeners and hospital leadership
 - Facilitates communication with families about screening
 - Facilitates communication between screener and other clinicians
 - Educates team on best practices for implementation
 - Helps screeners troubleshoot implementation barriers
 - Documents problems and successful solutions to screening
 - Promotes psychosocial care matched to need to support health equity
- Passionate about the importance of psychosocial risk screening for health equity and enthusiastic about the activities related to this role
- Champions have included oncologists, psychologists, and nurse managers



Monthly Consultation Calls (TIER only)

- Monthly video group calls for the three sites randomized to TIER in each cohort
- The site PI, screeners, and the champion attend
- Provides an opportunity to obtain ongoing consultation on implementation of the PAT
- Creates a learning collaborative environment







Aim 3: Develop and disseminate a web-based PAT implementation toolkit to facilitate implementation of systematic, universal, psychosocial screening

- We have begun the process of designing the implementation toolkit website by integrating existing project data:
 - Review of methods for toolkit design
 - Mixed methods analysis of data from consultation calls and exit interviews
 - Analysis of quantitative survey data on barriers and facilitators of implementation
- We will conduct cognitive interviews with diverse stakeholders in iterative approach presenting storyboards and initial website versions to revise and finalize the toolkit
- We plan dissemination through multidisciplinary networks and organizations

Summary: Screening all families is a strategy to promote health equity and the goal of our research

- Psychosocial care in pediatric cancer is an important component of comprehensive care but it is not generally delivered in an equitable manner, assuring that *all* children and families have access to early assessment and intervention
- The PAT is an evidence-based screener of family psychosocial risks and resources with its results guiding clinical care that contribute to outcomes in the delivery of care more generally
- Although systematic, universal psychosocial screening is a standard of care, implementation is limited due to work force, work flow, and systemic barriers
- Results of the PAT implementation RCT are forthcoming in 2024--we will apply the results of what we have learned to launch a widely disseminated web-based PAT Implementation Toolkit

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We look forward to partnerships to assure broad dissemination of the PAT Implementation Toolkit and opportunities to further promote the implementation of family risk screening Thank you! Questions?