

Study unpacks how medical systems harm the intersex community

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Intersex people's (people whose sex characteristics do not fit within the strict binary categorizations of male or female) health care has received a lot of media attention recently, particularly with the uptick in anti-transgender legislation, which often also targets this community. Discrimination and mistreatment in social and medical settings, largely due to the stigma of not conforming to binary views of sex, results in many intersex individuals experiencing isolation, secrecy and shame, which can have a lasting impact on their mental health.

A new study from researchers at Boston University Chobanian &

Avedisian School of Medicine highlights the need for a systemic shift in the way health care providers view intersex variations. These findings have been published in the journal *Social Science and Medicine*.

"This is a community that has been greatly harmed by the health care system and the false ideas that sex and gender exist as a strict binary. One such example is how many intersex infants and children are subject to non-consensual 'normalizing' genital surgeries, which have been shown to cause both physiological and psychological harm," explains corresponding author Kimberly Zayhowski, MS, CGC, assistant professor of obstetrics and gynecology.

The researchers conducted and analyzed 15 interviews with members of the intersex community about their experiences with health care providers and perspectives on how their care could be improved. The study points to areas of health care where intersex people have experienced medical trauma and highlights the need for health care providers to use a trauma-informed approach. In their interviews, intersex people highlighted the need to normalize intersex variations and incorporate comprehensive teachings of intersex history and medical care into medical curricula to relieve the burden placed on patients to be their own medical experts and advocates.

According to the researchers, this study challenges the commonly held notion that sex exists as strictly male and female—an idea readily refuted by science but which is all too often defended through misrepresentation or misunderstanding of biology. The study also highlights the importance of bodily autonomy and trauma-informed care, which are frameworks that benefit everyone.

"This study has implications for the [medical care](#) of anyone with an intersex variation, also called variations of sex characteristics. Sometimes physicians will use the term 'disorders of sex development'

(DSD) to describe intersex variations, but the intersex community has largely rejected this language because it is pathologizing," says first author Darius Haghighat, MS, CGC, assistant professor of obstetrics and gynecology at the Boston University.

The researchers believe that the study participants have been failed by a medical system that discriminated against, violated and misled them. "Systemic change is paramount to address these disparities, oppose abusive practices, and provide the care that the intersex community deserves," adds Haghighat.

More information: Darius Haghighat et al, Intersex People's perspectives on affirming healthcare practices: A qualitative study, *Social Science & Medicine* (2023). [DOI: 10.1016/j.socscimed.2023.116047](https://doi.org/10.1016/j.socscimed.2023.116047)

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