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Medical Trauma in Young Adults: Centering the Patient Voice

Kiran Rachamallu, BS[1], Sneha Dave, BA[1], Meg Didier, BS[1], and Katherine Melton, PhD, RN[1,2]

Abstract

Introduction: Young adult patients with chronic conditions face many barriers when navigating the healthcare system and accessing care, and these challenges can lead to the development of medical trauma. However, there has been little consensus, particularly from the patient perspective, on what exactly these barriers are and how they should be addressed. **Methods:** In a roundtable hosted by Generation Patient, young adult patients and medical professionals convened to discuss medical trauma and identify solutions to how the healthcare community can best support patients experiencing medical trauma. **Results:** The discussion centered on elevating young adult patient voices, integrating mental and physical health, and identifying effective interventions. **Conclusions:** Several avenues exist to address medical trauma in young adult patients, but this focus needs continued exploration through future, formal research studies.

Keywords

Behavioral and Mental Health, Clinician-Patient Relationship, Community Engagement, Person-Centered Care, Shared Decision Making

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Introduction

Medical trauma is defined as a patient's psychological and physiological response to negative experiences in the medical setting.[1] Medical trauma and mental health challenges are key issues faced by young adult patients, especially those with undiagnosed and medically complex conditions. Many young adult patients may feel that their concerns are dismissed by medical professionals and can feel overwhelmed trying to navigate the system, faced with a barrage of appointments, testing, and conflicting advice.[2] Moreover, the fragmented nature of the United States (U.S.) medical system adds another layer of complexity to the experiences of young adult patients, who must navigate health insurance benefits within a system that is often challenging and rarely patient-centered. These barriers facing young adult patients make it challenging to access care, leading to negative experiences and increasing the risk of developing medical trauma. To address this complex issue, an invited group of young adult patients, clinicians, and other key partners in the healthcare community convened in a roundtable hosted by the patient advocacy organization Generation Patient to discuss the challenges that young adult patients face and what changes the healthcare community can make in order to support the mental health of these patients and reduce instances and severity of medical trauma. The goal of this discussion was to bring together patients and healthcare professionals to discuss potential solutions to prevent and mitigate medical trauma among young adult patients.

[1]Generation Patient, Indianapolis, Indiana, USA
[2]Nursing Professional Practice, Brown University Health, Providence, Rhode Island, USA

Corresponding author:
Katherine Melton, PhD, RN, Generation Patient, Indianapolis, Indiana, USA; Rhode Island Hospital, 593 Eddy Street, Providence, Rhode Island 02903, USA.
Email: kmelton@brownhealth.org

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Facilitated by a young adult patient leader, the roundtable discussion consisted of introductory presentations by patient and clinician representatives, followed by a sixty-minute roundtable discussion structured around a series of open-ended questions. The roundtable format provides an opportunity for valuable dialogue between the healthcare and patient communities, allowing for discussion and strategizing towards the common goal of improving healthcare experiences for young adult patients. Participants were selected based on topic area expertise and/or lived experience and included young adult patients, physicians, and mental health clinicians, among others. The session was recorded and a notetaker was present to record observations about the discussion. The first and last author reviewed the transcript and independently generated themes, using the roundtable discussion questions as a guiding framework. They then met to discuss and reach consensus on the final themes generated from the discussion. The primary goal of this discussion was to identify recommendations to inform future practice and research, rather than generate new knowledge using formal qualitative methods. The following Industry Insights article summarizes the key themes and actionable recommendations developed from this roundtable.

Actionable Insights

One of the key themes echoed by patients in the roundtable was that the voices of patients need to be centered, both to prevent future and address previous medical trauma. Centering patients can take many forms, but it includes actively listening to patients, acknowledging their concerns without dismissal, and letting them be the driver in their treatment. Too often, patient care can be top-down, with medical professionals prescribing treatments without engaging in shared decision-making. Roundtable participants expressed that patients can often feel dismissed because the clinician is perceived as the "expert" and that knows what is "best", limiting opportunities for patient voices to be heard and valued. A patient participant shared about the importance of, and challenges associated with advocating for oneself in a medical system that is often inaccessible and challenging to navigate: "… We don't just have to be like passive agents. Because it feels like there's so much that's inaccessible to us to even understand about how everything works." This lack of inclusion of young adult patients in the care determination process and the subsequent feelings of judgment can lead patients to feel like the healthcare system is ignoring them, contributing to the development of medical trauma. One physician commented on the importance of partnering with patients, "I think like not making an assumption…keeping the space open to have those conversations." Participants emphasized that patients know their bodies best, and that this knowledge should be combined with their provider's medical expertise to develop a treatment plan. Without being open and letting patients have the first word and the final say over their treatment, we risk additional harm. Ultimately, patients should lead the conversation about their care, with their healthcare provider as a trusted advisor rather than the final authority.

In discussing the prevention and treatment of medical trauma, participants emphasized the importance of using an integrated, trauma-informed approach to proactively address the mental health needs of young adult patients. Participants shared that young adult patients are expected to be able to manage and process their conditions while at the same time achieving the typical milestones of young adulthood. Juggling all this and navigating dismissal and other challenges in the medical environment can lead to extended stress and feelings of despair that can lead to or worsen medical trauma. Multiple studies have shown elevated levels of posttraumatic stress symptoms in young adults with chronic conditions, including Type 1 diabetes.[3] Additionally, a recent systematic review and meta-analysis found that 37% of patients with chronic somatic disease reported clinically relevant post-traumatic stress symptoms.[4] In discussing mental health and medical trauma, our roundtable participants emphasized the importance of normalizing the inclusion of mental health care into the standard of care for young adult patients with the goal of increasing access and reducing stigma. One patient participant shared their views on the importance of integrating concurrent mental and physical health needs of young adults with chronic conditions:

> "Mental health and physical health have been taught with such a binary and realizing that [it] is actually very real that a lot of us young adults with chronic conditions have experiences like depression and anxiety and just feeling not heard along with having to continue to navigate like insurance and medical stuff."

This type of integrated approach is also supported in the literature. Existing research on this model of care has shown that integrated medical-behavioral health care resulted in improved rates of service use.[5] Many participants in the roundtable shared what they thought the benefits of this integration could be. A physician commented, "And if you're always asking about emotional health, it's like you've set that precedent for the family and the adolescent or young adult to be willing to talk with you about it." Integrating mental and physical health concerns together can allow for more holistic, patient-centered care, potentially offering an upstream approach to addressing and even preventing medical trauma. However, participants also emphasized that in order for an integrated approach to be successful, providers need training in trauma-informed care to equip them with the skills needed to take a comprehensive approach to the healing process through empowerment, transparency, and collaboration.

Successful advocacy for system-level changes requires data to make a strong business case to health systems. Patient participants highlighted the importance of leveraging the patient voice in future research, particularly through qualitative methods and patient advisory councils. One patient participant shared: "But I guess something that I think has been super beneficial are…like patient advisory councils… And I think a follow up to that, that's also been interesting, has been like a needs-based assessment, and also just like getting qualitative data." Participants concluded that in the United States, healthcare changes are most likely adopted when they align with business priorities and cost savings. Outcomes which are linked to cost and quality can help to make a business case for interventions to mitigate the effects of medical trauma, as one participant shared: "And I think one area [for research] is things that hospital systems as a business care about like missed appointments and emergency room visits…". Participants concluded that both quantifying and describing the impacts of medical trauma through future research is an essential step forward.

Practical Recommendations

Our roundtable participants offered individual, system-level, and research-related suggestions for improving understanding, treatment, and prevention of medical trauma among young adult patients. Based on this roundtable discussion, three practical recommendations for healthcare organizations and clinicians were developed. First, we recommend adopting patient centered approaches to care in individual patient care encounters, including shared decision making and active listening. Second, it is imperative to work towards seamless integration of mental health care into the standard of care of chronic illness treatment to both reduce stigma and increase access. Third, we offer recommendations for future research including the use of qualitative and health services research methods to strengthen the business case for system-level changes which promote the prevention of and early intervention for medical trauma.

By convening topic area experts and individuals with lived experience, participants in this roundtable co-developed recommendations which healthcare leaders, clinicians, and administrators can leverage to improve care experiences. At the individual healthcare provider level, our roundtable participants emphasized the importance of shared decision-making, encouraging patient autonomy, and taking a whole-person approach to caring for young adult patients. To support these individual-level changes, system-level changes were suggested, including integrating mental health care into the standard of care for chronic illness and incorporating principles of trauma-informed care into medical education. Participants also shared the need for more research to determine effective interventions. A preliminary step in creating meaningful change is to generate quantifiable evidence to measure the impact of the harm associated with medical trauma on individual patients and the healthcare system. Measuring the impact of medical trauma is inherently challenging as these experiences can be subjective and difficult to measure. To address these challenges, roundtable participants suggested research approaches which center the patient voice including using qualitative approaches and leveraging patient reported outcome measures (PROMs). In addition to leveraging qualitative methodologies and patient-reported outcome measures, health services research approaches that quantify the financial impact of medical and microtraumas were also recommended. Combining patient-centered research methods with a health services research approach will help to identify both patient-level and system-level indicators of harm from medical trauma.

Conclusion

Medical trauma is a key issue faced by young adults with chronic conditions, which can be exacerbated by the challenges of navigating the healthcare system as a young person with chronic medical needs. In this roundtable discussion, young adult patients and clinicians engaged in dialogue and identified three key themes relating to medical trauma in this population: increasing the patient voice in their healthcare decisions, integrating mental health services into chronic illness care, and generating research to support the importance of care and prevention of medical trauma. Roundtable participants reached agreement on a variety of ways that the healthcare system can support young adult patients, both in managing their mental health and preventing medical trauma from taking place. Participants emphasized that healthcare providers need to let go of their biases and truly listen to what their patients need. Ultimately, our participants concluded that system-level change is necessary. Prevention and early treatment of medical trauma requires an integration of mental health services into the standard of care, as well as ensuring clinicians are trained in how to address these issues. Research must be done in areas such as the measurement of patient outcomes, which can demonstrate the benefits of addressing medical trauma and mental health needs of all patients, especially the young adult population. This work is limited by its design as informal discussion among patients and industry leaders. Future work in this area would benefit from a rigorous qualitative study to further explore the themes generated by this discussion. By integrating these principles into clinical practice, clinicians and the rest of the healthcare system can create an environment that supports young adult patients as they navigate the complexity of their conditions, enabling them to truly thrive.

ORCID iD

Katherine Melton https://orcid.org/0000-0002-3486-8794

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