Letter to Editor

Experiences of Disclosure among HIV-serodiscordant Couples in Durban, South Africa

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Dear Editor

The incidence of HIV in South Africa has declined slowly since 2000, with antiretroviral treatment (ART) and condom promotion contributing most significantly to this decline.[1] However, research findings suggest that increasing ART availability in resource-limited settings without risk reduction strategies may not be sufficient to control the epidemic of human immunodeficiency viruses (HIV) in the post-ART era.[2] Couples' voluntary HIV counselling and testing (CVCT) is a high-impact HIV prevention intervention in the Sub-Saharan Africa, and voluntary disclosure of one's HIV status is one of the key measures of secondary prevention in the global fight against the HIV epidemic.[3] However, disclosure of one's HIV status may not always be perceived as a favourable option due to the stigma and the negative psychosocial effects that disclosure can have on a couple's relationship, identity, and social support. In case one partner is HIV negative and the other one is positive, serodiscordant couples are often expected to disclose their HIV status to intimate partners, family members, children, friends and healthcare workers; however, the process of disclosing such sensitive personal information to someone else is not always an easy one. For these reasons, the rates of status disclosure are low; for example, a study on HIV-positive, pregnant women in the Mpumalanga province of South Africa reported that only 59% of the participants had disclosed their status to their partners and 75% were not aware of their partner's HIV-status.[4] Disclosure may render people vulnerable to discrimination and exploitation by others because such information will be changed from being privately owned to being co-owned. Once this information is disclosed, there is an expectation that it will be kept private and confidential. As such, disclosure always involves some degree of risk. This perceived risk leads to people creating boundaries around which information is considered public and private. In our study, we explored experiences of disclosure among 30 serodiscordant couples through focus group discussions in Durban, South Africa. Patients were recruited from private hospitals within the city centre of Durban. Group meetings comprised three 6-hour workshops held on Saturdays. The meetings were scheduled 4 weeks apart over a period of three months, with each couple attending a total of 3 workshops. Each workshop had a theme for discussion, according to the intervention curriculum, disclosure being one of them. We used the communication privacy management theory to understand how couples manage sensitive information such as disclosure of their HIV status. According to this theory, disclosure has both benefits and risks; thus, people must balance their competing needs for privacy and disclosure.[5] The benefits of disclosure range from self-expression

to relationship development, social control, and the risks include loss of face, status, or control. When people disclose, they give over something that is private to them, and, therefore, they feel they should retain the right to control it, even after disclosure. Using these boundaries as a point of reference, our participants reported that they were able to control who had access to the information. These findings confirm that couples experience various psychosocial conflicts about whether to disclose their HIV status and of that of the partner or not. Within the South African context, multiple social dialogues, especially the intersection of family responses, were considered important by participants. This is in the same line with collectivist cultures in which the wellbeing of oneself is interlinked to that of significant others within one's social system. Disclosure to family members also posed questions as to whether disclosure would activate support or create stigma from family members. The critical role that family members play emphasizes the need for a greater focus on disclosure to families for social support in HIV counselling protocols. Our findings also indicate that disclosure was not only limited to the couples, but also filtered down to their children. Disclosing to children living with HIV-infected person came with its own set of challenges, i.e., whether disclosure would empower children or cause emotional problems. In our study, some participants sought to protect the child by disclosing the status to promote treatment adherence, whilst others feared the possibility of self-destruction following disclosure. This information is useful to health care workers working with parents who are making decisions about disclosure both in terms of providing the parents with information about how their children may react, as well as normalizing a particular child's reaction to parental disclosure. Results from a local study showed that some health care workers had poor understanding of the concept of serodiscordant couples,[6] thus negatively impacting on their ability to carry out risk-reduction interventions aimed at these couples, such as promotion of disclosure. Further research in this area is necessary to inform the design of future risk-reduction interventions, to pay specific attention to the complexities of disclosure in collectivist cultures, where disclosure has ripple effects on multiple levels of the couples' psychosocial and relational systems.

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