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“How can I tell?” Consequences of HIV status disclosure among couples in eastern African communities in the context of an ongoing HIV “test-and-treat” trial

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Abstract

People living with HIV/AIDS anticipate HIV-related stigma and fear disclosure to intimate partners. Yet, disclosure is critical to reducing HIV transmission and improving care engagement. This qualitative study characterized HIV disclosure experiences and normative beliefs among couples in communities participating in an HIV test-and-treat trial in Kenya and Uganda (Sustainable East Africa Research in Community Health, NCT#01864603). In-depth interviews were conducted with care providers ($n = 50$), leaders ($n = 32$) and members ($n = 112$) of eight communities. Data were analyzed using grounded theoretical approaches and Atlas.ti software. Findings confirmed gender differences in barriers to disclosure: while both men and women feared blame and accusation, women also feared violence and abandonment (“I did not tell my husband because [what if] I tell him and he abandons me at the last moment when I am in labor?”). Positive consequences included partner support for increased care-seeking and adherence (“My husband keeps on reminding me ‘have you taken those drugs?’”) Yet negative consequences included partnership dissolution, blame, and reports of violence (“some men beat their wives just because

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of that [bringing HIV medications home]). Among HIV-infected individuals in discordant relationships, men more often reported supportive spouses (“we normally share [HIV-risk-reduction strategies] since I have been infected and she is HIV negative”), than did women (“my husband refused to use condoms and even threatened to marry another wife”). Care providers lent support for HIV-positive women who wanted to engage partners in testing but feared negative consequences: “They engaged the two of us in a session and asked him if we could all test.” Findings demonstrate differing experiences and support needs of women and men living with HIV in eastern Africa, with HIV-positive women in discordant couples particularly vulnerable to negative consequences of disclosure. Efforts to strengthen capacity in health systems for gender-sensitive clinician- or counselor-assisted disclosure should be accelerated within test-and-treat efforts.

Keywords

HIV-related stigma; sub-Saharan Africa; HIV sero-discordant couples

Background

The proportion of HIV-infected individuals accessing antiretroviral therapy (ART) has dramatically increased as the ART rollout has progressed in sub-Saharan Africa (UNAIDS, 2014); yet only half of people living with HIV/AIDS (PLWHA) regionally are aware of their status, and PLWHA find disclosing their status, a complex decision-making process, challenging (Greeff et al., 2010; King et al., 2008). A systematic review of HIV status disclosure revealed heterogeneous disclosure rates across diverse populations and settings in sub-Saharan Africa (Obermeyer, Baijal, & Pegurri, 2011). Concealment of HIV-positivity may expose HIV-negative partners to infection, increase reinfection among HIV-positive partners, and create missed opportunities for HIV care (King et al., 2008; Vu et al., 2012). Studies in both rural and urban settings across sub-Saharan Africa have shown disclosure of HIV-positivity to be associated with positive outcomes including increased social support (Maman et al., 2003; Ogoina et al., 2015), reduced internalized stigma (Geary et al., 2014), improved mental health (King et al., 2008), and safer sexual behaviors (Rujumba et al., 2012). Other research in the region associates disclosure to sexual partners with increased understanding and support (Medley, Garcia-Moreno, McGill, & Maman, 2004; Obermeyer et al., 2011), trust (Atuyambe et al., 2014; King et al., 2008), and HIV care uptake (Deribe, Woldemichael, Wondafrash, Haile, & Amberbir, 2008; King et al., 2008).

Studies assessing barriers to HIV disclosure among predominantly female PLWHA participants report significant anticipated stigma (Mkwanazi, Rochat, & Bland, 2015) and fears of abandonment, rejection, and violence (Greeff et al., 2010; Rujumba et al., 2012). Disclosure outcomes substantiate these fears; negative consequences include loss of social support, social rejection, and abandonment (Medley et al., 2004; Obi & Ifebu-nandu, 2006), breaches of confidentiality (Bott & Obermeyer, 2013), violence (Medley et al., 2004; Shamu, Zarowsky, Shefer, Temmerman, & Abrahams, 2014), and stigma (Osinde, Kakaire, & Kaye, 2012). Literature on barriers to disclosure only among males is more sparse; Deribe et al. suggest that men are more concerned about consequences of exposing their own

infidelity and are sensitive to causing their partners to worry (Deribe et al., 2010). Negative consequences are exacerbated among women, who face more stigmatizing attitudes and intimate partner violence (Gari, Habte, & Markos, 2010; Iliyasu, Abubakar, Babashani, & Galadanci, 2011; Medley et al., 2004) in response to disclosure of HIV-positivity. Psychosocial support to assist disclosure in sub-Saharan Africa is lacking as in many resource-poor settings, yet is needed among women who fear disclosure will result in abuse or divorce (Mucheto et al., 2011). Although substantial evidence documents disclosure consequences, limited information exists on experiences and social norms surrounding disclosure within the contexts of universal HIV “test-and-treat” interventions, which aim to saturate communities with HIV testing and link positive individuals to HIV care programs. Little is known about the effects of rapid community introduction of test-and-treat on the social dynamics of disclosure processes, including positive and negative consequences for PLWHA of disclosing, and of concealing, their status. We aimed to explore normative beliefs surrounding disclosure and disclosure experiences in communities participating in an ongoing test-and-treat trial, Sustainable East Africa Research in Community Health (SEARCH), (NCT#01864603) in Kenya and Uganda.

Methods

Research team

A gender-balanced team of six trained qualitative researchers from Uganda and Kenya collected the data. Interviewers were matched to participants’ gender (i.e., women interviewed women and men interviewed men.) Analyses were conducted collaboratively by the data collection team, the research coordinator, and the lead investigator who provided training and mentorship.

Study design

Data are from a qualitative study embedded within SEARCH, a community-level cluster randomized control trial currently underway in Uganda and Kenya. SEARCH aims to increase HIV testing and care uptake through community-led, multi-disease, and patient-centered approaches; study details are published elsewhere (Chamie et al., 2016). Study communities are predominantly rural, low socio-economic status areas typical of resource-poor settings in the region. The qualitative study is conducted within 8 of the 32 SEARCH communities: 2 matched intervention and control communities in southwestern Uganda, 2 in eastern Uganda, and 4 in western Kenya. The overall aims of the qualitative study in SEARCH are to ascertain how a large test-and-treat effort influences community norms, beliefs, attitudes, and behaviors related to HIV and, in turn, how these changes influence the uptake and success of this effort. The study’s objectives are to characterize the diverse social and cultural contexts of the intervention, to describe heterogeneity in implementation processes across these regional contexts, and to compare changes in community contexts over time and across SEARCH intervention and control arms. Ultimately the study is designed to enable an understanding of why the test-and-treat intervention works, why it fails if it does in some communities, and how it works in different settings.

Sample selection

The study used purposive and stratified random sampling techniques for establishing three in-depth interview cohorts: community leaders, community members, and HIV care providers. Cohort members were recruited at baseline between February and December 2014 (Table 1). For the community leader cohort ($n = 32$), four leaders were purposively selected per community to represent a gender-balanced diversity of leaders involved in SEARCH mobilization, including members of local councils, Village Health Teams, and fishing community leaders. The provider cohort ($n = 50$) was purposively selected from a list of government facility providers to include the range of cadre engaged in HIV care, including clinical officers, nurses, research assistants (engaged to track lost to follow up patients), HIV counselors, community health assistants, and peer educators. The community member cohort ($n = 112$) was randomly selected from a household listing established by the SEARCH socioeconomic survey (Chamie et al., 2016, within strata defined by gender and HIV status: 5 HIV-negative and 9 HIV-positive individuals per community (3 with CD4 count above 500 cells/mm³, 3 on ART, and 3 eligible for ART but not linked to care at sampling).

Data collection

In-depth semi-structured interview guides consisted of open-ended questions with specific inquiry for HIV-positive individuals on their experiences with and attitudes towards disclosure of HIV status to intimate partners (Table 2); guides also explored perceived social norms, beliefs, and practices related to HIV testing, disclosure, and care-seeking among all participants. Community member and leader interviews were conducted in private settings at home or nearby location, while provider interviews were conducted at clinics, following procedures to obtain informed consent for participation; interviews were 40–90 minutes in length.

Data analysis

Research team members were native speakers of Lusoga, Lugwere, Ateso, Runyankole, and Dholuo, and conducted interviews in participants' preferred language, then translated and transcribed audio recordings into English. A priori codes were developed based on theory-informed interview guides. The coding framework was iteratively refined during data collection by team-wide review and discussion of empirical findings, in accordance with grounded theoretical approaches (Charmaz, 2006). Transcripts were coded using Atlas.ti 7.0. Disclosure-specific data were extracted for analysis. The full research team was involved in coding, analysis, and interpretation of qualitative data, under guidance of the lead investigator.

The study received ethical approvals from the University of California San Francisco Committee on Human Research, the Ethical Review Committee of the Kenya Medical Research Institute, the Makerere University School of Medicine Research and Ethics Committee, and Uganda National Council for Science and Technology.

Results

Below we present findings on barriers to and facilitators of disclosure, as well as disclosure experiences (including positive and negative consequences of both disclosure and concealment) among study participants. Our analyses, informed by grounded theoretical approaches in which empirical findings inform theoretical categories, revealed gender as a critical analytical lens for interpretation of the data. The salience of gender as a category for analysis of disclosure perceptions and experiences was not determined *a priori*, but rather emerged from the empirical data. Thus, we present gendered dimensions of normative beliefs surrounding disclosure (including anticipated stigma and fears), followed by disclosure experiences, in the results below.

Anticipated stigma

Analyses of interview data revealed gender differences in anticipated stigma, specifically the types of fears men and women expressed that inhibited disclosure of their HIV seropositive status to intimate partners. Female PLWHA expressed anxiety about partner abandonment and relationship dissolution and feared violent responses if partners were to learn their status. Data from interviews with both providers and community members revealed concerns centering on women's vulnerability due to financial dependence on partners, as shown in the following quotes:

I did not tell my husband because I was thinking if he turns out to be like the other ones that I hear about, I tell him, and he abandons me at the last moment when I am in labor, how will I manage? (Female community leader, Uganda, female)

They [wives] are saying ... "How will I start [ARVs]? My husband will send me away and marry somebody else ... where will I keep these drugs?" (Provider, Kenya, male)

Since [women] are dependents, it is their husbands to provide them with transport. When their husbands find out that they are sick, they will chase them away [...] they do not have alternatives. (Provider, Uganda, Female)

One woman described her husband's violent reaction to his own HIV testing as rationale for not disclosing her HIV status:

I am told that [my husband] beat up [a health care provider] [...] From this incident I guessed that he is HIV-positive, and out of that brutal incident, I do not want to share with him about HIV. (Female community member, Kenya)

In contrast, the most commonly mentioned barriers to disclosure for male PLWHA were fears of accusation and blame, due to prevalent expressed moral arguments surrounding male "promiscuity". Multiple respondents indicated men were less likely to disclose "for fear of marital conflict, as most women believe that men are the most promiscuous". While some men also mentioned fearing abandonment by their partners, this fear was only reported by HIV-positive men in partnerships of known or presumed serodiscordance.

Strategies to avoid disclosure

HIV-positive individuals who had not yet disclosed their status to their partners reported a variety of strategies undertaken to avoid disclosure, such as care-seeking in remote facilities, hiding HIV medications, and abandoning care. As illustrated by the following quotes, men often enrolled in HIV care without telling their partners, whereas women found difficulty starting care or adhering to medications due to fear of their partners finding out:

I discovered that he was getting his HIV treatment [...] over 180 km [away]). I used to see him take his medications, but he would say that “I have worked a lot today— let me take paracetamol to avoid problems”. (Female community leader, Uganda, HIV-concordant)

I also realized that [my husband] and my co-wife were already on care. [...] He was enrolled for care elsewhere and could not tell me. (Female community member, Kenya, HIV-concordant)

If a pregnant woman tests positive for HIV and we give her drugs, she is scared to tell her husband that she is positive; she fears to take the drugs and hides them away from her husband and keeps them at the neighbor’s place. (Provider, Uganda, female)

While narratives of non-disclosure often involved no HIV-risk behavior modification, some individuals took action to protect their partners from infection without disclosing. This appeared easier for male than female PLWHA due to gender differences in sexual decision-making power. Several males discussed initiating condoms use under the pretext of family planning; for example:

I used to play protected sex ... I [began] using condoms pretending that I was supporting her sentiments of having fewer children. (Male community member, Kenya, HIV-discordant)

Non-disclosed women also discussed wanting to protect their partners from HIV; however, initiating condom use presented a challenge in contexts in which women wanted partners to test and use condoms, without disclosing their own status:

He became very sick at one time, and I requested him if we could go for HIV testing [...]. I told him this without disclosing my status to him, but he never yielded to my request [...] During our stay together, he never used condoms; he finally left without going for the test. (Female community member, Kenya)

I know [my husband] will definitely re-infect me because when he comes and makes sexual advances to me I cannot refuse. What can I tell him? He can kill me. He does not even want to wear a condom. (Female community member, Uganda)

You are very much aware how hard it is to deal with men. They will always assume power and walk away with anything they want and you just have to be submissive to him. (Female community member, Kenya)

Consequences of non-disclosure

Participants also discussed consequences of actively concealing one's HIV status from a partner. Non-disclosure was a major obstacle to the uptake of HIV care. Reported outcomes of non-disclosure included avoiding care, or not adhering to ART regimens, in efforts to avoid suspicion and inadvertent disclosure. As one provider in Uganda noted, "Sometimes, she forgets to take the drugs [...] because they hide them outside their own homes." A man in Kenya described having never started care because of his fear of disclosure to his wife:

"I have never gone ... I can't lie that even today, no I haven't gone [...] You know in that house I am living with my wife [...], there is no place I can keep these drugs without her finding out. That is what is hindering me. I will keep the drugs somewhere and in that house she will definitely get them. Secondly, if I start taking drugs in the morning and evening she will ask me "*Which disease is this, that drugs are just take continuously?*" So if she asks me like that, how will I respond? (Male community member, Kenya)

Participants also reported substantial anxiety as a result of actively concealing their status, as illustrated in the following quotes:

I got disturbed and worried [...], and my wife continually asked me what was wrong, though I repeatedly denied that nothing was wrong. (Male community member, Kenya, HIV-concordant)

[The women say], "my husband is going to see me taking this medication and say I have brought diseases to our home; my husband might chase me away, so I do not know how I am going to be swallowing this medication." (Provider, Uganda, female)

Consequences of disclosure

A number of positive narratives of disclosure emerged from the analysis, demonstrating that many partners accepted an intimate partner's HIV status. Some who disclosed reported an increased ability to engage in HIV care, and a sense of personal empowerment that led them to encourage their partners *and* others to test, engage in care, and initiate ART. Furthermore, successful disclosure within intimate partnerships often led to engagement in risk-reduction strategies. These themes are illustrated in the following quotes:

My husband keeps on reminding me "have you taken those drugs?"[...]"Oh, thank you for reminding me, I was forgetting", even when I am busy listening to the radio. (Female community member, Kenya)

We normally share [HIV risk reduction strategies] since I have been infected and she is HIV negative, that she should take good care of herself and even pass on the advice to the children [...] I also encourage her to remain faithful or continue using condoms. (Male community member, Kenya, HIV-discordant)

Negative consequences of disclosure also occurred, ranging from minor to severe, and were significantly patterned by gender with the most severe consequences reported by women, particularly in HIV-discordant partnerships. These included marital dissolution,

abandonment, blame, denying access to care, and in a few instances, physical abuse. A woman describes abandonment by her husband following her HIV-positive status disclosure:

This was the greatest problem [...] I tested positive after my first born and my husband refused to use condoms and even threatened to marry another wife [...] He insisted that if we must use condoms, then he ceases to be called my husband and will not take responsibility of our children [...], that I raise our children alone. This continued for five years without any support from him. (Female community member, Kenya, age 36)

Providers reported male partners reacting violently to the discovery of their partner's positive status, preventing women from accessing ART by forbidding access to the facility, discouraging treatment, and destroying their partner's HIV medication:

Some [newly-diagnosed HIV-positive women] do accept to take [ART] drugs but when they go back at home [...] the male partner has not been tested, it becomes very difficult for them to take these drugs. Some men even beat their wives just because of that [bringing the drugs home]. (Provider, Kenya, male)

This is a woman we initiated on ARVs she took the drugs home [...] the husband took the drugs and burnt them [...] when we followed up she had not taken the drugs since time of initiation because of interference [by] the husband. (Provider, Uganda, female)

Community members recalled rejection and accusations among couples in response to an HIV-positive status disclosure:

She tried to tell her new husband to go for HIV testing, but he refused, saying that she is the one that could have infected him. (Provider, Uganda, male)

He decided to get tested and he was found to be HIV-positive too. Later on war erupted [...] on who brought the disease to the family [...] For a long time, the man believed that [his wife] infected him. (Male community leader, Kenya)

Facilitators of disclosure

Potential facilitators of positive disclosure experiences were also identified. Clinic-based couples testing was a preferred strategy for accomplishing disclosure among women, as it avoided designating one individual as the source of the infection if both tested positive:

I decided to tell my husband, "For the sake of the baby's health, we have to know our HIV status". He didn't become stubborn so we all went to the hospital. When we arrived, the doctor asked whether I was going to be enrolled [in ART], and I told him that I couldn't be enrolled first before knowing [my husband's] status. (Female community member, Kenya)

Health care providers and counselors were supportive of PLWHA, and provided disclosure assistance, especially with HIV-positive women who feared negative consequences, and women whose male partners had unknown serostatus and had refused testing. Facilitators of disclosure did not emerge as a major theme within men's narratives. The following quote

illustrates the extent to which providers strategized with their HIV-positive patients, particularly women, to find opportunities to engage partners in testing:

... The nurse then insisted that it was high time my husband knows my status and she promised to take care of the process. They then planned a “trick” to lure him to test, taking advantage of our daughter who was graduating from catechism class. He attended the graduation and this was the opportunity for the nurses. They engaged the two of us in a session [...]. (Female community member, Kenya)

In the above instance, the husband was found to be HIV-positive, and did not blame his wife. She noted, “he promised not to turn his back on me, as he did not know the source of my infection”.

Discussion

Findings of this qualitative study highlight substantial gender differences in barriers to disclosure, strategies to avoid disclosure, and consequences of disclosure, in the baseline year of the SEARCH trial. Negative consequences of disclosure were reported disproportionately by women, who also reported more severe consequences. Women expressed anxieties around partner abandonment or violence whereas men shared fears of their partners perceiving them as promiscuous. Among those who had not disclosed, men were often enrolled in HIV care secretly or in distant clinics while women found challenges initiating or staying engaged in care. Interview narratives highlighted needs, particularly for women, for facilitated couples disclosure.

Data collection for this study was undertaken during a very rapid scale up of HIV testing in the study communities, which resulted in approximately 89% coverage of HIV testing in the stable adult population by the end of the baseline year of the trial (Chamie et al., 2016). That is, during the same time period in which the qualitative data for this study were collected, major changes were underway in the study communities in the numbers of individuals tested for HIV and confronted with new challenges related to HIV status disclosure. The test-and-treat intervention thus precipitated new opportunities and anxieties related to disclosure for couples in which one or more members became newly aware of an HIV-positive status. The findings suggest not that the test-and-treat context changed the nature of experiences and norms related to disclosure right away, but rather that quite quickly, large numbers of individuals were suddenly presented with the dilemmas inherent to the decision whether or not to disclose. These dilemmas were patterned strongly by gender, in concert with the findings of prior research.

That research has shown that, as in our study, HIV-negative women more often than HIV-negative men report remaining in HIV-discordant relationships. Moreover, notably in our study, among the HIV-positive members of discordant couples, men, exclusively, reported supportive spouses. These findings may reflect the gendered livelihood opportunities within these communities; women may be less likely to leave their partner due to concerns around financial stability. Women’s fears of losing material or financial support from their partners has been found to be a major barrier to HIV disclosure in Uganda (Rujumba et al., 2012), and evidence suggests dissolution of HIV-discordant relationships is more prevalent in

couples in which the HIV-infected partner is female (Floyd et al., 2008; Mackelprang et al., 2014; Porter et al., 2004). Our findings are consistent with prior literature demonstrating more prevalent and severe negative consequences of disclosure among women, including abandonment, denial of care access, and violence (Brou et al., 2007; Medley et al., 2004). As has been previously documented, women in our study feared severe consequences such as physical violence or abandonment. Yet, both men and women feared rejection and experienced blame and accusation from intimate partners, and delayed HIV disclosure for fear of being accused; our findings supported research suggesting that members of couples who test first are often blamed for the infection (Deribe et al., 2010; Medley et al., 2004; Walcott, Hatcher, Kwena, & Turan, 2013). Maintaining non-disclosure was stressful for men and women. Strategies to avoid disclosure while protecting partners included condom use, introduced by men under the pretext of family planning, and by women when they were unsure of their partner's HIV status. However, consistent with prior research, women reported substantial difficulties in negotiating condom use (Jewkes & Morrell, 2010).

Among some study participants, disclosure of HIV-positive status to partners led to positive outcomes including increased knowledge of the HIV status of partners, partner communication, and efforts to practice safer sex. Rich narratives illustrated successful risk-reduction efforts undertaken by members of HIV-discordant and -concordant couples who had openly discussed HIV. These findings confirm prior research showing associations between disclosure and adoption of preventive sexual and increased care-seeking behaviors such as condom use, reduction of sexual partners, partner testing and disclosure, HIV care-seeking, and improved partner relationships. We speculate that other factors in relationship contexts that were beyond the scope of this exploration – such as partner trust, levels of intimacy, mutual support and gender-equitable beliefs and practices – may have facilitated positive disclosure outcomes in some couples.

Findings reveal the important role of health care providers (counselors, peer educators, and nurses) as facilitators of disclosure. There were numerous accounts of providers undertaking strategies to help women who feared disclosure to engage partners in testing. While this study's findings support previous research indicating that HIV-positive women in the region prefer clinic-based couple's testing as a method of partner disclosure (Walcott et al., 2013), findings also revealed reluctance among many men to participate in clinic-based couples testing. Thus, efforts are needed to both meet women's needs for the security and support of care providers with disclosure, and explore men's preferences for testing and disclosure support, which could include home-based couples testing and assisted disclosure in non-facility settings. Previous literature suggests various support systems have improved HIV disclosure experiences (Maman, Cathcart, Burkhardt, Omba, & Behets, 2009; Rujumba et al., 2012; Shrouff, Mafara, Saint-Sauveur, Taziwa, & Vinales, 2013; Walcott et al., 2013).

Limitations to our study include self-reported data from individuals and providers, which are subjective and potentially affected by recall and social desirability biases. All community participants in this study were PLWHA attending clinical care in communities undergoing rapid ART scale up, thus limiting external generalizability; yet study contexts are illustrative of similar communities in high HIV prevalence regions. Moreover, findings are enriched by

triangulation of data from diverse sources, illustrating provider, community member, and community leader perspectives across diverse geographic settings in eastern Africa.

The substantial gender differences in barriers to HIV disclosure and disclosure experiences and outcomes revealed in our study demonstrate a strong need for attention to the differing disclosure experiences and support needs of women and men living with HIV in eastern Africa. Expanding support for assisted disclosure for couples is critical; and efforts to strengthen health systems capacity for clinician- or counselor-assisted disclosure should be accelerated. Yet such strategies should be gender-sensitive, and attuned to men's and women's very different experiences and needs. As the experience of this test-and-treat trial demonstrates, the rapid scale-up of HIV testing and ART rollout makes a critical mass of individuals newly aware of their diagnosis of HIV, and newly presented with the dilemmas of disclosure, rendering the need for a robust programmatic response all the more urgent.

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Table 1

Methods, samples and data sources by region (baseline year of SEARCH).

Methods and samples/sources	Kenya	Uganda SW	Uganda E	Total <i>n</i>
IDIs with community member cohort	56	28	28	112
IDIs with community leader cohort	16	8	8	32
IDIs with health Care provider cohort	28	12	10	50

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Table 2

Interview guide questions and probes around disclosure of HIV status.

Interview guide questions: HIV status disclosure	
•	Can you tell me about your experiences sharing your HIV test results with other people after you were last tested?
•	Have you shared your HIV test results with anyone? <i>If yes:</i> whom?
•	Please tell me about your decision to share your test results: Why did you choose this person to disclose to?
•	Were there other people you wanted to disclose your status to, but felt you couldn't? Please tell me more about that.
•	What makes it difficult for you to share your results with this person?
•	[...]
•	Did you share your HIV test results with your sexual partner?
•	<i>If no:</i> Can you tell me why you found it hard to disclose your test results to your partner?

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