

PROJECT | Understanding the effects of chronic medical procedures in children with Inflammatory Bowel Disease (IBD): A qualitative study of patient, parent, and nurse perspectives

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Background | Children and youth with special health care needs (CYSHCN), such as those with chronic illnesses like inflammatory bowel disease (IBD), often suffer medical trauma from frightening and painful medical procedures. Such trauma reduces patients’ quality of life and can have long lasting negative effects on mental and physical health. This qualitative study will examine the experience and impact of medical procedures on pediatric patients with IBD, their parents, and nurses, potential coping mechanisms, and the feasibility and acceptability of a virtual reality intervention to mitigate the negative impact of medical trauma. This study has the potential to elucidate the key components of interventions that can effectively improve health and well-being for both CYSHCN patients and families exposed to medical trauma.

Potential Impact | CYSHCN often suffer medical trauma, which limits their quality of life and can have long-lasting negative effects on health. In our knowledge few studies have engaged patients, parents, and nurses in examining the variability of this experience and factors that may alleviate negative consequences and improve outcomes. There is little understanding of how pediatric patients and their parents currently deal with the stress of undergoing procedures, how this experience varies, and what they think would make it better. Additionally, since parental psychological functioning is also affected by their child’s chronic illness and plays an important role in the patient’s well-being, interventions that could also address parental well-being would be optimal. Parental input regarding interventions that would help themselves as well as their children is critical to developing a more family-centered approach for dealing with iatrogenic medical trauma. Finally, nurses bring a unique perspective to understanding this experience and designing interventions given their medical background, close interaction with patients, and understanding of feasibility of potential interventions in the clinical setting. They are an overlooked population of healthcare workers who suffer secondary traumatic stress and could benefit from interventions that provide resilience. This study will make important contributions to the medical trauma literature by including perspectives of patients, parents, and nurses.



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Publication

Child and Family Perspectives on Adjustment To and Coping With Pediatric Inflammatory Bowel Disease

Organizations Involved
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