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CASE AND COMMENTARY: PEER-REVIEWED ARTICLE

How Should Clinicians Help Homeless Trauma Survivors Make Irreversible Surgical Care Decisions?

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Abstract

Important but frequently overlooked childhood trauma outcomes can manifest later in patients' lives and include neurophysiological influences on language perception and expression, memory, attention, abstract reasoning, emotional regulation, and executive functioning. Therefore, when interacting with patients experiencing homelessness, mental illnesses, and substance use disorders, clinicians should adopt a trauma-informed approach to generating deeper understandings of patients' neurobiological makeup and psychosocial histories, especially when discussing interventions and during informed consent.

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Case

M is a 32-year-old transgender woman who is unsheltered. She has an extensive history of physical, emotional, and sexual abuse, which began when she was 5 years old. M has had many encounters with the health care system and, when admitted as an inpatient, frequently left against medical advice. During her last hospital admission, a surgical team recommended that M undergo an amputation. M left against medical advice but was readmitted 4 days later with tachycardia, hypertension, and a fever. A surgical team again emphasized that amputation was very likely needed to save M's life. Despite many conversations, M remained frightened and refused surgery, but the surgical team had no good reason to doubt her capacity to make health decisions.

When M spoke with the team's social worker, SW, she explained that she felt rushed to consent to amputation and that she neither trusted her physicians' desire to help her nor understood why she needed an amputation to live. She expressed frustration with clinicians "who use big words to make me feel stupid and force me to do what they want." M continued, "They have no idea what my life on the streets is going to be like when I don't have this limb anymore." M also shared with SW that she often does not understand what she is told, is scared, and needs more time to think and ask questions.

Based on these conversations with M, SW suggests to her fellow team members that slower speech, short sentences, writing down key points, and making more time for questions could help clinicians feel less frustrated about M refusing indicated and much-needed surgery. It would also help M consider what such surgery would mean for her now and when she leaves the hospital.

Commentary

The US Department of Housing and Urban Development estimated that 18 of every 10 000 people in the United States were experiencing homelessness on a single night in January 2020.¹ Research on causes of homelessness indicates that child abuse is a leading cause of homelessness among adolescents and adults, especially women.^{2,3,4} Patients experiencing homelessness are also psychosocially complex, have numerous comorbidities, and have had many encounters with health care professionals and organizations.⁵ This article examines how psychosocial trauma can affect decision-making capacity and argues that clinicians interacting with patients experiencing homelessness, mental illnesses, and substance use disorders should adopt a trauma-informed approach to deepen their understanding of patients' neurobiological makeup and psychosocial histories, especially when discussing interventions and during informed consent.

This Decision in Patient Context

Patients experiencing homelessness experience tremendous adversity and instability in their everyday lives, so, as any of us might, they tend to strive for control and autonomy, especially in acute care settings, which can be triggering for some patients. Making a high-stakes decision about an irreversible intervention is enmeshed in unfamiliar, sometimes intimidating power dynamics. Lack of careful attention to patients' responses and nonverbal cues can compound patients' grief and sense of feeling overwhelmed. Under pressures of managed health care, clinicians tend to spend less time with patients, which can compromise the quality of consent processes and undermine patient-clinician trust. Behavioral and cognitive consequences of extensive, prolonged childhood trauma experiences negatively affect memory system development (including the hippocampus, amygdala, and frontal cortex) as well as the development of brain structures involved in executive functioning (including the orbitofrontal cortex, cingulate, and dorsolateral prefrontal cortex).^{6,7} These developmental compromises result in slowed processing of language and information and the need for more time for decision making and problem solving.^{6,8,9} Posttraumatic stress disorder (PTSD) can also prompt childhood trauma survivors' heightened perception of threat in ambiguous situations and negative interpretative bias.¹⁰ Add some clinicians' limited understanding of patients' neurocognitive trauma histories, and you have a perfect storm of factors bound to make patients who are already navigating myriad uncertainties of life on the streets refuse interventions they might need.

Importantly, altered cognition does not necessarily imply that trauma survivors have compromised decision-making capacity.¹¹ Capacity can vary over time for many of us. In M's case, the stress of making an important decision, lack of privacy, power inequity in patient-clinician communication, distrust, and feeling that she lacks agency are key contextual features of the decision she faces. Acting beneficently and without doing harm also requires clinicians' sensitivity to neurobiological effects of trauma when assessing M's capacity. Facilitating M's self-determination responsibly means assessing her capacity under the most favorable conditions,¹² perhaps with cognitive enhancements (eg, visual education, repeated conversations, corrective feedback, and

plain language use), which could improve her understanding and her capacity to give informed consent or informed refusal. The delivery of prospective risks and benefits of an intervention to patients like M should create and nourish conditions that minimize triggers, avoid retraumatization, promote emotional well-being, and express respect for autonomy. A careful and sensitive informed consent process based on enhanced communication, trust, and respect facilitates patients' sense of control in their care and their lives.^{13,14}

Communicating for Self-ownership

Self-ownership is a concept critical to health care workers' interactions with childhood trauma survivors. These patients' experiences of self-ownership situate their capacity and agency in processes of informed consent or refusal. In my experience, patients like M tend to be acutely aware of possible threats to their integrity and dignity, so helping them motivate their self-determination and strivings for autonomy are essential in patient-clinician relationships and communication. Common conditions in acute care settings (eg, lack of privacy, limited control) can trigger patients with PTSD to respond with "flight-fight-freeze," which we can easily observe in M's behavior. Flight is expressed in her history of leaving against medical advice; fight could be understood in her resistance to consenting to indicated care recommendations; and freeze could be understood in her befuddlement about this decision and attempts to make sense of unfamiliar environs, behaviors, and words. Clinicians have ethical obligations to consider how patients with trauma histories can be disadvantaged by those histories (eg, by not being able to process information quickly or efficiently) but not necessarily disabled by them when making decisions about their health and lives (eg, they can weigh prospective risks and benefits and evaluate consequences).¹⁵

Clinicians caring for patients with psychosocial trauma who also experience homelessness should have a solid working understanding of how to avoid retraumatizing patients like M. A 2020 report by the Substance Abuse and Mental Health Services Administration on the specific role of the COVID-19 pandemic in our social interactions is applicable more generally to trauma-informed communication and to our thinking about M's case:

COVID-19 has caused major economic devastation, disconnected many from community resources and support systems, and created widespread uncertainty and panic. Such conditions may stimulate violence in families where it didn't exist before and worsen situations in homes where mistreatment and violence has been a problem.¹⁶

Trauma-informed communication means incorporating understanding of how psychological and neurophysiological effects of a patient's trauma history can affect how that patient responds to the delivery of complex clinical information. A careful, sensitively stewarded informed consent process will support and foster patients' right to give informed consent or refusal and nourish their sense of self-ownership and agency. Trauma-informed communication also means that time must be allowed; as considered earlier, a rushed conversation before a procedure can be a trigger for patients with minimal capacity to cope with unfamiliar information and decision pressure. Clinicians are ethically obligated to help all patients make decisions about their care in the context of their values, goals, and personal histories. To do so requires establishing trust, a strong therapeutic relationship, and, for patients like M, an understanding of how they are situated by their backgrounds to make decisions.

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