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BACKGROUND

The Silences Framework (Serrant, 2011) offers an opportunity to better understand sensitive issues and marginalized perspectives on health, particularly HIV. Exploring 'Silences' means gathering a deeper understanding of 'unsaid' or 'unshared' aspects of an individual/group's belief and value systems that directly or indirectly impact their understandings of health and health behavior. Body Maps have helped unravel multilayered and often silenced health experiences and their impact on health-seeking behaviors (Gastaldo, 2018). Recognizing the need to explore such 'silences' in the lived experiences of young people accessing HIV services, a two-day community workshop was organized in New Delhi to deconstruct complex HIV experiences through body map storytelling.

METHODS

The workshop brought together 32 young participants representing key population groups including transwomen, men having sex with men (MSM) and People living with HIV (PLHIV) to understand silenced and gendered health experiences with regards to access to HIV prevention services. It employed participatory research tools including body-map storytelling bringing together visual and narrative approaches to explore intersectionalities, common themes and 'screaming silences'. Participants were divided in four groups to draw a life-size outline of the human body, scan it from top to bottom and visually map: a) personal/community health concerns; b) layers of stakeholders impacting health or health decisions; and c) lived experiences showcasing the nature of this impact. The body-maps were used to trigger open 'community conversation' bringing out silenced experiences, which were analyzed deductively using a theoretical thematic approach.



Body-map creation and presentation

RESULTS

The body-maps elicited sharing of lived experiences and sparked conversation on the intersectionalities between HIV, sexual and reproductive health (SRH), stigma, gender disparities to care and access to health services. The following two themes emerged clearly:

A) Breach of trust by close confidantes with respect to disclosure of HIV status resulting from multi-layered stigma and HIV-related misinformation. Individuals' construct of self and capacity to cope with stigma beyond their immediate circle was greatly impacted by the loss of agency in how, where and when to disclose their HIV status. This "breach of trust" also impacted their trust in healthcare services and motivation to seek care, and was experienced across various settings including the workplace, school, and in family and social networks.

B) Fear of relationship loss emerged as a major factor influencing the health choices and behaviors of young people, including uptake of interventions. Young people often found themselves in situations where uptake of HIV and/or SRH services was pitted directly against relationship goals and intimate partner preferences. In addition to directly impacting agency – especially in relationships and contexts where socially assigned power dynamics were more pronounced – health-related decision-making was often guided by perceived and/or actual impact on relationships with intimate partner(s).



The 'screaming silences' relating to "fear of relationship loss" encompassed a range of fears, including: a) the perceived impact of medication on desirability, libido and fertility; b) restrictions on ability to devote time and energy to the relationship and meet socially-designated 'obligations'; and c) anticipated shifts in power dynamics due to independent health choices and their potential ramifications on the long-term sustainability of the relationship.

CONCLUSION

Silenced health experiences – though often invisible and missed out by traditional methods of inquiry – have an indelible impact in shaping people's health choices. They represent critical pockets of inquiry that need further research and consideration in order to inform the design of the next-generation strategies to create more relevant and responsive HIV prevention services. The participatory activities and loosely structured discussions offered an open and safe space for unmasking marginalized perspectives, exploring shared silences, and facilitating experience sharing and co-learning between people affected by HIV in different ways.

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