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Medical Misinformation in Sexual Violence

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Medical Misinformation in Sexual Violence

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In “Addressing Dissociative Trance Disorder Patients in India: An Interpretative Phenomenological Analysis of Adolescent Girls’ Help-Seeking and Encounters with Inaccurate Medical Information” in this issue, Varshney et al raise concerns about medical misinformation regarding mental health and trauma-related symptoms. They describe the experiences of 6 adolescent and young women in Sikkim, India. All 6 of the patients exhibited significant and life-threatening mental health concerns, including concerns for self-harm, suicidal ideation, depression, anxiety, and post-traumatic stress disorder. All 6 manifested their symptoms through related dissociative states. None of the patients received timely and appropriate healthcare to address these concerns due to medical misinformation, resulting in further delays in treatment. Notably, all 6 patients improved after engagement in evidence-informed mental and behavioral healthcare.

What is even more striking is that 5 of the 6 patients reported sexual violence as the primary underlying causative factor that created the mental health crises and dissociative states. Each patient reported concerns for sexual violence to family members or trusted figures but were not believed or were blamed for the events.

The United Nations defines sexual violence as "any sexual act, attempt to obtain a sexual act, or other act directed against a person’s sexuality using coercion, by any person regardless of their relationship to the victim, in any setting. It includes rape, defined as the physically forced or otherwise coerced penetration of the vulva or anus with a penis, other body part or object, attempted rape, unwanted sexual touching and other non-contact forms".[1] The World Health Organization reports that in India, 21% of women aged 15-49 years experienced sexual interpersonal violence over their lifetime.[1]

In North America, at least 15% of women aged 15-49 years report nonpartner sexual violence. It is well established that these are likely vast underestimates of true prevalence, given the extensive concerns for stigmatization related to reporting.[2] According to the Centers for Disease Control and Prevention, 1 in 4 girls and 1 in 13 boys in the United States report child sexual abuse, with 91% of the perpetrators being someone known to the family. The Adverse Childhood Experiences (ACE) study estimated that 24.7% of women and 16% of men reported a history of sexual abuse.[3]

The negative impacts of not addressing sexual trauma are enormous. The ACE study demonstrated that exposure to adverse childhood experiences, including sexual violence, increases risks for mental health, cardiovascular health, and other chronic illnesses. These physical healthcare needs contribute significantly to the burden of chronic illness and rising healthcare costs in the US, with an estimated $9.3 billion as the total lifetime economic burden of child sexual abuse.[4]

Patients who experience sexual violence may have long-lasting repercussions on their health and well-being. Increased frequency, depth, and presence of additional toxic events have a related increase in physical and mental health impacts. Patients with a history of sexual violence have a marked increase in adverse mental health outcomes compared with those not experiencing sexual violence.[5] These same harms were demonstrated in the Varshney article for the 5 patients who reported a history of sexual violence.

It is clear that sexual violence is common, has significant negative health impacts, and is underreported and underdiagnosed. The Varshney article also described the harmful delays in accessing appropriate and needed health care for the patients and argued that the delays may be ascribed to medical misinformation.

Southwell et al defines medical misinformation as ". . . scientific misinformation as publicly available information that is misleading or deceptive relative to the best available scientific evidence or expertise at the time and that counters statements by actors or institutions who adhere to scientific principles without adding accurate evidence for consideration" (page 100).[6] They go on to describe that " . . . misinformation could take the form of a social media post, a billboard, or even a fraudulent research paper" (page 100)[6] and that "although misinformation can hold cognitive or emotional consequences for individuals, misinformation is not necessarily the same as a single human's misperception" (page 101).[6]

Using these definitions as the lens through which to view medical misinformation, erroneous information regarding sexual violence perpetuated to the public that influences behaviors can be considered medical misinformation. In the Varshney article, the patients described multiple accounts of reporting concerns for sexual violence to responsible caregivers and adults. Rather than addressing the sexual violence, it is possible the caregivers and

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adults interpreted the reported concerns through a lens of medical misinformation. This medical misinformation may have taken multiple forms. In some cases, caregivers may have chosen to believe that sexual trauma was not possible for children without any physical symptoms, or that sexual trauma was the result of the patient initiating acts with the alleged perpetrators. In other cases, caregivers may have believed that sexual trauma was best managed through work or redirection, rather than it being a healthcare-related concern. It is also possible that the caregivers did not access healthcare for reasons other than medical misinformation – they may have chosen to minimize the concerns due to societal and cultural pressures, such as concerns of shame for premarital sexual contact. Finally, another possibility is that the caregivers had other motives to minimize or deny the reported concerns for sexual trauma, such as keeping the household intact to maintain financial stability.

These examples highlight the challenge in identifying and addressing concerns for medical misinformation in the space of sexual trauma. What is the overlap between medical misinformation, sociocultural factors, and individual factors in influencing decisions that impact survivors?

Medical misinformation is rampant regarding sexual trauma. There is a wide body of evidence-informed and peer-reviewed literature on sexual trauma. It is well established by the scientific community that it is normal to have delayed disclosure about sexual trauma.[7] Sexual abuse does not typically have physical findings, even when it involves vaginal penetration.[8] The best practices for management of sexual trauma are referrals to mental health professionals for evidence-informed treatments, such as trauma-focused cognitive behavioral therapy.[7] Despite this clearly established literature, medical misinformation is posted on publicly available social media sites. For example, sites describe the use of a “two-finger test” to determine if someone has had vaginal penetration, others provide links to health professionals for “virginity certificates,” and others offer hymenal surgeries – all of which are based on medical misinformation and cause harm.

Sociocultural factors also directly impact decisions about healthcare access for sexual trauma and mental health. In the Varshney article, sociocultural factors were a significant deterrent to mental health treatment. Belief in spiritual forces that create the symptoms experienced by the patients provided an alternative to

the accurate diagnosis of sexual trauma and mental healthcare needs. In the US, there have been long-standing beliefs that concerns for sexual violence are best managed by families and should not be shared outside the family circle. Anecdotally in our child abuse and neglect medical evaluation clinic, many of our patients' caregivers report their own history of sexual trauma as children. They describe their experiences of reporting concerns to their caregivers, with decisions made to keep the concerns in the family. The caregivers share their frustration with their childhood experiences due to lack of validation, protection, and healthcare. They describe their belief that their children, who have now experienced similar trauma, are more supported and will have improved outcomes due to early engagement with healthcare services. While these anecdotal experiences would need further exploration through structured research studies to draw definitive conclusions, they suggest a factor that merits consideration.

Individual factors continue to play a role in influencing access to healthcare. Caregivers may need the financial supports provided by the alleged perpetrators. This is especially true for families with limited financial means, as well as undocumented families and caregivers impacted by interpersonal violence with power differentials. There may be a significant internal conflict in caregivers, and sometimes patients, keeping the family unit together while wanting safety for the patient. Finally, some caregivers may be passively or actively complicit in the traumatic events.

There is marked overlap across the spectrum of medical misinformation, sociocultural factors, and individual level factors. Individuals may be influenced by their own needs, as described above. These needs alone may be sufficient to overcome if they were in a sociocultural context that would facilitate the prioritization of the patient's needs over their own. For example, a caregiver who is financially dependent on the alleged perpetrator may benefit with engagement with social services, who may assist the caregiver in accessing alternative financial supports that enable independence. However, in the absence of these facilitating sociocultural factors, the individual factors may dominate, leading to inaction on behalf of the patient.

Similarly, the presence or absence of medical misinformation may be a significant determinant of decision-making. In the example above, the individual caregiver may be influenced by

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financial pressures to not report the concerns for sexual violence and to not engage the patient in mental health services. The presence of certain sociocultural factors may offer a counterargument to the individual factors. Sociocultural norms supporting care for survivors of trauma and promotion of mental health care might be sufficient to override the individual drive to deny care. This is where medical misinformation can hold enormous sway. In the absence of medical misinformation, the caregiver may overcome their individual drives to meet sociocultural factors to acknowledge the trauma and engage the patient in care. However, the presence of medical misinformation in this setting may provide the caregiver justification to prioritize their individual drive over the sociocultural drive. For example, social media may spread medical misinformation that overstates the harm that occurs to the patient in engagement in mental health care and investigative services to address the trauma. The caregiver may use this misinformation to rationalize their individually driven desires to minimize the concerns by representing this as truth. This may be sufficient to overcome the sociocultural factors that may promote access to mental health care.

Therefore, the presence of medical misinformation may fundamentally impact caregiver behaviors in addressing reported concerns for sexual trauma. Unfortunately, healthcare and community professionals may also be influenced by the medical misinformation. Evidence-informed, peer-reviewed literature has established that sexualized behavior in children and teens does not necessarily indicate sexual trauma. Regardless, healthcare professionals may be influenced by medical misinformation available publicly that suggests sexualized behaviors indicate sexual abuse. If healthcare providers are at risk for influence from medical misinformation, they are less available to counsel patients and families on navigating the medical misinformation themselves.

To optimize the care of patients with sexual violence and related mental health care needs, we must address the individual, sociocultural, and medical misinformation factors that influence healthcare access. Generating change at the individual and sociocultural levels may be challenging for healthcare professionals and may take significant time that may not meet the current needs of patients. As healthcare professionals, perhaps the more actionable intervention is to address medical misinformation regarding sexual violence. Healthcare and survivor advocacy

organizations focus efforts on educating the public. There are many peer-reviewed and evidence-informed articles, educational modules, and webinars available to train the public on sexual violence. Some states have enacted legislation requiring healthcare professionals to complete mandatory training on sexual violence. Although these efforts are appreciated and necessary, medical misinformation continues to be present.

A parallel approach may be to address the medical misinformation on sexual violence more overtly. Labeling inaccurate content as “medical misinformation”, clarifying the definition by using suggested descriptors from the literature as previously described, may be helpful in highlighting the nature of the inaccurate content. Overt labeling of inaccurate content as “medical misinformation” may allow the public to better distinguish a difference of opinion verses true misinformation. This approach may mitigate the influence that the medical misinformation may have in the decisions made by caregivers. Now, rather than feeling empowered to use the publicly available content to justify decisions that prevent care for the patient, overt labeling of the content as medical misinformation may reduce the strength of influence.

There are drawbacks to this approach that need to be considered. Robust and respectful dialogue is critical to advance healthcare and increase knowledge. Labeling of inaccurate content as medical misinformation must be done judiciously to avoid silencing needed dialogue. Finally, any labeling must be done in a respectful and professional manner, as the intent behind the misinformation may not be known. Starting with active listening and engagement, openness to learning for all, with meaningful dialogue, and then labeling if applicable may be the most appropriate and balanced approach.

The challenge of meeting the needs of patients with sexual violence is complex. It requires a multifactorial approach of addressing individual, sociocultural, and medical misinformation factors that influence behavior. Given the marked prevalence of sexual violence, and the significant consequences when engagement in healthcare does not occur, a thoughtful and comprehensive approach is warranted.

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