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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Background

The proportion of HIV-infected individuals accessing antiretroviral therapy (ART) has increased in sub-Saharan Africa (SSA) [1]; yet only half of people living with HIV (PLWH) are aware of their status, and find disclosing their status challenging [2,3]. Concordance of HIV-positive status may influence HIV-positive individuals’ choice of marriage partners, and negatively impact on social relationships and psychological well-being [4].

Methods

To assess the factors that influence HIV status disclosure, we conducted a qualitative study in communities participating in an HIV test-and-treat trial in Kenya and Uganda (SEARCH, NCT01884603) [12].

Table 1: Samples and Data Sources by Region (Baseline Year of SEARCH 2014)

<table>
<thead>
<tr>
<th>Methods and Samples Source</th>
<th>Region</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Els with Community Member Cohort</td>
<td>Kenya</td>
<td>28</td>
</tr>
<tr>
<td>Els with Community Leader Cohort</td>
<td>Kenya</td>
<td>6</td>
</tr>
<tr>
<td>Els with Health Care Provider Cohort</td>
<td>Kenya</td>
<td>12</td>
</tr>
<tr>
<td>Els with Community Member Cohort</td>
<td>Uganda</td>
<td>36</td>
</tr>
</tbody>
</table>

Results

Gender Differences in Anticipated Stigma

Female PLWH expressed anxiety about partner abandonment, relationship dissolution, and feared violent responses.

“I did not tell my husband because I was thinking if he turns out to be the other likes that I hear about, I told him, and he abandon me at the last moment when I am in labor, how will I manage?” Female community leader, Uganda

Male PLWH expressed fears of accusation and blame due to arguments surrounding male ‘promiscuity’. Fear of abandonment was only reported by HIV-positive men in partnerships of known or presumed serodiscordance.

Avoidance strategies included care-seeking in remote facilities, seeking HIV medications, and abandoning care. Men often enrolled in HIV care without telling their partners; women found difficulty starting care or adhering to medications due to fear of their partners finding out.

“I actually 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-discordant

Consequences of Disclosure

Stratified random sampling and purposive sampling were used to establish three IDI cohorts:

- Community members (n>32) - a gender-balanced diversity of leaders involved in SEARCH mobilization: local councils (LCs), Village Health Teams (VHTs), and fishing community leaders.
- Providers (n=60) - government facility providers: rural and urban nurses, HIV care coaches, community health assistants, and peer educators.
- Community members (n=112) - randomly selected members from a household listing [12]: 5 HIV-positive women (n=15), 5 HIV-positive men (n=15), and 8 HIV-negative members (n=11).

Facilitators of Disclosure

Outcomes included avoiding care or not adhering to ART regimens. As one provider in Uganda noted, “Sometimes, she forgets to take the drugs [. . .] because she hides them out from their 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 stand that even today, I haven’t gone […] I [know in that house that I am living with my wife, even if no place to keep these drugs without her finding out. That is what is hindering me.].” Female community member, Kenya

Conclusions

SEARCH precipitated new opportunities and anxieties related to disclosure for partners newly aware of an HIV-positive status.

- Women experienced anxiety around partner abandonment or violence whereas men shared fears of their partners perceiving them as promiscuous.
- Men were often enrolled in HIV care secretively or in distant clinics; women found challenges initiating or staying engaged in care.
- Condom use was introduced by men under the pretext of family planning, and by women when they were unsure of their partner’s HIV status; women reported substantial difficulties in negotiating condom use.
- HIV-negative women more often remained in HIV-discordant relationships. Among the HIV-positive members of discordant couples, men, exclusively, reported supportive spouses.
- Women experienced more prevalent and severe negative consequences of disclosure including abandonment, denial of care, and violence.
- Disclosure among some partners led to increased knowledge of the HIV-status of partners, partnership communication, and efforts to practice safer sex.
- Health care providers were important facilitators of disclosure - especially for women.

The substantial gender differences in barriers to HIV disclosure and disclosure experiences and outcomes demonstrate a strong need for attention to the differing disclosure experiences and support needs of women and men living with HIV in eastern Africa.

References


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