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Considerations for purposeful HIV status disclosure among women living with HIV in Ghana

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ABSTRACT

Although disclosure of positive HIV status has recognized benefits, enacted and perceived stigma is a continuing problem in Ghana, especially affecting women living with HIV (WLHIV). This qualitative study investigates how WLHIV make these decisions. We interviewed 40 WLHIV, analysing their transcripts using thematic content analysis. Four themes emerged from the data: selectivity in disclosure; disclosure for education, prevention and to provide support; concern for the potential confidant, and safety in secrets. Women's awareness of and concerns about HIV-related stigma led them to seriously weigh the costs and benefits of disclosure decisions. Overall, our participants disclosed only when they believed that disclosure would benefit them or the confidant. They did not condone open disclosure, and preferred non-disclosure to minimize harm to themselves and loved ones. Though disclosure occurred for HIV education and prevention purposes, personal safety was the priority. We recommend revision of current post-HIV testing and pre-treatment counselling procedures to incorporate WLHIVs' judgements about disclosure and discussion of the perceived benefits of disclosure. Disclosure is an intricate process that involves support seeking and educating others while averting harm. Continued research of the factors related to disclosure is important to enhance understanding of the disclosure process.

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HIV; disclosure; decision-making; stigma; women

Introduction

In Ghana, HIV prevalence has remained low compared to other Sub-Saharan African countries - 1.3% in 2013 (Ghana AIDS Commission [GAC], n.d.; UNAIDS, 2013), with approximately 132,763 women living with HIV (WLHIV) compared to 98,442 men (GAC, 2014). Like other women in the region (Cordero-Coma & Breen, 2012; Rhine, 2015), Ghanaian women have restricted power to negotiate condom use, are financially dependent (Mill & Anarfi, 2002), and may be with men who have other sexual partners (Anarfi & Owusu, 2011; GAC, 2014). If revealed, HIV positivity can trigger loss of shelter and food security for a woman and her children (Wright & Mwinituo, 2010).

Previous research has revealed factors affecting disclosure, with few studies in Ghana. Studies in Zambia and Togo indicated that disclosure is done for support but avoided to prevent negative labelling (Bond, 2010; Moore & Williamson, 2011). In South Africa, Visser, Neufeld, de Villiers, Makin, and Forsyth (2008) found that pregnant women disclosed to partners to encourage preventive behaviour and to historically supportive

family/friends; fear of a confidant's reaction prevented disclosure.

Ghanaian studies found that non-disclosure was aggravated by fear of severed relationships, abuse, or the public announcement of their status ("outing") (Obiri-Yeboah, Amoako-Sakyi, Baidoo, Adu-Oppong, & Rheinländer, 2016). Mill (2003) found that shame also increases hesitancy; pursuing emotional or financial support may provoke disclosure, however (Asiedu & Myers-Bowman, 2014). A national study revealed that people living with HIV (PLHIV) inform few confidants (Asante, Poku, Owusu, & Zekeng, 2011). Given the vulnerability of Ghanaian WLHIV to stigma, we studied conditions that influence disclosure decisions, aiming to provide information to improve post-HIV test and disclosure counselling, and follow-up support.

Methods

This qualitative study was part of a larger project investigating HIV-related concerns and experiences among WLHIV residing in the Greater Accra region and stake-

holders. Here, we examine data from convenience samples of WLHIV ≥ 18 years of age recruited from an HIV-focused non-governmental organization (NGO) and a healthcare facility. NGO officials and healthcare facility staff invited eligible registrants to participate and directed interested women to the research team who explained the study and administered oral consent. We interviewed consenting women in closed offices in the respective facilities and provided snacks and GHS 10 (USD 4.36 on 21 January 2014) as compensation for their time and transportation.

Based on participants' preference, the first author conducted 22 English interviews and 3 Akan interviews with a female translator; a Ghanaian female research assistant conducted 15 Akan interviews. Interview questions were constructed to allow participants to tell their stories freely. The interviews were audio-recorded and transcribed verbatim; two Ghanaian female assistants completed Akan-to-English translation, with independent validation by two Akans. The Institutional Review Boards for the University of Ghana and the University of Texas Health Science Center at Houston approved the study which took place during January–March 2014.

Analysis

We used a thematic content approach to analyse the data (Lieblich, Tuval-Mashiach, & Zilber, 1998), with ATLAS.ti (version 7) for transcript management. Emerging codes were generated during transcript review and reapplied during repeated reviews. The first author completed primary coding; all authors participated in discussions to generate final themes. To confirm

trustworthiness of our data, we compared our findings to previous literature and data from the stakeholders (data not shown).

Results

Sample description

Table 1 displays participant characteristics. All 40 were on antiretroviral therapy (ART), with reported ages of 32–60 years and low- or middle-incomes. Main themes are described below.

Selectivity in disclosure

Many participants chose confidants based on their predicted trustworthiness and ability to provide psychological, financial, spiritual or other support. As one woman described, “If you think, you need help [from] somebody, and without telling her the person cannot help you, you can tell ... You decide ... did I need to tell this person and if I tell, [what] am I going to get?” (Married, diagnosed 13 years). Family members who revealed their secrets, friends who gossip, and others with a history of callous behaviour or uncertain commitment were eliminated. One woman summarized this concept, “You see, because of stigma ... if you don't trust the person you can't tell ... ‘this is my situation’” (Widow, diagnosed 11 years). One married woman explained, “Oh, I had wanted to tell all my siblings but I am scared. I do not know their mind”.

Disclosure for education, prevention and to provide support

Disclosure to deter friends or siblings from continuing risk behaviours was described by a remarried divorcee, “... some of my friends, they are playing dangerous games [having multiple sex partners]. So whenever I'm talking to you and you don't want to [pay attention] then I disclose to you ... so most ... friends [know] ... ” (Diagnosed 10–15 years). This sense of responsibility was sometimes applied to the general population:

People didn't believe that, there's HIV/AIDS ... So I want them to change their life-attitude. Because of that I will start [talking to people about HIV]. And I want them to protect [themselves]. So [at] any time I'm talking [to] them about condom, condom, condom. (Diagnosed 10 years)

Disclosure was also intended to address misconceptions or negative attitudes towards PLHIV. Their healthy appearance caused others to change their perception and see them as normal. Similarly, participants sometimes disclosed to newly diagnosed women during volunteer

Table 1. Participant demographics.

	(n)	(%)
<i>Marital status</i>		
Married	11	27.5
Remarried widow	2	5.0
Divorced, remarried	3	7.5
Separated	1	2.5
Divorced	7	17.5
Widowed	7	17.5
Unmarried	7	17.5
Not stated	2	5.0
<i>Years from diagnosis</i>		
≤ 5	11	27.5
6–10	12	30.0
11–15	9	22.5
>15	4	10.0
Not stated	4	10.0
<i>Employment</i>		
Petty trader	22	55.0
Food service	1	2.5
Hairdresser/salon work	4	10.0
Laundry service	1	2.5
Seamstress	1	2.5
Not currently working	7	17.5
Not stated	4	10.0

activities. One volunteer explained, “... in the hospital if someone [is diagnosed] ... and they want to kill themselves then I show them my medicines, that I am positive so they should have hope” (Married, diagnosed 16 years).

Concern for the potential confidant

Factors that could make a potential confidant unsuitable include immaturity or ailing health. Regarding her son, one mother explained “... when I am sick, he could cry all throughout... he is about to [take school] exams so I had wanted to tell him when he finishes” (Divorcee, diagnosed 5 years). Disclosure was even retracted, as one married woman described, “... I told my mom and, she was crying, crying, crying, and I said ‘mm, I have to turn back and tell my mom it’s a lie. If not, she will kill herself. ... So my mom doesn’t know” (Diagnosed 8 years).

Safety in secrets

Most interviewees did not condone open disclosure, withholding disclosure when they could not assure safety from a negative outcome. They protected themselves and their loved ones by remaining silent. Although she disclosed to her husband and two additional individuals, one woman explained her rationale, “... because, maybe, if I tell [others] it will create a problem for me. Maybe stigma[tize] me-I don’t know. So, I decided not to tell anybody ... Because of my children” (Married, diagnosed 8 years).

Women living in rented housing or family compounds feared eviction. Others did not disclose to preserve important relationships. One divorced woman explained “My father and my mother do not know. If they knew, they wouldn’t talk to me again” (Diagnosed 5 years). One mother recounted desiring to disclose to encourage HIV-positive neighbours to initiate treatment, but she had to put her family’s safety first:

... Last year, two people in my community were diagnosed HIV-positive ... if I ... tell [them] my status, [their] children will [inform others] ... I wish I could tell them just join me to the clinic for ART, but how can I tell them? How can I tell them? That idea, in fact it’s ... it’s worrying me a lot. (Remarried widow, diagnosed 12 years)

Without clear potential for a positive outcome, disclosure was often suspended.

Discussion

Our research indicates that a woman would disclose if it benefitted her or a confidant. Similar to Asiedu and

Myers-Bowman (2014), we found that women disclosed for comfort and support. As Visser et al. (2008) found among pregnant WLHIV, women chose non-disclosure to protect confidants’ well-being. Women prioritized their personal safety, yet the need to provide HIV risk reduction information to others could lead them to disclose. Women weighed disclosure decisions against the risk of high HIV-related stigma, choosing non-disclosure to minimize harm.

Our findings highlight that, as Bond (2010) concluded regarding disclosure and HIV testing in Zambia, revisiting when and why disclosure should be done is necessary to provide safe, comprehensive care to both PLHIV and their communities. Safety from stigma should also be considered comprehensively during post-test counselling and follow-up appointments to routinely revisit patient understanding of risk reduction strategies and intention or readiness to disclose. Discussion of reasons why PLHIV believe specific individuals should/should not be informed may be particularly helpful. Re-training of healthcare providers and counsellors is needed to focus on the recommended improvement strategies.

Our participants were residing in an urban area when interviewed, where exposure to accurate HIV-related information is more prominent. Disclosure decision-making may differ for women in rural areas, particularly considering the greater potential for stigma and misguided perceptions of PLHIV. Our participants were on ART and in contact with a support organization and/or healthcare facility. Consequently, they may have more exposure to disclosure counselling and other support services than their counterparts. Such exposure could result in greater fear of disclosure (Obiri-Yeboah et al., 2016) and more deliberate disclosure.

Our discussion is limited to purposeful disclosure; we did not cover instances of “outing”, forced disclosure, and assumptions of an HIV-positive status by others, although sometimes non-disclosure was necessitated to avoid or address accusations of HIV positivity. Exploration into disclosure situations that occur outside the control of the women is warranted. Disclosure is a multifaceted event that includes seeking comfort, educating others and securing protection, but these themes do not complete the phenomenon. Additional research is needed to investigate other aspects of disclosure and tie the pieces together to create complex insight into the process.

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