

**Trends in Pediatric Palliative Care Research (TPPCR) 2024; Special Edition #01 – Parent Perspectives: Commentary on *Dewan et al.***

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Parent

**Abstract:**

This TPPCR commentary discusses the 2023 paper by Dewan et al., “Experiences of medical traumatic stress in parents of children with medical complexity. Child: care, health and development” published in Child: Care, Health and Development.

*This commentary is a part of the Trends in Pediatric Palliative Care Research commentary series. To learn more or to sign up for our monthly newsletter visit: <https://pediatricpalliative.com/research-blog/>*

### *Trauma Informed Practice for Parents of Children with Medical Complexity*

For parents of children with medical complexity the labyrinth of healthcare can often feel overwhelming. Between countless medical appointments, intricate care routines, and the emotional toll of navigating a complicated system, we as parents are frequently confronted with significant stress and anxiety. As someone who has navigated these challenges first-hand, I believe implementing trauma-informed practices in both research and healthcare can make a meaningful difference.

I can recount several pivotal moments where trauma-informed practices greatly alleviated my concerns. One such instance occurred during a particularly distressing period of my son's unexplained medical issues. To manage constant panic and the need for immediate attention, a healthcare professional suggested weekly scheduled phone visits. This simple yet profoundly effective measure helped me feel more at ease, knowing that there was a dedicated time each week to address my concerns.

Another example involved coordinated team meetings with specialists. These collaborative sessions allowed healthcare providers to work together and make collective decisions about my son's care, fostering a sense of teamwork and comprehensive understanding. Additionally, being shown how to perform specific medical procedures on my own was empowering for me. It gave me a deeper sense of control and competency in managing my child's health.

### *Effective Support Systems*

Support systems play an equally crucial role in alleviating the burdens faced by parents like mine. For example, having a local nursing support coordinator has been a significant piece of our team. This individual not only provided troubleshooting advice and regularly checked in but also assisted in procuring necessary medical supplies and equipment. Such support is indispensable for families, offering both practical help and emotional reassurance.

The importance of healthcare providers willing to engage deeply, even in the absence of knowledge about a rare disease, cannot be overstated. One of my son's providers exemplified this by committing to understand his condition, manage symptoms, and learn alongside our family. This willingness to collaborate and provide ongoing support, despite uncertainty, mitigated feelings of isolation and builds trust.

### *Barriers to Wider Implementation*

Despite its benefits, there are significant barriers to the broader adoption of trauma-informed practices in healthcare for families with complex medical needs. Often, the fragmented nature of healthcare departments impedes holistic care. Specialists typically operate in silos and lack a comprehensive understanding of children with medical complexity. Moreover, healthcare systems often lack the flexibility required to accommodate frequent users, like children with complex medical needs. The current system forces many of these children into emergency rooms when direct admission to a ward would be more suitable and less traumatic.

Another critical barrier is the inadequate representation of parents and patients during decision-making

processes. More collaboration across various sectors involved in a child's care would lead to more integrated support. Alongside this, increased resources and tools are essential to bridge the gap between departments and provide a cohesive care experience.

### *Enhancing Trauma-Informed Research*

To better serve the needs of parents and caregivers dealing with ongoing medical traumatic stress, trauma-informed research must also adopt more parent-centred approaches. These are my suggested strategies for achieving this:

1. Recognize that parents and caregivers may struggle to participate fully in research due to the demands of caregiving.
2. Provide logistical, financial, and mental health support to facilitate their involvement.
3. Offer significant reimbursement and acknowledgment for their contributions.
4. Conduct personal conversations with researchers to discuss potential triggers and ensure the comfort of participants.
5. Develop a deep understanding of the parents' and caregivers' experiences, including their demographic backgrounds.
6. Implement robust follow-up and reassurance practices to build trust.
7. Clearly communicate the value and impact of the research on their lives and others.

Additionally, let me underscore a further pressing issue: discrimination against children with disabilities. This discrimination often leaves both the children and their families feeling invisible, isolated, and neglected. Effective inclusion remains a substantial challenge, with numerous barriers still to be surmounted.

### *Conclusion*

For parents like me, trauma-informed practices provide a vital lifeline, offering practical solutions and emotional support during daunting times. By understanding our experiences, providing comprehensive support systems, and addressing the systemic barriers in healthcare, we can create a more compassionate and effective approach to caring for children with medical complexity and their families. Through collaborative efforts and sustained commitment, we can mitigate the stress and isolation our families face, and foster a more inclusive and supportive environment for all.