

Program Evaluation for the Alongside Network Wellbeing Groups

Capstone Paper

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The Hubert H. Humphrey School of Public Affairs

The University of Minnesota

Hannah Dalsheim

Aimee Gillespie

Dr. Jamie Lohr

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In collaboration with:

Associate Professor Maria Hanratty, Capstone Instructor

Jen Aspengren, Client, Alongside Network, Founder & Chief Executive Officer

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Executive Summary

The Alongside Network is a national start-up based in Minneapolis, MN. The Alongside Network “works to shift the system of care for families who have a child with a life-threatening illness or injury” by offering mental health support to caregivers, and working with hospital systems to integrate mental health best practices into the hospital and recovery experience, using a Whole Child, Whole Family framework. In particular, the Alongside Network offers Wellbeing Groups, which are mental health support groups specifically for caregivers of children affected with severe illness or injury. The Wellbeing Groups use cognitive behavior therapy concepts and are co-facilitated by a licensed mental health counselor, as well as a “lived experience” facilitator who has been a caregiver to a child with illness or injury and completed the Wellbeing Group curriculum.

For this program evaluation, we aimed to assess the effectiveness of the Wellbeing Groups, as well as investigate further opportunities for The Alongside Network to collaborate with healthcare systems. We had three research questions to guide our inquiry:

- What is the impact of the Alongside Well Being Groups on caregivers, and families?
- What else could Alongside Network do to address the short and long-term mental health and community needs of families with PMTS?
- What are the key leverage points within the medical care system to shift the culture of care for children and families to reduce PTMS?

To answer these questions, we interviewed participants and facilitators of the Wellbeing Groups, as well as local healthcare providers. From these interviews, we synthesized a number of key themes, including:

- The Alongside Wellbeing Groups’ greatest strength is how it fosters a shared sense of community.
- Most Wellbeing Group participants found a way to implement mindfulness strategies into their daily lives, despite initial skepticism.
- In addition to mental health support, most families needed additional resources, including guidance on navigating their child’s school system after hospitalization.
- Families and children of color, especially non-English speakers, face many barriers to accessing quality healthcare for their child, including mental health resources following hospitalization.
- Education in PMTS is limited and trauma reduction techniques and treatments of traumatic stress are not uniformly incorporated into acute care settings.

Based on the above findings, as well as the ones later in this report, we recommend that The Alongside Network explore alternative formats of support in addition to Wellbeing Groups to reach families who are not able to commit to a weeks-long support group. We also recommend improving connections with impacted families with marginalized identities by reaching out to trusted community organizations, and creating culturally relevant and accessible outreach materials. Finally, we recommend that The Alongside Network partner with healthcare organizations to provide training and resources to patient-facing staff.

Table of Contents

Abbreviations and Definitions	5
Introduction	6
About the Alongside Network	6
Background on Pediatric Traumatic Medical Stress	7
Goal of Capstone Project	10
Methodology	11
Data Analysis	14
Results	15
Recommendations	24
Conclusion	27
References.....	29

Abbreviations and Definitions

- AN – Alongside Network
- AWBG – Alongside Wellbeing Groups
- Caregiver – parent or guardian of a newborn, child or adolescent who has experienced acute or life threatening illness or injury requiring hospitalization in a Pediatric ICU or Neonatal ICU
- Child Life - clinical support provided by dedicated providers trained in child development and intervention in the acute care setting
- NICU- Neonatal Intensive Care Unit
- PICU – Pediatric Intensive Care Unit
- PMTS - Pediatric Medical Traumatic Stress
- Provider - Master’s or Doctorate level trained healthcare professional with interest and expertise in pediatric traumatic medical stress
- PTSS - Pediatric traumatic stress symptoms

Introduction

This capstone group designed and carried out a program evaluation for the Alongside Network. The specific work agreed upon was 1) a program evaluation of the Alongside Network's Wellbeing Groups (AWBG); and 2) informational interviews with healthcare providers with interest and expertise in traumatic medical stress to identify areas in which Alongside Network could support systematic efforts to reduce traumatic stress for patients and families. Alongside Network's Wellbeing Groups are facilitated virtual meetings designed to provide validation, networking and mental health support to family members and caregivers of children who have been hospitalized due to severe illness or injury. Alongside Network will use this information to help support program growth, access and collaboration with partners to support children and families who have experienced traumatic medical events.

About on the Alongside Network

The Alongside Network (AN) is a national non-profit start-up based in Minneapolis, MN. The need for family support after a child's illness and hospitalization became clear to AN founder Jen Aspengren years ago when one of her children required hospitalization and surgery for a life-threatening illness. Her goal for the AN is to provide validation, networking and support to families of children who have been hospitalized due to severe illness or injury, while at the same time working to systematically improve incorporation of mental health care for children and families into medical care during and after hospitalization.

The vision for Alongside Network became a reality in 2021. In April of 2022, the AN began Alongside Wellbeing Groups (AWBG). These groups are open to parents and caregivers and provide seven weeks of virtual meetings facilitated by a trained behavioral counselor and a lived experience facilitator. Participants have been recruited by word of mouth and internet presence. The AWBGs connect parents, validate their experiences and give community, along with providing focused methods to address the stressors of post-hospitalization care. AN has currently completed a series of three Wellbeing groups and both participants and facilitators will be recruited to participate in our program evaluation.

The AN staff and Advisory Board currently include Jen Aspengren, MPP, Founder and Chief Executive Officer; Jessica Torres, Communications Specialist; Amber Ross, LCSW, Community Group Lead Facilitator and Founding Advisory Group Member; and Amanda Kalstabakken, Ph.D, LP, Program Development and Evaluation Lead, Founding Advisory Group Member.

In addition to the AWBG, the AN is currently working with clinical partners and families to facilitate integration of mental health support for both patients and their families throughout hospitalization and recovery, for as long as that may take. They intend to help implement research based interventions to improve family-centered care in pediatric and neonatal critical care settings. Their vision is that this care will be equitable, reach all patients and families, and normalize mental health care as an integral part of optimizing outcomes for patients and families.

Background on Pediatric Traumatic Medical Stress

Over four million children ages 0-18 are hospitalized each year for a major acute or chronic illness, injury, or disability (National Child Traumatic Stress Network, 2018). Meanwhile, up to 80% of ill or injured children and their families experience some traumatic stress reactions following a life-threatening illness, injury, or painful medical procedure. Up to 30% of parents and 25% of children and siblings experience persistent reactions that impair daily functioning and affect treatment adherence and recovery (National Child Traumatic Stress Network, 2018). One in five parents whose child is diagnosed with a life-threatening condition experiences enduring and debilitating distress that adversely affects daily functioning and the wellbeing of family members (Peterson, 2018). Despite the impact of medical stress on patients and families, pediatric healthcare systems currently have significant gaps in how they address this issue.

As noted above, children and families experience significant stress during interactions with the pediatric healthcare system. Pediatric Medical Traumatic Stress (PMTS) was defined in 2003 by the National Child Traumatic Stress Network as “a set of psychological and physiologic responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences” (Kazak, 2006). PMTS can lead to poor medical and psychological outcomes in not only pediatric patients, but also in their parents and siblings (Oral, 2015; Shonkoff, 2012). Medical stressors in the Pediatric Intensive Care Unit (PICU) include treatment related to acute illness or injury and life-threatening chronic illnesses, such as cancer, congenital heart disease and diabetes. In the Neonatal Intensive Care Unit (NICU), hospitalization may be related to expected or unexpected prematurity, perinatal injury or congenital defects in newborns.

PMTS can manifest in patients and parents as anxiety, depression and dissociation (Kahana, 2006). Both patients and parents can experience hyperarousal, avoidance and flashbacks in subsequent medical settings. The severity of PMTS is unique to the family, and can be impacted by prior adverse experiences as well as exposure to health care disparities, which often impact patients who are rural or have a low socioeconomic status, are non-English speaking, are disabled, or belong to racial and ethnic groups that are poorly served in the healthcare system. In the NICU, PMTS can impact parental mental health, postpartum bonding and infant development (Knafl, 2021).

The cumulative burden of adverse experiences causes negative effects on psychological, cognitive, behavioral and physiologic functions in patients and their families (Oral, 2015). Physiological effects of severe stress can include changes in brain development and neuronal architecture, alterations in the levels of stress hormones, and stimulation of inflammatory pathways. Changes in the brain can manifest as anxiety, fear, difficulty with memory and learning, and increased risk for long term mental health concerns (Oral, 2015). Physiologic

impacts can include decreased immune system function and activation of inflammatory pathways that can impact wound healing and resistance to infection but also increase risk for long term health effects including an increased risk of cardiovascular disease (Shonkoff JP, 2012).

In 2006, Kazak et al, proposed a family-centered model for PMTS based on recognition that PMTS does not impact a child in isolation, but in the context of a family; and that the stress related symptoms associated with PMTS were a continuum and did not have to meet stringent diagnostic criteria for post-traumatic stress disorder (PTSD) or acute stress disorder (ASD) to impact the mental and physical health of the patient and family members. This model describes three stages of traumatic stress as shown in Figure 1 (from Kazak, 2006). *Phase I*, or peri-trauma, is impacted by the preexisting experiences and relationships of the patient and family and the subjective experience of the trauma in the family context. Interventions at this time are aimed at changing the subjective experience of potentially traumatic events. *Phase II* is the early, ongoing and evolving phase. In this phase, there are ongoing challenges related to the medical event and follow-up. Reactions to stress may impact medical care and long-term well-being. There are opportunities for intervention and adjustment in this phase, along with barriers to identifying patients and families in need (Kazak, 2006). In *Phase III*, long term stress reactions may impact both patient and family members. Interventions are aimed at long term coping and adaptation of patient and family members.

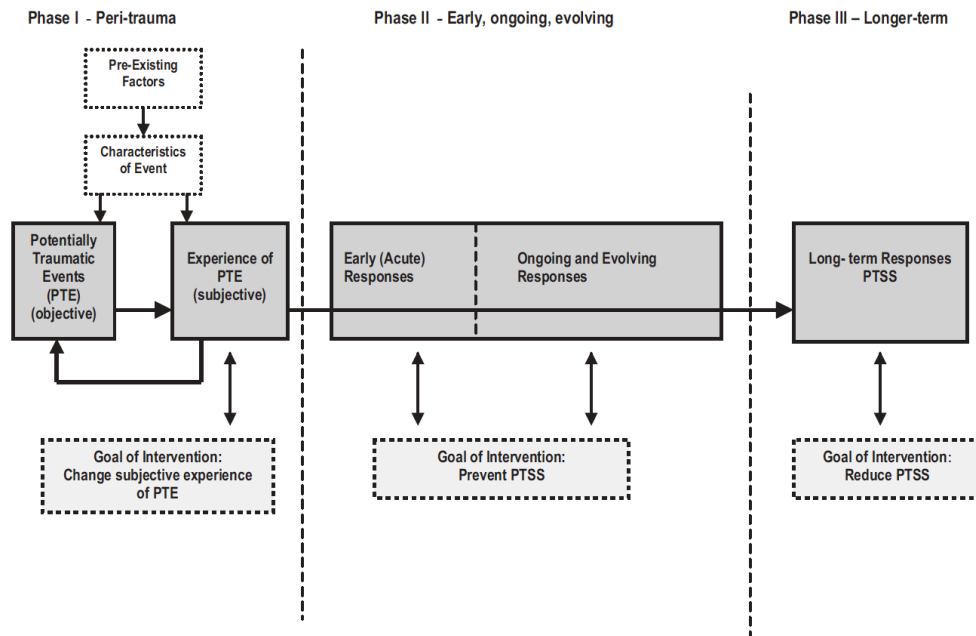


Figure 1: A model of PMTS for patients and their families from Kazak AE, Kassam-Adams N, Schneider S, et al. 2006. An integrative model of pediatric medical traumatic stress, *Journal of Pediatric Psychology*,31(4): 343-355.

Treatment of PMTS includes recognition of stress and reduction of stressors, within the context of the family's needs and experiences. In *Phase I*, modifying the subjective experience of traumatic stress (sometimes called trauma-informed care) includes educating healthcare providers to recognize or screen patients and families for pediatric traumatic stress related symptoms and training health care providers at all levels of patient facing care (including phlebotomists, radiology technicians, food service and janitorial staff, as well as nurses, physicians and trainees) in trauma informed care principles. These principles include providing anticipatory guidance about stress reactions; use of pharmacologic treatment of pain and anxiety; and including parents in care decisions, with special attention to families who may be marginalized or discriminated against in health care settings. (Kazak, 2006; Marsec, 2016). Other interventions include an increased presence of Child Life Specialists and/or Pediatric Psychologists trained in PMTS in the inpatient healthcare setting. Increasing support for health care workers to reduce their own stress and time limitations, as well as addressing the impact of traumatic medical events on staff, may also improve stress on families in the medical setting (Kazak, 2006).

Interventions in *Phase II*, or early, evolving and late PTSS, include screening for PMTS related symptoms or other psychosocial concerns in families. Resources include validated screening tools available for PICU and perinatal/NICU care. Screening tools are available for symptoms related to acute injuries, psychosocial wellbeing in chronic illness, and family beliefs regarding illness and perceived illness severity (Kazak, 2006). Intervention for families at this stage can be limited to primary care follow-up with later referral for services if stress related symptoms are persistent, or can include social support and cognitive or family therapies (Kazak, 2006). Interventions for evolving and late PTSS (Phase III) include cognitive and behavioral therapies (Kazak, 2006), pharmacologic therapies (Stuber, 2006) and programs like the "Take a Breath" Program which uses a therapeutic approach based on Acceptance and Commitment Therapy to provide professional and peer support, mindfulness training, values clarification and goal setting to caregivers in an accessible online format that allows remote attendance and attendance of both caregivers and partners (Raynor, 2016).

The Alongside Network Wellbeing Groups (AWBG) provide intervention during late Phase II and Phase III PTSS that is similar to that used in the Take a Breath Program (Figure 2). The AWBG curriculum includes support and networking with other caregivers in an online format to improve accessibility. Clinical facilitators teach acceptance and mindfulness techniques. Participants are self-referred, primarily through online contact. In addition to these offerings, The AN strives to help shift the culture in pediatric healthcare to alter the experience of trauma in the healthcare system through increased education of providers and increased recognition of PTSS in patients and families, with referral to accessible mental health services when needed.

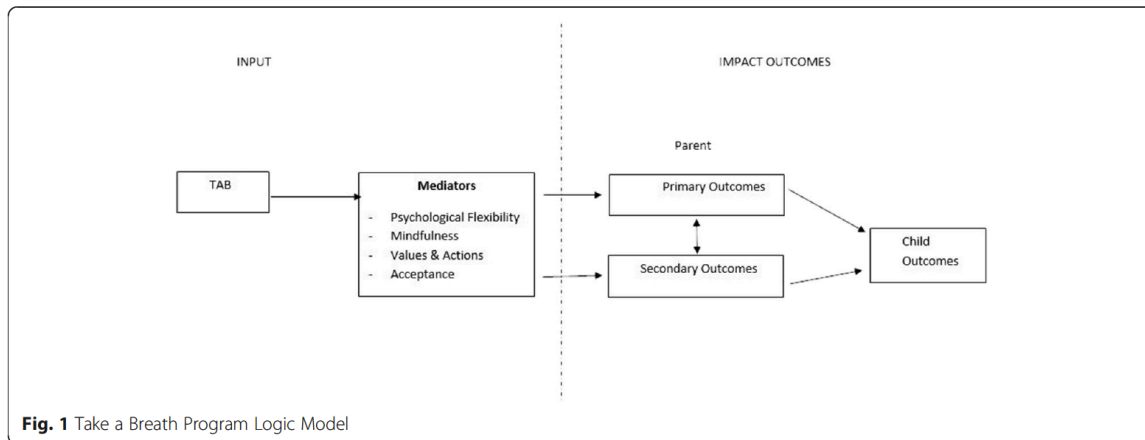


Figure 2. Logic model for online “Take a Breath” Program as intervention for mid to late symptoms of PMTS. From Rayner M, Muscara F, Dimovski A. et al. 2016. Take a Breath: study protocol for a randomized control trial of an online group intervention to reduce traumatic stress in parents of children with a life threatening illness or injury. *BMC Psychiatry*16:169

Goal of Capstone Project

Problem/Opportunity Statement Driving this Study:

Families who have children with life threatening illness or injury often do not have adequate resources to deal with the traumatic stress associated with this experience. Current hospital care often exacerbates this stress. Acute and chronic major medical events in infants and children can result in pediatric medical traumatic stress (PMTS) in patients and families. Hospital and post hospital care providers often fail to recognize and address these issues for families. The Alongside Network provides the Alongside Well Being Groups which include facilitated weekly meetings that provide validation, connection and coping skills for parents/caregivers with children who have had a major medical event. The Alongside Network is looking for feedback from caregivers and facilitators in the program, as well as insight on how to limit PMTS and provide mental health support for patients and families experiencing PMTS in the medical setting .

Questions Pursued in this Evaluation:

1. What is the impact of the Alongside Well Being Groups on caregivers, and families?
2. What else could Alongside Network do to address the short and long-term mental health and community needs of families with PMTS who have participated in the Alongside Well Being Groups?

3. What are the key leverage points within the medical care system that can be addressed to shift the culture of care for newborns and children to reduce PTMS and prioritize both mental and physical health during and after hospitalization?

Methodology

Overview of evaluation design:

Literature review and summary: Independent literature review of topic using PubMed, Google Scholar and literature provided by the client and by interviews, both professional and AWBG participants and facilitators. Summary will include the recognition and impact of PMTS, interventions to reduce or mitigate PMTS that have been studied, the obstacles to implementation and a review of published recommendations for implementation and growth of programs similar to the Alongside Wellbeing Groups (ie. the “Take a Breath” Program).

Program Impact and Administration: This analysis included qualitative interviews with program participants and facilitators to describe the impact of the Alongside Wellbeing Groups on program participants; to assess the strengths and weaknesses of the program and to identify additional mental health and community support needs of program participants. This information was obtained through semi-structured focused interviews with volunteer participants who have completed the AWBG program and volunteer facilitators who have led at least one group as a clinical or lived experience facilitator.

Potential participants were identified by the AN and contacted via email. Interested program participants and program facilitators responded directly to the Capstone team for interview scheduling. Alongside Network was not aware of the identities of scheduled or interviewed project participants. A total of two program participants were interviewed. One of these program participants has also served as lived experience facilitator. Interviews were conducted with two clinical facilitators.

All participant and facilitator interviews were conducted via zoom and led by one capstone team member with the others recording notes and contributing follow up questions. Interviews lasted no more than one hour. Interview participants received a gift card for \$20 as a thank you for their participation. Interviews were not recorded. Notes were transcribed and de-identified immediately after interviews. Interview notes were reviewed and analyzed using standard methods of thematic qualitative data analysis . Care was taken to be sure that all data shared with the client is composite and/or de-identified to maintain confidentiality.

Alongside Network: Program Evaluation 2023

Logic Model

Inputs	Activities	Outputs	Short-Term Outcomes	Impact
Human-centered approach (theory)	Mental health Alongside Wellbeing Group facilitators recruited	Several Alongside Wellbeing Groups facilitated annually	Caregivers learn mindfulness practices for processing trauma	Engage impacted families with the pediatric healthcare system
Take a Breath program	Outreach to families impacted by pediatric medical trauma	Partnership built with Community Organizations	Caregivers develop sense of community and shared experience	Embed mental health care best practices into pediatric healthcare system
Grant funding	Client intake and coordination of Alongside Wellbeing Groups	Provide continuing education to healthcare providers	Caregivers gain skills to advocate for themselves and their families	Decrease stigma around mental illness/health
Insurance reimbursement	Facilitation of Alongside Wellbeing Groups	Increase methods of outreach	Increased training of medical providers to prevent trauma	Increase equity in health care
Executive & board leadership	Evaluation of Alongside Wellbeing Groups	Develop relationship with pediatric care systems	Improved relationship with medical providers	Increase community involvement in health care and family support
Mental health practitioners	Continuing education for pediatric medical providers		Decreased medical provider burnout	
Partnerships with pediatric medical providers	Mental health advocacy incorporated in medical care			
Partnerships with insurance payers				
Partnerships with medical education institutions				
Partnerships with community organizations				

Assumptions: Families experience trauma during and after their child's hospitalization · Families desire more mental health resources · Scientific validity of Take a Breath program

External factors: Systemic lack of access to mental health care · Racially marginalized families and families experiencing poverty face larger

barriers to accessing care · Social stigma of mental illness · Trauma-informed care not widely integrated in healthcare settings.

Sample Interview Questions - AWBG Participants and Facilitators

- What is the greatest impact of the Alongside Wellbeing Groups?
- What was the interval between when you first learned about Alongside, how long before you became involved?
- What was it like to meet other caregivers/families who had gone through medical trauma?
- How did participating in the Alongside Network Wellbeing programs impact you while you were participating?
- Would you recommend the Alongside Wellbeing Groups program to other families?
- How could the program have helped you more?
- What's the best way for the Alongside Network to reach out to families?
- What other help did you need during and after? When did your family most need this support?
- After the program ended, did you enroll in anything else/seek other resources? What other resources did you try? Were they helpful?
- What would have been helpful while you were in the hospital?

Opportunities for culture shift and systematic change:

In order to better understand the current practices to address PMTS and mental health care in the PICU and NICU, informational interviews were conducted with health care providers with varied levels of interest and expertise in this topic. A total of seven interviews were conducted. Health care providers interviewed included Master's level clinically trained Child Life providers and pediatric social workers, pediatric psychologists, and pediatric critical care physicians (PICU and NICU). Providers were selected for interviews based on training and expertise; referral from other experts; and availability to participate in a virtual interview with the Capstone Team.

Interviews were semi-structured and lasted no more than one hour. Notes were de-identified and reviewed for clarity upon completion of the interviews. Standard methods of thematic quantitative analysis were used to identify themes related to the subject

matter. These included but were not limited to minimizing traumatic stress for both patients and parents/families in the ICU setting; obstacles to minimizing stress; availability and use of mental health or child life specialists; resources for follow up care for mental health; opportunities for improvement and opportunities to partner with AN to improve mental health care and family support.

Sample Questions for Health Care Providers

Questions:

- Can you tell us about your role in the care of PICU and/or NICU patients?
- What is your background and training in supporting patients and families through acute life-threatening illnesses/medical stress?
- What are some of the interventions in current use to mitigate trauma for your young patients and their families?
- How successful are current programs in addressing traumatic medical stress during and after hospitalization?
- Thinking of all the ways trauma can be prevented/mitigated while a child is in the hospital... What else do you wish could be done?
- How can a family centered organization like the Alongside Network best work with the healthcare system to address medical stress and mental health care during hospitalization? After Hospitalization?
- How and when do you think it is most helpful for groups like the Alongside Network to reach out to families?
- Is there any other information that you think is important for the Alongside Network to know to improve their support of mental health care for families who have experienced PMTS

Data Analysis

The data was analyzed using principles of qualitative thematic analysis, discerned themes using a combination of inductive and deductive reasoning. In particular, we looked for themes in the interviews relating to AWBG impact, caregiver and family support needed, barriers to access, racial equity, and levers for policy change in healthcare.

Results

Program Participants: We spoke with two program participants. Program participants expressed enthusiasm and appreciation for the Alongside Wellbeing Groups. Overall, the participants said the greatest value they gained from participating in the groups was a feeling of camaraderie with other caregivers. While the AWBG did not focus on processing each individual's experience with medical trauma, the participants reported that it was helpful to gain skills in mindfulness from the facilitators and other participants. Caregivers said it was very meaningful to be asked specifically about their wellbeing.

One participant reported that they participated in the AWBG two years after the traumatic event occurred with her child. She said that a time period of a few months to a few years felt appropriate to her, as it would have been very challenging to make time or have the mental capacity to participate in a support group like this one.

Program Facilitator: We talked to four interviewees that had served as either clinical or lived experience facilitators. In each AWBG cohort, there is always one clinically trained facilitator and one lived experience facilitator in each AWBG group. Facilitators help teach mindfulness techniques to help participants learn why it is important to take time to take care of your mental wellbeing. Each session builds on the last, with each lesson overlapping on top of each other to cement the ideas they have learned to be able to remember and take it with them at the end of the seven weeks. Interviewees shared that it is important for facilitators to set the tone and create a safe, cohesive and validating environment for all participants. It is important to have a space that is outside of the hospital, but still can give some guidance on how to not only help with mindfulness for each participant, but create a space that each participant feels seen and listened to too. In one group, facilitators found that 75% of participants came in with some sort of skepticism in how effective the wellbeing groups would work.

THEMES IDENTIFIED

Sense of Community

“No one had asked me before how I was doing”

“It feels like a big warm hug”

Whether it was the participants first group experience or their fifth, the Alongside Network Wellbeing groups provided a sense of community for every person we spoke to. The Wellbeing Groups provided a safe space for caregivers to openly discuss and process their experience. Because hospital stays can be traumatic for the entire family, when talking in a more public setting many caregivers believe they need to edit their story when telling it to others, leaving out the more “gruesome” or graphic details of their hospital experience in order to protect the person they are speaking to. In these groups, participants finally felt that they didn't need to filter themselves, they could just speak freely. The Wellbeing Groups also provided a space that wasn't condition specific, not excluding anyone based on what kind of diagnosis their child got. This allowed for different perspectives on what each person's hospital stay looked like and

provided a space for caregivers who couldn't find a space to discuss their specific experience and helped normalize this kind of open discussion.

Embrace Mindfulness

Many participants felt skeptical about the Alongside Wellbeing Groups, and unsure of what they could gain from mindfulness practices. One participant pointed out that “mindfulness” is used in so many different contexts, especially online, that the term is practically meaningless. However, many participants finished the program with an understanding that mindfulness and other psychoeducation concepts could not only be beneficial to their lives, but easily implemented as well. One facilitator mentioned “red light” mindfulness activities that were quick and simple enough for a participant to use in an anxious moment at a stoplight, for example. Participants also learned an array of sensory and grounding exercises that allowed them to slow down, process their feelings of anxiety, and eventually move on from them in the moment. Using these tools to harness anxiety helped participants also helped feel empowered and more in control of their mental health.

Time Commitment

During the interviews with participants, we asked each person how they felt about the time commitment required to participate in the Wellbeing Groups. We also asked when the best time would have been for a group like The Alongside Network to reach out to them. Most participants said that it would have been useful to receive information about The Alongside Network's Wellbeing Groups while in the hospital, but that they likely would not have had time to attend until a few months to a few years after their child's hospitalization. Most participants said that the seven-week length of the groups was a good length of time, and facilitators reported that it would be difficult to condense all of the material into fewer sessions, as skills learned in each session build off of the prior week. However, facilitators and participants both noted that the time commitment could be cumbersome, and create barriers for caregivers who cannot commit to the full 7 weeks, and that shorter time commitments or one-off events may be effective in reaching larger numbers of caregivers.

Mothers as Caregivers

“It's always moms at the bedside.”

It is widely documented that women are more likely to act as caregivers for sick family members, oftentimes putting their careers on hold to do so. We recognized this gender disparity in our program evaluation as well. Nearly all participants of the Alongside Wellbeing Groups were women, and every caregiver and lived-experience facilitator we interviewed is a mother. During our conversations, we learned that about half of the mothers worked outside of the home, while others worked inside the home as stay-at-home mothers. Each participant we spoke to acted as the primary, day-to-day caregiver to their child during and after the hospitalization, and each one described a sense of overwhelm during this period that they were unable to address, or

even recognize, their own struggles as a result of their child's hospitalization. Participants mentioned pushing their feelings and struggles to the side so they could "be strong for their child."

During our interviews with medical providers, many providers referenced mothers as the main point of contact for healthcare providers as well. As one physician aptly described, regarding parent figures present at the hospital, "it's always moms at the bedside."

Desire for Sibling Support

When asked what else The Alongside Network could do to help families navigate their child's hospitalization and resulting trauma, many families said that it would be helpful to have a support group, similar to the Wellbeing Groups, available for siblings of children who have been hospitalized. When a child experiences a life-threatening illness or injury, it changes their entire family's routine and dynamic, and many siblings struggle to navigate this change. Participants mentioned that siblings may feel jealous or resentful towards their hospitalized sibling, but then guilty for feeling this way. Participants said it would be helpful to have a sibling support group where children would have a judgment-free environment to share complex emotions that they may not be able to articulate to their parents.

Self Advocacy Education

In addition to the physical changes or limitations that children and families may experience due to severe illness or injury, all AWBG participants reported challenges transitioning back to "regular life" following hospitalization. One issue caregivers mentioned was how their child struggled to find social connection with their peers following hospitalization. Children facing life-threatening illness or injuries often miss weeks, months, or years of in-person schooling, and find it difficult to connect with peers after a prolonged absence. Additionally, several caregivers we spoke to mentioned difficulties they had with their children's schools. According to one particular parent, all children in public schools are entitled to IEPs, or individualized education plans, but it can be very difficult to obtain one. One participant in particular said that schools seldomly offer extra services upfront, but rather, parents must advocate heavily for their child upon reentry to the school system. Many participants said that in addition to mental health support, they would have benefitted from self-advocacy education, with a special focus on advocating for their child in various life settings following hospitalization.

Interviews with Healthcare Providers

We interviewed seven healthcare providers with varied roles and education. All had significant knowledge and experience with PMTS. Providers interviewed included:

Child Life Specialist/Manager
Pediatric Clinical Social Worker
Pediatric Psychologist

Neonatology Fellow
Attending Neonatologist
Attending Pediatric Critical Care Physician (2)

General Findings

All of the providers were aware and informed about the impact of PMTS on patients, families and providers. All of the providers had a clinical or research interest in PMTS, trauma informed care, family centered health care, mental health care or health equity and ethics. When asked to rate the quality of care given relative to minimizing medical trauma, providing patient and family support and addressing psychosocial needs and mental health care all of the providers gave their individual institution rankings from 0.5-4 on a scale of 1-10, and systemwide health care in the US a 0-3 ranking on a scale of 1-10, with 10 being the highest performing system.

THEMES IDENTIFIED

Systemic Barriers to Care

“The system sees reducing trauma as tasks, not an integral part of care”

Providers noted that there are many systemic barriers to providing optimal care to identify, reduce and treat medical stress for patients and families. Systemic barriers include lack of adequate staffing, lack of adequate training for existing staff, lack of reimbursement for support services (child life and social work), lack of adequate time due to patient loads and documentation, and provider traumatic stress due to exposure to illness, trauma, personal life and pandemic related changes in medical practice.

Inadequate staffing is the result of loss of workforce in healthcare. This was exacerbated by the recent worldwide pandemic. There is increased turnover at all levels of healthcare staffing, with one of the most limited areas in nursing. There has been a loss of experienced nurses in all areas, and there is a less experienced critical care workforce. Several providers noted that a critical care nurse is now often considered senior with one year of nursing experience. This impacts care as nurses often spend the most time with patients and families.

Nurses and physicians are often tasked with caring for more patients with fewer resources and more documentation. This leads to time constraints and less communication with patients and families. Some providers noted that there was not adequate time to address families' needs, while others felt that with training on how to ask the right questions, addressing families' needs was actually a time saver. One provider noted that it *“often gets so busy that it is easy to depersonalize patients”*.

In addition to fewer nurses, there is limited access to trained professionals with mental health or psychosocial support expertise. There is significant understaffing of social work and child life

positions. Availability can be limited, especially after hours or on weekends. One contributing factor, according to our interviewees, is that these positions are funded by the hospitals, without the ability to bill for reimbursement from health insurance. This limits hiring and availability. In both child life and social work, grant funding and philanthropic funding are used to fill needed positions, which makes them vulnerable to loss of funding. There is a lack of trained mental health professionals nationwide. There is a crisis in child and adolescent mental health, without adequate resources for care, both in the hospital setting and in outpatient and community settings. Ideally each unit would have a dedicated mental health professional. At the time of this report our interviewees are only aware of one unit in the metro area that has a dedicated pediatric psychologist.

Lastly, healthcare providers suffer from fatigue, traumatic stress, and frustration with working conditions and limited resources for patient care, especially during and after the COVID19 pandemic. There are very few resources for peer trauma counseling or mental health care. Stressed providers are less able to meet the needs of patients and families.

Provider Education

“The way to change providers is to change residents and trainees”

A very small proportion of physicians receive training in reducing traumatic experiences in the healthcare setting. They rely on other trained providers, generally Child Life Specialists, Social Workers, or Psychologists to intervene to minimize trauma or address symptoms of medical traumatic stress. In general, current medical students and resident physicians receive a few hours of training on the effects of medical stress on patients and families. Nursing students receive even fewer, and ancillary service providers may receive little to none. Older physicians likely had no training at all. Most ongoing educational experiences related to traumatic stress are voluntary and attended by those with interest in the topic. Interventions to better and more broadly educate health care providers need to be directed at all patient facing providers and technicians, including but not limited to physicians, nurses, advanced practice providers, lab and radiology technicians, phlebotomists, EMT’s, and food service and custodial workers.

Barriers to training include lack of mandatory classes for providers, lack of paid time for attendance at classes, and lack of understanding of the importance of the topic. As noted by one physician provider, *“Providers set the tone and culture for the work that we do”*. If providers have inadequate training in the recognition of PMTS, its long term consequences and interventions to reduce subjective stress and address PTSS in patients and families, then the mitigation of traumatic stress becomes “a task” and not an integral part of healthcare.

Educating families about PMTS engages the family as a partner in reducing trauma and recognizing signs of PTSS. Families who are aware of medical traumatic stress and involved in the care team, through rounds or other regular interaction, can develop agency and educate providers and other staff about how best to meet their needs. . Barriers to family involvement on the care team include lack of family availability at bedside due to other work or family needs, cultural differences in expectations and communication, and lack of availability of effective

interpreters. Families who are not able to be at bedside for provider interaction on a daily basis should ask for and expect regular communication with primary providers via telephone, with appropriate interpreter services or other accommodations as needed. .

Increasing provider skill in reducing medical stress and recognizing and managing PTSS during and after hospitalization is integral to incorporating mental health care for patients and families into pediatric medical care. Recognition and treatment of PTSS in families includes provider modeling of trauma informed care, engaging experts (child life, social work and psychology), creating patient and family support networks and improving communication between families and providers. Effective mitigation of patient and family PMTS can improve short and long term patient outcomes. Improved communication and outcomes can also reduce traumatic stress in providers, which improves job satisfaction and may reduce provider burnout and staff turnover.

Defining Medical Trauma

“let the individual in front of you define their trauma”

Medical trauma is a subjective experience. It is experienced in the context of pre-existing family interactions, relationships, and culture, and is different for each individual and family. Some experiences are routinely traumatic (painful or invasive procedures) while others may impact patients and families differently based on their collective medical and non-medical experiences. An integral part of pediatric trauma informed care is recognizing that events that may be “routine” to providers may cause fear and anxiety in patients and families. The converse is also true, that a medical event that would be disturbing to the provider, may pale in comparison to the trauma from other lived experiences for the patient and family, or not be traumatic in the context of their prior experience and cultural beliefs. In general, providers need to “meet families where they are”, meaning that it is important to understand the impact of illness or injury in the context of the families’ life. This requires early and ongoing effective communication, including language and cultural interpreters. This often requires engaging trusted relatives, community members or primary health care providers in acute and long term care to facilitate communication. Early recognition of traumatic events and traumatic stress symptoms (anxiety, fear, withdrawal) can help direct interventions to improve communications or provide increased support for the patient and family.

Trauma Informed Care Benefits Patients and Providers

“[Patients] don’t need to be medicalized, they need to be humanized”

Early medical experiences can impact our lifelong interactions with the medical care system. One of our providers noted that in her experience, everyone remembers their first visit to the doctor- and the memory is either of the “poke” (generally an immunization) or of the reward they received after the visit. Every medical interaction compounds these experiences. Traumatic

medical experiences can lead to anxiety, depression and hesitancy to interact with the medical care system in both children and parents.

Several of our interviewees with expertise in NICU care noted that social and medical interactions in the NICU can have short and long term impact on maternal-infant bonding, infant pain response and infant development. In both the NICU and PICU, traumatic experiences can cause both acute stress responses and long term anxiety and depression in parents. Traumatic experiences in these acute care settings can impact communication with providers, causing further stress. This traumatic stress can increase anxiety and fear for children and parents in future medical interactions and impact willingness to engage in needed medical care in the future.

Interventions to reduce acute pediatric medical stress include improved communication techniques. These include asking about what is important to the patient and family, within both the context of medical care and their daily lives. Providing guidance and information in plain language can reduce fear and anxiety. Providers can improve communication by listening, validating and acknowledging patient and family concerns and addressing them in an appropriate developmental context. According to our interviewees, use of trained Child Life specialists to augment communication can improve patient and family experience and outcomes in acute care settings, although little data exists to validate the impact on long term outcomes.

Improved communication, use of psychosocial providers trained in patient and family communications, and improved training of providers in recognition of PTSS not only improves patient experiences and outcomes, but can improve provider efficiency, increase provider satisfaction, and reduce provider stress, limiting turnover and burnout. Using trauma-informed methods of care including adequate anticipatory guidance and preparation for interventions, adequate sedation and pain medication, and engaging support from trained Child Life professionals can also mitigate patient, family and provider stress. As one of our interviewees told us, “no one likes to hold down a screaming child”.

Racism and Discrimination

“It may take families a long time to recognize an experience as trauma. ...So many people live with continuous trauma that is just their life.”

“To recognize an experience as trauma is a very white, middle class perspective”

Racism and discrimination are widespread in healthcare. Our interviewees noted that the impact of discrimination was apparent in day to day care on pediatric acute care units. Several examples were given and included the process of assigning core or primary nurses to patients and families. Bedside nurses volunteer to be a “primary” or “core” nurse for a patient and family. These primary nurses are assigned to the patient whenever possible and share the journey with the patient and family, providing familiarity, comfort and support. Our providers noted that it is common for white, middle class families to have three or four primary nurses that provide their

child's care, while non-white or non-english speaking families often have no primary or core nurses assigned, meaning that they get significantly less consistent nursing care and do not have the opportunity to develop trust and supportive relationships.

Providers also noted that racism and discrimination impacted the way families were perceived in acute care units. Families who could not be at the bedside during the day or were non-english speaking were much less likely to participate in daily rounds with providers, got fewer updates at bedside or by telephone, and were less likely to participate in interventions to reduce parental stress or improve parent-child bonding (bedside ipads, recordings of parent's voices played for child, participation in hospital sponsored supportive events for patients or families). Black families were more often described as "aggressive", "unavailable" or "difficult" when distressed, rather than recognizing behavior as stress symptoms or describing them as "protective" "involved" or "concerned" as many white parents are described. Parents who are unable to be at the bedside during the day are unable to speak with primary providers, child life specialists, social workers or medical subspecialists, when in fact they may be the most in need of support due to external stressors including work, child care, transportation and finances.

One pervasive theme through our provider interviews was the poor quality of currently available interpreter services and how this impacts both quality of care and family and provider stress. Prior to the COVID19 pandemic, interpreters for common languages were often available in the hospital and met with families and providers at scheduled times on a daily basis. These in person interpreters established relationships with patients and providers that facilitated communication despite language and cultural barriers. With the onset of the pandemic, all interpreters became virtual and this persists in our current pediatric care model. Barriers to good communication with online interpreters include difficulty hearing, lack of incorporation of non-verbal communication into conversation, and variable interpreter skill and investment. Both parent and provider satisfaction with interpreter services has decreased, with all parties reporting incomplete and inaccurate interpretation. Poor communication increases the risk of unexplained progress or interventions. Poor communication also makes it difficult to understand what is important to patients and families and increases stress and frustration for patients, parents and providers.

Our interviewees all acknowledged the contribution of racism and discrimination to PMTS. Historic trauma and ongoing PMTS contributes to distrust of the healthcare system and can adversely impact both mental healthcare and physical healthcare in marginalized populations.

Reaching Families in Need

Provider recommendations for reaching families in need varied from methods to engage families in the acute care setting to reaching families with post hospitalization concerns or chronic illnesses in their communities.

All providers thought that engaging Child Life and social worker involvement with patients during hospitalization was important and should be utilized as available. All providers wished there were improved availability of both inpatient and outpatient pediatric psychology care for patients and parents with PTSS or PMTS. As noted previously, the providers interviewed knew of only one PICU in the metro area with a dedicated pediatric psychologist. All providers expressed the desire for a dedicated psychologist available on acute care units and increased availability of providers equipped to deal with PTSS and PMTS in the outpatient setting.

Ideas for reaching families in the acute hospital setting included brochures available in the hospital, posters with QR codes and links to support groups on units, invitations to support group or networking meetings during or after hospitalization and written information and links for support groups and mental health services in discharge paperwork. There was no agreement on the overall utility of each of these methods.

Providers did agree that it was critical that outreach to families continued in the outpatient setting. Opportunities for outreach include information available through primary care providers (Pediatricians or Family Physicians), in subspecialty medical offices, and through home nursing care providers.

Providers acknowledged that many families, particularly those that are non-english speaking may have difficulty utilizing these resources. Recommendations to reach out to these families included finding trusted community members, including health care providers or social workers within the community and political or religious leaders. These contacts could help facilitate communication with families in need.

Finding Healthcare Champions

All of the providers interviewed recognized the importance of incorporating mental health care into medical care, reducing traumatic stress in healthcare and improving communication and access to mental health care during hospitalization, before procedures and after discharge. Barriers to improved care discussed with providers included time, lack of knowledge and training for most providers, and lack of funding and availability of specialized providers with advanced knowledge and ability to intervene to reduce PMTS and PTSS.

Recommendations for intervention included improved education during and after training for all levels of patient facing healthcare providers such as technicians, facilities workers, nurses, and physicians. Our interviewees felt that Increased awareness of the benefits of trauma informed care to both patients and staff would help gain increased support from and “buy-in” from patient facing healthcare workers. The providers we interviewed also felt that the benefits of trauma-informed care needed to be made clear to administrators (medical and nursing directors, non-medical financial and business leaders) using both qualitative and quantitative data on satisfaction, efficiency, physical and mental health outcomes and provider turnover . Most felt that this would best be accomplished by strong physician advocates in conjunction with trained

psychosocial teams including child life, social work and pediatric psychology. The goal of this “high level health care education” would be to improve funding for mental health care in both inpatient and outpatient care settings by increasing funding from payors, increasing support for specialized provider education and providing paid education for all patient facing hospital employees.

CAPSTONE RECOMMENDATIONS FOR ALONGSIDE NETWORK

Based on our review of the literature, program evaluation and informational interviews with providers, our Capstone Team has formulated three sets of recommendations for the Alongside Network to consider. These three sets of recommendations are centered around alternative formats of support that might benefit caregivers, methods of improving connection with families impacted by PMTS, and methods of improving provider knowledge and support of interventions to reduce PMTS.

Recommendation 1: Explore Alternative Formats of Support

During our interviews with AWBG facilitators and participants, we learned that the length of the seven-week curriculum could be a barrier to families and caregivers who do not have time to attend. Additionally, we learned that families have various, ongoing needs after hospitalization, and may benefit from shorter programs or events focusing on areas that also affect mental health, such as re-entering school systems. For these reasons, we recommend that The Alongside Network consider exploring alternative formats of support, in addition to the Wellbeing Groups, to attract more caregivers into The Alongside Network’s programming, and make PMTS resources more widely available. Based on our discussions with participants, facilitators, and healthcare providers, we specifically recommend adding a self-screening tool to The Alongside Network’s website to help parents and caregivers recognize PMTS within themselves. We also recommend hosting one-off events, such as community workshops, that are held in accessible locations and focus on relevant topics, such as advocating for a child at school, addressing concerns with siblings, and more.

Summary of Recommendation 1:

- Add a self-screening tool to AN website for caregivers
- Expand options for virtual support groups
 - Shorter series of meetings
 - Opportunity to do 1-2 meeting refreshers or repeat ANWG
- Provide focused educational activities
 - Meetings/Webinars on relevant topics
 - navigating school concerns/IEP’s,
 - addressing needs of siblings,
 - advocating for your child/family in a medical setting

Recommendation 2: Improve Connections with Impacted Families

To date, most of the participants in the AWBG have found the AN through internet searches or referral by a non-medical connection. As the AWBG increases the number of trained clinical and lived experience facilitators, we recommend reaching out to families in need in other ways. This includes partnering with local, regional or national health care partners to provide information to families about traumatic stress symptoms and the benefits of AWBG support to caregivers. This information can be specifically provided initially on brochures or posters with QR links in acute care units, pediatrician's offices or subspecialty providers, or provided to hospital Child Life, social work and psychology professionals to hand out to families who inquire about mental health support. As provider relationships with the AN are strengthened, these recommendations can be provided on acute care discharge summaries or in after visit summaries provided at outpatient visits with primary care providers or subspecialists. These can be easily incorporated into documents as "smart phrases" with educational information on PMTS, benefits of support for caregivers, and AN programs and contact information. Additional methods of outreach include existing support groups, facebook groups and other social media presence.

We learned from our evaluation that many families most impacted by PTMS are also discriminated against within the health care system, increasing distrust, lack of needed follow-up and putting their child and family at risk for poor medical and psychosocial outcomes. The impact of PMTS may not be recognized in the setting of historic trauma and/or lived experiences in these families. The AN has clinical facilitators with expertise in health care disparities and may be uniquely suited to serving families with PMTS compounded by discrimination. Recommendations from our providers to reach these families included connecting with trusted community organizations. These may include community clinics, healthcare providers (physicians, nurses, social workers), and community or religious leaders. These community leaders can help ensure that communication is culturally responsive, that outreach methods are culturally appropriate and that interventions address needs in a culturally centered and respectful way.

Summary of Recommendation 2:

- Reach families in need by connecting with them through local, regional or national healthcare partners.
- Include posters or brochures with QR codes in acute care settings, and primary and subspecialty care outpatient clinics
- Provide AN network information to Child Life, social work and psychology providers
- Incorporate PMTS education, benefits of caregiver support, and summary of AN programs in smart phrases used in inpatient discharge summaries or outpatient after visit summaries (requires ongoing relationship with care providers)

- Expand services to reach families in need who have experienced disparities in health care settings due to discrimination, cultural or language barriers.
 - Support assignment of primary nurses and physicians to all families in acute care units
 - Support in person or community partners to provide accurate and culturally competent interpreter services.
 - Connect with trusted community members including healthcare providers, community or religious leaders
 - Use these connections to identify families in need and facilitate culturally appropriate communication and support.
 - Reach out to community clinics (ie CUHHC Clinic, La Salida)

- Explore varied means of communication and outreach
 - Provide education and empowerment to families through existing in person and online forums (family support groups, disease specific support groups or educational websites, facebook or other social media groups)
 - Expand AN social media presence

Recommendation 3: Provide PMTS Education to Healthcare Workers

“The care in caring has disappeared in healthcare.”

During our interviews with healthcare providers, we learned that some of the healthcare workers with the most patient interaction have the least amount of training on working with children to prevent trauma during a medical event. Our group recommends that AN consider partnering with programs and schools that train licensed practical nurses (LPN’s), emergency medical technicians (EMT’s), radiology technicians, and phlebotomists. In many settings, these professionals interact with children directly, giving “sticks and pokes” as quickly and efficiently as possible. However, even if these interactions are brief, they can be traumatic for children and difficult for parents and staff as well. Technical colleges that provide these degree and training courses should be aware that trauma-informed practices not only benefit children and families, but improve medical care and help prevent provider stress. Additionally, according to our provider interviewees, an EMT, LPN or RN who is knowledgeable about PMTS and how to address it is much more likely to get hired for a competitive position.

Nursing and medical training also lack adequate training in PMTS, its prevention and sequelae. In order to provide integration of mental health and physical health care, nurses and physicians must understand and be willing to incorporate best practices of trauma informed family centered care into all medical care. They must also understand the importance of professionals trained in providing developmentally appropriate, family centered care including Child Life, social work and pediatric psychology. The providers we interviewed recommended a concerted effort to teach trainees - nursing and medical students, pediatric residents and fellows and young family

members, as bedside nurses and physician providers “ set the culture of care”. Continuing education opportunities after training should be mandatory, paid and if possible interactive. Family testimonials are also valuable for professionals.

The Alongside Network may consider creating some short webinars that are easily accessible to healthcare professionals for training purposes. According to the healthcare providers we interviewed, personal testimonies from patients about the importance of interventions to reduce PMTS can be more impactful for healthcare providers than lecture-style presentations.

Lastly, the AN and invested healthcare providers can serve to educate healthcare administrators and payers on the benefits of reduction, recognition and treatment of PMTS. Incorporation of mental health care with medical care in acute care and outpatient settings requires a commitment of hospital systems and payors to increased education for families and health care providers, and improved access to and reimbursement for trained child life, social work and psychology providers. This approach to care has been shown to improve short and long term patient and family outcomes, as well as provider satisfaction.

Summary of Recommendation 3:

- Advocate for increased training on PMTS reduction and recognition for all patient facing providers (EMT’s, LPN’s, phlebotomists, technicians)
- Support PMTS training for nursing and medical students, along with mandatory, paid continuing education for nurses and physicians, particularly during training and early career
- Provide live or recorded Webinars on PMTS for families and healthcare providers that include family testimonials
- Educate healthcare administrators and payers on the benefits of reducing PMTS and incorporating mental health care into physical health care on both the patient and family outcomes as well as staff satisfaction and retention.

Conclusion

Pediatric medical traumatic stress is common in healthcare settings and impacts the wellbeing of patients, families, and healthcare providers. At this time, most healthcare systems do not adequately educate about PMTS, or provide care to prevent or treat it. The recommendations provided in this paper address ways that The Alongside Network can help support families with PTSS or PMTS, improve education and integration of mental health care into pediatric healthcare systems, and support improvement of those systems through the Whole Child, Whole family framework.

Additional mental health resources for perinatal, postpartum and neonatal care

Pregnancy & Postpartum Support Minnesota (PSI-MN) ppsupportmn.org
parent resources, partner support during postpartum depression, grief and loss support

University of Minnesota Department of Psychiatry Women's Well Being program
<https://med.umn.edu/psychiatry/news/program-provides-mental-health-support-women-during-one-most-vulnerable-times-their-lives>

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