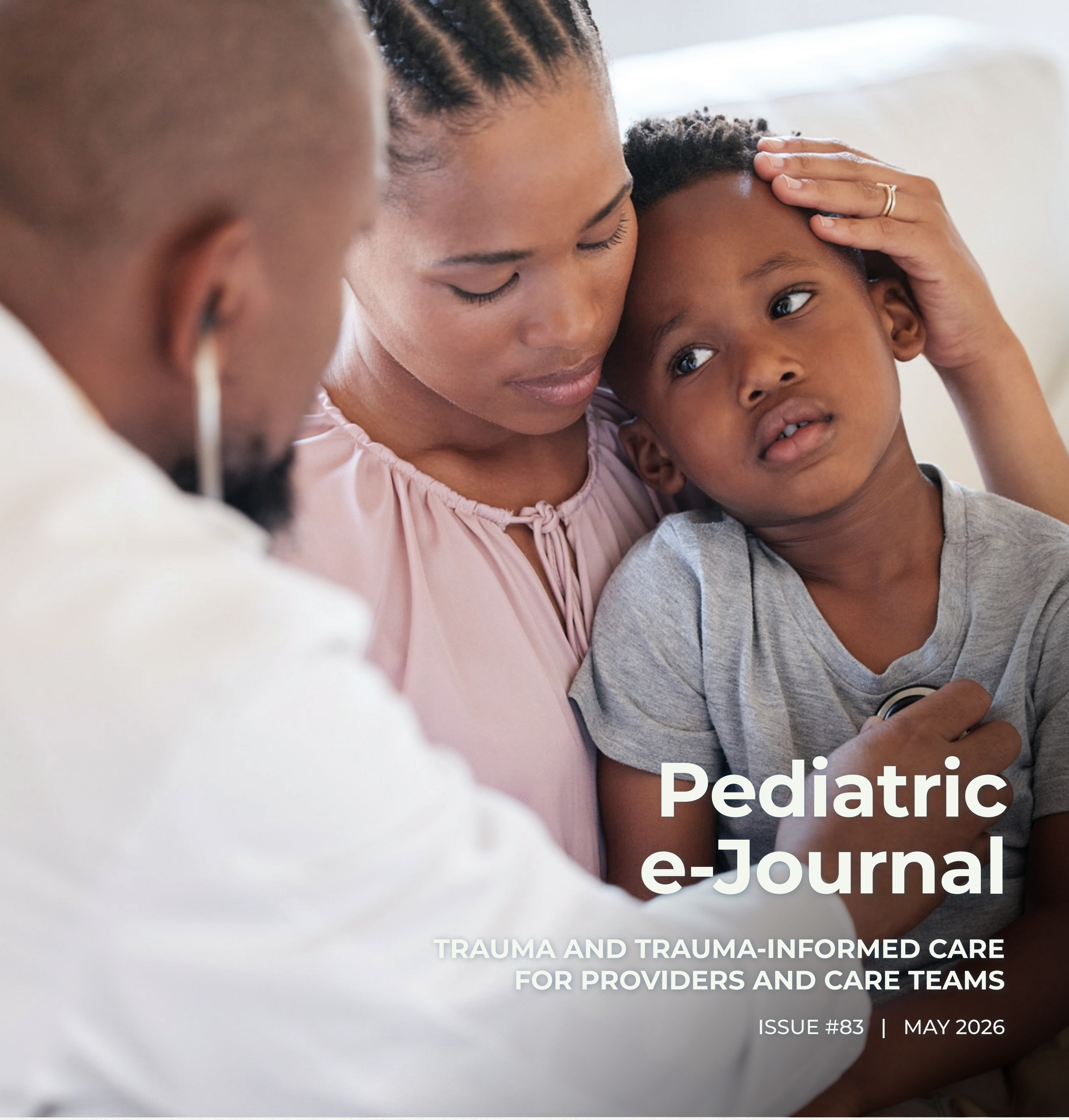

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TRAUMA AND TRAUMA-INFORMED CARE FOR PROVIDERS AND CARE TEAMS

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Issue Topic: Trauma and Trauma-Informed Care for Providers and Care Teams

Welcome to the 83rd issue of our Pediatric e-Journal. The focus of both this issue and the one that immediately preceded it is on topics that relate to trauma and trauma-informed care. This issue specifically addresses trauma and trauma-informed care as they involve providers and care teams. Issue #82 addressed trauma and trauma-informed care as they involve patients and families.

Unfortunately, trauma and the need for trauma-informed care are all too frequently encountered in pediatric hospice and palliative care. Even two issues of our e-Journal will likely not be sufficient to address these subjects in a comprehensive fashion. However, by addressing these topics in two distinct issues, we hope that the articles offered here will spark broad discussion of this important subject area.

This e-Journal is produced by the Pediatric e-Journal Workgroup and is a program of the National Alliance for Care at Home (the Alliance). The Pediatric e-Journal Workgroup is co-chaired by Christy Torkildson and Melissa Hunt. Chuck Corr is our Senior Editor. Archived issues of this publication are available at allianceforcareathome.org/pediatric-e-journal/

Comments about the activities of the Pediatric e-Journal Workgroup or this issue are welcomed. We also encourage readers to suggest topics, contributors, and specific ideas for future issues. Our tentative plan is for Issue #84 to focus on how cultural or religious differences affect pediatric hospice and palliative care. We have some ideas for Issue #85, but we are open to suggestions. If you have any thoughts about these topics or other subjects and/or potential contributors (including yourself?) for future issues, please contact Christy Torkildson at Christy.Torkildson@gcu.edu or Melissa Hunt at melissa.hunt@handsofhopese.com

Views expressed in this and other issues of the Pediatric e-Journal are exclusively those of the authors and do not necessarily reflect the views of the Pediatric e-Journal Workgroup, the Pediatric Council, or the National Alliance for Care at Home.

Produced by the Pediatric e-Journal Workgroup.

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Heather Bemis, PhD, and Linda M. Radbill, PhD

These authors begin with the following observations: “For those serving families facing serious illness, it bears noting that the intensity of the hospital environment and medical treatment for a serious illness are also distressing in such a way that can predispose individuals to traumatic stress. The context we work in is inherently ripe for children and caregivers to experience disruptions to their sense of safety, control, bodily privacy, predictability, and normalcy.” The goals of this article are to show how trauma presents in pediatric palliative care, to identify the principles of trauma-informer care, and to explain and advocate for reflective practice in trauma-informed PPC.

Teaching Providers through a Trauma-Informed Framework: A Pathway to Safer, More Effective Care p. 7

Jennifer Brodie, DNP, CPNP-PC, CNE

“This article examines how educators can incorporate trauma-informed teaching and learning (TITL) principles into provider education to enhance their ability to deliver trauma-informed care and support improved patient outcomes.” The article discusses why trauma-informed teaching matters, the Four Rs of trauma-informed care, and how to implement trauma-informed strategies across a variety of educational settings. The article concludes: “Ultimately, embedding trauma informed approaches within medical training not only enhances individual provider competence but also contributes to a more compassionate, equitable, and patient centered health care system.”

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Shawnna Cunning, DNP, APRN, FNP-C, NEA-BC, CNE

This author asserts that, “Trauma-Informed Care (TIC) is an approach that promotes awareness of the prevalence of trauma and an understanding of its effects and how they may impact physical health and behaviors. The application of trauma-informed care is essential for care providers to deliver effective, compassionate, and holistic support to individuals who have experienced trauma. This approach is beneficial for both patients and providers as it fosters collaboration and often compliance.” She then describes types of trauma, assessment, provider applications, impacts on providers and caregivers, and benefits for the future. An appendix in the form of a table compares traditional care and trauma-informed care on 17 metrics.

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Oralea Marquardt, LCSW-QS, ACHP-SW, and Emery Boyd, MSW

This article argues that, “While often introduced at the level of individual clinical interactions, a truly trauma-informed approach must extend beyond bedside practice to encompass organizational culture, policies, and workforce development.” The authors add that, “embedding trauma-informed principles into organizational systems supports staff well-being, strengthens retention, and enhances continuity and quality of care for patients and families. In pediatric palliative care, where relationships are central and sustained over time, this integration is not optional but essential.”

A Trauma-Informed Approach to Supporting NICU Providers p. 26

Silvia P. Schibeci-Oraa, MD

Focusing on the NICU as an environment of chronic stress for providers, “This article explores how trauma-informed care can address moral distress of providers and systemic communication barriers to support the resilience of the NICU team in the setting of periviability.” To understand the impact of this chronic stress, the author “conducted an electronic survey of 163 NICU providers at a single-center, level IV high-acuity NICU, including bedside nurses (RNs), advanced practice providers (APPs), and physicians (MDs).” The survey received a response rate of 75% while showing “a significant rift in perceptions” between bedside nurses on the one hand and the physician/advanced practioner group on the other hand, a rift whose implications are explored in this article.

Impact of Physician Language & Attitudes on Pediatric Patient Well-Being & Outcomes p. 29

Matthew Misner, DO, MS, MAPS, and Jihoo Yun

This article focuses on physician attitudes and language as they affect children and family members. The authors state that, “Because trust is built or eroded in real time through communication, the language and attitude that physicians choose can meaningfully lead to a safe, respectful, and collaborative experience for the child and family.” A hospice provider case study illustrates how detrimental experiences can lead to parental fears, as for example when a mother and child feel scorned. However, at the same time there is always an opportunity to engage appropriately so that the mother and child now feel supported. The authors conclude that, “All together, these findings [illustrate] the importance of ethical and clinical responsibility of healthcare professionals to remain vigilant as to how language and attitudes are experienced by pediatric patients and their families. Incorporating trauma-informed, compassionate communication into routine practice represents an opportunity to reduce harm, strengthen trust, and support both immediate and downstream well-being. In pediatric care, how clinicians speak may matter just as much as what they do.”

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Jessica Sturgeon Pope, CLS, MT-BC, HPMT, NICU-MT

This author observes that, "The inclusion of Creative Arts Therapies (CAT), such as music or art therapy, is often thought to be a 'fun outlet' to help cope with trauma; however, there are many considerations, contraindications, approaches with the inclusion of Integrative and CAT that must be explored to prevent ongoing traumatization and to help funnel supportive services in the appropriate manner. As an introduction, this article sets forth information that is intended to encourage ongoing and comprehensive discussions in co-treating and referring children to CAT under a trauma-informed lens." She then explains the importance of how to approach child patients and families, and explores considerations and contraindications for creative arts therapies. She concludes by stating: "By practicing ethically and collaboratively, children with trauma and mental health disorder have a greater chance for building a strong foundation that can hold the structure of ongoing psychological care."

Self-Care & Resiliency: Vital Keys to Sustaining Essential Practices in Compassionately Supporting Those Entrusted to Our Care **p. 38**

Judy Zeringue, MAPL, BSN, RN, RTSCBC, CPLC, CHPPC

In this article, the author explains that the "passion to provide the most compassionate presence to those entrusted to our care and to sustain our resiliency and maintain our personal wellness is a delicate balancing act which requires strategic planning to always have some reserve in our tanks when the need arises." With that in mind, she explores multiple ways to build resilience, all founded on good self-care.

Adaptation & Beta Testing of Group Problem Management+ for Family Caregivers of Children with Rare Diseases: Rare Group PM+ **p. 43**

Danielle Schwalk, BS, Abdulla M. Ali, BA, Thevaa Chandereng, PhD, Debra S. Regier, MD PhD, and Maureen E. Lyon, PhD

"The primary objective of this study was to adapt Group PM+ [a five-session, evidence-based intervention] for family caregivers of children with rare diseases and to administer it through telehealth." This article describes the methods used, outlines the content of the five sessions, and explains follow-up, data sources, and measures. Results included participant characteristics (e.g., "participants reported that the group helped reduce their isolation, increase their self-worth, made them feel more supported and less alone in their struggles caring for their child") and discussion (e.g., "Participants showed reductions in the severity of their symptoms of anxiety, depression, and PTSD, highlighting the potential efficacy of Rare Group PM+"). The authors add, "One of the unmeasured effects of the group was to address head on the 'blameless guilt' of parents whose child had an inherited disease. Participants who were feeling guilty came to understand a fundamental tenant of psychology, parental self-care did not come at a cost for their child, as they had feared, but benefited both."

Trauma-Informed Foundations: Enhancing Compassionate Care for Others & Ourselves

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Introduction

Recent data collected among U.S. adolescents show that 80.5% (or 4 in 5) endorse at least one adverse childhood experience (ACE) (Swedo et al., 2024). Some groups are at increased risk secondary to racial trauma and other sociodemographic factors. The National Council for Behavioral Health reports 70% of adults (roughly 223.4 million people) in the U.S. have lived through a traumatic experience in their lives, and those rates were found to be consistent in a worldwide study (Benjet et al., 2016). For those serving families facing serious illness, it bears noting that the intensity of the hospital environment and medical treatment for a serious illness are also distressing in such a way that can predispose individuals to traumatic stress. The context we work in is inherently ripe for children and caregivers to experience disruptions to their sense of safety, control, bodily privacy, predictability, and normalcy. Taken together, the data and our collective experience show that pediatric palliative care (PPC) providers are likely to work with patients and families with trauma histories, which may be further triggered by the environment in which we provide care. Due to exposure over time, PPC providers are also at risk of secondary traumatic stress themselves. For providers with their own trauma histories (we are not exempt from the statistics), this can lead to intensified experiences when faced with trauma reactions manifested in patients' and families' behaviors. The purpose of this article is to promote awareness and acknowledgement of these experiences, while offering some foundational approaches in Trauma-Informed Care and Reflective Practice to enhance how we care for others and ourselves.

Trauma Presentations in PPC

Traumatic stress symptoms may present in various and unexpected ways. Traumatic stress symptoms broadly include physiological arousal, re-experiencing or intrusive memories, avoidance, and mood alteration. Because the fight or flight response is impacted, adults may exhibit angry outbursts, disconnection/detachment, agitation, sleep difficulties, or being easily started. Children often demonstrate some similar behaviors with regard to becoming easily upset, jumpy, or irritable, as well as appearing distracted or frequently changing topics when they are struggling with the topic of conversation or other environmental stimuli. Traumatic stress responses can impact communication, engagement or adherence, information retention, emotion regulation, and regression (particularly in children)—areas of significant relevance to palliative care. For example, it may appear that someone is having difficulty attending to a conversation, needing information repeated, argumentative, withdrawn, or on alert for negative outcomes—while these behaviors are frequently labeled as "difficult" in medical care, they can often be reframed through a trauma-informed lens.

Generally speaking, hospice and palliative care providers are accustomed to sitting with sadness and recognize it as a response to a difficult situation, but medical systems often find it more difficult to frame angry or aggressive behaviors in the same context. Trauma-informed care principles offer a guiding foundation in responding to distress to minimize negative impact for both the patients/families and the providers. PPC providers, whose role entails responding not only to patient emotional needs but also to those of their colleagues, face unique challenges in this parallel process, but are also well suited to lead and model the implementation of trauma-informed practice across systems of care.

Principles of Trauma-Informed Care

Universal trauma-Informed care entails awareness of the prevalence, impact, and expression of traumatic stress, and responsiveness to these factors in ways that can mitigate (or avoid exacerbation of) trauma's effects. It need not entail soliciting trauma histories or treating trauma—rather, noting and responding sensitively and enlisting mental health consultation as indicated (e.g., Raja, 2015). Six core principles of trauma-informed care address how traumatic stress can disrupt one's basic sense of security:

SAMHSA Guiding Principles of Trauma-Informed Care	
Safety	Collaboration and Mutuality
Trustworthiness and Transparency	Empowerment, Voice, and Choice
Peer Support	Cultural, Historical, and Gender Issues

(Substance Abuse and Mental Health Services Administration, 2014)

In trauma-informed PPC (TI-PPC), this can include practices such as respecting privacy (knocking before entering patient rooms, offering to step out during cares, introducing yourself each time, letting the patient know what to expect from the visit, e.g., whether or not they can expect to be touched); involving patients in their treatment and planning in developmentally appropriate ways; offering choices whenever possible ("Is now an ok time for you to talk?" "Do you want to do this now or tomorrow?"); maximizing coordination among health care providers, patients, and their families in organizational and treatment planning; setting clear expectations and following through.

At its core, trauma-informed care calls for a perspective shift: consciously shifting our thinking and approach away from a problem-focused conceptualization of challenging behaviors ("What's wrong with this person?") to a more compassion-based, contextualized framework ("What's happened to this person?" "What's going on for them?"). Importantly, TI-care does not require knowledge of trauma history and instead involves awareness that due to high prevalence rates of trauma in the general population, it should be taken into account in understanding behavior.

Reflective Practice for Enhanced TI-PPC

Reflective practice, or *self-awareness and appraisal of our own personal state* (thoughts, feelings, behaviors, and role in a situation) is an essential yet often overlooked component of effective TI-care. Asking ourselves—honestly and without judgment—"What's going on for me?" is a necessary step in managing one's own emotions in a stressful situation, and in responding more calmly and sensitively. In other words, it is a key tool in supporting patients and putting our own oxygen mask on as we move through challenging situations together. Reflective practice requires a two-way perspective taking into consideration the world both from another's perspective and curiosity about our own. It is a skill that requires practice and involves mental effort, as it is not the typical way our busy, efficient brains work, as we tend to rely on mental shortcuts. Reflective practice in TI-care involves the recognition that all behaviors serve a purpose and if it is not readily known, we must pause/slow down to consider the underlying message being communicated.

Sincere acceptance of our own challenges, particularly in our professional work, can be challenging in a variety of ways. For some, it may trigger impostor syndrome or fuel fears or self-doubt about our own contribution in worsening a situation. For others it may require an acknowledgment of other problems that are interfering with provision of care. It may also entail the recognition that as providers, we may also need supports in coping with our own traumatic stress. While at times uncomfortable, this reflective process—examining our internal narrator and acknowledging that our own humanity entails histories, experiences, stressors, triggers, and emotions that we cannot always fully leave at the door—enhances our clinical reasoning and helps us to stay regulated, connected, and able to build better relationships. (Lavender, 2003; Pally, 2017). PPC providers are uniquely equipped to leverage their existing skill set in applying reflective practice and championing TI-care.

Practicing Reflective Practice

Trauma has at times been described as an invisible suitcase. What are the things you may be carrying in your suitcase today? We can simply start by acknowledging our own current stressors at work and home —and can include, but doesn't need to start with, potential secondary traumatic stressors we face in our profession, as well as prior traumatic stress histories. It is human for challenging interactions to trigger challenging emotions, and entering interactions with awareness of our current baseline, triggers, and needs can help us manage and meet them.

Then (and only then), we can be more present and engaged in considering others' needs. Reflective practice in TI-PPC entails genuine curiosity about "what is going on for them?" and humility in including our own potential role in the response. Here are some additional suggested questions to help guide reflective assessment and application in practice:

REFLECTIVE ASSESSMENT

What is this person communicating to me via their actions/behaviors?
- What could be going on for them in this moment?
- Do they feel safe?

What do they need in this moment?
- Common basic needs include safety, physical comfort, feeling heard, to be a good advocate and caregiver, some predictability and controllability

What am I uncomfortable with/what do I need?
- Where else/with whom else can I get my needs met in a healthy way?
- Can I sit with this response?

What else might I be bringing to this interaction (unintentionally, culturally, or based on my role)?
- Regardless of my intentions, what are they perceiving?

What other cultural/systemic factors are relevant to the interaction/communication?
- Am I aware of the biases I may be bringing into this interaction?

What data are my own emotions and bodily sensations giving me?
- What is showing up for me? What am I noticing in my body?
- If something's showing up repeatedly—what information is it giving me about my own values and comfort; what do I really care about?

EXAMPLE: REFLECTIVE STATEMENTS/STRATEGIES

"I can see by your emotions how much you really care about [your child/ your value]."

"It seems like this approach is not being so helpful to you."

Ok to ask clarifying questions ("Did I get that right? What did you mean by….?") and to say, "I don't know what to say."

Consider disruptions to predictability or control that can be addressed or compromised on; offer choices

Humility, patience, and follow-through in connecting and earning trust

PPC providers are primed to lead this kind of approach towards more compassionate (and self-compassionate) care. Like much of our work, engaging in TI-Care and Reflective Practice are not end-point skills, but rather ongoing, evolving processes that necessitate continued effort and refinement. It requires maintaining active awareness of trauma's prevalence—amongst our patients, our colleagues, and ourselves; the ways that traumatic stress may show up in the stressful contexts we work within; and reflecting that everything someone does is an expression of something going on for them, and that the same is true for ourselves.

Additional Resources:

- ACES statistics: https://www.cdc.gov/vitalsigns/aces/pdf/vs-1105-aces-H.pdf
- The National Child Traumatic Stress Network: https://learn.nctsn.org/
- Center for Health Care Strategies: https://www.traumainformedcare.chcs.org/what-is-trauma-informed-care/
- Center for Pediatric Traumatic Stress: https://www.healthcaretoolbox.org/
- Key ingredients for successful trauma informed care implementation. https://www.samhsa.gov/sites/default/files/programs_campaigns/childrens_mental_health/atc-whitepaper-040616.pdf
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Teaching Providers Through A Trauma-Informed Framework: A Pathway to Safer, More Effective Care

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Health care systems today serve increasingly complex patient populations, many of whom have experienced trauma across the lifespan. Research consistently reveals that trauma is not an exception but a widespread public health issue that greatly impacts physical health, behavioral health, treatment adherence, and health care outcomes (Shoptaugh et al., 2025). As a result, trauma-informed care (TIC) has become a critical education component for modern medical and behavioral health providers.

While the principles of trauma-informed care are widely discussed—safety, trust, transparency, choice, empowerment, collaboration, and cultural responsiveness—the methods used to teach these principles are often overlooked (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). Many times, providers attend didactic sessions or one-time trainings that explain trauma's prevalence and impacts, but walk away without the confidence, emotional grounding, or practical skills necessary to implement TIC in real clinical environments. Teaching providers through a trauma-informed framework, not just about trauma, is critical to stop the current cycle. When educators model the same principles they hope clinicians will apply with patients, providers experience firsthand the power of empathetic, respectful, and safety-centered interactions (Thornton et al., 2025; Shoptaugh et al., 2025; SAMHSA, 2014). This type of experiential training truly transforms learning into practice. This article examines how educators can incorporate trauma-informed teaching and learning (TITL) principles into provider education to enhance their ability to deliver trauma-informed care and support improved patient outcomes.

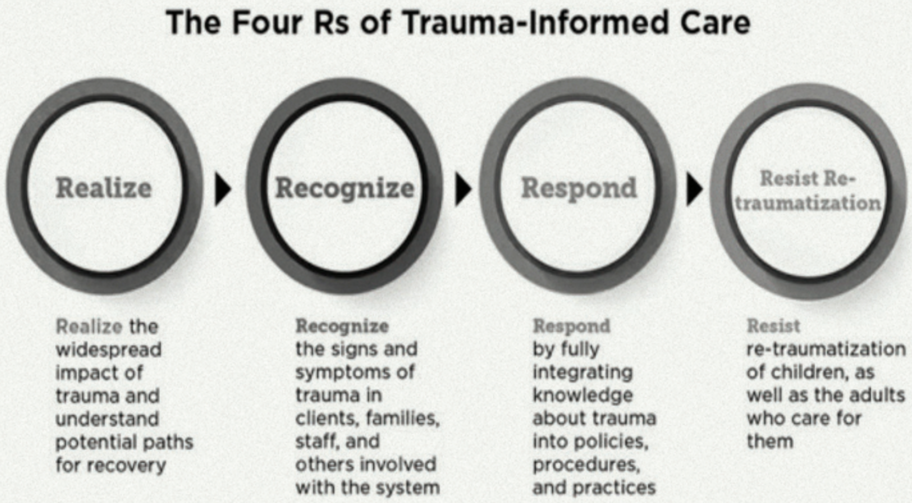
Why Trauma-Informed Teaching Matters

Trauma affects how people learn. It shapes attention, memory, executive functioning, perception of safety, and capacity for collaboration. Gallup's U.S. wellbeing trends show a national rise in emotional strain: daily loneliness has reached 20% among U.S. adults, the highest level in two years, and U.S. depression rates remain historically high, affecting over 18% of adults—with rates doubling among young adults since 2017 (Goddard et al., 2022; Gallup, 2024). These mental health pressures impair cognitive bandwidth, reduce stress tolerance, and hinder learning engagement—effects that carry directly into healthcare settings (Gallup, n.d.). Trauma in childhood and adolescence is defined by U.S. Centers for Disease Control and Prevention (CDC) as adverse childhood experiences (ACEs); a traumatic event occurring before age 18 (CDC, 2019). The latest analysis of the Youth Risk Behavior Survey (YRBS) shows the most common types of ACEs are emotional abuse reported at 61.5% and physical abuse at 31.8% (Swedo et al., 2024). Another way to interpret the data is that approximately three in four students (76.1%) experienced one or more ACEs, while about one in five students (18.5%) experienced four or more ACEs (Swedo et al., 2024). The long-term impact of ACEs ranges from maternal and child health problems to chronic illness such as diabetes, cancer, or heart disease (CDC, 2019). This data speaks about the magnitude of trauma and its impact on the population.

Health care providers are no exception. They operate in chronically high stress environments and frequently encounter suffering, loss, and secondary trauma. Although Gallup does not publish healthcare worker burnout rates specifically, their broader U.S. emotional health indicators reveal the conditions under which clinicians are working. For example, Gallup's global emotional data show that 37% of adults experienced significant stress and 40% experienced worry the previous day, while 26% experienced sadness—all emotional states that are higher today than a decade ago (Gallup, n.d.). These trends reflect escalating strain in the general population, which healthcare professionals both absorb and manage through their frontline roles (Gallup, 2024).

These emotional burdens compromise neural pathways associated with learning. When providers are already depleted—emotionally taxed by workload, staffing shortages, grief exposure, and moral injury, new information is harder to integrate, less likely to be retained, and more likely to trigger defensiveness or overwhelm. Trauma informed teaching integrates the six principles of trauma-informed approach: safety, trustworthiness and transparency, collaboration and mutuality, empowerment, voice, and choice, and cultural, historical, and gender issues (SAMHSA, 2014). It moves away from traditional top down instruction and into an approach that is relational, predictable, empowering, and culturally attuned (DeGagne & Oermann, 2025).

By modeling these six principles in the learning environment, educators create conditions that support cognitive flexibility and resilience. The training process itself becomes a living demonstration of the four Rs of trauma informed care—helping providers experience, not just understand the principles they are expected to use with patients. See Figure 1.



Realize the widespread impact of trauma and understand potential paths for recovery

Recognize the signs and symptoms of trauma in clients, families, staff, and others involved with the system

Respond by fully integrating knowledge about trauma into policies, procedures, and practices

Resist re-traumatization of children, as well as the adults who care for them

Figure 1. The Four Rs of trauma-informed care adapted from Substance Abuse and Mental Health Servies administration (2014).

The result is a clinical environment where providers feel equipped to assess trauma, patients feel understood, and the entire system moves closer to equitable, compassionate, and effective care (Thorton et al, 2025). Trauma-informed teaching is not an optional enhancement; it is an essential component of modern health care education and a catalyst for systemic transformation.

Trauma-Informed Teaching Strategies Implemented

This section describes trauma informed teaching principles that are commonly implemented across a variety of educational settings, ranging from nursing and medical curricula to independent healthcare education sessions. Both approaches have been successful in educating future and current healthcare providers (Bourassa et al., 2024; Clarke, 2023; Shoptaugh et al., 2025).

Building Safety from the Start

Establishing a safe environment at the outset is central to trauma informed teaching. Warm welcomes, rapport building practices, and clearly posted agendas help learners anticipate what to expect and reduce anxiety associated with uncertainty. Collaboratively developing group agreements or ground rules further reinforces predictability and shared responsibility which eases anxiety of the unknown (Clarke, 2023). When learners participate in defining the norms of engagement, they experience a greater sense of agency and connection, which strengthens their capacity to engage in challenging discussions and reflective practice, all while being supported by faculty. Cultivating a safe learning environment fosters a productive learning experience letting learners feel safe and better able to understand trauma and its clinical implications (Thornton et al., 2025).

Teaching Through Trustworthiness and Transparency

Role-modeling is important to building trust and promoting transparency in the educational setting. Instilling clear expectations while promoting professionalism is foundational to establishing trust and facilitating transparency. Implementing active listening with learners and respecting their views in a meaningful way demonstrates professional behaviors (Clarke, 2023). Establishing trust and setting clear expectations promote effective knowledge acquisition while enhancing comfort and confidence with trauma informed care, which in turn leads to improved implementation in clinical practice (Shoptaugh et al., 2025).

Connection and Support

This principle emphasizes maintaining regular communication with students to check in on their well being. These interactions provide opportunities to recommend resources, offer support, and strengthen a sense of community and safety within the learning environment (Clarke, 2023). Be creative with class communications to encourage engagement and connection. Video announcements and audio feedback can help create a more personal presence, and even small gestures—such as addressing students by name—can foster rapport. Connection can also begin before the course starts, using a pre class email or phone call to introduce yourself and learn about students' expectations. These early communications help break the ice and reduce stress as students enter the class. By emphasizing an open and strong connection, students feel supported entering the class and more open to learning.

Collaboration and Mutuality

Effective trauma informed instruction integrates interactive strategies that promote deep engagement while maintaining emotional safety. Reflection exercises, structured role plays with clear boundaries, and small group collaboration can create opportunities for meaningful skill development when facilitated thoughtfully (Clarke, 2023). Case studies should be presented with sensitivity, ensuring that scenarios avoid graphic or excessively detailed descriptions of trauma that could cause distress. By carefully curating content and providing clear guidelines for participation, educators support a learning process that is both experiential and psychologically safe.

Facilitating Empowerment, Voice, and Choice

A core principle of trauma informed pedagogy is the affirmation of strengths. Educators should intentionally highlight what providers already do well, acknowledging the expertise and resilience they bring to their work. By building on existing competencies, instructors reinforce learners' professional identities and counteract deficit based narratives that may undermine confidence (Clarke, 2023). This strengths oriented approach supports learning that is both empowering and sustainable, fostering an environment where providers feel valued and capable of integrating new trauma informed practices. Shoptaugh et al. (2025) shared that following a virtual TIC education session 98% of pediatric providers described the value of the education as “Useful” or “Very useful” while 72% of the participants acknowledged they would apply the new TIC skills in clinical practice. Discussions about trauma can evoke strong emotional responses, making skilled facilitation essential. Educators should normalize a range of emotional reactions, emphasizing that such responses are both common and valid within trauma related learning contexts (Bourassa, 2024). Providing explicit opt out options allows learners to maintain autonomy and protect their emotional well being. Structured debriefing or reflection after difficult conversations further supports learners’ processing and integration of complex material, ensuring that emotional activation does not linger unmanaged or impede subsequent engagement (Clarke, 2023).

Consideration for cultural, historical, and gender contexts

An inclusive and trauma informed learning environment is one in which diverse perspectives are welcomed and respected. Educators must cultivate conditions that allow all learners to participate without pressure to disclose personal trauma histories. Establishing clear boundaries and emphasizing participant autonomy promotes psychological safety and supports meaningful engagement. Additionally, trauma and healing are shaped by cultural worldviews, community norms, and collective histories; therefore, educators must remain attentive to how these factors influence classroom dialogue. Through culturally responsive communication strategies, educators can help providers develop a more nuanced understanding of how cultural values, expressions of distress, and help seeking behaviors vary across communities. This includes educators examining their own explicit and implicit biases and avoiding stereotyping (Clarke, 2023). This higher understanding of trauma’s impact enables providers to develop deeper empathy skills fostering strong patient and family connections (Thornton et al., 2025).

Creating a trauma informed learning environment requires explicit recognition of the historical and systemic traumas that disproportionately affect marginalized communities. Black, Indigenous, LGBTQIA+, refugee, and other historically oppressed groups have endured structural inequities that shape their encounters with trauma and their access to healing resources. These groups also experience ACEs at higher rates, with a significant proportion reporting four or more ACEs (Swedo, 2024). A trauma informed framework acknowledges that trauma is not solely an individual experience but is deeply interconnected with sociopolitical systems. Educators who incorporate this awareness help ensure that learning spaces do not unintentionally perpetuate oppressive dynamics and instead affirm the lived experiences of diverse learners (Clarke, 2023).

Encouraging Self care and Resilience

Promoting self care and resilience is an essential component of trauma informed teaching and can reduce the likelihood of re-traumatization (Bourassa et al., 2024). Educators can model healthy boundaries and incorporate micro–self care practices—such as breathing exercises, grounding techniques, or brief reflective pauses—throughout instructional sessions (Clarke, 2023; Bourassa et al., 2024). These strategies not only support immediate well being but also demonstrate practical tools that providers can use in their own professional routines (Clarke, 2023). By emphasizing how trauma informed care strengthens provider resilience and decreases burnout risk, educators highlight the mutual benefits of trauma informed approaches for both clients and the professionals who serve them. This, in turn, fosters positive work and learning environments. Thornton et al. (2025) reveals when providers completed TIC education they developed stronger empathy skills improving patient and family connections.

Conclusion

There is a place in medical education for trauma-informed care principles as the research supports improved provider knowledge and skill equally have a positive impact on clinical practice (Thornton et al., 2025). Teaching providers through a trauma-informed framework is more than an educational technique, it is a commitment to reshaping health care culture in the academic and clinical settings. By modeling safety, transparency, collaboration, empowerment, and cultural humility throughout the learning process, educators help clinicians internalize the very skills their patients need most, thus avoiding re-traumatization. Ultimately, embedding trauma informed approaches within medical training not only enhances individual provider competence but also contributes to a more compassionate, equitable, and patient centered health care system.

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Advancing Trauma-Informed Care: Understanding Impacts & Holistic Strategies Across Healthcare Systems

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> *Trauma is not what happens to us, but what we hold inside in the absence of an empathetic witness.*
>
> **– Peter A. Levine**

Trauma can occur at any time during the lifespan and in a variety of ways. The term refers to an emotional and psychological response to an event or series of events that are deeply distressing or disturbing to an individual with lasting effects that can manifest physically, mentally, and/or spiritually. Sources of trauma can include natural disasters, political conflicts and wars, violent and nonviolent physical trauma, and emotionally traumatizing events. The most commonly referenced definition is from the Substance Abuse and Mental Health Services Administration (SAMHSA): “Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual’s functioning and mental, physical, social, emotional, or spiritual well-being” (2024a).

Trauma affects many people in a variety of ways. The response to a traumatic event can be determined by a variety of factors. The long-term manifestations of trauma often arise from Adverse Childhood Experiences (ACEs) such as abuse, neglect, separation from caregivers, exposure to violence, or the loss of a loved one. Trauma can have a profound and long-lasting effect on a child’s physical, emotional, social, and cognitive development. These effects last into adulthood and can take on a variety of behaviors, habits, and mindsets that affect the person and lead to health issues. However, the adverse effects of trauma can be prevented and mitigated through holistic services that are trauma-informed (Champine, Hoffman, & Matlin, 2022).

The prevalence of trauma is high, making it a subject that healthcare providers must be aware of and educated about. Six out of every ten men (60%) and five out of every ten women (50%) in the United States (U.S.) experience at least one form of trauma in their lifetime (United States

Department of Veterans Affairs, 2023). Healthcare providers must be educated on the effects of trauma and trauma-informed care strategies to optimize health outcomes. Despite the widespread experience of trauma in the population, a trauma-informed approach has not been universally integrated into the clinical standards of healthcare delivery. This article seeks to explore the causes, types, aspects, and effects of trauma. The information will be synthesized to outline trauma-informed strategies for healthcare providers.

Trauma Informed Care

Trauma-Informed Care (TIC) is an approach that promotes awareness of the prevalence of trauma and an understanding of its effects and how they may impact physical health and behaviors. The application of trauma-informed care is essential for care providers to deliver effective, compassionate, and holistic support to individuals who have experienced trauma. This approach is beneficial for both patients and providers as it fosters collaboration and often compliance. Trauma-informed care minimizes the potential for medical care to trigger trauma reactions, provides emotional support for the entire family, encourages positive coping, and offers anticipatory guidance regarding the recovery process. These practices enhance the quality of care for patients and their families, as well as the well-being of medical professionals and support staff (Marsac et al., 2016).

TIC does not replace a provider's clinical expertise; it enhances assessments and interventions by recognizing the profound impact of trauma and ACEs on health, behavior, and physical healing. TIC prioritizes physical and emotional safety through a relationship of trust that supports awareness of trauma, patient choice, collaborative communication, and patient empowerment. It provides a safe and respectful healing environment that considers the avoidance of triggers, each person's specific needs, patient engagement, and patient-provider or caregiver partnerships in the treatment process.

Types of Trauma

Toxic stress is a common form of trauma. Children growing up with toxic stress exhibit social issues, including difficulty forming healthy and stable relationships. They may also have unstable work habits as adults and struggle with finances, job stability, and depression or other mental health issues throughout their lives. These effects can also be passed on to their own children (Center for Healthcare Strategies, 2025).

CHILDHOOD TRAUMA

Childhood trauma can exist in three ways: individual, interpersonal, and collective trauma, including intergenerational trauma (APA, 2024). Individual trauma occurs as an event, series of events, or set of circumstances experienced by an individual as physically or emotionally harmful or life-threatening that has lasting and profound adverse effects on the individual's functioning, mental, physical, social, emotional, and/or spiritual well-being. Interpersonal trauma is an adverse childhood event that occurs within the family or a close network and includes child maltreatment, domestic and sexual violence, human trafficking, elder abuse, etc. The trauma can be personally experienced or witnessed. Interpersonal trauma consists of adverse events, including child maltreatment or neglect, domestic and sexual violence, or human trafficking. Collective trauma refers to cultural, historical, social, political, and structural traumas such as racism, bias, stigma, oppression, and genocide that impact individuals, families, and communities across time, distance, and generations (Grossman et al., 2021). Similarly, intergenerational trauma occurs when events experienced by one generation influence the psychological well-being and behaviors of subsequent generations (APA, 2024).

ACES SCREENING TOOL

Adverse childhood experiences, or ACEs, are potentially traumatic events that occur in childhood (0-17 years) (Center for Healthcare Strategies, 2025). Examples of ACES include experiencing or witnessing violence, abuse, or neglect, and having an unstable home with substance use, mental illness, instability, a family member attempting suicide or death by suicide, or the incarceration of a family member. Childhood traumas can be assessed using a variety of tools, including the ACES survey.

The ACES survey provides a score that can trigger a provider or educator to be alerted to the need for trauma-informed care. According to Swedo and colleagues (2024), preventing ACEs could reduce many health conditions. The authors contend that it is feasible that identifying and treating ACEs could reduce suicide attempts among high school students by as much as 89%, prescription pain medication misuse by as much as 84%, and persistent feelings of sadness and hopelessness by as much as 66%.

Assessment

Trauma is not defined by the event itself but by the individual’s experience and perception of the event. What is traumatic for one person may be less so or not traumatic for another person. Symptoms of trauma can also vary and include anxiety, depression, difficulty concentrating, aggression, hypervigilance, negative thoughts about oneself, feelings of guilt or shame, and self-harm or suicidal behaviors. The ways the body reacts to trauma (physical and psychological) can also vary. Trauma does not always manifest symptoms such as crying or sadness. It can show up as physical symptoms like tiredness, sleep issues, inability to focus, body aches, or feeling sick without a clear reason. These are the body’s ways of saying, “I need help!” Mental and physical problems are often meaningful responses to traumatic experiences.

The effects of trauma on physical health are varied and complex. Scherrer and colleagues (2019) found a range of mediators between PTSD and cardiovascular health, including depression, smoking, substance use, anxiety disorder, sleep disorder, obesity, diabetes, hypertension, and hyperlipidemia. A meta-analysis of 20 observational studies (both cross-sectional and longitudinal) conducted by Padhi and colleagues (2024) found that people with PTSD had an increased risk of any cardiovascular disease, including myocardial infarction and stroke. Hormone imbalances, particularly stress hormones (including cortisol), can dramatically increase, causing problems such as hypervigilance, chronic fatigue, weight gain, or malaise, and impaired cognitive and emotional functioning (Khoddam, 2021). In children, stress from traumatic events can slow down growth and development and cause learning difficulties or low academic performance (NCTSN, n.d.).

Provider Applications

A comprehensive approach to trauma-informed care must be adopted at the clinical and system levels. The traditional medical model focuses on identifying “What’s wrong with you?” rather than “What happened to you?”, which hinders a holistic trauma-informed approach. Providers and health systems often attempt to implement trauma-informed care at the clinical level without the support necessary for broad organizational culture change. This can lead to poorly implemented and often failed or unsustainable efforts to change day-to-day operations. A trauma-informed approach must include non-clinical staff, such as front desk workers and security personnel, and other associates who often have significant interactions with patients and can be critical to ensuring that patients feel safe (Center for Healthcare Strategies, 2025).

A TIC approach begins with training service and healthcare providers on the impacts of trauma and TIC. This involves changing the dynamics of human service roles so that workers who deal with trauma victims learn the “Four Rs” (realize, recognize, respond, resist re-traumatization). Implementing trauma-informed care requires a systematic and comprehensive approach that addresses several crucial elements within organizations and service delivery systems. The following strategies serve as foundational pillars in creating environments that are sensitive to the needs of trauma survivors:

- Realize and Acknowledge Trauma’s Impact: It is essential to recognize the widespread effects that trauma can have on individuals, families, and staff members. This awareness allows organizations to appreciate the far-reaching consequences of trauma and the importance of providing appropriate support.
- Recognition of Trauma Symptoms: Providers and staff must be able to identify the signs and symptoms of trauma not only in clients but also in families, colleagues, and others within the system. Early recognition is critical to ensuring that those affected receive the care and interventions they require. This includes screenings as part of routine assessments.
- Integration of Trauma Knowledge: Organizations should respond to trauma by thoroughly incorporating trauma-informed principles into their policies, procedures, and daily practices. This integration ensures that the entire system is aligned to support recovery and resilience among trauma survivors.
- Active Resistance to Re-traumatization: Efforts must be made using language and communication strategies that are sensitive to the patient’s experiences and avoid triggers. This commitment to safety and support helps create a healing environment. This includes using language and communication strategies that are sensitive to the patient’s experiences and avoid triggers.

Designing healthcare environments that promote a sense of safety and comfort with elements of privacy and teams that work together toward trauma-informed approaches can be beneficial. When a variety of health care practitioners and mental health clinicians work together, integrated care improves patient health outcomes by addressing the impacts of trauma on mental and physical health. An example of this is a working relationship between the emergency department, public health, and behavioral health department that facilitates a culture of care continuity and staff understanding of TIC (Goldstein et al., 2024). Together, these strategies support the development of trauma-informed environments that are attentive to the unique experiences of trauma survivors and that foster recovery, safety, and trust throughout all levels of interaction within the organization.

Impacts on Providers and Caregivers

Trauma-informed care has gained momentum due to its benefits for patients, but it is also an effective tool for providers, payers, and healthcare organizations. TIC fosters trust and communication, which can enhance the ways that patients interact with providers, promoting treatment adherence and collaborative care. Providers who use proactive trauma-informed delivery practices have improved job satisfaction with reduced compassion fatigue and burnout. Care based on trust and collaboration that promotes compliance will organically reduce costs through less emergency services utilization and better health outcomes. Trauma-informed care is a framework for human service roles that assumes that most individuals are more likely to have a history of trauma, and it acknowledges the role that trauma may play in the lives of service users, care providers, and the public. The victim ultimately gains a sense of lost control that was taken from the traumatic event (Berring et al., 2024).

Although the value of TIC is documented, individuals in helping professions, including nurses, physicians, psychologists, and teachers, are at risk for health issues. Professionals who work to mitigate suffering among individuals with mental health and physical health problems are at risk of adverse outcomes, such as secondary traumatic stress or burnout in relation to their work. Exposure to devastating stories of trauma, verbal abuse, or violence from the individuals served professionally, or harassment from colleagues, can cause mental and physical sequelae. These reactions may be exacerbated if the service providers themselves have experienced trauma in the past. Organizations should support a culture of staff wellness to ensure care providers are supported to prevent burnout from dealing with trauma (Center for Healthcare Strategies, 2025).

When individuals suffering from unaddressed trauma are not helped, it can influence the care provided and the workplace culture. For example, on a nursing unit, one individual with trauma in their past can create an unsafe organizational culture with constant arousal, untrusting relationships, unpredictable or inappropriate behavior, and struggles in coping with day-to-day life. This can be disruptive to the work and the culture and trigger other trauma-afflicted workers to also be on high alert and not function optimally. Thus, there is a significant need for organizational programs and leadership approaches that aim to change how the helping professions work with trauma and prevent victimization and self-traumatization (SAMHSA, 2024b).

Benefits for the Future

Collectively, policymakers, providers, schools, communities, and payers have a compelling call to confront the short- and long-term impacts of trauma. Through collaboration and focused efforts, these providers and those served can benefit from the effects of trauma-informed care, thereby improving health outcomes and reducing healthcare costs. All organizations that work with the public in a nurturing manner, including healthcare organizations, physician practices, schools, skilled care facilities, home care agencies, and others, should be educated on trauma-informed care. In a study by Lelinneth et al. (2024), physicians who participated in the research were asked to estimate the percentage of their patient caseload who have experienced trauma. Only 16% of the participant respondents reported that more than 50% of their patients experienced trauma, despite the documented high prevalence of trauma in the U.S. population. This could reflect a lack of familiarity with the pervasive nature of trauma or a lack of routine screening for trauma history and effects in patients.

Upstream prevention efforts should include providing high-quality trauma-informed approaches for new mothers and young children to strengthen parenting capacity and prevent trauma (Menschner & Maul, 2016). The identification of childhood traumatic issues and providing appropriate referrals is foundational for schools, healthcare service delivery organizations, and primary care providers. ACES and other screening tools can be used to identify and begin treating children who have experienced trauma. Early identification can trigger steps for appropriate interventions, as well as preventive strategies to reduce the risks of repeated traumatization.

One of the most significant advancements in trauma-informed healthcare is the integration of technology to improve access to care and innovative treatments. Telehealth platforms, mobile applications, and virtual reality therapies are being used to provide remote support and interventions for individuals who may face barriers to traditional, in-person care. These tools can improve outcomes and also potentially reduce emergency inpatient services utilization. Additionally, maintaining physical and mental health through proactive, collaborative, holistic, trauma-informed care is intrinsically more cost-effective than current treatment models.

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Appendix A: Comparison of Traditional Care vs. Trauma-Informed Care

Aspect of Care	Traditional Care	Trauma-Informed Care
Underlying Assumption	Focuses only on symptoms, diagnoses, and compliance	Awareness that many have trauma histories that affect health and behavior
Core Question	"What's wrong with you?"	"What happened to you?"
View of Patient Behavior	May interpret behaviors as resistance, noncompliance, difficult	Understands behaviors as adaptive responses to trauma
Approach to ACEs	ACEs are unrecognized or not assessed	Recognizes ACEs as significant contributors to lifelong health outcomes
Screening Practices	Routine clinical screening without trauma context	Trauma-sensitive screening with follow-up
Communication Style	Directive, task-focused	Respectful, empathetic, collaborative
Power Dynamics	Provider-driven decision-making	Shared decision-making and patient empowerment
Patient Choice	Limited choices, standardized processes	Choices offered whenever possible (timing, positioning, involvement)
Touch and Procedures	Touch may occur without explanation or consent	Explains procedures, asks permission, and prepares patients for what to expect

Aspect of Care	Traditional Care	Trauma-Informed Care
Response to Emotional Distress	May be seen as disruptive or inappropriate	Recognized as a trauma response requiring support and care
Care Environment	Efficiency-driven, may feel rushed or chaotic	Emphasizes physical and emotional safety and predictability
Focus on Safety	Primarily physical safety	Physical and psychological safety
Provider Role	Expert authority	Partner in healing
Staff Well-Being	Burnout and secondary trauma often unaddressed	Acknowledges vicarious trauma; supports staff resilience
Leadership Approach	Productivity and task completion emphasized	Psychological safety, trust, and supportive leadership prioritized
Impact on Outcomes	Short-term compliance	Improved engagement, satisfaction, adherence, and long-term outcomes
Risk of Re-traumatization	Higher due to a lack of awareness	Actively works to prevent re-traumatization

Implementing Trauma-Informed Care in Pediatric Palliative Care Through Organizational Development: Moving Beyond Training to Systems Change

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Trauma-informed care (TIC) has emerged as a critical framework in healthcare and social services, grounded in the recognition that exposure to trauma is widespread and shapes the experiences of patients, families, and healthcare providers alike. At its core, TIC acknowledges the pervasive impact of trauma and prioritizes the creation of environments that foster safety, trust, and dignity, with the explicit goal of preventing re-traumatization (Substance Abuse and Mental Health Services Administration [SAMHSA], 2014). While often introduced at the level of individual clinical interactions, a truly trauma-informed approach must extend beyond bedside practice to encompass organizational culture, policies, and workforce development (SAMHSA, 2014; Center for Health Care Strategies, n.d).

This broader lens is particularly important in pediatric palliative care settings, where clinicians encounter families who are experiencing chronic stress, anticipatory grief, and child loss. Furthermore, the family-centered approach of pediatrics is deeply relational work and can extend over long periods of time. For community-based pediatric home care and palliative care providers, additional challenges arise from delivering care in the patient's home. Challenges include limited immediate access to interdisciplinary team support, the potential for blurred professional boundaries, and deeper emotional engagement with patients and families. Further intensifying these challenges are systemic factors such as staffing shortages and administrative demands. Garnett, Mensa, and Nguyen (2023) describe how each of these components can contribute to emotional exhaustion in care providers and increase the risk of secondary traumatic stress, compassion fatigue, and burnout. The intensity of these experiences underscores the need for organizational approaches that proactively support provider well-being by embedding trauma-informed principles in both clinical care and organizational structures (Maslach & Leiter, 2016; Cavanagh et al., 2020).

At our organization, a MSW intern-led initiative was developed to introduce trauma-informed care principles to staff within a community-based pediatric palliative care program. Grounded in schools of social work that emphasize trauma-informed frameworks, this initiative aimed to equip interdisciplinary team members with foundational knowledge of trauma, its impact on both patients and providers, and strategies for delivering care through a trauma-informed lens. As an educational effort, it represented an important step toward aligning clinical practice with trauma-informed values.

The MSW intern-led training increased awareness of trauma and its impact, encouraged reflective practice, and promoted more intentional, empathetic interactions with patients and families. Staff were introduced to key concepts of TIC as outlined by SAMHSA (2014) and educated on the stress-response system, the impact of adverse experiences, and the importance of safety, trust, and cultural humility in care delivery. However, this initiative also revealed an important limitation: training alone is insufficient to sustain trauma-informed practice. Without parallel changes to organizational culture, policies, and leadership practices, the responsibility for implementing trauma-informed care remains largely on individual clinicians. This can inadvertently contribute to the very outcomes trauma-informed care seeks to prevent, including compassion fatigue and burnout. Thus, the MSW initiative not only served as an entry point for trauma-informed care but also highlighted the need to move beyond education toward a comprehensive organizational framework.

TIC starts within the organization because healthcare employees cannot implement it if they are not receiving it themselves. Kim and colleagues (2021) highlight a study by Felitti and colleagues (1998) on Adverse Childhood Experiences, in which over half of the participants experienced at least one traumatic event. These results show that it is more than likely that the employees who are treating victims of trauma have also experienced trauma. Thus, at the organizational level, the culture must include reframing the mindset from “What is wrong with you?” to “What happened to you, and what do you need to feel safe, respected, and supported?” (Center for Health Care strategies, n.d). One strategy to make this shift is to implement a Trauma-informed Care Self-Assessment for all employees which would allow the organization to know where to start with integrating a trauma-informed culture (Kim et al., 2021). Additionally, it is crucial to train the staff, including leadership, interns, clinicians, administrative staff, and volunteers, on trauma, the stress-response system, emotional regulation, and cultural humility. This training will help all staff respond to patients and each other without judgment or bias. Staff training must include identifying the signs of secondary traumatic stress, compassion fatigue, and burnout, and ways to lessen their impact such as resilience training and self-care.

At the organizational level, trauma-informed care requires structural commitments that extend beyond assessment and trainings alone, including the intentional integration of trauma-informed principles into workforce support, operational policies, and organizational culture (SAMHSA, 2014). Creating an environment for staff to express their thoughts and feelings without fear of judgment or repercussions is paramount to fostering psychological safety in an organization. Implementing reflective supervision, manageable caseloads, debriefing on difficult cases, and wellness resources so staff feel supported will further prevent burnout. These strategies represent system-level interventions that shift trauma-informed care from an individual responsibility to an organizational priority.

By addressing workload, access to support, and team-based care structures, organizations can proactively mitigate the conditions that lead to compassion fatigue. Building on the foundation established by the MSW intern-led training, these organizational strategies create the conditions necessary for trauma-informed care to be practiced consistently and sustainably across all levels of the organization.

Overall, implementing trauma-informed care at an organizational level ultimately requires a sustained culture shift that recognizes the impact of trauma on both clients and employees. Without these systemic supports, the burden of trauma-informed practice remains on individual providers, increasing the risk of burnout and turnover. In contrast, embedding trauma-informed principles into organizational systems supports staff well-being, strengthens retention, and enhances continuity and quality of care for patients and families. In pediatric palliative care, where relationships are central and sustained over time, this integration is not optional but essential.

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A Trauma-Informed Approach to Supporting Nicu Providers

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In neonatology, conversations about life and death often begin simultaneously, sometimes weeks before a baby is born. We know the general rule: maturity equals better outcomes. When neonates are born in the “grey zone,” the periviability threshold between 22 and 25 weeks gestation, the clinical team enters a space of profound uncertainty. Here, the struggle is as emotional and moral as it is medical. Because these premature patients cannot advocate for themselves, the team must also guide families through high-stakes decisions, often before parents can truly grasp the lifelong weight of their choices. When the “right to life” clashes with the “right to die,” the resulting tension creates a lingering traumatic residue, affecting not only the family but the doctors, nurses, advanced practice providers, and therapists providing the care.

Therefore, there is an “invisible patient” in the room who frequently goes forgotten: the healthcare provider. Tasked with the heavy responsibility of navigating families through impossible choices, these providers become permanent witnesses to repeated suffering and complex ethical dilemmas. While trauma-informed care (TIC) typically focuses on the feelings and interactions of the patient, in high-stakes environments like the neonatal intensive care unit (NICU), the provider also carries a significant traumatic burden. In this setting, where the clinical and the emotional are inextricably linked, the healthcare provider truly becomes the “invisible patient” in the room.

This article explores how trauma-informed care can address moral distress of providers and systemic communication barriers to support the resilience of the NICU team in the setting of periviability.

Trauma-informed care is frequently discussed as a framework for patient interaction, emphasizing safety, trustworthiness, and empowerment. However, a critical second component of TIC involves its impact on the care team, and this part is often forgotten. In a trauma-informed system, we must acknowledge the “Parallel Process”: the concept that the way an institution treats its staff will be reflected in how that staff treats its patients.

If a nurse feels silenced by hierarchy, or if a physician feels the weight of a decision alone, the “safety” of the unit is compromised. TIC for providers acknowledges that the NICU is an environment of chronic stress. In this setting, communication is not just a soft skill; it is a clinical tool for trauma mitigation. When communication breaks down, it results in more than just “mismatched expectations”; it results in moral injury.

To understand the depth of this impact, we conducted an electronic survey of 163 NICU providers at a single-center, level IV high-acuity NICU, including bedside nurses (RNs), advanced practice providers (APPs), and physicians (MDs). The high response rate of 76% speaks volumes; the staff is not just willing to talk about these issues, but they are desperate to be heard.

The survey revealed a significant rift in perception. While the team works in the same physical space, they often live in different emotional realities. We found that, in general, 51% of respondents felt team communication was only "sometimes optimal," while 27% felt it was "rarely optimal." Most tellingly, in the physician/advanced practice provider group, not a single participant believed communication was "always optimal." This widespread dissatisfaction is a primary driver of staff burnout and secondary traumatic stress.

One of the most striking findings of the study was the discrepancy regarding the periviability threshold. When asked if they agreed with resuscitating a neonate born at 22 weeks, only 4% of RNs agreed, compared to 28% of physician/advance practice providers.

This gap highlights a fundamental source of trauma for the bedside nurse. While physicians may focus on the latest literature and the "possibility of survival" (the principle of beneficence), the nurse is at the bedside 24 hours a day. Nurses are the ones performing the "pain-inducing procedures" and witnessing the daily suffering of a neonate who may have no realistic path to a functional life. When nurses are required to participate and support aggressive resuscitation that they believe is not in the baby's best interest, they experience moral distress. Over time, being forced to act against one's moral compass leads to professional detachment and emotional exhaustion.

A trauma-informed workplace requires safety and transparency. However, our qualitative data showed that hierarchical dynamics continue to muzzle the care team. Lateral communication among peers was reported as "frank and expansive," while communication across disciplines was described as guarded.

Bedside nurses reported feeling "invisible" during rounds, stating that their clinical observations, and the intimate fears confided in them by parents, were often ignored. In a TIC framework, this exclusion is a form of systemic trauma. It creates a culture where the "frontline" feels unsupported by the "leadership," leading to a breakdown in trust that eventually reaches the family. If the team cannot trust one another, the family cannot trust the team.

This breakdown in trust is further exacerbated by a lack of prognostic alignment among the physicians themselves. Because neonatologists rotate frequently, the absence of a standardized, thorough handoff process often results in a "fragmented" plan of care. When physicians are not on the same page, each new provider may offer a slightly different perspective to the parents. This inconsistency not only confuses families but also leaves ancillary staff feeling as though they are providing care without a clear, unified front.

However, the distress is not limited to those at the bedside; it reaches the very top of the medical hierarchy. Physicians also carry a unique, silent burden. Their hands are frequently tied by the ethical duty of honoring and respecting parental autonomy, even when a family's choice results in interventions the doctor knows to be futile. Physicians possess the clinical wisdom to recognize when a certain course of action will lead to suffering without benefit, yet it is incredibly difficult to explain this foresight to new parents who have not witnessed the realities of the "grey zone."

Watching different families repeat the same heart-wrenching choices, knowing from years of experience exactly where that path leads, creates a cumulative moral distress among physicians. For the physician, the trauma is not limited to just a single event; it is the weight of repeatedly witnessing avoidable suffering while feeling powerless to prevent it. Ultimately, the "invisibility" felt by the nurses and the "entrapment" felt by the physicians are two faces of the same coin: a systemic failure to protect the moral and emotional integrity of the care team.

As we approach May 2026, the science of neonatology will continue to push the boundaries of what is possible. But as we advance our ability to "save" smaller and smaller lives, we must also advance our ability to support the humans doing the work.

The findings of this study confirm that communication failure is not just an administrative issue; it is a source of trauma. When we ignore the bedside nurse, when we use ambiguous language with parents, and when we fail to provide continuity, we are inflicting a moral injury on our care teams. Furthermore, we must acknowledge the "ethical coercion" of the physician, who is often forced to facilitate interventions they know to be futile, bound by a duty to honor autonomy while carrying the heavy burden of predicted suffering.

Protecting the moral integrity of the NICU staff is essential. A provider who is drowning in moral distress cannot provide the compassionate, clear-eyed guidance that families in the "grey zone" so desperately need. By implementing trauma-informed systemic changes, we don't just improve communication, we uphold the very humanity that makes neonatal care possible.

Impact of Physician Language & Attitudes on Pediatric Patient Well-Being & Outcomes

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Introduction

Physician language and attitudes, as they pertain to pediatric well-being and outcomes, are relevant both in clinical and hospital settings. Children represent a uniquely vulnerable position in that children demonstrate limited control and exhibit increased heightened sensitivity to tone, body language, and relational cues. Their parents also are open to duress while supporting their children through medical interactions. In this environment, “trustful relationships” should be integrated with professional behaviors and contextual factors to build a dynamic, reciprocal connection. Such relationships lead to reduced anxiety, better engagement, and improved health outcomes for children (Dickens et al., 2025). Because trust is built or eroded in real time through communication, the language and attitude that physicians choose can meaningfully lead to a safe, respectful, and collaborative experience for the child and family (Dickens et al., 2025).

Hospice Provider Case Study

A wonderful 16 y/o female with a normal birth and past medical history first presented to her primary care office approximately 3 years ago with concerning gastrointestinal findings. She demonstrated increased abdominal pain, as well as food intolerance with associated vomiting at that time. She was initially treated for reflux disease and cyclical vomiting syndrome for approximately one and a half years by her gastroenterologist with little benefit. She was subsequently diagnosed with Median Arcuate Ligament Syndrome (MALS) by an outside specialist and underwent a surgical procedure in Pennsylvania. Her symptoms stabilized for approximately six months afterwards before she developed recurrent vomiting. She then was diagnosed with Superior Mesenteric Artery Syndrome (SMA) and underwent a second surgical procedure (Alveolar) in Texas, with some benefit, yet overall guarded condition persisted. Her vomiting events increased as well as her overall pain, while her overall well-being decreased. Currently, both the patient and her mother remain stressed, and their medical interactions have now led to certain distrust about the patient's future. The patient entered palliative care services to ascertain what other options might exist for her.

Detrimental Experiences Lead to Parental Fears

Normalization of shorthand labels and dehumanizing language in a clinical setting can subtly shift how patients and families are perceived. Many medical records contain stigmatizing descriptors, and these can transmit bias to subsequent clinicians. Also, experimental evidence indicates that exposure to such language is associated with more negative attitudes toward patients and less active management recommendations (Goddu et al., 2018). Notably, harm through language not only occurs through what is said to families and patients, but also through what they overhear or what they sense through a healthcare team's energy and demeanor. One particular study notes how overheard diagnostic language can be damaging to perioperative patients, and it explicitly states to avoid dehumanizing or devaluing language as it risks patient/family loss of trust and increased distress (Katz et al., 2022). In pediatrics, these negative dynamics can lead to severe consequences, where parents often interpret communication as a representation of whether the team is truly with their child.

This matters a lot in our pediatric settings because child illness and hospitalization can be traumatic in their own right, and the relational aspect is part of the care that they receive. A systematic review of pediatric medical post-traumatic stress disorder (PMTS) pinpoints hospital practices and interactions with healthcare professionals as key contexts for traumatic experience (Marcev et al., 2025). Importantly, poor communication, such as indifferent or detached update delivery, overlooking parent expertise, and "distressing language and terminology," are highlighted as high-risk factors for PMTS risk for both parents and children (Marcev et al., 2025). The same article also stresses that communication by healthcare members and hospital environments is connected to PMTS, underscoring that communication is not a soft variable and that it is a changeable aspect of clinical risk and recovery (Marcev et al., 2025).

Mother and Child In Case Feel Scorned

During the first palliative care visit, both the mother and pediatric patient appeared tentative to speak during the session. When given the opportunity to freely engage, they expressed hope that “more could be done” but were hesitant to fully trust the process. Although they earnestly sought to mention positive experiences, as it related to their original experience, it was obvious that they also were quite wounded. The mother shared that during the initial medical process, the family was “fired” by their assigned gastroenterologist because they were not receptive to the idea that the patient needed psychotherapy for her symptoms. The mother requested further workup including a surgical consultation when initial medicinal treatments proved ineffective. She felt dismissed when her child was referred to a therapist instead and therefore sought surgical intervention on her own, which later proved fruitful. Furthermore, the mother shared that intermittently various staff members acted “cold” towards the patient because of the repetitive nature that she returned to various hospital emergency rooms or floors when suffering. Instead of welcoming the opportunity to continue to improve the patient’s medical condition, the patient was reminded of her inability to “not adequately take the meds prescribed”, “not doing the necessary steps already mentioned,” and essentially placing the patient in a sense of blame. Her mother further shared that her daughter adamantly requests her meds at their scheduled times, avoids foods that appear to agitate her stomach, and essentially does truthfully want to get better. It is hard to imagine what any adolescent must feel like while in a similar situation, but hopefully without the burden of representing a “frequent flyer,” “attention seeking,” or any of the other stigmatized terminology intermittently heard on medical floors.

Always Opportunity To Engage Appropriately

Building and maintaining healthy clinical settings through language and relational practice requires recognizing the pressures on care teams and building systems that support compassionate, trauma-informed communication. Another systematic review emphasizes the need for compassionate care of children and young adults. They, as well as their family units, need caring respectful validation, active listening, and open communication as foundational elements of a therapeutic partnership (Scannelli, 2022). The authors also describe how ignorant attitudes and power imbalances damage connection and trust (Scannelli, 2022). It is crucial to note that families consistently feel trust-building when physicians value parental expertise and make space for genuine dialogue (Vusio, Odentz, & Plunkett, 2025). Taken together, this literature supports a central premise for trauma-informed pediatric care: clinician language and attitudes can influence immediate distress, trust, shared decision-making, and downstream well-being for both child and family.

The Mother and Patient Now Feel Supported

At the end of the first visit, the mother requested that I contact a tertiary center two hours away to have the patient admitted for further testing and possible nasojejunal tube (NJ) placement. The patient now vomited at least four times daily and lost over 10% of her body weight in the past two months. I called her later that evening after first speaking with one of the gastroenterologists at the requested facility. The established goal was to have the patient first examined in the outpatient setting then consider further workup if necessary afterwards. The mother’s first reaction was one of frustration and shared that palliative care "didn't seem to do any more that anyone else cared to do." I asked her politely for patience with the process noting that it was a weekend and that the center did not have a prior relationship with the patient. I further mentioned that I was clearly supporting the overall needs of the patient, that I believed that the patient's condition was real, and that I would continue to work for her in any way possible to help her achieve better health. I called the mother the following day and she was quite tearful and moved to apologize for "striking out at me." I shared that she was in fact respectful in her approach and I could only imagine how stuck she actually felt. I was able to make the needed referral to the center, and the patient began the necessary workup as requested. She was actually hospitalized accordingly for her stated condition and her mother and I have entered a relationship that I can only hope remains fruitful enough to help reestablish some of her hope and more importantly the patient's overall health.

Conclusion

Language and attitudes in the clinical setting play a significant role in pediatric patient well-being, forming trust, emotional bonding, and long-term engagement with care. As shown in the hospice provider's case and supported literature, communication functions as a modifiable clinical variable that can either aggravate distress or enhance healing. For children and families with chronic and complex illness, the words, tones, and relationships built by physicians can greatly influence perception of legitimacy, hope, and partnership.

This case illustrates how continuous exposure to stigmatizing language shaped parental fear, erosion of trust, and emotional harm, even without malevolent intent. On the other hand, efforts such as using validating language, acknowledgement of parental expertise, and transparent advocacy contributed to a therapeutic alliance and allowed care to move forward constructively. Most importantly, novel medical intervention was not required for this transformation, rather only a deliberate shift in communication and relational engagement.

All together, these findings tell us the importance of ethical and clinical responsibility of healthcare professionals to remain vigilant as to how language and attitudes are experienced by pediatric patients and their families. Incorporating trauma-informed, compassionate communication into routine practice represents an opportunity to reduce harm, strengthen trust, and support both immediate and downstream well-being. In pediatric care, how clinicians speak may matter just as much as what they do.

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Trauma Considerations With Creative Arts Therapies

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Per the Center for Disease Control (2025), it is estimated that approximately 21% of children between the ages of 3 and 17 have been diagnosed with a mental, emotional, or behavioral disorder. With high percentages of children suffering from anxiety (11%) and depression, this statistic would indicate a high degree of adverse childhood events and trauma that can then have a lasting effect on development and interaction. In fact, an AAP article by Forkey and colleagues (2021) indicates that the physiologic effect of trauma can include brain connectivity, epigenetic changes such as methylation patterns, and immune dysfunction. It is essential that all clinicians and healthcare professionals working with children utilize trauma-informed approaches in their practice to help mitigate the ongoing mental health crises of children and young adults.

In a therapeutic context, literature often focuses on the psychological and medical approach with children who have a history of trauma or are anticipated to experience trauma due to a diagnosis or treatment. The inclusion of Creative Arts Therapies (CAT), such as music or art therapy, is often thought to be a “fun outlet” to help cope with trauma; however, there are many considerations, contraindications, approaches with the inclusion of Integrative and CAT that must be explored to prevent ongoing traumatization and to help funnel supportive services in the appropriate manner. As an introduction, this article sets forth information that is intended to encourage ongoing and comprehensive discussions in co-treating and referring children to CAT under a trauma-informed lens.

Approach

As a referring source for CAT, it is imperative to take into account the special circumstances surrounding the child’s situation, existing familial and psychological supports, and the resources at hand (Hicks, 2008). Although tempting to refer for enjoyment or distraction, proper assessment should take place to ensure that the referral is appropriate and rooted in clinical reasoning. This may include emotional processing, decreasing anxiety, promoting positive coping, and more. Ongoing collaboration may be indicated to ensure that CAT approaches remain in line with the care plan and within their scope as the creative arts therapist.

As a creative arts therapist, treatment planning and assessment should take place to ensure that therapeutic goals are addressing the primary issues prior to the secondary (Heiderscheit & Murphy,

2021) and that interventions are limiting the potential for traumatization. Assessment will include a thorough history of any past traumatic instances, prolonged stress, complex medical or psychological needs, and stress response indicators (such as a tendency for fight, flight, or freeze). Additionally, CAT trauma assessment should include a summary of all the protective factors and support available to the child that will be ongoing and consistent.

Interventions should target at enhancing resilience and coping by promoting existing mechanisms in place. When we take Lazarus and Folkman's Stress Coping Model (1984), we know that stress is not merely a response to external factors, but also how someone perceives and evaluates those stimuli as it is presented. This indicates the importance of engaging with a child in the creation of their care plan and allowing the them the space to share their own story rather than anticipating or assigning their stress/trauma based on observation. Looking at resilience is a key factor in identify appropriate strategies within CAT that would be safe and effective. For example, looking at the THREADS Model published by Forkey, Griffin, and Szilagyi (2021) that outlines the adaptational mechanisms of resilience that should be assessed:

T: Thinking and Learning Brain (Cognitive Development)
H: Hope, Optimism, Faith in Oneself
R: Regulation and Self-Control
E: Efficacy (Sense that one can impact their environments/outcomes)
A: Attachments
D: Development and Mastery
S: Social Context

The Creative Arts feature exploration, production, and analysis; this allows the child to bring emotions as well as their coping and resilience strategies to the forefront. Intervention should be fluid and responsive to the needs as they arise with proper supports in place both for the child and the clinician themselves.

Considerations and Contraindications for Creative Arts Therapies

In working with individuals at any age, consideration must be taken into the range of trauma experiences, symptoms and the individual's response (Forkey, Griffin, & Szilagyi, 2021). Children will often process and respond to trauma differently than an adult as dependent on their age, brain development, and protective factors. CAT can promote an opening of the mind, spirit, and heart with a unique ability to adapt to the client quickly despite atypical presentation. This can be validating, meaningful, and expressive for children as they are accessing their own thoughts and feelings from an experience. However, all clinicians should take special care at "reducing potential for triggering symptomatology, traumatic memories, or experiences" (Heiderscheit & Murphy, 2021) when bringing these thoughts and feelings forward. In CAT, extensive assessment and monitoring can help reduce this potential in conjunction with the appropriate level of supervision; however, the therapist should also be prepared and practiced in the skill to mediate moments with traumatic memories and experiences are brought to the surface during sessions.

CAT has the capability to connect with children in a developmentally appropriate and accessible manner; however, this connection can also prevent, hinder, or exacerbate any disorder in attachment. In children, there should be significant weight placed on attachment and the recognition that trust, safety, and security are essential building blocks (Forkey, Griffin, & Szilagyi, 2021) to both rapport and ongoing response to psychological treatment. The Creative Arts Therapist should take special precautions of intervention that could disrupt this and consider the length of treatment and boundaries placed on engaging with the child and family.

Although there are many aspects of trauma to which CAT can respond and provide healing assistance to children experiencing or with a history of trauma, there are also contraindications of when CAT should be initially referred. That is to say that there should be special care and pause when utilizing CAT if one of the following are present:

- Active trauma/Peri-Trauma referring to situations in which medical providers are caring for children as the traumatic events are unfolding (Forkey, Griffin, & Szilagyi, 2021)
- Limited training or access to consultation or ongoing supervision
- Child and/or Family have limited support systems, both socially and psychologically

All clinicians, practitioners, therapists, and providers have a responsibility to operate within their professional scope with adequate training and supervision as appropriate. By practicing ethically and collaboratively, children with trauma and mental health disorder have a greater chance for building a strong foundation that can hold the structure of ongoing psychological care.

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Self-Care & Resiliency: Vital Keys to Sustaining Essential Practices in Compassionately Supporting Those Entrusted to Our Care

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In Pediatric Palliative Care, we strive to provide an additional layer of support, mitigate suffering in all its forms, and try to make every day the very best it can be! This passion to provide the most compassionate presence to those entrusted to our care and to sustain our resiliency and maintain our personal wellness is a delicate balancing act which requires strategic planning to always have some reserve in our tanks when the need arises.

According to the HPNA (Hospice and Palliative Nurses Association) Palliative Nursing Manual: Pediatric Palliative Care, "Pediatric hospice and palliative care nursing requires specialized knowledge, training and sensitivity to families enduring some of the most arduous moments of their lives."1 In palliative care, we "lean in" to support those in great need. "Providing this type of care throughout the illness process, from diagnosis until death, can be simultaneously challenging, physically and emotionally draining, enriching and meaningful."[1]

To serve well, it is essential that we take good care of ourselves. This allows us to do our best in supporting those entrusted to our care. Remember to be gentle with yourself! Practice an attitude of gratitude to promote resiliency!

"Palliative nursing has an ethos, a moral character, that builds meaning in the context of serious illness and death and dying."[2] Each individual draws upon their own sources of strength and meaning in their life and in the calls they pursue in their life work. To maintain a focused and healthy outlook, we must strive for ways to recharge and find meaning and gratitude. We are then better able to offer authentic presence and compassion with those entrusted to our care.

Walking with those entrusted to our care is a humble privilege. This is a time when patients and families may feel most vulnerable. We may offer our expertise and compassion to walk beside them on their journey as an additional layer of support. Attentive listening is so important to carefully hear their desires and wishes.

An important coping skill can be hope. “When we have a gentle, healthy, and strong inner life, we are part of the healing stillness in the world which offers places of hope to all who suffer and yearn for justice, solace, and encouragement.”[3]

> *“I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.”*
>
> **– Maya Angelou**

“Perinatal and neonatal palliative professionals bear witness to families’ experiences of serious illness when birth and death are separated by the briefest of timeframes.”[5]

This tender work of caring for perinatal, neonatal, and pediatric patients is impactful on many levels, emotionally, spiritually, and physically. Thus, all caregivers should make a commitment to nurture and practice self-care to maintain and build resiliency.

Building resilience is important in rebounding or recovering from difficult events. It is our coping skills developed along the way to help us adapt to stress or trauma that helps us to build upon our resiliency. This is a flexible process which may be strengthened and developed. In Pediatric Palliative Care, resilience may also function as “the capacity to see each clinical encounter as a new opportunity to learn and be helpful to the self and others.”[4]

A beautiful reflection with gratitude and grace for those who provide compassionate care to our beautiful babies, children, teens, young adults and families. It is so important for our resiliency and sincere compassion. You are certainly worth it!

Grace

Give me the grace To care,
Without neglecting my needs,
The humility To assist, Without rescuing,
The kindness To be clear, Without being cold,
The mercy To be angry, Without rejecting,
The prudence To disclose, Without disrespecting my privacy,
The humor To admit human failings, Without experiencing shame,
The compassion To give freely,
Without giving myself away

– Source Unknown

Good Self-Care is Essential to Continue to Provide Compassionate Care

What do you do to relax and recharge? Healthy Habits to promote stress reduction:

Diet and exercise
Rest well
Time with family and friends
Stay positive- develop an attitude of gratitude!
Keep the Faith- time in prayer
Hobbies- crafts, reading, cooking
Quiet time for reflection
Whatever brings you joy!

Keep in mind that you cannot give what you do not have!

One way to honor those we care for is to support them in rituals during the sacred time they share with their beloved. These can be personal experiences which have deep meaning for families. Debriefing with the care team is an important aspect for processing and honoring those whom we have cared for and the impact they have left on us.

A wonderful chapter included in Handbook of Perinatal and Neonatal Palliative Care focuses on Strategies to Honor Professional Well Being in Perinatal and Neonatal Care. I would like to provide a summary of suggestions which I feel are quite applicable to all those who also compassionately serve our pediatric, teens and young adult patients and families.

“Perinatal and neonatal palliative professionals bear witness to families’ experiences of serious illness when birth and death are separated by the briefest of timeframes.”[5]

To honor professional well-being, is a way of building on our resiliency so recovery and restoration can take place as we care for many patients and families entrusted to our care. Without an intentional pause to reflect and recharge, a health provider runs a great risk of burnout, thus impacting the ability to care for others as well as themselves. Let us take a close look at these suggestions and see what works well for everyone. It will be unique for each individual, yet exploring the options may offer valuable opportunities. This allows us to proactively build up our reserve and resiliency while we compassionately care for our patients and families, ourselves, and our family. Helping to set priorities and maintain a healthy perspective will allow us to give our best selves in our lives.

May the summary of words and suggestions “offer permission to pause, reflect, and hold space for reconnecting to that which is most important.” As we reflect on these suggestions,” may each reader feel re-energized and reminded of the unique gift of self they bring to each patient encounter.”

> “We can’t practice compassion with other people
> if we can’t treat ourselves kindly.”
>
> **– Brene Brown**

SELF-INVENTORY:

“Knowing oneself is a lifelong activity essential to both personal and professional well-being, reflection on personal beliefs, preferences, strengths and challenges.”[5]

4 STEP PRAM MODEL BEFORE EACH ENCOUNTER:

Pause (perhaps take a deep cleansing breath)
Reflect- anticipate the visit at hand
Acknowledge–any expectations, emotions, or thoughts
Mindful–focus on being present to those we serve

REFLECTIVE PRACTICE:

- Consider practices to incorporate into your routine which may be beneficial. Such as a deep breath, silent prayer or inspirational thought at arrival to work to start your day.
- Develop an end of the day ritual to transition from work to home. This may be as simple as shedding your nametag or playing some music in your car on the way home.

JOURNALING:

What brought you, Joy?

A difficult moment that you impacted with compassion and expertise.

LETTER WRITING:

Write a letter to yourself with ways to promote good self-care after a challenging day.

GRATITUDE JOURNAL

Gratitude Journal to focus on those things we are thankful for and bring joy and meaning!

Please allow yourself to reflect on the kindness and grace we give to ourselves each day.

"Through the giving of self to the smallest of patients in your care
May you experience fulfillment,
find meaning,
and experience daily reminders
Of the value that is wrapped up in the incredible gift of you.
May the work of your hands and heart, continue to be blessed."[6]

Thank you for sharing your passion to serve those entrusted to your compassionate care!

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Adaptation & Beta Testing of Group Problem Management+ for Family Caregivers of Children with Rare Diseases: Rare Group PM+

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There are few scientifically rigorous pediatric studies of the psychological impact of rare diseases on family caregivers. Psychological evaluation and support for family caregivers of children with rare disorders was highly variable.[1] Parents consistently report elevated levels of depression, anxiety, and stress.[2] Rare disease support groups are an important source of emotional and practical support. However, there is no trial evidence on the risks and benefits of these groups or what is needed to sustain them.[3] Most support groups are informal online groups, some of which are disease specific.[4,5] Three-fourths of Facebook support groups for rare pediatric diseases are private.[6]

We consulted with our Rare Community Advisory Board (CAB) about what kinds of psychological group support they would prefer. A traditional 12-week psychotherapy group was unacceptable because of time constraints. The World Health Organization's (WHO) Group Problem Management Plus (Group PM+),[7] a five-session evidence-based intervention, was an acceptable alternative. Prior randomized clinical trials demonstrated that Group PM+ was effective in providing psychological support for adults impaired by distress in communities exposed to adversity.[8,9] This model uses trained nonprofessionals to administer the intervention under the supervision of a licensed professional, increasing its scalability and deceasing cost.

The primary objective of this study was to adapt Group PM+ for family caregivers of children with rare diseases and to administer it through telehealth. Benchmarks for acceptability and feasibility were: retention rate of greater than 85% at two weeks post-intervention; attendance at greater than 50% of 5 sessions; greater than 90% data completeness. Secondary objective was to evaluate the mean change in self-reported symptoms of anxiety, depression and post-traumatic stress disorder (PTSD) at 2 weeks post-intervention.

Methods

We conducted a single-arm development, feasibility, and acceptability study which also examined initial efficacy of the adapted intervention. We used a non-experimental, pre-test post-test design to test if mean changes in scores for anxiety, depression, and PTSD, improved from baseline to approximately 2 weeks post-intervention. Eligibility criteria were: >18.0 years at enrollment; the legal guardian and caregiver of a child with a rare disease. Secondary screening determined the potential participant was not actively homicidal, suicidal, psychotic, or cognitively impaired but experiencing psychological distress. Families were recruited from Children's National Hospital. Families from the CAB were excluded. The group facilitators/researchers were not involved in the clinical care of participants.

ETHICS APPROVAL STATEMENT

The institutional review board (IRB) of Children's National, IRBear, approved this protocol. The approval IRB ID number is IRBear STUDY00001049. Participants provided written informed e-consent. There were no waivers or exemptions from ethics approval. No participant compensation or incentives were provided.

STUDY PROCEDURES & TRAINING

Participants were recruited by their providers between May 15, 2024, and March 18, 2025. The first group ran from October 19, 2024 through November 26, 2024, from noon to 1:30 p.m. The second group ran from March 18, 2025 through April 15, 2025, from 5:15-6:45 pm. Training of facilitators (DS, AA), who were not mental health professionals, followed the WHO training curriculum for Group PM+.[7] DS and AA co-facilitated one group each with Dr. Lyon present.

RARE GROUP PM+ INTERVENTION

Session 1. Managing Stress

Session 1 began with brief introductions, an outline of logistics, and expectations, including confidentiality. Participants learned a brief stress management strategy which focused on slow breathing. Other effective local relaxation methods were introduced.[6] Managing Stress was practiced at the end of every session.

Session 2. Managing Problems

This strategy was applied to situations where a participant was experiencing practical problems. Participants work together to consider possible solutions to the problem that was causing them the most concern. Jointly, they choose solutions that were most helpful to influence their problem and then planned a strategy to carry out these solutions in the coming week.

Session 3. Get Going, Keep Doing

This strategy targeted depression and inactivity. It aims to increase participants' activity levels (e.g. social activities or carrying out necessary tasks or jobs), which had a direct impact on their mood.

Session 4. Strengthening Social Support
Family caregivers of children with rare diseases often feel isolated from supportive people and organizations. Strengthening participants' social support (e.g., with trusted friends, family, co-workers or community organizations) promotes well-being. If a participant appears to have good social support and uses it regularly, they were encouraged to continue to do so. However, for other participants, time was spent discussing how they could strengthen their social support and help them to develop a practical plan to receive greater social support.

5. Staying Well and Looking Forward
This session is a review of all of the PM+ strategies. Discussion highlighted how to stay well and plan for the future. The session ended with a closing ceremony and the suggestion that the group members keep in touch in the future.

FOLLOW-UP

Attendance was recorded to assess effects of full vs. partial participation in Rare Group PM+. Study staff obtained follow-up measures from families at approximately 2-weeks post-intervention (study window of +/- 2 weeks) by telemedicine. Missed sessions were made up by using the individual module (2 participants used this on one occasion each) which contained the same skills and strategies as the group session.

DATA SOURCE AND MEASURES

Participants completed questionnaires via Telemedicine at baseline and 2-weeks post intervention. To control for literacy, understanding, and to ensure data completeness, the researcher read the questions aloud on a shared screen and entered the family's responses directly into the REDCap database.

Demographic Questionnaire: age, education, marital status, work status.

Generalized Anxiety Disorder-7 (GAD-7) is a well-established screening tool to assess symptoms of generalized anxiety disorder.[10] The GAD-7 items include Nervousness, Inability to stop worrying, Excessive worry, Restlessness, Difficulty in relaxing, Easy irritation, Fear of something awful happening.

Patient Health Questionnaire-9 (PHQ-9) is a well-established screening tool to assess symptoms and severity of depression over the past two weeks.[11] One of the nine items assesses suicidality and was used to screen for suicidality and referral.

Post-Traumatic Stress Disorder (PTSD) Symptoms Checklist for Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (PCL-5)[12] is a 20-item self-report measure of the DSM-5 symptoms of PTSD.

Results

PARTICIPANT CHARACTERISTICS

Participants (N=8) were mean age 40 years; 88% were female; 12% were Black/African American; 12% were Asian; 12% Hispanic; 63% were White. 50% were full-time employed. Thirty-eight percent were married. Initial eligibility criteria were met by 27 referred participants. Of these, 5 declined and 10 were unreachable. Of those interested in participating, 4 were not consented and 8 were consented and enrolled. All passed secondary screening, leaving an enrollment rate of 47% (8/17).

Of those enrolled, 100% attended Sessions 1 through 5. Three participants missed one session each, all of which were remediated individually prior to the next session. The overall retention rate at 2-week follow-up was 100% (8/8), exceeding our benchmark of 85% retention. During Session 1 participants were asked to list barriers they needed to overcome to join the group. Of note were (1) planning around their children's medical appointments and school, (2) concerns for re-traumatization when sharing their stories, (3) worries that confidentiality may not be maintained, (4) trusting that participants can stay respectful to one another, (5) uncertainty on if the group would be beneficial, and (6) preference for a disease specific group.

Regarding initial efficacy, participants reported that the group helped reduce their isolation, increase their self-worth, made them feel more supported and less alone in their struggles caring for their child. PCL-5 and GAD-7 scores improved from baseline to follow up (Figure 1). PCL-5 went from a median of 29 to 17.5, GAD-7 from 11.5 to 4.5. Although PHQ-9 median scores dropped, our analysis showed no significant difference between the two. Of note, one of the participants had a PCL-5 score of 38 at baseline, meeting the criteria for diagnosing PTSD. Her score decreased to 16 at the 2-week follow-up, putting her below the threshold for PTSD.

Discussion

The adapted Rare Group PM+ curriculum was completed for on-line administration through telehealth. Rare Group PM+ was acceptable, exceeding the retention benchmark of 85% at 2-week post-intervention with 100% retention. Rare Group PM+ was feasible, exceeding the benchmark of 50% attendance at the 5 sessions with 100% attendance, including the willingness to attend one-on-one make-up sessions. Feasibility was demonstrated with 100% data completeness. The recruitment rate was 47% (8/17), close to the target of 50%.

Participants showed reductions in the severity of their symptoms of anxiety, depression, and PTSD, highlighting the potential efficacy of Rare Group PM+. This finding replicates previous randomized clinical trials of Group PM+ using the same outcome measures,[8,9] strengthening the likelihood that this is a true effect.

One of the unmeasured effects of the group was to address head on the "blameless guilt" of parents whose child had an inherited disease.[13] Participants who were feeling guilty came to understand a fundamental tenant of psychology, parental self-care did not come at a cost for their child, as they had feared, but benefited both. The group provided support, and in one case led to a participant conducting a power point presentation for her friends, so they could be partners in the care of their child, rather than minimizing the seriousness of her child's disorder. Rare Group PM+ facilitated the practice of self-care in different arenas each week. As most rare disorders are chronic and complex, Rare Group PM+ shows promise as a scalable, no-cost, evidence-based intervention for caregivers of children with rare diseases who live under conditions of adversity and are experiencing psychological distress.

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Items of Interest!

Please help us keep the items of interest up to date. Share your news, upcoming conferences or webinars. Are there particular podcasts that may be of interest to our readers? Send any items of interest to Christy at Christy.Torkildson@gcu.edu**. Thank you.**

Events/Conferences

1. **Pediatric Palliative Care Webinar Series for 2026** has started with our greatest number of participants. Do not miss out! Calendar and more information, including how to register, can be found at https://www.ppcwebinars.org/
2. **The National Alliance for Care at Home Annual Meeting & Exposition** will be held October 27-30, 2026, in Washington DC – Registration and the **Call for Proposals is open! Deadline for proposals is May 29th.** Information can be found HERE
3. **The Hospice and Palliative Care Nurses Association** (HPNA) Annual Conference is in Lake Buena Vista May 7 & 8; virtual options available; more information can be found HERE Additionally, HPNA is partnering with ELNEC to provide several upcoming course. Information can be found HERE
4. **The National Alliance for Care at Home Finance & Technology Summit** will be on July 12-14, 2026, in Boston. Registration is now open. More information can be found HERE.
5. **National Alliance for Care at Home Advocacy Week** is September 13-16 in Washington DC; please save the date! More Information can be found HERE.
6. **HPNA** is also hosting HPNA on the Hill September 21-22, 2026. This includes a day of advocacy training in Washington DC. More information can be found HERE
7. **Please save the date! The National Alliance for Care at Home Annual Meeting & Exposition for 2027 will be held October 19-22 in Seattle, WA.**

Additional Resources:

8. **Free music resource (music gift for patient/families) on behalf of Songs of Love…**
   Pediatric clinicians can offer Songs of Love as a joyful and uplifting gift for children facing medical or emotional challenges. By directing families to //songsoflove.org/request, they can request a completely free, personalized song written just for their child in any style or language, filled with the child's favorite things, people, and dreams. These songs bring smiles, laughter, and moments of pure happiness, helping children feel special, brave, and supported while giving families a lasting memory during a difficult journey.

9. **A wonderful resource that may be helpful is "Not if, but When),** a website that "encourages and supports sharing good books and stories about death and loss with children and teens throughout their lives." Website: https://www.notifbutwhen.org/
10. **Courageous Parents Network** has a whole new website! There is a wealth of resources for family members and providers. Click HERE for more information.
11. **Academy Health: Enhancing Systems of Care for Children with Medical Complexity Newsletter** is a collaborative project with the University of San Francisco, Family Voices, Boston Children's Hospital, Patient Insight Institute, and Patient Advocate Foundation. More information can be found HERE.
12. **The Lucille Packard Foundation for Children's Health publishes the Children and Youth with Special Health Care Needs Network Newsletter** – includes news, policy updates, resources, events, and advocacy opportunities from across the nation. You can subscribe to the newsletter by clicking HERE.

Additional Opportunities:

Are there any Items of Interest you would like to share? Are there resources that you love? Please email Christy at Christy.Torkildson@gcu.edu

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